Ezobudoda ('manhood things')
A qualitative study of HIV-positive adolescent boys' and young men's health practices in the Eastern Cape Province of South Africa

Lesley Blinn Gittings
GTTLES001

Thesis Presented for the Degree of
DOCTOR OF PHILOSOPHY
in the division of Social and Behavioural Sciences, School of Public Health and Family Medicine
UNIVERSITY OF CAPE TOWN
September 2019

University of Cape Town



The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

University of Cape Town

Declaration

I, Lesley Gittings, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree at this or any other university. I authorise the University of Cape Town to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

This dissertation has been submitted to the Turnitin module, and I confirm that my supervisor has seen my report and any concerns revealed by such have been resolved with my supervisor.

This thesis uses Harvard referencing style.

Name: Lesley Gittings
Student number: GTTLES001

Signed by candidate

Signature: Date: 25 September 2019

Permission to include publication

I confirm that I have been granted permission by the University of Cape Town's Doctoral Degrees Board to include the following publication in my PhD thesis, and my co-authors have agreed that I may include the publication. This publication constitutes Chapter Seven of this thesis.

> Gittings, L., Hodes, R., Colvin, C. and Zungu, N. (Accepted). Things less spoken: HIV research with adolescent boys and young men – implications for theory, policy and practice. In Govender, K. and Poku, N.K. (Eds.), *Adolescence and HIV Prevention in Africa: Emerging Evidence and Intervention Strategies*. Abingdon: Routledge. Forthcoming in 2020.

Signed by candidate

Signature: **Date:** 25 September 2019

Student Name: Lesley Gittings **Student Number:** GTTLES001

Contribution of student and co-authors:

I conceptualised and conducted the analysis, led data interpretation and drafted the initial manuscript to which RH, CC and MZ provided their input. RH and CC directed data collection and provided intellectual guidance for this work as my PhD supervisors. RH, CC and MZ and assisted with data interpretation. RH co-conceptualised the research study (Mzantsi Wakho) with another PI, from which these data arise, and which formed the basis of my field research funding and support. CC's division provided additional research support and funding for my living expenses during this work. All authors read and approved the final manuscript.



SUPERVISOR'S APPROVAL OF SUBMISSION OF DISSERTATION FOR EXAMINATION

I confirm that I have seen/have not seen the final version of Lesley Gittings' dissertation and that it is submitted for examination with my approval.

Signature Removed

Supervisor's Signature

25 September 2019

Date

Signature Removed

Co-supervisor's Signature

25 September 2019

Date

Abstract

Ezobudoda ('manhood things')
A qualitative study of HIV-positive adolescent boys' and young men's health practices in the Eastern Cape province of South Africa

Lesley Blinn Gittings

25 September 2019

Men are less vulnerable to HIV acquisition than women, but have poorer HIV-related outcomes. They access HIV services less often and later, and are more likely to die while on antiretroviral therapy (ART). The adolescent HIV epidemic presents further challenges, and AIDS-related illness is the leading cause of death among adolescents in sub-Saharan Africa. Such deaths have tripled since 2000, while declining in all other age groups. There is a clear need to better understand health practices for adolescent boys and young men living with HIV, and the processes through which these practices are formed and sustained.

This doctorate explores the biosocial lives of adolescent boys and young men living with HIV in the Eastern Cape Province of South Africa. It engaged health-focused life history narratives (n=36), semi-structured interviews (n=32) and analysis of health facility files (n=43), alongside semi-structured interviews with traditional and biomedical health practitioners (n=14).

Young male participants were among the first generation to grow up with access to ART and democratic freedoms. In a context where HIV-positivity and men's inability to fulfil traditional roles are considered signs of social and moral decay, they felt pressure to be 'good' HIV-positive patients and respectable young men. As younger children, they performed to norms of HIV-positive patienthood. As they became older, norms of masculinity, including financial achievement, ulwaluko (traditional initiation/circumcision), 'moral' behaviour and engaged fatherhood became more important and began to conflict with performances of 'good' patienthood. This was most apparent during and following ulwaluko, where societal norms made it difficult to engage with biomedical treatment and care. Despite this, participants and their families demonstrated agency, creativity and resilience in subverting and re-signifying these norms.

Participants did not access traditional products or services for HIV-related issues, a finding that deviates from much of the literature. This study suggests that health practices are mediated not only by gender and culture, but also childhood experiences of growing up deeply embedded in the health system, through which participants forged additional health-seeking tools. Findings affirm the syncretic nature of traditional beliefs, documenting the plural and complementary ways that participants engaged with traditional products and services.

Acknowledgements

This dissertation is the culmination of the support of many generous people.

Foremost thanks to my supervisors, Dr Rebecca Hodes and Associate Professor Christopher Colvin, for ensuring that I had every form of support needed to write this doctorate. Thank you for your unwavering presence, and for providing me with the academic community that has sustained me. Thank you also for ensuring that I had the space and funding that I needed.

Rebecca, thank you for being the first person to encourage me to do a PhD, for inviting me into the Mzantsi Wakho team, and for being my tireless mentor and enthusiastic supporter. I admire your unshakeable commitment to academic rigour and to the creation of a more just and equal future for all. You have been an immense source of strength, learning, vocabulary and laughter.

Chris, thank you for your steadiness and the astute feedback and sharp insights from which I have learnt a great deal. I appreciate your commitment to the creation of academic community that interfaces with health activism. Thank you for including me in the SASH programme and for welcoming me into the Division of Social and Behavioural Sciences.

This research was made possible by a group of adolescent boys and young men, traditional and biomedical health workers and a number of clinics, community health centres and public hospitals in the Eastern Cape. Thank for generously sharing your time, experiences and insights which formed the basis of this research.

To the Mzantsi Wakho team, I owe a huge gratitude. This evidence was gathered within the auspices of a large, longitudinal study on medicines-taking in the Eastern Cape, the Mzantsi Wakho study. I am grateful to Principal Investigators Dr Rebecca Hodes, Professor Lucie Cluver and Dr Elona Toska, study collaborators at the Universities of Cape Town and Oxford, and the researchers who supported data collection and analysis.

Thank you to Dr Elona Toska for the many ways that you have enthusiastically rallied to support me and this doctorate, from conception to conclusion. Sally Medley, I'm grateful for your practical as well as emotional support and laughter. To Phakamani Kom and Sinebhongo Mbula, the researchers who worked tirelessly on the Ezobudoda study, thank you for being my compassionate and steadfast companions during long, bumpy drives, and in many interviews, transcriptions, clinic file extractions, analysis meetings, debriefs, dissemination activities, referrals and data verification meetings. Thank you also to Zukolwethu Jentjies for your research support in the earlier piloting of this study.

At the University of Cape Town, thank you to Thobani Ncapai for providing early transcription and translation support for interviews, and to the rest of the UCT-based team including Nondumiso Hlwele, Sarah Walters, Nicci Scheepers and Becky Maughan-Brown for your help. Thank you to the Oxford team, including Professor Lucie Cluver, the co-Principal investigator of Mzantsi Wakho for hosting me at the Department of Social Policy and Intervention in Oxford and having me on your team. A special gratitude to Camille Wittesaele and Roxanna Haghighat

for inviting me into your home and for providing intellectual and emotional support throughout this process. Thank you to Dr Marija Pantelic for your friendship and wisdom.

To the rest of the Mzantsi Wakho team, in the Eastern Cape and all over the world, it has been a privilege to work with you. This project is a huge collaboration, including many people: S Banzana, O Barns, P Bellem, N Bhambra, N Bobrowitz, N Boqwana, W Booi, N Boqwana, M Boyes, N Bungane, L Button, L Campeau, A Carlqvist, C Carty, M Casale, KE Chademana, M Coqui, J Doubt, M Dukata, Y Dunkley, C Dyer, A Egan, N Ella, J Ellis, N Galela, C Gilmer, VE Gutierrez, N Gwebecimele, O Green, E He, A Heusel, S Hoeksma, N Homani, M Isaacsohn, V Jali, J Jochim, R Jopling, C Kama, B Kamile, C Kelly, J Kelly, K Kidia, B Kinana, N Langwenya, V Luke, O Madikane, B Madondo, S Mahleza, K Makabane, B Makwenkwe, S Malunga, T Mampangashe, Z Marikeni, D Mark, X Matebese, A Mayekiso, A Mbiko, A Mboyiya, N Mdi, F Meinck, F Menziwa, A Mfeketo, D Mhlauli, M Michaloupoulou, B Mkati, N Mendu, F Menziwa, P Mngese, S Mngese, P Mjo, S Mona, M Moshabela, T Moyikwa, S Mpimpilashe, M Mpumlwana, S Mqalo, Z Mqhashane, S Mwellie, N Myeketsi, P Myoyo, A Naik, H Natukunda, M Neel, U Ngesi, S Ngozi, P Nobatye, N Nurova, A Nyamweda, M Orkin, M Pancoast, L Parmley, L Pilard, T Ramncwana, A Redfern, A Robb, J Rosenfeld, W Rudgard, B Saliwe, J Sandelson, I Savage, D Sephula, N Shah, A Sharma, L Sherr, Y Shenderovich, N Sibanda, L Sidloyi, M Simandla, U Simandla, N Simaya, I Skracic, R Smith, N Sontsonga, J Steinert, X Swelindawo, B Taleni, M Thabeng, S Tshaka, T Tsiba, B Vale, J Van der Wal, T Walker, P Wardle and A Yakubovich.

Thank you to Mzantsi Wakho collaborators, including Eastern Cape Provincial Departments and to Dr Paul Cromhout from the Small Projects Foundation for championing the dissemination Ezobudoda findings. Thank you also to colleagues and collaborators at PATA.

Thank you to Christina Laurenzi for your thorough and punctual edit of this thesis, McKenzie Berezin for your referencing support, and to Siyanai Zhou for some of the preliminary quantitative analysis presented in this thesis.

Camagwini to Thando Ntombecamagu May for helping me to navigate and translate between spiritual and academic worlds. Thank you Dr Thulani Mkhize for your isiXhosa expertise, including naming this study and editing the glossary. Thank you to Professors Robert Morrell and Mosa Moshabela for your intellectual guidance and support.

I had the privilege of being a fellow of the SASH programme, which has provided me with a tremendous academic community. Thank you to the SASH faculty including Professor Mark Lurie, Associate Professor Abigail Harrison, Professor Don Operario, Associate Professor Jennifer Pellowski, Professor Caroline Quo and Dr Alison Swartz. To my SASH cohort fellows Alice Clarfelt, Hanne Haricharan, Brian Kanyemba, Samantha Malunga, Tebogo Mokganyetji, Obrian Nyamucherera, Bey-Barrie Schmidt, Namhla Sicwebu, Remmy Shawa, Myrna van Pinxteren and Lario Viljoen, it has been an honour (and a lot of fun!) to learn and grow with you.

Financial support for myself and this study was provided by a range of funders to whom I am very grateful. These have included the South African National Research Foundation (NRF) Innovation scheme for doctoral students, Evidence for HIV Prevention in Southern Africa

(EHPSA), a DFID programme managed by Mott MacDonald (MM/EHPSA/UCT/05150014), the South African Social Science and HIV (SASH) Programme, an initiative funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development of the National Institutes of Health (Award #R24HD077976), the AIDS and Society Research Unit, UCT's postgraduate funding office, the Max & Lillie Sonnenberg Scholarship, NRF travel funding support and the the Regional Inter-Agency Task Team for Children Affected by AIDS - Eastern and Southern Africa (RIATT-ESA).

The Mzantsi Wakho Study was funded by the Nuffield Foundation [CPF/41513], but the views expressed are those of the authors and not necessarily those of the Foundation; Evidence for HIV Prevention in Southern Africa (EHPSA), a UK aid programme managed by Mott MacDonald; Janssen Pharmaceutica N.V., part of the Janssen Pharmaceutical Companies of Johnson & Johnson; the Regional Inter-Agency Task Team for Children Affected by AIDS - Eastern and Southern Africa (RIATT-ESA); UNICEF Eastern and Southern Africa Office (UNICEF-ESARO); the International AIDS Society through the CIPHER grant [155-Hod; 2018/625-TOS]. The views expressed in written materials or publications do not necessarily reflect the official policies of the International AIDS society. Further funding was provided by: Oxford University Clarendon-Green Templeton College Scholarship; Claude Leon Foundation [F08 559/C]; Oak Foundation [R46194/AA001]; the Leverhulme Trust [PLP-2014-095]. Additional funding was provided for the research team by: the John Fell Fund [103/757; 161/033]; the University of Oxford's ESRC Impact Acceleration Account [IAA-MT13-003; 1602-KEA-189; K1311-KEA-004]; Research England; the European Research Council (ERC) under the European Union's Seventh Framework Programme [FP7/2007-2013]/ ERC grant agreement n°313421, the European Union's Horizon 2020 research and innovation programme/ERC grant agreement n°737476). The views expressed in this thesis are those of the author, and not necessarily those of the aforementioned funders.

To all of these people and organizations, I owe a huge gratitude. All shortcomings of this work are mine alone.

My family and friends have been an immense source of support throughout this doctorate. To my parents, Susan and David Gittings, thank you for your unrelenting commitment to the growth, development and well-being of your children (even when we move across oceans!) and for the myriad ways that you remind me that I'm loved. Mom, I admire how you always strive to learn, grow and contribute to the world around you and I am grateful to have had you as my first role model. Dad, thank you for your gentle kindness, your practical showing up and for your larger than life sense of humour. Among other things, this thesis is about masculinity, and I'm grateful to have moved through life with such a positive and loving man as a father. To my siblings, Elizabeth McManus and Matthew Gittings, thank you for being my biggest teachers. Beth, you are my pillar and my first and best friend. Your love, wicked humour, support and gentle wisdom sustains me. Matt, I'm in awe of your intelligent curiosity. Thank you for understanding the trials and triumphs of writing a thesis. I am grateful to my grandparents, Edward and Joyce Gittings, 'Bud' Morden, Alison Morden-Smith, and Jack Smith, and to the lineages I carry in my blood, including the Blinns, Gittin(g)s, Gruneruds, Kettlehuts, Maxwells, Mordens, Nielsens, Olufsens, Sands and Smiths, among others, and to my gifts, guides and teachers. When things get difficult, I rest into your resilience.

Baba Masechaba, thank you for taking me as child of your ancestral and spiritual lineages. With remarkable grace you navigate the roles of teacher, healer, activist and member of many diverse communities. You live a love, wisdom and humility that humbles and inspires me. I appreciate those who you carry with you, who have taught and held me, including the Dlaminis, Ntulis, Mnyakenis, and those of uMkhulu uDinkwe, the Maimanes and the Mpores. Thokozani Makhosi!

Thank you to the Rotary Foundation for supporting me to come to South Africa under the Ambassadorial Scholarship Programme, and to my hosts, Terence, Connie, Michelle and Nicole Matzdorff for being my family in South Africa. Much gratitude to Bob and Mary Jean Gallagher for encouraging me through the application process and for being my honorary Aunt and Uncle. Thank you to Angela Wellman and Julie Cugalj for your mentorship.

I am blessed to have friends who have held and supported me through this process and throughout the years, among them Antonia Aphantitis, Vinay Arora, Andrea Bolen, Adrian Cardamone, Alice Clarfelt, Joanne Corrigall, Elsa Dinsdale, Venetheo Goosen, Cathy Janecka, Linda Kaoma, Vishan Naidoo, Rameez Nordien, Tebogo Mokganyetji, Andrew O'Ree, Andrew Parker, Julie St Cyr and Erin Stern. A special gratitude to Gabriella Garnett who has been the fiercest of champions.

This thesis is dedicated to my Nana, Alison Morden-Smith (nee Maxwell) for supporting and encouraging us to pursue higher education, although you did not have the same opportunity. It was a dream of yours to study, and you sacrificed this first in defence of freedom and humanity in the Second World War, and second for love. I respect and honour the woman you chose to become and your bravery and resilience in imagining different futures for yourself and your family. You crossed an ocean for your truth, which has allowed me to do the same. *Reviresco!*

Table of Contents

Abstract 5

Acknowledgements 6

Table of Contents 10

Acronyms and abbreviations 13

Glossary 14

List of figures 16

List of tables 21

List of appendices 22

Chapter One: Introduction 23

Chapter Two: Literature review 31

Conceptual and theoretical frameworks 31

Empirical literatures: HIV and adolescence, men and masculinit(ies) and traditional health practices 40

Chapter Three: Study setting, research design and methods 57

Chapter Four: 'I used to hate myself when I first knew, but there was a thing that whispered in my ears…' - Young HIV-positive masculinities throughout the life course 112

Introduction: 112

Conceptual and theoretical frameworks: Personhood and redemption 115

Methods overview and introduction to key themes 119

Findings Section 1: Childhood and inherited misfortunes 123

Findings Section 2: Masculinity, identity and pathways to personhood 143

Conclusion 167

Chapter Five: "If you are found taking medicine, you will be called names and considered less of a man" - Engagements with HIV treatment and care during and following ulwaluko 170

Introduction 170

Background: voluntary medical male circumcision and ulwaluko 173

Findings and discussion 175

Conclusion 200

Chapter Six: 'I use them for dirty spirits, not for things like sicknesses…'Health beliefs and practices of adolescent boys and young men living with HIV 203

Introduction **203**

Background and definitions **207**

Findings and discussion **212**

Conclusion **270**

Chapter Seven: Things less spoken - HIV research with adolescent boys and young men – implications for theory, policy and practice ***273***

Abstract **273**

Introduction **274**

Theory, concepts and definitions **276**

Background: Adolescence, health and masculinity **278**

Findings and discussion **279**

Conclusion **292**

Chapter Eight: Discussion and conclusion ***297***

Background **297**

Key Findings **299**

Limitations **306**

Methodological Insights **307**

Recommendations table **310**

Conclusion **313**

References ***314***

Appendices ***352***

Appendix 1: Life history narrative tool (English) **352**

Appendix 2: In-depth, semi-structured interview tool (English) **357**

Appendix 3: Interview Guide and Questions – Biomedical Health Worker **364**

Appendix 4: Interview Guide and Questions – Traditional Health Practitioner **369**

Appendix 5: Interview Guide and Questions – Key Informant **375**

Appendix 6: Details of the informed consent/assent process, and it's underlying principles **381**

Appendix 7: Information guide and informed consent form (English) for adolescent participants. **385**

Appendix 8: Information guide and informed consent form (English) for traditional and biomedical health workers and key informants. **391**

Appendix 9: Researcher hiring and training criteria **394**

Appendix 10: HIV status-non disclosure additional information 395
Appendix 11: Pre and post interview checklist 397
Appendix 12: Reflection form 399
Appendix 13: Confidentiality Agreement 402
Appendix 14: Referrals and legally mandated reporting 404
Appendix 15: Dissemination activities 408
Appendix 16: UCT HREC Ezobudoda ethics approval & renewals 414
Appendix 17: EC DoH Ezobudoda ethics approval 428
Appendix 18: Mzantsi Wakho ethical approvals (UCT Centre for Social Science Research) 429
Appendix 19: Risks and benefits of participation, mitigation procedures 430

Acronyms and abbreviations

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretrovirals
AZT	Zidovudine (AZT, Retrovir)
BCMM	Buffalo City Metropolitan Municipality
ESA	Eastern and Southern Africa
HIV	Human immunodeficiency virus
HSRC	Human Sciences Research Council
NGO	Non-governmental organisation
PMTCT	Prevention of mother-to-child transmission
STI	Sexually transmitted infection
TAG	Teenage advisory group
TB	Tuberculosis
THP	Traditional health practitioner
UCT	University of Cape Town
UNAIDS	The joint United Nations programme on HIV and AIDS
UNICEF	The United Nations Children's Fund
UTT	Universal test and treat
VMMC	Voluntary Medical Male Circumcision
WHO	World Health Organization

Glossary

Amafufunyana	Spirit possession by means of sorcery; often manifest as a mental disorder
Umkhwetha (singular) / Abakhwetha (plural)	Initiate(s)/trainee(s); as used here, initiate(s) of ulwaluko
Bhuti	Brother
Ezobudoda	Manhood things; the name of the sub-study that informed this doctorate
Gogo	Grandmother; also used to refer to a traditional health practitioner amongst traditional health practitioners trained within certain traditions (such amaZulu, emaSwati)
Ibhoma (singular) / amabhoma (plural)	Temporary structure(s) in which initiates sleep
Igqirha (isiXhosa) / isangoma / sangoma (isiZulu)	Traditional health practitioner/diviner (often used interchangeably)
Ikhankatha (singular) / amakhankatha (plural)	Traditional caregiver(s)/guardian(s); as used here, for initiates during ulwaluko
Ikrwala (singular) / Amakrwala (plural)	New graduate(s); as used here, new graduate(s) from ulwaluko or a new man/new men
Ilulwane	A bat; understood to be an 'in between' creature, not a bird, nor a rodent; used to refer to someone who is neither a boy nor a man
Ingcibi (singular) / iingcibi (plural)	Traditional surgeon
Indoda (singular) / amadoda (plural)	A traditionally circumcised person; a man/men
Inkwenkwe (singular) / amakhwenkwe (plural)	Boy(s)

Inqalathi (singular) / amanqalathi (plural)	Boy(s) who bring abakhwetha food and provide other help to them
isiDoda	Manhood language
ixhwele (isiXhosa) / inyanga (isiZulu)	Traditional health practitioner (herbalist)
Kraal	Enclosure for animals and livestock; also a space of ceremony for men
Muti[1] (isiZulu)	Traditional medicine, derived from the word umuthi (tree)
Mzantsi Wakho	Your South / Your South Africa; the study under which this research was conducted
Nyamezela	Persevere
Ubungoma	Traditional healing tradition
Ukubhabha	To fly (as a bat does); used here to describe someone who does something that renders ulwaluko incomplete
Ukuthwasa	The process of initiation to become a traditional health practitioner
Ukuqinisa	To strengthen/to fortify; a process administered by traditional health practitioners using ceremony and medicine, commonly by putting traditional medicine into the body via small cuts in the skin
Ulwaluko	Rite of passage from boyhood to manhood (Ntombana, 2011) of traditional initiation/circumcision; entails circumcision followed by a three- to six-week period of separation from society (Mfecane, 2016)
Imbeleko	Rite of birth; ceremony to introduce a child to the ancestors
Wena	You

[1] British colonial misspelling. Originally spelt 'muthi', it has become commonly accepted to spell without the h.

List of figures

Figure 1: Traditional health practitioner prepares traditional medicine at one of East London's traditional medicine 'muti shops'. East London, South Africa. 18 September 2015.

Figure 2: The provision of medicines at a South African public hospital. Available at: https://rightepharmacy.co.za/our-projects/. Last accessed 11 September 2019.

Figure 3: Map of South Africa (top left), and the Eastern Cape province (bottom right). Arrows denote the Amathole District (in purple) and Buffalo City Metropolitan Municipality (in red) where this research took place. Available at: https://en.wikipedia.org/wiki/List_of_municipalities_in_the_Eastern_Cape. Last accessed 17 May 2019.

Figure 4: Image of a peri-urban area, Amathole district (top left). 3 October 2017.

Figure 5: Image of a rural area, Amathole district (top right). 19 August 2017.

Figure 6: Image of a rural area, Buffalo City Metropolitan Municipality (bottom left). 6 December 2017.

Figure 7: Image of an urban area, Buffalo City Metropolitan Municipality (bottom right). 30 June, 2013.

Figure 8: Ulwazi (13) conducting a pilot life history interview with researcher Zukolwethu Jantjies. 26 November 2016.

Figure 9: Luya (17) writes about important life events during a pilot life history interview. 26 November, 2016.

Figure 10: Luya (17) life history interview drawing depicting the death of his mother. 26 November, 2016.

Figure 11: Khwezi's (20) life history drawing. 6 October 2017.

Figure 12: Page of a health facility file of Khwezi (20) which depicts some of the events shown in his life history narrative, such as the death of his mother. Photograph taken 22 March, 2018.

Figure 13: Screenshot of a WhatsApp conversation with researcher Phakamani Kom describing his difficulty in finding health facility files. 3 May 2018.

Figure 14: Researchers Phakamani Kom and Sinebhongo Mbula conducting a participant visit. 30 September 2017.

Figure 15: Participant pack including socks, handkerchief, snack, notebook and pen (left). 18 November 2016.

Figure 16: Participant pack including socks, handkerchief, deodorant and a t-shirt (right). 22 August 2017.

Figure 17: Researcher Phakamani Kom conducts an interview with a participant in the back of a research vehicle (left). 4 October 2017.

Figure 18: Researcher Sinebhongo Mbula walking with a participant into his home to conduct an interview (right). 19 August 2017.

Figure 19: Example of a life history narrative interview where a participant discloses psychological distress and former suicidal ideation. 4 February 2017.

Figure 20: Interview with traditional health practitioners. 22 November 2016.

Figure 21: Sinebhongo Mbula and Phakamani Kom translating, transcribing and co-analysing pilot participant interviews. 25 April 2017.

Figure 22: Verification meeting between Sinebhongo Mbula and Lesley Gittings, reviewing a thesis chapter. 4 February 2019.

Figure 23: 'Merle' the research vehicle used for Ezobudoda fieldwork. 18 April 2017.

Figure 24: Researcher Phakamani Kom, trying to contact hard-to-find research participant using roster. 26 August 2017.

Figure 25: Screenshot of location pinning and communications between researchers (left). 15 September 2017.

Figure 26: Screenshot of location pinning and communications between researchers (middle). 14 September 2017.

Figure 27: Screenshots of location pinning and communications between researchers (right). 19 August 2017.

Figure 28: Getting stuck in the mud (left). 19 August 2017.

Figure 29: Getting stuck in the mud (right). 5 October 2017.

Figure 30: Stolen car tire. 5 April 2017.

Figure 31: Roster update note on the desk in the King William's Town office. 19 August 2017.

Figure 32: Article about controversial movie *Inxeba (The Wound)* in the Eastern Cape newspaper, the Daily Dispatch. 2 February 2018.

Figure 33: Khwezi (20) drawing in his life history narrative interview. 6 October 2017.

Figure 34: Khwezi's (20) life history drawing. 6 October 2017.

Figure 35: Page of a health facility file of Khwezi (20) which depicts some of the events shown in his life history narrative, such as the death of his mother. Photograph taken 22 March 2018.

Figure 36: Buja (19) depicts looking for his mother in 2012 using a crying and confused emoji. 16 September 2017.

Figure 37: Jeveno's (17) life history drawing depicting the death of his mother. 19 August 2017.

Figure 38: Zane (16) life history drawing depicting his caregiver moving home. 30 November 2016.

Figure 39: Page of a health facility file of Mayor (16). Photograph taken 22 March, 2018.

Figure 40: Page of a health facility file of Svij (25) from 2009 describing that he has not been disclosed to. Photograph taken 22 March 2018.

Figure 41: Page of a health facility file of Svij (25) from 2009 describing his inadvertent disclosure. Photograph taken 22 March 2018.

Figure 42: Khwezi's (20) life history drawing depicting the absence of his father and parental kin with an angry emoji. 6 October 2017.

Figure 43: Ulwazi (13) drawing himself in 2026. 26 November 2016.

Figure 44: Jeveno (17) depicts his hopes for the future, drawing his family, and desired home. 19 August 2017.

Figure 45: Page of Ndoda's (18) health facility file where a health worker documents that he needs to be disclosed to. Photograph taken 15 April 2018.

Figure 46: Page of Mluthwana's (16) health facility file where a health worker explains how antiretrovirals work.

Figure 47: Page of Khwezi's (20) health facility file documenting his use of traditional medicines. Photographed 22 March 2018.

Figure 48: Page of Ngamla's (21) clinic file from when he was 11 years old documenting his use of traditional medicines. Photographed 5 May 2018.

Figure 49: Ulwazi (13) conducting a pilot life history interview with researcher Zukolwethu Jantjies. 26 November 2016. (Repeat of figure 8).

Figure 50: Mzantsi Wakho team members in abstract development training and mentorship session. 13 April 2017.

Figure 51: Image of pamphlet on uwaluko and medicine-taking based on Ezobudoda findings, distributed by Eastern Cape non-governmental organisation in schools.

Figure 52: Researchers Phakamani Kom and Sinebhongo Mbula discussing circumcision findings with school boys prior to the December circumcision period. 2 November 2017.

Figure 53: Researchers Phakamani Kom and Sinebhongo preparing to deliver an oral poster presentation at the 2017 AIDSImpact Conference. 12 November 2017.

Figure 54: Image of front pages of policy documents including finding from the Mzantsi Wakho study.

Figure 55: Various forms of evidence dissemination from the Mzantsi Wakho Project.

List of tables

Table 1: Participant Table: Adolescent boys and young men

Table 2: Participant Table: Biomedical and traditional health workers and key informants

Table 3: Laws, guidelines and policies that guided the ethical considerations for this research

Table 4: Recommendations table

List of appendices

Appendix 1: Life history narrative tool (English)

Appendix 2: In-depth, semi-structured interview tool (English)

Appendix 3: Interview guide and questions – Biomedical health worker

Appendix 4: Interview guide and questions – Traditional health practitioner

Appendix 5: Interview guide and questions – Key informant

Appendix 6: Details of the informed consent/assent process

Appendix 7: Information guide and informed consent form (English) for adolescent participants.

Appendix 8: Information guide and informed consent form (English) for traditional and biomedical health workers and key informants.

Appendix 9: Researcher hiring and training criteria

Appendix 10: HIV status-non disclosure additional information

Appendix 11: Pre and post interview checklist

Appendix 12: Reflection form

Appendix 13: Confidentiality agreement

Appendix 14: Referrals and legally mandated reporting

Appendix 15: Dissemination activities

Appendix 16: UCT HREC Ezobudoda ethics approval & renewal

Appendix 17: EC DoH Ezobudoda ethics approval

Appendix 18: Mzantsi Wakho ethical approvals

Appendix 19: Risks and benefits of participation, risk mitigation procedures

Chapter One: Introduction

In July 2000, Xolani Nkosi Johnson made history when he spoke at the 13th International AIDS Conference in Durban. He was 11 years old, and at the time, he was the oldest known child born with HIV. An activist, he called for the South African government to roll out zidovudine (AZT) to HIV-positive pregnant mothers to prevent mother to child transmission of HIV. He died in 2001 at the age of 12.

Fortunately, things have changed since Nkosi's death. Although there is still no cure, antiretroviral therapy (ART) provides pregnant mothers with the possibility of reducing the risk of transmitting HIV to their infants. ART also provides children born with HIV the opportunity to live healthily into adulthood. However, in this era of ART and universal test and treat (UTT) (WHO, 2016b), health and social systems continue to fail many adolescents and young people. Despite much-needed increasing policy and programmatic focus on this group, many adolescents living with HIV have persistent, dismal health outcomes. Notably, they are poorly retained in the HIV cascade of care and have poor adherence to ART (Nachega *et al.*, 2009; Hudelson and Cluver, 2015; Cluver *et al.*, 2018). For this reason, AIDS-related illness is the leading cause of death amongst adolescents and young people in Eastern and Southern Africa, and the second-leading cause worldwide (WHO, 2015). Since 2000, AIDS related-deaths have tripled amongst adolescents (ages 10-19), while declining in all other age groups (WHO, 2015).

Alongside the urgent scale-up of effective responses, an expanded evidence base on the needs and challenges faced by this group is required. Using exploratory, process-focused and qualitative methods that highlight the voices, embodied knowledge and lived experiences of adolescents and young people is crucial to building this evidence base. When adolescents and young people are adequately supported and engaged, these methods may foster knowledge to better support their health and well-being (Campbell *et al.*, 2009; Skovdal and Cornish, 2015; Skovdal *et al.*, 2017). Participatory research and work may offer similar benefits. Such methods have the potential to transform gender norms and support well-being when they engage with positive aspects of masculinity and the vulnerabilities of men and boys (Gibbs, Vaughan and Aggleton, 2015; Stern, Clarfelt and Buikema, 2015).

Both the adolescent and adult HIV epidemics are gendered. Women and girls are more likely to contract HIV for biological and social reasons, and men have poorer AIDS-related outcomes. In Eastern and Southern Africa, men are more likely to die of AIDS-related illness, less likely to adhere to ART, and less likely to be retained in the HIV cascade of care (Nattrass, 2008b; Cornell *et al.*, 2010; Cornell, McIntyre and Myer, 2011; Johnson, 2012). It has been suggested that these poor health outcomes are related to two factors. Institutional supply-side barriers, including opening times, locations and services provided do not meet men's needs (Dovel *et al.*, 2015). In addition, harmful hegemonic masculine norms equate illness with emasculation and place pressure on men to act tough and suppress emotion (Jewkes *et al.*, 2007; Colvin, Robins and Leavens, 2010; MenEngage, Promundo and Sonke Gender Justice, 2015). This deters men from accessing health services. In line with global trends, men in South Africa die, on average, 6.2 years earlier than women (Statistics South Africa, 2018).

Men's poorer AIDS-related health outcomes, and the need to better engage men and boys in HIV prevention and treatment initiatives, are being increasingly acknowledged (Colvin, 2019). The (2017) UNAIDS report '*Addressing a Blind Spot in the Response to HIV'* argues that improving men's access to prevention and treatment services would result in a 'triple dividend', benefitting boys and men themselves, as well as their sexual partners and families. In July 2019, activists, academics, scientists and programme implementers gathered at the first Men & HIV pre-conference forum at the International AIDS Society Scientific Conference in Mexico City—reflecting a growing international acknowledgement of men's poor outcomes across the HIV continuum of care. Like adolescents, increased evidence and programmatic and policy attention is needed for men within the HIV cascade of care (Colvin, 2019).

A growing literature now explores issues of masculinity and HIV in Southern Africa (Morrell, Jewkes and Lindegger, 2012). However, Mfecane (2018b) suggests that gender and health interventions within this region have seen limited success because they are not adequately grounded in local contexts and theories of gender. A small literature also suggests that men are more likely to access 'traditional' than 'biomedical' health services, and that such pluralism, depending on how it is practiced, has great potential to support health outcomes or to be heavily

damaging, if men initiate later onto ART (Beck, 2004; Nattrass, 2005b, 2005a; Wreford, 2005b; Wreford and Esser, 2008; Mills, de Paoli and Grønningsæter, 2009; Chikovore *et al.*, 2016; Moshabela *et al.*, 2017). There has been little in-depth recent exploration of medical pluralism amongst men, which may be an important area of enquiry (Colvin, 2019). Even less research has been conducted on adolescence and medical pluralism. The term 'medical pluralism', as it is used throughout this thesis, describes the use of both traditional and biomedical products and services.

It has been suggested that a 'neglect in focus on adolescent boys and young men means that we have failed to understand how gender affects and drives the burden of ill health for adolescent boys and young men' (Makusha, 2019). Despite a few promising research projects and interventions that focus on HIV and adolescent boys and young men, the HIV response for this group is largely 'absent, except for voluntary medical male circumcision' (Makusha, 2019). Few studies have explored masculinity-related gendered aspects of HIV-positive adolescence. Troubling recent evidence makes a strong case for such work. A recent study of adolescents living with HIV in Cape Town found that elevated viral load was significantly associated with being male, and older age (Brittain *et al.*, 2017). Similarly, a study with adolescents living with HIV in Zambia found that being male was a factor significantly associated with reporting incomplete adherence, and that males were almost double as likely to report missing two or more days of medicine than their female counterparts (Denison *et al.*, 2018). These age and gender-specific health practices, and the processes that form them, require further elucidation.

There is also a small body of literature about child and adolescent masculinities and the pressures to perform to hegemonic masculine norms in contexts underlain by poverty, HIV and disempowerment (Govender, 2011; Shefer, Kruger and Schepers, 2015; Hensels *et al.*, 2016). This work highlights the vulnerability and uncertainty of adolescent boys and young men, and demonstrates the importance of better understanding adolescent boys, rather than simply considering them in contrast to vulnerable adolescent girls (Gibbs, Vaughan and Aggleton, 2015). These studies point to gaps in research on HIV-positive adolescent masculinities, and highlight the importance of considering and exploring the challenges and needs of boys as well as girls.

Although this thesis focuses on HIV-positive adolescent boys, findings are also relevant to prevention efforts, which are a growing concern for this demographic group. Young males are the only group with increased HIV incidence in South Africa. In the recent Human Sciences Research Council (HSRC) survey, young men's HIV incidence went up by 11% (HSRC, 2018). This is potentially demonstrative of the efficacy of intervention targeting adolescent girls and young women, a clearly important initiative in this high-incidence group. It also shows that efforts are also needed to shift incidence patterns in male youth.

The health practices of adolescent boys and young men living with HIV represent an important line of enquiry for a number of reasons. First, there is a need to gather evidence to inform responses to the adolescent HIV epidemic. As mentioned above, the severity of the adolescent HIV epidemic includes poor health outcomes, low rates of adherence to ART and high mortality. Second, exploring the processes through which HIV medicines-taking and service engagement behaviours are formed and sustained for adolescent boys and young men may provide valuable insights on men's poorer AIDS-related health outcomes, onwards transmission, and higher mortality. Third, despite strong evidence that medical pluralism represents both opportunities and risks amongst adults living with HIV, there has been little enquiry into adolescent medical pluralism, although it may contain the same potential benefits and harms. Fourth, we can expect that adolescent boys and young men as a group will see sharp increases in HIV prevalence in their later years, suggesting that adolescence may be a critical time for identifying how vulnerabilities and risk behaviours form among boys, and where interventions may be most successful. Exploring the experiences and choices of adolescent boys may provide insight into the processes that create the conditions for men's poorer HIV-related health outcomes as they enter into their mid-20s and early 30s. This is especially relevant in light of emerging evidence from the HSRC (2018) dataset that young males are the only group in which rates of HIV incidence are increasing. Lastly, age-disparate sex between older men and younger women is a key driver of the heterosexual epidemic. HIV prevalence increases sharply amongst men in their 20s and into their 30s, which also puts their partners at risk.

Research questions

This study explored the health practices of adolescent boys and young men (ages 13-22) living with HIV in the Eastern Cape Province of South Africa. It asked '***What are the practices of health-service engagement of adolescent boys and young men living with HIV, and through what processes are these practices formed and sustained***?'

Sub-questions included:

1) In what ways do adolescent boys and young men living with HIV engage with 'traditional' and 'biomedical' health services? What types of services do they seek, with whom, and for what purposes? How are these behaviours taken on and sustained, or supplanted and replaced?
2) What key beliefs and experiences influence the perceptions of adolescent boys living with HIV about what it means to be a man and hegemonic norms of masculinity(ies)? How do these influence their health behaviours, including circumcision, medicines-taking, and engagement with 'traditional' and 'biomedical' health services?
3) How do adolescent boys living with HIV manage medicines-taking during and after ulwaluko (traditional circumcision/initiation)?
4) What are adolescents boys' and young men's understandings of an HIV-positive status, including in 'biomedical' and 'spiritual' terms? How are these understandings formed? How do they relate them to their own practices of health seeking?

Research context, methods and methodologies

This research was conducted as a sub-study of the Mzantsi Wakho (isiXhosa for 'Your South Africa') research project. In 2019, Mzantsi Wakho is the largest known community-traced, longitudinal, mixed methods research study of adolescents living with HIV. This study combined qualitative and quantitative methods to study risk and resilience-promoting factors for ART adherence and sexual health among adolescents living with HIV (n=1,060 adolescents living with HIV and n=467 community controls) (Hodes *et al.*, 2014).

The sub-study, which formed the basis of this doctoral work, was called Ezobudoda (isiXhosa for 'Manhood Things'). Methods included art-based life history narrative interviews with adolescent boys and young men ages 13-22 living with HIV (n=36), as well as in-depth, semi-

structured interviews with the same group (n=32), and analysis of their health facility files (n=43). It also included individual and group in-depth semi-structured interviews with traditional and biomedical health practitioners (n=14) to gather external, but related, perspectives. Data were collected in rural, urban and peri-urban areas in the Buffalo City Metropolitan Municipality and Amathole District of the Eastern Cape Province. The research design and methods chapter provides more detail about the research context and methods.

This research engaged a broad theoretical and conceptual framework in relation to gender, health practices and adolescence. It used a life history approach, alongside a social theories of practice approach (Blue *et al.*, 2016) to understand how life histories and experiences shaped health and gender-related practices. The concept of hegemonic masculinit(ies) was employed, where appropriate, to understand normative contextual masculine ideals and practices. Masculinity within the study site is organised around inkwenkwe (boyhood) and indoda (manhood), with the successful completion of ulwaluko (traditional initiation/circumcision) as the organising factor that defines these two states. These concepts were central to the research design, analysis and findings. This thesis also employs the lens of medical pluralism to consider participant practices of engagement with both traditional and biomedical health services. The literature review chapter provides more detail on these theoretical and conceptual frameworks.

Study aims and objectives

This thesis explores the health practices of adolescent boys and young men living with HIV, and how these practices are formed and sustained. In doing so, it aims to contribute to knowledge and respond to the need for more in-depth and contextually-grounded gender and health research with this under-researched group. It considers health practices more broadly than within solely biomedical contexts. By engaging art-based life history narratives, and triangulating youth voices and stories across various data sources, this work also contributes methodological findings that elicit new forms of evidence. It forefronts the voices of young people, rather than drawing on adult perspectives as proxies, and considers the ethical and methodological benefits and challenges of this approach.

Overview and structure of the thesis:

This introductory chapter, Chapter One, presents the overall aims of the research, and provides background to its relevance. It briefly outlined the methods used, presented the research questions that guided this work and provided a high-level overview of key findings.

Chapter Two reviews three relevant literatures: (1) masculinities and HIV, (2) HIV and adolescence, and (3) medical pluralism and traditional healing. It provides an overview of the theories and approaches that make up the conceptual framework for this study.

Chapter Three describes the research design and methods. It provides a brief historical and contextual overview of the study sites and outlines the study design and methods for data collection and analysis. It describes participant demographic characteristics, and uses a case study to map out some key ethical and methodological questions and challenges encountered during data collection. It also includes a section on positionality and reflexivity.

This thesis is comprised of four findings chapters, which respond to different aspects of the research question. **Chapters Four to Seven** present the main research findings.

Chapter Four sets the foundation for an investigation into the biosocial lives of participants across their life courses, presenting their life and health histories, gender identities and future hopes. It considers how they navigate the twin dilemmas of growing up as boys and living with HIV. This chapter focuses on participant HIV-related childhood experiences as younger children, and documents how masculinity-related norms, experiences and future ideation came to the fore as they become older.

Chapter Five considers ulwaluko as a key organising factor of masculinity within the study site, and how this rite of passage influences health practices of HIV-positive adolescent boys and young men. During and following ulwaluko, strong societal norms forbidding engagement in biomedical care made it difficult for many participants to take their pills and attend the clinic. Despite this, participants and their families demonstrated agency, creativity and resilience in

subverting and re-signifying these norms. This chapter argues for the importance of engaging contextually-grounded notions of masculinity and the way they influence health practices.

Chapter Six explores and documents participant health practices, beliefs and experiences using the lens of medical pluralism. It investigates how HIV affects participant performances of masculinity, and conversely, how masculinity influences how HIV-positive young men engage with traditional and biomedical health services. Findings elucidate how health behaviours are formed, reproduced and interrupted during this life phase.

Chapter Seven considers how methodological findings from this study may be applied to HIV-related initiatives with adolescent boys and young men. It highlights the significance of positionality and inter-subjectivity, explores strategies for engagement and considers the potential opportunities, shortfalls and challenges of research and interventions with this group. It has been accepted for publication as a book chapter, and, with the approval of the doctoral degrees board, is included as it will appear in the book.

Chapter Eight concludes this thesis. It discusses the key findings that form the backbone of this research and outlines their contribution to knowledge. It synthesises data-driven and methodological findings, and considers what they might lend to further research, policy and programming.

Chapter Two: Literature review

This chapter has two sections. It starts with an overview of the theoretical and conceptual frameworks that guide this research. These are organised into the categories of gender, adolescence and health. Following this, three distinct, but related, empirical literatures are reviewed. These are: HIV and adolescence; HIV, men and masculinit(ies); and, traditional health practices and medical pluralism.

This chapter provides an overview of the literature and concepts relevant to the overall findings of this thesis. However, each findings chapter also provides a more in-depth review of the literatures relevant to that chapter's findings. This approach was taken because of the breadth of literatures relevant to the topics explored. It also demonstrates how findings are situated within these various bodies of knowledge, and what the findings contribute to them.

Conceptual and theoretical frameworks

Gender

Masculinities theories within gender studies emerged prominently in the 1980s, and have been central to the inclusion of men within the field of gender research (Morrell, Jewkes and Lindegger, 2012). Feminist thought and activism has been central in forming social movements and studies that include issues of men and masculinities (Gardiner, 2005). The concept of 'hegemonic masculinity' has played a foundational role in masculinity studies and is defined as 'the configuration of gender practice which embodies the currently accepted answer to the problem of legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women' (Connell, 2005). Considered to be the dominant and idealised form of masculinity within a society, hegemonic masculinity imposes meanings about the position and identity of other forms of masculinity and femininity (Connell, 2005).

Within the South African context, hegemonic masculinity as an academic concept was first applied by Morrell (1998, 2001) to 'explain the nature, form and dynamics of male power'

(Morrell, Jewkes and Lindegger, 2012, p. 12). Acknowledging the presence of multiple dominant masculine ideals, the concept was broadened to include multiple hegemonic masculinities. This concept has been applied as a way to understand male behaviour, and to examine how male dominance is reproduced in hierarchies among men and over women (Jewkes and Morrell, 2010; Morrell, Jewkes and Lindegger, 2012). The emergence of masculinities research in South Africa in the late 1990s changed conceptions of men as a 'conceptually unproblematic (yet highly problematic), gender-neutral category' (Morrell, Jewkes and Lindegger, 2012). Ratele (2014b) has suggested that in South Africa, close attention must be paid to grounding gender equality in practice. He has documented how gender equitable beliefs and narratives may be held in 'the abstract', but not enacted in meaningful, practical ways. The contexts and conditions of men and masculine gender norms are also a central consideration in gender work (Bhana, 2005). Authors including Mfecane (2016, 2018a, 2018b), Ratele (2013) and Morrell (2016) have suggested that gender norms from the 'Global North'[2] or the 'West' must be carefully considered in their use and applicability within the South African context.

In many settings, hegemonic forms of masculinity promote values and practices of independence, physical strength, sexual prowess, and restraint in displays of emotion or vulnerability. These values and practices are, in turn, seen to act as powerful barriers to avoiding health risks and managing health problems effectively when they do emerge (Courtenay, 2000). This understanding of the potential links between hegemonic forms of masculinity and poor health has been applied to the field of HIV and health research as a way to understand men's worse engagement in health services, risky sexual practices and poorer HIV-related outcomes (Gibbs, Vaughan and Aggleton, 2015), which are described further later in this chapter. Such 'performances' of masculinity can be understood through the theory of performative gender, that gender is socially constructed, performed and reproduced (Butler, 1988). Gender norms vary between societies and are based on history, situation and positionality. They are fluid and change over time. Within the realm of masculinities, it is recognised that there are multiple masculinities within a given society, and that masculinities are dynamic and situational, with values and

[2] The limitations of literal and/or simplistic interpretations of geographical terms describing regions and locations have been noted by scholars such as the Comaroffs (2012), who suggest that power and marginality are important considerations in interpretation.

practices varying in different contexts (Jewkes *et al.*, 2015). Messerschmidt (2018) suggests that hybrid hegemonic masculinities are hegemonic masculinities that include feminine or subordinate masculine displays. Paradoxically, such masculinities can serve to reinforce hegemonic masculinities. The concept of hybrid hegemonic masculinities has relevance here, in that it provides conceptual grounding for multiple enactments of masculinities.

The concept of hegemonic masculinity encompasses diverse behaviours and identities, produced contextually and relationally (Wetherell and Edley, 2014). This thesis recognises the changeability and multiplicity of masculinities, and the limitations of the concept of hegemonic masculinities in its application to individual-level analysis. Hegemonic masculinity is used as an interpretive framework through which to view the practices of adolescent boys and young men, in relation to the research at the centre of this thesis. This thesis considers how hegemonic masculine norms were interpreted, practiced, reified and subverted within the study context.

Social scientists in Southern Africa have a rich history of emphasising the importance of context in limiting or enabling the effectiveness of HIV interventions (Hodes and Morrell, 2018). In his theoretical work on Xhosa masculinity, Mfecane (2016, 2018b) argues that 'Western' gender theories are limited in their application to Xhosa masculinit(ies) in which the concept of indoda[3] is central. Similarly, in her work on social representations of AIDS and narratives of risk, Zungu (2013) found that the meanings of some HIV prevention messages as constructed within a 'Western' paradigm may be in conflict with meanings within other contexts. Oyěwùmí (1997) posits that dominant gender narratives and interpretations of the social world 'cannot be assumed uncritically for other cultures' in her writing about her work in Nigeria. The ways that gender and masculinity are understood locally must be central to the design and evaluation of research and interventions. It is for this reason that Mfecane (2018b) suggests that an absence of contextually-grounded theory and practice has limited the success of masculinities and health research and intervention in South Africa.

[3] Constructs of masculinity in the research site hold a strong distinction between a 'boy' (in isiXhosa *'inkwenkwe'* – uncircumcised boy) and a 'man' (in isiXhosa '*indoda*' – a traditionally circumcised person), which are defined by whether a person has completed the process of *ulwaluko*.

This thesis employs notions of both hegemonic masculinities and Xhosa masculine identities encapsulated within the terms *indoda* and *inkwenkwe* to examine how boys and young men perform, reconstruct, and resist health-related masculine norms in the study context. It has been suggested that the use of the concept of hegemonic masculinity may be limited in Xhosa conceptions of manhood (Mfecane, 2016). However, this concept has been used in places in this thesis to explore masculinity-related norms within the study context, including as a framework to understand how power is articulated within indoda. For example, in addition to engaging the aforementioned Xhosa masculine identities, Chapter Five on ulwaluko engages the concept of hegemonic masculinities to explore the liminal and stigmatised masculine identity of *ilulwane*, which participants aimed to avoid at high costs. Findings in Chapter Five also explore how various masculinities are enacted during participants' time as abakhwetha (initiates) and amakrwala (new men) living with HIV. Zungu (2013) also explored multiple constructs of Xhosa masculinities and their relation to HIV risk. *Isishumane* is a stigmatised masculinity, used to refer to men without partners or with only one partner (Mfecane, 2004; Hunter, 2005; Zungu, 2013). *Ubushumane* is considered to be a marginalised masculinity that may be associated with risky sexual behaviour. It has been used to describe men who do not conform to hegemonic norms of masculinities and are labelled as bewitched, weak, stupid or mad (Frosh, Phoenix and Pattman, 2003; Mfecane, 2004; Sideris, 2005; Zungu, 2013). *Isoka* (an isiXhosa term for 'a player' or 'Casanova') masculinity is considered to be desirable and admirable. The cultural imperatives of *isoka* masculinity have been long been associated with sexual health risk, sexual conquest, multiple partners and disease (Varga, 1997; Hunter, 2005; Mfecane, 2008; Zungu, 2013) and more recently, linked to HIV transmission risk (Mane and Aggleton, 2001; Walker, Reid and Cornell, 2004; Zungu, 2013).

Underpinning this research is also a feminist methodology, which seeks to grapple with the negative effects of a global system of male dominance and patriarchy on the physical and emotional well-being of gender non-conforming people, transgendered and cisgendered men and women, boys and girls. Patriarchy, the system of male domination and power (Bradshaw, 1994) is present throughout the world, including within South African societies. Although it ensures that men generally have more privileges, opportunities and power than women, this system is damaging to men as well as women, albeit in varying degrees and different ways (hooks, 2004).

This study carefully employed the concept of hegemonic masculinities. It considered both its patriarchal and harmful aspects, as well as how men and boys conform to and resist hegemonic masculine norms. Connell (2005) acknowledges that hegemonic masculinities are rooted in male dominance and power, conveying both benefits and harms to men. As a concept, hegemonic masculinities also allows for a distinction between global systems of power and patriarchy from men, boys and individuals, while acknowledging that there is a complex interplay between structural factors and lived experiences. However, as Hunter (2010) argues, enactments of hegemonic masculine norms are linked to patriarchal power, which is difficult to shift and subvert. In recognising that there are both positive and harmful norms of masculinities, the concept avows the potential for more gender-equitable masculinities. It is also important to give attention to asymmetrical power relations within and between men, women and gender non-binary people. Masculine power dynamics are not only fluid, but differ by ethnicity, class and age (Shefer *et al.*, 2007).

Intersectionality

Despite a generally higher social status and position than women, girls and non-binary people, men's and boys' experiences of power and privilege are far from uniform. The theory of intersectionality, developed by civil rights advocate and scholar of critical race theory Kimberlé Crenshaw, is a core conceptual element of this study and participant identities are considered through this lens. This thesis engages the term, acknowledging that identities and power can and do shift across time and in different environments. Crenshaw (1990) puts forth that it is not enough to look at power disparities and oppressions through a single lens. Rather, lived experiences are informed by multiple and intersecting privileges and marginalisations. For example, contextual factors at the fore of shaping participant experiences included structural and historical contexts of racialisation, marginalisation and poverty. Ratele (2014a) suggests that in South Africa, Black men embody a space of hegemony within marginality, and that the material conditions of poor, Black men are necessary to consider in studying masculinities and health within the South African context. Similarly, evidence suggests that gender transformation interventions with men who are unemployed or poor needs to also address their economic exclusion from the capitalist system (Silberschmidt, 2001; Greig, 2009; Gibbs, Sikweyiya and Jewkes, 2014; Dworkin, Fleming and Colvin, 2015; Gibbs, Vaughan and Aggleton, 2015). This

study's findings support this imperative, and document the intersecting impacts of economic exclusion, HIV and joblessness for participants growing up with HIV and reaching working age. Other factors contributing to diminished power for participants as a group include that they were living with HIV, which remains highly stigmatised, and were young people living in a society with strong age-based hierarchies.

The next section reviews age-related conceptual frameworks, including the ecological model of youth development and adolescent resilience and vulnerability.

Adolescence

Rather than focusing solely on individual agency and practices, it is important to pay attention to social structures that perpetuate unequal power relationships when considering frames of resilience, risk and vulnerability for adolescents and young people living with HIV.

Risk and vulnerability framings have changed and evolved over the course of the HIV epidemic (Hodes and Morrell, 2018). Although the vulnerability of HIV-affected children and adolescents has been a focus of public health and HIV literature to date (Edwards, 1996; Boyden, 1997; Fassin, 2008), there is also a growing literature documenting children's agency and resilience in contexts of vulnerability and HIV (Govender, 2011; Skovdal and Daniel, 2012; Betancourt *et al.*, 2013). It has also been suggested that ideas of childhood 'innocence' have limited the HIV-related information children receive, displacing their right to information about sexual health (Bhana, 2008). The 'new social studies of childhood' perspective sees children as competent, active social actors who can shape their own realities and appropriate their social worlds (Matthews, Limb and Taylor, 1998; Holloway and Valentine, 2000; Christensen and O'Brien, 2003). This approach aligns with the 'ecology of youth development' approach which conceptualises mutually influential relationships between individual, biological and contextual factors as important to youth development, resilience and well-being (Lerner, 2005). This study recognises the creativity, agency and resilience of HIV-positive adolescents and their communities, while also exploring the contextual factors that may enable or limit their ability to exercise agency, build resilience and achieve good health (Hutchby and Moran-Ellis, 2005; Skovdal and Andreouli, 2011; Skovdal and Daniel, 2012). For this reason, this thesis forefronts

the voices of young people themselves, rather than using adult perspectives as proxies for their practices and experiences (Hodes *et al.*, 2014).

A robust scholarly literature documents how HIV alters the 'social ecology which undergirds healthy child development' and 'disrupts variables at the individual, family and peer/community level' (Benard, 1995) that ordinarily mitigate risks and promote resilience (Werner, 1989; Cowan, Cowan and Schulz, 1996; Betancourt *et al.*, 2013). An emerging literature highlights a clear need for further focus on the experiences and resilience-enhancing factors of adolescents living with HIV in resource-constrained settings (Skovdal and Daniel, 2012; Betancourt *et al.*, 2013; Toska *et al.*, 2016), including to elucidate how a variety of multi-level factors influence resilience and well-being (Masten and Powell, 2003; Sapienza and Masten, 2011; Skovdal and Daniel, 2012).

In line with international practice (such as in UNICEF 2017), this thesis defines adolescents as people between the ages of 10-19. Participants over the age of 19 are referred to as 'young people'. Otherwise, they are denoted by whether or not they have been traditionally circumcised, and referred to either as inkwenkwe (an uncircumcised boy) or indoda (a traditionally circumcised person, a man). This is done to acknowledge the centrality of these concepts as organising factors in masculinity and age within the study site.

Theories of Health

Theories of health were also central to this study, given its focus on the biosocial lives and health practices on HIV-positive adolescent boys and young men. Ecosocial perspectives of health consider the dynamic interaction between various individual, communal and structural factors, similar to ecosocial approaches to youth development. These integrate 'biological and social reasoning and a dynamic, historical and ecologic perspective to develop new insights' (Krieger, 2001). It has been suggested that 'investigations that leverage social ecological theories in the context of HIV/AIDS can help broaden what is known about factors contributing to children's long-term well-being, and can contribute to the growing evidence base on protective processes that help children achieve good functioning despite exposure to a range of difficult life circumstances.' (Betancourt *et al.*, 2013, p. 424).

As multidimensional and dynamic frameworks, ecosocial theories of health integrate both social and biological reasoning and history, considering living standards as well as non-economic factors (Susser and Susser, 1996; Krieger, 2001). Such theories are a starting point for understanding patterns of disease, health and well-being as 'biological expressions of social relations', and the ways in which 'social relations influence our most basic understandings of biology and constructions of disease' (Fleck, 1935; Krieger, 2000a, 2000b, 2000c; Levins & Lewontin, 1985; Rosenberg & Golden, 1992; Krieger, 2001). The term 'eco' (or 'ecological') demonstrates how these theories include the study of evolving interactions amongst organisms, energy and inanimate matter over space and time and the 'social' aspect indicates that ecological analysis is not a substitute for social analysis (Peterson and Parker, 1998; Roughgarden, 1998).

Ecosocial theories can be used for analysis, inquiry and action for population patterns of disease as they relate to biological, social and ecological organisations (Krieger, 2001), and have been applied in HIV research by scholars such as Feldacker et al. (2011) and Mburu et al. (2014). Such an orienting model allows for an exploration of the processes and relationships between inter-related dimensions of individual, familial, community, cosmological and socio-structural factors. More recently, King (2017) documented ways in which political and environmental conditions produce health inequities using case studies of HIV in South Africa and climate change in Botswana. His work suggests that the role of sociopolitical factors are too often minimised in research and policy.

A life-course perspective and social theories of practice approach were the two inter-related concepts applied in this study to conceptually ground an ecosocial framework.

A life-course perspective suggests that one's health at any given age is reflective not only of current conditions but also previous living circumstances, starting in utero (Krieger, 2001; Kuh *et al.*, 2003). In the realm of HIV, the social, psychological and biological impacts and harms of HIV and AIDS are joined together throughout the life course and inter-generationally (Richter, 2016). The 'first 1000 days of life', spanning the period in utero until around the second birthday is considered to be an important period in development (Cusick and Georgieff, no date). Inter-

generational aspects of a life-course perspective resonate with the traditional knowledge systems in the study site, which are discussed and defined later in this chapter. Both perspectives acknowledge that a variety of inter-generational factors and experiences shape lived experiences, health and well-being. As described further in the research design and methods chapter, health-focused life history narratives were used as a tool to understand how individual and family histories, processes and contexts are experienced, performed and embodied.

Social theories of practice can provide for greater insight into the ways in which health-inequalities are reproduced. Despite being part of a broader theoretical terrain, social theories of practice are useful in extending and enriching ecosocial theory. Focusing on the dynamics of social practices allows for understandings that come out of focus in macro-level analysis or when focusing on individual-level choices, relationships and processes. They consider how people's participation in certain practices is recruited and sustained, rather than taking individual motivations and desires as explanations for behaviours (Blue *et al.*, 2016). For example, medicines-taking or going to the clinic or traditional health practitioner are not single behaviours. Rather, they exist in the domains of human activity 'that are reproduced and transformed through the re-enactment and performance of specific social practices, coordinated and synchronised across space and time' (Blue *et al.*, 2016). The chances of someone becoming a practitioner of a certain health behaviour will depend on what the practice requires, what resources are available and how the individual's previous life histories (Blue *et al.*, 2016), the very factors that an ecosocial approach and a life-course perspective consider.

The opportunities for and access to certain practices are closely linked to structural conditions, which influence how social inequalities become embodied via practice (Blue *et al.*, 2016). Social theories of practice can map out pathways to health and embodiment, given that they provide a framework to understanding how 'specific practices do and do not 'capture' participation in light of unequal distribution of materials, competences and meanings that are required for participation' (Blue *et al*., 2016). The construct of embodiment suggests that lived experiences, practices and contexts manifest in people's physical bodies – that 'our bodies tell stories about our existence' (Krieger, 2005, p. 350).

Skovdal and colleagues (2017) have applied a theories of practice lens to examine how people interact with HIV services in six countries in sub-Saharan Africa. They found that interactions with HIV services were shaped by a variety of factors, which they categorised as 'materialities' including the availability of HIV medicines and services; 'competencies' which referred to knowledge of how to live with HIV; and 'meanings' such as HIV-related stigma and trust in HIV services (Skovdal *et al.*, 2017). A number of other factors also shaped engagements with HIV services, such as work and children (Skovdal *et al.*, 2017). Similar to an ecosocial approach, practice theory acknowledges patterns of health inequality and the inadequacy of individual-focused approaches. Practice theory can link these patterns to social processes, how practices and health inequalities become embodied (Blue *et al.*, 2016).

This sub-section has provided an overview of an ecosocial approach, and two separate but inter-related concepts. A social practices lens allows for an exploration of how the contextual and individual-level factors outlined in an ecosocial model form medicines-taking and health services engagement. A life-course perspective provides a long-term view of how these practices are formed, reproduced and performed.

This concludes the conceptual and theoretical framework section of this chapter, which has provided an overview of concepts and theories of gender, health and adolescence used in this thesis. The second half of this chapter reviews the literature on HIV and adolescence, HIV and masculinities and traditional healing and medical pluralism.

Empirical literatures: HIV and adolescence, men and masculinit(ies) and traditional health practices

HIV and adolescence in sub-Saharan Africa

Many perinatally infected children are now surviving into adolescence and adulthood due to increased access to ART. However, the adolescent epidemic is a continuing public health issue. AIDS-related illness is the leading cause of death amongst adolescents in sub-Saharan Africa (WHO, 2015). In Eastern and Southern Africa, the number of adolescent AIDS-related deaths has tripled since 2000, while decreasing in all other groups (WHO, 2015). The majority of the

world's children (ages 0-14) with HIV live in sub-Saharan Africa, and 1.2 million of the 1.6 million adolescents with HIV in sub-Saharan Africa live in Eastern and Southern Africa (UNICEF-ESARO, 2015).

Adolescents are underserved by existing HIV services, have significantly worse access to ART than adults do, and show lower rates of adherence, virological suppression and immunological recovery (Nachega *et al.*, 2009). The evidence shows that a significant proportion of HIV-positive adolescents are struggling to initiate and remain on treatment and engaged in the HIV cascade of care (Nachega *et al.*, 2009; Hudelson and Cluver, 2015; Cluver *et al.*, 2018). Once initiated onto ART, high rates of non-adherence (estimated to be between 27-90%) have a harmful impact on adolescent health outcomes and survival (Bakeera-Kitaka *et al.*, 2008; Al-Dakkak *et al.*, 2013). The Mzantsi Wakho study found that at baseline, adolescent participants self-reported non-adherence rates of 36% (past-week) and 52% (past-year) (Cluver, Hodes, Toska, *et al.*, 2015). In a plenary session on the first day of the AIDSImpact conference in July 2019, a presentation from the South African HSRC's HIV incidence survey highlighted low levels of viral suppression among youth ages 15-24, and documented that youth as a demographic category are less likely to be on ART (Zuma, 2019).

Documented risk factors for ART non-adherence among adolescents include various social and structural issues. These include disrupted family structures and caregiver-child relationships, non-disclosure of HIV-positive status to children by an appropriate age, mental health issues, stigma, caregiver physical illness and emotional challenges, the inability of overburdened clinic teams to provide holistic, integrated and comprehensive care, and difficulties faced by caregivers in understanding complex treatment regimens (Lam, Naar-King and Wright, 2007; Campbell, Williams and Gilgen, 2010; Campbell *et al.*, 2012; Dempsey *et al.*, 2012; Cluver, Hodes, Toska, *et al.*, 2015; Hudelson and Cluver, 2015; Cluver *et al.*, 2018).

A body of literature details the myriad operational, clinical and experiential challenges that adolescents face in engaging with and accessing health programmes (Nduna and Jewkes, 2012; Cluver, Hodes, Sherr, *et al.*, 2015; Delany-Moretlwe *et al.*, 2015; Hudelson and Cluver, 2015; Toska, Cluver, Boyes, *et al.*, 2015; Vale and Thabeng, 2015; Visser, Zungu and Ndala-Magoro,

2015; Toska *et al.*, 2016). Barriers to accessing health services and adhering to ART include treatment and travel costs, distances to clinics and pill burden and palatability (Posse *et al.*, 2008; Paediatric AIDS Treatment for Africa and World Health Organization, 2015; Hodes *et al.*, 2019). Even when access to treatment and adherence support are present, there are complex social issues such as stigma, psychological distress and fear, family conflict, and caregiver challenges that may contribute negatively to the health of adolescents living with HIV (Lowenthal and Marukutira, 2013; Sherr *et al.*, 2014; Vale and Thabeng, 2015; Hodes, 2016b).

In South Africa, there are pronounced gender- and age-related differences in HIV prevalence. The most recent HSRC survey[4] found that over one-third of all new HIV infections were in the youth age group, and that youth incidence was three times higher among females than among males (HSRC, 2018). HIV prevalence is similar among South African boys and girls in the 0-14 age range (HSRC, 2018). However, between the ages of 15-19, prevalence for girls increases sharply due to increased incidence, creating a substantial gendered prevalence difference (HSRC, 2018). Prevalence increases sharply for males in the 20-24 age range, and peaks for men between the ages of 35-39, while female prevalence peaks earlier.

Emergent findings, which bear further elucidation, also suggest that young males were the only group with increasing HIV incidence, which went up by 11%, while decreasing by 26% in young females (HSRC, 2018). More evidence is needed here, but this is potentially demonstrative of the efficacy of intervention targeting adolescent girls and young women, a clearly important initiative in this high incidence group. It is evidence that further intervention is needed to shift incidence patterns amongst youth.

While acknowledging the value of working with boys and men, this study explicitly recognises the importance and urgency of addressing issues affecting women and girls. The biological and social vulnerability of women and girls is well-documented, and accordingly much of the gendered HIV research to-date has focused on these groups (MenEngage, Promundo and Sonke Gender Justice, 2015). A strong case has rightly been made for equality and attention to the

[4] This most recent HSRC survey is not yet publicly available as a full report. These citations are based on a summary presentation on their website and will be updated when the report is published (likely in October 2019).

needs of girls and women, within a global context of patriarchy, which sees that men and boys have most determinants of health in their favour (Shefer *et al.*, 2007) and renders women and girls more vulnerable. Within this vulnerability, relational gender dynamics manifest in complex ways. Jewkes and Morell (2012) document some of these nuanced dynamics, describing multiple, dynamic femininities and the ways in which young women's agency varies situationally and by relationship stage. Far from being a homogenous and defenseless group, young women experience a 'multiplicity of … hopes and desires and circumstances of emotional and relational fulfilment' (Jewkes and Morrell, 2012) as both victims of the patriarchy, as well as performers and proponents of an established gender order (Jewkes and Morrell, 2012).

A growing literature has documented the pressures that boys and men experience to conform to hegemonic masculine norms in contexts of marginalisation, poverty and HIV (Steinberg, 2008; Langa, 2010; Govender, 2011; Shefer, Kruger and Schepers, 2015; Hensels *et al.*, 2016). This work documents uncertainties and vulnerabilities of adolescent boys and young men. In doing so, it demonstrates the importance of going beyond framing boys and men in relation to vulnerable adolescent feminities, to better understand their challenges for their own sake. These texts suggest that initiatives to address social and community-level factors, alongside participatory identity construction work, are better placed to shift harmful gender norms than individual-level initiatives.

Focusing on individual behaviours and attitudes on their own may result in an oversight of important institutional and structural factors that shape behaviours (Pease and Flood, 2008). As a time of rapid physical and psychosocial change, adolescence is a risky period for many people. It might also been an opportune time to influence the development of health, gendered and sexual behaviours. Gender transformative approaches have been defined as those that alter harmful gender practices, beliefs and ideas in recognition of the benefits of gender equitable environments (Betron *et al.*, 2012). A growing evidence base suggests that gender transformative work with boys and men can shift harmful gender norms and practices that might put them and their partners at greater risk of contracting HIV and having poor AIDS-related outcomes (WHO, 2007; Dworkin, Fleming and Colvin, 2015).

There is also a literature that documents the experiences of boys and young men in relation to HIV, stigma and risk, which is not focused solely on young masculinities but has relevance here (such as Dawes et al., 2004; Deacon & Stephney, 2007; Shisana et al., 2009; Simbayi et al., 2005; Stern, 2013). For example, Stern's (2013) study on adult masculinities using sexual history narratives found that men described early experiences of sex by respect, vulnerability and intimacy, where decisions around sexual debut were often related to peer pressure, and safer sex was often not a consideration (Stern, 2013; Stern, Clarfelt and Buikema, 2015). Alarming results from a recent study of gender differences in children (ages 4-13) living in high HIV-affected communities in South Africa and Malawi found that boys were significantly more often subjected to violence, performed worse in school and had more behavioural problems (Hensels *et al.*, 2016). Adolescent adherence and virological outcomes may also be gendered, with older boys seeing experiencing worse outcomes than girls and younger boys (Brittain *et al.*, 2017; Denison *et al.*, 2018), although further evidence is needed to support these nascent findings. These studies point to gaps in research on HIV-positive adolescent masculinities, and highlight the importance of considering and exploring the challenges and needs of boys as well as girls.

Despite a few promising interventions such as Stepping Stones (Jewkes *et al.*, 2008; Gibbs *et al.*, 2015) and the work of Sonke Gender Justice, Grassroots Soccer and the iALARM project, research and interventions focusing on HIV services and needs of adolescent boys and young men are largely absent. Voluntary medical male circumcision is one of the only areas where there is any substantial funding or attention for adolescent boys and young men. Makusha (2019) suggests that this 'neglect in focus on adolescent boys and young men means that we have failed to understand how gender affects and drives the burden of ill health for adolescent boys and young men'. It is necessary to accelerate HIV service delivery and uptake for adolescent boys and young men, and to develop male-centred, age-specific interventions that acknowledge that adolescent boys and young men are not a homogenous group, differing in terms of identity, age, experience and circumstances, mode of transmission and context (Makusha, 2019).

HIV and masculinity

There is increasing recognition of the importance of better considering men within the HIV response (Colvin, 2019). Worldwide, men have higher mortality rates for all leading causes of

death and shorter life expectancies (Shefer *et al.*, 2007) due to health behaviours related to norms of masculinity (Baker *et al.*, 2014). In South Africa, men live shorter lives than women (Institute for Health Metrics and Evaluation, 2014). The 2018 reported life expectancy for women was 67.3 for women, and 61.1 for men, a difference of 6.2 years (Statistics South Africa, 2018).

Men in South Africa are significantly underrepresented in HIV/AIDS testing, treatment and psychosocial support services as well as other sexual reproductive health (SRH) services (Cornell *et al.*, 2010; Cornell, McIntyre and Myer, 2011; Johnson *et al.*, 2013). They are more likely to default or die on ART and seek treatment less and at a later stage than women (Nattrass, 2008b; Cornell *et al.*, 2010; Cornell, McIntyre and Myer, 2011; Johnson *et al.*, 2013). It has been theorised that men's poorer health outcomes are a result of hegemonic masculine norms, which have a negative effect on health-seeking and protective behaviours.

While acknowledging how hegemonic masculine norms vary by context and shift throughout time, commonalities in global hegemonic masculine constructs include emotional and physical strength, courage, independence and self-sufficiency, toughness, sex with multiple partners, fearlessness and men's exercise of control over women and other men (Courtenay, 2000; Mfecane, 2008; Lindegger and Quayle, 2009). In an attempt to perform to these ideals embedded in hegemonic masculinity, it may be difficult for men to seek or accept health care—including HIV prevention, testing and treatment services, and other forms of support (Colvin, Robins and Leavens, 2010; Mfecane, 2010). Hegemonic norms of masculinity may make it harder for men to access necessary care because of the associations between accessing care and femininity and weakness (Jewkes *et al.*, 2007; Colvin, Robins and Leavens, 2010; MenEngage, Promundo and Sonke Gender Justice, 2015; Chikovore *et al.*, 2016).

Acceptance and disclosure of an HIV-positive status may also be different for men and women because of conventional views of male identity, fear of shame, secondary stigma and isolation from loved ones (Iwelunmor, Sofolahan-Oladeinde and Airhihenbuwa, 2015). Being HIV-positive can be seen as a barrier to having intimate relationships, children and breadwinning, obstacles to conforming to hegemonic masculine norms (Mfecane, 2008; Wyrod, 2011). HIV stigma has been documented as affecting men and women differently (Beck, 2004; Colvin, Robins and Leavens, 2010; Wyrod, 2011) and men living with HIV report more internalised

stigma, are less likely to discuss their HIV status with their friends, are more likely to have lost a place to stay or job, and more likely to report being treated differently since they tested positive (Simbayi *et al.*, 2007). Men living with HIV also report less social support and a greater likelihood to use alcohol and drugs to cope with depression (Simbayi *et al.*, 2007).

It has also been suggested that institutional supply-side barriers such as inaccessible clinic locations and hours, health providers and services that do not meet their needs contribute to men's poor testing and treatment rates (Dovel *et al.*, 2015). These barriers may include the services delivered, when they are delivered, and who they are delivered by. Deterrents for men accessing clinic-based health services include the perception of public clinics as 'women's spaces', poorly equipped and unwelcoming clinics, or feeling that clinic staff are being unfriendly or disrespectful (Colvin, Robins and Leavens, 2010; Faull, 2010; Chikovore *et al.*, 2016). Poor treatment by clinic staff, including rude and judgmental female nurses (Levack, 2005; Colvin, Robins and Leavens, 2010; Faull, 2010; Leichliter *et al.*, 2011), has also been cited as deterring men from accessing clinic-based services,[5] although less is known about the experiences of adolescent boys. Many men may be reluctant to receive health services from female carers because of gendered power dynamics, a preference to share intimate health information with someone of the same gender, as well as, in some cases, negative associations of women as untrustworthy gossips (Levack, 2005; Orner *et al.*, 2008; Colvin, Robins and Leavens, 2010; Faull, 2010; Leichliter *et al.*, 2011; Gittings, 2016).

However, men's poorer clinic attendance and engagement with the biomedical health sector does not mean that they do not seek support or make efforts to be healthy. For example, Chikovore and colleagues (2016) documented how men preferred traditional medicine in a recent treatment-as-prevention trial. Others have suggested that men may be more likely than women to access traditional health practitioners and medicines instead of clinic- or hospital-based HIV care and treatment (Beck, 2004; Nattrass, 2005a, 2005b; Wreford, 2005b; Wreford and Esser, 2008; Mills,

[5] This is not to say that clinics are 'women-friendly' either. Women are commonly subject to unfriendly and oppressive treatment in clinics, but may not have the option of choosing not to access services due to the necessity of maternal and child care (Bradford, 1991; Dickson *et al.*, 2003; Wood and Jewkes, 2006). SRH policy implementation and service delivery for women in South Africa have been inadequate, despite the presence of a strong policy framework (Cooper *et al.*, 2004).

de Paoli and Grønningsæter, 2009). Wreford and Esser (2008) suggests that traditional health practitioners may be able to support men's social, spiritual and physical well-being and, at the same time, encourage HIV testing and initiation onto ART. Given the high mortality of men living with HIV in South Africa, exploring the traditional and biomedical health practices of HIV-positive boys and men is an important line of further enquiry.

Traditional South African approaches to healing may allow for a construction of illness that does not place accountability and blame on the individual, therefore masking individual men's vulnerability (Mills, 2005; Simwaka, Peltzer and Maluwa-Banda, 2007; Wreford and Esser, 2008). Traditional health practitioners may situate illness within an emotional, spiritual, familial or ancestral context—an approach less directed at the individual. An indirect approach to discussing issues of health and well-being has been documented as a tactic well-tolerated by male clients, as it does not directly challenge hegemonic performances of masculinity (Gittings, 2016), perhaps explaining men's propensity towards traditional health practitioners. The evidence on men's poor HIV-related health outcomes, and high rates of medical pluralism, makes a strong case for greater attention to men's health practices. This study considers practices of traditional as well as biomedical practices in the critical time of adolescence for this reason.

Illness representations in many African settings emphasise uncontrollable and external factors of a supernatural nature (Bogart *et al.*, 2011). Such beliefs may associate disease and illness with an external locus of control, that is, that certain illnesses may be beyond personal control and unrelated to one's own behaviour (Lau, 1988). Ideas of fate, punishment and divine intervention have also been documented as associations with AIDS in Malawi (Simwaka, Peltzer and Maluwa-Banda, 2007). In exploring perceptions of HIV risk among young men, Wight (1999) documents that the concept of 'fate' may be used as a way to explain something that the self does not have control over. Zungu (2013) found that many male participants cited 'biology', 'fate', 'chance' and 'luck' as playing a role in men's risk of contracting HIV. In contrast, men viewed women's HIV risk as physiological. Zungu's study also found that social representations of AIDS were prominent among male participants' narratives—including that AIDS has supernatural roots and that it is a disease that afflicts Africans. This AIDS may be understood as *sisifo sabantu* ('a Black person's disease'), that can only be cured by African traditional health

practitioners and is different from the 'Western' bio-medically construction of AIDS (Mabuza, 2009; Zungu, 2013). Embedded in these concepts is the idea that AIDS is not a new disease, but one that existed in the past, contradicting 'biomedical' claims that HIV emerged in the 1980s as a global epidemic (Niehaus and Jonsson, 2005).

The literature on HIV-positive masculinities maps rich and complex relationships between an HIV-positive status and a multitude of religious and spiritual beliefs and practices. For example, Mfecane (2010) documents the tendency of people diagnosed with HIV to seek spiritual interventions in order to heal and reconstruct identities, while Nguyen (2013) draws parallels between disclosure of an HIV-positive status and religious 'confession'. It has been suggested that for men, an additional element of 'confession' is present—that of having conformed to harmful hegemonic norms of masculinity (Gittings, 2016).

Medical pluralism, traditional and biomedical health products and services

The previous section provided an overview of documented conceptions of HIV as relating to issues of a supernatural origin, and how men may be more likely to enact traditional health practices than women for HIV-related issues. This section builds on the last section, by defining traditional medicine and medical pluralism, and exploring the literature on medical pluralism for people living with HIV.

Traditional medicine: definitions and limitations

The World Health Organization (WHO) defines traditional medicine as 'the sum total of the knowledge, skills and practices, based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health and in the prevention, diagnosis, improvement or treatment of physical and mental illness' (WHO, 2000). Traditional medicine refers to 'health practices, approaches, knowledge and beliefs incorporating plant, animal and mineral-based medicines, spiritual therapies, manual techniques and exercise applied alone or in combination to treat, diagnose and prevent illness or maintain well-being'. (WHO, 1976). Traditional South African knowledge systems include collective wisdom of knowledge that has been handed down over generations (Ashforth, 2005), and may encompass herbal and spiritual treatments of illnesses (King, 2006). African traditional medicine has been

described as a rich and diverse body of knowledge developed and accumulated over thousands of years. It is includes examination and diagnosis, therapies and treatment, and the prevention, promotion and rehabilitation of the physical, mental, social and spiritual well-being of humans and animals (Gundidza and Kassilo, 2015). African Traditional Medicine has been conceptualised as combining elements of philosophy, religion, psychiatry, physiology and biology (Gundidza and Kassilo, 2015).

This traditional concept of illness has been characterised as considering health issues within the context of an underlying psychosocial, spiritual, communal or ancestral issue, while biomedical approaches focus on curing as a biological process, resulting in the disease being cleared from the physical body (Moshabela, Zuma and Gaede, 2016). Within some traditional African spiritual beliefs, good or ill health is considered to include the interaction and relationship between nature, the cosmos and particularly the relationships between the individual and other human beings, including the ancestors, who play an important role in well-being and healing (Gundidza and Kassilo, 2015). Traditional health practitioners may conceptualise health beyond the individual person and their biochemistry, into 'the consequences of social relationships for health and disease' (Green, 2012, p. 6). It has been suggested that traditional and biomedical understandings of illness differ and include different approaches and measure different things—biomedicine with a 'scientific' lens, and 'traditional healing' using an 'indigenous knowledge' lens (Moshabela, Zuma and Gaede, 2016). It has been suggested that these systems may have different strengths: biomedicine for its biological curative approach, and traditional healing from a spiritual, emotional and familial perspective (Flint and Payne, 2013).

In South Africa, traditional healing systems have been categorised into five broadly clustered types: diviners (iZangoma in isiZulu/amagqirha in isiXhosa), faith healers, herbalists, traditional birth attendants and traditional surgeons (Pretorius, 1999; Gqaleni *et al.*, 2007; Peltzer, 2009; Moshabela, Zuma and Gaede, 2016). These categories are porous and malleable, and in practice, they vary and overlap. For example, traditional health practitioners will often be trained in, and practice in multiple roles, for example, as *sangoma* (isiZulu) / *igqirha* (isiXhosa) and *nyanga* (isiZulu) / xhwele (isiXhosa) (Moshabela, Zuma and Gaede, 2016; Zuma *et al.*, 2016). Despite being broadly useful, these labels may inadequately account for the myriad systems, experiences

and practices that often fall under the broad and indistinct definition of 'traditional healing'. The label of 'traditional healing' itself has been argued to be reflective of colonial and apartheid-era perspectives and the way that they have influenced traditional health care provision settings (Rautenbach, 2007).

The terms ***tradition*** and ***traditional*** are used throughout this thesis as an imperfect approximation with conceptual limitations to describe belief systems and health practices. This thesis acknowledges that traditions are contested, fluid and subject to changes from internal and external influences and processes (Flint, 2008). Traditional beliefs are porous, mutable and context-contingent in practice, although they may retain underlying principles.

Traditional beliefs, medical pluralism and HIV

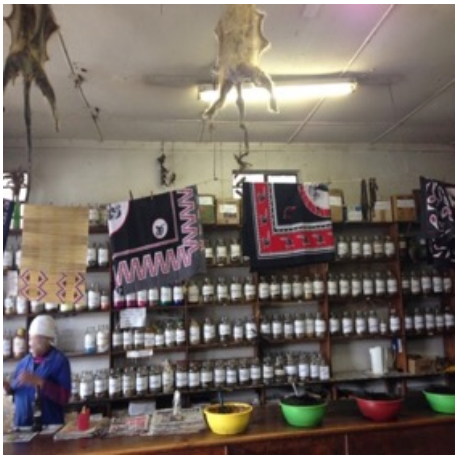



Figure 1 (left): Traditional health practitioner prepares traditional medicine at one of East London's traditional medicine 'muti shops'. East London, South Africa. 18 September 2015.
Figure 2 (right): The provision of medicines at a South African public hospital. Available at: https://rightepharmacy.co.za/our-projects/. Last accessed 11 September 2019.

That individuals understand health and illness in many ways has been documented by scholars including Janzen (1978) and Steinberg (2008). Medical pluralism is an important lens through which to consider how individuals demonstrate health-seeking behaviours within a range of health care practices and belief systems.

Traditional African aetiological explanations of illness, including AIDS, may incorporate biomedical understandings while drawing on 'traditional' or other forms of knowledge, culture

and spiritual beliefs and looking for 'ultimate' causes (Goldstuck, 1994; Semali and Kincheloe, 2002; Kalichman and Simbayi, 2004; Wreford, 2005b, 2008a; Liddell, Barrett and Bydawell, 2005; Nattrass, 2005a, 2005b; Campbell *et al.*, 2007; Wreford and Esser, 2008; Jali, 2009; Mfecane, 2010; Zungu, 2013; Rubincam, 2014). Participants in a variety of studies (including Mfecane, 2010; Nattrass, 2005a; Posel et al., 2007; Rubincam, 2014; Wreford & Esser, 2008; Zungu, 2013) have found cultural representations of AIDS including spiritual forces and witchcraft[6]. Associations between beliefs of witchcraft and AIDS has been nationally reported (Shisana *et al.*, 2005, 2014) and a core traditional belief of disease amongst the amaXhosa, and in many other African cultures is that ill health can be caused by violations of cultural taboos, and witchcraft (Ngubane, 1977; Urbasch, 2002; Posel, Kahn and Walker, 2007; Zungu, 2013). In the context of AIDS, there is a 'distinct symbolic resonance between AIDS, witchcraft, poison and pollution' (Stadler, 2003 in McNeill, 2009, p. 355). *Isigulo sabantu,* an isiXhosa term loosely translated as 'sickness of the people/death of the people' is used to explain illness and its sources, similar to the isiZulu term *ukufa kwabantu* (Ngubane, 1977; Zungu, 2013). This context dependent cultural-social representation tied to African groups highlights a spiritual dimension to health and illness and gives meaning to AIDS within the African knowledge system (Zungu, 2013). A variation of this term, *izinto zabantu* ('African things'), is used to describe ill health or misfortunes of a supernatural origin, often linked to pollution, spirit possession, or the call from ancestors to initiate as a traditional health practitioner (Zungu, 2013).

There is robust evidence of the use of both traditional and biomedical products and services (medical pluralism) in South Africa, including for people living with HIV and AIDS (Baer, 1995; Wreford, 2008a; Wreford and Esser, 2008; Sorsdahl, Ipser and Stein, 2009; Sorsdahl *et al.*, 2010; Moshabela *et al.*, 2011; Pantelic *et al.*, 2015; Moshabela, Zuma and Gaede, 2016). Traditional health practitioners are often the first health care providers patients visit when they become ill (Langlois-Klassen *et al.*, 2007; Audet *et al.*, 2014). For example, a KwaZulu-Natal

[6] The terms 'witch' and 'witchcraft' are derogatory and misleading (Ashforth, 1998). They are used here in the sense they are used within the cited studies, and because they are difficult to avoid – 'Not only are the English words common in African usage, but the indigenous terms such as the Zulu ubuthakathi have long been inflected with notions deriving from Europe as much as Africa. Nor is it possible to insist on definitional clarity and precision without obscuring the ways in which the words are actually used in everyday practice.' (Ashforth, 2001, p. 20). Like Ashforth, I use these words loosely, 'while seeking to tease out from the investigation of the context what they might mean' (Ashforth, 2001).

clinic-based study found that 70% of patients had consulted a traditional health practitioner before going to a clinic (Puckree *et al.*, 2002). In Limpopo, it has been estimated that 67% of people visit traditional health practitioners regularly (Mathibela *et al.*, 2015), and a 2008 survey of patients living with HIV (n=618) in three KwaZulu-Natal hospitals found 51% using multiple healthcare modalities (Friend-du Preez and Peltzer, 2010; Peltzer *et al.*, 2010). In Bushbuckridge, Mpumalanga, 69% of people living with HIV reported visiting both traditional and biomedical practitioners routinely for the treatment of HIV, side-effects of ART, and opportunistic infections (Moshabela *et al.*, 2011).

In line with this assertion that traditional medicines are used for the treatment of HIV (Langlois-Klassen *et al.*, 2007; Peltzer, 2009), Puoane and colleagues (2012) found that traditional medicines were often combined with ART in KwaZulu-Natal and the Western Cape. Participants in this study reported using traditional medicines for HIV-related symptoms, as well as other chronic conditions (Puoane *et al.*, 2012). Audet and colleagues (2017) documented how traditional health practitioners in a rural area of South Africa continue to treat HIV symptoms in patients, demonstrating an ongoing demand for such services. A study in Pretoria found that 15.6% of HIV-positive patients on ART used non-prescribed medicines concurrently (Malangu, 2008), and Katz and colleagues (2015) found that HIV-positive patients, regardless of whether or not they were using ART, sought out traditional medicines to boost their immune systems, as an enhancement for, or a substitute for treatment. It has also been suggested that high levels of medical pluralism are driven by dissatisfaction with the biomedical health system and socio-cultural beliefs (Wreford, 2008b; Sobiecki, 2014), and that this is particularly true in rural areas (Sobiecki, 2014; Zuma *et al.*, 2018).

The literature documenting the benefits of traditional health care, as well as some negative outcomes of the ways that pluralism is often practiced is discussed below. Negative outcomes potentially include delays in reaching biomedical services and interruption in HIV-related care, costs, poorer ART outcomes, traditional medicine toxicity, and worsening of AIDS-related symptoms due to dehydration related to traditional purgatives (Barker *et al.*, 2006; Summerton, 2006; Sorsdahl, Ipser and Stein, 2009; Moshabela *et al.*, 2011; Nxumalo *et al.*, 2011; Pantelic *et al.*, 2015; Moshabela, Zuma and Gaede, 2016; Wringe *et al.*, 2017). In addition, patients visiting

biomedical services may be unlikely to disclose their involvement in traditional healing, due to the stigma of accessing traditional services. A systematic sampling of KwaZulu-Natal ART patients found that 90% of participants who were taking herbal therapies had not told their biomedical healthcare provider (Peltzer *et al.*, 2008). There have also been accounts of claims of unsubstantiated traditional cures, with devastating consequences.

These harms and opportunities strengthen the case for nurturing new ways of knowing beyond this biomedical and traditional health binary. They also point to the need for greater inter-sectoral collaboration and research to better understand how practices of medical pluralism are formed and reproduced. Flint (2008) suggests that considering how different groups of people understand illness and health could result in more effective, culturally appropriate treatments. In a review of literature on traditional health practitioners and HIV, Leclerc-Madlala et al. (2016) conclude that traditional health practitioners provide important behavioural, information and linking services. It has been suggested that medical pluralism in South African contexts constitutes a rich opportunity to provide patients with a more complete, culturally-appropriate, plural healthcare system that combines psychological, biological, social and spiritual approaches (Moshabela, Zuma and Gaede, 2016). There is great potential for improving the success of health programmes through collaborations between the traditional and biomedical health sectors in South Africa (Wreford, 2005b; Wreford and Esser, 2008; Leclerc-Madlala, Green and Hallin, 2016; Moshabela, Zuma and Gaede, 2016).

There is limited evidence on the biological effects of traditional medicine on HIV-related health-outcomes. However, high rates of use of traditional health practitioners, combined with their documented role of supporting the communal, psycho-social and spiritual well-being of people living with HIV make a case for greater acknowledgement and engagement with such practices in research, policy and practice. It has been suggested that if the HIV response does not better take into account medical pluralism, HIV programming successes will continue to be hindered and HIV prevention and control goals will not be realised (Leclerc-Madlala, Green and Hallin, 2016). Successful collaboration between ‘traditional’ and ‘biomedical’ health will require mutual understanding and respect (Wreford and Esser, 2008; Mokgobi, 2014; Moshabela, Zuma and Gaede, 2016). As documented above, it has been suggested that medical pluralism for HIV might

be more common among men than women, and that this is an important area of enquiry in better understanding men's HIV-related health practice (Colvin, 2019). Even less research has been conducted on adolescence and medical pluralism, which is a gap in the evidence with which this thesis aims to respond.

Disrupting the 'traditional' / 'biomedical' binary

A critique rendered against the concept of 'medical pluralism' is that there are more similarities than distinctly different features between traditional and biomedical services and medicines, and that the key structuring mechanism of medical systems is based on the commodification of health care and the political economy of the societies that create these distinctions (Han, 2002). Just as the gender binary serves to reproduce a given dominant culture (Foucault, 1978; Butler, 1988), binaries between traditional and biomedical knowledge may serve to perpetuate dominant norms. Flint and Payne (2013) posit that traditional and biomedical sectors, are often understood to be mutually opposing world views in policy and research, and a variety of scholars (such as Leclerc-Madlala et al., 2016; Moshabela et al., 2016; Wreford, 2005) have documented how traditional and biomedical health care providers often operate in parallel but separate arenas. Underlying such critiques are notions that these silos do not reflect the ways in which many people conceptualise health and engage with both systems. For example, Taylor (1979) has argued that the power-disparate assumptions between traditional and biomedicines may undermine the problem-solving capacity of communities, and the social, psychological, spiritual and physical functions of traditional health practices, and Green (2012) has called for a shift in this binary approach in order to create space to develop and nurture different ecologies of knowledge. This polarisation between 'traditional' and 'biomedical' medicines and services occurs in a knowledge production economy which may place greater value on ways of knowing that can be quantified (Green, 2012; Wreford, 2005). This continued bifurcation and polarisation of these two systems—and the associated denouncing of one side over the other—can be counter-productive to the development of new ways of knowing, and can undermine 'nurture, care and well-being' (Green, 2012, p. 108).

Biomedicine is often seen as framing disease mechanistically 'against the background of a largely uninterested universe' (Flint and Payne, 2013; Moshabela, Zuma and Gaede, 2016, p.

86), in a way that is neutral, realistic and culture-free. On the other hand, traditional healing is often framed as 'full of dangerous and ultimately mistaken metaphors', and as a set of health-inhibiting and harmful practices for the uneducated (Waldron, 2010; Flint and Payne, 2013; Moshabela, Zuma and Gaede, 2016, p. 85). It is evident that defining traditional medicine and biomedicine as separate, univocal belief systems does not offer an adequate framework to capture the beliefs, lived experiences and practices of many people living with HIV. Indeed, traditional health practitioners often have a variety of biomedical beliefs and practices. These terms are imperfect approximations, and used as an entry point into beliefs and systems related to well-being, rather than with the intention of perpetuating binaries. They also reflect participant understandings of differences between health systems, and categories of traditional health practitioners. In excerpts from interviews translated from isiXhosa into English (or when participants otherwise used the terms in English-language interviews), the terms igqirha, ixhwele, izangoma and nyanga, are included, followed by parentheses with their English translation. Biomedical terms of 'biomedical health practitioner' and 'biomedical health system' are used to reflect public and private health system actors and structures[7]. Biomedical products and services are understood as those received through health facilities, and from people formally employed within the health system, including those who have qualified as nurses and doctors.

Although in some ways reifying this binary between traditional and biomedical health systems, the concept of medical pluralism also provides a theoretical lens for exploring how individuals demonstrate health-seeking behaviours within a range of health care practices, and a framework for understanding the creative ways with which people engage in these sectors. Chapter Six of this thesis focuses on beliefs and practices related to accessing health products and services. It is by considering how participants' lived experiences and beliefs influence their practices, and how their practices influence their beliefs and experiences, that this thesis explores the complex overlapping of health systems. In doing so, this research aims to contribute to the transdisciplinary body of literature that complexifies the conceptual boundaries of traditional and biomedical health. It does so through exploring how HIV-positive adolescent boys engage with a range of health practices.

[7] The isiXhosa term often used to refer to biomedicine is 'Amayeza asentshona' (Translates as 'Western Medicine').

Despite the aforementioned conceptual limitations of the terms ‘traditional medicine’ and ‘biomedicine’, these labels are used throughout this thesis to describe a variety of health practices which are engaged by participants. As Butler (1993) points out, it is difficult to directly counter dominant narratives because of how they have come to be seen as ‘objective’ and ‘natural’.

This chapter has reviewed the conceptual and theoretical frameworks on gender, health and adolescence, as well as relevant literature on adolescence, masculinities and medical pluralism. Next, Chapter Three presents the research design and methods, which is followed by a presentation of findings in Chapters Four to Seven.

Chapter Three: Study setting, research design and methods

What would it really mean to study the world from the standpoints of children (adolescents) both as knowers and actors? – Anne Oakley, 1994

Mzantsi Wakho, Ezobudoda & my research role:

This thesis is based on data collected from Ezobudoda, a sub-study of the Mzantsi Wakho study (www.mzantsiwakho.org.za) (n=1,060 adolescents living with HIV and n=467 community controls). In 2019, it is the largest known community-traced, longitudinal, mixed methods research study of adolescents living with HIV. IsiXhosa for 'Your South Africa', this interdisciplinary study combined qualitative and quantitative methods to study risk and resilience-promoting factors for ART adherence and sexual health among adolescents living with HIV (Hodes *et al.*, 2014). The principal investigators of Mzantsi Wakho are Dr Rebecca Hodes (University of Cape Town, and my co-supervisor), Professor Lucie Cluver (University Oxford) and Dr Elona Toska (University of Cape Town).

Ezobudoda (isiXhosa for 'manhood things'), a sub-study of Mzantsi Wakho, formed the basis of this doctoral work. The design, methods and aims of this study were complementary to the Mzantsi Wakho project. However, its conceptual focus on masculinities, engagement with traditional health services, and HIV medicines-taking during and after traditional initiation/circumcision (ulwaluko) distinguished it as a unique sub-study. It engaged complementary but separate methods of recruitment, data collection and analysis. It benefitted greatly from, and contributed to, the established Mzantsi Wakho human and physical resource infrastructure. As the lead investigator on the Ezobudoda sub-study, I was responsible for a set of logistical and research-specific tasks. These included: overseeing and managing conceptualisation, designing research tools and developing the study protocol (which drew heavily on and was complementary to that of Mzantsi Wakho). Further, I was responsible for obtaining UCT Faculty of Health Sciences' Human Research Ethics Committee and Eastern Cape Department of Health Ethical approvals, recruiting, hiring, training and managing researchers. I oversaw data collection, participant referrals, transcription of interviews, data management and storage, analysing and disseminating research findings. I developed content for,

facilitated, and supported multiple workshops with 38 adolescents living with and affected by HIV, who are part of the Teen Advisory Group (TAG) in the Western and Eastern Cape provinces.

I spent 16 months living in and immersed in the study site; 13 of these months were dedicated to primary fieldwork, and I made frequent trips to the study site before and following data collection. Primary data from this study is comprised of 87 interviews with 50 participants (36 adolescent boys living with HIV and 14 health workers and stakeholders). The Ezobudoda study builds on earlier research conducted within the Mzantsi Wakho study with 39 adolescents and 53 adult stakeholders, which is used as secondary data for this doctorate, and is described further below. Findings are also informed by my close personal work with traditional health practitioners over a period of five years, including being initiated into ubungoma (the practice of traditional healing) the through the process of ukuthwasa (initiation).

I have been involved in the Mzantsi Wakho study as a co-investigator since April 2015. The research questions that formed the basis of this doctoral work emerged from a 'community audit' research study on social protection services, which I managed under the supervision of Dr Rebecca Hodes. These research questions and tools were collaboratively developed and informed by supervisors Dr Rebecca Hodes and Associate Professor Christopher Colvin, and the Mzantsi Wakho team of principal investigators, co-investigators and researchers in the Eastern Cape, Cape Town, and the United Kingdom.

I was supervised and received considerable support at all stages of this study by my supervisors, Dr Rebecca Hodes, co-Principal Investigator on the Mzantsi Wakho study and head of the AIDS and Society Research Unit in the University of Cape Town's Centre for Social Science Research, and Associate Professor Christopher Colvin, Head of the Division of Social and Behaviour Sciences at the University of Cape Town's School of Public Health and Family Medicine.

Ezobudoda also received substantial financial and logistical support from the Mzantsi Wakho study, without which data collection would not have been possible. This support included assistance from teams of Eastern Cape, Western Cape and United Kingdom staff, including project managers, fieldwork coordinators, researchers and administrators. In addition to the

supervisors and principal and co-investigators that shaped and contributed greatly to the conceptualisation, design, analysis, interpretation and dissemination of this work, the Eastern Cape based research team was actively involved in the development of research questions, research tools and in the analysis and interpretation of findings. The main researchers on this study were Sinebhongo Mbula, Phakamani Kom, and, in its early iterations, Zukolwethu Jantjies[8]. These three Eastern Cape-based researchers conducted the majority of interviews with adolescent boys and young men and provided substantial input into the study design, research tools, analysis and dissemination. The process of recruitment of these researchers and their strategies of engagements with young male participants are discussed as a research topic in Chapter Seven. The methodological complexities of translation and analysis are discussed later in this chapter and in the conclusion.

The Mzantsi Wakho team has strong working relationships with members of different government departments, civil society organisations and academics based at a number of universities. These include partnerships among the University of Cape Town, the University of Oxford, the South African National and Eastern Cape Departments of Health, Social Development, and Basic Education, Paediatric Adolescent Treatment Africa (PATA) and the Small Projects Foundation in East London, among others.

Research setting

Mzantsi Wakho and Ezobudoda were set in the Buffalo City Metropolitan Municipality (BCM) and Amathole districts of the Eastern Cape province of South Africa. Although contexts differ greatly, these sites were selected for their relative regional representativeness of other resource-limited, high HIV prevalence areas in Eastern and Southern Africa. Data were collected in rural, urban and peri-urban areas. Mzantsi Wakho had two Eastern Cape offices, one in East London (eMonti) and the other in King William's Town (eQonce) where the Ezobudoda study was based.

[8] The researchers requested that their names be used throughout the thesis, although in the book chapter (and therefore Chapter Seven) pseudonyms were used.

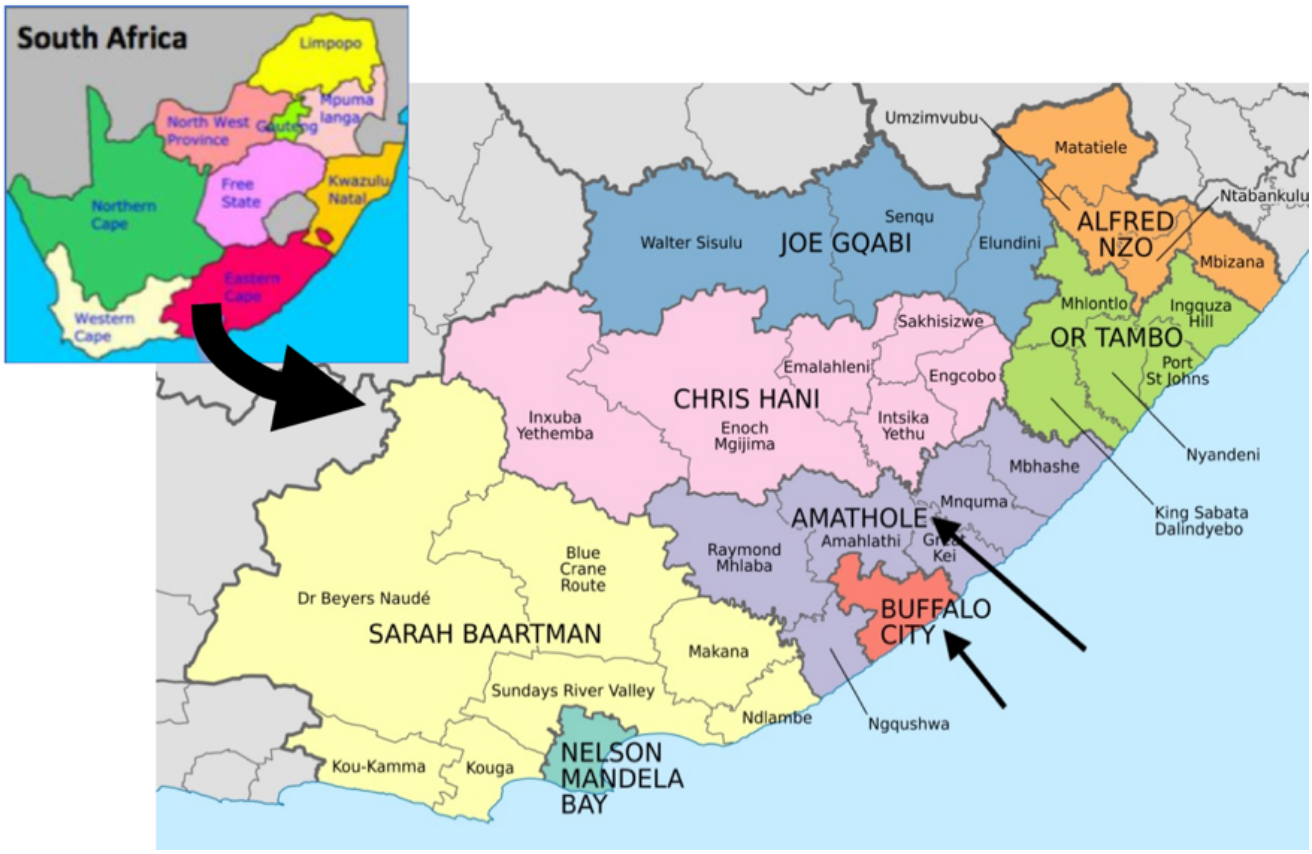


Figure 3: Map of South Africa (top left), and the Eastern Cape province (bottom right). Arrows denote the Amathole District (in purple) and Buffalo City Metropolitan Municipality (in red) where this research took place. Available at: https://en.wikipedia.org/wiki/List_of_municipalities_in_the_Eastern_Cape. Last accessed 17 May 2019.



Figure 4: Image of a peri-urban area, Amathole district (top left). 3 October 2017.
Figure 5: Image of a rural area, Amathole district (top right). 19 August 2017.
Figure 6: Image of a rural area, Buffalo City Metropolitan Municipality (bottom left). 6 December 2017.
Figure 7: Image of an urban area, Buffalo City Metropolitan Municipality (bottom right). 30 June, 2013.

The Eastern Cape is South Africa's third largest province with a population of 6,996,976, or 13.5% of the country's population (Statistics South Africa, 2016). It is also one of the country's poorest provinces. The 2016 South African Community Survey reported that it had the lowest access to water and electricity in South Africa and the highest proportion of households that had skipped a meal in the past year (Statistics South Africa, 2016). The HIV prevalence among adults (ages 15-49) in the Eastern Cape is 25.2%, higher than South Africa's national adult prevalence of 20.6%. The Eastern Cape has the country's third highest adult HIV prevalence after KwaZulu-Natal (27%) and the Free State (25.5%) (HSRC, 2018). In national reporting and national household surveys, young people are grouped into age categories of 0-14, and 15-19,

making the calculation of HIV prevalence among children and adolescents, in the age range of 10-19, difficult.

Study design, participants and data collection methods and tools

Research methods & tools: Adolescent boys and young male participants

It was imperative that this study included adolescent boys living with HIV as participants. The poor health outcomes of adolescents and young people living with HIV and the gap in evidence with adolescent boys and young men make a strong case for such research. Involving adolescent boys and young men living with HIV as participants provided a powerful opportunity to highlight their lived experiences as a way to better understand the adolescent HIV epidemic. The ability of adults to act as proxies for adolescent experiences in research has been question (such as Morrow & Richards, 1996). When adolescents are approached in a sensitive manner, they can participate competently and meaningfully in research (Hodes *et al.*, 2014). Others have written about the ethical and methodological challenges and benefits of conducting research with minors, and other vulnerable populations (Cluver, Boyes, *et al.*, 2015; Skovdal, M., and Cornish, 2015).

Inclusion criteria and sampling

Between the ages of 13 and 22[9] which was the age range of Mzantsi Wakho study participants (who at baseline were between the ages of 10-19).
Self-identified as male.
Selection was organised by circumcision status, given its centrality to identities and meanings of boyhood and manhood in the study site. The study included participants who were inkwenkwe (uncircumcised boys) as well as indoda (circumcised men), and interviewed some participants before and after ulwaluko.
Living with HIV, and initiated onto ART.
When possible, participants were recruited who researchers had observed to be willing and engaged participants in Mzantsi Wakho. It is acknowledged that selecting participants who

[9] This was participant age at first interview. There was one participant who was 25 at first interview, as his date of birth had been misrecorded in our initial roster.

seemed to enjoy talking that this may have introduced bias into the selection of participations for this study, which is discussed further in the 'limitations' section.
Provided verbal and written informed and voluntary consent (18 or over), or if they were under the age of 18, provided verbal and written informed and voluntary assent alongside the verbal and written informed and voluntary consent of their legal guardian.

Recruitment

Thirty-six adolescent boy and young male participants (ages 13-22) were recruited from the pool of Mzantsi Wakho study participants. In engaging participants already enrolled in Mzantsi Wakho, this study continued work with a cohort of participants who the project already had a relationship with. This fieldwork took place concurrently with the third round of follow-up interviews for the Mzantsi Wakho quantitative sample. Participants were selected for recruitment based on recommendations from the team of Mzantsi Wakho researchers who were responsible for data collection, and had developed strong rapport with participants over the course of three years of data collection. This may have meant that participants already had a degree of familiarity with the project. When a researcher recommended a participant, they followed up with them alongside the Ezobudoda researcher who would be conducting interviews. Recommended participants were contacted telephonically to be asked if they would be interested in participating. In the case of participants under the age of 18, their caregivers were contacted first to explain the purpose of the study and ascertain if the caregiver would allow for their participation. For those who answered affirmatively, a time and place for the interview was set. In cases where the participant could not be reached telephonically, they were visited at home to ascertain their interest and set a time and location for the interview. Special attention was given to ensure that participants were not recruited during stressful periods (for example, exam times). A list of participants is provided below. Unless otherwise noted, they selected their own pseudonyms. Pseudonyms were only changed in situations where they were too close to the participants' actual names.

Pseudonym	Age at first interview	Location	Traditional circumcision status[10]	Data collected
Unathi*	16 years	BCM, urban	Not circumcised	Life history interview - 16 September 2017 Health facility files (3) extracted – 22 March 2018, 22 March 2018, 21 April 2018
Ndoda	18 years	BCM, urban	Circumcised	Life history interview – 6 September 2017 Semi-structured interview – 25 November 2017 Health facility file (1) – 15 January 2018
Buja	19 years	BCM, urban	Circumcised during study period	Life history interview – 16 September 2017 Semi-structured & pre-initiation interview – 25 November 2017 Post-initiation interview – 17 March 2018 Health facility files (2) – 22 March 2018
Khwezi*	20 years	BCM, urban	Circumcised	Life history interview - 6 October 2017 Semi-structured interview - 20 January 2018 Health facility files (3) – 22 March 2018, 22 March 2018, 18 April 2018
Layzdu	18 years	BCM, urban	Circumcised	Life history interview - 6 September 2017 Semi-structured interview – 25 November 2017
Sakhiman	20 years	BCM, urban	Circumcised	Life history interview - 16 September 2017 Semi-structured interview – 1 December 2017 Health facility files (1) – 17 January 2018
Listar	18 years	Amathole, rural	Not circumcised	Life history interview – 30 September 2017 Semi-structured interview – 4 December 2017 Health facility files (1) – 13 January 2018

[10] Circumcision status is provided here due to its centrality in age and gender-based hierarchies within the study site. Further detail on this is provided in the second findings chapter.

Ngamla	21 years	Amathole, peri-urban	Circumcised	Life history interview – 23 August 2017 Semi-structured interview – 6 December 2017 Health facility files (2) – 22 March 2018, 15 March 2018
Machete	22 years	Amathole, peri-urban	Circumcised	Life history interview – 5 October 2017 Semi-structured interview – 5 December 2017 Health facility file (1) – 11 January 2018
Mluthwana	16 years	BCM, urban	Not circumcised	Life history interview – 6 October 2017 Semi-structured interview – 24 February 2018 Health facility file (1) – 22 March 2018
Lullo	22 years	BCM, urban	Circumcised	Life history interview – 14 September 2017 Semi-structured interview – 20 January 2018 Health facility file (1) – 22 March 2018
Mayor	16 years	BCM, urban	Circumcised	Life history interview – 15 September 2017 Semi-structured interview – 27 January 2018 Health facility files (2) – 22 March 2018, 22 March 2018
Zane[11]	16 years	Amathole, peri-urban	Not circumcised	Life history interview – 24 November 2016 Semi-structured interview – 17 February 2018
Tonxo	22 years	Amathole, rural	Circumcised	Life history interview – 22 August 2017
Dee	19 years	Amathole, urban	Circumcised	Life history interview – 17 October 2017 Semi-structured interview – 4 December 2017 Health facility files (2) – 11 January 2018, 22 March 2018
Mr Shade	17 years	BCM, peri-urban	Not circumcised	Life history interview – 26 August 2017 Semi-structured interview – 3 February 2018 Health facility file (1) – 5 May 2018

*Pseudonym changed in order to ensure anonymity.

[11] Not living with HIV. This was the only participant in this study who was not living with HIV.

Ulwazi*	13 years	BCM, peri-urban	Not circumcised	Life history interview – 26 November 2016 Health facility file (1) – 5 May 2018
Jeveno	17 years	Amathole, peri-urban	Circumcised during study period	Life history interview – 19 August 2017 Pre-initiation interview – 24 November 2017 Semi-structured and post-initiation interview – 24 March 2018 Health facility file (2) – 16 March 2018, 3 May 2018
Movite	18 years	BCM, urban	Circumcised	Life history interview – 13 September 2017 Semi-structured interview – 30 November 2017 Health facility file (1) – 22 March 2018
Ta Saider	21 years	Amathole, peri-urban	Circumcised	Life history interview – 22 November 2016 Semi-structured interview – 8 February 2018 Health facility file (1) – 28 March 2018
Nginduyi	16 years	Amathole, peri-urban	Not circumcised	Life history interview – 23 September 2017 Semi-structured interview – 29 November 2017 Health facility files (2) – 15 March 2018, 5 May 2018
Sne	19 years	Amathole, rural	Unknown. (Planned to go but could not find for a follow-up interview)	Life history interview – 9 September 2017 Semi-structured & pre-initiation interview – 7 December 2017 Health facility files (1) – 5 July 2018
Nkweza	18 years	BCM, urban	Not circumcised (rejected at clinic during study period)	Life history interview – 23 August 2017 Semi-structured interview – 30 November 2017 Health facility files (1) – 20 March 2018
Svij	25 years	BCM, urban	Circumcised	Life history interview – 13 September 2017 Semi-structured interview – 20 February 2018

				Health facility file (1) – 22 March 2018
C'Vig	19 years	BCM, urban	Circumcised	Life history interview – 26 August 2017 Semi-structured interview – 10 February 2018 Health facility files (1) – 5 May 2018
Sividge	21 years	BCM, urban	Circumcised	Life history interview – 3 October 2017 Semi-structured interview – 28 February 2018 Health facility file (1) – 5 May 2018
Soso	21 years	Amathole, rural	Circumcised	Life history interview – 23 September 2017 Semi-structured interview – 5 December 2017 Health facility file (1) – 6 July 2018
Ndofaya	18 years	BCM, rural	Circumcised	Life history interview – 5 October 2017 Semi-structured interview – 10 February 2018 Health facility file (1) – 26 April 2018
Akhona*	19 years	BCM, urban	Not circumcised (rejected at clinic during study period)	Life history interview – 7 October 2017 Semi-structured & pre-initiation interview – 30 November 2017 Post-initiation interview – 20 March 2018 Health facility file (1) – 28 March 2018
Ringo	17 years	BCM, urban	Circumcised during study period	Life history interview – 30 September 2017 Semi-structured & pre-initiation interview – 25 November 2017 Post-initiation interview – 17 March 2018 Health facility files (2) – 15 January 2018, 15 July 2018
X-man	22 years	Amathole, peri-urban	Not circumcised (rejected at clinic during study period)	Life history interview – 22 August 2017 Semi-structured & pre-initiation interview – 29 November 2017 Post-attempt to go to initiation interview – 20 March 2018

				Health facility file (1) – 20 March 2018
Zube	17 years	BCM, urban	Not circumcised	Life history interview – 5 October 2017 Semi-structured interview – 3 February 2018 Health facility file (1) – 21 April 2018
Luya	17 years	BCM, urban	Not circumcised	Life history interview – 26 November 2016 Semi-structured interview – 26 November 2017 Health facility file (1) – 20 March 2018
Loza	21 years	BCM, peri-urban	Circumcised	Life history interview – 23 September 2017 Semi-structured interview – 6 December 2017 Health facility file (1) – 15 March 2018
Bele	19 years	BCM, urban	Circumcised	Life history interview – 19 August 2017 Semi-structured interview – 6 December 2017 Health facility file (1) – 11 January 2018
Stenza	13 years	Amathole, peri-urban	Not circumcised	Life history interview – 9 September Semi-structured interview – 10 February (interview stopped)

Table 1: Participant Table: Adolescent boys and young men

This thesis draws on data from life history narratives (n=36), semi-structured interviews (n=32) and clinic files (n=43) with 36 adolescent boys and young men. These tools are described in greater detail in the following section. In total, life history narrative interviews were conducted with 36 participants, of whom 32 conducted a follow-up semi-structured interview. Of the four who were not interviewed a second time, one was excluded because the participant became very emotional, after which the interview stopped and a referral[12] was undertaken; one moved out of the study area; one declined participation; and one was not followed up because his short and formulaic answers in the first interview led us to believe that he was not fully consenting to participate. All participants except one were HIV-positive. In the case of the HIV-status

[12] Referrals involved referring a participant to the relevant social service on the basis of need. These are explored further in the 'research' process section of this chapter.

unknown participant, we incorrectly believed he was living with HIV when he was recruited. We only found out that he had never tested HIV-positive during the second interview, and then excluded his data from analysis. All other participants were confirmed to be living with HIV. An additional five interviews were conducted for participants that went to traditional circumcision, or had planned to get traditionally circumcised, during the study period.

In total, 73 interviews were conducted with 36 adolescent male participants. In addition, health facility files were extracted for adolescent participants. Health facility file extraction included, with the consent/assent of the participant and their guardian, locating participant files in one or more health facilities, and photographing them and analysing the information. This valuable data provided additional insight into participant health histories, which was analysed alongside interview and life history data as explained below. A total of 43 files were found for 32 participants at 14 health facilities, including three public hospitals, one community health centre and ten clinics.

Research methods & tools: adolescent participants

It has been suggested that participatory, visual research methods in research with young males are useful in facilitating collaborative, contextually grounded and credible data (Blackbeard and Lindegger, 2015). Certain 'ways of knowing' are not considered within formally acknowledged or accredited knowledge because there are no technologies to measure the sensory forms of data that this knowledge is based on (Green, 2012). Ethnographic and qualitative methodologies and research can generate new knowledge (Green, 2012). Traditional approaches and beliefs about health and well-being are one such 'way of knowing' that may benefit from such methods given that 'the processes involved in traditional healing do not lend themselves to evaluation and measurement, and precise data…are still lacking' (Mathibela et al., 2015 in Zuma et al., 2016, p. 306). This study engaged qualitative methods in order to gather rich, context-specific information and to allow for the subjective experiences and stories of participants to be explored (Watts, 2006; Skovdal and Cornish, 2015). Using a variety of methods—both traditional and innovative—can help to address some of the ethical and methodological issues that arise in conducting research with adolescents (Punch, 2002), and guard against the bias of using a single method.



Figure 8: Ulwazi (13) conducting a pilot life history interview with researcher Zukolwethu Jantjies. 26 November 2016.

The first interview included life history narratives, as well as additional semi-structured questions (research tool in English attached at *Appendix One*). Consistent with a life course approach, life history narratives involve the narration of one's life experience, including highlighting the most important aspects in the domain of inquiry (Atkinson, 1998). The domain of enquiry in these narratives was health. Such an approach provides interviewees with a degree of agency to discuss what they feel is important and to interpret their life stories, and it can capture nuanced and holistic perspectives of risk and agency (Brittijn, 2013; Stern, 2013). It is a way to gather data to improve understandings about how adolescent boys see themselves, to shed light on topics that participants might not otherwise disclose, and for participants to answer questions that researchers might not think to ask (Smith, 2000; Cornwall, 2007; Stern, 2013). Building on Stern's (2013) study which used sexual history narratives to ascertain sexual behaviours and gendered attitudes among adult men, data were collected with the aim of gathering insight into the more recent memories of young people living with HIV. These first

interviews also allow researchers to become acquainted with the participant and the aspects of their lives that they deem important, which could be later followed up in additional interviews.

Participants were prompted to share a minimum of three events that were important to them in their lives. Following this, they were asked if they had any health events that they wanted to overlay onto their life histories. In the majority of cases, participants had relayed one or more health events as major life events and this prompt was not necessary. Although some participants shared pleasant or happy life events, the majority relayed challenges they had faced. From these, common themes emerged. After or during drawing, participants would often elaborate on their experiences.

Participants were given the option of drawing, writing or speaking about life events, using the metaphor of a 'river of life'. Some participants opted to speak, while others drew their river. Participants were also given the option of selecting items such as stones and glass of different colours and shapes to represent themselves and members of their family. Emoji stickers provided participants with the option to represent their feelings using social media imagery, a strategy also used by Hodes and colleagues in a participatory study of young people's perceptions and experiences of medicines-taking (Hodes *et al.*, 2019).

Two examples are presented below as case studies to demonstrate methods and how they were triangulated. The first demonstrates how Luya (age 17) drew, wrote and spoke about his first life event.



Figure 9: Luya (17) writes about important life events during a pilot life history interview (left). 26 November, 2016.

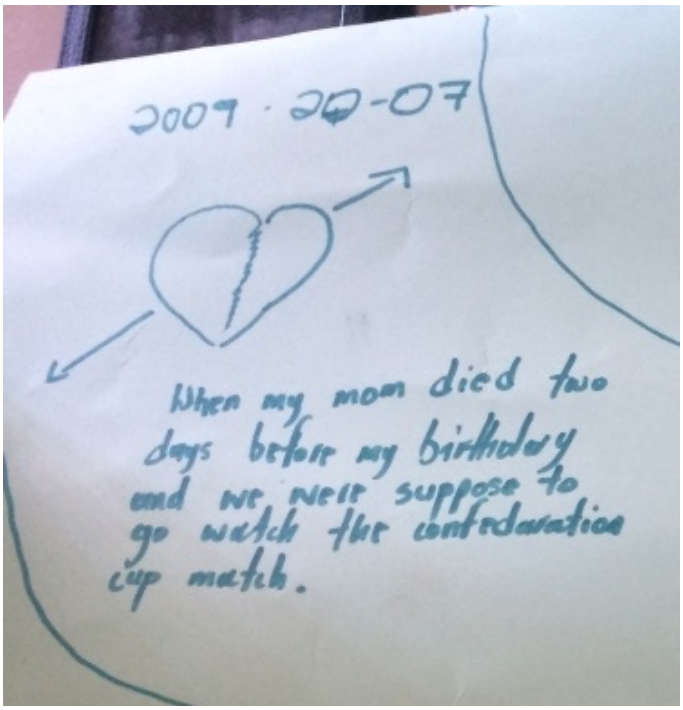


Figure 10: Luya (17) life history interview drawing depicting the death of his mother. 26 November, 2016.

As can be seen in the example above, as part of this research tool, this optional 'river of life' exercise was used as a way for participants to write or draw important life experiences to allow for alternative ways of expression. Luya used drawing and writing to depict his major life events. His first event was the death of his mother. As can be seen in the above right image, he represented this with a broken heart and a caption that says 'When my Mom died two days before my birthday and we were supposed to go watch the confederation cup match.' The interview transcript below demonstrates how participants often then spoke about their life events after drawing them.

> It's a broken heart, it shows that moment was difficult for me to know that my mother is not alive anymore and the worst part was that she promised that we were going to watch a Confederation Cup match on the 24 of July for my birthday. Unfortunately two days before my birthday she passed away, so everything was just lost. I was doing grade four at that time, even at school my levels just dropped down.
> (Luya,17)

The second, example of Khwezi's interview, demonstrates how participants sometimes used objects in their drawings and metaphors, and how data were triangulated with clinic files.



Figure 11: Khwezi's (20) life history drawing. 6 October 2017.

Khwezi used a different approach. As can be seen above, he traced objects (round pieces of different coloured glass) to represent the people in his household and family. He placed them to represent his physical and emotional proximity to these family members. He depicts his childhood home, his sisters, mother and grandmother as all living together. He places himself close to his mother, and used emojis to demonstrate how he felt over certain events. He uses metaphors from the items that he selected to describe his family members (e.g. a 'diamond' – a clear shiny piece of glass for his lost mother).

To complement this data, participant clinic files were also extracted with the consent of participants. This process included photographing them at the health facility and then analysing images alongside participant interview data. Participant files from one or more health facilities were analysed alongside life history narratives and semi-structured interview data. These often validated and provided different perspectives on participants' life experiences. Finding files often

proved challenging, given the different, sometimes disordered filing systems and limited time of health facility staff.

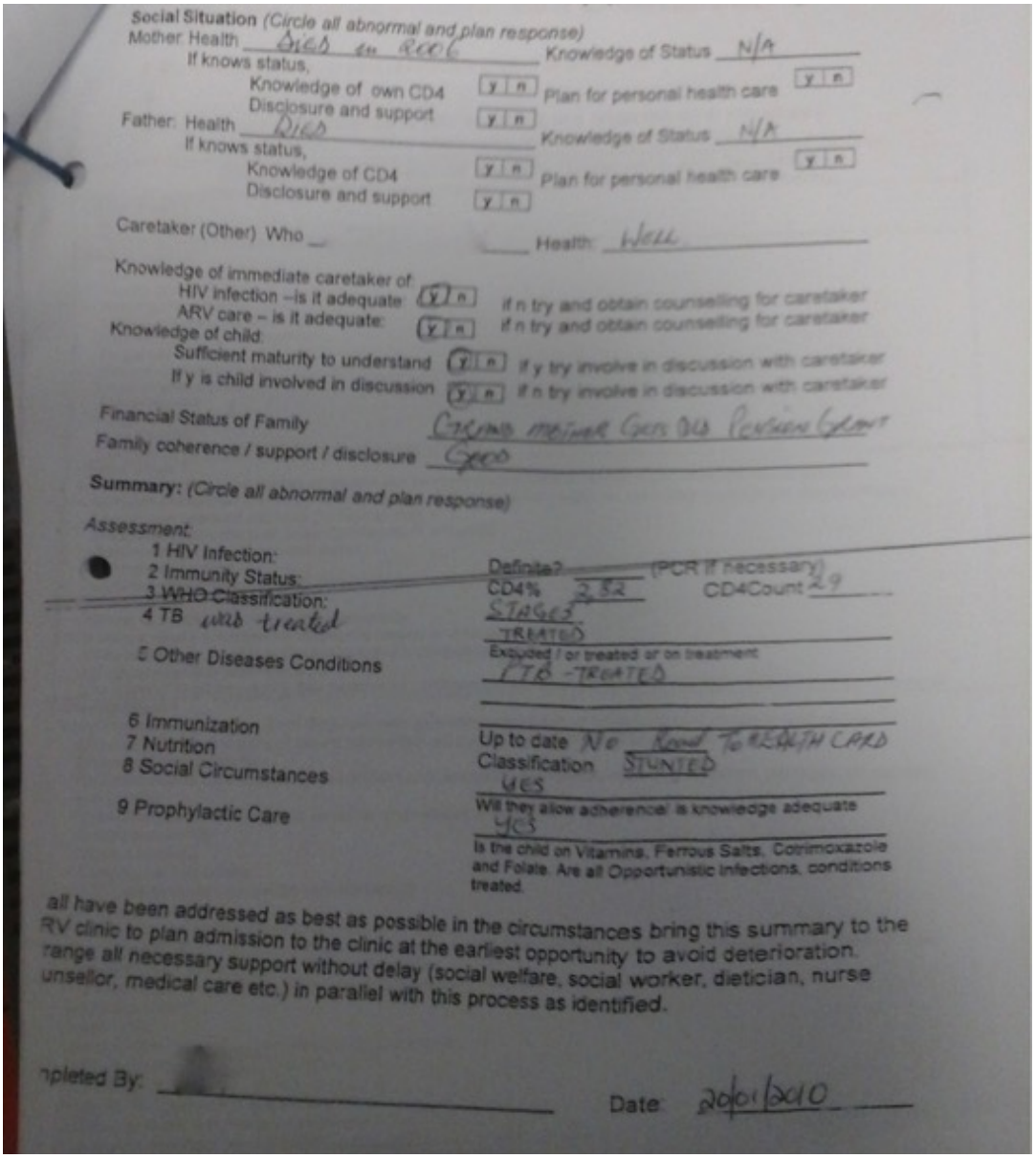

Social Situation (Circle all abnormal and plan response)
Mother: Health DIED ca 2006 Knowledge of Status N/A
If knows status,
Knowledge of own CD4 y n Plan for personal health care y n
Disclosure and support y n
Father: Health DIED Knowledge of Status N/A
If knows status,
Knowledge of CD4 y n Plan for personal health care y n
Disclosure and support y n
Caretaker (Other) Who Health: WELL
Knowledge of immediate caretaker of:
HIV infection – is it adequate: y n if n try and obtain counselling for caretaker
ARV care – is it adequate: y n if n try and obtain counselling for caretaker
Knowledge of child:
Sufficient maturity to understand y n if y try involve in discussion with caretaker
If y is child involved in discussion y n if n try involve in discussion with caretaker
Financial Status of Family Grand mother Gets Old Pension Grant
Family coherence / support / disclosure Good
Summary: (Circle all abnormal and plan response)
Assessment:
1 HIV Infection:
2 Immunity Status: Definite? (PCR if necessary)
3 WHO Classification: CD4% 2.52 CD4Count 29
4 TB was treated STAGE 3 TREATED
5 Other Diseases Conditions Excluded / or treated or on treatment: PTB - TREATED
6 Immunization Up to date No Need To HEALTH CARD
7 Nutrition Classification STUNTED
8 Social Circumstances YES
9 Prophylactic Care Will they allow adherence/ is knowledge adequate YES
Is the child on Vitamins, Ferrous Salts, Cotrimoxazole and Folate. Are all Opportunistic infections, conditions treated.
all have been addressed as best as possible in the circumstances bring this summary to the RV clinic to plan admission to the clinic at the earliest opportunity to avoid deterioration. range all necessary support without delay (social welfare, social worker, dietician, nurse unsellor, medical care etc.) in parallel with this process as identified.
npleted By: Date: 20/01/2010

Figure 12: Page of a health facility file of Khwezi (20) from 2010 which depicts some of the events shown in his life history narrative, such as the death of his mother. Photograph taken 22 March, 2018.

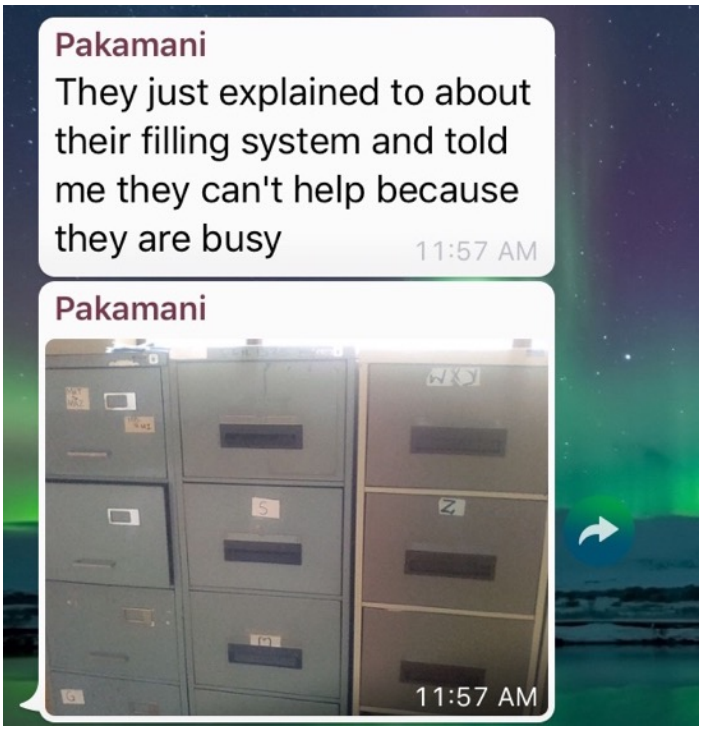


Figure 13: Screenshot of a Whatsapp conversation with researcher Phakamani Kom describing his difficulty in finding health facility files. 3 May 2018.

In order to relate boys' beliefs and experiences to external behaviours and their impacts, in-depth, semi-structured individual interviews (attached at *Appendix Two*) gathered further information about participant perspectives on masculinity and biomedical and traditional health-seeking. They were conducted between one and four months following the initial life history interview. For participants who attended ulwaluko during the study period, an additional interview was conducted in relation to their experiences of health services engagement before, during and after.

Congruent with social process theory, these multiple, complementary methods provided for insight into changes of expressions of social norms for men, the life stages that were influential for these changes, and how expressions of masculinity change over time (Stern, 2013). An embodiment and social process lens was applied to the design, data collection and analysis of data in order to aid in a rich exploration of the lived experiences and behaviours of adolescent boys and young men living with HIV. Chapter Four includes further detail, images and examples of these methods, as well as a case study of how they were triangulated, co-analysed and used.

Research process

The research tool was first piloted with five participants to test the acceptability and comprehensibility of the questions and exercises. Based on piloting, the research tool was modified and divided into two separate instruments (as described above), one which focused on life and health narratives, and a semi-structured interview which focused on health beliefs and practices. The efficacy and validity of research instruments were checked after each interview in a reflection process between myself and the researcher who conducted the interview. Research tools were drafted in English with the input of Eastern Cape-based researchers, then translated into isiXhosa and back-translated into English by the research assistant(s) responsible for conducting interviews.



Figure 14: Researchers Phakamani Kom and Sinebhongo Mbula conducting a participant visit. 30 September 2017.

Prior to each interview, participants were provided with information about the study and informed consent of participants over 18 was obtained. In the case of adolescent minors, their guardian's informed consent and the participant's assent was sought. The process of obtaining informed consent, and, in the case of adolescent minors, assent, was guided by the University of Cape Town's Human Research Ethics Committee's standard operating procedures (HREC SOPs)

on Research Involving Children (2013) and Informed Consent (2014), as well as the National Health Act (2003) and the National Department of Health's 'Ethics in Health Research: Principals, Process and Structures' guideline (Greef, 2015). It also follows the Mzantsi Wakho protocol (Hodes *et al.*, 2014). The details and principals of the informed consent/assent process are attached at *Appendix Six*. The information guide and informed consent/assent forms for adolescent boys and young male participants are attached at *Appendix Seven*.

Interviews took between 40 and 90 minutes, with most taking 45 to 60 minutes and were audio-recorded with the consent of participants. All 36 adolescent participants consented to be recorded.

Participants were asked in the interview if they would be open to being interviewed again. Follow-up interviews were then organised after initial transcription and translation and generally occurred one to four months following the initial interview. For boys who were initiated during the study, they were also asked to participate in an additional interview. In these situations, participants were interviewed at least one month after returning home from ulwaluko.
At no stage in the research process, including when introducing the study or seeking informed consent, were participants told that the study focus was HIV. Instead, Ezobudoda was broadly framed as a study about young masculinities and health, including engagement with biomedical and traditional health services. The Ezobudoda study put substantial measures in place to reduce the risk of disclosing a participant's HIV status to them (if they were unaware of their own status) or to others. This was also measure to mitigate stigma, so the study did not become known as an HIV by participants and communities. Like the Mzantsi Wakho study, information sheets did not include mention of HIV/AIDS. These information sheets can be found at *Appendices Seven and Eight*. Acknowledging the highly sensitive nature, and potential associated harm, of discovering one's HIV-positive status in an inappropriate way, caregivers of participants were approached on the assumption that the child and caregiver were unaware of the adolescent's HIV-positive status.

Stigma mitigation was an important consideration, given that the research was conducted in environments where communities were interested in the research and its purposes. Efforts were

made so that researchers and research project vehicles would not be identified and linked to an HIV research project. Mzantsi Wakho recruited and interviewed HIV-status unknown participants from the same household or community as a measure of stigma mitigation and confidentiality (Hodes *et al.*, 2014). An additional stigma mitigation measure was that a participant's HIV status was never discussed publicly and explicitly within the research project. In order to minimise the risk of inadvertently disclosing or traumatising participants, the research assistants were local men, trained in the complexities and sensitivities of adolescents living with HIV in the Eastern Cape, for whom the hiring and training criteria have been outlined at *Appendix Nine* and discussed in more detail in Chapter Seven. Additional information is provided at *Appendix Ten* on HIV status non-disclosure.

Participants were not reimbursed financially. This decision was made so as not to undermine their ability to participate voluntarily in the study; if a monetary incentive was provided, this may constitute a form of coercion in such a resource-poor area. In addition, reimbursement was not provided in attempt to avoid generating desirability bias, where participants give the answers they think are desired by the interviewers because they are being reimbursed for their participation. There was also concern that providing financial resources might cause conflict within homes, families and communities.

Instead of financial reimbursement, participants were given a 'participant pack' regardless of whether they consented to participate in the study. This included a snack (including biscuits and juice) and small tokens of appreciation (such as a notebook and pen, toothpaste and toothbrush, deodorant, t-shirt and socks or a handkerchief). For participants who conducted an interview after returning from ulwaluko, a blanket was provided. Approximate value of participant packs were ZAR150-200.



Figure 15: Participant pack including socks, handkerchief, snack, notebook and pen (left). 18 November 2016.
Figure 16: Participant pack including socks, handkerchief, deodorant and a t-shirt (right). 22 August 2017.

Following each interview, the research assistant completed the steps set out at *Appendix 11* (the protocol checklist for preparing for and completing an interview), which included a verbal reflection about the interview and completing a written reflection form (attached at *Appendices 11 and 12*). Whenever possible, the verbal reflection was conducted as a recorded conversation with myself and the researcher. When not possible, the researcher audio-recorded the verbal reflection and sent it to me within 24 hours of completing the interview. The exception to this 24-hour period was for immediate referrals—for example, if the participant reported abuse, neglect or maltreatment and/or was at serious and immediate risk. In these situations, the protocol required that the researcher contact me immediately, although in practice no such emergency situations occurred. Referrals are discussed later in this chapter, *Appendix 14* contains additional information about referrals and legally mandated reporting.

Confidentiality and privacy

Given the personal and sensitive nature of this research, confidentiality was of utmost importance. Participant identifier numbers from participants recruited from the Mzantsi Wakho quantitative cohort were used, alongside pseudonyms for all participants. All identifiers that could be used to recognise the participants were removed during analysis and writing and

participant details are not attached to the data in any way that discloses their identities. A password-protected master list of participants containing participant names, contact details and linked pseudonyms and Mzantsi Wakho participant numbers was kept and was accessible only to me.

All researchers involved in data collection were trained on procedures to uphold participant confidentiality and required to sign the confidentiality agreement (modified from the Mzantsi Wakho Confidentiality Agreement – attached at *Appendix 13*) before beginning the research. Participants chose the time and location of engagement with the researchers, given that they met the project's rigorous safety standards (Hodes *et al.*, 2014). For example, participants chose to be interviewed in a project vehicle, a local park, a restaurant or a community centre. Researchers agreed to these locations in order to ensure that participants were comfortable as long as they upheld confidentiality. In the cases pictured below, the participant opted to do the interview in the back of the research vehicle—a large, closed-cab bakkie (pickup truck), and the other in his home.





Figure 17: Researcher Phakamani Kom conducts an interview with a participant in the back of a research vehicle (left). 4 October 2017.
Figure 18: Researcher Sinebhongo Mbula walking with a participant into his home to conduct an interview (right). 19 August 2017.

If a participant wished to be interviewed at home, he was asked if there was a space where they

would be comfortable conducting the interview that would be free from interference. In the case of home-based interviews, the participants were also made aware that the researchers could not guarantee that interference would not occur in the interview, and that this might be a limitation to confidentiality. Participants were also informed that at any time before or during the interview, that the researchers could recommend an alternate, secure space to conduct the interview if they preferred.

As set out in the reporting protocol, confidentiality is bounded by the legal requirement to report cases of maltreatment, neglect, physical abuse causing harm, and sexual abuse. As per the principles and processes for obtaining informed consent, participants (and in the cases of participants under the age of 18, their guardians as well) were informed that what they said in the interview would be kept confidential, except in circumstances where they had been harmed or been at risk of harm. This rule applied in cases of maltreatment, neglect, physical abuse causing harm and sexual abuse. It also applied when the research team reasonably suspected that a participant had tuberculosis or another notifiable disease, which are required by law to be reported to a health professional. In practice, no cases arose that required mandatory reporting.

Reporting of abuse, maltreatment and neglect

The law requires reports of violence, maltreatment, and non-consensual sexual activity to the South African Police or the Department of Social Development. Although our protocols mapped out how to respond in instances of sexual or physical abuse, maltreatment, and neglect, these issues did not emerge.

Referrals

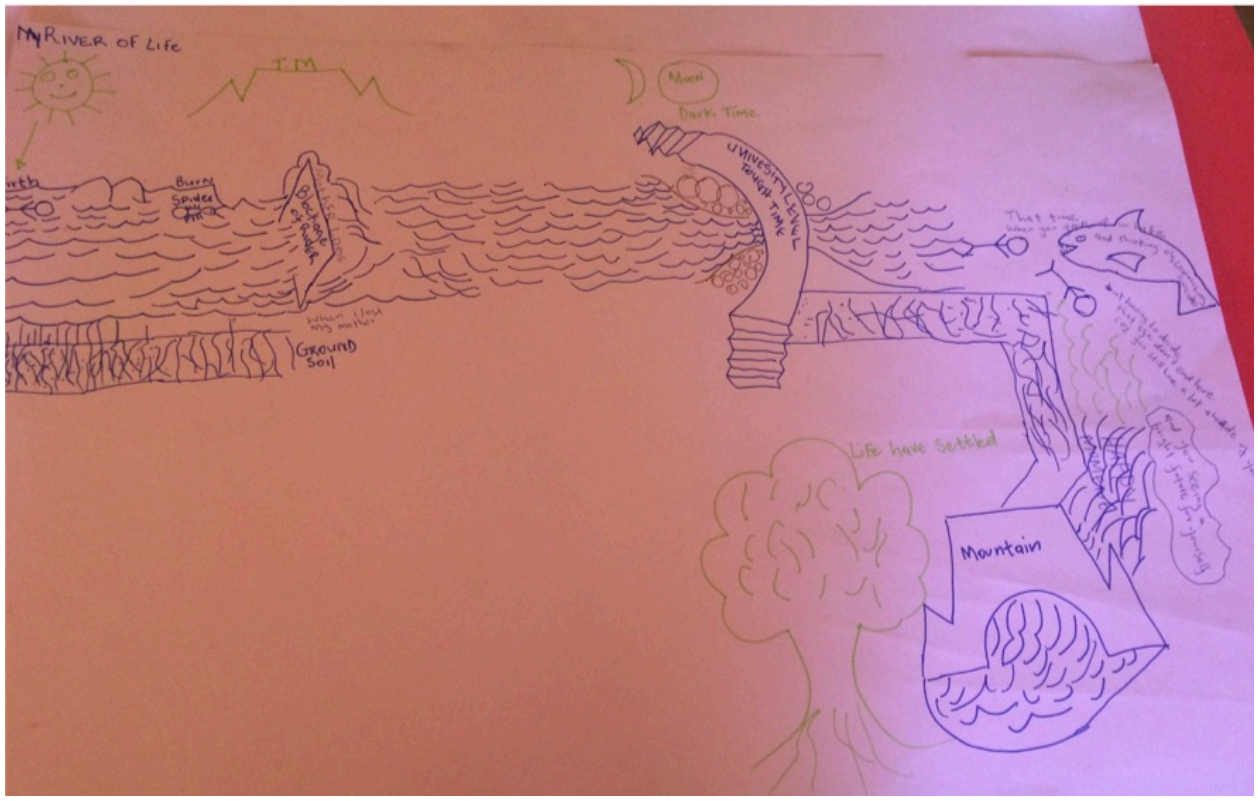


Figure 19: Example of a life history narrative interview where a participant discloses psychological distress and former suicidal ideation. Image on top right of the shark says 'That time when you give up in life and when you are thinking of committing suicide' followed by 'but beginning to decide that life doesn't end here coz you still here and a lot ahead of you…and you seeing a bright future for yourself'. 4 February 2017.

In the course of this research, challenging experiences such as health and psychological challenges, substance abuse, and the inability to meet basic needs were disclosed. These arose due to a high presence of cases of extreme need within the study sample, and likely because this may have been be one of few opportunities that an adolescent had to discuss the details of their lives with a trusted adult (Hodes *et al.*, 2014; Cluver, Boyes, *et al.*, 2015). In total, about a third of participants (n=12) received referral support. These included food parcels in cases of extreme food insecurity, linkage to and driving to counselling services for addictions to substances, and referrals to other social support services**.** For example, in the life history narrative image above, a participant disclosed having previously had suicidal thoughts in the course of his life history interview. This example shows how such methods elicit accounts of sometimes intimate and challenging life events. The extent of these referral cases, and methodological findings from

challenges are explored in Chapter Seven. The case study contained in this chapter also explores some of the complexities of referral cases.

Interviewers

Two young Xhosa male researchers were responsible for conducting interviews with adolescent boys, under my supervision, although I did not sit in on most interviews. Despite the drawbacks of not being in the interview, the reasons my non-attendance of interviews included: participant comfort, and the high likelihood of generating social desirability bias in the presence of a foreign, 'white'[13], female researcher with limited isiXhosa language abilities. Further details, including the drawbacks and ethical and methodological findings around research demographics, are included in Chapter Seven.

Research methods & tools: biomedical and traditional health workers and key informants

In-depth, semi-structured interviews with 14 additional participants were conducted to gather their observations, experiences and perspectives about adolescent boys' and young men's health services engagement. These included four biomedical health workers, including three nurses and one doctor. Two of these (one nurse and one doctor) were also traditional health practitioners. Eleven traditional health practitioners (which includes the two listed above who were also biomedical practitioners) were also interviewed. Most interviews were individual, but two small group interviews also took place with traditional health practitioners. One stakeholder who works with a circumcision programme was also interviewed.

Pseudonym[14]	**Gender**	**Profession**	**Location**
Sister Nomxolisi	Female	Biomedical Health Worker - Nurse	BCM
Sister Funeka	Female	Biomedical Health Worker - Nurse	Amathole
Dr Malibongwe	Male	Biomedical Health Worker - Doctor, Traditional health care worker	BCM
Sister Nceba	Female	Biomedical Health Worker - Nurse, Traditional health practitioner	BCM

[13] Racial identifiers when used are put within quotation marks ('') to denote that these categories are socially constructed. Insofar as possible, this study aims to avoid reproducing these categories. However, this thesis does use racial identifiers at points to acknowledge these historical and on-going constructs when relevant to this study.

[14] In a few cases, adult stakeholders requested that their real names be used. Otherwise they provided pseudonyms or requested us to select pseudonyms for them.

Mbelelo	Male	Stakeholder - circumcision unit	BCM
Tamella	Female	Traditional health worker	BCM
Mamj Ciky Vuza	Female	Traditional health worker	BCM
Gogo Nosi	Female	Traditional health worker	Amathole
Luthando	Male	Traditional health worker	BCM
Ngubesilo	Female	Traditional health worker	Amathole
Tata Bongikhaya	Male	Traditional health worker	BCM
Camagu	Female	Traditional health worker	BCM
Funeka	Female	Traditional health worker	BCM
Langa	Male	Traditional health worker	BCM

Table 2: Participant Table: Biomedical and traditional health workers and key informants

Recruitment and data collection: Biomedical health worker, traditional health practitioner participants and key informants

Biomedical health worker participants were recruited through Mzantsi Wakho relationships with local hospitals and clinics, including paediatric, ART and circumcision clinics. As a complementary method to the aforementioned data collection with young male participants, in-depth, semi-structured interviews were conducted. A general interview question list is attached at *Appendix Three*. Interviews with biomedical service providers gave insight into the health behaviours and choices of adolescent boys living with HIV from the perspectives of those who provide them with health services.

Consent was obtained from health facilities before interviewing health care providers and extracting participant files. I conducted the interviews with biomedical practitioners, all of which were in English. Informed consent was obtained for every health worker. Given that many public sector health care workers in the study area are overburdened, utmost care was taken to schedule interviews at convenient times and to ensure that the interview length was acceptable to participants. Interviews took between one and two hours, based on the participant's level of engagement and available time. Biomedical health worker participants received a non-monetary incentive which included something to eat and another item that may be relevant to them or their work, such as a re-usable coffee mug or water bottle. Approximate value of such gifts were ZAR150-200.

Traditional health practitioner participants were recruited through my network of contacts,

including those who have already participated in Mzantsi Wakho research to date. I attended meetings of the Eastern Cape traditional healers association, and also recruited participants from there. In depth, semi-structured interviews (a general interview question list is attached at *Appendix Four*) were used. As a complementary method, conducting interviews with traditional health practitioners provided insight into the health behaviours, beliefs and choices of adolescent boys living with HIV, as well as their families.

Written and verbal consent was obtained as per the consent protocol set out in this document. A copy of the information and consent form can be found at *Appendix Eight*. This document also applies to health care workers and key informants.

I conducted interviews with traditional health practitioners. In cases where the participants did not speak fluent English, or preferred to speak in isiXhosa, an isiXhosa speaking researcher attended to provide translation support. Informed consent was obtained for every traditional health practitioner.

Traditional health practitioner participants received a non-monetary incentive such as an ancestral cloth and candles. Approximate value of such gifts was ZAR150-200. Where incurred, transport costs for participants were reimbursed.

The South African National Department of Health's 'Ethics in Health Research Principles, Processes and Structures' (Greef, 2015) outlines the impetus for respecting participants in research involving 'indigenous cultures and traditional values', including treating the beliefs and traditional medical systems with respect and protection. This guideline indicates that the context of the interaction or research activity as important for determining the way in which to incorporate 'traditional values' and their cultural expression in research (Greef, 2015). To this effect, practices of greeting, acknowledgement and respect were followed in interviews. In only one situation did another researcher attend to support with translation. In this situation, they were briefed on such practices prior to the interview. Details of practices that are considered secret, or otherwise inappropriate for broader sharing are not included in this thesis.



Figure 20: Interview with traditional health practitioners. 22 November 2016.

In respect of traditional health practitioner's time, and in acknowledgement that for many, their practice is also their primary source of income, care was taken to schedule interviews at convenient times, and ensure that the interview length is acceptable to participants. Interviews took between 60-150 minutes, based on the participant's level of engagement and available time.

Secondary Sources

This research built on data and findings from two secondary sources. These included a 2016 research report on the role of child and adolescent-sensitive social protection in supporting ART-adherence and sexual health (RIATT-ESA, 2016). Unpublished data and findings from the 'community audit', a qualitative study that explored service provider and adolescent perspectives

on social protection and HIV prevention activities in the Eastern Cape were used as a secondary source. This study was conceptualised by Mzantsi Wakho, and I conducted data collection. These two sources represent consultations with 39 adolescents and 53 adult participants within a variety of sectors, including: government service providers; health workers, educators, and social workers; faith leaders and traditional health practitioners; government administrators from local and regional bodies; national and regional NGOs; regional and international organisations; and researchers and academics.

Ethics approval for the aforementioned two sources was obtained through approvals for the Mzantsi Wakho study and collected under the Mzantsi Wakho study which are discussed under the ***'Ethics'*** section in this chapter.

Data

Data translation and transcription

Interviews were audio-recorded (with the consent of participants), and transcribed. Three adult research participants (a key stakeholder, one traditional health practitioner and one biomedical health practitioner) did not wish to be audio-recorded and notes were taken with their consent. Non-English interviews were translated and transcribed simultaneously by the researchers who conducted the interviews. Transcriptions were reviewed for quality, with corrections and re-transcriptions made as necessary.



Figure 21[15]**:** Sinebhongo Mbula and Phakamani Kom translating, transcribing and co-analysing pilot participant interviews. 25 April 2017.

Data analysis

Data were analysed using thematic analysis, a 'method for identifying, analysing and reporting patterns (themes) within data', which provides for flexibility and the ability to provide a 'rich and detailed, yet complex account of data' (Braun & Clarke, 2006, p. 78/9). In keeping with the principles of grounded theory, the themes that emerged most strongly from the data were the focus of analysis and writing.

Thematic analysis included the following steps:

(1) **familiarisation** with data through debriefs and discussion after every interview, as well as reading and re-reading notes and transcripts and reviewing visuals (clinic files and 'river of life' drawings);

(2) **thematically coding text** both deductively (by using research questions and literature) and inductively (using the raw data). NVivo was used to manage themes as well as individual 'cases'

[15] Image adjusted due to poor lighting. Other than situations such as this where the image was difficult to see, images have not been manipulated or edited, other than to anonymise participants.

of participants. This software was used to assist in the management of a large data set and to aid in the analysis process (Zamawe, 2015).
(3) **displaying and indexing data** by writing detailed memos to themes, both qualitatively (by noting key concepts, specific vocabulary, and intensity of expressions) and quantitatively (by noting the duration, frequency, size or quantity of phenomenon);
(4) **data reduction** where data within each main theme was summarised across groups;
(5) **data mapping and interpretation** to explain meanings of data and ensure that interpretations were trustworthy (Ritchie and Spencer, 1994; Ulin *et al.*, 2005; Olagbuji, 2017).

I kept detailed notes of observations and interviews, methodological approaches and the reasons for their use, as well as thoughts, feelings and perceptions. Data were coded in order to combine and differentiate data (Miles and Huberman, 1994). Themes were iteratively named, reviewed, combined and redefined. The process of data collection and analysis was reflexive and iterative, in order to allow for adjustment of the data collection instruments to strengthen the data and explore unexpected and interesting findings (Ulin *et al.*, 2005). During analysis and interpretation, sources (traditional and biomedical health service providers, adolescent participants, and key informants) were triangulated (Patton, 1999; Olagbuji, 2017), as well alongside data and findings from other Mzantsi Wakho research. Chapter Four presents a case study of triangulation across methods for greater detail.

At the time of Ezoboduda interviews, the Mzantsi Wakho study had already conducted a quantitative health-focused survey with each Ezobudoda participant a minimum of twice, and a maximum of three times. When we sought consent to conduct an interview with adolescent participants, we also sought consent to access Mzantsi Wakho participant data, including school and clinic data collected as part of the Mzantsi Wakho study, and consent to access health facility files. Triangulating this data was valuable in gathering a more holistic understanding of understanding participant behaviours and experiences related to the research questions. Co-analysis and verification with researchers also occurred throughout the data collection and writing process. This process happened through phone calls, WhatsApp messages, and in-person meetings.



Figure 22: Verification meeting between Sinebhongo Mbula and Lesley Gittings, reviewing a thesis chapter. 4 February 2019.

Data management and storage

Transcripts, interview recordings, participant contact information and any other electronic data (e.g. pictures of 'river of life' drawings, images of clinic files) collected during the course of this study were stored in a password-protected folder on my computer, in NVivo, and backed up on a DropBox account for which only the myself and the study researchers had access. Papers were stored in a locked cabinet in the Mzantsi Wakho King William's Town office, and then transported to a locked drawer at the University of Cape Town's AIDS and Society Research Unit (ASRU) when I completed data collection. They will be stored at ASRU for five years subsequent to the conclusion of this research, and will then be destroyed. Consent forms and copies of mandatory reporting forms will be destroyed three years after the study is completed.

Publication, dissemination and capacity building

Peer-reviewed publications including data from the Ezobudoda sub-study are listed below.

Co-authored book chapter based on this research (a version of which is included in this thesis as Chapter Seven):

> Gittings, L., Hodes, R., Colvin, C. and Zungu, N. (Accepted). Things less spoken: HIV research with adolescent boys and young men – implications for theory, policy and practice. In Govender, K. and Poku, N.K. (Eds.), *Adolescence and HIV Prevention in*

Africa: Emerging Evidence and Intervention Strategies. Abingdon: Routledge. Forthcoming in 2019.

Co-authored paper with Dr Hodes, which included data collected during the course of this research:

Rebecca Hodes & Lesley Gittings (2019): 'Kasi curriculum': what young men learn and teach about sex in a South African township, Sex Education, DOI: 10.1080/14681811.2019.1606792

In preparation for submission:

Gittings, L., Mbula, S. And Kom., P. "If you are found taking medicine, you will be called names and considered less of a man": HIV-positive adolescent boys' engagement with HIV treatment and care during and following ulwaluko (traditional initiation/ circumcision) in the Eastern Cape Province of South Africa.

Beyond the University's Code for Research Involving Human Subjects, the study team and I upheld the ethical imperative to document, record and disseminate findings in a way that accurately and confidentially represented participants. With the support of the Mzantsi Wakho project and the South Africa Social Science and HIV (SASH) programme, the team endeavoured to share findings broadly in a way that upheld confidentiality with Eastern Cape-based stakeholders, nationally and internationally.

Whenever possible, the researchers who conducted interviews with adolescent boys and young men were involved in dissemination activities. This practice served the purpose of ensuring that the researchers (people who will continue to live and work in the study context) were familiar with and could continue to disseminate findings when the I left the Eastern Cape. It was also part of the ethos of the project to support capacity-building of local researchers in conducting, disseminating, and presenting research, and for people from the study site to present findings that affected their communities. To this effect, the researchers were involved in dissemination activities at all Eastern Cape sites, as well as delivering an oral poster presentation at the AIDSImpact conference in Cape Town in 2017.

Eastern Cape-based dissemination included: developing a pamphlet on medicines-taking during ulwaluko delivered to 46 schools by a local NGO; presentations to the two largest public hospitals in Amathole and Buffalo City; and presentations to provincial stakeholders including the Eastern Cape AIDS Council and the Eastern Cape Department of Health. The team also endeavoured to share findings broadly in domestic and international fora. Findings from this work have been included in a total of 19 presentations, including at the Universities of Cape Town and Oxford, events attended by policymakers and practitioners, with funders, and at conferences (four South African and five international conferences). Further details about dissemination, including a list of presentations and trainings, is included at *Appendix 15*.

Ethics, ethical & methodological challenges

Case study

The below case study aims to highlight some of the ethical and methodological challenges that we encountered during the course of this research and is modified from my field notes.

The Ezobudoda team (a researcher and myself as a driver) went to request a follow-up interview with an Ezobudoda pilot research participant. A 23-year-old male from a rural area outside of King William's Town, he had participated in a pilot interview the year before. In the initial interview, he participated actively, seemed to enjoy the interview and consented to be contacted again for another interview. When we tried to follow up with him telephonically to request a second interview, the phone numbers we had on file for him were no longer working, so we drove the research vehicle (image below) to his home.



Figure 23: 'Merle' the research vehicle used for Ezobudoda fieldwork. 18 April 2017.

There were a number of reason for bringing this vehicle. In addition to being the allocated vehicle from the Mzantsi Wakho study for Ezobudoda work, it was also capable of driving the rural roads to the participants' homes. It was also often common for participants to wish to be interviewed outside of their homes, and they sometimes opted to be interviewed in this research vehicle, which had a large closed-back cab which was outfitted with benches. It was one of a number of similar looking Mahindra trucks, all of which had been brightly spray painted.
Upon arriving outside of the participant's home, his neighbour started calling loudly for him. He did not emerge, and we decided to leave, not wanting to bring more attention to him. Our concern was that he was home but choosing not to come out of his house. 'Stigma mitigation' (Hodes *et al.*, 2014) was an important aspect of the study—and a central concern given that research was conducted in environments of high surveillance, where people were observant of and interested in the presence of researchers, and because of the highly stigmatised nature of HIV. For these reasons, the fact that the Mzantsi Wakho and Ezobudoda studies focused on HIV was not disclosed to participants. Instead, the study was broadly framed as about young masculinities and health. Mzantsi Wakho also recruited and interviewed HIV-status unknown participants from the same households and communities, as a measure of stigma mitigation and confidentiality. Given that the research vehicles were highly visible, we wanted to ensure that they were not identified as related to an HIV research project.

A few days later, we visited the participant in a way that minimised our visibility. A Xhosa male driver drove the researcher, rather than me, and they went in a smaller and more ordinary looking

car. When they arrived, the participant answered the door and agreed to be interviewed. He was dressed stylishly in a crisp white t-shirt, jeans and wore a large wooden cross around his neck. He had a severe-looking rash over his face and visible parts of his body. He said he was available for an interview at that time, and asked that the interview take place at KFC in King William's Town.

In the car on the way to the interview, the participant, unprompted, opened up to the researcher and driver. He told them that he had stopped his HIV medicines since coming back from initiation in 2012, six years prior. This is a theme that emerged strongly amongst participants, and practices of medicines-taking during and after ulwaluko are explored in Chapter Five. He also spoke about how, prior to initiation, he had 'part-timed' on his medicines. He also disclosed that he did not want to go back to the health facility because the sister-in-charge used to shout at him. The dynamics of shouting nurses and stigmatising health facilities was also a common theme that is discussed in Chapter Six. The participant, Ta Saider, expressed his concern in not having accessed biomedical health services or taken medicines for so long and was worried about getting sick. He also requested support from the researchers on a matter that he had not spoken to anyone about. He said that his foreskin was not completely removed during ulwaluko and asked for information about how to get medically circumcised. He raised his concerns about his medicines-taking and foreskin again during the interview when he was asked about which areas of his life that he wanted to improve. Here he speaks about 'cutting' in relation to both his remaining foreskin and his perceptions of associated health risks:

> **Ta Saider:** Like to what we have talked about, circumcision and health. What I would like is I want to go back to my treatment, as I was defaulting on treatment. I want to be circumcised. I have already done that, but I want to cut that 30% and also take my treatment.
> **Interviewer:** When you talk about 30% what do you mean?
> **Ta Saider:** The 30% - you are cutting the high risk of HIV.
> **Interviewer:** So you want to go back and cut?

Ta Saider: I want to go and cut again because in initiation they did not do the proper cutting. They said I've got a thick foreskin. So if I could cut again my health will be good, and I can go back to treatment.
Interviewer: Did you go and try and ask at a clinic or hospital?
Ta Saider: No I have not done that yet.
Interviewer: You said before that you want me to ask for you where you can get help? (referring to car ride to interview)
Ta Saider: Yes I want that.
(Ta Saider, 21)

The ethical issues here are complex and difficult to navigate. The participant disclosed that he was not taking essential medicines, and it is possible that his rash was a symptom of an opportunistic infection due to his weakened immune system. He requested support in re-engaging with biomedical health services, but did not want to present at the same health facility in his area. He also asked for help to access another biomedical intervention—medical male circumcision. However, his rationale for wanting to get medically circumcised demonstrated that he had incorrect information about the benefits of medical male circumcision. As he was already HIV-positive, 'cutting the high risk of HIV' did not apply to him, showing that he had received and internalised circumcision-related messaging but did not have a proper understanding that the protective benefits of HIV-risk reduction are for men who are not living with HIV.

As we did for other challenging referrals, the researcher and I discussed this case with the project manager of the King William's Town office. In line with the referrals protocol, we agreed on a course of action. We contacted the circumcision manager for the area, who advised that we refer the participant to a large public hospital in King William's Town which has both a circumcision clinic and an adult and paediatric ART unit. We contacted the sister in charge of that paediatric ART unit, with whom we work closely on referral cases. She recommended that the participant could come speak to her and she could advise him on circumcision and also offer blood testing and re-initiate him onto HIV medicines if he wanted to. We did not provide any identifying details of the participant to either of our referral contacts.

Following this, we tried contacting the participant on the more recent phone numbers he had given us, but were unable to reach him. The researchers went back to his house in the same discrete car but did not find him at home. Not wanting to stigmatise him, we did not follow up again. A few weeks later we went to extract clinic files at the health facility that he used to attend. His file showed that he had presented recently at the facility for the first time in years.

This case study is provided here to offer insight into some of the complex ethical and methodological challenges faced in the course of this study. Although a unique case, it highlighted broader common challenges in conducting HIV research with young people living with HIV in resource-limited and high surveillance settings. These challenges included: (1) participant disengagement from essential biomedical health services and medicines; (2) participants requesting referral support from the research project; (3) difficulties reaching research participants; and (4) stigma mitigation and visibility issues with research vehicles in high surveillance areas. These are each discussed briefly below.

(1) The Mzantsi Wakho and Ezobudoda protocols state that in cases where participants disclosed non-adherence to HIV and other essential medicines, that the interviewer would discuss the importance of adherence with the participant and also encourage them to consult a healthcare worker or adherence supporter.

(2) The Mzantsi Wakho and Ezobudoda referral protocols map out the process for referral cases. Some required mandatory reporting (which in the course of this study did not occur), whereas others such as food insecurity and substance abuse were more common. This study received a significantly higher proportion of requests for support and referrals than the Mzantsi Wakho study, the content of and dynamics of which are explored in detail in Chapter Seven**.** These requests posed both an ethical and methodological challenge. We wished to be supportive, but not want to create alternative systems through which participants came to rely on the project and became more vulnerable when we left. We also did not want to skew study findings by intervening and had limited human and financial resources to provide support. We managed this by streamlining the referral process into the broader Mzantsi Wakho referrals, by reporting it to the King William's Town office manager, so that we could receive additional support from the

broader team who were more knowledgeable and better equipped to handle such cases. We also tried to ensure that the referrals we conducted provided options for greater sustainability, particularly in relation to food access. For example, when delivering food parcels, we included seeds so that participants might grow their own food (if they desired to do so and resources such as land availability and arable soil pending), and we aimed to refer participants to accessible referral partners, such as counselling services. We also took notes about the referrals, and reviewed these when going back to participants. In the case of the participant above, despite not reaching him directly to provide a referral, it is likely that our intervention resulted in him re-engaging in HIV care.

3) Reaching research participants was often challenging with changing phone numbers and homes. We also wanted to balance our understanding of their informed consent. That is, we wanted to balance their requests for support with their privacy and the possibility that they did not want to be contacted again. In some cases, like the one above, this was unclear. He actively chose to participate in an interview and repeatedly requested support. Whether he was intentionally unavailable when we tried to respond is difficult for us to know.

4) During the study design phase and throughout the study, extensive efforts were taken to minimise risks of stigmatising participants. Some of these are described briefly above, and they are mapped out comprehensively in the Ezobudoda and Mzantsi Wakho protocols. However, in the car on the way to the interview, the participant discussed above said explicitly that he did not want to be associated with a Mahindra (most of the project vehicles were the same highly-visible make of car). He did not explicitly link this to his HIV status, but it is possible that he had made the connection:

> **Interviewer:** So you were saying once the Mahindra stops in front of your house they assume that there is something wrong?
> **Ta Saider:** Yes. As I am a secretive person so I don't want anyone to know my status.
> **Interviewer:** So what have they suspected now?
> **Ta Saider:** No there is nothing, but as I think that it can cause problems
> **Interviewer:** So you don't want to see the Mahindras?

Ta Saider: No.
(Ta Saider, 21)

That he did not want to be seen associated with a Mahindra on its own is an ethical concern. Despite the aforementioned stigma mitigation measures, including interviewing family members and neighbours, after almost three rounds of interviews with most of the study's approximately 1500 participants (over a 1000 of whom are HIV-positive), this interview suggests that some participants had linked our study to HIV. The participant did not want to be associated with that Mahindra, but also wanted to be interviewed.

Did we do the wrong thing by going back to his house in a different car? Were other community members aware that Mahindras were linked to an HIV study, or had the participant speculated that the study was HIV-related and was worried about being visibilised in the Mahindra? If it was the former, what might be the effects been of this inadvertent disclosure and stigmatisation on his, and other young people's lives? Did we harm this participant through stigmatising him or causing him to worry about stigma?

At the same time, is it possible that he also benefitted by taking part in the research by being provided the opportunity to speak openly with supportive adults outside of his regular day-to-day interactions, and being encouraged to re-engage in clinical care? Was there, like he and other participants sometimes suggested, therapeutic benefit to taking part in this research? And if so, was the benefit enough to outweigh potential harms and make it worthwhile for them to participate? In choosing this research encounter, how much agency did he have? And was taking his word at face value about his interest in participating affirming of his agency, or might we have missed something?

And, will the findings of this research be able to shape further research, policy or intervention in a way that benefits a larger group of young people, like this young man who are facing the same challenges?

This case study speaks to a multiplicity of ethical and methodological quandaries present in this research. They are raised here as questions, with the acknowledgement that these in some way are unanswerable in a simple way. These questions speak to some of the complexities of benefit and harm implicit in this research. Although the primary objective of research is to do no harm, this case study is an example of how research is not neutral.

Ethics approvals and protocols

Ethical approval for this protocol was sought by the University of Cape Town's Faculty of Health Science Human Research Ethics Committee (HREC) (approval number 314/2017). It was renewed for a second year and third year and is currently valid until September 2020. My primary supervisor, Associate Professor Colvin, was the UCT Principal Investigator for the purposes of the Faculty of Health Sciences Human Research Ethics Committee processes. Ethical approval was also obtained from the Eastern Cape Department of Health. Ethics approvals for this study are attached at *Appendices 16 and 17*. This study was also guided by a number of laws, guidelines, and policies as outlined in the table below.

The University of Cape Town's '*Code for Research Involving Human Subjects*' (2018)
The South African National Department of Health's 'Ethics in Health Research Principles, Processes and Structures' (Greef, 2015)
The South African National Health Act (Parliament of South Africa, 2003)
The 2008 Helsinki Declaration (The World Medical Association, 2008) The Sexual Offences Act of 2007; (Parliament of South Africa, 2007b)
The Children's Act of 2005, (Parliament of South Africa, 2005) and the Children's Amendment Act of 2007 (Parliament of South Africa, 2007a);
The University of Cape Town's Human Research Ethics Committee's (HREC) standard operating procedure (SOP) on Research Involving Children (University of Cape Town, 2013)
The HREC SOP on Informed Consent (Human Research Ethics Committee, 2014)

Table 3: Laws, guidelines and policies that guided the ethical considerations for this research

Given that this proposed research was a sub-study of the Mzantsi Wakho study, an overview of the Mzantsi Wakho ethics approvals and their relation to this sub-study is provided below with the aim to provide a comprehensive background to this ethics application for this study. Prior to enrolling in my doctorate, I conducted research under Mzantsi Wakho study ethics, which were provided by Research Ethics Committees at the Universities of Oxford (SSD/CUREC2/12-21) and Cape Town (CSSR 2013/4 – attached at *Appendix 18*), and the Eastern Cape Departments of Health and Basic Education.

An ethical protocol (Hodes *et al.*, 2014) for the Mzantsi Wakho project was written as part of the process of obtaining permission for the study in 2014, and updated in 2017. It maps out the process of informed consent (from both participants and their guardians in cases when participants were minors), legal obligations for reporting maltreatment, neglect and abuse, and includes a process to respond to participants who become distressed during their participation in the study (Hodes *et al.*, 2014). The Ezobudoda protocol was complementary to this Mzantsi Wakho protocol, which is referenced frequently in this document. Both protocols highlight the importance of building trust and rapport with participants, as well as reflexivity and consultation during data collection, analysis and reporting (Hodes *et al.*, 2014).

The ethical dilemmas, complexities and challenges posed by studies on HIV and adolescence have been mapped out in an extensive literature, such as Vale and Thabeng (2015), Cluver and colleagues (2015) and Hodes and colleagues (2018). The intimate nature of sexual health, gender and spiritual beliefs, coupled with the young age and HIV-positive status of participants, required a very intentional, sensitive and participatory research design and execution. To this effect, the research techniques used aimed to make participants feel comfortable and safe, protect their confidentiality, and build trust. These techniques are documented in the recruitment and data collection sections of this document and the appendices.

The primary ethical concern with this research was that it not make participants more vulnerable in the research process nor by any research products (Anthropology Southern Africa, 2005). In line with section 28(2) of the South African Constitution (1996), the best interests of the child are of paramount importance, including in research with children. As per the Children's Act (Parliament of South Africa, 2005), criteria to determine a child's best interest include their age, maturity and stage of development. This research was only conducted with older children (ages 13 and older) who, it was hoped, had the ability to understand the implications of participation in this research. The principles and processes for ensuring that adolescent minor participants understand the meaning of their participation are mapped out in the informed consent process section of this chapter and the appendices.

There were additional ethical and methodological challenges that should also be noted. Many of these challenges complement the above case study, and are shared to provide insight into some of the ethical and methodological complexities of this work.

Finding young people, even after they had expressed interest to participate in interviews, was often challenging. Reasons for this included high geographic and caregiver mobility (as discussed in Chapter Four), changing phone numbers and changing adolescent plans. A number of strategies were employed to locate participants in rural areas and places with unmarked street names. In addition to detailed address notes kept in the Mzantsi Wakho and Ezobudoda rosters, the Mzantsi Wakho researcher or driver who had interviewed participants often accompanied the Ezobudoda researchers to the home for the first time. WhatsApp location pins were also used as a way to document locations, which meant that they could be easily found next time. This method also served as a safety measure to ensure that the research team knew where field-based researchers were.



Figure 24: Researcher Phakamani Kom, trying to contact hard-to-find research participant using roster. 26 August 2017.



Figure 25: Screenshot of location pinning and communications between researchers (left). 15 September 2017.
Figure 26: Screenshot of location pinning and communications between researchers (middle). 14 September 2017.
Figure 27: Screenshot of location pinning and communications between researchers (right). 19 August 2017.

Many logistical issues were vehicle and transport-related. Despite having a large research vehicle capable of driving in poor conditions, the roads were challenging in some rural areas. In a number of instances, getting stuck, vehicle break-ins and stolen parts delayed fieldwork. As can be seen in the images above, project cars were visibly demarcated with spray paint. However, this caused additional ethical and logistical issues. In 2017, during this study, there were concerns in some of the project sites over news of kidnappings. As a result, some people living in the neighbourhoods within the study sites became suspicious of NGOs and research projects (worrying they were kidnappers) and the cars made us easily identifiable. At this time, a decision was taken to re-paint many of the project vehicles white.

After three years of follow-up, there was a concern that project vehicles and the Mzantsi Wakho project would become associated with HIV research. Despite the stigma mitigation measures to avoid this, such as interviewing neighbours and other children in the same household, it became apparent that some participants felt seen or made visible by research vehicles, although the extent of this was difficult to ascertain.



Figure 28: Getting stuck in the mud (left). 19 August 2017.
Figure 29: Getting stuck in the mud (right). 5 October 2017.



Figure 30: Stolen car tire. 5 April 2017.

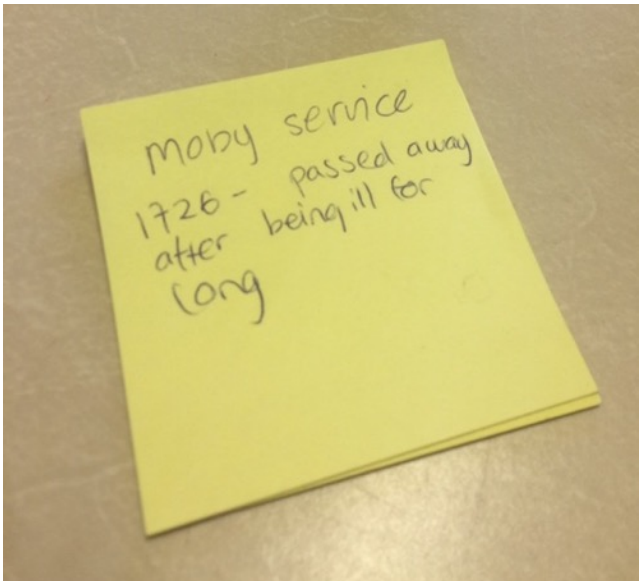


Figure 31: Roster update note on the desk in the King William's Town office. 19 August 2017.

Unfortunately, the Mzantsi Wakho study also had a high death rate: 3.4% of participants living with HIV passed away between baseline and the third wave of interviews. Participant illness and death align with data on adolescent HIV, and although not unexpected, took a psychological and emotional toll on research staff. Vicarious trauma is common amongst research assistants and researchers working with adolescents living with HIV. Within the Mzantsi Wakho study team, it was estimated that about half of us suffered at some point from vicarious trauma. Throughout the course of this research, the researchers and I were exposed to many participant narratives of hardship and trauma (some of which are presented in Chapter Four). In line with the Mzantsi Wakho referral and safety protocols, Ezobudoda researchers and I accessed psychosocial support

services to help us cope with psychosocial challenges that we encountered during the course of the research. I also conducted frequent 'check-ins' throughout the course of the study and after at its completion with researchers. These check-ins provided researchers opportunities to debrief about their work and its impact on their well-being, and provided psychosocial and logistical support to address challenges they encountered during the course of the project. I accessed frequent support services to cope with and process the psychosocial impacts of this research on my well-being.

It is important to note the multiple, intersubjective power dynamics inherent in this study, especially between adolescent participants, researchers and myself. These included dynamics associated with age, class, gender, race and language. Many of these power dynamics and their consequential inequalities were also present with caregiver, biomedical and traditional health worker participants. These are explored in the 'reflexivity' section of this chapter. In order to be aware of these inequalities, and avoid harm they may cause, I engaged in a sensitive, participatory research design and pursued reflexivity throughout all phases of data collection, analysis and presentation. Research assistants were also trained on navigating unequal power relations and awareness of roles and social positions. The potential risks and benefits of participation, as well as their mitigation procedures are attached at *Appendix 18*.

Every effort was made to minimise risks to researchers. These efforts included following safety considerations, guided by the Mzantsi Wakho (Mzantsi Wakho, 2016) safety protocol which was extensively reviewed and considered by Mzantsi Wakho principal investigators, co-investigators and those working at the study sites. In line with the protocol, all staff were trained in safety measures and read and signed the Mzantsi Wakho safety protocol before commencing work. Staff also travelled in groups of at least two when there was a safety concern.

Interviews were not conducted in any situation or location in which researchers felt unsafe. In addition, the team frequently monitored safety situations in the locations in which research is conducted. During times of protests, 'taxi wars' and political instability, they did not enter or conduct research in the areas where these events were taking place. Additionally, the research team did not work on the first Saturday of every month as social grants were distributed earlier

that week. Local team members reported that this was a potentially more dangerous time to be working in the field due to increased alcohol consumption and associated increased potential of violence and road injuries.

Researching ulwaluko

Primary research regarding the ritual of ulwaluko is difficult because it is taboo to discuss with women and 'outsiders', and contains highly sensitive and secret components (Vincent, 2008; Mavundla *et al.*, 2009; Kepe, 2010). These sensitivities were clear when the movie *Inxeba (The Wound),* which was set against the backdrop of ulwaluko, came out in theatres during the course of this research. As can be seen in the newspaper clipping below, screenings of the film were stopped from showing in the study site due to protests. This indicates the sensitivity of public engagement with this topic, which I explore further within the 'reflexivity' section of this chapter.



Two springbuck find themselves in a dangerous place, in the middle of an East Coast road with traffic zooming past. They were pictured near Chintsa this week

Picture: MICHAEL PINYANA

Outrage over controversial film about circumcision

By MALIBONGWE DAYIMANI
Crime Reporter

THE premiere of the controversial award-winning movie Inxeba (The Wound) will continue as planned today despite mounting moves to block it from being shown on the big screen.

This was confirmed by the Films and Publications Board (FPB) yesterday amid a storm over the perceived ritual insensitivity and distortion of the Xhosa circumcision tradition in the film.

The Commission for the Promotion and Protection of the Rights of Culture, Religious and Linguistic Communities recommended that the producers should make four changes before releasing the movie.

It included:

- Increasing the age restriction from 16 to 18;
- Translating the English subtitles verbatim so that they truly and properly reflected what was being said in isiXhosa;
- The film should carry a blasphemy classification as the ritual of initiation is very sacred to many African communities. The film also mentions that Jesus Christ and King Shaka Zulu were maybe homosexuals; and
- The producers of the film must put an advisory disclaimer at the beginning of the film wherein they categorically state that the scenes people are about to see do not depict a true and proper African traditional ritual of initiation, and might offend Christians and AmaZulu communities.

The findings are contained in a letter dated January 26 that was addressed to FPB chairwoman Thoko Mpumlwana.

In the letter the commission confirmed that it had launched a probe after receiving complaints of cultural insensitivity from AmaXhosa King Mpendulo Zwelonke Sigcawu, AmaNdebele Royal House leader Nkosi Mahlanga, the Man and Boy Foundation and Contralesa on November 30.

But FPB spokesman Manala Botolo said the movie had been classified and rated by the FPB's classification committee and deemed perfect for release in July last year.

"It is important for the public to note that decisions of the FPB's classification committee cannot be changed through any other procedure but through the FPB appeals tribunal.

"Appeals can only be heard 30 days after a classification decision has been made."

In the Eastern Cape, traditional leaders are planning to protest outside the Hemingways Mall today as they will be voicing their anger at the film being shown in cinemas.

Yesterday, Advocate Matthew Mphahlwa, who was instructed by Sigcawu to block the movie from being shown in cinemas, threatened legal action if the producers failed to make the changes.

"If they fail then they leave us with no choice but to move for a competent urgent relief."

Inxeba producer Kate Pansegrouw said the production company had not received the letter.

— *malibongwed@dispatch.co.za*

Can my traditional healer book me off work?

I've been struggling with bad dreams for many weeks, causing me to sleep badly. Nothing seems to help and it is affecting my work. Is attending my traditional healer's course on unpaid sick leave for a period of five weeks to attend a traditional healer's course on would be well advised to consider the merits of each

Until such time as this Act

Figure 32: Article about controversial movie Inxeba (The Wound) in the Eastern Cape newspaper, the Daily Dispatch. 2 February 2018.

Questions related to health-seeking practices during and after ulwaluko were included in this study following the initial interview pilot, as challenges with medicines-taking and disengagement from care during and after ulwaluko emerged as a theme. In order to minimise potentially sensitive and harmful aspects of this research, researchers who were Xhosa men and had undergone ulwaluko acted as ethical advisors. They co-designed questions related to

ulwaluko, and ensured that questions only engaged with non-secretive aspects of ulwaluko. This was done by focusing only on health-related issues in interviews. In cases where participants disclosed more sensitive aspects of ulwaluko in interviews, or spoke isiDoda (secret 'manhood language') they alerted me not to listen to these interviews, and did not transcribe this data. Wherever possible, the researchers also disseminated ulwaluko findings to stakeholders.

While engaging with general knowledge norms, this work does not engage with the secretive and less-spoken aspects of ulwaluko. In line with the ethical imperative to share health and well-being related findings, this thesis, and specifically Chapter Five**,** aims to represent participant perspectives and experiences while respecting the sensitivities of this tradition. Findings focus solely on participant experiences of HIV treatment and care during and following ulwaluko, and the implications of this for adolescent boys and young men living with HIV.

Promisingly, these findings have been well-received by the Buffalo City Metropolitan Municipality, and are being disseminated in schools by a non-governmental health and education organisation in the Eastern Cape. They have also received traction with community organisations in the Western Cape, as well as the Western Cape Department of Health. Further efforts will be made to share findings in a way that can reach decision-makers such as policymakers, health professionals and traditional leaders that can improve the well-being of adolescent boys and young men living with HIV undergoing the process of ulwaluko.

Study limitations

Although this study intends to provide for in-depth consideration of the research questions, adolescent boys' needs and experiences are not homogenous. Although not the intention of this study, these issues do not lend themselves to generalisable findings or simple, 'silver-bullet' solutions. Given that the study participants had been tested for HIV and initiated onto ART, they represent a population that may be more proactive about their health, or have proactive caregivers, and may not be broadly representative of adolescents living with HIV who are unaware of their status or who have yet to initiate medication. To generalise how all adolescent boys seek health would ignore their personal and demographic differences.

This study takes place in urban, peri-urban and rural areas in the Eastern Cape province of South Africa, a province identified for its similarity in health and social service provisions to other poorly-resourced and high HIV prevalence areas in Eastern and Southern Africa. While the context of this research has relevance and applicability for other sites of health and social service provision in the region, each location has its own unique combination of social and epidemiological determinants of risk and resilience (Hodes *et al.*, 2014). Given the locality of this research, it is important to note that findings are context-bound. Context must be recognised as paramount in designing, tailoring and monitoring effective programmes according to the specific needs of local populations (Skovdal and Cornish, 2015; RIATT-ESA, 2016; Hodes and Morrell, 2018).

Health-seeking behaviour, despite being an important concept, is also limited in that it does not lend itself to an exploration of the relationship between health systems and populations as much as between health systems and individuals (Mackian, Bedri and Lovel, 2004). When looking at health-seeking behaviour, it is easy to focus on individual-level behaviour rather than considering a broader societal context. Despite this construction of health-seeking behaviour, the research strived to avoid simplistic, individual-focused explanations of a much more complex issue, and has employed approaches that consider contextual and relational factors. This topic touches on many different disciplines and required background research in different fields (e.g. HIV/AIDS, adolescence, traditional and biomedical health care, gender and masculinities).

Methodologically, life history approaches are retrospective, a limitation which may affect the validity and reliability of narratives (Stern, Clarfelt and Buikema, 2015). In addition, although research with both men and women may include performances to conform with social expectations, men's dialogues about behaviour might be more performative, as a way to mask anxiety and insecurity perceived as 'unmanly' (Frosh, Phoenix and Pattman, 2003; Connell, 2005; Stern, Clarfelt and Buikema, 2015). Such social desirability bias is likely to be present to some degree in this research with adolescent boys, the dynamics of which are explored in greater detail in Chapter Seven in relation to masculinity-related study findings, and in relation to traditional health findings in Chapter Six. Additionally, participants were selected in part because

researchers had observed that they were engaged and willing participants in the Mzantsi Wakho study. This selection likely presented a bias that is important yet difficult to measure.

Lastly, it is also important to note that dominant global framings of health and childhood may not be completely applicable within the study context. Much biomedically focused research in the field of child and adolescent well-being has been driven by globally dominant notions of childhood and health that are '…guided by a biomedical paradigm that uses standardised scales and measures (often developed in the 'global North') at the expense of qualitative and resilience-focused research that brings forward the perspectives of children and can be used to appropriate psychosocial responses'(Skovdal, 2012; Skovdal and Daniel, 2012, p. 156). These findings make a strong case for qualitative research that prioritises participant perspectives and considers local contexts.

Reflexivity

I was a student in South Africa during the time of the #RhodesMustFall and #FeesMustFall protests, which were at their height in 2015 and 2016 while I was in the initial stages of my doctorate. This was a time of protest action by a group of students against the institution at which I was studying, and later, against the state. During this time, myself and fellow students grappled with what it meant to engage with the symbolic and pedagogical remnants of colonialism. Although I am not South African, this was a space of deep learning and reflection as someone of European ancestry who was born and grew up in Canada, on the traditional territory of the Mississaugas of the Credit First Nation. Many of the issues being raised and discussed were similar to those of the country of my birth, although they had unique historical and present-day contours.

During the student protests, we attended meetings and discussions at the Medical School and on Upper Campus at the University of Cape Town, and at the University of the Western Cape. We brought medical supplies to protests, held support groups for fellow students in distress, wrote to local newspapers and were sometimes shut out of our workspaces during campus shutdowns. As part of a commitment to ethical health and social sciences research, we started a group with fellow students within the South Africa Social Science and HIV (SASH) programme at the

University of Cape Town. The group was called *Disrupting dominant practice in HIV and social science research.* Through participatory activities, reading and discussion we aimed to grapple with issues of power and ethics within our field of study and in the South African and international academies.

This time was one of growth and hope for myself and many fellow students, and was also emotionally, psychologically, intellectually and financially challenging. This is shared here, without conclusion, because it is an ongoing reflection pertinent to my work and life. The intellectual, home and community spaces in which I live, study and work in South Africa and Canada continue to be spaces of reflexivity, growth, discomfort, and hopefully, resistance. This doctorate, and any work coming out of it, will inevitably reflect these shortcomings, challenges, and learnings.

Research is inherently motivated by ideological, political and/or social agendas (Tamale, 2011). Morrell et al. (2012) note the presence of a moralistic binary which links hegemonic masculinities to 'bad men' and stigmatises certain behaviours and attitudes of African men in general, and young, 'Black' and unemployed African men in particular. I am critically reflexive about my positionality as a middle-class, 'white' Canadian woman conducting this research, and about the long history of foreigners constructing Africans as the 'other', in often exotic terms that are always 'different from European/Western sexualities and self' (Arnfred, 2004). There is an implicit co-construction of the European/Westerner as rational, civilised and modern (Arnfred, 2004). Such a 'dark continent discourse' continues to structure ways of seeing and understanding, and can add to the potential of a problematic 'gaze' of the researcher (Arnfred, 2004; Comaroff and Comaroff, 2012).

The premise that 'knowledge cannot be separated from the knower' (Steedman, 1991) implies that the beliefs, values and lived experiences of the researcher will inevitably affect the process and outcomes of research. I have aimed to be reflexive throughout the research process and contemplate how my personal beliefs and lens inform the way that I interact with participants, analyse the data and present findings. This reflexivity includes considering the asymmetrical power relations between myself and the participants, acknowledging that power can shape the

accuracy of the research outcomes (Roller, 2012; Skovdal and Cornish, 2015). This research also has aimed to complicate conventional ways of knowing, and through participatory methods also to engage in the production of knowledge in a way that shifts power.

There are many linguistic, cultural, age and gender differences between the study participants and me. I aimed to minimise the potential harmful effects of such power imbalances by engaging local research assistants who share more similar linguistic, cultural and gender identities with the participants and who provided valuable insight into data collection and analysis. Findings, including the benefits and drawbacks of this approach, are explored in Chapter Seven. I also attempted to minimise the potentially harmful power dynamics in this study by shaping the research as problem-driven, with an aim to contribute to transformative social and health change and policy influence. I strived to be self-aware and sensitive to social norms, and understand that attempts to make participants feel comfortable, break down barriers, and make the research participatory may not shift the power dynamics in this study.

My experience of training and learning with traditional health practitioners through the process of ukuthwasa which began in October 2014 has also influenced my understandings of traditional health products, services and cosmologies. It has also shaped my engagements with traditional health practitioner participants, in some ways both an ‘outsider’ and an ‘insider’. I aimed to undertake the research process in a way that engaged these multiple paradigms of knowledge, and various understandings of health, well-being and personhood that drew on local wisdom, knowledge and theory. I engage with and will continue to encourage feedback and dialogue, including from young people, people living with HIV, and Xhosa men whose experiences form the bases of this research.

Chapter Four: '*I used to hate myself when I first knew, but there was a thing that whispered in my ears…*' - Young HIV-positive masculinities throughout the life course

Introduction:

This first findings chapter explores participant life histories and sets the foundation for investigating the biosocial lives of HIV-positive adolescent boys and young men in the Eastern Cape. It focuses on two powerful social organising factors – masculinity and an HIV-positive status – and documents how these factors shaped participants' lived experiences, relational identities and imagined futures. It explores how participants navigate these two aspects of their lives and considers their intersecting identities as young Black people, growing up in contexts of precariousness and constraint.

Key themes that emerged from life history narratives included: (1) parental/caregiver absence and death; (2) geographic and financial precariousness; (3) childhood illness and learning of their HIV-positive status; and (4) questions of (paternal) identity. Participants narrated how these issues were often shrouded in silence and secrecy, underneath which – this chapter suggests – is inherited misfortune passed down through generations of which HIV is symbolic.

Findings dovetail with the suggestion that AIDS-related deaths are often considered as a part of 'long procession of misfortunes' (Becker and Geissler, 2009, p. 11). rather than a single event. For participants and their families, growing up with HIV was often part of more broadly precarious[16] realities. Participant narratives revealed confusion and anger over not being told of a parent's death, or of their HIV-positive status, until they were older. As young people in a society with entrenched age-based hierarchy, they felt unable to break this secrecy, and did not

[16] The terms 'precarious', 'precariousness' and 'precarity' are used throughout this chapter. 'Precarious' is defined by the Merriam dictionary as 'a lack of security or stability that threatens with danger' (Merriam-Webster Online, 2018). The concept of 'precarity' is used to 'denote a general, pervasive ontological condition of vulnerability, displacement, and insecurity…' (Kasmir, 2018). Precarity, and precariousness have been used distinctively, with the suggestion that precarity is related to inequality, as experienced by the marginalised, poor and disenfranchised (Butler, 2004; Kasmir, 2018). This term has its roots in historical and political arguments about class, capitalism and social movements and acknowledges the creation of conditions of temporary and informal work and the ways that these manifests in livelihoods (Kasmir, 2018).

disclose their HIV-positive status, or ask questions about HIV or parental deaths in their homes. In this way, HIV remained an omnipresent, yet often invisiblised reminder of familial misfortunes.

These findings align with the suggestion that HIV is seen to represent a social problem in the form of weakened social cohesion and declining morality (Posel, Kahn and Walker, 2007). It also builds on this idea to suggest that failure to perform to certain aspects of masculinity is also seen to represent social problems from which participants aim to distance themselves. For participants, masculinity and their HIV-positive status sit as two inter-related tensions that have taken on representations of social decay and disorder to which they must respond for themselves, their lineages and their communities. To compensate, participants strove towards various notions of personhood in different spheres of their lives: (1) as emerging respectable men, and (2) the imperative is to be a 'good patient', encompassing ideas of health and therapeutic citizenship.

These pressures came into conflict with one another as they got older. As the first generation able to survive into adulthood because of widespread access to ART, the primary pressure they experienced during childhood was to appear to be 'good patients' and to take their pills. As they entered working age, they came up against what it means to be good adult citizens, within the lofty but often unattainable narratives of freedom within a recently democratic South Africa (Freund, 2018). They are living within contexts of difficult-to-obtain ideals of respectable masculinity. These encompass family leadership, wealth and legitimised marriage and children. Despite striving to norms of masculinity and responsibilised health citizenship, participant behaviours and circumstances often diverged from such narratives in practice. In this way, embodied experiences and enacted performances of HIV and masculinity can be seen to represent the challenges and possibilities of relational personhood for adolescent boys and young men living with HIV in South Africa. These struggles and aspirations reflect a convergence of idealised but hard-to-achieve forms of personhood, including 'rainbow nation' citizenship, and that of responsible patients and young men. Such aspirations are not solely individualistic, but are also intricately and irrefutably bound up in their sense of morality and personhood.

This chapter's findings agree with Vale's (2016) suggestion that through certain forms of behaviour and health citizenship, young people living with HIV strive to redeem lost mothers. Building on this work, this chapter suggests that adolescent boys and young men living with HIV also strive to redeem absent fathers and marginalised masculinities through aspiring to certain masculine norms.

Although life history narratives were peppered with examples of love, community and reflective of forms of idealised boyhood, all participants chose to share mostly challenging events. By contrast, each interview concluded with a section on future ideation, in which future aspirations drastically different from their lived experiences and realities were shared. These consistently included material stability and financial achievement, followed by legitimised heterosexual relationships and responsible and engaged fatherhood. These findings align closely with a literature that suggests that provision and leadership in families and material wealth are hegemonic masculine norms within the study site. These imagined futures represent avenues towards respect, personhood and the realisation of possibilities that were not available to their forebears. Such futures exist under conditions that were largely unavailable to them as children, as most of these participants grew up in precarious financial circumstances and locations, and without fathers.

Striving towards certain hegemonic masculine norms and ideas of health citizenship offer two pathways towards personhood, transformation and redemption. Such pathways may be made additionally important and challenging because of poverty. This chapter suggests that underlying these two forms of responsibilised behaviour is the hope and desire of attaining respectable male personhood and shifting fortunes. In this way, participants' lives and lineages may be seen as a continuum, with familial and individual adversity sitting in the past, and the possibility of realised personhood, progeny and familial wellbeing in the future. Individual and collective aspirations for redemption and well-being hinge on these young men's ability to transform this 'long processions of misfortunes' into different futures.

Drawing on participant life experiences, hopes and self-stated masculine identities, this chapter suggests that for adolescent boys and young men living with HIV in the Eastern Cape, there is a

chasm between the everyday and the aspirational, the enacted and the achievable. Central to these findings are issues of identity and a quest towards legitimised and respected personhood.

This chapter begins by providing an overview of the conceptual and theoretical frameworks it engages. It then provides a case study to illustrate how data were triangulated and analysed across methods. Following this, findings are presented using the chronological frames of childhood, where health citizenship is performed, and older adolescence and early manhood where performances of masculinity become more important.

Conceptual and theoretical frameworks: Personhood and redemption

This chapter draws on theories and concepts reviewed in the literature review chapter on gender, intersectionality, and hegemonic masculinities within the South African context. It also engages two other lenses - personhood and redemption - which are defined and discussed below.

Personhood

The concept of personhood[17] is employed in this chapter as a working framework to understand participant experiences and motivations. Mfecane (2018b) describes three features of personhood that were relevant to many participants and the study site. These include: that human beings are understood to have both physical and non-physical elements (Menkiti, 2004; Mfecane, 2018b), that personhood is relational – not only in the sense of the living, but kinship relationships with those who have passed on (De Craemer, 1983; Mbiti, 1990; Hoekeman, 2008; Mfecane, 2018b), and that personhood status is acquired progressively throughout one's life (Menkiti, 2004; Hoekeman, 2008; Mfecane, 2018b). He suggests that such contextually grounded notions of personhood are an often-missing feature of research and practice with men in South Africa. These aspects of personhood were present in this study in the following ways.

[17] There is large philosophical literature on personhood which encompasses discipline-specific (i.e. justice, bio-ethics) and location-specific theories (i.e. philosophies of personhood in African cosmologies). These span a broad and rich history of philosophy and intellectual thought too substantial to explore adequately within this thesis. However, the concepts presented above in relation to personhood are used, where they fit, to interpret and contextualise the data.

Cosmologies of health and wellbeing within this setting encompass not just the physical body, but also relationships, family systems and community. The World Health Organization definition of health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 1946), is relevant here as it provides for a more holistic understanding of health and wellbeing. Similarly, Germond and Cochrane (2010) consider overlapping concepts of holistic health and well-being, including the person, family, village, nation, religion, which this chapter considers.
Participant cosmologies and the physical and non-physical understandings of themselves and their health are also considered in this chapter, as discussed in the literature review chapter, and further explored in Chapter Six.

The notion that personhood is acquired progressively throughout one's life, including through rituals of incorporation (Menkiti, 1979, 2004) was also relevant. Important rituals of incorporation within the study site include imbeleko, which serves to introduce one to the ancestors, and ulwaluko, which serves to legitimise them as adult men.

This chapter also suggests that such notions of personhood within this study site have gendered aspects. For example, ulwaluko is an important ritual of incorporation which defines manhood. Additional documented relational pathways to respectable adult manhood include having children legitimised through marriage, who will carry on their names, head a household and support a family (Gibbs, Sikweyiya and Jewkes, 2014). In this way, the importance of being respectful and respectable men is grounded in their relationships with their families and communities. The next section on ancestral beliefs and redemption considers how relationality also extends to those who have 'passed on'.

Ancestral beliefs and redemption

It was common that participants' belief systems included ancestral beliefs and conceptions of self related to family, community, place and history (De Craemer, 1983; Mfecane, 2018b), although such beliefs were by no means homogenous. Anthropologists such as White (2001), Vale and Thabeng (2016) and Henderson (2012) have documented how kin might take up inappropriate or incomplete actions of past relatives to be addressed in the present. In this way,

living relatives can serve as proxies for incomplete work, which, through its completion, will diminish the burdens they and other surviving kin inherit (White, 2001; Vale and Thabeng, 2016). Just as intergenerational illness and moral and social decay is collective, relational and inter-generational, so then are the possibilities for healing. In redeeming, healing and appeasing the ancestors, they diminish the burdens they and other surviving kin inherit and open the possibility to receive better fortunes for themselves and their kin in the present and future. The work of engaging with the challenges and misfortunes of the ancestors is relational and reciprocal. By not appeasing the ancestors or healing their challenges, misfortune and difficulty continue to be experienced by individuals and the family. However, taking on the healing of inherited issues provides for an opportunity for individual and communal healing, which is understood to heal 'up' the bloodline (to ancestors) and 'down' the bloodline to future generations. In this sense, the work of healing and pleasing the ancestors represents an investment in the well-being of oneself and one's family across time.

The following transcript of an interview with a traditional healer elucidates this view. Gogo Nosi uses the example of young men who have been to prison who come to her for cleansing. Drawing on metaphors from the natural world, she illustrates the belief that ancestral issues may manifest in a variety of challenges. These may include health or other problems, such as crime and substance abuse which are discussed here as symptoms of unresolved ancestral trauma.

> **Gogo Nosi:** With guys… (ages) 16 to 30. That age group, they just have their own dilemma.
> **Interviewer:** Like what?
> **Gogo Nosi:** Drinking, smoking, going to prison, crime.
> **Interviewer:** What is happening with them?
> **Gogo Nosi:** That's what I want to know actually, because we can't keep treating the tree without actually finding out, is it the soil? Or what is it? We need to find the root… we can not keep treating the tree when you don't know what is wrong... What is it?… I think, because we are Africans, we carry out our old people's (ancestors') baggage. We carry trauma and what my forefather was doing, I will carry that load. And if I can not deal with it the correct way, I will end up doing things I shouldn't be doing.
> **Interviewer**: So you think they are acting out their ancestor's issues?

Gogo Nosi: Exactly…

The belief that Gogo Nosi presents here is that, in order to heal societal ills and personal challenges, it is important to identify and heal ancestral misfortunes and traumas. In doing so, people can stop 'carrying their (the ancestors) load'. Beyond creating more comfortable realities, ancestral healing comes with it the possibility of creating different futures. The quest towards redemption and creating new futures is not solely about healing oneself and one's lineages. There is an impetus to go beyond what came before, to move forward into new states, to grow and evolve. In this way, their lives may serve as platform which those who come after can stand on, and hopefully build and grow themselves.

The term 'redemption' is used throughout this chapter to describe participant aspirations and actions to compensate for the challenges of those who came before them. In this way, redemption represents a form of vindication or atonement to absolve for past unresolved issues which they have inherited. Redemptive acts function as an attempt to make amends for, recover and heal those who came before them. In the process, these acts also serve the purpose of redeeming the participants themselves and their families.

As will be discussed later in this chapter, with dead parents, pill-taking and 'good' patienthood represent forms of redemption to their parents potentially 'bad' patienthood, or 'immoral' behaviours that had caused them to get HIV (Vale and Thabeng, 2016). In the case of legitimised masculinity, this redemption involved respectful and respectable behaviours, and being able to accrue the funds needed to create and maintain a family, which their forefathers had been unable to do for reasons of poverty, HIV and forced migration under the apartheid labour system (Beinart, 2001). These dilemmas of masculinity and of HIV-positivity had separate pathways to redemption and personhood, which began to conflict as participants moved into adult masculinity when 'good' patienthood began to conflict with hegemonic masculine norms.

This chapter argues that participant lives are often understood to be bound up in family histories and situations, rather than just reflecting individual challenges, hopes and circumstances. In the same way, hopes for the future are both individual and collective. This lens of redemption is

engaged throughout this chapter to understand: (1) the ways in which participants and their families engage with a variety of familial misfortunes of which HIV is symbolic; (2) how participants perform to certain forms of patienthood as a form of ancestral redemption; (3) the importance for older participants in connecting with their paternal lineages for protection and support, and to alleviate challenges as they enter into manhood; and (4) the reasons why certain forms of masculinities are engaged to appease and redeem broken patrilineages and forms of unfulfilled masculine personhood.

Methods overview and introduction to key themes

This chapter draws on data from life history narratives, semi-structured interviews and health facility files. Life history narrative interviews formed the primary source of data for this chapter, while interviews and health facility files validated and provided additional perspectives on participant life experiences. These methods were described in Chapter Three. An example of one participant, presented in Chapter Three, is elaborated on as a window into some of the key themes, demonstrating how data from multiple sources was triangulated and interpreted.



Figure 33: Khwezi (20) drawing in his life history narrative interview (left). 6 October 2017.
Figure 34: Khwezi's (20) life history drawing (right). 6 October 2017.

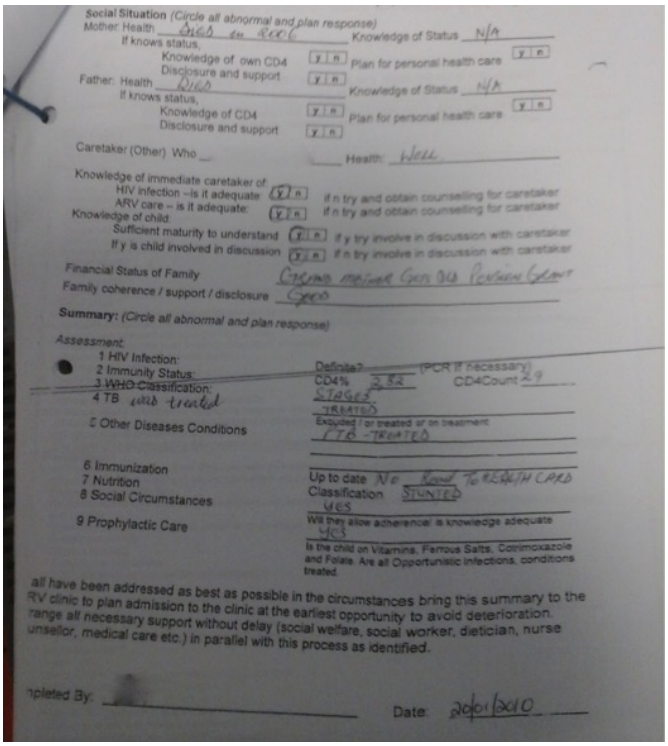

Social Situation (Circle all abnormal and plan response)
Mother: Health DIED in 2007 Knowledge of Status N/A
If knows status,
Knowledge of own CD4 y n Plan for personal health care y n
Disclosure and support y n
Father: Health DIED Knowledge of Status N/A
If knows status,
Knowledge of CD4 y n Plan for personal health care y n
Disclosure and support y n
Caretaker (Other) Who Health: Well
Knowledge of immediate caretaker of:
HIV infection –Is it adequate: y n if n try and obtain counselling for caretaker
ARV care – is it adequate: y n if n try and obtain counselling for caretaker
Knowledge of child:
Sufficient maturity to understand y n if y try involve in discussion with caretaker
If y is child involved in discussion y n if n try involve in discussion with caretaker
Financial Status of Family Grandma mother Gets Old Pension Grant
Family coherence / support / disclosure Good
Summary: (Circle all abnormal and plan response)
Assessment:
1 HIV Infection: Definite? (PCR if necessary)
2 Immunity Status: CD4% 282 CD4Count 29
3 WHO Classification: STAGE 3
4 TB was treated
5 Other Diseases Conditions Excluded / or treated or on treatment
TB - TREATED
6 Immunization
7 Nutrition Up to date No Road To Health CARD
8 Social Circumstances Classification STUNTED
9 Prophylactic Care Will they allow adherence/ is knowledge adequate
YES
Is the child on Vitamins, Ferrous Salts, Cotrimoxazole and Folate. Are all Opportunistic infections, conditions treated
all have been addressed as best as possible in the circumstances bring this summary to the ARV clinic to plan admission to the clinic at the earliest opportunity to avoid deterioration. Arrange all necessary support without delay (social welfare, social worker, dietician, nurse counsellor, medical care etc.) in parallel with this process as identified.
Completed By: Date: 20/01/2010

Figure 35: Page of a health facility file of Khwezi (20) which depicts some of the events shown in his life history narrative, such as the death of his mother. Photograph taken 22 March 2018.

As can be seen above in the top right-hand image (repeated from the methods chapter), this participant visually represents his physical and emotional proximity to his family members including his sisters, mother and grandmother living together in his childhood home. He visually demonstrates his closeness with his mother and used crying emojis to demonstrate his sadness over her death. As can be seen in the transcript below, he uses metaphors from the items that he selected to describe his family members (e.g. a 'diamond' – a clear shiny piece of glass for his lost mother). The three life events that he spoke about were his mother dying in 2007, finding out his HIV-positive status, and the absence of his father and patrilineal kin during his transition into manhood. He demonstrates this visually by placing his father further away, and used an angry emoji to describe his frustrations over the absence of this side of his family in his life.

These events – parental death, learning of an HIV-positive status and the absence of patrilineal kin – were the three most common events that participants shared, and each of them will be explored throughout this chapter. These events were also reflected in other forms of data. For example, the participant's health facility file, shown above, documents his mother's death (which

he presented as his first life event). The event is recorded as occurring in 2006, alongside the details of his finding out about his HIV-positive status (his second life event). His very low CD4 count (29) and recording of having third-stage HIV infection and pulmonary tuberculosis demonstrate that he was physically sick when he was diagnosed with HIV, aligning with his narrative and providing context to his presentation of this event as a challenging time. The below excerpt from this interview provides an example of how participants often spoke about life events, alongside their drawings.

> **Interviewer:** Let's talk about your life events, let's start with an important one and the one that you remember it well...
> **Khwezi:** Firstly it was the death of my mother, it was like being dumped by your precious thing.
> …
> **Interviewer:** Why did you put item there (gestures to clear round stone he used to represent his mother)?
> **Khwezi:** She was like a diamond to me… Ever since the day my mother died that day will always be in my mind.
> **Interviewer:** Do you know the date?
> **Khwezi:** I don't know the exact date but I know the exact words.
> **Interviewer:** What do you mean when you say exact words?
> **Khwezi:** That she is no more and I had to accept that Luluama* is gone and I won't see her again.
> (Khwezi, 20)

As can be seen above, the participant's clinic file and life history narrative and artwork shared similar events from different perspectives. For example, the participant spoke about the nature of his parental relationships, and the events of their death and absence. Visual and verbal context is provided by the crying emoji, alongside the verbal explanation of feeling like he was 'dumped' by his 'special thing'. The clinic file (pictured above) also records the event of parental death,

*All family and place names have been changed in order to keep participants anonymous.

alongside the caregiver relationship and material situation of the participant. His grandmother, depicted as close to him in his drawing, is recorded as his primary caregiver and as receiving an old age pension grant. His father is also recorded as dead. In his life history narrative, he did not speak about the death of his father, although he spoke about the absence of his father and patrilineal kin from his life. He visually depicted his father as outside of his immediate family unit, and used an angry emoji to represent his feelings towards his father and his family. In explaining his anger, he spoke about how not having received support from paternal kin and not having performed rituals for his paternal ancestors may affect his well-being and success. Issues of identity in relation to patrilineal ancestry were a key theme that will be explored in the second half of the findings section.

> **Khwezi:** Not knowing my father at this certain age it affects me somewhere somehow because I need things like rituals from my father's side. I know that I've done circumcision with rituals from my mother's side. Maybe somewhere, somehow at this certain age I have to know my father's rituals that could affect me. That is why I regard this as a life event.
> **Interviewer:** Did you try to reach out to his family especially for the ritual things?
> **Khwezi:** His family knows that their son has a son, his family knows that he has a son that was born in Phakalani* location. They know that my mother left me in 2007. So they know all those things, that I'm a man and I have needs concerning my manhood, they even know my family in Phakalani*. I went to them before I came here. I was a boy then, and my caregiver met one of their family members and she told her that I was going to the bush. They didn't even show support or even show up or bring me some drinks. (Khwezi, 20)

Khwezi's example has been presented to explain how data were analysed and triangulated across methods. It introduces common themes of parental death, absent paternal families and HIV, which will be analysed throughout this chapter.

Findings are presented below in two parts. The first section begins by providing an overview of key themes from participant childhoods, including experiences of parental death and absence,

HIV disclosure and secrecy, and financial and geographic precariousness. These themes are then discussed in relation to participant performances of 'good' patienthood as a way to garner the support of adults, and to redeem dead parents, and to ameliorate difficult family histories.

The second section presents key themes in relation to participant masculine identities, and the avenues through which they strive towards respectable adult masculinities that also serve redemptive and aspirational functions. Findings suggest that as children and young adolescents they used modes of health citizenship, and as they became older they engaged performances of adult masculinities as avenues for familial redemption and the creation of new futures.

Findings Section 1: Childhood and inherited misfortunes

Section 1.1: Silent burdens: Parental death, precariousness and HIV

The most commonly presented life events in participants' life history narratives were parental death, learning of their HIV-positive status, and financial and geographic precariousness. This section presents and explores these themes and documents their inter-relationships. It argues these challenges are often understood as part of a broader set of misfortunes that they aim to redeem and re-signify by their HIV-related health seeking behaviours.

1.1.1: Parental death

Death of one or both parents was one of the strongest, and usually first-mentioned themes in life history narratives, with 18 participants describing this as their first important life event. Of the 36 participants in this study, a total of 26 had lost one or both parents. Five had lost both parents, fifteen had lost their mothers and five were aware that their fathers had died. An additional eight did not know anything about their fathers, although in some clinic files – like the one above – fathers' deaths were recorded. As will be explored later, many participants who had living fathers met them immediately before attending ulwaluko and thus did not grow up with them.

The theme of parental death aligns with the high rates of orphanhood in the Mzantsi Wakho quantitative study (2018), which found that 44% of the HIV-positive sample were maternal orphans, 30% were paternal orphans and 16% were double orphans. In the 1990s and early

2000s, adult AIDS-related deaths increased, and created a phenomenon of AIDS orphanhood (Richter and Morrell, 2006). It is estimated that 23% of South Africa's AIDS orphans live in the Eastern Cape (Hayward, 2015). Examples from two participants, X-man and Buja, are presented below to illustrate how participants spoke about parental death:

> **X-man:** I was not told about what happened, they hid it from me. I just noticed that my mother was not around and they told me when I was mature enough that my mother passed away a long time ago... It was very painful, it didn't sit well in me. I ended up blaming my family asking "*why did they tell me now*"? I didn't know it and in my mind I believed that my mother was still around, and I blamed them and they knew. I was not good at all. I would cry alone, had hatred and there was something eating me inside. I was asking myself "*why did they only tell me now*?"
> **Interviewer:** How much time did it take for you to accept this?
> **X-man:** It took years just because it didn't sit well in my head that it was the truth. I thought maybe sometimes they were trying to scare me or they are just fooling around, but they were serious. In my head it didn't register that my mother was no more.
> (X-man, 22)

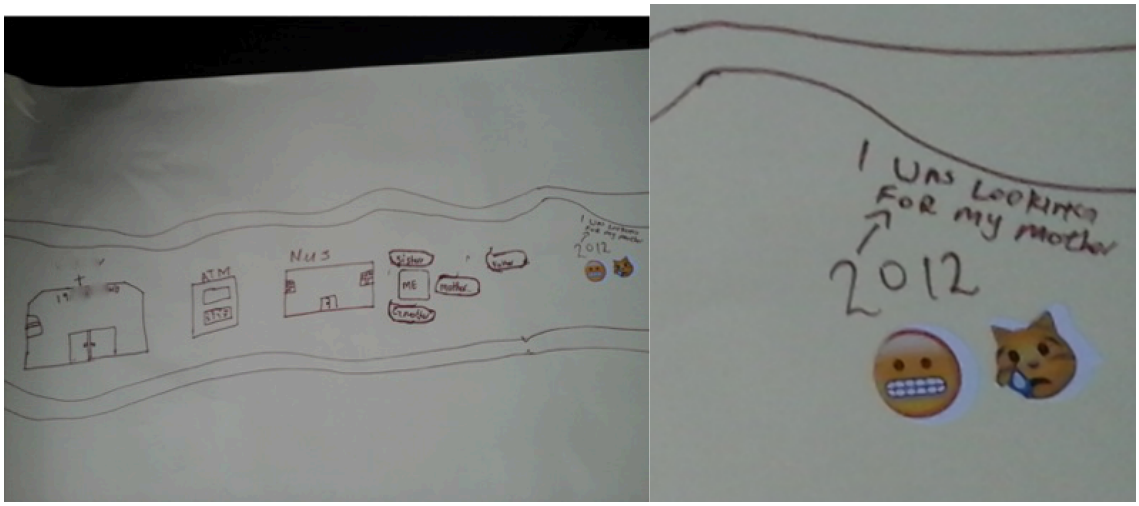


Figure 36: Buja (19) depicts looking for his mother in 2012 using a crying and confused emoji. The below transcript provides further detail into this life event. 16 September 2017.

Interviewer: Tell me about your life event… one that you remember well and that is most important to you.

Buja: The story that I want to share is I wanted to know my mother. Even now, they don't have pictures to show me what she looked like, but they explain what was she like. She was short just like me, and the way I behave I'm like her…

Interviewer: How did you feel then?

Buja: Very sad. Even me, I'm sick at the moment. There is a treatment that I'm taking. So I was at the hospital and the doctor told me to go and see the social worker. That's where I heard the story that my mother died because of HIV and I was crying.

Interviewer: After hearing that your mother died of HIV, how did you feel?

Buja: It was very painful at that time because I wanted to know her.

(Buja, 19)

As can be seen above, narratives of parental death were often imbued with pain, tenderness and intimate details. Similar to Buja who spoke about looking for his mother and not being told about her death until he was older, many participants were not explicitly informed about their parents' deaths. Many were moved silently and without explanation to live with other family members. As demonstrated below, participant narratives of their parent's deaths were often related to other challenging life events. These included: (1) not being told about their parents' death until they were much older, or if they were aware of the death, not being involved in conversations or ceremonies around the death; (2) precarious realities of shifting caregiver relationships, moving homes and poverty; and (3) links to their own HIV-positive status. These are described below.

Many participants were moved between caregivers without receiving explanations about what was happening. For example, Jenovo spoke about waking up next to his dead mother, and being told that she was asleep and not to disturb her. He was picked up later that day by family and moved to a new town.

Jenovo: It (mother's death) was in 2005.

Interviewer: Ok, sorry. Can you pick any emoji that tells the feeling at that time?

(Participant selects and places 5 sticker emojis depicting sadness and surprise)

Interviewer: Why did you choose these ones?

Jenovo: It's because it was not nice at that time.

Interviewer: Ok sorry bro… What happened…?

Jenovo: It was at night, the two of us, me and my mum in the bed. When I woke up in the morning and I tried to wake her up she did not wake up. I ran to call Inkosazana* to tell her that mother is not waking up. She told me that my she is asleep let me not disturb her, it was around 4am in the morning. Then my sister started to phone my aunts in Knightsbury*, then a car arrived and picked her (mother's body) up that day. Then our aunts came to fetch us here to go to Isivivana*.

(Jenovo, 17)



Figure 37: Jeveno's (17) life history drawing depicting the death of his mother. The isiXhosa language test says 'My mother passed away' alongside emojis with crying and sad and surprised faces. 19 August 2017.

Like Jenovo, many participants were not told about their parent's deaths, or afforded the opportunity to grieve. They recounted feelings of anger, blame and confusion over not being told, and spoke about how it took a long time to come to terms with finding out this difficult news. Despite this, many made sense of this silence with the belief that their family didn't want to hurt them or that they were not yet mature enough to know. For example, X-man (22), who had been moved from Cape Town to the Eastern Cape without being told that his mother had died, explained that 'Maybe it was because they didn't want to hurt me'.

The literature on parental HIV death dovetails with these findings. Van der Heijden and Swartz (2010) found that people avoid talking with children about death because they are seen as too vulnerable to deal with death and loss, while Wood and colleagues (2006) suggested that caregivers may feel helpless and unable to manage children's distress over their parent's deaths in a constructive way, and that this may be amplified by AIDS-related stigma. A number of studies in sub-Saharan Africa document children not being told about parental death or involved in ceremonies. For example, Mdleleni-Bookholane and colleagues (2004) document how Xhosa practices around death involve whispering in the child's ear during their sleep because it is considered in poor taste to speak of things connected with death, and so as not to awaken the ancestors before the deceased are settled. Cook and colleagues (2000 in Van der Hejden and Swartz (2010)) document how younger children in Malawi are not told about the death of their parents, and Richter and colleagues (2004) write about how children are kept away from ill or dying people and excluded from rituals in KwaZulu-Natal to protect children from emotional trauma, and for reasons of pollution, misfortune and witchcraft. Shona children may be told that their parents have gone away using indirect language, euphemism and silence, and only realise when they are older what this meant (Wood, Chase and Aggleton, 2006).

In addition to being concerned about a child's ability to process the news of their parent's death, an added element of the death being AIDS-related made speaking about these deaths even more challenging. Niehaus and colleagues (2001) posit that HIV is stigmatising because of its relationship to death, and Posel and colleagues (2007) document how AIDS-related deaths are considered a form of 'bad' death, an unspeakable sign of moral and social decay. Given that most participants had inherited HIV from their mothers, the death of their parents was also related to their own possibility of becoming sick and dying from AIDS-related illness. This chapter suggests that for participants and their families, the dynamics of inherited misfortunes, in the form of an HIV-positive status passed down through the bloodline, are present.

1.1.2: Shaky starts – moving homes, changing caregivers and poverty

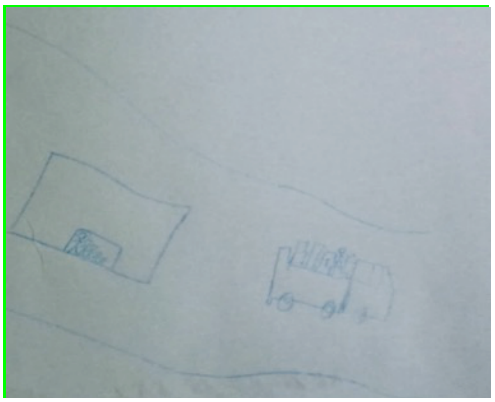


Figure 38: Zane's (16) life history drawing depicting his caregiver moving home. 30 November 2016.

Parental deaths were often a misfortune that came with other related challenges. Most participants had complex narratives of changing homes and caregivers, and of highly geographically and materially precarious lives. At the time of this study, two participants lived with both parents, seven lived with their mother, one with their father, 12 lived with one or both grandparents (usually maternal grandparents), and 14 lived with other caregivers, most commonly aunts, cousins or other family members. Although children are often raised by their grandparents or other family members, in these cases, such high mobility was often related to parental death, financial instability and family tensions.

The conditions of shifting caregivers often meant that participants were less materially secure. For example, Movite (age 18) described his confusion and fear of his stepmother who did not give him as much food as she gives her biological children. Below, X-man (22) spoke about growing up with changing caregiver relationships, and being afraid that he would not have his basic needs met:

> My life as I grew up was not good due to the fact that I lost both of my parents while I was still young… my father took another wife and left me with my stepmother (when he died). Then after sometime she also left (died), and it was really hard after that because I didn't have parents to take care of me. My needs… would take time to be taken care of, and sometimes I could see myself crying alone because I didn't have anyone to turn to. I thought about my parents and wished they were here so that I can be taken care of… it

was very painful and I couldn't believe it, because I was thinking 'who am I going to talk and also where would I ask for things?.
(X-man, 22)

Almost all participants in the Ezobudoda sub-study had changed homes and caregivers at least once. About half of the participants in this study spoke about highly mobile childhoods – changing caregivers and homes multiple times – mostly within the Eastern Cape, but sometimes also between Cape Town and Johannesburg. Moving between multiple caregivers and homes was often described as challenging and confusing. For participants who lost parents, this may have made performances of HIV-positive patienthood both more difficult and more important, as ways to please caregivers, or to not cause trouble that might risk the support they needed being withheld.

High rates of poverty were also documented within the Mzantsi Wakho quantitative sample: 66.0% of the Mzantsi Wakho sample reported lacking basic necessities like food or soap (Toska *et al.*, 2019). Moving homes was also common, and preliminary quantitative analysis from Mzantsi Wakho baseline data showed that more than 64.0% of participants had reported moving homes during their lives, with 20.1% reporting moving in the past year. In this analysis, about 9.2% of participants found it hard to take medication due to changing homes or schools, and 7.4% said they were not able to get to their clinic appointments in the last year for the same reason (Savage *et al.*, 2017).

As can be seen above, participants often spoke about the inter-related emotional, geographic and material challenges of caregiver deaths. These findings align with the literature on AIDS orphanhood which suggests that children who have lost a caregiver due to HIV/AIDS face a variety of burdens related to socioeconomic environments, psychological development, survival and health needs, and suffer from loss of material provision as well as important family bonds, role models and nurturers (Van der Heijden and Swartz, 2010). Orphaned South African children from poor communities may have anxieties over social and economic conditions and fears of not having their material needs met, and may not have the support networks to get help when they have problems (Van der Heijden and Swartz, 2010). Beyond affecting grief in complex ways,

poverty, precarity and parental loss also shape access to social services to support, including inadequate access to social capital and networks that can support children to cope (Cattell, 2001). In this way, the destabilising effects of parental AIDS deaths are not isolated, but rather experienced alongside other hardships. Within the quantitative study, Sherr and colleagues (2018) found that maternal death was a significant factor with long-term impacts on participant health. Parental deaths were sometimes also related to participants' diagnosis, or disclosure of their own HIV-positive status, as is discussed below.

1.1.3: HIV diagnosis/disclosure

This section documents how narratives of parental death and moving caregivers and homes were not isolated, but rather bound up with other challenges. After losing parents, learning of their HIV-positive status was one of the most common themes that emerged from life history narratives. Without HIV-specific prompts, 32 participants disclosed their HIV-positive status, mentioning it either as an important life or health event. Their experiences of HIV diagnosis and disclosure will be explored further in Chapter Six which considers how having grown up deeply embedded within the medical system has shaped their health-related beliefs and experiences. This theme is mentioned here based on its prominence within life history narratives and clinic files, and its relationship to other important life events.

Participants described growing up engaging with biomedical products and services. This often included being hospitalised and experiencing severe illness. Other health sector engagements included attending the health facility monthly, taking pills daily and frequently interacting with healthcare workers. Their entanglements in this set of biomedical engagements meant that HIV was hyper-present in their lives. However, it was largely unspoken within family and home contexts. It was common that families did not explicitly speak about the participant's HIV-positive status, the parent's AIDS-related deaths, or mode of acquisition. Under such silence and secrecy may be the fear of inherited misfortunes passed down through generations.

There is a literature that documents how familial, personal and societal misfortunes are usually discussed as related to wider social ills rather than a biological disease (Becker and Geissler, 2009). A large body of anthropological work has shown how spiritual arguments are often seen

to underlie historical and political-economic processes. Within the South African context, Niehaus (2009) documents narratives of degeneration of social and ethical standards. In the case of HIV/AIDS, it may be seen as 'but one of the scourges that have befallen Africa over the past century' (Becker and Geissler, 2009). Talk of AIDS in the study context is often imbedded in narratives of confusion, destruction and loss, which resonates with broader stories of misfortune since early in the last century (Cohen and Odhiambo, 1989).

The above summary is presented to provide context for how the HIV-positive status of a child may be seen to represent an embodiment of familial misfortune, also carried by their parents. Silence and stigma also held inter-generationally – representing both a bigger and harder-to-keep secret, and an implicit collective harm in need of healing. Participants did not speak directly about this, but many alluded to their beliefs that HIV was related to supernatural or conspiratorial causes (as discussed in Chapter Six). Beyond this, they spoke generally about societal and moral degeneration, using coded and distancing language when discussing the relationship of these to their own familial challenges.

Traditional health practitioners had varied thoughts on HIV. Some, like the one quoted below, understood HIV as inter-generational household 'pandemonium' rooted in an ancestral issue of supernatural origin. This aligns with the aforementioned suggestion that HIV is often understood as part of broader misfortune.

> HIV … usually it is about the home. You find out the mother is HIV-positive, the daughter is HIV-positive, then you find out in that household there is a lot of drinking, there is casual sexuality, there is pandemonium. When I look at those things, I find out, no, there is a curse. Your intuition will tell you, no, the grandmother there was a witch and used to do some funny things to other families, so it is coming back.
> (Tamella)

The assertion that HIV represents misfortunes of a supernatural nature aligns with a substantial literature on HIV in Southern Africa. HIV is often understood within a cosmology that frames illness as rooted in disharmony: be it through unresolved issues, witchcraft, violations of cultural

taboos or ancestral displeasure (Ngubane, 1977; Urbasch, 2002; Posel, Kahn and Walker, 2007; Zungu, 2013). There is a symbolic similarity between HIV/AIDS, witchcraft, pollution and poison (Stadler, 2003), with cultural representations of AIDS, including associations between beliefs of ancestral callings, bewitchment and pollution being documented in a number of studies (Nattrass, 2005a; Shisana *et al.*, 2005, 2014; Wreford and Esser, 2008; Mfecane, 2010; Zungu, 2013; Rubincam, 2014). Similarly, Posel, Kahn and Walker (2007) documented how AIDS is understood to be a new form of other long-standing, traditional illnesses. This context-dependent cultural-social representation highlights a spiritual dimension to health and illness and gives meaning to AIDS within this knowledge system (Zungu, 2013).

Implicit in these understandings is that illness is relational, occurring in families and symptomatic of an underlying issue. Such issues can present in many ways, including, but not limited to, physical illness. It can also manifest as misfortunes such as family problems, poverty and trouble with finding or keeping work, social issues, substance abuse and mental health challenges. For participants and their families, the pervasive silence around HIV may be related to an unresolved perceived familial misfortune that the child's HIV status has come to represent.

Similar to parental death, participants were often told late, and after a long period of silence about their HIV-positive status. The reasons for these late disclosures are likely similar. Having acquired HIV from their parents, they had also inherited the possibility of an early 'bad' death, from which their families were unable to protect them. Sometimes explicitly spoken, but often implicit, was the awareness of their own mortality that came with the diagnosis of living with a chronic condition that requires medication for long-term survival.

Biomedical engagements such as daily pill-taking, monthly hospital appointments and telling a child that they are HIV-positive ruptured these silences. Participants often kept their questions to themselves about their parents' deaths and their own HIV-positive status. In doing so, they avoided placing blame and defying the silence of family authorities by opening up what has been carefully and deliberately hidden. An example of one such situation is provided in the below narrative, where Akhona describes frequent health facility visits as a child, and suspecting that something 'was wrong' until he was told his HIV-positive status.

Akhona: I suspected that there was something wrong in me but I didn't know. So when I was told (about my HIV-positive status) I just accepted it.

…

Interviewer: How did you contract the virus?

Akhona: That is the one thing that I want to understand too but when I look at it I suspect that I was born with it. Even at school we learn about HIV but I still don't get the roots of it. I'm not even sure if my mother is also HIV-positive or she is hiding it but I'm sure my father doesn't have the virus. How did I get it? I don't know.

Interviewer: Is your mother on treatment?

Akhona: I sometimes bust her taking pills but I'm not sure about them because they are not the same as the ones that I'm taking so that's where it confuses me… I think about asking her sometimes but then I decide to let it go.

…

Interviewer: Who supports you in most of the time?

Akhona: …Here at home no one is checking on me about treatment or going to the clinic. I have to do those things by myself.

(Akhona, 19)

Despite saying he accepts his HIV-positive status, Akhona wonders out loud about how he contracted HIV, expresses his confusion about how he contracted it, and the discomfort that stops him from asking for more information from his family. He says he 'sometimes busts her (his mother) taking pills' but says he does not know why she takes them. This language demonstrates a secrecy and misconduct to her medicines-taking, a clandestine act that he should not know about. He also describes how taking ART and attending the health facility are his own responsibilities, for which he receives little support from his family.

It was common for participants to not have a firm understanding about their mode of HIV acquisition, and to express that they felt they were missing information in relation to their HIV-positive status, but were unable to ask for more information from their families. For example, Zube, 17, said 'I was very surprised. I didn't think I was infected with HIV… I didn't ask (how I

became infected)' and Layzdu, 18, said 'Why do I have this because I never did anything with anyone?... Maybe (I got it) from my father or my mother'. Others, such as Ringo, 17, explained that his grandmother (or another caregiver) supports him on his treatment but that they never talk about HIV. Mayor, 16, was disclosed to by a health worker, and decided to ask his caregiver about it: 'I once asked her about the pills and she didn't answer me. She just cried and she called the neighbours'. Following her tearful and avoidant response, he never asked her again. Caregiver fears of the potentially negative impacts of disclosure on the health and well-being of adolescents have been documented as a reason for their reticence to disclose (Kidia *et al.*, 2014; Mattes, 2014). The impact of late or inappropriate disclosures on participant health practices are discussed more in Chapter Six.

The examples provided above demonstrate the common familial silences around HIV. Given the stigma of living with HIV, including its relationship to death, immorality and misfortune, it is perhaps unsurprising that the HIV-positive status of a child and the AIDS-related death of a parent were met with silence within the home and family. Caregivers and family members may also feel guilty and vulnerable for not being able to protect the child from their illness and misfortune, because the child's illness reflects on the well-being of the family, and their failure to ensure healthy progeny. This lack of knowledge, and the familial secrecy and pervasive silence about HIV, stands in stark contrast to participants' detailed understandings of mechanisms of HIV transmission and acquisition, learned from school and the clinic, which they demonstrated during their in-depth semi-structured interviews. In this way, HIV stigma within families was both averted and continued by silence around their HIV acquisition – implicitly through parents who had acted immorally and some of whom who had died 'bad' deaths.

1.2: Rupturing the silence: biomedical health services, authority and anger

This next section explores how biomedical health services documented, perpetuated and ruptured the aforementioned silences. It uses examples of clinic files and participant narratives to discuss some of the tensions and 'paradoxical forms of agency' (Vale *et al.*, 2017) that the health services represent for young people living with HIV and their families. It documents how health services act as different authorities than caregivers do, and how health citizenship messaging was taken up and re-signified by participants.

The below (anonymised) file shows how health files contain stories of HIV-related silences. This participant, Mayor, had not had his HIV status disclosed to him by an appropriate age. This clinic file from when he was 12 years old documents his late disclosure, and the repeated adherence counselling and social support provided to his family. This image from his clinic file shows multiple months of poor adherence (ascertained from pill counts) 'terrible pill count – came week late' 8/8/12), alongside notes from hospital staff that say 'Not disclosed yet, best we disclosed together' (6/9/12) and 'Aunt to go to adherence counselling'(11/05/12).

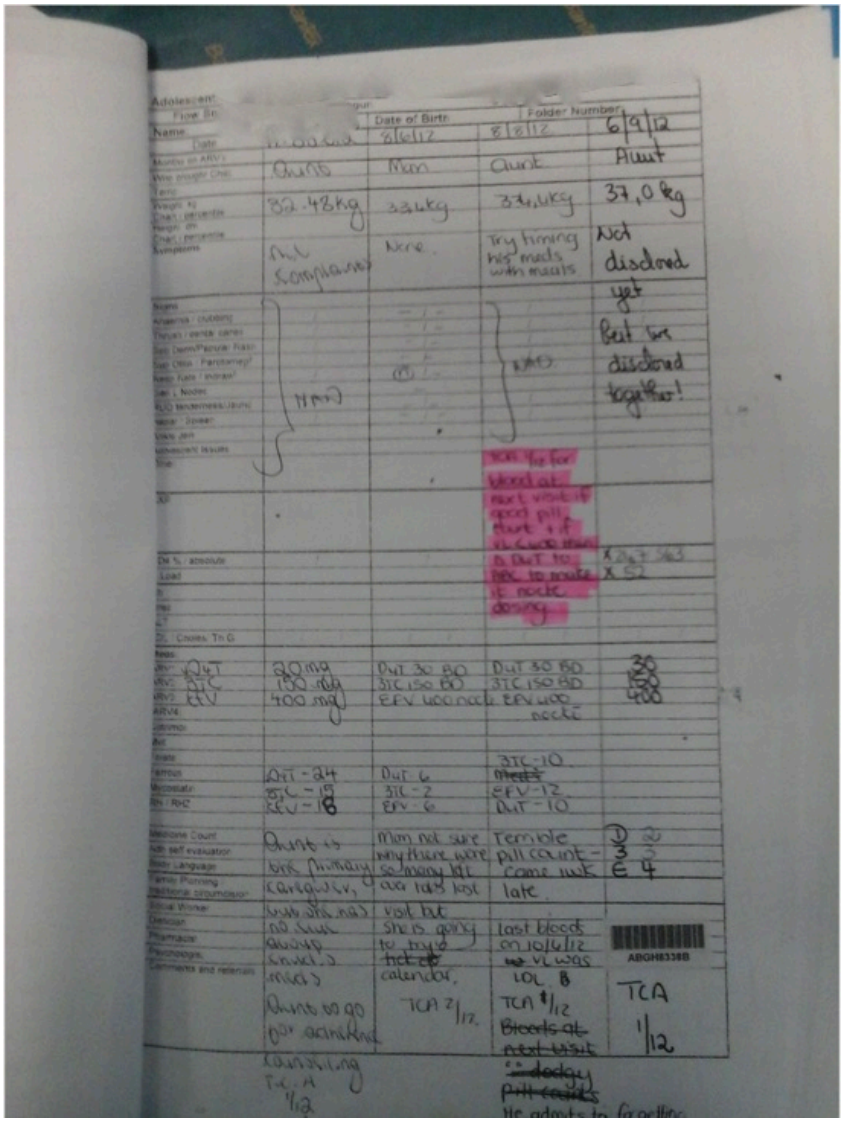


Figure 39: Page of a health facility file of Mayor (16). Photograph taken 22 March, 2018.

This participant's health facility file reflected a number of common themes from this research. First, as described above, he was told late about his HIV-positive status, and not provided with clear information by his family about his HIV. Clinic files often prescribed psychosocial support for the caregivers of undisclosed and non-compliant participants. In this way, the importance of accepting an HIV-positive status was also extended to the families and caregivers of children living with HIV. Beyond the suggestion that caregivers need to accept a child's HIV-positive status in order to support them, it is possible that this suggestion was a broader reflection of non-acceptance of the presence of HIV in a family. For biological parents who were alive, this might reflect their own HIV-positive status and misfortune that they had passed on to their children. For caregivers of children with dead or absent parents, they may have trouble accepting the HIV-positive status, or 'bad' AIDS-related death of a family member of loved one.

Another common theme was of how late disclosure resulted in anger and confusion for the participants. The case study below demonstrates the emotional and social challenges of late disclosure. It also demonstrates how participants speak retrospectively about their life events in comparison to the narratives contained in health files.

Case study: Svij's late & inadvertent disclosure

Svij was taking pills every day, but did not know he was living with HIV. His mother had died and his great-grandmother was his primary caregiver, although she herself was sick. The health facility had been documenting Svij's non-adherence to his pills. A number of entries demonstrated referrals to social services for caregivers and efforts to ensure that he was disclosed to by his caregiver. When Svij was 14, he was inadvertently disclosed to by a girl at school. She told a friend of his that he was HIV-positive, and that his mother had died of AIDS-related illness. He responded by getting angry, and physically attacking her. In his life history narrative, his HIV-positive status was at the forefront of his main life events. His narrative demonstrates that he links his HIV status and his inadvertent disclosure as painful and definitive life events:

> I will tell you about what happened in my life and that is HIV.. I didn't know it was HIV, I was just taking pills in the morning and afternoon. Before I knew about my status a girl that was a friend of my sister (told everyone)… she didn't even say it to me straight, she

told a friend of mine that "you see your friend… he has HIV and he is taking treatment". That was the only thing that nearly destroyed me, I was bitter because my status was very important to me… I couldn't control my temper… So I beat that girl out of anger… I klapped (hit) her…

A review of his health facility file before this event demonstrates how health workers were concerned that he had not yet been disclosed to, and how they advised his caregiver to disclose to him.

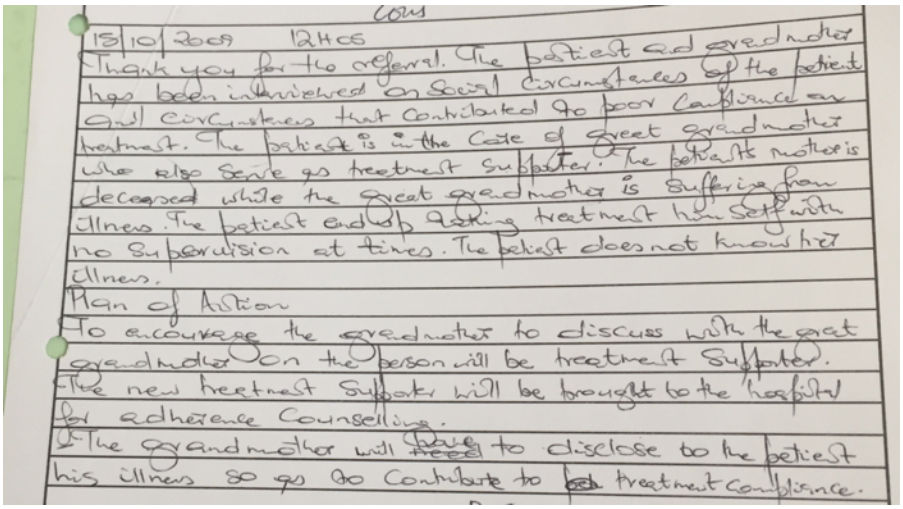

15/10/2009 12H05
Thank you for the referral. The patient and grandmother has been interviewed on Social Circumstances of the patient and circumstances that contributed to poor compliance on treatment. The patient is in the Care of great grandmother who also serve as treatment Supporter. The patient's mother is deceased while the great grandmother is suffering from illness. The patient ends up taking treatment himself with no supervision at times. The patient does not know her illness.
Plan of Action
To encourage the grandmother to discuss with the great grandmother on the person will be treatment Supporter.
The new treatment Supporter will be brought to the hospital for adherence Counselling.
The grandmother will have to disclose to the patient his illness so as to contribute to treatment compliance.

Figure 40: Page of a health facility file of Svij (25) from 2009 describing that he has not been disclosed to. Photograph taken 22 March 2018.

(18/10/2009) Excerpt from clinic file:

> The patient is in the care of great grandmother who also serves as treatment supporter. The patient's mother is deceased while the great grandmother is suffering from illness. The patient ends up taking treatment himself with no supervision. The patient does not know their illness. Plan of action: … the grandmother will have to disclose to the patient his illness so as to contribute to treatment compliance.

The story of his inadvertent disclosure, and how he attacked his classmate in response is also depicted in his file in referral form to counselling services. It states 'Please see above child who

beat another girl up in school because she disclosed his HIV status to class. He got very angry. Please do some sessions of how to handle situations, positive attitude. Thank you.'

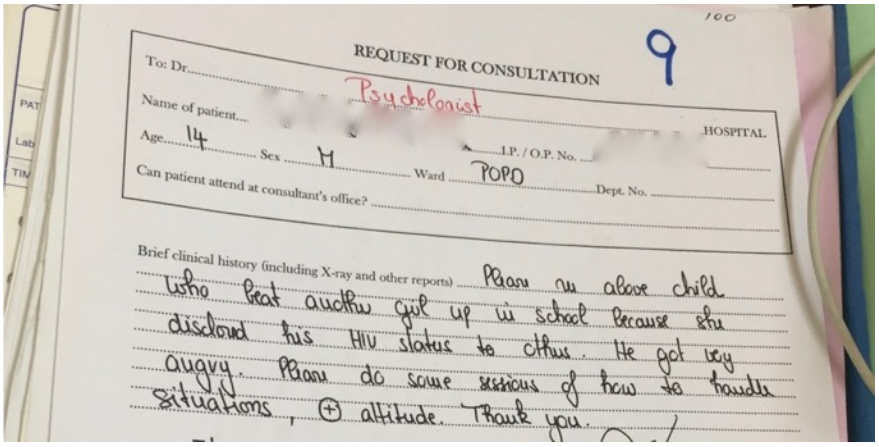


Figure 41: Page of a health facility file of Svij (25) from 2009 describing his inadvertent disclosure. Photograph taken 22 March 2018.

This case provides an example of the themes of late disclosure and its psychosocial impacts. It demonstrates the centrality of learning about their HIV-positive status in participants' lives and demonstrates how events are depicted differently by participants and health care workers. In many cases, major life events shared by participants were reflected within the bureaucracy of the biomedical system. Factually, the accounts are the same: non-disclosure of an HIV-positive status to a child at an appropriate age and hitting a girl. While the participant spoke about the challenges of these situations as painful, frustrating and largely outside of his control, the image that emerged from the clinic file was of a family who needed to better handle the child's HIV-positive status and a child who needed to learn how to control his emotions and take his pills properly: that is, a family and patient who had to get better at patienthood. In this way, the files speak to what Vale (2017) calls a 'paradoxical form of agency' between the coercive discipline of the state and the potential for agency and empowered health citizenship of ART users. Also relevant here are the HIV-related assumptions that sharing secrets is healing, that it is necessary to overcome personal illness in order to heal, and that people are empowered through working on themselves (Nguyen, 2013). These assumptions were clear from clinic files and participant narratives alike; encouragement for disclosure and counselling to accept an HIV-positive status were common. These were applied to caregivers of HIV-positive children, as well as the children themselves. These findings also align with the suggestion that health system understandings of

healing hinge on the re-configuration of silence and stigma as prerequisites for such responsibilised citizenship and pill-taking (Nguyen, 2005).

Within this study, it was not just the person living with HIV (in this case, the child or adolescent participant), but rather the whole family that was provided messaging on what it meant to be responsible health citizens. Responsibilised health citizenship, in this way, may be understood as an imperative to heal family issues through being a 'good' HIV-positive patient or family.

Narratives of coming to accept an HIV-positive status often began with anger and confusion, followed by aspects of seeking redemption, similar to how parental deaths were handled. For example, Svij spoke about how finding out his HIV-positive status 'nearly destroyed him' and spoke about other losing hope and questioning his life:

> That was the most painful thing that ever happened to me. When I looked at myself I used to hate myself when I first knew about my status. But there was a thing that whispered in my ears. The devil wanted me to commit suicide and God on the other hand wanted me to accept this and move on with my life.
> (Svij, 25)

The next sections consider the processes through which participants made meaning of living with HIV to move through anger and hopelessness to imagining better futures. It documents how participants spoke about their HIV status using frames of morality because of how they acquired it. Doing so created distance between themselves and the misfortunes, immorality and 'bad' deaths of their parents. Next, the ways in which participants performed to notions of being 'good' HIV-positive young people are presented with the suggestion that this strategy has a redemptive function.

1.3: Redemption: 'Moral' HIV acquisition & responsibilised patienthood

One mechanism through which participants came to terms with and re-configured the stigma of living with HIV was through their mode of acquisition. They suggested their HIV was different because they had contracted it in the absence of action, and therefore without choice. As opposed

to behavioural acquisition, which was associated with immoral behaviour, they emphasised their mode of acquisition, asserting that they did not 'do anything' to acquire HIV. Framings used by participants in relation to accepting their HIV acquisition included: not 'making themselves' get HIV, not being at fault, or being without choice. In these ways, participants framed their HIV-positive status in a way that upheld their morality and distanced themselves from how their parents acquired HIV. Their HIV thus stood in contradistinction to the ways that their parents contracted HIV, and their parent's 'bad deaths' or immorality (Posel, Kahn and Walker, 2007; Vale and Thabeng, 2016). Participants frequently said that they were able to accept their HIV status for this reason.

While being born with HIV and losing parents were outside of their control, participants also spoke about medicines-taking as something within it. As a form of health citizenship, it also served as a way to gain legitimacy and acceptance in the eyes of caregivers and health facility staff and to seek futures different from their parents. Participants also used frames of responsibilized patienthood as pathways to heal ancestral pasts and to create different futures.

The term 'responsibilised citizen' was coined by Barry and colleagues (1996), and variations of this idea have since been used in different contexts, including ART treatment programmes. The concept of 'therapeutic citizenship' was developed by Nguyen (2005) and introduced in the South African context by Robins (2008) as 'health citizenship'. These terms reflect a neoliberal public health discourse which posits that people are individually responsible for their own health. In the case of ART, there is a suggestion that becoming a 'good' patient through medicines-taking and adhering to clinic appointments represents the process of becoming a political being. Responsible citizens are thus developed by the process of treatment-taking and monitoring. Others have applied this concept to suggest that ART has provided new modes of biosociality which span from disciplined and dependent citizenship to rights-driven empowered citizenship (Meinart, Morgensen and Twebaze, 2009; Mattes, 2011; Richey, 2012; Vale, Hodes and Cluver, 2017). For example, Colvin and colleagues (2010) demonstrate how a support group for men living with HIV responded to government discourses of responsibilisation and citizenship by using gendered frames of social responsibilities. Vale and colleagues (2017) posit that HIV-

positive adolescents are encouraged to take ART as a way to heal the moral degeneration represented in an HIV-positive status, redeem their lost mothers and reinstate authority.

Findings from this study agree with those of Vale (2017), and suggest that managing their HIV-positive status differently than their parents did has a redemptive function. Participants leveraged notions of therapeutic citizenship through performing pill-taking and health facility attendance to please the adults in their lives, who included caregivers and biomedical health workers. They expressed a sense of duty to their caregivers because of the support that they had received from them, and framed their pill-taking as an expression of their love and gratitude. For those who were concerned over not having their basic needs met, or who were in shifting or strained caregiver situations, this may have been additionally important as an attempt to ensure their survival by avoiding upsetting them. Participants also spoke about their obligation to making things 'right' between themselves and their biomedical health workers, who were central adult authorities in their lives. This could only be achieved by complying to their demands to adhere to ART and clinic appointments.

As Vale (2017) suggests, complying with pill-taking also served the function of redeeming parents who may have disappointed their families or were not able to take medication. Bernays and colleagues (2017) have also found moral framings for HIV medicines-taking, likening non-adherence to committing a 'sin'. Participants spoke about their medicines-taking in relation to choosing to live, in contrast to their parents, many of whom died. Through successfully managing an HIV-positive status through pill-taking and retention in care, participants may be understood to be redeeming parents by doing something that they were unable to do.

Just as participants spoke about coming to terms with parental death, it was through finding meaning, often in the form of therapeutic citizenship, that they imagined differed futures and strove to create different realities. In response to the misfortune that their HIV-positive status represented, frames of therapeutic citizenship were also used to put adult authorities at ease, distance themselves from the possibility of their own 'bad death', re-signify their HIV-positive status, and redeem their parents and lineages. The suggestion here is not that participants had

exemplary adherence to ART or health facility appointments. Rather, they strove to be seen to be a ‘good patient’ regardless of their health practices.

The context in which participants performed such therapeutic citizenship is important to consider. As children and adolescents among the first generation born in a newly democratic country, they have been subject to narratives of democratic and financial freedoms that are largely unattainable to them. ART represents a pathway to (healthy) living and the attainment of collective dreams of the new South Africa. As young citizens, the biomedical health system is both a form of bureaucratic democratic inclusion and a disciplining authority of state sanctioning and control (Vale *et al.*, 2017). The site of home and family offers a different paradoxical and relational form of citizenship where participants strive to be 'good' persons through taking pills, a mechanism to fulfil family responsibilities. Like Vale and colleagues (2017), this study found that in cases where parents had died HIV-related ‘bad’ deaths, representing social and moral decay, their children may serve as living proxies for them. Participants faced pressures to redeem their parents as the health citizens that they could not be. Using frames of therapeutic health citizenship, they might heal unresolved issues in their lineages, demonstrate their worthiness of caregiver and health worker support, and create the possibilities of different futures for themselves and their families.

This first half of this findings chapter has provided an overview of the key themes in participant narratives of parental death, HIV, moving homes and caregivers and poverty. It also has suggested that these issues may be understood as part of family misfortunes passed down through the bloodline, of which their HIV-positive status is symbolic.

It has documented the pervasive familial silence around these significant and challenging life events, suggesting that such silence is grounded in associations between HIV, misfortune and ‘bad’ parental deaths. The child’s HIV-positive status may be seen as a reminder of these, as well as a failure of the family to protect the child from such issues. Although their HIV-positive status is shrouded in silence in the home, it is hyper-evident through embodied enactments of health facility visits and pill-taking, and sometimes, illness. Participant used justifications of their ‘moral’ HIV acquisition and enactments of ‘good’ HIV-positive young patienthood as avenues to

redeem such misfortunes, please adult caregivers and health providers, and create different futures.

The second half of the chapter furthers this argument, suggesting that as participants get older, they use enactments of masculinity as pathways to redeem family pasts, and to strive towards different futures.

Findings Section 2: Masculinity, identity and pathways to personhood

This section suggests that in striving towards respectable adult masculinities, participants continue to redeem difficult family pasts and create different futures. They aim to bridge the chasm between precarious realities and their aspirations for different futures.

This section begins by providing contemporary and historical context about fatherhood in South Africa, followed by an exploration of the importance of knowing one's paternal ancestry. Following this, it explores participants' complicated, layered and sometimes conflicting framings of masculinities, including: (1) continuing their lineages through legitimised, engaged fatherhood; (2) making money and providing for their families; (3) 'moral' behaviours; and (4) ulwaluko.

2.1: Fatherhood

2.1.1: Fatherhood in South Africa: Background

The previous half of this chapter began by providing an overview of participant narratives of parental death. Although many participants lost one or both parents, more were maternal orphans. This may be because they acquired HIV from their mothers, who then died of AIDS-related illness. Given that childcare has also been feminised, it is possible that participants spoke more about the effects of losing mothers because this had a greater impact on their lives. This section explores experiences of absent fathers and patrilineal families. Absent fathers, as discussed here, are fathers who did not achieve fatherhood in the eyes of participants, either through insufficient presence or provision, or those who died or were unknown.

A key theme in life history narratives was of that of deceased and absent fathers. Of the participants in this sample, 10 had lost their fathers (five of whom had also lost their mothers) and an additional eight said that they did not know anything about their fathers. Thus, half of the participants in this study had either dead or unknown fathers. Of the remaining half, most did not live with their fathers, and they had varying relationships in terms of closeness; many of these participants met their fathers for the first time immediately prior to ulwaluko.

These findings align with the literature which demonstrates that it is common for South African children to be raised without social or financial contribution from their fathers (Richter and Morrell, 2006) and that patrilineal kin provide less contribution towards child care (Anderson, 2005). Despite the unique contextual aspects of absent fatherhood in South Africa, this is a common global phenomenon. A large minority of fathers do not live with their children across the globe, with data from 43 countries showing that about 30% of men ages 25-39 who fathered a child do not live with their children (United Nations, 2011). Within many societies throughout the world, adult masculinity is defined in terms of provision, breadwinning and working, and not working may result in not being socially recognised as an adult man (Gennrich, 2013).

The historical roots and contemporary contexts around fatherhood in South Africa are important to consider. The conditions of absent men and fathers have intentional, historical roots in the colonial and apartheid migrant labour systems, under which social structures were severely weakened (Bonner, 1990; Walker, 1990; Ramphele, 2000; Hall *et al.*, 2018). The under-development and under-resourcing of the 'Black' homelands, including those in the Eastern Cape, was a deliberate act by the apartheid government where labour laws forced Black men to leave their families behind to travel to work in mines and urban areas far from these homelands (Nell, Hill and Binns, 1997; Richter and Morrell, 2006). Earlier on, the discovery of diamonds and gold in South Africa during the colonial period forced many men to leave their homes in rural areas to work in mines. Mines were the main employer of men in South Africa until the 1990s, when levels of employment started to decline (Sharp, 1994; Hunter, 2006).

The impacts of not having adult male role models present in boys' lives have been explored in a large literature. Children who grow up in households where fathers are not present are more

likely to have emotional disturbances such as aggression and violent behaviours (Garbarino, 1999; Richter and Morrell, 2006). It has been argued that a lack of good male role models can contribute to a 'crisis' in development for boys (Richter and Morrell, 2006), and that factors such as poverty and unemployment can exacerbate these issues (Langa, 2010). For example, a 2002 study found that boys who did not have father figures in Cape Town were more vulnerable to violence, gang activities and drug abuse (Ramphele, 2002). Ratele and colleagues (2012) document the importance of spending quality time, developing strong relationships and performing to non-violent and nurturing forms of care. However, they also advise caution in such discourses, arguing that within the South African context, the absence of biological fathers has been constructed as a problem for children and especially boys, which implicitly demonises female-headed, non-heteronormative and non-nuclear households (Ratele, Shefer and Clowes, 2012).

Within this study, participants spoke about the absence of paternal family members with frustration and concern for two inter-related reasons. The most prominent was in relation to issues of identity, and the second was the emotional and material impacts of these absences. Both are discussed below.

2.1.2. Fatherhood: Forging patrilineal ties and bridging identities across generations

This section begins by exploring the importance of knowing one's patrilineal ancestry, suggesting that this becomes increasingly important as participants get older, and especially around the time of ulwaluko. For many participants, resolving issues of identity by connecting with their patrilineal ancestors is a pre-requisite to their ability to fulfill requirements of respectable adult manhood. Connecting with their (previously unknown) ancestral lineages has both a preventative and a supportive function. By being known to their ancestors, they can call on their ancestors for support, receive their protection, and also be assured that they will not experience the misfortunes that come from ancestral disconnection and sicknesses of identity.

While mothers were often more involved in participants' lives prior to their deaths, fathers were often discussed in relation to issues of kinship and identity, bound up in patrilineal family ties. Disconnection from paternal ancestry and concerns over the accompanying consequences were

common amongst participants. Such absences represented a vulnerability and a challenge in relation to identity, which had the potential to manifest in the form of negative life events. Connecting with patrilineal kin was important because it may solve difficulties or prevent or address misfortunes.

The underlying belief here is the same as presented in the first section of this chapter. Through having a strong relationship with the ancestors – including through performing ceremonies to connect with them and call upon their support – long-standing difficulties ranging from material challenges to health and relationship issues can be addressed or avoided. South African researchers including Nduna and Jewkes (2011) and Mfecane (2018b) have written about the search of youth for their paternal families in order to know their surnames for these reasons. The basis of this belief is that displeasing the ancestors, or not being connected with them (sometimes expressed by participants as having a 'proper' identity and using the 'right' surname) are at the root of such challenges (Mfecane, 2018b).

An example which captures some of these themes is provided below, where Khwezi speaks about never having met his father, and the disengagement of his patrilineal family. He expresses a sense of helpless frustration that without their support, things might not go well for him in his life. His disappointment also comes in the form of their absence of acknowledgement and support to him during ulwaluko – an important ritual of incorporation which legitimised him as a man. This lack of support is symbolic of their disregard for his well-being.

> I know where he (my father) lives but I never saw him in reality, I know his photo and I went to his home once… Like even when I grew up, I wouldn't say I had a father. I knew I had a father by rumours just because you know no one can be conceived without a father. My mother was a sole parent to me. I never saw my father with my two eyes, and I don't know him I just heard that his name is Sinethemba*. I don't even know his surname...
>
> Not knowing my father at this certain age it affects me somewhere, somehow because I need things like rituals from my father's side. I know that I've done circumcision with rituals from my mother's side, but maybe somewhere somehow at this certain age I have

to know my father's rituals (because) they could affect me. That is why I regard this as a life event…

His family knows that their child has a son…They know that I'm a man and I have needs concerning my manhood… my (grand)mother met one of their family members and she told her that I was going to the bush. They didn't even show support or even show up or buy me some drinks.

(Khwezi, 20)



Figure 42: Khwezi's (20) life history drawing depicting the absence of his father and parental kin with an angry emoji. 6 October 2017.

In this interview, Khwezi speaks about his father's absence, not knowing his surname and his disconnection from his paternal ancestry. In his life history narrative, he depicted his father far away from the rest of his family. He used an angry emoji to express his frustration about the lack of presence and support from his father and paternal family. He also visually represented the gap he feels in his life for not knowing his father during his transition into manhood, something that he says is important to him in his current life stage. In this way, his father and his patrilineal kin represent an important life event through their absence. The significance here is that not knowing his father's surname and clan name represents a disconnection from one side of his ancestry, meaning he cannot receive the support or protection of this side of his lineage. Not being introduced to his paternal ancestors places him in a vulnerable and precarious position. Such a gap in identity may be understood to have the potential to affect one's life in catastrophic ways, including through misfortune or ill health. This is an example of how unseen elements of

personhood may play a role in shaping the kinds of people that boys and men become (Schrock and Schwalbe, 2009; Mfecane, 2018b).

Issues of identity in relation to masculinity and disconnection from paternal ancestry were also present in conversations with traditional health practitioners. They explained the belief that being connected with one's lineage was important for reasons of protection and well-being. In the interview below, this traditional health practitioner spoke about certain issues for men that are symptomatic of not knowing their paternal ancestry. Referring to them as 'family' issues, she describes challenges with sexual performance, getting married and having children. In this way, these issues mean that men are unable to perform to certain hegemonic masculine norms.

> I'm always consulted by the men… I will find that, there is guy who is an older man, age of 40 with a problem with his manhood (i.e sexual performance), only to find out that it is about his identity. It is an issue with ancestors… I will say '*hey, I see something that you might not understand. There is a problem with your identity, your clan name…your ancestors are looking for you*'.
> (Tamella)

She then spoke about the significance of identity in relation to two ceremonies, both important rites of passage within the study context. The first ceremony is imbeleko, a ceremony to introduce someone into the family or clan (Bogopa, 2010). The other, ulwaluko, is the ritual of incorporation that will legitimise them as adult men. If not performed earlier in the child's life, imbeleko should be performed prior to ulwaluko. These ceremonies are explored in more depth in Chapters Six and Five, respectively. Aligning with Menkiti's (1979) writing on how rituals of incorporation serve as pathways towards personhood, these ceremonies are a means to connect with ancestry and become adult men.

> The boys need to be taught their identity. I always preach about identity. Even if the home does not tell you, you will see… My father died and was not married because he wasn't using a clan name. He was using the clan name from his mother's house... How can you get married if you don't know your true identity?

> I will always say that in the company of men - they will come to me and say '*this thing is what is happening to me*' (explain a problem they are having), only to find out that they have to… slaughter a goat and do imbeleko.
> (Mamj Ciky Vuza)

Forging relationships with fathers or paternal families just before ulwaluko was common for participants. At this time, fathers or paternal family members would often emerge to support with imbeleko, or other prerequisites to the successful completion of ulwaluko. Here the importance of this introduction to the ancestors is manifold. The initiate should be known by the ancestors before attending ulwaluko, so they can support and protect him during this challenging and otherwise potentially dangerous rite of passage. He should also be able to call on them for support and acknowledge them, using their names. As ulwaluko is considered to be the gateway into manhood, knowing the ancestors will also be important for next phases of his life, as successful completion is necessary for getting married, attending and performing ceremonies for the ancestors, and having legitimate children that will carry on their family names.

The absence of fathers or paternal family members thus brings up challenges and questions in relation to identity, masculinity, and ultimately the ability to become persons. By not knowing their identities as they get older, their ambitions and abilities as adult men might be thwarted. In this way, the challenge of absent fathers, aggravated by historical and societal conditions as well as by HIV, represent challenges towards desired futures and adult male personhood.

What is unknown of one's blood – in relation to both HIV and kinship - represent important aspects of well-being. As put by one traditional health practitioner in speaking about the importance of knowing one's identity and HIV status:

> This thing (illnesses of identity), they say it is in the blood. And this HIV, it is in the blood. Blood and blood.
> (Mamj Ciky Vuza)

Parallels and entanglements between the challenges, and possibilities for redemption, can be seen in participants' quests for identity, and their aforementioned attempts for redemption through health citizenship.

There are similarities between how families held secrets in relation to paternal identity, as discussed in this section, and HIV and parental death, as discussed earlier in this chapter. Just as the knowledge of an HIV-positive status – a virus carried within blood – is deemed within the clinical setting as important for pill-taking and physical health, knowledge of one's ancestral lineages represents a different importance of understanding of one's blood. In both cases, becoming aware of what one carries in their blood is important for well-being.

Participants aimed to respond to and compensate for these silences in different ways. They aimed to compensate for lost parents and HIV through performing to norms of 'good' health citizenship. Similarly, they searched for identity through knowing their paternal ancestry, and as will be discussed below, compensate for shortcomings through performing to norms of masculinity available to them.

This section has documented participant challenges in relation to issues of identity brought up by absent fathers and patrilineal kin. It has suggested that these issues make achieving forms of respectable, legitimised male personhood more challenging and drawn parallels between sicknesses of identity and HIV. The next section considers other aspects of fatherhood that participants spoke about. It suggests that while participants sought to redeem lost mothers through 'good' health seeking behaviours, many used frames of masculinity to recuperate fatherhood and to become respectable adult men. It explores how participants imagine themselves as adult men, and documents how they strive towards respectable adult manhood through pathways of being legitimatised and engaged fathers, accruing wealth, behaving respectably and successfully completing ulwaluko.

2.1.3: Fatherhood ideation



Figure 43: Ulwazi (13) drawing himself in 2026 as a doctor (left of drawing) and as a man wearing a suit and tie with his wife (a woman in a dress) and child (a baby crawling) (right of drawing). 26 November 2016.

The previous section explored how forging relationships with patrilineal kin was important for many participants to set the foundation for stable and healthy adult male lives. This section suggests that desires to be 'good' fathers themselves – defined by participants as being present, legitimised, financially providing and emotionally caring – represents an aspiration towards achieving respectable adult male personhood.

When asked about fatherhood ideation, 34 of the 36 participants said they wanted children, and all except one (who alluded to being homosexual) spoke about having a female partner, legitimised as a wife, to have children with. This spoke to the strong presence of norms related to the sanctioning of partnerships via marriage, which requires substantial financial input for lobola (bridewealth). These norms are bound up with many different frames of respectable masculinities, such as financial stability, marriage, social reproduction and having progeny that will carry on their names.

The below interview demonstrates how participants represented their desired futures. Partnerships and children legitimised through marriage, having professional careers and making money, owning homes and having cars were common. An example is provided in the image

below (bottom right), which has the words ‘having a lovely family’ accompanied by an emoji of a man, woman and child huddled together happily. Beside this he wrote ‘be an accounted’ (accountant), and above, ‘I want to have 3 children’ (translated from isiXhosa). On the top right corner he drew his house, a sizeable, concrete home with big green trees. This image demonstrates how participants hope for professional and financial success and families. In the interview excerpt below, Jenevo spoke about the type of father he wanted to be, that is, a ‘good’ father, like the father that he never had.



Figure 44: Jeveno (17) depicts his hopes for the future, drawing his family, and desired home. 19 August 2017.

> **Participant:** I want to be there every time they (my children) need me I don’t want them to grow without a father like me.
> **Interviewer:** Is it important for a child to have a father?
> **Participant:** I can say that… I want to see that I can be a good father to my children
> **Interviewer:** Who will be the person next to you?
> **Participant:** I would say it’s my children and my family.
> **Interviewer:** Will you be married?
> **Participant:** Yes.
> (Jeveno, 17)

Participants drew on responsibilised narratives of fatherhood and demonstrated a strong awareness of the financial implications of having children. They spoke about the timing and the number of children they wanted in relation to finances, demonstrating that they had a strong awareness of the costs of having children, and desire to act as material providers. Such forward thinking stands in stark contrast to the dominant assumption that young, poor and Black men are irresponsible, an assertion documented and challenged by Pattman (2007). Participants' answers are also demonstrative of how economic aspirations are tied up in family and the gendered role of 'provider' (Richter and Morrell, 2006). It has been suggested that the role of breadwinning and 'heading' of the family and home are key markers of masculinity (Silberschmidt, 2001; Ampofo and Boateng, 2007; Morrell, 2007; Mfecane, 2008; Shefer, Stevens and Clowes, 2010).

It is likely for these reasons that material provision was one of the most important aspects of fatherhood that participants strove towards, alongside love and physical presence. They commonly spoke about their desires to be present, supportive fathers in contrast to their own experiences as children, most of who had dead or absent fathers.

> I want to give my child what I never had, that love…. Even now (I don't have that). So I want that bond with my child, to have time for my child.
> (Mr Shade, 17)

> **Interviewer:** How do you want to be part of your child's life?
> **Ndoda:** I want them to stay with me so that whenever they need something, I can give it to them. I don't want them to be like me, because look at me I grow up in a shack. That's hard.
> (Ndoda, 18)

> **Buja:** I want to give them love, educate them and pay all the fees for them.
> **Interviewer:** Will that make you a great father?
> **Buja:** Yes it will.
> (Buja, 19)

As can be seen above, material provision and emotional presence were important aspects of fatherhood for participants, who spoke about these in contrast to their fraught relationships with their own fathers. The connection between material provision and physical and emotional presence is important. It has been suggested that the failure to be primary providers is experienced as intolerable for many men (Richter and Morrell, 2006), who may see the abandonment of their children as an only option, and a way out of poverty (Ramphele, 2002; Hunter, 2005, 2006). It has been suggested that if men are unable to provide, they may begin to neglect children's other needs, such as emotional support and care giving (Richter and Morrell, 2006). This is important in a context where poor employment opportunities make it difficult for men to make money and occupy the role of the traditional patriarch (Bank, 2001). Men who cannot pay lobola (bridewealth) or 'damages' for impregnation may be seen as men without power (Campbell, 1992; Hunter, 2006). The frustration over not being able to meet expected fatherhood-related social roles such as building a home and providing for children (Reid and Walker, 2005; Hunter, 2006; Langa, 2010), can undermine the sense of value and success for men. This is especially true for poor men and those who are unable to live up to expectations, including for reasons of HIV and illness (Mfecane, 2008).

HIV/AIDS has weakened family structures and highlighted the question of fatherhood (Richter and Morrell, 2006). For children who lost parents to AIDS-related illness, living to become fathers may also represent survival and the ability to carry on their lineages. In a context where an HIV-positive status is seen as a barrier to intimate relationships, having children, and breadwinning (Mfecane, 2008; Wyrod, 2011), becoming a father may also represent being able to do something that is considered outside of the realm of HIV-positive masculinities. Steinberg (2013) suggests that because many men are living in contexts where they do not have the material resources to begin families within traditional institutions that legitimise them as men, an HIV-positive status may represent men's failure to 'procreate as patriarchs do'. In this way, being HIV-positive may be seen as 'a mark of their diminishment, a biological manifestation of their social uselessness' (Steinberg, 2013, p. 506), which participants may aim to overcome through striving to make money, get married and start families.

These findings dovetail with Langa's (2010) study on adolescent boys talking about their absent fathers in Alexandra township, Johannesburg, which found that boys aspired to be engaged and present fathers. Findings also affirm a literature, reviewed below, that documents how material provision, breadwinning and working are symbols of legitimised fatherhood and masculinity, and likely why participants often spoke about their desire to be providers, alongside being physically and emotionally present fathers.

A literature offers potential explanations as to why it was important for participants to be different from their own fathers in terms of physical presence and material support. Fonagy and Target (2003) and Langa (2010) suggest that such desires can be understood as a way to fulfil unfulfilled needs through children. In this way, being a loving and caring parent can be a form of compensation for unfulfilled childhood wishes, and a mechanism to not repeat the suffering they experienced as a child (Langa, 2010). Another interpretation is offered by Gibbs and colleagues (2017) who document how men's engaged involvement in fathering children is often linked to conservative masculine norms around establishing an household, a finding with which this study agrees.

This section has suggested that striving towards certain norms of fatherhood has a redemptive function. Through being engaged, emotionally and financially present fathers, participants may redeem the failed patriarchs of their family pasts. Although this is not the only pathway to masculinity, such forms of fatherhood serve the functions of: (1) social reproduction to carry on their lineages; (2) a display of respectable adult masculinity and material security that was not available to their forefathers; (3) a way to overcome the perceived limitations of being HIV-positive and male; and (4) an opportunity redeem challenging childhoods, including their patrilineal shortcomings.

This section has suggested that participants saw fatherhood as an avenue towards redeeming challenging childhoods, the failures of their forefathers and as an avenue to respectable adult manhood. The next section provides more information on other pathways to respectable adult masculinity, including how participant's spoke about their desires for financial success, completing ulwaluko correctly and moral behaviour. It suggests that there are multiple,

sometimes conflicting layers and definitions of masculinities, and that in the absence some of these avenues, that participants may compensate by relying more strongly on others.

2.2: Beyond fatherhood: other pathways to adult manhood

2.2.1: Earning money as a marker of masculinity

As previously discussed, having enough money to be legitimised and financially supportive fathers was important to participants. In addition to their fatherhood aspirations, earning money was a central theme when participants spoke about their other dreams for the future. The majority said they wanted to become professionals, with doctors, lawyers, businessmen, engineers and pilots being commonly desired professions. Sound engineer/DJ, businessman and 'working with money' were also mentioned multiple times. Participants consistently said that in their ideal futures they wanted to build or fix family homes, be financially independent, and have car(s). As demonstrated in the quotes below, participants defined being a man in relation to material security, independence and provision for families:

> When you become a man, it means you can be independent. When you are a man you must have your own things… (X-man, 22)

> … you must know how to do your things. You also you have to be able to provide for family. (Bele, 19)

> You have to own things and do things in the right way. (Khwezi, 20)

Reflective of the demographics of South Africa and the Eastern Cape, most participants in this study were unemployed or studying. Many had either dropped out of school, or were performing poorly and years behind. The majority lived in female-headed homes where the main income was derived from government grants. It was also clear that the shame, stress, depression and social identity challenges related to unemployment and underemployment (United Nations, 2011) were present for participants, many of whom requested advice and psychological and material support from the researchers. A central factor in participants' lives was the desire to

shift their financial realities as a means of survival and family support, and to become self-sufficient adult men. Participants consistently spoke about their desire to find work or pursue further education as areas of their lives that they would like to improve. They linked their educational aspirations directly to their future material prospects. It was common for participants to speak about work being 'scarce' and financial challenges as the most difficult aspects of their lives.

> First, I want to go back to school because I did not finish. Second, I also want to work because if you are uneducated you will never get work... Third, it is a good thing to help with family in terms of finance.
> (Soso, 21)

> **Interviewer:** Now we will talk about different part of our life… which one do you feel like you want to improve in?
> **Listar:** Work.
> **Interviewer:** Why?
> **Listar:** I can do well in any other areas but if I don't work nothing will work out.
> (Listar, 18)

> 'The most difficult area of my life is finding work.'
> (Machete, 22)

There was a pronounced contrast between participant future ideation and current realities. In considering issues of masculinity and power, it is also important to consider social conditions of adolescent boys and young men, including experiences of (un)employment and poverty (Ratele, 2008). South Africa has very high rates of unemployment, particularly amongst young men. The national percentage of young men ages 15-24 who were not in employment, education or training was 30.5%, and 36.8% among young men ages 15-34 (Statistics South Africa, 2019).

The Eastern Cape is one of South Africa's poorest provinces, and has the highest number of people migrating out of the province; of the middle generation, many have passed away, and those who remain typically move around in search for work (Schatz, 2007; Statistics South

Africa, 2018). The aspirations for disenfranchised South Africans who have been excluded from the financial system has been documented by James (2014) and have relevance here. These aspirations were difficult to achieve for participants' forbearers under the colonial and apartheid systems because of racialised exclusion and marginalisation. Modes and enactments of acquisition and materialism are features that have shifted form with the advent of democracy for men and families (James, 2014).

Although experiences of poverty and precarity are not unique to adolescent boys and young men, their sense of responsibility to make money and provide for their families may have gendered contours. Following apartheid, men are increasingly on the peripheries of domestic reproduction (White, 2001), with the number of women working outside of the home continuing to rise and female-centred homes becoming more common (Walker, 1995; Casale and Posel, 2002). More recent structural reasons for this shift include the targeting of the state social security system to women and female-headed homes, under which grandmothers have replaced wage-earning men as the cornerstone of households (Bank, 2001; Patel *et al.*, 2012).

Masculine norms of and aspirations for wealth and financial provision stand in stark contrast to the reality of most young Black South African men. Without the material means to legitimise themselves as men, participants leaned on other pathways to masculinity that were within their control, such as their behaviours.

2.2.2: 'Moral' and respectable behaviour: 'A man is a man by the way he acts.' (Loza, 21)

A central theme in how participants defined respectable adult masculinity was through their actions and behaviours. As put by one participant: 'There are those men who you don't need to even ask. You see that he is a man in deed.' (Luya, 17)

What deeds constitute this type of masculinty? Common traits and behaviours that were central to participant narratives of respectable adult manhood were confidence, independent decision making, taking care of the home, self-knowledge, strength, participation and leadership in families and communities, and acting in a way that earns the respect of others. Behaving in a way that was seen to uphold the dignity of others, and embodying the inter-related traits of being

respected and respectable were important to participants. Respectable masculine behaviours have a communal aspect, as they reflect on other family members and kin. Similar to how 'good' health citizenship was important because it reflected on adult authorities and those who had passed on, respectable masculinity was both a sign of adult manhood and relational personhood. As put by one participant **'**I don't do bad things around the community that will backfire on me at home.' (Bele, 19)

Participants spoke about respectful and respectable behaviours as defining their masculinity, and emphasised the importance of behaving in exemplary ways that reflect well on themselves and their families:

> A man should be a respected person. Like, to be seen by your work. I mean a man should be an example to other people.
> (Ta Saider, 21)

> You must know who you are and you must differentiate between wrong and right things and be present in what is happening in the community. Also take care of your home, clean it. Treat people nice, be a person that is protecting people that are close to him.
> (Nofaya, 18)

> It is to become the leader of the family… for example there are guys coming after you, like your younger brothers. You should set an example for guys coming after you.
> (Sividge, 21)

Efforts for young men to be considered respectable have also been explored and discussed in a robust literature (Bhana, de Lange and Mitchell, 2009; Msibi, 2019). For example, Rudwick and Posel (2014) posit that being respected and respectful are foundational characteristics of a dignified person in their work with Zulu men. Mchunu (2005) writes about respect and discipline in Zulu masculinity, while Msibi (2018) documents how performances that uphold respectability are vital task. Respect is important for the individual, as well as the family, to keep with a cultural script of protecting the reputation of the family from embarrassing acts (Epprecht, 2004;

Msibi, 2019). Similarly, Gibbs and colleagues (2014) found that 'traditional' respectable masculine norms such as heading a household and supporting a family were largely unavailable to young men in an urban informal settlement in KwaZulu-Natal, a finding which aligns with those presented here. Despite cultural and contextual differences between study sites, this finding is relevant here and provides context for why participant performances to certain masculine norms were so important.

In line with the assertion that respectable and respectful behaviour was a pathway to adult male personhood, many participants differentiated between men on the basis of their actions. They also defined their own (good) masculinity in relation to other (bad) masculinities, or their own former (bad) behaviours. These included using substances, crime, violence, staying out late and associating themselves with people who do these things or otherwise do not behave respectably. Participants spoke about learning about 'moral' male behaviour from elders and older boys or men during ulwaluko, as well as through their own observations.

> **Ta Saider:** There are other men you see them walking the walk, you can see he has respect and that shows he knows where he comes from… there are other men that are men by name (only)… What I mean is to be a man you need to be seen by your walk (*taken here to mean how he conducts himself*).
> …
> **Ta Saider:** There are men who are men and there are those who call themselves men.
> **Interviewer:** So what do you mean by that?
> **Ta Saider:** There are those men who you see by the way they are talking that 'this is a man'. There are those who call themselves men and you can see that he is not a man because of what he shows with his actions.
> (Ta Saider, 21)

> To be a man it doesn't mean that you must go to initiation. To become a man, it is only the way you act that can determine you.
> (Listar, 18)

> Some are the true reflections of what a men should be like and some they do housebreak-ins but they call themselves men…You can't do robberies and still be considered a man. (C'vig, 19)

As can be seen in the quotes presented above, participants perceived masculinities to be bound up in 'moral' behaviours. They used the terms 'men by name' and 'those who call themselves men' and the examples of ulwaluko and robberies to demonstrate how they believed manhood to be defined by certain types of behaviour. This demonstrates some of the complexities of masculinity within the study site, documenting the multiple ways that participants understood masculinity, and the various avenues to performing to desirable adult masculinities.

Having completed ulwaluko properly or having financial resources on their own did not constitute masculinity in the absence of respectable 'moral' behaviours, although these were also important avenues to achieving desirable masculine personhood. In this way, participants demonstrated the presence of multiple hegemonic masculine norms, some of which they determined were 'good', respectable and to be aspired to, and others which were 'bad', immoral and undesirable. The assertion that morality is essential to personhood is relevant here (Menkiti, 2004). They also suggest that norms of having successfully completed ulwaluko, being present and legitimised husbands and fathers or being financially successful are not on their own constitutive of adult masculinity.

Participants placed themselves within narratives of morality, using frames that were available to them to make the case for their own 'good' masculinity. This was done through distancing themselves from other 'bad' forms of masculinity in two ways. First, they suggested that they are different from other boys and men by focusing on their own moral behaviours and contrasting them to the 'immoral' behaviours of others. Second, they spoke about their own transformative journeys towards respectable male personhood. The quotes below demonstrate how participants framed their masculine identities by contrasting their actions to those of other men.

> I am not the same as other men… I treat myself good and I behave… even in the streets you will hear nothing about me.

(Loza, 21)

Interviewer: Are you the same as other boys?
Buja: No.
Interviewer: What's the difference?
Buja: Some boys they smoke and drink booze, I'm not that type of a boy.
Interviewer: What kind of a boy are you?
Buja: I'm that boy who doesn't like to talk a lot and I don't like to associate myself with a group of people. I like to keep my circle of friends small.
(Buja, 19)

Interviewer: Are you the same as other boys?
Nginduyi: No am not…Because they smoke and are committing crime…I stay at home.
(Nginduyi, 16)

Although masculinity was also understood to include independence, leadership and financial security (which they had not attained), participants defined themselves as 'real' boys and men through their behaviours. How they spoke about their masculinity by contrasting their moral behaviours in opposition to other men's 'immoral' ones parallels how they spoke about their HIV-positive status using their mode of HIV acquisition as a frame. Through distancing themselves from behaviours and actions that could be perceived as immoral, they differentiated themselves from certain forms of masculinity and HIV-positivity. In these ways, they situated themselves morally and respectably in frames of health citizenship and masculinity.

Participants also constructed their identities in relation to their own (previously) 'bad' behaviour. Differentiating their 'current' selves from their 'former' selves was another way that participants distanced themselves from negative and harmful masculine norms. It was common for participants to say that boys are 'naughty' and that manhood is defined by behaving in respectful and respectable ways. There was a common belief that upon completing ulwaluko that their behaviours must change to reflect what they were taught there about being a man.

> … when I was boy I was very naughty, I was also involved in heisting, stealing and hijacking but ever since I became a man I didn't live the same way as I did as a boy. My ways of doings things changed… I felt that it was not right and the only solution was to distance myself from the criminal activities and this might end up me being rejected by community and my family.
> (Bele, 19)

> My eyes started to open and see the mistakes, but as we live we are given a chance to correct our mistakes… I learned myself - even at school when I see that that a person is older but is doing stupid things, I see I should not follow in those footsteps I must do better…
> (Mr Shade, 17)

> I believe that when you are a boy, a boy knows nothing about life even though he can make some decisions, a boy does silly things because everything he does it's because of his peers. A boy is stupid. What I learned as an adult is that dignity is very important and I am very composed and relaxed. Even the guys in the community I don't spend lot of time with them - I just greet them because I am trying to avoid things, that is how a man should be.
> (Sividge, 21)

As can be seen above, participants rejected their own previous ways of being that they deemed 'bad' on their basis of the negative effect they have on others and their communities. This finding aligns with the suggestion that personhood status is acquired throughout one's life, and that people move towards personhood by developing 'moral or quasi-moral qualities' of value to others, or, at a minimum that are useful to the rejection of attitudes that are detrimental to community (Menkiti, 2004). Such performances were part of an effort to strive towards an idealised form of personhood using frames of behaviour when material means were not available.

Participant self-stated masculine identities also challenge dominant stereotypes of young, Black men as violent, hedonistic, dangerous and irresponsible. Pattman (2007) suggests that such discourses silence the life stories, and nuanced experiences and practices, of poor young Black men. Like in this study, Gibson and Lindegaard (2007) document the multiple hopes and beliefs of boys and men, dominant narratives and violent constructions and practices of masculinity. Instead, they suggest that it is important to consider masculinities as subjective, within context and through a process lens.

Representing one's identity in positive terms by contrasting it with one's previous and less 'moral' self has also been documented in adult men living with HIV. For example, Nguyen (2013) speaks about the reconstruction of an HIV-positive identity through 'confession', and Mfecane (2010) speaks about reconstruction and healing through spiritual intervention. Similarly, in a study with HIV-positive men and their male community health workers, I found that men framed themselves in a positive light by speaking about two aspects of their previous selves – as people who contracted HIV as a result of their 'unhealthy' behaviours, and as men who had upheld harmful norms of masculinity (Gittings, 2016).

This study found that participants used frames of 'morality' as redemptive mechanisms in relation to both HIV and masculinity. As discussed in the first section, they framed their acceptance of their HIV-positive status in relation to their mode of acquisition. They implied that having acquired HIV vertically as a child (and, without 'choice') was more acceptable than sexual acquisition. Similarly, despite expressing concerns over their inability to perform to masculine norms of making money, and in some cases, attending ulwaluko, they framed themselves as 'good' boys and men by nature of their actions, in contrast to immoral behaviours of other men. In emphasising that they behaved in line with communal codes of morality, they sought to reframe themselves in positive terms. In this way, participants represented themselves in ways that distanced themselves from certain 'types' of men and HIV-positive people, representing attempts at personal redemption in the face of immutable biological and (almost) immutable material realities.

Though participants differentiated themselves as 'good' boys and men through speaking about moral forms of masculinity and patienthood that they ascribed to, in practice, many participants did use substances (a few of whom requested help to deal with drug addictions), did not take their medication or go to the clinic, and were involved in violence and crime. In this way, some of their responses demonstrated a disjuncture between certain idealised moral forms of masculinity and patienthood that they ascribe to and their actions. Performing to such masculinity and health citizenship awarded them acceptance, and in the case of masculinity, power.

Ulwaluko was also another important, and contested, pathway to adult male personhood for participants. It is discussed briefly below, and is considered further in the next chapter (Chapter Five) in relation to health practices.

2.2.3: Ulwaluko as a pathway to adult male personhood

Participants had varying perspectives about ulwaluko as a pathway to masculinity, although they all felt strong pressure to undertake this rite of passage correctly in order to be legitimised as men.

Ulwaluko is an important organising factor in Xhosa masculinity (Mager, 1998; Mfecane, 2016), and about a quarter of participants spoke about ulwaluko as defining of masculinity, saying things like '… a man is a person that went to initiation.' (Sne, 19) and 'a man must go to the bush and have dignity.' (Mluthwana, 16). However, others questioned the role of ulwaluko in defining manhood.

> Some men are men because they went to the bush. But the way they think it's not the way the men should think, and also the way they behave is not the way the men should do things.
> (Khwezi, 20)

> I don't care how you look or what you have, you are just a man to me… even if you went to the hospital (for circumcision) you are a man to me.

(Layzdu, 18)

Although all participants felt strong pressure to undergo ulwaluko and to follow the rules of initiation, the unprompted assertion by some participants that ulwaluko was not the sole basis for manhood demonstrates that many participants understand masculinity to be much more complicated. As described above, they suggested that manhood is also grounded in behaviours and action. The ways that participants defined manhood demonstrated layered understandings of masculinity beyond ulwaluko. Some participants expressed their perceptions that having attended ulwaluko was not an absolute marker of masculinity outside of the ways that men behave. This complicates the assumption that ulwaluko forms an absolute and irrevocable link to legitimised masculinity.

Successfully completing ulwaluko was seen by many participants to be important because of what others would think about them. That is, it was important because it reflected on them and also their families. In the example below, X-man (22) was refused a clinic certificate to attend ulwaluko for several consecutive circumcision seasons because of his high viral load. He spoke about the pressures placed on him by his family and the associated shame he felt for not having undertaken this rite of passage:

> Even the family members are complaining about me and my medication taking… they always say to me that I'm embarrassing them "people don't say these things to you but we (the family) are the ones that are subject to that kind of talking, and it is really embarrassing".
> What is happening is that people think because I don't have (grand)parents, that my family doesn't care about me. Whenever those things happen my grandfather calls me and asks "what are you doing? you are embarrassing the family".
> (X-man, 22)

Similarly, in interviews with traditional health practitioners, they spoke about how, if adolescent boys come to them before attending ulwaluko, the focus is not on the boy and his needs, but rather on the family:

> …most of the time Gogo, young boys, when they are going to the mountain, the attention is more on family than to consult (with boys). So even if there is (we have) an intuition (that the boy needs individual attention), because the family is there, and the family is not interested in anything. There is no chance of one on one. You know, the young boys, are being depressed, they aren't given the space for themselves.
> (Mamj Ciky Vuzav)

As can be seen from the above excerpts, the function of ulwaluko is also familial and communal, which may place pressure on boys, or come up against their individual needs. It is possible that certain aspects of their well-being may get lost in the collective interest for them to complete this ritual of incorporation, although it may also offer them individual benefits as well.

The second section of this chapter has explored participants' complicated, layered and sometimes conflicting framings of masculinities, suggesting that participants enact, and hope to enact, norms of respectable adult masculinities as pathways to redemption and the creation of new futures. It has demonstrated layered and varied understandings and enactments of masculinities. These included legitimised, present fatherhood, respectful and respectable 'moral' action, financial achievement, and the successful completion of ulwaluko. Participants faced some contradictions and challenges in relation to achieving such masculinities due to poverty and their HIV-positive status. To navigate some of these challenges and compensate for shortcomings, participants leaned on frames of moral and respectable masculinity as something that was within their control.

Conclusion

For the adolescent boys and young men in this study, their HIV status and gendered identities were central themes to their biosocial lives and two avenues to redeem challenging family pasts and imagine new futures. This chapter has suggested that participants aim to heal family pasts and create better futures by performing to certain frames of HIV-positive patienthood and masculinity. As children they engaged notions of 'good' patients, and as they became older they strove to be seen as 'good' men. The tensions and convergences between these two avenues are

explored in detail in relation to ulwaluko in the next chapter (Chapter Five) and their health practices in Chapter Six.

This chapter began by providing an overview of participant life histories and suggested that their HIV-positive status is understood as part of broader misfortunes. These were also evidenced through parental death, poverty, changing homes and caregivers and absent fathers. As adolescents and young people living with HIV, participants are among the first generation to have the prospect of living long lives with HIV due to access to ART. When they were younger, they engaged performances of 'good' HIV positive personhood as a way to garner the approval of adults, redeem their parents lost to AIDS-related illness and heal family misfortunes.

As young Black men from racially and financially marginalised backgrounds, they are also growing up as 'born frees', the first generation of young people born into democracy within a former 'Bantustan homeland'. They are among the first in their families to have democratic freedoms. As they come into adulthood, they feel the pressure to realise livelihoods not available to their forebears. Although the discourse of the 'rainbow' nation of harmonious race relations and democracy espouses principles of equity and opportunities, in practice, there is a marked gap between the social and economic realities for many (Asmal and James, 2002; Walker, 2005; Visagie and Posel, 2013). This 'rainbow nation narrative' suggests that in the 'new South Africa' opportunities are available to everyone to flourish, a concept that exists in stark contrast to participants' realities and prospects. The effects of this have certain gendered contours because financial earning, provision to families and legitimised progeny are considered to be key markers of masculinity. For most participants, these were unachieved by their fathers – most of whom were absent, deceased, or living in poverty – and unable to take up the role of a legitimatised patriarch.

It is against this backdrop that participants ideated and strove towards certain respectful and respectable masculine norms. These included: (1) being 'good' fathers, defined as being present, loving and providing materially for their children within the contexts of legitimised heterosexual relationships sanctioned through marriage; (2) being financially secure and providing for their families, (3) 'moral' behaviour, and (4) successfully completing ulwaluko. These different avenues demonstrated some of the complications and contradictions of masculinities that were

present for participants. Participants struggled to be seen as respectful and respectable men within contexts characterised by poverty, broken patrilineal relationships and high unemployment rates, while appearing strong and invulnerable. The difficulties of achieving such masculinities, and ultimately, adult manhood, represents a chasm between the aspirational and achievable. Participants never overtly acknowledged the gap between their current and idealised realities but expressed their desires to close it by sharing their concerns about making money, finding work and acquiring education. These findings build on the literature on adult masculinity in South Africa, which suggests that it is important to consider multiple intersecting aspects of male identities, and poor and working class men's exclusion from the financial system (Silberschmidt, 2001; Greig, 2009; Gibbs, Sikweyiya and Jewkes, 2014; Dworkin, Fleming and Colvin, 2015; Gibbs, Vaughan and Aggleton, 2015).

To realise the promises of biomedical and democratic citizenship, participants performed to notions of 'good' patienthood as children and younger adolescents, and later, to 'good' masculinity. In these ways, they aimed to liberate themselves from the inherited burdens of the past, to redeem lost parents and failed patriarchs, and to move towards brighter futures. The promise of these possibilities clashes with the opportunities available to them, creating a myriad of pressures to achieve what is almost impossible in the face of poverty, illness and precarious physical and social environments. It is in this milieu that they must transform the 'long procession of misfortunes' from which they have come into different futures. For participants, these modes of performance hinge on their individual behaviours, but their impetus represents the hopes of the collective. To accomplish this would be an achievement for their families and lineages, and an offering to their progeny, societies and nation.

Chapter Five: "*If you are found taking medicine, you will be called names and considered less of a man*" - Engagements with HIV treatment and care during and following ulwaluko

Introduction

This chapter explores the experiences and strategies of engagement with biomedical care and treatment for HIV-positive initiates (abakhweta) undergoing traditional Xhosa initiation/circumcision (ulwaluko) in the Eastern Cape Province of South Africa. Findings demonstrate that the ulwaluko rules of not engaging with biomedical care and treatment during initiation (generally 3-6 weeks) pose a challenge for initiates living with HIV who are taking ART. Initiates' fears of inadvertent disclosure of their HIV-positive status collided with the pressure to successfully complete ulwaluko in order to be legitimised as men indoda[18] (singular) / amadoda (plural) —a traditionally circumcised person). In response to this dilemma, participants engaged a variety of strategies during ulwaluko. These strategies included taking ART in secret by hiding medication, having a trusted person deliver medication discretely, and stopping medicine-taking altogether. Initiates who successfully navigated medicine-taking during this time drew on family support and social support stemming from familial relationships with traditional caregivers (amakhankatha), private sleeping spaces (amabhoma—temporary structures that initiates live in), and in a few cases, medical advice.

New initiates (amakrwala) who are HIV-positive also face a distinct challenge in accessing biomedical care during the three months immediately following ulwaluko. From the time an initiate is circumcised until he heals and is re-integrated into his community as a man, his behaviour is under intense scrutiny, with his 'manhood character…tested and pushed to the limits' (Mfecane, 2016, p. 208). In this time of high surveillance, initiates feel unable to present at the clinic or hospital for fear of being thought to have had a botched circumcision, or to have contravened 'manhood rules' and left initiation before having healed properly. To avoid

[18] The terms indoda (singular) / amadoda (plural) and inkwenkwe (singular) / amakhwenkwe (plural) are used throughout this chapter, rather than their English translations of men and boys as a way to acknowledge the importance context and nuance of these masculine identities. Although adolescence is an important conceptual age category in the academic and policy literature, wherever possible it is used with signifiers of boyhood and manhood in isiXhosa or English in acknowledgement of the important distinctions within this study site.

complications or suspicions, most participants engaged caregiver pick-ups in order to obtain their ART.

Beyond outlining these biomedical care and treatment strategies for abakhweta living with HIV, this chapter considers the broader meanings of these findings in relation to HIV and young masculinities. The social imperatives of non-engagement with biomedical care and treatment during ulwaluko (Kepe, 2010) pose a dilemma for HIV-positive initiates, where they weigh the perceived health risks of performing to these requirements against a certain social death if they are seen to have contravened the rules of manhood.

These issues combine with other documented challenges that HIV-positive men face in conforming to hegemonic masculine norms, such as fears of stigma and being seen as sexually undesirable, barriers to engagement with clinical care, and perceptions that men living with HIV are unable to make money and have children. For Xhosa adolescent boys becoming men while living with HIV, these already-present challenges are aggravated by additional difficulties in the form of 'manhood rules' related to non-engagement with biomedical care and treatment. For abakhweta who are already feeling emasculated due to their HIV-positive status, this may be especially challenging.

At a time of elevated surveillance where abakhwetha and amakrwala (initiates and new men) are highly visible and under scrutiny, the risks of being seen taking HIV medicine or engaging in HIV care are two-fold. First, there is the risk of the inadvertent disclosure of their HIV-positive status, and second, the risk of not being legitimised as men due to breaking the rules of non-engagement with biomedical treatment and care. Thus, added to their fears of HIV-related stigma and desires to keep their HIV-positive status secret, the rules of non-engagement with biomedical products and services pose an additional challenge to their being legitimised as men. Against the backdrop of being told that uninterrupted HIV medicine-taking is crucial to their survival, participants are subject to conflicting imperatives – that of compliance to HIV treatment and care, and of compliance to the rules of manhood.

Findings also document the creativity and resilience of participants and their families in their biomedical engagements during this time, demonstrating that behind a façade of static and all-powerful masculine norms, that many attempt to, or succeed in subverting these norms through their health practices.

This chapter builds on the work of a robust scholarship demonstrating the importance of locality and context in gender and health research and intervention (Oyěwùmí, 1997; Mfecane, 2018b). It suggests that these findings are a case study for the importance of context in understanding relationships between an HIV-positive status and masculine health-related behaviours. Despite some suggested theoretical tensions between Mfecane's work on Xhosa masculinities and Connell's hegemonic masculinit(ies), this chapter employs the work of both scholars, with the understanding that the concept of hegemonic masculinities is expansive enough to include contextual masculine norms. Drawing on Connell's (1995) concept of hegemonic masculinit(ies), it suggests that the stigmatisation of being seen to have contravened biomedicine-related manhood rules represents a marginalised masculine identity. Mfecane (Mfecane, 2016, p. 208), argues that 'the circumcised body of a Xhosa speaking person is not a stable, fixed entity' and calls for further research to understand the uncertain conditions under which people can qualify as amadoda. This presentation of evidence responds to his call, and builds on his exploration of Xhosa masculine identities by using engagement with biomedical products and services during ulwaluko as a lens.

As discussed in the methods chapter, life history narrative interviews were conducted with 36 participants, 35 of whom were known to be living with HIV. Of these 36 participants, follow-up interviews were conducted with 32 using an in-depth, semi-structured questionnaire which asked questions about traditional and biomedical health service engagement, knowledge and perspectives on HIV transmission, and medicine-taking during ulwaluko. The participant who was not living with HIV was interviewed, but he did not have input about navigating ulwaluko while taking medicine. Of the thirty-one participants that inform this section, eighteen had gone through the process of ulwaluko when this research began and were thus considered either amakrwala (new men) or amadoda (traditionally circumcised people, men). An additional four were traditionally circumcised within the duration of the study, each of whom completed a pre-

and post-ulwaluko interview. We were unable to trace one participant who we conducted a pre-ulwaluko interview with to confirm if he got initiated and to hear his experience. An additional two participants planned to go to initiation but did not receive the requisite clinic approval due to HIV-related health issues (they were virally unsuppressed). Follow-up interviews were conducted with both of these participants to explore their experiences of being 'rejected from the clinic'. A total of eight participants, including these two, were uncircumcised when the study was completed.

Background: voluntary medical male circumcision and ulwaluko

Voluntary medical male circumcision is being scaled up in Eastern and Southern Africa due to documented HIV prevention benefits for men (Auvert *et al.*, 2005; Gray *et al.*, 2007; Siegfried *et al.*, 2010; WHO, 2016a). However, male circumcision is not new to some groups, and has long been traditionally practiced, including by the amaXhosa (Deacon and Thomson, 2012). An anthropological literature documents some aspects of this secretive month-long tradition, which includes both circumcision and initiation into manhood – usually at the end of teenage years (between the ages of 16 and 20). The practice of ulwaluko has also been in the public eye, including being discussed in Nelson Mandela's (1995) autobiography '*A Long Walk to Freedom*', and more recently in the controversial movie '*Inxeba (The Wound)*' (Trengove, 2017) which was temporarily banned in the Eastern Cape.

This thesis includes ulwaluko-related findings, because of the centrality of this practice to participant constructions of identity and masculinity and because of how it influenced their health practices. As discussed in the research design and methods chapter, it has also been a controversial research topic. Primary research regarding the ritual of ulwaluko has been documented to be difficult because it is taboo to discuss with women and outsiders, and contains highly sensitive and secret components (Vincent, 2008; Mavundla *et al.*, 2009; Kepe, 2010). Early writings on ulwaluko focused on descriptions of the process and its significance within Xhosa societies such as Cook (1931), Gitywa (1976), Mayer (1971), Ngxamngxa (1971) and Soga (1931). More recent media coverage and writings have focused on a 'mounting crisis' of increasing injuries and deaths of initiates, such as the work of Meintjes (1998a) and Peltzer and Kanta (2009), and the tensions arising between government and traditional leaders (Kepe, 2010).

The reported public health concerns about traditional circumcision include potential complications such as penile gangrene and sepsis, partial or complete penile loss, dehydration, septicaemia, renal failure and death (Deacon and Thomson, 2012). Long-term potential complications, although rare in South Africa, result from use of shared blades and can include Hepatitis B or C, and HIV (Deacon and Thomson, 2012). Older evidence suggests that 10-14% of all traditional circumcisions reported in the Eastern Cape had complications, and mortality rates were at 6% for initiates referred to public hospitals (Meintjes, 1998a; Deacon and Thomson, 2012). Death tolls in the Eastern Cape suggest that there are ongoing health risks with traditional circumcision (Meintjes, 1998b; *Mail and Guardian Online*, 2009). Although little research has compared complications between traditional and medical circumcision (Deacon and Thomson, 2012), it has been suggested that there are fewer complications associated with medical circumcision, possibly due to the conditions of the circumcision and aftercare (Muula *et al.*, 2007). Despite speculation about the protective effects of traditional circumcision on HIV acquisition, a recent study in Lesotho found that traditional circumcision did not have the medical benefits of voluntary medical male circumcision, nor were there differences in sexual risk activities (risk compensation) between men who had undergone traditional and medical male circumcision (Maffioli, 2017).

In response to critiques about the harmful aspects of the practice, Ntombana (2011) posits that the practice be redefined, rather than abolished, due to its significance in Xhosa societies. Research and initiatives, including by Bogopa (2007), the Eastern Cape Department of Health, and others, are suggesting ways to better understand and address the harms of the practice, while focusing on its potential benefits. Ulwaluko also serves an educational function (Deacon and Thomson, 2012; Hodes and Gittings, 2019). While recognising the potential risks and benefits of this practice, this chapter does not place any judgments on the process itself, but rather aims to share the medicine-taking experiences of abakhweta living with HIV. Such findings may be of interest to decision-makers and programmers concerned with their well-being, including traditional leaders, policymakers and governmental and non-governmental organisations.

This thesis acknowledges the ethical and methodological sensitivities of writing about this highly sensitive and secretive practice. The research design and methods chapter discusses some of these nuances and the ways that they were navigated.

Findings and discussion

Bats and biomedicine: Caught between manhood rules and HIV-related stigma

It was general knowledge amongst study participants that engagement with biomedical products and services during ulwaluko is considered to be a contravention of the norms and rules governing the process (Kepe, 2010). Underlying this belief was the idea that taking biomedicine would be seen to interrupt 'natural' healing or minimise pain and would render the process improperly completed and in contravention of the rules of manhood. The challenges faced by initiates who end up engaging in biomedical care due to infections or challenges with the circumcision process have been intimately explored in Mgqolozana's (2009) novel '*A Man Who is Not a Man'*. The protagonist ends up in the hospital and narrates his experience with the nurse:

> …the cowards among them have chickened out; 'them' being us, of course, the supposed initiates. She was openly insulting us for having landed up at the hospital—we cowards! She was bringing home the disgrace of our being survived by our empty huts at the mountain and impressing on us our invalidity—the manhood rejects that we had become by fleeing to the hospital and the sub-human status that we were about to assume in society as a result. Her reaction might seem extreme, but it was typical of the mockery and censure that we could expect to encounter outside…

This excerpt represents the highly stigmatised nature of being seen to engage with biomedical care or treatment during ulwaluko. Though different from being seen to be taking HIV medicine, this passage serves to illustrate the severity of not following the biomedical engagement rules of ulwaluko.

The three-month period following initiation also represented a challenge for amakrwala living with HIV. During this time, amakrwala wear formal men's clothes (a cap, blazer, trousers and formal shoes) and are highly visible. This period is characterised by intense scrutiny and testing

by other men to verify if they have learned the rules of manhood and are following them properly.

It is considered inappropriate to be seen at the clinic within this phase, and the underlying assumption is that amakwrala would only be accessing biomedical care if their circumcision was botched or they left initiation before having healed properly, a contravention of manhood rules. Some participants also asserted that being seen in the clinic may signal they have an affinity to biomedicine, which would raise questions about if they engaged with biomedical treatment during ulwaluko. These dynamics will be explored later in this chapter.

In these two aforementioned situations—taking HIV medicine during ulwaluko, and clinic attendance in the three months following—participants were deterred from engaging with biomedical care and treatment out of fear. They were afraid of jeopardizing their identities as men and being marginalised by the nature of being seen to have not completed ulwaluko and not followed the rules of manhood properly. Not following the rules properly would risk being said to 'have flown' (isiXhosa—ukubhabha—to fly).

> **Interviewer:** So when you were ikrwala how did you do (get medication)? Did you go to the clinic by yourself?
> **Layzdu:** I sent someone.
> **Interviewer:** Why did you send someone?
> **Layzdu:** Ikrwala is not allowed to go to hospital or clinic because he will fly. (Sinebhongo's – the interviewer – explanation: 'to fly, it is when they call you names saying you did not finish what you went there for' i.e. you left without having healed fully.)
> (Layzdu, 18)

> **Interviewer:** So when you were ikwrala did you go and collect your medication at the clinic?
> **Ndofaya:** No, it was my mother who was collecting them for me she was around at that time.

…

Interviewer: Do you know that call a kwrala who goes to the clinic?

Ndofaya: Yes, they say he will fly.

Interviewer: What advice would you give to amakwrala that are taking medication?

Ndofaya: I don't want to lie or mislead them—a kwrala does not go to the clinic. We can never dismiss something that was done or said by our elders.

(Ndofaya, 18)

Being said to 'have flown' is synonymous with being called a bat (isiXhosa—ilulwane). A bat is considered to be part rodent and part bird, and is used as a metaphor for something incomplete, or 'in-between'—neither one thing, nor another. Applied to this situation, a person who does not follow the manhood process and rules correctly, such as leaving initiation with an unhealed circumcision, or taking biomedicine during initiation, is said to 'have flown' as a bat does. An additional meaning suggested by informants is that bats are blind and fly at night, a contravention of the rules of manhood where new initiates must not be seen outside or speak isiDoda ('manhood language') after dark. Being said to have 'flown'—that is, to have contravened the norms of manhood—is to have cast oneself into a liminal social state, that of a man who is not fully a man on the basis of his actions. He is not indoda, for he did not correctly complete the manhood process, despite bearing the mark of being circumcised traditionally and having received the teachings of ulwaluko. In the same way, he is not inkwenkwe, for he has been circumcised traditionally and received the teachings of manhood. As put by one researcher, he is a 'plastic man', that is, someone who might appear to be a 'real man', but who has not demonstrated that he has what it takes (in other words, 'a fake'). Researchers spoke about how people given this label will be teased, and have their pockets pulled inside out to represent bat wings. As explained by one researcher, such a spoiled masculine identity is not easily forgotten, and will be carried throughout one's life: 'Once you are a bat, you are always a bat. We (will) tell you even when you are a grandfather that you are a bat. Remember that.' (Phakamani).

Mfecane (2016) states that amadoda who act in a way contrary to their manly status do not lose their status as men. He argues that manhood status and honour masculinity is grounded in the physical body by nature of having been circumcised traditionally. For study participants who are

abakhwetha and amakrwala and weighing up whether to engage in HIV biomedical care and treatment, they are in the process of becoming amadoda, but have yet to be recognized as full men. During this time they feared being cast into a spoiled masculine identity of ilulwane, a person who is not one thing or another, not a boy nor a man. Although ilulwane have been circumcised traditionally, they are subject to marginalised masculine identities. Ilulwane represented a masculine identity so feared and stigmatised by study participants that it drove them to drastically change their patterns of engagement with biomedical care and treatment. Many participants made sense of their disengagement from HIV treatment and care by explaining that they were taking health risks in exchange for being acknowledged as indoda. Although their traditional circumcision is grounded in their physical bodies, they are terrified to act in a way that will cast them as ilulwane. This transition period, and the possibility of becoming ilulwane, are time-related and situational nuances to the indoda/inkwenkwe binary. Importantly, participants were not concerned about the act of engaging with biomedical care and treatment itself, but rather that they would be seen as doing so by people who might say things about them. They did not have the same concerns with people who they trusted, such as family members and family friends, as well as in some cases, their traditional caregivers (amakhankatha). Such relationships often represented sites of support and quiet subversion to the rules of manhood, which in this case could be understood as hegemonic masculine norms.

For abakhwetha and amkrwala living with HIV, the fear of being known to contravene manhood rules and face the above-described mockery and 'sub-human status' converges with HIV-related stigma, which has been said to affect men and women differently (Beck, 2004; Colvin, Robins and Leavens, 2010; Wyrod, 2011). Compared to women living with HIV, men living with HIV report more internalised AIDS stigma; are more likely to have lost a job or a place to stay; are less likely to discuss their HIV-status with their friends; and are more likely to report being treated differently once they are known to be HIV-positive (Simbayi *et al.*, 2007). They also are more likely to use alcohol and drugs to cope with depression and report less social support than women (Simbayi *et al.*, 2007). Conventional views of male identity fear of shame, secondary stigma and isolation from loved ones may also make acceptance and disclosure of an HIV-positive status different for men and women (Iwelunmor, Sofolahan-Oladeinde and Airhihenbuwa, 2015). Being HIV-positive can also be seen as an obstacle to conforming to

hegemonic masculine norms because it is considered to be a barrier to having intimate relationships, to having children and making money (Mfecane, 2008; Wyrod, 2011).

For this reason, participants in this study were unwilling to disclose their HIV status as their reason for engagement with biomedical care and treatment. Such a disclosure might distance them from the stigma of biomedical engagement during ulwaluko, since their ART would be seen as separate to biomedicine use for pain relief and healing. If their fellow initiates knew they were HIV-positive, their medicine-taking would be less likely to be an issue because the purpose of the medicine would be known. However, they would instead face HIV-related stigma, which could also undermine their masculine social identities. Participants thus simultaneously avoided the stigma of living with HIV and the stigma of being seen to contravene the norms of manhood. This avoidance took the form of hiding their engagements with biomedical care and treatment during and after ulwaluko, or disengaging completely during this time. Only one participant took his HIV-medicine openly during ulwaluko. Perhaps unsurprisingly, he was also the only participant in the sample who had disclosed his HIV status. A body of work has suggested a positive relationship between disclosure of an HIV-positive status and adherence to ART, with the underlying belief that sharing secrets and 'confession' can lead to new forms of selfhood and healing (Nguyen, 2013). This lens could be applied to understand how boys who have not disclosed their HIV status face additional challenges related to medicine-taking during ulwaluko.

Having provided an overview, the next two findings sections now explore in-depth participant experiences and strategies of (dis)engagement with HIV medicine-taking during ulwaluko, and health facility attendance in the three months following.

Stress, strategies and disengagement from care – HIV medicine-taking during ulwaluko

As discussed above, participants were acutely aware that taking medication and engaging in biomedical care during initiation was considered a contravention of the rules of ulwaluko.

> …it is an initiation school so when you carry aspirin or something else they say that you are going to be something (e.g. less of man)…So I run away from that…
> (Ta Saider, 21)

> You know, if you are found taking medicine, you will be called names and considered less of a man.
> (Jenevo, 17)

Wedged between two different types of stigma—that of a sullied masculine identity due to engagement with biomedicine during ulwaluko, and that of a stigmatised identity as a young man living with HIV—participants felt forced to make decisions about HIV medicine. Caught between avoidance of these different stigmas, all participants but one decided to make it appear that they were not taking medication either by taking their treatment in secret (12), or ceasing medicine-taking altogether (10).

Most narratives of participants who took HIV medicine during ulwaluko described that they found the experience to be challenging as they navigated the stress of taking their medication in secret, alongside the feeling that they needed to take their medication 'properly'. The interview below demonstrates a participant's feelings of unease and internal conflict over wanting to both take his medication 'properly', while also wanting to be seen to be following the rules of initiation correctly so as to avoid assuming a stigmatised masculine identity.

> **Interviewer:** Can you explain how were you feeling when it comes to that, while you were there and you had to take your medication?
> **Ta Saider:** I was so stressed, I was so stressed. The thing that made me stressed, on one side I was focusing on the treatment, and on the other side I was focusing on my initiation school, but I found a way to manage. I was so stressed, because I was looking for the initiation, at the same time on the other side I was taking treatment, but I managed to arrange to do all of that at the same time.
> (Ta Saider, 21)

The following interview transcript demonstrates a participant's efforts to distance himself from biomedicine-taking when it was accidentally revealed to his fellow initiates. Implicit in this

narrative is the fear of being associated with biomedicine, alongside a guarding of his HIV-positive status.

> **Interviewer:** If you take any medications, was it difficult to take them during initiation?
> **Sakhiman:** The first [day that] all my older brothers were working… they left [the initiation school] due to the fact that they had to work. So they gave my ikhankatha (traditional caregiver) my medication and he was drunk that day and he gave them to another guy that was also an ikhankatha… When they arrived, I was with my fellow initiates... He just threw the pills to me and told me - 'here are your pills don't die here'.
> **Interviewer:** Just like that?
> **Sakhiman:** Just like that and I was so angry. When he left I burned those pills in front of my fellow initiates because I was going to be in trouble—people would talk and say I was taking pills that they did not know what they were for. So I did not take my medication at the bush just because of that.
> (Sakhiman, 20)

The accounts of these two participants demonstrate the pressure that they felt to not be seen to be associated with biomedicine during ulwaluko. The reasons for not wanting to be seen with their medication were two-fold. First, there was the aforementioned fear of being seen to be taking biomedicine, and its association with contravening the rules of manhood which would place them within life-long marginalised masculine identities. Second, they were unwilling to disclose why they were taking biomedicine—that is, they did not want to disclose their HIV-positive status for fear of being stigmatised.

The strategies participants used to take their medications varied. They included having trusted people, including male family members, amakhankatha and amanqalathi bring medication to them discreetly. In this way, many participants and those close to them worked together to quietly subvert masculine norms that would interrupt their health practices. In one case, a participant walked home from the initiation school unseen in the dark, and was met by his father in the kraal to give him his medication.

The below narratives demonstrate some of the experiences of participants who had medication brought to them. They demonstrate the difficulty of taking medicine in secret and the potential risks of being seen.

Interviewer: If you were taking any medication did you take it at initiation, and was it difficult?
Ta Saider: It was difficult because traditionally if you are seen taking any form of medication you will not be regarded as men so that was difficult because I was hiding it so that people don't see or know about it.
Interviewer: How were you hiding it?
Ta Saider: When the medication was coming I was hiding it so that no person will know about it. It was my secret.
Interviewer: Who was bringing the treatment?
Ta Saider: It was my ikhankatha.
…
Interviewer: So you explained to him the situation?
Ta Saider: Yes.
Interviewer: So he also did not tell anyone?
Ta Saider: No, it was our secret.
(Ta Saider, 21)

Interviewer: Did you take your medication during initiation?
Machete: Yes.
Interviewer: Was it difficult to take them?
Machete: Yes, it was very difficult.
Interviewer: What made it difficult, how did you take them?
Machete: My aunt went to the clinic for me then she gave them to my inqalathi (person who carried food to initiates), there were times where I did not take them because when I was with my fellow initiates. If they should see me taking the pills it would be another thing.
Interviewer: So other initiates did not know?

Machete: No it was my cousin only, the one that I went to initiation with.
(Machete, 22)

Four participants kept their medication with them at initiation, and kept them hidden in their amabhoma (a temporary structure where they slept during the time of initiation). The below interview demonstrates this form of strategy:

Interviewer: When you were in initiation you took your medication?
Bele: Yes I did.
Interviewer: How?
…
Bele: They were hidden in something like a toiletry bag so that no one would see them.
Interviewer: Who knew that you were taking medication at initiation?
Bele: It was my family and my ikhankatha.
…
Interviewer: How did you feel about the difficulties that you came across on your medicine taking during initiation?
Bele: It was really hard and that stressed me in those days.
(Bele, 19)

Not all participants said that HIV-medicine taking was a challenge during ulwaluko. A few shared their experiences of relative ease in medicine-taking. Common aspects in these narratives included participants having made a detailed plan in advance, and/or had strong social support in the form of their male family members and amakhankatha. Participants who had their own ibhoma also found it easier, as they had moments of privacy for pill-taking. Interview excerpts documenting these strategies are included below:

Layzdu: To me it was easy because I was alone in my ibhoma and it was big and I wanted no one in my ibhoma.
Interviewer: So no one saw you taking your treatment until you came back from initiation?

Layzdu: Yes no one saw me ‘til I came back.

…

Interviewer: How did your medication get to your ibhoma?

Layzdu: They came with me.

Interviewer: With you how?

Layzdu: I was there when my ibhoma was built and I hid them in a grass.

Interviewer: With whom did you build your ibhoma?

Layzdu: Me and my older brother.

…

Interviewer: So you never stopped taking your medication?

Layzdu: I never stopped.

(Layzdu, 18)

C’Vig: I took my medication there my caregiver knew about that

Interviewer: Who was your caregiver?

C’Vig: It was someone from the family.

Interviewer: Was it difficult to take your medication?

C’Vig: It was not difficult.

Interviewer: How did you take them?

C’Vig: There were not many people that visited us so that made it easy for me to take them.

…

Interviewer: Did your fellow initiates knew about this?

C’Vig: No.

Interviewer: What about your inqalathi?

C’Vig: He knew about it.

Interviewer: Who was you inqalathi?

C’Vig: It was someone from my family.

Interviewer: How did they reach you?

C’Vig: He used to fetch them from me… They were mixed with my food… they were squashed and turned into powder.

Interviewer: Who knew about that?
C'Vig: It was only my family.
Interviewer: Who told you to take your medication during initiation?
C'Vig: At home they understood.
Interviewer: Does that means you knew about that before you went to initiation?
C'Vig: Yes.
(C'Vig, 19)

The other ten participants reported not taking their HIV medicine during ulwaluko. Of these, four were told by their health providers that they could take a month break from treatment. All of these participants attended a large public hospital that has a circumcision clinic and first had blood tests taken to ascertain if it would be safe for them to go off their medication. The transcripts below reflect participant experiences with this.

Interviewer: What did you do to prepare before going to initiation?
Svij: I went to the clinic to check my CD4 count… they saw that everything was good. (They said) I can go there and that it would only be one month that I would be defaulting...
Interviewer: Did you have the initiation certificate?
Svij: Yes I did have it.
…
Interviewer: Did you take your treatment while you were at the bush?
Svij: No I was told not to take it at the hospital.
(Svij, 25)

Lullo: I started at the clinic where I was told that they will give me a gap of 1 month that I will be spending in the bush, so I was given that gap not to take medication. Then I was given the certificate.
…
Interviewer: If you were taking any medication at the bush was it difficult?

> **Lullo:** They don't allow you to take treatment because they will say you are using the pills for the initiation so they don't allow any kind of pills.
> (Lullo, 22)

Participants who received biomedical advice to stop medicine-taking for their time at initiation school did not face the same challenges as participants who took their medication secretly, or those who stopped altogether. Feeling certain that they would not face health challenges as a result of such a 'treatment holiday' freed them from the opposing imperatives complying with medicine-taking and manhood rules simultaneously. Such treatment interruptions may be met with resistance by some biomedical practitioners, because they would interrupt the dominant narrative that uninterrupted HIV-medicine taking is crucial for survival. The below interview with the nurse manager of an ART unit at a public hospital demonstrates this:

> **Interviewer:** Would you ever consider telling someone to stop (HIV) treatment for one month?
> **Sister Nceba:** No, because we are talking about adherence with treatment. Adherence and treatment is for life. So we emphasise that you cannot stop your treatment, instead we find ways of taking it. For example, what time is it convenient?
> **Interviewer:** So they must make it work with their lives?
> **Sister Nceba:** Ayiyi! They must not stop.
> (Sister Nceba)

Those who subscribe to the above narrative may be concerned that providing a 'treatment holiday' might cause long-term behavioural changes. However, in this study all of the participants who stopped medicine-taking for the duration of ulwaluko at the advice of a healthcare worker resumed afterwards. They said that it was not difficult to re-start on their ART, with the exception of one participant who said it took him some time to get back to his routine. Despite being a sample of only four participants, this suggests that such a treatment holiday for young people who already demonstrate strong adherence patterns may be unlikely to become enacted as a long-term process of defaulting and disengagement from care. It is possible that this is because the participants who received the advice to stop medicine-taking were virally

suppressed due to their strong adherence, and therefore at low risk of long-term disengagement from HIV medicine and care. It is also possible that this experience was one of a positive engagement with biomedical care that helped sustain further visits because practitioners ensured that their patient needs were met.

Rather than encouraging medicine-taking for participants who are virally suppressed, the approach of encouraging 'treatment holidays' seemed to work well for the participants who received this advice. Additionally, the mandatory pre-ulwaluko engagement with biomedical care may present an opportunity in a similar way that pregnancy is approached for girls and women. It could be further leveraged as a way to engage with an adolescent boy/young man who might not otherwise be presenting at the clinic as a way to refer to services, offer tests create a positive experience of biomedical care.

The remaining six participants did not receive a 'treatment holiday' from healthcare workers but did not take their medication due to social pressures 'Because if I could get caught taking medication I would be called names so I did not want that.' (Jenova, 17). This displays a lack of uniformity in healthcare worker approaches to HIV medicine-taking during initiation. The reason for ceasing medicine-taking was consistently the aforementioned fear of being stigmatised in their masculinity.

The following transcripts reflect participant experiences of ceasing medicine-taking without the guidance of healthcare workers. They demonstrate how they felt that they had to choose between adhering to HIV medicine, and adhering to the rules of ulwaluko and described their fears of not knowing what would happen to their bodies if they stopped taking medication. Underlying these narratives was also a sense of guilt that they were doing something wrong by disengaging in care, and a fear that they might get in trouble from healthcare workers upon returning. Similarly, Bernays and colleagues (2017) document guilt, fearing healthcare worker reprimand, and hurting relationships with biomedical providers due to non-adherence to ART.

Interviewer: During initiation did you take your medication?

Akhona: No… but when I was at initiation I was worried about getting sick while I was there because I wasn't taking my medication.
(Akhona, 19)

Interviewer: What was your experience like at initiation?
Sividge: Ok, when I went to initiation I went there knowing my status. In fact, I knew my status in January 2012. I told myself in 2013 that '*I want to go to initiation'* so I took my treatment for the whole of 2012 and 2013. When I was at initiation I broke the rules—in fact I did not break them, I bent them because I did not take my treatment for the whole process when I was at initiation - because you know what happens there. So, I thought '*no I am good and my CD4 count is high.'*
Interviewer: Did you enjoy it there?
Sividge: I enjoyed it there. What I was scared of is that I grew up, since I said to you I knew about my status since 2012. In 1996 I was born with HIV, so I grew up with my parents telling me that I had umlambo (a skin condition). So when I went to initiation I was scared that I will take time to heal since when I have sores they take time to heal. But after I took treatment from 2012 and my body soldiers were good then I stopped experiencing that. But before 2012 my sores were taking about 3 to 4 weeks to heal, but (at initiation) I recovered because I was the first to heal from the initiates that were there.
(Sividge, 21)

In the above transcript, the participant spoke about his decision to stop taking his ART, referring to it as 'bending the rules'. He used the two years pre-ulwaluko as a motivator to take his ART regularly and strengthen his immune system in preparation for his month-long break from his medication. The below participant also deviated from his prescribed medicine-taking. He speaks about how he rationalised temporarily stopping his medicine, and describes his decision as 'not caring about his health' during initiation:

Interviewer: How did you take care of your health at the bush?
Movite: I did not care about it.
Interviewer: What do you mean by that?

Movite: Because I did not take my pills, my pills were here and I was at the bush.
Interviewer: So you did not take you treatment there?
Movite: No I did not.
(Movite, 18)

Relevant here is how participant's HIV-positive status and related embodied biomedical experiences and needs throughout their life courses shape their experiences, behaviours and health practices during ulwaluko. In speaking about the process of ulwaluko, Mfecane (2016, p.208) explores this concept, positing that 'from the moment a person is circumcised, he enters a liminal stage characterised by uncertainty about his future as a man'. Similarly, for the participants in this study, they faced another layer of uncertainty and concern over their bodies in this process. For them, their HIV-positive status, given their perceived imperative to take biomedicine might cause them physical health issues during initiation. This can be seen in the above narratives of fear of the results of *'bending the rules'* and *'not taking care of health'*.

The below transcript demonstrates an uncircumcised participant's frustration of the challenge his HIV status poses to his body and how it limits his ability to attend ulwaluko

Interviewer: When are you going to initiation?
Sne: 16th December.
Interviewer: So how do you feel about that?
Sne: I am happy but at the same time I'm scared.
Interviewer: Can you explain?
Sne: Because I don't know what will happen, so that's why I am feeling that way.
Interviewer: So for preparations what will you do? Did you go to the clinic?
Sne: Yes I did go to the clinic to get tested and I also requested the certificate for initiation.
…
Interviewer: At the clinic did they say you are ready to go?
Sne: They told me that if I want to go I must take my treatment and wait for the next December, and I don't want to wait for the next December. (If I go this December) I must

expect that anything can happen.

Interviewer: When they say you must expect anything, what do they mean?

Sne: Since I have stopped taking my treatment. Maybe they saw when they tested (my blood) that I am not (taking treatment).

Interviewer: And how do you feel about that?

Sne: It hurts me because I just want to be okay so that I can do my things properly.

Interviewer: When you say okay, do you mean going to initiation?

Sne: Yes, because most of things I can't do because I am a boy.

Interviewer: And the others the same age as you?

Sne: They went to the bush long time ago.

…

Interviewer: So what have you decided?

Sne: I decided to go this December I will see when I am there, whatever happens (I will accept it) as the nurses already said I must.

…

Interviewer: So preparations are underway?

Sne: Yes.

Interviewer: So the only thing left is for you to go there?

Sne: Yes its only me...

(Sne, 19)

In this narrative, the participant speaks of his decision to go to initiation, against medical advice due to his poor immune health. He describes feeling frustrated that he does not have the same privileges as males in his peer group who have already been circumcised. This frustration and pressure has resulted in him deciding to undergo ulwaluko despite being told by healthcare workers that 'anything can happen' if he goes before he is healthier. He describes the fear and hurt this causes him, but has resolved to take the risk anyways.

Another participant was also told by the clinic that they would not give him a certificate to go to initiation because his CD4 count was too low. Since 2013, he had attempted to get clinic permission to attend initiation in both the December and June seasons, and consistently did not

received sign-off due to their concerns about his immune health. In a series of interviews before and after his rejection for the December 2017 season, he narrated feelings of frustration, familial and social ostracisation and self-blame over substance abuse issues and ART non-adherence. His self-blame (alongside the blame of his family and the clinic) is based on the understanding that his body would not have a compromised immune system if he took his medication rather than drinking and partying. He narrates feelings of conflict over both wanting to party and celebrate, and the stress of not being able to attend initiation if he doesn't take his medication. This participant disclosed multiple substance abuse issues, including drinking alcohol, that have affected his HIV medicine-taking.

Interviewer: What did you do to prepare yourself before going to initiation?
X-man: I did go to the clinic.
Interviewer: When?
X-man: Today.
Interviewer: Did you get your clinic certificate?
X-man: No.
Interviewer: Why?
X-man: It is because I've been doing things that I was not supposed to do. It was the (time of) pre-initiation ceremonies, so I mixed up things that don't go together (booze and medication). I went to the clinic for the check-up and the nurses were angry and they told me that they will report me and by 7 pm I should be at home. They told me that they will make plans to do another check-up and the results will come back in a day or two and that will determine if I am going to initiation or not, so everything it's up to me (taking his medication)… I was supposed to go to initiation next week, but when I came back to the clinic they were very angry at me because they warned me about attending these pre-initiation ceremonies and drinking that booze. When they talk to me I hear them - but on the other side the happiness in the street is calling me. But now I've told myself to calm down.
Interviewer: Do you understand the stress you might have if they could reject you again in the clinic?
X-man: Yoooooh…..that is why I told myself to stop and from now on they will see me

all the time at home and they won't be complaining anymore because I understand what they are complaining about.
(X-man, 22)

To better understand this participant's situation, we interviewed his healthcare worker, the nurse in charge of the paediatric and adolescent HIV programme at his clinic. She narrated the challenges he faces and the reasons why she has not granted him permission to go to initiation.

Interviewer: What about X-man**?*
Sister Funeka: (Sighs) X-man doesn't have parents, he is staying with aunt and uncle, it is him and his sister. They both defaulted ARVs… When he is sick he comes to the clinic for medication, when he is better, he stops taking it. We did hear that he is smoking dagga (marijuana). He also wants to go to circumcision school, but we refused several times because his viral load is very high. We said to him '*let's wait up until the viral load is suppressed*'.
Interviewer: Will you only approve if they are completely suppressed?
Sister Funeka: I don't want to be in a tight corner when the child dies out there. I want to sign something, I am releasing him when he does well on treatment and viral load is suppressed.
(Sister Funeka**)**

Evident in this narrative is his healthcare worker's awareness of his living situation and the issues affecting him and his adherence. She is worried about his wellbeing, and for this reason will only sign off on his attendance once he adheres to his treatment and achieves viral suppression. Her frustration over his adherence could be felt strongly and was evident in both the interview with her, and with the participant.

After being 'rejected by the clinic' yet again, X-man narrates the social consequences of his continued status as inkwenkwe and being in a subordinate position to his peers. He also faces familial consequences, as his family does not want to be perceived as neglecting him or being

unable to afford the costs associated with ulwaluko. He speaks about his desire to get initiated as a motivator for adhering to his medication.

> **Interviewer:** How did you feel about not going to initiation?
> **X-man:** I was so stressed big time…Even on this month I'm going to the clinic so that they can take my blood again, in these days whatever I'm doing, it stops. When it is that time to take my medication I just go home and take my pills… this time around I'm going to do everything straight because even these young boys are going to initiation before me and I have to say *"Bhuti*" (isiXhosa – brother) to them…my grandparents…are monitoring me, and even the family members are complaining about me and my medication taking. Also they always tell me they want to leave me at least as a man because no one will ever take care of me after they die.
> **Interviewer:** When are going to initiation now?
> **X-man:** June.
> **Interviewer:** How do people in your village say?
> **X-man:** At my grandparents' house that is what they always say to me, that I'm embarrassing them "*people don't say these things to you but we are the ones that receives those kinds of talking and it is really embarrassing*". What is happening is that people think because I don't have parents that my family doesn't care about me. Whenever those things happen my grandfather call me and asks "*what are you doing? you are embarrassing the family*". He asks what is my problem because they do everything for me. I can say I am the one who has problems because I don't want to take my pills. If I do, I don't even wait an hour after taking my medication—if there is booze I go and drink. I don't even wait for those hours they say we must wait and when I drink booze after taking the medication I always vomit. I say to myself what I'm doing is wrong. (X-man, 22 - Follow-up interview after he is rejected from the clinic to attend ulwaluko)

In this rich interview, the participant describes the multiple, intersecting challenges of substance abuse, getting distracted from taking his medication, familial and healthcare worker pressure to take his medication, and family and social pressure to 'become a man' so as not to be an embarrassment. He demonstrated some of the conflicting pressures and challenges he faces

coming of age living with HIV. The below text demonstrates how he responds to the healthcare worker 'comply or die' narrative by saying he will take his medicine, while not intending to do so.

> **Interviewer:** If at the clinic they allow you to be initiated but on one condition which is to take your medication while you are there, will you take them?
> **X-man:** I will say yes and they already told me that.
> **Interviewer:** How will you take them?
> **X-man:** I say yes to them but I know I will never do that……I will never, I don't want those things near me (pills). I would never—people from this place will call me all sorts of names and I will take the treatment if they give me, but I will leave it at home then take it when I come back. I know what I'm protecting myself from so I won't take them at all.
> (X-man, 22)

We also spoke to other participants who had not been initiated. Two others had faced 'rejection' at the clinic multiple times. All three of these participants were open about planning not to take their medication during ulwaluko and were already taking ART irregularly, or not at all. Of the participants who had been rejected multiple times from attending, it is possible that they were already less likely to take their HIV medicine due to a variety of factors ranging from non-acceptance and shame to substance abuse and other social issues. The adherence limiting and supporting factors have been mapped out in a body of literature, as discussed in the literature review chapter.

The other six uncircumcised participants responded that they were planning to take their medication, or they were uncertain what they would do. Despite this, all participants were steadfast in their resolve to undergo ulwaluko and were aware that it was highly stigmatised to take biomedical treatment and care during that time. Of the participants that planned to take their medication, one was not sure how, one said he would ask his inqalathi to bring them, and the other said he would ask someone else, but he wasn't sure whom. The other three participants said that they planned to seek the advice of healthcare workers in deciding what to do:

Interviewer: If you are taking any medication will you continue taking it?
Mr Shade: That is why I want to go to the clinic.
Interviewer: What do you want at the clinic?
Mr Shade: I want them to explain about taking medication and the nurse at the clinic said they will try something for the period that I will be at initiation.
Interviewer: How will they try, will they say stop taking medication or you will continue taking it during initiation?
Mr Shade: Yes they said I will continue taking it but I am not sure I will hear when I am at the clinic.
(Mr Shade, 17)

Interviewer: So will you take your medication during initiation?
Listar: I wouldn't say so because that's the other thing that I will have to ask about it at the clinic… I have not thought about that yet I still have to think about it and also ask about it because they say we need to take them.
(Listar, 18)

Similar to the variety of strategies reported by already initiated participants, those who had yet to go had planned different strategies for medicine-taking. These followed the same categories—not taking medication, and taking it in secret by hiding it, or having trusted older men bring the medication to them discreetly.

'They say amakrwala should not go to the clinic'

It was not just the four-week period of ulwaluko where participants struggled with (dis)engagement from HIV treatment and care. The three months following ulwaluko, where amakrwala are highly visible, was also a time of disengagement in care. This next section details participant experiences and strategies of navigating HIV treatment and care as amakrwala.

As mentioned earlier, amakrwala do not present at the health facility in the three months following ulwaluko. This was a rule of which all participants were aware. The underlying belief is that amakrwala would only be going to the health facility if their circumcision had been

botched or they had left initiation before it had healed properly, a contravention of manhood rules. This was confirmed by the ART unit manager of a public hospital in the Eastern Cape:

> 'I never saw them in krwala attire… when the family members come to take treatment for them, we let them, we don't query. I've never seen them, a krwala. We allow that if the prescription is still valid.'
> (Sister Nceba)

In response to their fear of being seen at the health facility as amakrwala in the three months following initiation, the majority of participants who continued to take their medication after initiation asked caregivers to pick up medication. Thirteen of the twenty-two initiated participants reported engaging caregiver pick-ups, and one had the clinic drop his medication off at his home. In the excerpts below, participants explained why they didn't go to the health facility as amakrwala.

> **Interviewer:** Did the way you take your medication change after initiation?
> **Mayor:** Yes it did because when I was ikrwala I didn't go to the hospital to fetch my medication.
> **Interviewer:** Why?
> **Mayor:** Ikrwala doesn't go to the hospital/clinic.
> **Interviewer:** Who was doing the medication pick up then?
> **Mayor:** It was my mother.
> **Interviewer:** For how long?
> **Mayor:** It was for a long time up until I changed my ikrwala clothes.
> (Mayor, 16)

> **Interviewer:** After initiation did you take your medication by yourself?
> **Khwezi:** No, because ikrwala can't go to the clinic/hospital.
> **Interviewer:** Who took the medication for you?
> **Khwezi:** It was my big sister.

Interviewer: Who told you that amakrwala doesn't go to the clinic/hospital?
Khwezi: Everyone from the community knows that.
(Khwezi, 20)

Interviewer: Did you pick them up yourself?
Ngamla: No my aunt did, amakrwala cannot go to the clinic because people will talk.
(Ngamla, 21)

Participants who had yet to go to initiation also said that they would not go to the clinic afterwards, because 'ikwrala does not go to the clinic'(Listar, 18). The impassioned quotes below demonstrate that uncircumcised adolescent boys living with HIV already possess a strong awareness of these social norms and that they are thinking about how they will access HIV medicine post-initiation.

Interviewer: Will you pick them up yourself after?
Zube: I will ask someone until I change my ikrwala clothes.
Interviewer: Why?
Zube: Yoh hey, a krwala in the clinic? No! No! No! I don't see that happening.
Interviewer: You never saw ikrwala at the clinic?
Zube: Never, they will say I'm not healed that is why I'm going to the clinic.
Interviewer: Who will you ask for your medicine pick up?
Zube: It is my father. Even my medication, he is the one that will be taking it into the bush.
(Zube, 17)

Interviewer: After circumcision, will you pick up your medication by yourself?
Ringo: Eish!!!I don't think I will go there by myself maybe I will hire someone to take them for me.
Interviewer: Why?
Ringo: Because I'm a very shy person.
Interviewer: What makes you shy?

Ringo: It is because some people will gossip about seeing an ikrwala to the clinic, they will ask themselves some question like "I wonder what is he doing in the clinic"?' (Ringo, 17)

Of the twenty-two interviews conducted with participants who had been circumcised, only four picked up their medication themselves. Of these, one recounted going to the clinic to pick up his medication for the first time after coming back from initiation. He was intercepted on the way back by a group of men who advised him that it was inappropriate for him to be at the clinic as ikrwala. Following this, he asked a caregiver to pick up his medication. Of the other three that picked-up their own medication, two explained that they felt stressed going to the clinic but didn't see an alternative—'I was scared but I had no choice but to go.'(Movite, 18)

Interviewer: After initiation did you go by yourself to pick up medication?
Dee: I picked up my medication by myself.
Interviewer: Didn't other men's complain about that?
Dee: They did complain about that.
Interviewer: What did you say to them?
Dee: I would tell them that I'm not going to the clinic for the reason you are thinking about.
Interviewer: What did they say?
Dee: They would joke to me in isiDoda (manhood language).
(Dee, 19)

Only one participant did not have a problem with medication pick-ups. He was also the only participant who took HIV medication during ulwaluko and who speaks publicly about his HIV status. He reasoned that he could tell people the reason why he was at the clinic so they knew it was not in relation to his circumcision. Because he was undeterred by HIV stigma, he was able to provide the reason for his clinic attendance:

Interviewer: What advice would you give to participant who are on treatment and about to go to initiation?

Svij: I would advise them to take their medication when they come back they shouldn't be afraid of what they hear that an ikrwala can't be seen at the clinic/hospital. I used to go to the clinic when I was ikrwala...
Interviewer: After initiation did you go and pick up your medication by yourself?
Svij: I took them by myself.
…
Interviewer: What did other men have to say about this?
Svij: They didn't talk much because I had their answers because I would tell you the truth and ask what would you do if it was you? If he goes around gossiping about me I would get him arrested.
Interviewer: You didn't mind disclosing to them?
Svij: I didn't mind at all I don't even mind telling a girl who is flirting with me I tell her that I'm HIV-positive and I'm taking care of myself very well.
(Svij, 25)

Of the remaining participants, two did not answer the question about medication pick-ups and three reported completely disengaging from biomedical care post-initiation. They said that they could not seek biomedical care as amakrwala. This aligns with preliminary analysis of Mzantsi Wakho quantitative findings, which suggest that boys who reported that 'it was hard during initiation school' were significantly more likely to report non-adherence to HIV medicine. It is likely that the participants who were most vulnerable to disengagement from care are those who were lost to follow-up after initiation. By contrast, those who were most adherent had the support and desire to keep taking HIV medicine after.

Interviewer: So when you were ikrwala did you pick up your medication by yourself?
Ta Saider: I stopped because that would get me into trouble.
Interviewer: So ever since then you have stopped taking medication?
Ta Saider: Yes…when I went to take my medication they give me trouble so I part time going to the clinic.
(Ta Saider, 21)

Interviewer: Did you take your medication at the bush?

Ndoda: No

…

Interviewer: You did not go when you were still ikrwala?

Ndoda: No.

Interviewer: So after how long?

Ndoda: In the middle of the year.

Interviewer: So we can say six months?

Ndoda: Yes, we can say that and you know that amakwrala don't go to hospital.

Interviewer: You did not send anyone to the hospital?

Ndoda: No, they would ask for me.

(Ndoda, 18)

Interviewer: So when you came back from initiation you never took your pills?

Loza: No.

…

Interviewer: So from 2015-2017 you not taking your medication, so it's been two years?

Loza: From 2015.

(Loza, 21)

As previously discussed, these participants narrated poorer adherence and seemed to be more likely to loss-to-follow-up anyways. It may be that the additional challenge of health facility stigma, combined with already shaky adherence made them more vulnerable to complete disengagement from treatment.

Conclusion

This chapter has focused on two separate but related ulwaluko norms about biomedical health sector engagement, that of not taking biomedicine during initiation, and not attending the clinic as new men. Both are strong social norms that, if not followed, would risk sullying the masculine identities of adolescent boys living with HIV. Though not being relevant only to HIV, an HIV-positive status during ulwaluko may be more socially difficult to manage, than other chronic

conditions such as diabetes due to stigma and the related fear of disclosure. This is not to say that other initiates who take chronic medicines don't also face challenges. In disseminating findings and speaking to key stakeholders, we heard many other stories about the challenges of initiates with diabetes, asthma and epilepsy.

Participants struggled with engaging with HIV medicine and being retained in HIV care, and also developed strategies that displayed their creativity and resilience. Underneath seemingly pervasive and static masculine norms, participants and their families subverted and resisted such norms through their covert biomedical engagements.

The compounding of HIV-related stigma and the fear of being ostracised and being seen as less of a man for failure to comply to these rules placed participants in a double bind. They wished to comply to norms of manhood that would legitimise them amongst their peers and in their communities, and to comply to the imperative of medicine-taking to support their health and well-being and avoid getting in trouble with healthcare workers. The threats of a stigmatised masculine identity, and of inadvertent disclosure of their HIV-positive status and the accompanying HIV-related stigma combined to create a situation where participants felt they had to risk their health or risk social ostracisation.

These findings align with the suggestion that locality and context are important in gender and health research and intervention (Oyěwùmí, 1997; Mfecane, 2016, 2018b) using the case of HIV-positive Xhosa masculinities. In addition to the documented challenges facing HIV-positive men in Southern Africa, these specific 'manhood rules' created additional barriers to conforming to hegemonic masculine norms.

Participants who may already be struggling to adhere, might be additionally vulnerable to disengagement from the HIV cascade of care. One month of ulwaluko and three months as amakrwala might converge with other challenges, including the documented general challenges that start to emerge in relation to masculinity (as discussed in Chapter Six). In this way, ulwaluko may represent a vulnerable time that may have long-term effects on health practices of young men living with HIV. This is an important topic that could benefit from further elucidation.

Participants who seemed more resilient to taking medicine and being retained in HIV care during this time had strong family support, planned in advance and already seemed to demonstrate exemplary adherence. Private amabhoma, planned treatment interruptions, and caregiver pick-ups of medicine afterwards were effective strategies in supporting continued engagement with care. The time prior to initiation where boys must get health facility sign-off also represents an opportunity for engagement in the health system, which could be leveraged for adolescent boys, regardless of their HIV status. Supporting advance planning with initiates and their families with how they will engage with biomedical treatment and care during and following ulwaluko will be imperative to better support this group. Another potential strategy for post-initiation, is to engage an existing cadre of community health workers to follow-up with initiates and drop off medications, or have other health facility systems to encourage re-engagement in care.

While respecting this long-standing tradition and acknowledging its secret and sacred elements for many people, the health implications of certain rules related to biomedicine for HIV-positive initiates bear consideration. Findings suggest that alongside initiatives to address HIV-related stigma, that policy-makers, biomedical practitioners and traditional leaders should be aware of, and address these challenges so that initiates living with HIV are not facing social and health risks.

Chapter Six: 'I use them for dirty spirits, not for things like sicknesses…'*Health beliefs and practices of adolescent boys and young men living with HIV*

Introduction

Practices of medical pluralism are common in South Africa, including for people living with HIV. Research suggests that men living with HIV may be more comfortable accessing traditional rather than biomedical healthcare. Research on access to traditional health services focuses largely on adults, but there has been little enquiry into adolescent medical pluralism. In the case of HIV-positive adolescents, many of whom were born with HIV, less is known about how they conceptualise their health and well-being. They represent a unique sub-population which has had distinctive experiences of growing into adulthood while living with HIV. This chapter explores the biomedical and traditional health beliefs and practices of this distinct sub-group of people who have grown up intensively engaged in biomedical HIV care with the aim to respond this evidence gap. Exploring the processes through which health services engagements and practices are formed and sustained for adolescent boys and young men might also shed more light on men's practices of engagement with traditional and biomedical health products and services. Given men's well-documented poorer HIV-related and general health outcomes, exploring the traditional health practices of adolescent boys and young men represents an important line of enquiry.

This chapter engages a 'social process' perspective, which considers how people's participation in certain practices is recruited and sustained (Blue *et al.*, 2016). Such an approach suggests that the chances of someone becoming a practitioner of a certain health behaviour will depend on their life histories, needs and resources. In this way, medicine-taking and accessing traditional or health-facility based services are not just single behaviours, but rather exist in domains of human activity (Blue *et al.*, 2016).

The research methods that we used aimed to ascertain experiences and practices of accessing traditional and biomedical health products and services over time—and how these shaped, and were shaped by, participant belief systems in relation to health, HIV, spirituality and well-being.

Data were collected using life history narratives, and in-depth, semi-structured interviews as described in the research design and methods chapter. Within life history narratives, if an experience of engagement with traditional or biomedical health services emerged, researchers asked follow-up questions to ascertain more about the event. A second in-depth semi-structured interview focusing on biomedical and traditional health practices and experiences was conducted following the first interview. In addition to data from adolescent participants, traditional health practitioners and biomedical practitioners also contributed insights. As described in the research design and methods chapter, data were derived from in-depth, semi-structured interviews, some of which were in groups, and others one-on-one.

This chapter documents the biomedical and traditional beliefs and practices of adolescent boys and young men living with HIV, and considers how these relate to their HIV and gender-related needs and performances. Findings point to the presence of both biomedical and traditional health beliefs and practices in participants' lives, and add detail to current understandings of how medical pluralism is practiced by this group. In line with a social process perspective, they suggest that health-related decisions and performances are mediated not only by gender, but also childhood experiences of illness and engagement in biomedical care. Although many adolescent participants in this study engaged with traditional products and services, they clearly distinguished HIV as requiring ART and biomedical care. This finding deviates from the suggestion that medical pluralism is common for HIV-related issues, and that this is especially true for men.

Although participants engaged with only biomedical products and services for HIV-related issues, many still held traditional beliefs and engaged with a variety of traditional products and services. This suggests that growing up with HIV and within the biomedical health system did not shift their belief systems in relation to traditional cosmologies of well-being, health and illness. This finding aligns with the assertion that traditional African cosmologies are syncretic in nature and that it is common for people to hold a variety of beliefs (which have been categorised as 'biomedical' and 'traditional') simultaneously and to enact them in complex and creative ways.

This chapter suggests a variety of reasons why this group has developed distinctive relationships to biomedical and traditional health practices as opposed to adolescents who are not living with HIV, and men who were diagnosed with HIV at a later stage in their lives. These include:

(1) having grown up living with HIV and accessing biomedical health services over an extended period of time has provided them with different tools and information for health-seeking;
(2) that their young age means that they will be subject to the decisions of caregivers, many of whom have had first-hand experience of living with, or caring for someone with HIV;
(3) that their embodied experiences over a period of time have resulted in them having first-hand experience of the efficacy of biomedicine for AIDS-related issues;
(4) the pressure to redeem lost parents and family misfortunes through medicine-taking (as described in Chapter Four);
(5) that they are more resilient against deterrents that older males would face, such as concerns over emasculation, stigma and privacy because these masculinity-related challenges emerged much later in their lives and after testing HIV-positive and being initiated onto ART; and
(6) that they do not face family expectations for leadership in relation to addressing spiritual problems because of their positioning within the family due to their (young) age. Although they are aiming to redeem their families through good patienthood and manhood (as suggested in the first findings chapter), they do not face the expectation, or pressure to spearhead the healing of family spiritual issues due to their age and developmental life stage.

This chapter argues that health practices were mediated by a variety of factors, which shifted over the life course of participants. When they were younger, the desire to please authorities and redeem family pasts (as suggested in Chapter Four), as well as caregivers' beliefs and embodied experiences, were key factors that influenced their health behaviours. As participants became older, other factors started to influence their practices. These included rebelling from caregiver and biomedical authorities, testing the information they had received using the bounds of their bodies, defining their own belief systems, exploring their own embodied experiences of illness and medicine-taking, and experiencing how peer pressure might influence practice. Gender-

related shifts also started to occur. Masculinity began to present a complication in relation to biomedicine, and participant health-seeking experiences and practices began to shift to reflect some of the problems that men face with accessing treatment and care. These included stigma and scolding healthcare workers as deterrents to accessing services. This chapter suggests that these become more pronounced when caregivers stop accompanying boys to the clinic, and within certain types of facilities and transitions. Participants also began to engage some traditional health practices alone as performances to certain hegemonic masculine norms such as success with sport, physical strength and sexual relationships with women. In this way, engaging with both clinical and biomedical care represented avenues to perform to, subvert and re-signify health-related hegemonic masculine norms. However, disengaging from biomedical care and deciding to use traditional care had separate motivations. These show how traditional and biomedical health practices are not always engaged in relation to one another. These were twin processes spurred by coming into adult manhood. Whereas traditional healing offered solutions to certain challenges of becoming a man, biomedicine complicated masculinity, but not in a way that was compensated by traditional medicine.

This chapter begins by providing background into HIV and medical pluralism in South Africa, including relevant evidence in relation to plural HIV-related health practices. It then presents findings of participant experiences of early illness and learning of their HIV-positive status, which were shared in life history narratives as formative events. It documents how the majority of participants in this study grew up thickly embedded in a set of biomedical practices and relationships including pill-taking and frequent health facility visits, hospitalisation, and interactions with healthcare workers, suggesting that these experiences have greatly shaped their HIV health-related beliefs and practices. Next, it describes how participants demonstrated strong awareness of biomedical understandings of HIV acquisition mechanisms and the potential dangers of mixing traditional medicine with ART.

Despite a clearly articulated use of biomedicine for HIV and strong biomedical HIV-related knowledge, a variety of understandings and beliefs about the origins of and underlying meanings of HIV were present. In this way, findings align with the assertion that health beliefs and practices are multi-layered, and that traditional beliefs may differ from biomedical

understandings in their conceptions of well-being and illness, cause and effect. In this way, experiences of misfortune and illness and how they are interpreted are qualitative (Mokgobi, 2014) and culture-dependent (Teuton, Bentall and Dowrick, 2007). For example, a traditional health practitioner may look at witchcraft, ancestors or family issues as potential causes, while a biomedical practitioner may look at chemical or biological basis (Mokgobi, 2014). This chapter then provides an overview of how participants determine which health systems to access and how participants engage with traditional products and services. It concludes with a discussion on how participants engaged different modes of health-seeking as avenues of performance to adult masculinities.

Background and definitions

Illness and health care systems are influenced by the culture of the societies from which they emerge (Craffert, 1997). That individuals understand health and illness in many ways has been documented by scholars including Janzen (1978) and Steinberg (2011). Kleinman (1980) suggests that people develop explanatory models in response to experiences of illness, and draw on these models to decide which type(s) of treatment to use, and from which sector.

Of fundamental importance to traditional understandings of health and well-being is how individuals are related to the world around them, and especially kinship relationships where family connections are rooted in progenitors or ancestors (Gundidza and Kassilo, 2015). This is a key concept in this chapter, along with the belief that physical issues may be manifestations of underlying issues of a supernatural origin. Understandings of, and responses to, physical health problems can contain perceptions of multiple layers of cause and effect. Such understandings of health and illness are presented in the literature review chapter and documented and explored in Chapter Four in relation to participant family misfortunes, of which living with HIV is a part.

Due to the prominence of biomedicine, the term 'traditional healing'[19] has been used to refer to

[19] This term is used throughout as an imperfect approximation with conceptual limitations. It is used to report, where participants have taken up this way of characterising their beliefs, rather than with the aim to make definitive, essentialist or reductive claims. This study acknowledges that this terminology is contested, and is part of longstanding debates and rich philosophical and epistemological discussions. It also acknowledges the porous, mutable and context-contingent aspects of these beliefs in practice. For the purpose of this chapter, it is used to

non-biomedical health belief systems and practices, although it is acknowledged there is a great deal of variety in traditional healing in different countries and regions (Good *et al.*, 1979; Mokgobi, 2014).

Any participants who have engaged with traditional products and services are understood here to have practiced a form of pluralism. By nature of the recruitment methods of the Mzantsi Wakho study (health facility lists), all adolescent participants in this sub-study had engaged with biomedical care and treatment because they had initiated onto ART. For this reason, this study may be biased towards young people who have biomedical beliefs, although it is not possible to make definitive conclusions from the dataset. It is possible that, by nature of having lived into their mid-to-late adolescence, that participants in this sample are more likely to possess biomedical beliefs and practices than people who acquire HIV later in life, and those who acquire HIV early and who passed away because they did not access biomedical treatment. The Mzantsi Wakho study saw high mortality rates, with 3.4% of HIV-positive participants dying between baseline and the third wave of follow-up. Although not common, accounts of participants passing away due to non-adherence based on their spiritual beliefs were present in the Mzantsi Wakho team. For example, in one chilling focus group discussion, researchers narrated the story of a Mzantsi Wakho participant's death after he and his family decided that he would not take biomedicine in the hope that products prescribed by a faith healer would work.

Although medical pluralism has been documented as existing across both traditional and faith-based systems (Wringe *et al.*, 2017), the focus of this study was centred on traditional rather than faith-based products and services, which in the study site are largely related to Christian forms of healing. Given that it was out of the scope of this work, it is difficult to ascertain how important faith healing is to the question of medical pluralism for adolescent boys and young men living with HIV. However, there is substantially less literature on faith-based services in relation to HIV, and it was not described in much detail participants.

---

describe to the traditional spiritual and health beliefs and practices in the study site.

There is strong evidence on practices of medical pluralism in South Africa, including for people living with HIV and AIDS (Baer, 1995; Wreford, 2008a; Wreford and Esser, 2008; Sorsdahl, Ipser and Stein, 2009; Sorsdahl *et al.*, 2010; Moshabela *et al.*, 2011; Pantelic *et al.*, 2015; Moshabela, Zuma and Gaede, 2016). Patients often seek traditional health practitioners first when they become ill (Langlois-Klassen *et al.*, 2007; Audet *et al.*, 2014). A KwaZulu-Natal clinic-based study found that 70% of patients consult a traditional health practitioner prior to going to a clinic (Puckree *et al.*, 2002). A Limpopo study estimated that 67% of people visit traditional health practitioners regularly (Mathibela *et al.*, 2015). Another survey of patients living with HIV (n=618), based in three KwaZulu-Natal hospitals, found that 51% engaged multiple healthcare modalities (Friend-du Preez and Peltzer, 2010; Peltzer *et al.*, 2010).

A study in Bushbuckridge, Mpumalanga, found that 69% of patients living with HIV reported visiting both biomedical and traditional practitioners routinely for the treatment of HIV, ART side effects and opportunistic infections (Moshabela *et al.*, 2011). Traditional medicine may be used for the treatment of HIV (Langlois-Klassen *et al.*, 2007; Peltzer *et al.*, 2008), and Puoane and colleagues (2012) found that traditional medicine were combined with ART in KwaZulu-Natal and the Western Cape. Participants in this study reported using traditional medicine for HIV-related symptoms, as well as other chronic conditions (Puoane *et al.*, 2012). Audet and colleagues (2017) document how, in a rural area of South Africa, traditional health practitioners continue to treat HIV symptoms, which demonstrates an ongoing demand for these services. A 2008 study in Pretoria found that 15.6% of HIV-positive patients on ART used non-prescribed medicine concurrently (Malangu, 2008), and Katz and colleagues (2015) found that people living with HIV sought out traditional medicine to boost their immune systems as an enhancement or substitute for treatment, regardless of whether or not they were using ART. There has been a suggestion that high levels of medical pluralism are driven by both socio-cultural beliefs and a dissatisfaction with the biomedical health system (Wreford, 2008b; Sobiecki, 2014), and that this is particularly true in rural areas (Sobiecki, 2014; Zuma *et al.*, 2018).

Zuma and colleagues found that, in the context of HIV/AIDS, it is difficult for people to separate spiritually-caused and biological illnesses, and that, despite the wide availability of ART, the use

of traditional products and services continues (Zuma *et al.*, 2018). However, this study also documents the perspective that traditional treatment should not be engaged for HIV-related issues (Zuma *et al.*, 2018), a possible divergence from the other aforementioned literature on this topic.

There is also a literature documenting the benefits of traditional health care, as well as some negative outcomes of the ways that pluralism is often practiced. Negative outcomes include: delays in reaching biomedical services, poorer ART outcomes, interruptions to HIV-related care, traditional medicine toxicity, worsening of AIDS-related symptoms because of dehydration related to traditional purgatives, and costs (Barker *et al.*, 2006; Summerton, 2006; Sorsdahl, Ipser and Stein, 2009; Moshabela *et al.*, 2011; Nxumalo *et al.*, 2011; Pantelic *et al.*, 2015; Moshabela, Zuma and Gaede, 2016; Wringe *et al.*, 2017). In addition, patients are unlikely to disclose their involvement in traditional healing to biomedical practitioners, due to the stigma attached to accessing traditional services. A systematic sampling of ART patients in KwaZulu-Natal found that 90% of participants who were taking herbal therapies had not told their biomedical health worker (Peltzer *et al.*, 2008).

There have also been accounts of the devastating consequences of claims of unsubstantiated traditional cures. For these reasons, there has been a focus on building an evidence base to understand patterns of medical pluralism. Leclerc-Madlala et al. (2016) conducted a literature review on traditional health practitioners and HIV and concluded that traditional health practitioners provide important information, behavioural and linking services. Medical pluralism in South African contexts is a rich opportunity to provide patients with more complete and plural healthcare that combines biological, psychological, social and spiritual approaches (Moshabela, Zuma and Gaede, 2016). Collaborations between the traditional and biomedical health sectors in South Africa offer great potential for improving the success of health programmes (Wreford, 2005b; Wreford and Esser, 2008; Leclerc-Madlala, Green and Hallin, 2016; Moshabela, Zuma and Gaede, 2016). Despite limited evidence on the biological effects of traditional medicine on HIV-related health-outcomes, high rates of use of traditional health practitioners, and their documented role of supporting the well-being of people living with HIV, make a case for their greater acknowledgement and engagement.

As previously discussed, medical pluralism—depending on how it is practiced—represents both an opportunity for improved well-being of people living with HIV and also harmful health consequences. These harms and opportunities strengthen the case for nurturing new ways of knowing beyond this binary, and for exploring processes through which both health-affirming and harmful pluralism practices are formed and reproduced. Colvin (2014) suggests that transdisciplinary public health and social science research is needed in order to respond to the imperative for new ways of thinking that complicate conventional ways of 'knowing' that restrict how and what we understand about health.

The majority of the aforementioned studies suggest that the concurrent use of traditional and biomedical products and services is common, for both HIV-related and non-HIV related reasons, even after ART has been made widely available. It has also been suggested that men may be more likely than women to access traditional health practitioners and medicines (Zuma *et al.*, 2018) including instead of, or prior to, seeking health-facility based HIV care and treatment (Beck, 2004; Nattrass, 2005a, 2005b; Wreford, 2005b; Wreford and Esser, 2008; Mills, de Paoli and Grønningsæter, 2009). Chikovore and colleagues (2016) found that many men preferred traditional medicine in a recent KwaZulu-Natal treatment-as-prevention trial. Reasons for this may include the privacy and respect afforded by traditional health services, which have been documented issues for men accessing care within the public health system. Medical pluralism for men living with HIV, depending on how it is practiced, has been documented as having great potential to support health outcomes, or to be heavily damaging (Beck, 2004; Nattrass, 2005a, 2005b; Wreford, 2005b; Wreford and Esser, 2008; Mills, de Paoli and Grønningsæter, 2009).

Zuma and colleagues (2018) also suggest that concurrent use of traditional medicine alongside HIV-related care has become less common amongst people living with HIV. The reasons for these differences in the evidence are difficult to ascertain. It is possible that these findings reflect the presence of multiple approaches in different places and among different populations, or that they represent a shift over time. Such a shift could be in response to the long history of HIV activism and public health education programmes, as well as the roll-out of universal HIV testing and treatment.

This evidence paints a complicated and varied landscape about the multiple ways people engage with and understand traditional medicine and biomedicine. Although practices change over time and are difficult to quantify, the findings from adolescent participants in this study diverge from much of the aforementioned literature, as well as from assertions of the traditional health practitioners that were interviewed. This chapter suggests that growing up engaging with HIV-related biomedical care and treatment has resulted in participants having clearly distinguished relationships with biomedical care and treatment for HIV. These relationships may not be as clear for adult men, some of whom might be more likely to use traditional healing, regardless of whether they have also embraced biomedical understandings of HIV. This chapter adds depth to findings presented in Chapter Four, which suggested that participants engaged performances of therapeutic citizenship and masculinity to redeem family misfortunes and create new futures. This chapter considers how traditional and biomedical health practices are formed, and shift throughout the life course, in relation to their HIV-positive status and male identities.

Findings and discussion

This section begins by presenting participant experiences of childhood illness and engagement in biomedical care, including hospitalisation, learning of their HIV-positive status and taking ART. It suggests that these early experiences have shaped their traditional and biomedical health-seeking practices in distinct ways. Following this, participant health-related practices are presented, demonstrating how the aforementioned experiences alongside caregiver influence have resulted in biomedical-only engagements for HIV-related issues. Next, participants' underlying beliefs about HIV origins and acquisition are described, painting a complex picture about how participants perceive underlying causes of illness and suggesting that participant understandings of HIV and its relationship to the supernatural are not uniform.

This section documents the ways in which participants use traditional products and services. It considers the ways in which practice and belief influence one another, and shift and evolve over the life course. The ways in which participants enact masculinity via traditional and biomedical health practices are also discussed.

Childhood experiences of illness and biomedical care

As discussed in Chapter Four, living with HIV was an important theme in life history narratives. Without HIV-specific prompts, 32 participants disclosed their HIV status, mentioning it either as an important life or health event. This section begins by exploring HIV-related experiences of childhood illness including illness and hospitalisation, HIV diagnosis and disclosure, and taking ART as an important health-related theme that shaped participant health practices for HIV-related issues. It considers how growing up deeply embedded within the biomedical health system has shaped their participation in biomedical and traditional health practices.

As discussed briefly in Chapter Four, participants often learnt of their HIV status after becoming very sick, or in relation to their parent's death(s). Experiences of severe illness and parental death are both significant and challenging life events, and demonstrate the impact of untreated HIV infection. For participants, learning of their HIV-positive status was often spoken about as a formative and disruptive life event with physical and psychosocial challenges:

> **Interviewer:** If you were to choose an item to represent your life while you were in Isivivana*, which item would you choose and why?
> **X-man:** A flower because I was happy living there and at that time I didn't know my (HIV-positive) status and didn't know that my father had HIV and he didn't know up until his last days. So that's where they (family) came up with a decision to have me tested.
> **Interviewer:** So your father passed away while you didn't know your status?
> **X-man:** Yes I didn't know but I saw him getting sick in front of me and no one knew… They decided to test me also and they found out that I'm also positive.… My self-esteem was low… it showed in me I was very sick. I used to be big but because I got very sick… All of my body was aching, I was going in and out of hospitals and my weight was thinner than now. It showed that there was something eating me inside.
> (X-man, 22)

This participant recounted finding out his HIV-positive status shortly after his father's death and spoke about becoming very sick himself and being in and out of the hospital. Many participants

spoke about how their HIV was related to other challenges. X-man spoke about how he was visibly ill ('it showed that there was something eating me inside') as well as suffering internally, that it affected his self-esteem and was an unhappy time. He contrasted this with a time when he was happy (representing it with a flower) before he knew about his father's and his own HIV-positive status. In this way, he described how HIV represented both physical and emotional disruption in his life. Similarly, the below participant also spoke about becoming very sick, and the physical and psychological impacts of this.

> **Lullo:** In 2007 I was in Grade 6. I was really sick and I did not finish that year at school…
> **Interviewer:** What happened?
> **Lullo:** I did not know what happened I thought I was just sick. I was told by my grandmother in the following year… She called me and sat me down she told me that I was sick, that I am HIV positive '*these pills that you are taking are for HIV but everything will be alright*'. It did not sit in well with me I was very upset.
> **Interviewer:** Ok, so for how long did you stay in the hospital?
> **Lullo:** Six months.
> **Interviewer:** And how old where you?
> **Lullo:** 12 years old.
> **Interviewer:** So how did that change your life after you found out that?
> **Lullo:** It changed a lot, what I was thinking was that I am going to die soon because at that time I know nothing (about HIV). I only knew what I learnt from school.
> (Lullo, 22)

Lullo shared his distress over learning about his HIV-positive status, and how his illness disrupted his schooling. Despite consolation from his grandmother who told him everything would be alright, he spoke about how he believed that living with HIV meant he would die soon. Similarly, other participants spoke about how becoming sick while growing up affected their childhoods and their lives. In narratives below, Machete (22) and Layzdu (18) both spoke about dropping out of school, and experiencing many different illnesses, likely due to compromised immune systems.

Machete: In school I was very sick. I was going in and out of hospital and I ended up dropping out of school in Standard 5 (Grade 7).
Interviewer: Were you taking medicine at that time?
Machete: Not yet because the virus was detected after some time in Ntuthu Hospital*… It was a difficult time of my life because I was in and out of hospitals so there was no time to attend school… I used to have many different sicknesses, there was no diseases that were passing by me. If it wasn't fever then it was something else… I would be admitted to the hospital two to three weeks then I would come out again.
(Machete, 22)

Layzdu: When I was at primary school I was very weak, it was really bad at school. The asthma…was killing me… I don't how I was in terms of academics because I was everywhere because I was very sick… they found out that it was the virus (HIV)… I was very sick and weak at that time..
Interviewer: Ok now we will ask you about life events, they can be good or bad or something that is important to you that you remember?
Layzdu:…the only thing that I will never forget it is when I was sick. When I was discharged at hospital and they said I will not get better… they said I would not heal. I was discharged and my grandmother told them that it was not right that I was discharged… then my grandmother took me to my mother's family and my mother's family asked my grandmother '*what are we going to do with him when he is this sick?*'... (then) sent me to my fathers' family because I was sick. I needed to be taken to hospital…
…
Interviewer: So how long did you stay at hospital?
Layzdu: I stayed for a very long time… I don't remember everything because I was very weak when I grew up… I was diagnosed a lot of times, at first it was TB… I was diagnosed with a lot of things…
(Layzdu, 18)

These participant stories of illness are shared here to provide a snapshot into the many ways that growing up while living with HIV has shaped their lives. Chapter Four mapped out childhood experiences, including parental AIDS death and experiences of disclosure, as broader challenges related to a 'long procession of misfortunes' (Becker and Geissler, 2009, p. 11) and performances of therapeutic citizenship as pathways to personhood. In this chapter, participant experiences of living with HIV and childhood illness convey the physical and emotional vulnerability of formative experiences of severe illness. The above narratives reflect some of the psychosocial challenges of fear and sadness, as well as participants' physical experiences of being sick, including missing school, moving between caregivers, and being in the hospital, and of the routine exposure to biomedical products and services that kept them alive. These findings align with a literature that suggests that HIV alters the social ecology which supports the healthy child development of children (Benard, 1995) that ordinarily mitigate risks and promote resilience (Werner, 1989; Cowan, Cowan and Schulz, 1996; Betancourt *et al.*, 2013).

As shown above, many participants first learned of their HIV-positive status when they became very sick or experienced the death of a parent. In both cases, learning of their HIV status was dually difficult: beyond learning that they were living with a stigmatised, lifelong illness, participants also experienced this disclosure during a time of physical or emotional hardship. They thus had to confront the possibility of their own early 'bad' death (Posel, Kahn and Walker, 2007), either through being sick, witnessing caregiver AIDS-related deaths, or because of family or community responses to their HIV-positive status. An example of how embodied experiences become enacted as practice, many participants associated their HIV medicine with these painful events, and reported stopping them in attempt to distance themselves from these memories:

> **Buja:** ….When I heard things about my mother and what was she like, some times when I take my pills I hate myself and ask myself "why do I have to take these pills?" and they say my mother transmitted it to me so I was infected. There were times when I wouldn't take my pills for three months and did not go to hospital because of my anger - that I don't want those pills. But then I would end up taking them again.
> **Interviewer:** When that feeling of hating them struck you, what caused it?

> **Buja:** I would see many people, even from my family are healthy and I'm the only one who took these pills, even when I see my friends, they are healthy. I would think '*this is for me and nothing can help it*' then I decide to take them… Sometimes I would wish I was not taking them.
> (Buja, 19)

The above participant spoke about ceasing treatment-taking after learning about his status. The refusal to take HIV-medicine could be understood as a way to create distance from his HIV-positive status and what it represented in his life: his difference, the death of his mother, and his pain over his family's secrecy. His pills, and ultimately, his physical body, became an outlet for this unprocessed anger and grief. Similarly in the following interview, the participant stopped taking his medication after being told of his HIV-positive status, a phenomenon that has been documented by Hodes, Vale and Toska in a forthcoming book chapter (no date). He described his anger and confusion about not being told by his mother about his HIV-positive status—he learned of it when she died—and learning his HIV status 'when he was already old'.

> **Ringo:** It was very painful after all these years I stayed with my mother she didn't tell me and now I've discovered that when I'm old so that really made me feel hurt.
> **Interviewer:** How old were you when you first know about your status?
> **Ringo:** I was 14 years… When I first heard about my status I didn't take my medication.
> (Ringo, 17)

Chapter Four suggests that such late disclosures were situated as part of a broader secrecy around death, hardship and familial misfortune. It described how narratives of late or inappropriate HIV disclosure were full of anger and confusion. As can be seen from the above interview excerpts, many participants described how such late disclosure poorly influenced their psychosocial well-being, and in turn, their ART-taking and health. In line with participant narratives, the negative impacts of late disclosure were documented in interviews with healthcare workers and in clinic files. As put by the sister in charge of an ART unit at a large public hospital:

> The caregivers disclose very late to these children. Because you find that one will be 15 years old and not know what treatment they are taking. If disclosure hasn't happened very early, it will affect how he will conduct himself with his treatment when he happens to know for himself. Because the others were so angry with their parents when they hear about it…. So then they don't want treatment…
> (Sister Nceba)

Healthcare worker concerns and frustration over non-disclosure of an HIV-positive status by an appropriate age could also be seen in clinic files, like the one below:

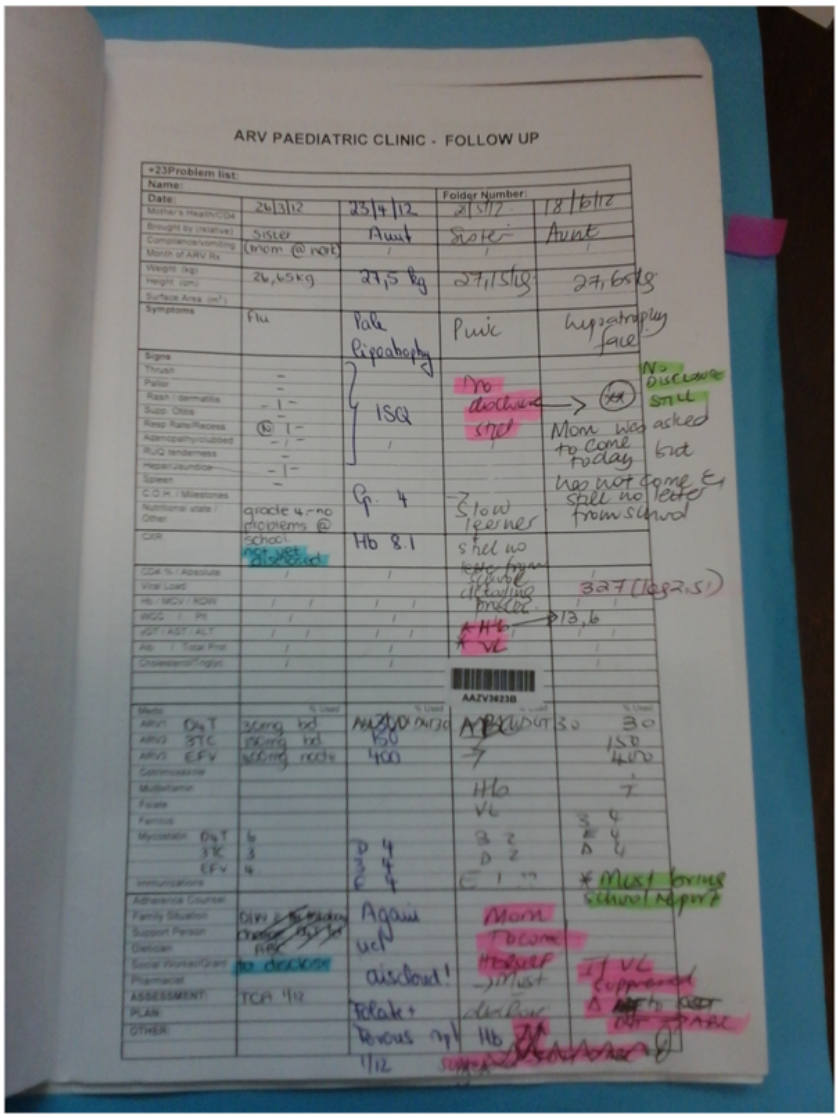


Figure 45: Page of Ndoda's (18) health facility file, when he was 12. The health worker documents that he needs to be disclosed to. Photograph taken 15 April 2018.

The above file shows monthly notes from a health care worker, most highlighted or annotated with exclamation marks or asterisks. In the image of this file, the participant (at age 12 in 2012) has been recorded as not having been disclosed to. Every month when he comes to pick up treatment, the nurse makes remarks about the imperative for disclosure: 'to disclose (highlighted in blue)' (26/3/2012), 'again not disclosed!' (23/4/2012), 'no disclosure still' (highlighted in pink) (21/5/2012), 'no disclosure still' (highlighted in green) (18/6/2012).

The findings presented above align with the literature on disclosure, which suggests that young people cope better psychologically and have better health outcomes if they are disclosed to by an appropriate age. Learning about one's own HIV status in a sensitive, developmental-stage appropriate and supportive way, and before adolescence has been found to be associated with improved adherence and health outcomes in these analyses, in line with a number of studies (Giacomet *et al.*, 2003; Bikaako-Kajura *et al.*, 2006; Williams *et al.*, 2006; Nabukeera-Barungi *et al.*, 2007; Polisset *et al.*, 2009; Li *et al.*, 2015). Non-disclosure can be a barrier to uptake for adherence to ART and clinic appointments, and also increase vulnerability in young people. Preliminary findings from the Mzantsi Wakho study have also identified protective impacts of early disclosure to adolescents of their HIV status on both adherence and sexual risk-taking (Cluver, Hodes, Toska, *et al.*, 2015; Toska, Cluver, Hodes, *et al.*, 2015). The literature also suggests that HIV disclosure for children is a process, rather than a once-off event (Kallem *et al.*, 2010; Vaz *et al.*, 2011). This has been reflected in international and national policies. For example, the South African guidance (2016) recommends a process of disclosure where children are given age-appropriate information over time and 'partial disclosure' happening between the ages of 3-9.

Hodes and colleagues (2019) document how medicine-taking is a multi-sensory experience, with memory and experience influencing attitudes towards pills. These findings are relevant here. Many participants overtly or implicitly related challenges with medicine-taking to emotional issues surrounding their HIV-positive status such as parental loss, illness and the frustration and shame of living with a highly-stigmatised chronic condition. Not taking medicine thus represents a form of rejection or detachment from what HIV has come to represent in their lives, a finding

that dovetails with Hodes and colleagues (2018) assertion that ART non-adherence can be a way to test authority and an enactment of rebellion and freedom for adolescents living with HIV. Many participants described their conflicted relationships with ART. Participants spoke about their desire to be 'normal' and, in not taking pills, to distance themselves from their HIV-positive status. They tested the bounds of their bodies by stopping their medicines, and then re-starting when they became physically sick. The below quotes demonstrate participant's decisions and practices of stopping and re-starting HIV medicines.

> **Ngamla:** I saw that my friends are laughing at me when I am taking my treatment and I thought *mxm voetsek* (*ugh, get lost/fuck off*) I must stop taking them for a while. So that's how I ended being sick… that's how I went to the hospital.
> **Interviewer:** How long did you stay at the hospital?
> **Ngamla:** I did not stay for long… maybe 3-4 weeks.
> **Interviewer:** So from then, how did you feel?
> **Ngamla:** I saw that I am killing myself here *voetsek*. No matter what they say I don't care. Let me take care of my health and take my treatment…
> (Ngamla, 21)

> **Interviewer:** After finding out that you are HIV-positive, you said that your self-esteem was low. What made you feel this way?
> **X-man:** I could say maybe it was because I was childish back then, I didn't understand it well… I didn't accept it and I didn't believe it was me because I saw myself as a healthy person, but they are telling me that and I didn't care what they said. But I believed it because I was very sick, I saw there was something when I almost died. But I was lucky.
> (X-man, 22)

> I hate them sometimes but when I don't take them I become weak. Then I take them again…
> (Mr Shade, 17)

Nkweza: I took them properly while I was 11 years but when I got to 17 I didn't take them… "yooooooohhhhhh!!! Hayi each and every day I have to swallow pills? hayi……hayi"

…

Interviewer: Do you ever think of quitting them?

Nkweza: Yes I do.

Interviewer: What makes you not to quit?

Nkweza: I may die.

…

Interviewer: How often do you take them?

Nkweza: I take them occasionally.

Interviewer: When was the last time you took your medication?

Nkweza: Last week.

…

Interviewer: Is there any difference when you taking your medication and when you not?

Nkweza: Yes there is a difference… When I didn't take them I'm alright but when I take them I become restless.

Interviewer: What do you mean when you say you are alright when you didn't take your medication?

Nkweza: You become normal just like any other person.

(Nkweza, 18)

In these narratives, it is clear that as participants became older, they would test the boundaries of their bodies, stopping pill-taking until health issues emerged and then re-starting. They described worrying about or experiencing illness after not taking them for some time, and re-starting them based on their desires to live and be healthy. In discussing what motivates participants to take their pills, many spoke about wanting to live, speaking to their awareness of the fatal consequences of long-term non-adherence. Seen from a biosocial lens, their desire to be 'normal' and not take pills was at odds with the biological imperative to take pills once their HIV-positive status began to affect their lives in physically noticeable ways. The act of non-adherence tested

the bounds of their physical bodies, and also the authority of biomedical advice from health providers and caregivers. For these participants, their decisions to stop taking their medicine affected their bodies, which then influenced them to re-start medicine, a cycle. In this way, participants also gained embodied experiences that shaped their beliefs about the efficacy of HIV medicine, which this chapter suggests is a reason why participants have distinct relationships of belief and practice to ART and biomedicine that men who contract HIV when they are older may not.

These findings align with the suggestion that it is important to be aware of the potential harms of inadvertent HIV disclosure (Hodes, Vale and Toska, no date). In their forthcoming book chapter, Hodes and colleagues document how inappropriately learning about an HIV-positive status can bring doubts and tensions to adolescents and their families, and how disclosure to young people may also take the form of reprimand and an exertion of control over their behaviour. In response, young people might assert their autonomy using health practices, such as ceasing medicine-taking.

A social process perspective is relevant here. Medicine-taking and accessing health services exist in the domains of human activity 'that are reproduced and transformed through the re-enactment and performance of specific social practices, coordinated and synchronized across space and time' (Blue *et al.*, 2016, p. 38). The chances of someone becoming a practitioner of a certain health behaviour will depend on what the practice requires, what resources are available and previous life histories (Blue *et al.*, 2016). Skovdal and colleagues (2017) examined interactions with HIV services in six countries in sub-Saharan Africa using a theories of practice lens. They found that interactions with HIV services were shaped by a variety of factors, including availability/absence of health services and medicine ('materialities'), knowledge of how to live with HIV ('competencies') and 'meanings' such as trust in HIV-related services, normalisation of HIV and HIV-related stigma (Skovdal *et al.*, 2017). They also found that a number of other life practices shaped engagements with HIV services, such as being a parent or working (Skovdal *et al.*, 2017).

This section has documented how all of the participants in this study grew up with frequent exposure to the biomedical health system in ways that HIV-negative young people and horizontally-infected men have not. Applying Skovdal and colleagues' (2017) model, such engagements affected materialities, such as access to paediatric HIV services, and competencies—namely, knowing about HIV-related products and services and how to navigate the biomedical health system. Additionally, their trust in the efficacy of biomedicine, and in certain health providers or services, was also present as a result of their formative childhood experiences of illness. These factors also applied to participants' caregivers, on whom participant's health practices were often based. Family relationships and life stage also affected participant engagements. While HIV health service competencies increased as participants aged, meanings, including HIV stigma and normalisation, shifted in ways that posed challenges to participants as they moved into adulthood.

As presented above, a number of health-related themes in relation to engagement in biomedical care were present in participant narratives. These included experiences of early illness and physical vulnerability, growing up deeply embedded in the health system and becoming sick when not taking pills and then re-starting them and getting better. This chapter suggests that these embodied experiences of the efficacy of ART shaped their HIV-related biomedical and traditional health beliefs and practices. This suggestion is derived from participant narratives of becoming sick and getting better upon engaging in HIV-related biomedical care. Possessing the embodied knowledge that ART works may be a reason why participants reported accessing exclusively biomedical services and products for HIV-related issues. These reports were triangulated across a number of methods, including a semi-structured questionnaire about traditional and biomedical health practices that was analysed alongside life and health history narratives and patient files. Below is an overview of participant traditional beliefs and practices as they relate to HIV, followed by a broader overview of their traditional health beliefs and practices.

HIV and health-related beliefs

All but one participant in this study said that he considered HIV to be an issue requiring biomedical treatment and care, and none reported believing that traditional health practitioners

could cure or treat HIV. Reports from participants, a review of health facility files and narratives of use of traditional medicine from life history interviews alongside semi-structured interviews suggested that participants access solely biomedical treatment and care for HIV-related issues[20]. Participants did not report use of traditional products and services for any HIV-related physical symptoms, although it is possible that they may have understood symptoms related to HIV infection as caused by something else. These findings diverge from the literature on adults living with HIV, as well as findings from traditional health practitioners in this study which suggest that it is common for some adults, and especially adult men, to practice HIV-related medical pluralism. Although such beliefs and practices are difficult to quantify and change over time, this chapter suggests that participants' aforementioned experiences with HIV-related biomedical products and services are one such reason for this.

All participants demonstrated strong biomedical understandings of HIV acquisition mechanisms and the potential dangers of mixing traditional medicine with ART. The below interview transcripts reveal how participants delineated issues that require traditional and biomedical attention, and how they deemed that HIV is an issue that traditional health practitioners cannot cure. The important issue here was not how they perceived the origin or cause of the issue, but what would be effective to treat it:

> There are illnesses that they (traditional health practitioners) cannot cure … like HIV/AIDS… As we know that there is no cure for HIV/AIDS because even the doctors are still searching for cure while they are still controlling it with ARVs.
> (Ulwazi, 13)

> **Interviewer:** Do izangoma/amaxhwele/inyanga/igqirha or faith healers have abilities or powers?
> **X-man:** Yes I can say so, because when you go to ixhwele to check yourself when maybe you are not feeling well, or your child has become mentally ill… he will tell you "*it is this person who did this*" and "*here is the medicine to heal the person*" and then

[20] Here, HIV-related issues are defined as physical health issues caused by HIV infection.

your child will be good and back to normal.

Interviewer: Can you give me an example of diseases that ixhwele/igqirha/sangoma/inyanga or faith healers can heal?

X-man: When you are swollen and you can't be cured at the clinic. But if you go to a certain traditional healer he will give you a bottle of medicine then you will drink it and be cured, or else you have a headache that doesn't end even if you take your headache pills, it doesn't end. But when you go to ixhwele he will just give you a bottle then you will be in good health again.

Interviewer: Do they have any diseases that they can't cure?

X-man: HIV they can't cure it at all.

(X-man, 22)

Interviewer: Do izangoma, amaxhwele, amagqirha and faith healers have powers?

Nkweza: Yes they do… Maybe if you can't sleep and there are evil spirits in your home they can fix that and cleanse your home.

Interviewer: Are there things that izangoma, amaxhwele, igqirha and faith healers they can't heal?

Nkweza: Yes the are things that they can't heal.

Interviewer: Such as?

Nkweza: Like HIV/AIDS.

(Nkweza, 18)

These narratives demonstrate how many participants believed that traditional health products and services could support certain aspects of well-being, but not HIV. Participants considered HIV, alongside some other illnesses such as TB, as treatable only with biomedical care. This however, did not necessarily mean that an underlying supernatural issue could not be responsible for the illness. It was notable that participants' biomedical HIV-related beliefs did not seem to undermine or shift their beliefs in relation to other types of health issues which might be understood to be supernatural. In a recent study by Zuma (2018) and colleagues, participants reported that HIV, TB, diabetes, blood pressure, stroke and arthritis were common ailments that required biomedical care for diagnosis and treatment. Similar to the findings presented in this

Chapter, the authors also found that traditional health products and services were not used as alternatives to ART, but rather to respond to different needs (Zuma *et al.*, 2018).

In line with a social process approach, this demonstrates how beliefs as well as health practices are underpinned by a variety of factors, including participants' embodied and lived experiences, cultures and traditions. HIV may have 'moved categories' from requiring traditional to biomedical treatment, but other types of illnesses or issues had not. Although speculative, this finding suggests that although participants embraced a clear and distinct way of thinking about HIV treatment and care, their belief systems and their broader worldviews that include traditional healing still exist. Given that many African traditional beliefs are syncretic in nature, it is not surprising that participants' beliefs encompassed aspects of both biomedical and traditional health beliefs and practices. A variety of historical accounts have documented that Xhosa culture has never been static (Soga, 1931; Wilson, 1936; McAllister, 1989; Mills, 1995; Reed, 2014), including in relation to the adaptability in the area of medicine's place in cosmology (Wilson, 1978; Hodgson, 1982; Mtuze, 2003; Suskin, 2014). This finding affirms that bifurcating health beliefs into traditional and biomedicine as separate, univocal belief systems is limiting (Green, 2012) and does not adequately account for the multitude of practices, beliefs and experiences for adolescent boys and young men living with HIV.

In contrast to the suggestion by adolescent participants that HIV could not be treated by traditional medicine, traditional health practitioner beliefs and practices around HIV varied in this study. While some also believed that it was a physical issue only that required biomedicine, others believed that it did not exist on its own, but was rather a symptom of issues of a supernatural origin. Some traditional health practitioner participants were also seeking a traditional cure. For example, one traditional health practitioner who was living with HIV disclosed buying traditional medicine from a KwaZulu-Natal-based provider, and testing them on his body to see if they would work. In another case, a group of traditional health practitioners reported having a ceremony to ask for a cure. About a year later, I received a call from the head of the traditional healing school to tell me that she had dreamed a cure and had to travel out of province to dig the plants she had seen in her dream. These findings align with the above-

reviewed literature that documents the use of traditional health products and services for HIV and AIDS related challenges, but diverge from adolescent participant narratives.

Another important factor in considering participants' beliefs about HIV, traditional medicine, and biomedicine is their age and developmental stage. Unlike some traditional health practitioners, who may feel like they have something to defend, participants in this study did not yet seem to see their practices or beliefs in relation to broader political or ideological issues.

In addition to asserting that traditional health practitioners cannot cure or treat HIV, adolescent participants also possessed strong scientific knowledge about HIV, including modes of acquisition, although this did not preclude their varying beliefs about the origins of and underlying meanings of HIV. The below excerpt demonstrates a typical participant's response to questions about what HIV is and how it is acquired:

> **Ta Saider:** It is Human Immune Virus (HIV). Then AIDS means Immune Deficiency Syndrome.
> **Interviewer:** Can you tell me the ways some people get HIV?
> **Ta Saider:** You can get the virus through blood or touching someone's blood and also having sex without using protection or from mother to child (answered in English)… (Ta Saider, 21)

When asked how people contract HIV, most spoke about unprotected sex and contact with blood. Some also spoke about sharing toothbrushes as a form of transmission, which has never been documented (Opeodu and Ogunrinde, 2015). From their narratives, participants consistently demonstrated strong biomedical knowledge about HIV and its acquisition mechanisms, although (as discussed in the Chapter Four), it often happened that there was silence and confusion within their families about their own acquisition.

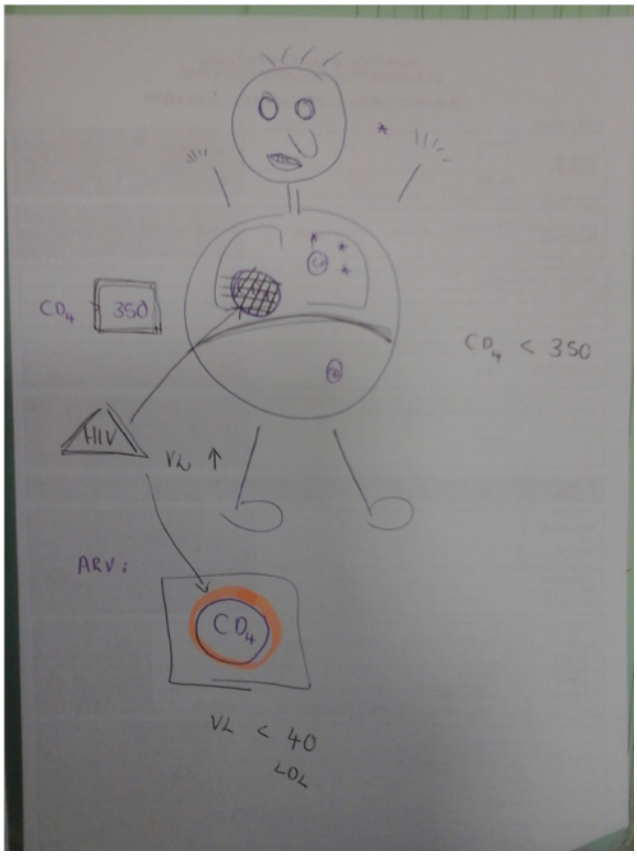


Figure 46: Page of Mluthwana's (16) health facility file where a health worker explains how antiretrovirals work.

The above image demonstrates how participants were often provided with biomedical information about HIV. It shows a pictorial depiction of how HIV affects the immune system and how ART works in the body. It was taken from Mluthwana's (16) file when he was 12 years old. The other side of the page documents his (late) disclosure. Like the file depicted earlier in this chapter, entries from the previous year and a half documented health facility staff's concerns over him not being disclosed to.

Biomedical engagements such as this one, alongside the HIV/AIDS communication interventions that younger people are more likely to have been exposed to (Savasta, 2004; Shisana *et al.*, 2009) may have contributed to the presence of more biomedical beliefs amongst participants. Such exposure to scientific information likely aligned with their (and their caregivers') understandings of HIV derived from their lived experiences in accessing biomedical care, including HIV testing and treatment, as described earlier in this chapter. Most participants

had experienced losing at least one parent to AIDS-related illness, and had themselves been hospitalised and been on and off ART. It is likely that these embodied experiences of ART efficacy had influenced their AIDS-related beliefs and practices, alongside substantial exposure to biomedical information and messaging resulted in such beliefs. These beliefs, in turn, shaped participant competencies in relation to HIV.

Similar to possessing biomedical beliefs about HIV treatment and acquisition routes, many participants also expressed their biomedical knowledge that ART should not be mixed with traditional medicine:

> The difference (between going to the traditional health practitioner and the clinic) is that when you go to clinic you will get help in different ways and you will get treatment. With traditional healers you can't mix the two medications, so what I prefer is to go to the clinic.
> (Ta Saider, 21)

> The ARVs must be separate from the ixhwele medication.
> (Nginduyi, 16)

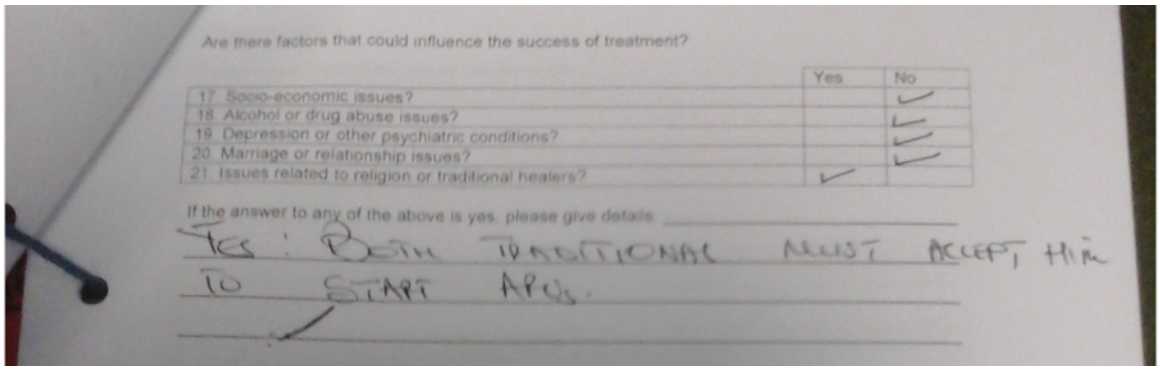
> **Interviewer:** Have you ever used the traditional way to heal yourself?
> **X-man:** No, even when I started to get sick (with HIV) I was told not to use traditional medicine.
> **Interviewer:** Who told you that?
> **X-man:** I was told at the house by my sibling, she told me she heard it from the nurses.
> **Interviewer:** You don't believe in those things (traditional products or services)?
> **X-man:** I do believe but I was told not to do it and if I'm being told not to use something then I don't.
> (X-man, 22)

In the above quotes, participants expressed their awareness of the potential adverse effects of mixing traditional and biomedicine, and their decisions to take ART only for HIV-related issues.

This finding is similar to that of Appelbaum Belisle and colleagues (2015) who document patient assertions that mixing traditional medicine with ART is irresponsible and ineffective. Similarly, Zuma (2018) found that participants were concerned about drug interactions and absorbency for people living with HIV using both biomedicine and traditional medicine.

Another aspect of why adolescent boys and young men living with HIV may not engage with biomedicine is also presented above: even though they might believe in traditional medicine, like X-man does, they may also be doing what they are told. That participants are or were recently children who are used to being subject to the authority of adults is another possible reason why they had a distinct relationship to biomedicine that adult HIV-positive men might not have. Although this may not apply to everyone, growing up being told by caregivers to take biomedicine, and feeling the pressure to do so as a way to please authorities, and in some cases, redeem lost parents, may have created certain patterns of health practices. As they became older, they may have chosen not to take their pills as a way to test authority and distance themselves from their HIV-positive status, but did not engage with traditional medicine because of these early experiences and teachings.

It was common knowledge among participants that traditional and biomedicine should not be mixed, and they spoke about choosing not to take traditional medicine for HIV-related issues for this reason. Evidence of being told to stop taking traditional medicine before starting taking ART could also be seen in some clinic files. Some hospital forms, like the one below, had a question about traditional medicine in the ART treatment readiness assessment.


Are there factors that could influence the success of treatment?

	Yes	No
17. Socio-economic issues?		✓
18. Alcohol or drug abuse issues?		✓
19. Depression or other psychiatric conditions?		✓
20. Marriage or relationship issues?		✓
21. Issues related to religion or traditional healers?	✓	

If the answer to any of the above is yes, please give details:

YES: BOTH TRADITIONAL MUST ACCEPT HIM TO START ARVs.

Figure 47: Page of Khwezi's (20) health facility file documenting his use of traditional medicines. It reads: 'Question: 'Are there factors that could influence the success of treatment? (Yes checked next to the box that says 'Issues related to religion or traditional healers?). Form: If the answer to any of the above is yes, please give details'. The healthcare worker wrote 'Yes: Both traditional must accept him to start ARVS.' Photographed 22 March 2018.

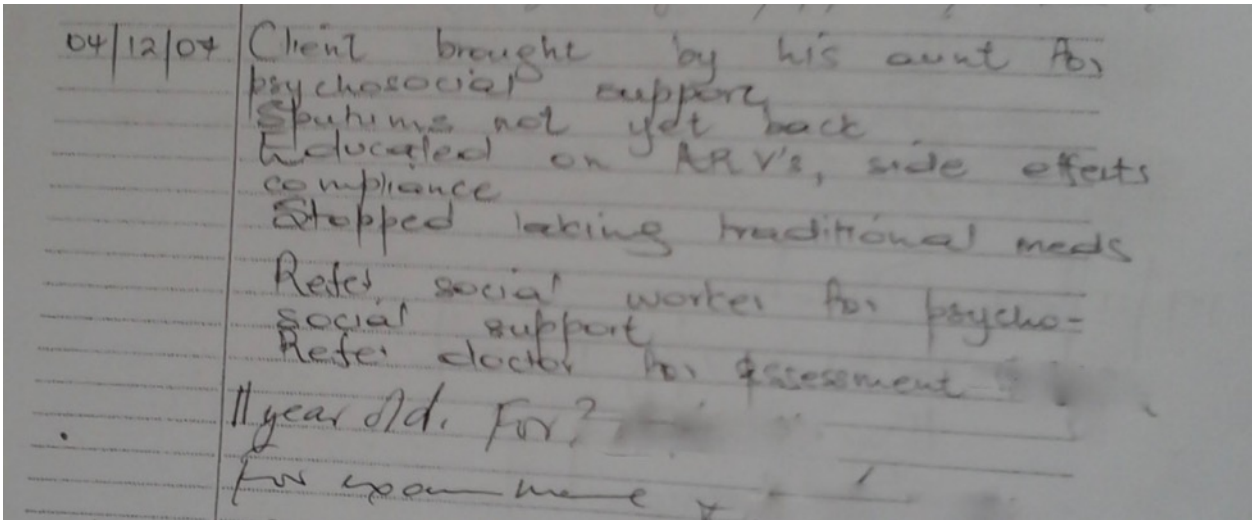

04/12/04 Client brought by his aunt for psychosocial support
Sputums not yet back
Educated on ARV's, side effects compliance
Stopped taking traditional meds
Refer social worker for psycho-social support
Refer doctor for assessment
11 year old. For?
For examine

Figure 48: Page of Ngamla's (21) clinic file from when he was 11 years old documenting his use of traditional medicines. This section of a clinic file says 'Client brought by his aunt for psychosocial support. Sputums not yet back. Educated on ARV's, side effects, compliance. Stopped taking traditional meds.' Photographed 5 May 2018.

These files demonstrate the type of information being provided to participants and their families about traditional medicine and HIV. Their decision to not take traditional medicine suggests that they internalised the advice about not mixing traditional medicine with ART. It is also possible that participants learned not to tell biomedical practitioners about their traditional medicine-taking, and extended this secrecy to the researchers. However, given their frankness about multiple practices that would be considered biomedically and socially undesirable, we believe that these findings are likely reflective of actual participant practice.

Other studies, such as those included in the background section of this chapter, suggest that HIV-related medical pluralism is common, and that many people mix ART with traditional medicine. However, Zuma et al.'s (2018) KwaZulu-Natal-based study dovetails with the findings presented in this section, which found that participants taking ART ceased to take traditional medicine, or that they are not taking traditional medicine for HIV-related issues. Hughes (2012) documented how few participants (16%) used traditional medicine after initiation onto ART, although the majority (79%) used traditional medicine before. This study also reported that being HIV-positive for a shorter amount of time was a significant factor in whether people used traditional medicine (Hughes *et al.*, 2012). Similarly, Peltzer and colleagues (2011) found that use of herbal therapies decreased post-initiation onto ART, with 36.6% of HIV-infected participants using traditional medicine prior to initiating ART, 8.0% after six months of initiation, 4.1% at 12 months post-initiation, and less than 1% percent after 20 months. The recency of these studies suggests either a variety of practices amongst many people living with HIV, and/or a change in previous years, perhaps due to increased biomedical information and universal test and treat. These studies align with one of the main arguments presented in this chapter: that most participants did not use traditional medicine for HIV-related reasons because of their long-standing experiences of HIV-related biomedical engagements.

This section has suggested that participants' biomedicine-only approach to HIV treatment and care reflects their early and long-standing experiences with, and exposure to, biomedical HIV treatment, care, and information. However, many participants reported accessing traditional products and services for other reasons that they perceived to be outside of the bounds of HIV. This is demonstrative of the presence of multiple understandings and practices in relation to health and wellness. Common methods of administration of traditional medicine will be explored later in this chapter. Reports of ingesting traditional medicine were relatively uncommon among participants, which is notable given the documented risks of dehydration and vomiting up ART when taking traditional medicine. As explored below, participant beliefs were varied about the origins of HIV, and the reasons why some people contract HIV and others do not. This suggests that participants' biomedical HIV-related practices did not hinge on their underlying HIV-related beliefs.

Common knowledge, a multiplicity of understandings: HIV origins & acquisition

Despite a strong awareness about HIV transmission, medicine and acquisition mechanisms, participants held varying beliefs about the origins of, and underlying meanings of, HIV. Of the 25 participants who elaborated their thoughts about the origins of HIV, five believed it had a supernatural origin, six thought it was spread by white people/Europeans as an experiment or as a way to harm Black people, and ten said that they didn't know. An additional three gave reasons such as Zimbabwean migration, that it came with soldiers, or that it was a virus latent in everyone. Thus, a large minority of participants held 'non-epistemic community' beliefs about the origins of HIV. The term 'epistemic community' is used here to describe certain scientific understandings about HIV that are popular in internationally-accepted policy and academic discourse. In this case, it refers to the belief that HIV exists, that it originated from the transmission of the simian immunodeficiency virus (SIV) in primates, that HIV causes AIDS and that ART is required in the long-term management of HIV. The term has been used in the study of HIV policy by scholars such as Youde (2005) and Fourie (2006).

Despite biomedical beliefs about HIV acquisition and treatment, a substantial minority of participants also believed it had supernatural roots. This aligns with the evidence that suggests that within some traditional African spiritual beliefs, good or ill health may be considered to include the interaction and relationship between nature, the cosmos, and particularly the relationships between the individual and other human beings, including the ancestors, who play an important role in well-being and healing (Gundidza and Kassilo, 2015). Traditional approaches to illness have been characterised as the consideration of health issues within the context of an underlying psychosocial, spiritual, communal or ancestral issue, in contrast to biomedical approaches which focus on curing as a biological process, resulting in the disease being cleared from the physical body (Moshabela, Zuma and Gaede, 2016). The below quotes reflect some participant beliefs that HIV has an underlying supernatural source.

> **Buja:** I think it is because HIV choses certain people, because it has its own reasons.
> **Interviewer:** Is it related to anything supernatural such as God, ancestors or witchcraft?
> **Buja:** I thinks it is related to ancestors.

Interviewer: Why you say so?
Buja: Maybe because it's been a while they (ancestors) left you with messages but you are ignoring them. Then when you go to the doctor you will find out that you are infected with the virus.
(Buja, 19)

Soso: … there is (God) and there is also witchcraft.
Interviewer: What do you mean?
Soso: Why do some people not get HIV? For example, I have HIV why don't they get it when they are helping me with my wound when they also have a wound?
Interviewer: So you saying its witchcraft?
Soso: Yes it is.
(Soso, 21)

If you remember, it is God who brought us on to this earth… I was born HIV-positive, and some weren't. I think it is God's will.
(Dee, 19)

These demonstrate some participants' beliefs that there is an underlying (supernatural) cause for transmission in the form of violation of ancestral wishes, witchcraft or divine will. These narratives align with the suggestion that HIV is associated with supernatural issues such as spiritual forces and witchcraft, which has been documented in a variety of studies (Ashforth, 2001, 2005; Nattrass, 2005a; Posel, Kahn and Walker, 2007; Wreford and Esser, 2008; Mfecane, 2010; Zungu, 2013; Rubincam, 2014). Such associations have been nationally reported (Shisana *et al.*, 2005, 2014), and are discussed in relation to familial misfortunes in the first findings chapter. Traditional and religious health beliefs may conceptualise health beyond the individual person and their biochemistry, into 'the consequences of social relationships for health and disease' (Green, 2012, p. 8). These findings align with a large literature that demonstrates that traditional African aetiological explanations of illness, including AIDS, may incorporate biomedical understandings while drawing on traditional knowledge, culture and spiritual beliefs and looking for 'ultimate' causes (Goldstuck, 1994; Semali and Kincheloe, 2002; Kalichman and

Simbayi, 2004; Wreford, 2005b, 2008a; Liddell, Barrett and Bydawell, 2005; Nattrass, 2005b, 2005a; Campbell *et al.*, 2007; Wreford and Esser, 2008; Jali, 2009; Mfecane, 2010; Zungu, 2013; Rubincam, 2014).

This may also explain how some participants, despite holding biomedical beliefs about HIV acquisition and practices of taking ART, possessed underlying supernatural beliefs about the origins and ultimate reasons beneath its acquisition. Implicit here is the belief that biomedicine may look at proximate biological processes, while traditional health beliefs look for underlying social and spiritual issues. It has been suggested that 'biomedical' and 'traditional' lenses measure different things and include different approaches (Moshabela, Zuma and Gaede, 2016). This traditional belief system differs from the biomedical in how it sees cause-and-effect, and conceptualises multiple, intersecting levels of well-being.

Another common belief in this study was that HIV was designed to harm or kill Africans by Europeans or white people:

> I think HIV is a virus created by a White people. It was created and put it into a human being… I don't believe that there could be a virus (like this) because there are a lot of people in the world… it is like Ebola, how could it come out of the blue? I don't understand… why does it (only) affect Africa when you say it's a virus? Because fever is natural because of weather - from Europe to Africa it is there, but then Ebola is here (only) in Africa. So I think it is made by a person that thing.
> (Luya, 17)

> **Akhona:** It was invented by some doctor and he took samples from the animals… it was taken from animals and they mixed it with chemicals and it was injected to people.
> **Interviewer:** Where do you think it comes from?
> **Akhona:** From Western countries, but I'm not sure which one.
> (Akhona, 19)

Variations of this HIV conspiracy theory – including that AIDS was created to harm and kill Black people has been documented by scholars including (Joffe, 1995; Finnegan, 2001; Niehaus and Jonsson, 2005; Campbell *et al.*, 2007; Bogart, Kalichan and Simbayi, 2008; Navario, 2009; Grebe and Nattrass, 2012; Nattrass, 2013; Zungu, 2013; Steinberg, 2017). It has been suggested that in aiming to understand the racialised roots of the AIDS conspiracy beliefs, that understanding the socio-historical contexts in which they exist and are reproduced are important to consider (Nattrass, 2013). Similarly, in making sense of findings of her study on social narratives of HIV amongst Xhosa men, Zungu (2013) draws on the examples of the forced sterilisation of African women (Zungu-Dirwayi *et al.*, 2007) and the bubonic plague as a justification to remove Africans from their homes (Airhihenbuwa, 2007) as examples of racist health-related conspiracies. In light of these, and within a context of ongoing racial oppression, it is perhaps unsurprising that such beliefs may continue to exist. As suggested by Heller (2015), conspiracy beliefs can be related to trust of a group of people, such as health professionals or a government, rather than as evidence of ignorance. Believing in conspiracies, or supernatural aspects of HIV, is often considered to be a result of lack of 'awareness' and education. However, the high level of scientific literacy about HIV displayed by adolescent participants and traditional healers demonstrated that this was not the case. Another apt biomedical example of denialism being related to trust, rather than to education or exposure, is that of vaccine deniers, many of whom are highly educated conspiracy theorists (Wolfe and Sharp, 2002).

Alternative explanations of the origin of HIV, both spiritual and conspiracy-based, also demonstrate the presence of multiple layers of knowledge and belief amongst participants. The variety of HIV origin beliefs expressed by participants represent complicated and multi-layered understandings of disease and illness, as well as variation amongst participants. It was difficult to ascertain if these were related to urban or rural location, age, family beliefs or other factors.

The responses below represent what the majority of participants believed – that HIV was not related to a conspiracy or anything supernatural. Common in these narratives was either 'not knowing' where it came from, or taking it as something that 'just is'. Notably, although these participants did not believe in conspiracy or supernatural origins of HIV, none spoke about the

generally accepted scientific evidence that HIV originated from the transmission of the simian immunodeficiency virus (SIV) to humans from primates (Worobey *et al.*, 2008).

> It's an illness like any other illness because HIV just came out of the blue without knowing where it comes from.
> (C'Vig, 19)

> I think it just came from nowhere - that is why it is incurable.
> (Ringo, 17)

Analysis of views of traditional health practitioner and adolescent participants, and a review of the literature reflect a complicated and uneven terrain of belief and practice, underpinned by a variety of multi-layered understandings. Findings from this and other studies suggest lack of cohesion of belief, and often, confusion in relation to HIV. It has been suggested that there are a variety of layered beliefs and practices around HIV, and that these are influenced by exposure to information, experiences, beliefs and family and social influences. One potential reason for this is that information about, treatment of, and visibility of HIV has undergone multiple shifts in its short history. It is a new disease, which has gone from being a death sentence to a chronic condition for many. There has been a move from treatment at different CD4 counts, taken as a proxy for illness stage, to being available to everyone. It has been highly political, and people in South Africa have been exposed to education-activism, via huge efforts spearheaded by the Treatment Action Campaign. HIV also brought about different ways of relating, and different forms of activism, sex education, and citizenship, against the backdrop of a political and social transition into democracy. In short, HIV and its effects and meanings have been in flux in ways that may be difficult to make sense of, especially within a changing political context with multiple syncretic belief paradigms and health systems.

This section has provided an overview of the variety of beliefs and perspectives among participants about the origins of, and reasons for HIV acquisition. In so doing, it demonstrates that far from being a homogenous group, participants had many different ideas about where HIV comes from, although there was a general coherence in their biomedical knowledge and beliefs

about HIV acquisition and treatment. A large minority of participant beliefs on the origins of HIV demonstrated the ongoing presence of commonly-documented explanations, including those of supernatural origins and conspiracy theories. Others said they did not know, demonstrating that either that they had not been exposed to scientific discourse about HIV's origins, that that they had not internalised it as a belief, or that they did not want to elaborate on what they did believe. Despite strong biomedical acquisition and treatment beliefs demonstrative of a high degree of exposure to this information, and experiences of the efficaciousness of biomedical responses, the 'underlying causes' remained varied and drew on a multitude of sources of information and belief-systems.

Do adolescent boys living with HIV access traditional health products and services?

This section presents findings on participant practices of engagement with traditional products and services for non-HIV-related issues. It starts by exploring how they reported on the use of traditional products and services qualitatively, documenting a divergence in reporting from the quantitative Mzantsi Wakho study. Following this, it presents the traditional products and services that boys reported using, and suggests that decisions around traditional health-seeking were mediated strongly by embodied experiences, beliefs and illness perceptions, and, for younger participants, by caregiver beliefs and practices.

Reporting on use of traditional products and services: methodological divergences

This study found that most participants had engaged with traditional health products and services, although their use was rarely reported within biomedical and quantitative framings. Of the 32 boys whose interviews are included for analysis in this chapter, when first asked if they had ever been to a traditional health practitioner, 10 answered 'yes' and 22 answered 'no'. After probing, or in other non-health focused interviews with the same participants, over half (n=18) described their use of traditional health products or services, with an additional two saying they intended to access them in the future. This means that a majority of the sample had accessed traditional health services at least once. By contrast, only 12% of quantitative participants at the Mzantsi Wakho baseline study reported using traditional products or services. Similar divergences between qualitative and quantitative reporting have been found in other studies on reporting of use of traditional medicine in the treatment of childhood illness (Moshabela, 2008;

Gittings *et al.*, 2019). Such divergences suggest that bifurcating health systems and research methods may limit our ability to understand and respond to the needs, beliefs and practices of children and adolescents. Beyond demonstrating the value of triangulating across methods, findings point to the importance of creating environments that enable open and accurate reporting of engagement with traditional products and services.

Why did so many participants answer 'no' despite having accessed traditional health services? There are at least two possible explanations. One is that participants were afraid of being stigmatised by virtue of having accessed traditional health products and services, and therefore answered in a way that they perceived to socially desirable. Social desirability bias 'occurs mainly for items or questions that deal with personally or socially sensitive content' (Lewis-Beck, Bryman and Liao, 2003). Because traditional healing is often framed as health-inhibiting or harmful practices used by uneducated people (Waldron, 2010; Flint and Payne, 2013; Moshabela, Zuma and Gaede, 2016), and this is especially true for HIV/AIDS, these responses may have been shaped by this bias. Another explanation is that traditional healing may also be stigmatised because it is perceived to be dangerous and related to witchcraft. These forms of stigma were described in an interview with two traditional health practitioners.

> **Mamj Ciky Vuza:** The reality is, first of all, the traditional practitioners are not taken as... it's not like a surgery... It's so secretive, because they don't want to be seen (going) into Gogo's place. Because they will say that '*I'm doing witchcraft, I'm a witch'*… sometimes they are accusing neighbours -'*my child has sickness; the neighbour is in on it*'.
>
> **Interviewer:** So they don't want to be seen?
>
> **Mamj Ciky Vuza:** Yes, because Sangomas have been stigmatised for a long time.
>
> **…**
>
> They take them just as '*they are those people who are not educated, who are dirty, who are not well, you see?*' and it is a long story, it's a long thing, because traditional practices have been stigmatised for a long time… it is a very low class thing.
>
> (Mamj Ciky Vuza)

In summary, two forms of stigma were put forth in this interview: (1) in relation to fear of witchcraft and the resulting secrecy over accessing traditional health services, and (2) perceptions of traditional health practitioners as dirty, mistaken, 'low class', and uneducated. These are quite different. While one suggests that traditional healing does not work, or health-inhibiting, the other suggests that it might be powerful or effective, but also risky or threatening.

The techniques that were used to minimise social desirability bias are discussed in Chapters Three and Seven. Interviewers asked variations on the same questions in different ways, and demonstrated open and non-judgemental attitudes to responses about belief systems, which may have reduced the risk of bias as the interview progressed. Although participants did not report accessing traditional health products and services when asked directly, in further probing or when telling stories, they disclosed that they had. Given the level of detail and openness in these answers, it is unlikely that they were fabricating responses. This suggests that their initial response (that they had not sought traditional health services or products) was the inaccurate one.

Another possibility is that participants perceive the Mzantsi Wakho research project to be interested in biomedical health issues, based on the questions that they had been asked in the quantitative survey. That is, the prior framing bias influenced their responses. At the time of their interviews on traditional health-seeking, they had participated in either two or three rounds of the quantitative survey, which focuses largely on biomedicine-taking and sexual health. If participants perceive a study to focus on biomedical health issues, they may filter responses to only include issues that they perceive to be biomedical in nature. By contrast, motivations for the use of traditional products and services may be unrelated to HIV or other biomedical issues and therefore considered outside of the scope of the study (Gittings *et al.*, 2019). The ways that participants who had accessed traditional health products and services conceptualised illness align with this suggestion, and are discussed in the following section.

What traditional products and services did participants use and why?

As documented in the above section about HIV, participants often distinguished between issues requiring biomedical and traditional care. This section explores how participants conceptualised and made decisions about using biomedical or traditional products or services. Participants often

juxtaposed issues requiring biomedical care against other forms of 'sickness' and ill health or misfortune of a supernatural origin. This aligns with the suggestion that individuals understand health and illness in a range of ways, and it is not possible to understand illness and healing solely through a biomedical lens (Steinberg, 2008).

The following quotes demonstrate how participants distinguished between issues requiring traditional and biomedical care:

> **Interviewer:** Do you believe in traditional healers?
> **Akhona:** Yes I do.
> **Interviewer:** What do you use them for?
> **Akhona:** I use them for dirty spirits not for things like sicknesses.
> (Akhona, 19)

> **Ta Saider:**… their medicine depends on your sickness. Let us say if you have evil spirits, so amagqirha (diviners) can help you with medicine, even the amaxhwele (traditional herbalists) are the people who can see bad things.. it depends on what your problem or your sickness is. If you are being followed by bad things, then amaqhira can help you and amaxhwele can also help you....'
> **Interviewer:** So you believe that amagqirha can help a person who is followed by bad things?
> **Ta Saider:** Yes, maybe that person has that problem which needs traditional medicine.
> (Ta Saider, 21)

It was common for participants to believe that certain issues require traditional products and services to be resolved. Often described in English as 'dirty spirits' or 'dirty things', participants referred to issues of pollution and bewitchment, which required traditional products and services and that couldn't be cured by biomedical practitioners. In many traditional African cultures, spiritual forces are an important part of people's worldviews (Zungu, 2013). A core traditional belief of disease amongst the amaXhosa and in many other African cultures is that ill health can be caused by violations of cultural taboos and witchcraft (Ngubane, 1977; Urbasch, 2002; Posel,

Kahn and Walker, 2007; Zungu, 2013). Such issues of bewitchment and pollution were understood to manifest in physical or situational issues. For example, after being accused of rape by his neighbour, a participant spoke about how his family sent him to the traditional health practitioner, hoping that they would cleanse him of the curse and the court case would turn out favourably for him. He described a process of cleansing and protection from a curse placed on him and his family by their neighbours. Here the family sought the intervention in response to a supernatural issue (witchcraft) manifesting externally in the form of a rape accusation. In another case, a participant shared a story of seeing someone physically healed after evil spirits were cleansed from him.

> They know how to get rid of evil spirits… I have seen one… One day a little boy arrived to the ixhwele very sick he couldn't even walk but when he came out of the house he was better and could walk by himself.
> (Dee, 19)

In both of these examples, traditional health services were sought with the hope that the underlying supernatural issue would be addressed and its physical/situational manifestations would go away.

Traditional health practitioners also spoke of behavioural issues demonstrative of problems of a supernatural origin that may cause caregivers to bring their children and adolescents to seek traditional services. These included not having performed certain ceremonies, bewitchment and *amafufunyana*. Traditional health practitioners discussed that amafufunyana, a common issue that affects young people, is something that caregivers will identify and seek traditional health services for with their children. Although not specific to only adolescents, amafufunyana has been described as a form of mental disorder where the person is being possessed by evil spirits (Ngubane, 1977; Mdleleni, 1990). Mlisa (2009) defines it as a human-made spirit used as a means of sorcery with negative intentions. In addition to accessing traditional health services for issues of bewitchment, pollution and kinship, participants described also accessing traditional products and services preventatively for protection against such issues. Ukuqinisa, meaning 'to strengthen'(Mlisa, 2009) or 'to fortify' is a common spiritual protection practice that can take

many different forms. It can apply to homes or items (such as cars), as well as to physical bodies. When performed on the body, it is often done via putting traditional medicine into the body via small cuts on the skin. In addition to having functions of cleansing, the use of traditional medicine for steaming and bathing can also have a protective function, as can wearing certain medicine or items on the body. In this way, these practices have a spiritual function, rather than solely a physical therapeutic one. The modes and contents of each treatment will vary on the traditional practitioner's diagnoses of their client's need, which includes use of intuition and ancestral direction. It also depends on the way that the traditional practitioner practices, which is based on their own abilities and specialisations, as well as training, ancestral direction and culture. For this reason, summarising the specific ways in which traditional practitioners work as one would do within the biomedical sector with specific guidelines and dosing is not possible.

Participant use of traditional products and services for protection were common. For example, when asked if he ever used traditional products, the participant below showed the researcher a rope he wore around his waist.

> **Nginduyi:** I went to put on this rope (lifts up his shirt and shows rope around his waist).
> **Interviewer:** What is this rope for?
> **Nginduyi:** To protect me from evil spirits like witches.
> …
> **Interviewer:** So did it work?
> **Nginduyi:** Yes.. Like in school, I did not like going to school but after I went there now I like going to school.
> (Nginduyi, 16)

Others, like those below described steaming, bathing or putting traditional medicine into the body via small cuts in the skin as forms of protection:

> **Bele:** I was applying the medicine throughout my body… I used to steam then after I would bathe. Then (use) another medicine… applied to the whole body.

Interviewer: What were the reasons why you were using the traditional medicine?
Bele: I was protecting myself against evil spirits.
(Bele, 19)

… (they) cut two tiny lines in the body and put black traditional medicine into those cuts to prevent dirty things.
(Ta Saider, 21)

The most common reason for going to a traditional health practitioner in this study was for protection before ulwaluko. Just under half of the participants in this study had done this, or said they planned to. In the interview below, a traditional health practitioner explained that it this is a very common time for adolescent boys and young men to engage with traditional health services, and outlines the belief that abakhwetha are vulnerable and need protection during this time.

The young boys, when they are about to go to the mountains, they will come… They want you to protect them... "*I am going to the mountains* (used to refer to the time in ulwaluko, regardless of whether the process takes place on the mountain or not), *I want you to give me something to protect me when I'm there in the mountains*"… Like I've said, when you are around home, the other people's spirits will protect you, but when you are on your own, that's where you need your ancestral guardians and protection. That's where you need to be protected the most. Because you are an easy target… to be bewitched, to be, you know, anything can happen to you and we will always blame who was treating you.'
(Gogo Nosi)

The belief conveyed by Gogo Nosi is that boys are physically and spiritually vulnerable during this time and require protection from bewitchment and evil spirits. The underlying concern is that this might result in something going physically wrong. Given the injuries and deaths experienced by abakhwetha, and the social risks of not completing ulwaluko (as explored in Chapter Five), this was a concern for many participants. Participants provided the same reasons as to why they would or had accessed traditional services before ulwaluko: that is they wanted to

be protected, with the understanding that ‘a lot of things’ are happening during ulwaluko that could go wrong.

> I went there for protection so that it can protect me from evil spirits while I was at the initiation school.
> (Dee, 19)

> Maybe if you are going to initiation school you are forced to be prevented so that bad things cannot come to you. Yes, these things do happen. Before you go to initiation school you have to do these things so that you can be protected from bad things.
> (Machete, 22)

In addition to protection and cleansing, issues of discord between kin were also common reasons for using traditional products and services. Within this traditional knowledge system, good or ill health is considered to include the interaction and relationship between the individual and other human beings, both living and dead (Gundidza and Kassilo, 2015). Another common reason for accessing traditional products and services was for ceremony or ritual. The role of ceremony, including imbeleko and ulwaluko, as rituals of incorporation were discussed briefly in the Chapter Four. Ceremonies are understood as a remedy to certain underlying supernatural issues, including those originating with the ancestors. As explained by one traditional health practitioner:

> And some of the issues are the issues that does not really need muti but needs the rituals, you see? It’s different, sometimes when a person comes to you, it is an issue that needs muti to heal, and sometimes it needs a ritual.
> (Tata Bongikhaya)

Imbeleko was frequently discussed as a ceremony by adolescent participants and traditional and biomedical practitioners that, if not performed, might cause issues. As explained by a traditional health practitioner:

> There is a ritual called imbeleko. It sets a foundation in our culture for any person. It is the first ritual that is a done in a human being. The families they differ. It is meant to be done at a very early stage of a child. If they don't do it, it can cause problems... sometimes a child can live an abnormal life. Maybe this person is coming from a good family, you see, but the way the person is conducting himself or herself he became a criminal. You see things like this in the family, the parents when they detect that they say "*no man, lets rather go to a sangoma to find out about this*". In that regard you will be told by the ancestors "*no, this person does not need any muti, but they owe a ritual*". (Tata Bongikhaya)

Imbeleko has been documented as a ceremony performed, usually to a baby or young person, to introduce them to their family community and the ancestors (Ramose, 1999; Mlisa, 2009; Ross, 2010), and associations between not performing imbeleko and misfortune are common (Ramphele, 2002). Traditional health practitioners also asserted that not having performed certain ceremonies for the ancestors may also cause issues with misbehaviour in young people. Like traditional health practitioners, some participants also spoke about having imbeleko performed as a traditional health service. Chapter Four spoke about the importance of imbeleko for introduction to the ancestors in the context of boys not knowing their patrilineal kin. Here, it was also spoken about as a way to heal the symptoms of not being introduced to their ancestors, which can manifest in issues, including physical illness.

> I was very weak at that time… I had sores everywhere... I got better when my father had a dream because he is igqirha (a traditional health practitioner). He dreamed that I should have imbeleko, and … (after imbeleko was performed) the sores (on my body) got better. (Layzdu, 18)

This example provides insight into the role of ceremony, such as imbeleko, in addressing supernatural issues, which in turn will address their symptoms such as misfortune or physical issues. Ceremony may also be required for issues of pollution, bewitchment, responding to a calling to become a traditional health practitioner, or other requests from the ancestors. Participants also described the use of ceremonies for a variety of home-related issues, including

protection, cleaning or appeasing the ancestors. Alongside these, traditional medicines were also often used, including in and around the home, and externally and internally by family members. These aforementioned forms of traditional health-seeking were related to the well-being of family and kinship relationships, as opposed to a biomedical-only conceptualisation, which focuses on curing as a biological process (Moshabela, Zuma and Gaede, 2016).

'It depends on what your problem or sickness is': How did participants decide whether to access traditional or biomedical health services?

The above section described the common reasons why participants would access traditional products and services, and the way that they used them. But how did they determine whether to use traditional or biomedical care or services, or both? When asked to describe the differences between biomedical and traditional care, a participant summed this up by responding: "It depends on the illness that you have—that's the difference."

The belief that some issues are supernatural in nature and require traditional products and services was also common among traditional health practitioners, as well as some biomedical practitioners who provided more insight into participant perspectives:

> It is the nature of the problem that actually makes that particular person decide as to whether they go to a doctor or a traditional healer… generally, when a person is sick he would go to a doctor, particularly when it comes to the physical sicknesses. But there are sicknesses that are not physical… For example, when a person is getting mad (mentally ill). The very first person the family will think of is the sangoma…. If the person, maybe at night if they have fears of the unknown, they would literally go to the sangoma, not to the doctor. Hence it depends on the nature of the sickness…
> (Tata Bongikhaya)

However, the distinction between issues requiring traditional services and those requiring biomedical care was not always clear-cut, especially for some physical issues that were understood to have an underlying spiritual cause.

It was generally understood that issues not manifest in the physical body, such as mental health, bad luck, bewitchment, family problems and issues with ancestors or evil spirits, required traditional care. It was also suggested that other issues grounded in the physical body—for example, headaches, stomach problems, swollen legs and rashes—may be ambiguous in terms of the care needed, potentially requiring one, or the other, or both. This aligns with the belief that traditional and biomedical health services can be used complementarily for some issues – the biomedical one to support symptom management, and the traditional ones to address the root issue. A traditional health practitioner provided an example of an infection caused by witchcraft: an infection obtained from stepping on a sharp object. In this example, the supernatural issue was witchcraft, in which the person was set up to step on something. This in turn caused a physical issue, an infection.

Like Tata Bongikhaya, other participants also understood that some physical issues, despite having supernatural roots, may require biomedical treatment, although participants' narratives did not suggest that they saw HIV as an illness requiring both. However, it was unclear from their narratives if they accessed traditional products and services for HIV-related symptoms, without being aware of those symptoms' relationship to HIV, or sought services in relation to the underlying causes of their HIV acquisition. Flint and Payne (2013) suggest that biomedical and traditional lenses have different strengths – biomedicine for its biological curative approach and traditional healing from a spiritual, emotional and familial perspective.

Sometimes participants were uncertain about what types of health products and services they required for a certain illness. In such cases, they documented a 'process of elimination'-style approach, where they first tried one type of care, and then another if the first did not work.

> **Interviewer:** So when you sick which one do you prefer to use first?
> **Bele:** I first go to the doctor.
> **Interviewer:** Why?
> **Bele:** So that he can detect what's the problem so that I can see whether the doctor's medication can help me or not so that I can make a decision on which one to use. (Bele, 19)

Participants in this study often sought biomedical care first, and then traditional services if the biomedical treatment did not work. It is possible that their histories within the biomedical care system influenced these decisions to access biomedical care first. Similarly, Zuma (2018) suggests that some people tend towards either traditional or biomedical explanations of illness, and that how the illness is perceived by the patient or their family determines the type of care they seek. In cases where they can't distinguish the cause, they are likely to seek both traditional and biomedical care (Zuma *et al.*, 2018). Other factors influencing decisions to access biomedical care first may include the costs of going to a traditional health practitioner.

It was suggested that accessing biomedical care first might be more common practice in urban and peri-urban areas. For example, Tata Bongikhaya suggested that decisions of which type of care to access would be dependent on the issue, but that most people would first access biomedical services:

> You see, when the person is physically ill, the first thing to think about is not the traditional doctors, but the doctors. The professional doctors. They would think of the medical doctors first. But depending particularly on the nature of the sickness… (Tata Bongikhaya)

Luthando, another traditional health practitioner, shared a similar perspective, but suggested that culture of the area may influence where a person might go to first, distinguishing between urban and rural approaches:

> It depends on where they live. In the township they will go to clinic, they will go to the sangoma for magic, but for physical things they will go to the clinic. Then in a village it is slightly different, because the culture is still much more on this (traditional) side. So a person may start from a sangoma, if they cannot be helped they will go to the hospital. (Luthando)

This trial-and-error approach demonstrates how experience may inform health beliefs and practices. In this way, the reasons why participants and their families sought different modes of health services is not just based on enacting a set of beliefs, but also a process of trying things out to see what works. As suggested by Tata Bongikhaya below, people are essentially seeking well-being and in doing so will try different products and services. He suggests that people decide where first to seek health care and services based on their desires, access and needs.

> …the issue here, what the person wants is to get healed whether it is through the medical doctor or through the traditional healer... What makes a decision is what the person needs and the knowledge he has about those two.
> (Tata Bongikhaya)

This assertion aligns with that of Green (2012) that the continued bifurcation and polarisation of these two systems, and the associated denouncing of one side over the other, can undermine 'nurture, care and well-being', which is what people are ultimately seeking.

The role of caregivers in making decisions about the health services that young people seek is also important to consider. As younger adolescents, participants accessed both biomedical and traditional products and services with caregivers. As dependents, they had experiences with health products and services based on their caregivers' decisions, beliefs and preferences. A traditional health practitioner spoke about how caregivers make decisions about the type of health products and services their children need:

> I've never seen a young boy come alone to our homestead. They will come with their parent, they will say "*hey mama I'm sick*". Then the mom will take responsibility, depending where (traditional or biomedical services) they are inclined. And mostly if it is a physical thing the mother is inclined to the clinic. What is not a physical thing? "*Hey that child at night, doesn't sleep, he went crazy. He was mumbling we couldn't even hear…*" I'm just making an example. Or "*this child just fainted*". They don't relate the fainting to a physical thing… they will diagnose it as a spiritual thing rather than going a

> physical thing. If the mom diagnosis it as a spiritual thing, she will take them and go into the consultation with them.
> (Luthando)

Here, Luthando suggests that the caregiver's belief system, alongside the nature of the illness, will influence the services that a caregiver will seek for their child. As discussed above, they will take the child to biomedical services issues considered to be a 'physical' thing, and to traditional health practitioners if they deem it to be a 'spiritual thing'.

Traditional health practitioners suggested that adolescents would access traditional health products and services if their caregiver thought they were experiencing an issue of a supernatural origin that required such care. In other situations, young people would participate in the use of traditional products or services if the issue affected the whole family.

How individuals are related to the world around them, and especially kinship relationships where family connections are rooted in an ancestor, is of fundamental importance to such understandings of health and well-being (Gundidza and Kassilo, 2015). For this reason, families are often treated together by traditional health practitioners, which is another reason that participants mostly accessed traditional products and services with caregivers and family members. Other studies have documented how the influence of family, and especially of elders, plays a significant role in family decisions to use traditional care (Puoane *et al.*, 2012; Zuma *et al.*, 2018). For participants in this study, decisions around health practices were directed by caregivers, especially for children and younger adolescents. That caregivers were either living with HIV, or had witnessed the death of a family member to AIDS-related illness, may have meant that they were more likely to support HIV-related biomedical practices for the children in their care. The point at which young people begin to make these decisions for their own, and the mechanisms through which growing up living with HIV mediates these decisions, is unclear from the data and merits further exploration.

Chapter Four suggested that participants' HIV-positive status was symbolic of and seen as part of a larger set of misfortunes. If these misfortunes have supernatural roots, why then did

participants not engage traditional products and services to address them? It is possible that participants due to their young age would not be expected to do this, and that older adults in positions of family leadership would rather make these decisions. Although participants may have been influenced to take part in familial engagements with traditional products and services, as young people they are unlikely to be expected to spearhead family spiritual issues. They may however be using performances of therapeutic citizenship and masculinity as avenues towards familial redemption and respectable personhood.

The role of knowledge and belief in influencing practice was also evident for participants in this study. The slight minority of participants who had never accessed traditional health products and services were mostly from families that held Christian-only beliefs. Of those who said they did not or would not access traditional health services, the reasons were that it was uncommon practice for their families—'No, we don't do those things here in my home' (Soso, 21)—or that they did not believe in traditional medicine. Sometimes this belief was stated overtly, as one participant described: 'I don't believe in those things' (Khwezi, 20). However, other times it was implied by holding a Christian-only belief 'I was trusting the Lord' (Svij, 25). Of the 32 participants in this sample, just over half (n=17) expressed that their spiritual beliefs included both a Christian God and the ancestors, reflecting that many practiced both 'Western' and traditional religions concurrently and used both traditional and biomedical health systems (Nigosian, 2015).

From these interviews, it was also clear that beliefs did not always manifest in health practices. Some participants who held ancestral beliefs did not access traditional products or services. This is interesting, given that African traditional religion, spirituality and healing are often interwoven (Mokgobi, 2014), and that this traditional lens of illness encompasses relationships between the ancestors, God and the cosmos or universe (Chavunduka, 1999). In many cases, this could be explained by participants making an active decision to not use such services on the basis of incompatible beliefs, poor experiences and/or strong negative associations with them. Such negative associations could be related to a sense that traditional health practitioners had the power to hurt people, and might be dangerous. The belief that traditional health practitioners could be scary and dangerous was alluded to (although not explicitly spoken) by participants,

regardless of whether they held ancestral and/or Christian beliefs. Some participants also shared that their negative associations with traditional health practitioners were related to these practitioners being charlatans, touting products and services that do not work as a way to make money. Like other decisions in relation to modes of health practice, this could be a result of things they had been told by others, or from first-hand experience. For example, the participant below spoke about not believing in traditional medicine or traditional health practitioners, although he had accessed them with his mother when he was younger:

> **Ngamla:** I used them a lot when I was young, and now, yho (exclaims), I don't.
> **Interviewer:** Tell me what happened?
> **Ngamla:** It was my Mom. I don't know what they said I had back then, but I wanted to get better and we went. The iGqirha (diviner) gave me some medicine. I kept drinking them up until I said "*Fok off, there is nothing happening*". Now I don't want to see them. (Ngamla, 21)

This participant narrative is demonstrative of how, through life histories and experiences, the uptake, reproduction or interruption of practices occurs. Here, Ngamla's experiences of taking traditional medicine and not experiencing a change influenced him to stop taking such medicine and accessing the services of traditional health practitioners. He also demonstrates how his decisions around health-seeking when he was younger were contingent on his caregiver. As he moved into older adolescence, he began to make individual decisions about health-seeking based on his embodied experiences of 'what works'.

This section has demonstrated that many participants used traditional products and services for a variety of issues unrelated to HIV, and that their health practices are strongly mediated by their caregivers, especially when they are younger. It also documents how beliefs, understandings of illness, and embodied experiences of what works influence modes of health practice. The next section explores further how participants used health to perform adult masculinity, and exercise autonomy from caregivers.

Health practices, autonomy from caregivers and performances of masculinity

The previous section suggests that some, but not all, adolescent boys and young male participants accessed traditional health services, and that as children, their health products and services depended on their caregiver beliefs and preferences. This section posits that as participants get older, their traditional and biomedical health practices serve as avenues for hegemonic masculine performances. In this way, they can demonstrate autonomy and separation from caregivers, and a shift into adult manhood.

Engagement with traditional products and services as avenues towards masculinity

Traditional health practitioners observations about adolescent traditional health practices are presented below. Although it is important to consider young people's behaviours and experiences as separate from adult perspectives, these narratives provided additional insights on the patterns and reasons for adolescent engagement with traditional and biomedical health services. These generally agreed with and provided depth to what adolescent participants said themselves. Traditional health practitioners suggested that adolescent boys sought traditional health services by themselves for issues of a 'personal' nature: namely, getting attention, success in sport, sexual performance and 'luck' with women and girls. They suggested that for adolescent boys, these were related to attempts to perform to hegemonic masculine norms as they become men. These stood in contrast to accessing traditional health products or services to address an underlying supernatural or familial issue.

> …If they come alone normally we'll find out they would go for their own personal reasons, you see? But… in most cases they will be taken by their parents.
> (Tamella)

Another traditional health practitioner also differentiated between issues for which adolescent boys and young men would seek traditional products and services along with their caregivers, and those for which they would go 'behind their (caregivers') back'.

> See young boys will use sangomas for other things. "*We are going to fight that side, I want to be this inkunzi*" (a Mpondo term for a dominant masculinity, a bull). They will go

> for magic stuff. To be made strong. '*I want girls to like me, give me something*'. '*We are fighting another village that side'*... Or they are playing a soccer match, so they go. Or it can be for cows, for livestock, '*ok I want to protect my resources, my assets*'. So that is the magic. But when it is physical, when you talk adolescents, because they are closer to their mothers because they are still adolescents. It's the clinic. I don't think a 16 year old will go by themselves for physical things… (They go) behind the parents back. They don't go to their parents and say they want to win this match, or to get girls. They will go behind their back.
> (Luthando)

In this quote, Luthando speaks about issues related to hegemonic norms of masculinity such as fighting, strength, being noticed by girls and material wealth as reasons why adolescent boys might access traditional health services without their parents. He differentiates these from physical health issues where their caregivers would take them to the health facility. He also spoke about an age distinction – suggesting that it is older boys and young men who do these things – especially after coming back from initiation, which has legitimised them as men.

> I'm talking about boys that are 19, not 15, 16 who are still closer to their mother's side. Those who are older, they are starting to realise their matureness, they are fighting, it is climbing the alpha-male ranking order…. when a boy starts becoming macho, he can stomach stuff. If he can stomach it, when he gets there you can see he is manning up, he flexes. He says ' *I need this thing, I want to get girls*'. The sangoma will play with him and see… he will have to be standing (up to them), '*no I need this*' (traditional medicine). His bravado wins the situation.
> (Luthando)

Here Luthando suggests that accessing traditional health services alone is part of a rite of passage, involving performances of hegemonic masculine norms. Going to the traditional health practitioner for these reasons and 'flexing' and acting with 'bravado' demonstrate to the traditional health practitioner that he has entered into a stage of adult manhood where he can access these services. In this way, the act of accessing traditional services in itself is a

performance to hegemonic masculine norms. The services sought are also engaged to support such performances.

Gogo Nosi, a female traditional health practitioner, also spoke about adolescent boys coming to see her alone in relation to issues related to masculine performances. Rather than using the word 'magic' (as Luthando did) or 'personal' (Gogo Tamella), she describes such matters as 'silly things'. She also differentiates them from the reasons why a participant would seek help with a parent.

> **Gogo Nosi:** …boys, wena, they want to be noticed. If that boy is there, they want everyone to see them, to notice them that they are there. So they want that thing that will give them, that thing that says "*look at me, I've arrived, look at me*"… if it's nje, (that silly thing) they will come alone.
> **Interviewer:** So they would never come alone for a physical issue?
> **Gogo Nosi:** No, they would drag a parent along.
> **Interviewer:** Ok, and in your experience in the area, do a lot of young people want to come?
> **Gogo Nosi:** They do. Our generation, oooooo ai! Our generation, they do come… (Gogo Nosi)

Similarly, Tata Bongikhaya described the issues for which young people would go alone to a traditional health practitioner as 'childish', 'personal' issues relating to seeking love and sex. In line with earlier presented findings, he was also clear that parents would accompany them for other issues:

> **Tata Bongikhaya:** But their own personal reasons mainly, you find it as the childish issues, you see? Ones where they want boyfriends and girlfriends, and ones when they have their own personal matters you see? There are some other sicknesses as well that they will go to a sangoma for at that early age. But like I said that some of the issues, they would tell their parents and then their parents would tell them "*no lets go to the sangoma"*.

…
at that (older) age… it would be the issues of girls… (and) some have issues with their manhood.
Interviewer: Sexuality? *(sexual performance)*
Tata Bongikhaya: Yes, sexuality, you see? Those are the personal things that I'm talking about, and those are the things that are triggering them.
(Tata Bongikhaya)

The insights of these four traditional health practitioners include that adolescent boys and young men clearly distinguish between issues that they would access health services (either traditional or biomedical) with family, and issues of a 'personal' nature where they would access such services alone. These issues were related to supporting gendered performances of masculinity, and emerged as they became older. This aligns with evidence which documents the use of traditional medicine for business success, money and sexual virility (Appelbaum Belisle *et al.*, 2015).

In line with these traditional health practitioner's assertions, issues of sport and being noticed were described by participants as reasons they had sought traditional health services alone. However, participants did not speak about sexual performance and 'luck' with women and girls. It is possible that this is not a widespread practice, or, given the highly personal, and perhaps embarrassing nature of this claim, it is plausible that participants had requested this type of services but did not feel comfortable sharing this experience.

Ndofaya: You just tell the healer that you want to shine in the field and perform, then the healer will give you something that you will use.
Interviewer: So do the things you get from the healer work?
Ndofaya: Yes, some do work and others don't work.
Interviewer: How do you see that it is working?
Ndofaya: You see at the end of the match, people will compliment you.
Interviewer: So what kind of stuff do they give you?
Ndofaya: Something to wash with, and something to put on your face… when you go to

the field

…

Interviewer: So to this healer you go alone or as a team?

Ndofaya: As a team, but when you want something alone you can go (alone). (Ndofaya, 18)

This section has suggested that adolescent boys may seek traditional health services alone for support in performing to certain hegemonic masculine norms such as strength and sport, sexual performance and 'getting noticed' by women and girls. They accessed such services alone, rather than with their families. In this way, such engagement in traditional health products and services served as both an avenue towards autonomy from family and as a performance of adult masculinity. The next section suggests that biomedical practices become aggravated by challenges of masculinity as participants get older, but that participants do not compensate this by engaging traditional services.

Biomedical health services (dis)engagement and performances of masculinity

Just as traditional health-seeking may serve as an avenue of performance to hegemonic masculinit(ies), it has also been suggested that accessing biomedical healthcare is a way to perform to hegemonic masculine norms. Worldwide, men have higher mortality rates for all leading causes of death and shorter life expectancies (Shefer *et al.*, 2007) due to health behaviours related to norms of masculinity (Baker *et al.*, 2014) and institutional supply-side barriers (Dovel *et al.*, 2015). In the case of HIV, men are more likely to default on ART, or die while on ART, and they tend to seek treatment less frequently and at a later stage than women (Nattrass, 2008b; Cornell *et al.*, 2010; Cornell, McIntyre and Myer, 2011; Johnson *et al.*, 2013). It has been suggested that hegemonic norms of masculinity make it harder for men to access necessary biomedical care because of its association with femininity and weakness (Jewkes *et al.*, 2007; Colvin, Robins and Leavens, 2010; MenEngage, Promundo and Sonke Gender Justice, 2015). These harmful norms inhibit health-enabling behaviours (Baker *et al.*, 2014). In South Africa, men live, on average, 6.2 years less than women (Statistics South Africa, 2018) and are significantly underrepresented in HIV/AIDS testing, treatment and psychosocial support services, as well as other sexual reproductive health services (Cornell *et al.*, 2010; Cornell,

McIntyre and Myer, 2011; Johnson *et al.*, 2013). The observations of adolescent male participants in this study agreed with this literature, and about half of participants suggesting that men have more trouble taking care of their health then women do:

> Boys are so stubborn, because no matter you can say a boy must take his tablets due to his sickness, but because he manages to walk with his feet he refused to take tablets. So when that illness gets worse and uncontrolled that person dies… A girl is very careful when she finds out she has a disease and also take her medication according to the rules.
> (Ulwazi, 13)

> Men are people who do not have patience, they take big things lightly, for example, if a man is HIV positive, they still decide to go for drink alcohol whereas they know that drinking alcohol is going to affect his life badly. When it comes to women, they always care for their health… So some (men) of them say that '*I can't eat tablets just because of HIV*' and they do not accept their situation. The problem is that most men are in peer pressure and they like to enjoy most of the time. Women always accept their situation and they also take their medication properly…
> (Ta Saider, 21)

> They (men) don't take it serious… Men don't show it to women that they are sick or when he is feeling a pain…
> (Soso, 21)

As can be seen above, the assertion that boys and men are less likely to take medication and acknowledge and respond responsibly to health issues was presented by participants in this study. In line with the literature on hegemonic masculinities, strength and independence were masculine norms that participants ascribed to (as discussed in Chapter Four). Biomedical healthcare workers also spoke about boys' and men's challenges with health-seeking, suggesting that they would access biomedical care and treatment only when health-related problems become too pronounced to avoid:

Dr Malibongwe: I think it is the psyche, that when men experience problems, even when it is with health, they are concerned about fixing that problem, rather than investigating why… it's very difficult, even for them to go to a public clinic to discuss those problems. It's a battle for them having to go to a doctor. So when they do come and present to you it's important that you treat that in the manner that they (can) handle it. It's not things that they talk about casually.
Interviewer: It sounds very sensitive.
Dr Malibongwe: It is very sensitive, yes.
(Dr Malibongwe)

Our problem as men, we only go to the clinic when we can't go on anymore.
(Mr. Mbelelo)

It's not easy for males to seek medical help. They only come when they are very sick… I'm sure it's part of their socialisation. It's like '*you must be a man*' even if it's for flu. (People will say) '*you can't have a flu, are you a female? You can't sleep because of this?'* Even boys this age (gestures to floor) when he falls down, when he is about to cry you hear the mother saying don't cry, a man doesn't cry. Nyamezela (persevere). They've been taught to endure. When they seek him, its beyond nyamezela, they can't endure it anymore.
(Sister Nceba)

In line with participant assertions and a growing literature, the above biomedical health worker narratives also suggest that men only present for biomedical care and treatment when an issue is severe. Implicit in these narratives is the suggestion that it is socialisation that deter men from acknowledging weakness, accessing care, opening up and seeking support. This aligns with the assertion that hegemonic norms of masculinities equate illness to weakness and weakness to emasculation, making it more difficult for men to access biomedical care and treatment (Jewkes *et al.*, 2007; Colvin, Robins and Leavens, 2010; MenEngage, Promundo and Sonke Gender Justice, 2015).

As discussed throughout this thesis, disengagement from health services and HIV-medicine taking was also common amongst participants. Chapter Five documented how during and after ulwaluko, many participants disengaged from care due to strong norms around medicine taking at this time. Earlier in this chapter, it was suggested that disengagement from HIV treatment and care was a way to test the bounds of their bodies and distance themselves from an HIV-positive status. This section posits that another reason for disengagement in HIV care and treatment is as a form of separation and autonomy and performance to hegemonic masculine norms, which affect adolescent boys more as they become older.

In this study, two commonly cited deterrents for adult men's disengagement in biomedical care were found amongst participants: (1) clinics as stigmatising spaces, and (2) mistreatment from health care workers. This section suggests that as participants got older and accessed clinic services by themselves, these issues may have acted as deterrents to engaging in biomedical care in a similar way that they do for adult men living with HIV.

Fear of 'being seen' to be accessing HIV-related health services was a common theme amongst participants. This was especially true for health care centres based in smaller communities (rather than large public hospitals), and in facilities where they had a process that separated patients with chronic conditions from others. For example, one community health centre had a separate section and bench for people picking up chronic medications, which is visible to people in other parts of the clinic. Those who are not there to pick up chronic medication sit in a general seating area. When it is a patient's turn to be seen, their name is called. This results in people picking up chronic medications being both visually separated and audibly identified. In a conversation about 'the bench' where people wait for chronic medications, a researcher who lives in this area described the dynamics of stigma at this facility:

> **Lesley:** So for example Phakamani, when you go there (to this health centre), are you looking to see who is on that bench?
> **Phakamani:** (laughs and puts fists to mouth) If I go alone, no, but if I go with friends they will look. People are curious - why are you sitting on that bench?
> **Lesley:** But the people could be there for diabetes medication?

Phakamani: You know Les, in our community, people are tested by eyes.

Here Phakamani suggests that people sitting in this area may be assumed to be HIV-positive. 'Testing by eyes' was a metaphor for how people make assumptions based on what they see. This was affirmed in participant interviews who accessed services at this health facility, or other facilities that separated people taking chronic medications:

> It is the eyes of the people. It seems like they are talking about me…
> I lie to them and tell them that I am here to collect medication for someone else…
> (Nkweza, 18)

> There are a lot of people I know there, like I am not ready for my status to be known by other people. So when they see me if I am there, there is no use. I just feel down when I have been seen by someone who knows me while I am fetching my medication… there is separation of departments between HIV, TB and others. I would (rather) like us to sit in the same waiting room. Remember that there is that thing called 'confidentiality' so we don't need to know... I don't feel good when I'm about to go to the clinic because even yesterday I was supposed to fetch my medication, but when I arrived after taking my folder I noticed pupils from my school at the other room so I went back home.
> (Luya, 17)

> When I'm going to the clinic I keep asking myself "*did anyone see me*"?
> … Sometimes there are children that I go to school with who are at the clinic and when the nurses are asking all the people who are there for treatment (chronic medication) to give her their books, if that particular person saw him giving the nurse the book then at school I will be a laughing stock because he/she will know that I'm taking treatment… I would never pass it on (give them my folder in front of someone he knows), but I would just stand up and go to the other rooms and report that I'm here for treatment.
> (Ringo, 17)

> At the clinic people that are living with HIV, it's like they are making a joke out of them. What I mean is being given those folders you see? … What I don't like is those folders. (Svij, 25)

The above excerpts speak about how being 'visibilised' as taking chronic medication at the health facility is a source of stress and discomfort. Participants spoke about trying to keep their HIV-positive status a secret within this challenging environment by lying, or leaving the facility if they see people they know there. In trying to keep their HIV-positive status a secret and avoid HIV-related stigma, participants were deterred from accessing HIV treatment and care. Additionally, the ART unit manager of a large hospital in the Buffalo City area suggested that getting older and not being under as close caregiver oversight played a role in treatment adherence. She posited that adolescent boys might have more trouble adhering as the HIV-related stigma that affects men also begins to affect them more as they grow up:

> …I cannot lie, when they are still under parents' care, they are still very young. When they haven't (yet) grown up to look after themselves, you find that they are adherent to treatment. But when they have been given that leeway that they must look after themselves, it's when there is a high rate of defaulting. Especially with the male adolescents, more than the girls. I'm sure it's the stigma attached, the same stigma that affects men. It also depends to other issues also. You'll find that there are other psychosocial issues that one hasn't dealt with, and they influence the way that one will behave and be adherent to treatment…
> (Sister Nceba)

Here this biomedical healthcare worker spoke about her observations about adolescents attending the ART clinic of a large public hospital. She suggests that two factors in relation to poorer clinic attendance and retention in care are present: (1) that of age and caregiver accompaniment, and (2) gender. The first corresponds with finding from the Mzantsi Wakho study that caregiver accompaniment is a significant factor in retention in care for adolescents living with HIV (Cluver *et al.*, 2018). When this healthcare worker speaks about 'leeway' as a reason why adolescents default, she is suggesting that when adolescents gain autonomy in deciding whether to access

biomedical care that they are more likely to disengage. This aligns with the aforementioned finding that younger children and adolescents are taken to access services with caregivers, and their practices largely hinge on caregiver decisions. When they become older, they often access biomedical care alone, as was the case for almost all participants in this study. Preliminary analysis from the third wave of the Mzantsi Wakho quantitative study (analysis in progress) shows that older vertically-infected adolescent boys (ages 15 and over) were slightly less likely to be accompanied to the clinic than girls of the same age group and mode of infection, with 30% of boys and 36% of girls being accompanied to the health facility. This may be because of gendered norms which see boys being less in need of accompaniment and support. The time when participants transitioned between types of health care, or began to attending the health centre alone, may have been a point during which participants felt the effects of masculine norms related to health-facility attendance more directly.

The nurse quoted above also asserts that boys are more likely than girls to disengage in HIV biomedical treatment and care, suggesting that the 'same stigma that affects men' is present for them. Given the size and nature of this study, it is not possible to ascertain age and gender differences in engagement with biomedical care. However, the narratives of biomedical and traditional health providers, observations in clinic files, and discussions with adolescent boys themselves align with the literature on adult masculinity and HIV stigma. It has been suggested that HIV stigma affects men differently than it does women (Beck, 2004; Colvin, Robins and Leavens, 2010; Wyrod, 2011). Men living with HIV report more internalised AIDS stigma, and acceptance and disclosure of an HIV-positive status may be different because of conventional views of male identity, fear of shame, and isolation from loved ones (Simbayi *et al.*, 2007; Iwelunmor, Sofolahan-Oladeinde and Airhihenbuwa, 2015). As they become adult men, it is likely that participants face the same challenges and risks around non-adherence and disengagement from care.

Related to stigma, fear of gossip was also a deterring factor in accessing health services and speaking openly with healthcare workers. Some participants spoke about not trusting nurses, and seeing them laughing and wondering if they are talking about them. Gossip and the fear of gossip have been well documented as a reason for South African patients not wanting to seek services

or disclose their HIV status (Maughan-Brown, 2006; Lane *et al.*, 2008). Studies specific to men and gossip have documented HIV-positive men's fear of gossip and disclosure of their HIV-positive status (Mills, de Paoli and Grønningsæter, 2009; Dageid, Govender and Gordon, 2012). Faull's (2010) study of men attending a men's clinic in Khayelitsha found that some men do not trust female health workers for fear that they will gossip and disclose their HIV status.

Participants also spoke about treatment by nurses at health facilities as a deterrent:

> Like the situation is since we have HIV they don't treat us good, they treat us like we are really sick people… they sometimes shout or put us in a separate room.
> (Ta Saider, 21)

> Some people treat us badly, like there is nurse who is taking care of us at the HIV side, she is rude and I don't like her. She likes to shout and insult us by saying that we are going to die… So she is always insulting for unnecessary things but she was trained and she should know how to treat people. I don't like her. When I am going to the clinic I don't like to be attended by her…. People are talking at the clinic that this woman is silly, you know mos, rumours.
> (Luya, 17)

> **Nkweza:** They shout at me… My nurse is upset with me because I don't take my treatment well, she doesn't want to talk to me she just wrote on the book and tell me to go and fetch my medication on the other side.
> **Interviewer:** How does that makes you feel?
> **Nkweza:** It's painful.
> (Nkweza, 18)

These participants discussed their experiences of being treated poorly at the health facility, which they link to being separated out on the basis of their HIV-positive status and being shouted at and scolded by nurses. This finding dovetails with the literature on adolescents living with HIV, as well as research on adult masculinity—where poor treatment by clinic staff, including rude and

judgmental female nurses, has been cited as deterring men from accessing clinic-based services (Levack, 2005; Colvin, Robins and Leavens, 2010; Faull, 2010; Leichliter *et al.*, 2011). Findings from the Mzantsi Wakho study also suggest that kindness is associated with better retention in care for adolescents living with HIV (Cluver *et al.*, 2018).

In addition to stigma, the fear of gossip, and poor treatment by healthcare workers, an HIV-positive status is often seen as an obstacle to conforming to hegemonic masculine norms. These include respect, status and strength as HIV is considered to be a barrier to breadwinning, having intimate relationships and bearing children. These dynamics in relation to masculinity and being subject to the control of healthcare workers were also discussed in an interview with a traditional health practitioner:

> Now you get to the hospital, it is also a government service. People go to the hospital because they are in a weak state, it affects their mental state, it affects them… but this male is coming from this patriarchal society that favours them. He goes into this ward, (they tell him) '*Man go there, just go straight, where is your folder? Why did you leave it? Go to that room!*'. He goes still, he still goes, but he dreads it. But this pain he is feeling, the sickness he has, he has to go…
> This man who is from this patriarchal society, then they become vulnerable in this space because they don't have authority. They are being told go there, they are in a queue. If they go to the sangoma, the sangoma knows that where he stays there that has 30 cows, he is a man. He even calls him by his clan name because he knows them. But when he goes to the hospital, that clout he thought he has, it is not there.
> (Luthando)

Luthando suggests that men might feel undermined and disrespected in the biomedical system, and speaks about how being abruptly instructed and bossed around by biomedical healthcare workers may act as a deterrent to accessing services, dynamics also cited by participants in this study. These factors may not be as present with participants due to their young age in a culture with a strong age-based hierarchy. However, they do speak to some of the potential additional sensitivities in relation to being reprimanded and scolded by healthcare workers that participants

may face as they get older. It is likely that a combination of masculinity and age-related factors play a role in boys' responses to fear of stigma and being shouted at and scolded at the clinic. It is difficult to distil which aspects can be attributed to gender, age, or an understandable general dislike of being shouted at or separated out. Since this sample did not include female participants, it is not possible to compare experiences. However, based on what is known about the gendered dynamics of accessing HIV-related health services, it is likely that such uncomfortable situations may affect adolescent boys and young men differently from how they affect women and girls. For example, the gendered dynamics of HIV-related stigma, and power dynamics of being shouted at, may have made male participants less resilient to these factors and more likely to disengage from care.

The literature on men's HIV-related clinic attendance is relevant here. Documented deterrents for men accessing clinic-based health services include the perception of public clinics as 'women's spaces', unwelcoming clinics, or the feeling that clinic staff are being unfriendly or disrespectful (Colvin, 2019)[21]. Similarly, it has been suggested that accessibility and privacy are key reasons why people, and especially men, may access traditional health services, especially in rural areas (Sobiecki, 2014; Zuma *et al.*, 2018).

Luthando also suggested that men might be more comfortable accessing traditional health services because of the respectful treatment they receive there; this is in line with the literature reviewed earlier. In contrast, findings in this research suggest that adolescent boys and young men do not access HIV-related traditional health products and services. This was also true as they became older. Although masculinity-related challenges began to aggravate their engagements with biomedical care, they did not compensate by engaging traditional health services. This chapter suggests that growing up accessing HIV-related biomedical care has created a distinctive set of practices for adolescent boys and young men in a number of ways. These formative experiences within the biomedical system and their knowledge of the limitations of traditional medicine were shaped by these practices and experiences. Unlike men who become

[21] This is not to say that clinics are 'women-friendly' either. Women are commonly subject to unfriendly and oppressive treatment in clinics, but may not have the option of choosing not to access services due to the necessity of maternal and child care (Bradford, 1991; Dickson *et al.*, 2003; Wood and Jewkes, 2006; Hodes, 2016a).

sick or test positive for HIV as adults, participants did not access traditional health services for AIDS-related issues because they do not believe that they provide a possible alternative to biomedical HIV-related care because of their younger experiences.

This chapter also suggests that, as adolescent boys and young men living with HIV get older and cease to have caregivers accompany them to the clinic, they might also be more affected by challenges that other men face. The significance of this suggestion and pathways towards such behaviours require further research and elucidation, including if adolescent boys and young men living with HIV have poorer HIV-related outcomes than their female counterparts, and, if so, when this effect becomes apparent. Preliminary Mzantsi Wakho quantitative findings agree that older boys and young men are less likely to adhere to medication than their female counterparts, and younger boys and girls. At the third wave of follow-up (median age=17), vertically-infected older adolescent males were significantly more likely than females to have missed one or more dose of ART in the past week (43% of boys and 33% of girls). A year earlier, this gendered difference was not significant. This analysis aligns with the findings presented here that as vertically-infected participants get older, gendered differences emerge in ART adherence patterns. This finding aligns with other emergent research with adolescents in Southern Africa. In a study of adolescents living with HIV in Cape Town, Brittain et al (2017) found that elevated viral load was significantly associated with being male, and being older. Similarly, a study with adolescents living with HIV in Zambia found that being male was a factor significantly associated with reporting incomplete adherence, and that males were almost double as likely to report missing two or more days of medicine compared to their female counterparts (Denison *et al.*, 2018).

Since male participants did not access other gender-related services such as birth control and reproductive health services, they might not have other routine reasons to access biomedical treatment and care. By contrast, girls and women may feel less stigmatised or that people will not assume that they are accessing HIV-related services. In addition to acknowledging that performances of masculinity may harm men's health, it has also been suggested that institutional supply-side barriers inhibit men's engagement in health services. Such barriers include the services that are available to men, and when and how they are delivered, which Dovel et al.

(2015) suggest are significant factors in men's poorer HIV-related health outcomes in sub-Saharan Africa.

The literature on gender and HIV also posits that women are more likely to access HIV-related services because reproduction is a common 'entry point'. By nature of having grown up and survived into adolescence with HIV, this was not true for male study participants who were familiar with the biomedical health system and had experience accessing HIV-related health services. Despite how masculinity-related issues began to aggravate participants' engagements in biomedical care as they became older, this chapter also suggests that their distinctive life experiences also made them more resilient to retention in the HIV cascade of care than men who acquired HIV at a later stage. Despite the substantial and clear disadvantages of growing up living with HIV, they have also forged new tools for health-seeking that adult men might not have.

In the Mzantsi Wakho study, participants (regardless of gender) who were horizontally infected had worse outcomes that those who were vertically infected (Sherr *et al.*, 2018). This suggests that despite the clear challenges of growing up living with HIV, that their early engagements with the biomedical system provided affected their health-seeking in a positive way. Further exploring the differences in health-seeking between young HIV-positive men who were vertically and horizontally infected may shine valuable light on how growing up HIV-positive affects HIV-related health outcomes in adulthood. Within the Mzantsi Wakho quantitative study, horizontally-infected adolescents were less likely to be retained in care, and more likely to report past week non-adherence (Sherr *et al.*, 2018). They also reported higher internalised stigma, anxiety and depression, alongside substance use and suicidality, although these may represent pre-existing challenges that put them more at risk (Sherr *et al.*, 2018). They suggest that there might be different explanations for these differences, including that those who are vertically infected with surviving parents could benefit from being linked to biomedical health services, and from shared experiences from parent or infected siblings (Sherr *et al.*, 2018). This aligns with findings presented in this chapter which suggest that caregiver support, decisions and practices greatly influenced participant health practices.

Findings from this research also demonstrate how embodied experiences play an important role in shaping health beliefs and practices, dovetailing with speculation that vertically-infected young people may have had extended exposure to HIV care and treatment, including more time for drug resistance challenges to their care regimens, and more opportunities for other challenges such as stigma (Lowenthal *et al.*, 2014; Sherr *et al.*, 2018).

Conclusion

This chapter has explored the health-related beliefs and practices of adolescent boys and young men living with HIV, most of whom acquired HIV vertically. It responds to a gap in the evidence about this distinctive sub-group of people, and considers how their health practices shape and are shaped by their HIV-positive status and male identities throughout the life course. Findings suggest that health practices are mediated not only by gender but also by childhood experiences of illness and engagement with biomedical products and services. They add detail to what is known about how medical pluralism is practiced by this group, and demonstrate the presence of biomedical and traditional health beliefs and practices for many participants. Despite this, most participants clearly distinguished HIV as requiring ART and biomedical care, deviating from the suggestion in much of the literature that medical pluralism is common for HIV-related issues, and that this is especially true for men. This chapter suggests that growing up deeply embedded in HIV-related biomedical care and treatment has resulted in this clear distinction for participants. However, findings also suggest that these experiences did not shift participant belief systems in relation to traditional cosmologies of well-being, health and illness. This aligns with the assertion that traditional African cosmologies are syncretic in nature and that it is common for people to hold a variety of beliefs and practices simultaneously and to enact them in complex and creative ways. Findings also agree with those of Zuma (2018) which suggest that healthcare decisions are influenced by a number of factors, including knowledge and beliefs, illness experiences, illness perceptions and social networks.

This chapter has suggested a number of factors that have forged this unique relationship to biomedical and traditional health practices. One such reason is that accessing HIV-related biomedical health services over an extended period of time has provided them with different information and tools to navigate biomedical health practices. Participant experiences of getting

sick and engaging with biomedical care have provided them with embodied experiences of the efficacy of biomedicine for AIDS-related issues. In addition, as children and young people, they are subject to the decisions of caregivers, many of whom have had first-hand experience of living with, or caring for someone with HIV. This might be additionally pronounced for participants who are engaging performances of 'good' HIV-positive patienthood as avenues to please adults and redeem deceased parents and familial misfortunes. At the same time, their young age when initiating into the HIV cascade of care meant that they did not experience the same masculinity-related deterrents as older men might, such as concerns over stigma, privacy and being humiliated and emasculated. Although these issues of masculinity become prominent later, they have better retention outcomes than horizontally-infected adolescent boys and men due to the tools they forged in accessing biomedical care when they were younger.

Despite not using biomedical care for HIV-related issues, participants held a variety of well-being-related beliefs and practices, demonstrating some of the complexities of multiple systems and layers of belief and practice. This chapter suggests that their intensive engagement in biomedical care did not influence their underlying belief systems, as many held traditional beliefs and practices. These included services where traditional medicine was not used, such as ceremony and divining, as well as that used muti externally (such as wearing, steaming or bathing in traditional products), and internally (including ingesting and putting it into the blood via small cuts in the skin). It was common to use a variety of the aforementioned modes of traditional products and services in combination, with divining and ceremony being often used alongside the preparation or administration of treatments including traditional medicine. These findings dovetail with the literature on adult medical pluralism in South Africa, demonstrating the possibility of holding beliefs that do not fit neatly into one system, and recognising the complex and non-linear relationship between practice-related beliefs and ultimate causes.

Findings suggest that biomedical decisions and traditional practices are mediated by a variety of factors which shift over the life course. For younger participants, their practices hinged largely on caregiver decisions. As they became older, other factors influenced their decisions and traditional and biomedical practices also became an avenue to demonstrate autonomy from caregivers and to perform to hegemonic masculine norms. These included testing the information

they had received and adult authorities using the bounds of their bodies, defining their own belief systems, and making their own decisions around health practices. Masculinity began to present a complication in relation to biomedicine at this time, and participants started to experience some of the problems of stigma, scolding healthcare workers and gossip reported by older men accessing treatment and care. This chapter suggests that these become more pronounced when caregivers stop accompanying boys to the clinic, and within certain types of facilities and transitions.

Despite issues of disengagement from biomedical treatment and care as participants became older, findings also suggest that through their experiences within the biomedical health system that they forged tools for health-seeking that men who acquire HIV later do not have. They also did not compensate for disengagement from biomedical care by engaging traditional practices. As they became older, they rather sought traditional health services and products alone for issues of a 'personal' nature, such as seeking success in sport and, potentially, in sexual relationships and performance. In this way, disengagements from biomedical care and decisions to use traditional care had separate motivations, suggesting that these were twin processes spurred by coming into adult manhood. Whereas traditional healing offered solutions to certain challenges of becoming a man, biomedicine complicated masculinity. Despite this, these complications were not compensated by traditional medicine. This finding demonstrates how traditional and biomedical health practices are not always engaged in relation to one another.

Chapter Seven: *Things less spoken* - HIV research with adolescent boys and young men – implications for theory, policy and practice

[This chapter has been accepted for publication as a book chapter and is included with the permission of the doctoral degrees board. The confirmation of permission, citation and author statement are included at the beginning of this dissertation.]

Authors: Gittings, L*[1,2]; Hodes, R[2]; Colvin, C[1]; Zungu, N[3,4]

[1]School of Public Health and Family Medicine, Division of Social and Behavioural Sciences, University of Cape Town, Cape Town, South Africa
[2]AIDS and Society Research Unit, Centre for Social Science Research, University of Cape Town, Cape Town, South Africa
[3]Human Sciences Research Council (HSRC), 134 Pretorius St, Arcadia, Pretoria, 0083, South Africa
[4,]Department of Psychology, University of Pretoria, Pretoria, South Africa
*Corresponding author email: lesley.gittings@gmail.com

Abstract

There is an increasing acknowledgement that men and boys must be better engaged in HIV prevention and treatment initiatives. The recently published UNAIDS report 'Addressing a Blind Spot in the Response to HIV' argues that improving men's access to prevention and treatment services would result in a 'triple dividend', benefitting boys and men themselves, as well as their sexual partners and families.

A growing literature explores masculinities in relation to HIV risk and HIV-related health outcomes. However, work with men and boys is often formulaic or does not adequately acknowledge multiple and complex masculinities and the experiences and conditions that shape them. Approaches and strategies are needed that dynamically and effectively engage adolescent boys and young men in research, policy and programming.

This chapter presents methodological and ethical considerations for working with this group. The authors draw on their experiences conducting qualitative research with adolescent boys and young men. While this chapter focuses on research, our findings are relevant to those working with adolescent boys and young men in policy, programming and advocacy.

Findings are comprised of three main components. They recount experiences and learnings from a research study with adolescent boys living with HIV, and are framed in relation to their wider implications for research and programming with boys and men. The first section asks, 'Who is best placed to work with adolescent boys and young men?' It highlights the significance of positionality and intersubjectivity. The second section uses the lens of hegemonic masculinity to explore the strategies for engagement used by young men working with adolescent boys. It focuses on how particular performances of masculinity may allow boys to move beyond dominant masculine scripts, allowing for the expression of alternative gender norms. The final section considers the potential opportunities as well as shortfalls and challenges of research and interventions focusing specifically on adolescent boys and young men.

Acknowledging the intimate link between HIV prevention and treatment, this chapter focuses on adolescent boys and young men living with HIV.

Introduction

There is an increasing acknowledgement that men and boys must be better engaged in HIV prevention and treatment initiatives. Improving men's access to prevention and treatment services would result in a 'triple dividend', benefitting boys and men themselves, their sexual partners, and their families (UNAIDS, 2017).

Although girls and women are more biologically and socially vulnerable to acquiring HIV, men access HIV prevention and treatment services less and at a later stage of disease progression and are more likely to die whilst on ART than women (Cornell, McIntyre and Myer, 2011; Johnson *et al.*, 2013).

The adolescent HIV epidemic presents further challenges. AIDS-related illness is the leading cause of death amongst adolescents in Eastern and Southern Africa, and these deaths have tripled among adolescents since 2000, while declining in all other age groups (WHO, 2015). Adolescent boys have significantly lower HIV prevalence in late adolescence and early adulthood than adolescent girls and young women. However, this group experiences sharp increases in HIV

prevalence in the years that follow, suggesting that adolescence may be a critical time where boys form risk behaviours and are exposed to new vulnerabilities.

Despite a growing number of interventions that work with men and boys, there is limited research that explores the processes, politics, limitations and challenges of such work (Gibbs, Vaughan and Aggleton, 2015). This chapter responds to this gap by presenting some methodological and ethical considerations in working with adolescent boys and young men.

The first sections of this chapter provide a theoretical and conceptual overview, and outline some current debates within masculinities research and HIV social science. The findings section is comprised of three main components, each detailing a particular occurrence from Gittings' doctoral research (supervised by Hodes and Colvin) which focuses on the health beliefs and experiences of adolescent boys and young men (ages 13-24) living with HIV in South Africa's Eastern Cape province. It is a sub-study of Mzantsi Wakho, a mixed-methods, longitudinal community-traced study of adolescents living with HIV (n=1057).

The findings section begins by asking, 'Who is best placed to work with adolescent boys and young men?', highlighting the significance of positionality and intersubjectivity. It then explores the strategies of engagement used by young men working with adolescent boys. It employs the dual interpretive frameworks of 'hegemonic masculinities' and the conceptualisation of both dominant and alternative masculinities bound up in Xhosa masculine identities. It focuses on how considered, contextually grounded performances of masculinity may encourage boys to move beyond dominant masculine scripts and allow for greater honesty, vulnerability and the enactment of alternative masculine norms. The final section considers potential opportunities, as well as pitfalls and challenges, of interventions and research focusing specifically on adolescent boys and young men.

This chapter highlights some methodological and ethical considerations for working with this diverse group, and challenges dominant assumptions about masculinity.

Theory, concepts and definitions

This chapter acknowledges the social construction of gender as a binary, which separates certain behaviours and attitudes into those deemed 'feminine' or 'masculine'.

Hegemonic masculinity has been described as the dominant form of an idealised masculinity within a society, which imposes meanings about the position and identity of other forms of masculinity and femininity (Connell, 2005). In many settings, the hegemonic forms of masculinity promote values and practices of independence, physical strength, sexual prowess and restraint in displays of emotion or vulnerability. These values and practices are, in turn, seen to act as powerful barriers to avoiding health risks and managing health problems effectively when they do emerge (Courtenay, 2000). This understanding of the potential links between hegemonic forms of masculinity and poor health has been applied to the field of HIV and health research as a way to understand men's poorer engagement in health services, risky sexual practices and poorer HIV-related outcomes (Gibbs, Vaughan and Aggleton, 2015).

The concept of hegemonic masculinity encompasses diverse behaviours and identities, produced contextually and relationally (Wetherell and Edley, 2014). This chapter recognises the malleability and the multiplicity of masculinities, while acknowledging the limitations of the concept. We use hegemonic masculinities as an interpretive framework through which to view the beliefs and behaviours of boys and young men, specifically in relation to their participation in the research at the centre of this chapter. We explore how hegemonic masculine norms were practiced within the study context amongst Xhosa men, and adapted through the processes of engaging with this research project.

Social scientists in Southern Africa have a rich history of emphasising the importance of context in limiting or enabling the effectiveness of HIV interventions (Hodes and Morrell, 2018). In his theoretical work on Xhosa masculinity, (Mfecane, 2016) argues that 'Western'[22] gender theories

[22] The limitations of literal and/or simplistic interpretations of geographical terms have been noted by scholars such as the Comaroffs (2012), who suggest that power and marginality are important considerations in interpretation.

are limited in their understanding in Xhosa masculinity, in which the concept of *indoda*[23] is central. Similarly, in her work on social representations of AIDS and narratives of risk, Zungu (2013) found that the meanings of some HIV prevention messages as constructed within a 'Western' paradigm may be in conflict with meanings within other contexts. Oyěwùmí (1997) posits that dominant gender narratives and interpretations of the social world '*cannot be assumed uncritically for other cultures*' in her writing about her work in Nigeria. The message here is that the ways that gender and masculinity are understood locally must be central to the design and evaluation of research and interventions.

This chapter employs notions of both hegemonic masculinities and Xhosa masculine identities encapsulated within the terms *indoda* and *inkwenkwe* to examine how boys and young men perform, reconstruct, and resist masculine norms in the study context. Despite some suggested theoretical tensions between Mfecane's work on Xhosa masculinities and Connell's hegemonic masculinit(ies), this chapter employs the work of both scholars, with the understanding that the concept of hegemonic masculinities is expansive enough to include these contextual masculine norms. Hegemonic masculinities may be a useful concept to characterise the construction of gender norms and practices, and in particular, the stark distinction between manhood and boyhood within the study context.

This chapter also draws on central tenets of feminism and gender studies, emphasising the multiplicity of gendered power dynamics and their interrelationship with health. The concepts of positionality and reflexivity are also used to reflect on the workings of embedded agency in interactions between researchers and participants. Reflexivity has been described as '*the project of examining how the researcher and intersubjective elements impinge on, and even, transform research*' (Finlay, 2002). It is a systematic, conscious reflection on research design, methods and findings, to provide insight into the subjective aspects of a study, and to enable validation of the experiential data provided by study participants. We use the term positionality to describe

[23] Constructs of masculinity in the research site hold a strong distinction between a 'boy' (in isiXhosa *'inkwenkwe'* – uncircumcised boy) and a 'man' (in isiXhosa '*indoda*' – a traditionally circumcised person), which are defined by whether a person has completed the process of *ulwaluko*.

aspects of identities, including race, gender and class, not as essential qualities but as indicators of relational positions (Maher and Tetreault, 1993).

Background: Adolescence, health and masculinity

Given that adolescence is a period marked by multiple physical and psychosocial changes, this time represents an often risky period in young people's lives. It may also be a crucial time in which to intervene to influence the development of health, gendered and sexual behaviours. A growing evidence base suggests that gender transformative work with men and boys has the potential to shift harmful gendered norms and practices that might put men and their partners at risk of contracting HIV and having poor AIDS-related outcomes (Dworkin, Fleming and Colvin, 2015). Gender transformative approaches aim to alter discriminatory gender practices, policies, beliefs, and ideas, recognising the benefits that gender equitable environments have for health (Betron *et al.*, 2012).

It has been theorised that men's poorer health outcomes are a result of hegemonic masculine norms, which have a negative effect on health-seeking and protective behaviours. While acknowledging how hegemonic masculine norms vary by context and shift throughout time, commonalities in global hegemonic masculine constructs include courage, independence and self-sufficiency, toughness, emotional and physical strength, sex with multiple partners, fearlessness and control over other men and women (Courtenay, 2000; Mfecane, 2008; Lindegger and Quayle, 2009). In an attempt to perform to these ideals embedded in hegemonic masculinity, it may be difficult for men to seek or accept health care—including HIV prevention, testing and treatment services, and other forms of support (Colvin, Robins and Leavens, 2010; Mfecane, 2010). Institutional supply-side barriers relating to the availability and delivery of healthcare services are also a significant factor in men's poorer HIV-related health outcomes (Dovel *et al.*, 2015).

There is a growing literature in the Eastern and Southern African region on childhood and adolescent masculinities that considers the pressures exerted on young males to perform to hegemonic masculine norms in contexts underlain by HIV, disempowerment and poverty (Langa, 2010; Govender, 2011; Hensels *et al.*, 2016). This work highlights the vulnerability and

uncertainty of adolescent boys and young men and the importance of better understanding this group, rather than simply framing them in contrast to vulnerable adolescent girls and young women. Adolescent boys and young men's childhood exposure to familial, community and structural violence may be internalised and find expression in harmful performances of masculinity, violence perpetration and behaviours that increase HIV acquisition risk (Jewkes *et al.*, 2011; Mathews, Jewkes and Abrahams, 2011).

These texts, alongside critiques of traditional approaches to behaviour change in the context of HIV, suggest that group participatory identity construction work, and initiatives to address social and community-level factors, are better placed than individual-level initiatives that focus on individual behaviour change as an end result. Similarly, a focus on attitudes in behaviour change may result in failure to consider important institutional and structural factors that shape behaviours (Pease and Flood, 2008).

Findings and discussion

Who is best placed to work with adolescent boys and young men? Positionality and intersubjectivity

This section focuses on positionality, and explores the ways in which intersubjective factors and identities shape HIV work with adolescent boys and young men. Such factors include demographic similarity and difference, personality and context. We suggest that it is important to take stock of the many intersecting factors that will shape interactions with participants, and that reflexivity is crucial in HIV prevention research and programming. We also interrogate the assumption that certain aspects of demographic 'sameness', such as geographic proximity, ethnicity or gender concurrence, mean that such interactions will be simpler. The following story explores how aspects of identity, alongside contextual issues, can shape engagements with adolescent boys and young men.

The Ezobudoda (translated from isiXhosa as 'manhood things') sub-study focused on HIV-positive adolescent boys and young men's engagement with traditional and biomedical health services. While establishing *Ezobudoda,* Gittings asked the research team for help determining the selection criteria for hiring researchers who would work on this project. After three years of

data collection, the research team had extensive experience speaking with adolescents and young people about HIV and sexual and reproductive health. Among key requirements for these positions were the need to be 'good with young people', fluency in local languages, and the commitment to the research team as a collective. In addition, the research staff suggested, without prompting, certain demographic requirements.

The researchers should be male, because, they explained, there are things that participants would not say to female researchers. Part of their argument was based on their perception that certain things are spoken about only by men. They described how certain traditional practices, including *ulwaluko*[24], a month-long initiation into manhood, are highly secretive and that it is a taboo to discuss them with women. Given that there were things about which Gittings, as a woman, should not have knowledge, they suggested that the male research assistants could also act as ethical advisors and mediators, controlling the flow of secretive information from research participants. Beyond collecting data, the researchers would also be crucial in supporting its interpretation due to their proximity to the topic.

They also suggested that it would be easier for male researchers to build relationships with participants and that that these interviews would generate richer and more honest narratives. This belief was based on the assumption that participants are generally more comfortable sharing intimate information with someone of the same gender, due to the perception that they have shared similar experiences.

That speaking about health may be more difficult for men is not surprising given expressions of physical or emotional vulnerability are delimited by hegemonic masculine norms (Connell, 2005). In order to collect richer and more accurate evidence, it would be important for participants to 'open up' and speak freely. Southern African interventions, such as *Stepping Stones*, *Brothers for Life* and *One Man Can* are premised on the idea that gender equitable beliefs and practices are better for the health and wellbeing of men, as well as their families and

[24] Referred to throughout this chapter as *ulwaluko* (isiXhosa), or traditional initiation/circumcision. A rite of passage, *ulwaluko* is a powerful organising factor in constructions of masculinity amongst the amaXhosa (Mfecane, 2016; Mager, 1998).

communities. These interventions are centred on in-depth work with men, usually facilitated by other men who encourage more gender equitable practices and enact these practices themselves. They have drawn on certain 'health-promoting' aspects of hegemonic masculinities, such as taking responsibility for the welfare of others (Colvin, Robins and Leavens, 2010). Such campaigns have not been without critique. It has been suggested that certain aspects of these campaigns may reify harmful hegemonic masculine norms (Fleming, Lee and Dworkin, 2014). Despite these potential shortfalls, the lesson we draw here is the way in which positionality may be an important consideration in 'who' does the work with adolescent boys and young men.

A male identity was not the only demographic characteristic advised by researchers as a necessity in their work. They also believed that age was important, and recommended that researchers should be no younger than 25. They reasoned that if the older participants saw the researchers as their peers, they would not be taken seriously. At the same time, they advised that the successful candidates should be no older than 45, because if participants saw them as an elder, they would not feel open to speak frankly to them. They explained that age-based hierarchy is an important factor, especially in a place where issues of sexuality are not usually discussed directly with elders. They also recommended that the candidate(s) should be isiXhosa-speaking, to circumvent the additional challenges of translation, and that they should themselves be *indoda*, having followed local traditions and customs of *ulwaluko*.

What was clear from these discussions was that the research team saw the positionality of the research assistant to be of vital importance, and that intersubjective identities were a crucial component of the research and analysis process.

As a result of this planning, the Mzantsi Wakho study hired two 29-year-old isiXhosa-speaking men. Mhlabeni was from Ginsberg, a township directly outside of King William's Town, and Mene was from Dimbaza, a larger urban location a bit further outside of King William's Town[25]. When deciding with which participants the new researchers would work with, they requested that they not work with participants in the communities in which they live. They suggested that

[25] Pseudonyms have been used for researcher names throughout this chapter.

Mhlabeni interview participants in Dimbaza, where Mene is from, and vice-versa. The reason, they explained, was that the close social proximity between residents in their communities meant that participants might not feel as safe speaking about intimate issues for fear that others would find out.

In this context, the concern was that participants might be uncomfortable during or after the interview, or less likely to open up for fear of unwanted disclosure of their HIV status or personal issues. Unspoken here was also that the researchers may also have been uncomfortable having in-depth and sensitive discussions with fellow community members, as these could complicate personal and professional boundaries. These findings align with evidence suggesting that geographic and social proximity may affect uptake and retention in HIV testing and care services, and that people may choose to visit health care providers or institutions in other localities in an attempt to maintain confidentiality (Mhode and Nyamhanga, 2016). This literature contrasts claims that long travel distances to clinics are a key factor in non-adherence. It suggests that in proximate health services, patients fear their HIV-status will be disclosed and their confidentiality breached, which may negatively impact on accessing health services.

Researchers calibrated certain types of similarity and difference within the research encounter. Despite believing that linguistic and gendered similarities could support the research aims, they also recommended some distance in terms of age and geographic proximity. In doing so, they challenged a popular assumption that differences between researchers and participants are complicating factors in the research encounter. The next section of this chapter further explores how ‘insider’ and ‘outsider’ roles shaped this research.

The ways in which different forms of identity shape interactions was also evident in an unanticipated aspect of the study. As hoped, participants were opening up to the researchers. They were also asking them to act beyond their research role. While drafting the protocol for the study, the ethical and methodological challenges and responsibilities that could be encountered were carefully considered, including when participants ask for help. Challenges of working with a group of vulnerable young people in an environment where social services are limited and inconsistent have been documented by Cluver and colleagues (2015). In one week alone, one of

the researchers, Mene, encountered a few self-referral cases where adolescent boys and young men disclosed that they were struggling with drug addiction and requested help. This type of referral was relatively uncommon in the Mzantsi Wakho quantitative survey. Mzantsi Wakho quantitative researchers more frequently encountered participants sharing accounts of violence and hunger, and the established response protocol upheld the ethical commitments and legal requirements of the study. However, accounts of substance abuse were shared more openly and frequently by the participants in the Ezobudoda sub-study. These referrals raised several questions: Was it because the participants were getting older? Was this a gender issue (i.e., more common with boys than with girls)?

Our hypothesis was that while age and gender played a role, it was possible that participants also felt comfortable sharing this type of challenge with Mene because they (rightly) assumed that he would be unlikely to judge or scold them. As someone with a laid-back demeanour and relaxed style, Mene may have given them this impression.

Mhlabeni's referrals were often different in nature. Participants sought assistance for multiple challenges, ranging from intimate subjects such as navigating romantic relationships, material concerns about securing food and work, and technology challenges such as how to fix a broken television. Boys frequently asked him for guidance on how to access social services (apply for social grants), and for advice related to circumcision and becoming a man. As someone who appeared to perform to Xhosa notions of being *indoda* in terms of his presentation, lifestyle and communication style, boys regarded Mhlabeni as an authority on masculine rites of passage.

Cluver and colleagues (2015) suggest that the presence of a caring, attentive adult is a reason why adolescent participants may open up and ask for help. Among study participants, many of whom did not have present fathers, being interviewed by a young man might have also been a rare occasion to have the positive attention of an engaged male figure. The requests for help made by the young men in this study may be attributed to a number of other interrelated factors. The research design saw researchers build relationships with participants over multiple interviews. These encounters also encouraged participants to speak freely, and provided opportunities for them to ask questions and direct the conversation based on their interests. An

additional factor may have been that participants demonstrated creativity and resilience by leveraging the research encounter as an opportunity to mobilise resources—a phenomenon that has been documented by Vale and Thabeng (2015). In the mix of all of these factors, given the different nature of referral cases that Mhlabeni and Mene met, a number of elements may have played a role in what participants felt comfortable to disclose. These may have included participants' perceptions of the researchers' interest in them and how they perceived the researchers' authority, expertise, abilities and personalities.

One finding here, which can be directly applied to HIV prevention research and programming, is that demographic factors coalesce with individual subjectivities and contextual circumstances in shaping interactions between adolescents and adults, and between participants and researchers/programmers. The above case study suggests that a close, reflexive consideration of how intersubjective identities operate alongside the research or programmatic aims is warranted in working with adolescent boys and young men. Contextual factors, such as access to social support and engagement with caring adult male figures, may powerfully influence interactions with participants.

Careful consideration should also be given to the contexts and needs of participants, and how to respond to requests for support. Researchers and programmers must undertake adequate planning and training prior to beginning a project, so that they are well-equipped to respond to the ethical and methodological imperatives of the work. Managing participant expectations and upholding the ethical commitments made are crucial steps to mitigating any mistrust or disappointment among participants and to guard against producing false expectations and empty promises. This process is especially important when working with adolescent boys and men in contexts of constraint and vulnerability.

Performing masculinit(ies) – Strategies for engaging adolescent boys

These above cases in some ways challenge the conventional belief that men do not seek care and support. One can infer that the participants had neither adequate access to social services and resources, nor people who could effectively refer them. But was there something beyond the researchers' positionality that allowed participants to express themselves? How did these

relationships form? In this section, we explore strategies to create more comfortable spaces for participants and argue that performances of both hegemonic and alternative masculine norms can foster the formation of such key relationships. We document how Mene and Mhlabeni performed to hegemonic masculine norms to gain trust and respect, and how they created spaces for alternative forms of expression by making boys feel comfortable.

While observing the researchers' engagements with participants, it became clear that they curated their performances of masculinity in order to make them feel comfortable and free to share. In the research setting, boys are often subject to instruction by older men and women, and a person is considered to be *indoda* only after completing *ulwaluko*. His age as a man begins from this point and is an organising factor that manifests in everyday interactions and traditional ceremonies alike. The process of initiation, and the time following, is often marked by instruction and testing by 'older' young men.

At the beginning of our research, 17 participants had undergone *ulwaluko*– mostly within the last year or two. This meant that even the 'oldest' participants were much younger, and in a different stage of life, than the researchers. The remainder were considered *'amakhwenkwe*' (translated from isiXhosa as 'boys') because they had not undergone ulwaluko.

Despite this evident hierarchy, in conversations with participants, the researchers often used descriptors such as 'my man', 'boss', '*bhuti*' ('brother' in isiXhosa) and 'my brother', treating participants in a manner that acknowledged their identities as emerging adult men. This approach affirmed participants' masculine identities and conveyed a sense of respect, familiarity, legitimacy and confidence. Although the researchers did not develop friendships *per se* with participants, they leveraged a different type of social capital that drew on their identities as employed, 'cool' young men to achieve the research aims. Making participants feel comfortable in this way supported the collection of rich data. However, this strategy also posed possible ethical challenges—including blurring boundaries between research and personal relationships, and demonstrating simultaneous authority and familiarity that may have made it difficult for participants to set the terms of engagement.

Also relevant here are the ways that researchers perform to 'insider' and 'outsider' roles, in order to encourage participants to speak openly. In her work on Xhosa men's narratives of HIV risk, Zungu (2013) leveraged her 'outsider' role (as woman of Zulu ethnicity) to probe sensitive matters that could not be spoken about in the presence of a Xhosa female. Despite speaking isiXhosa, and having worked for years in her research area, this 'outsider' role allowed her to engage participants as authorities and informers of the subject.

By contrast, Mene and Mhlabeni leveraged their role as 'insiders' by nature of having been legitimised as men by undergoing the process of *ulwaluko*. However, they also used the authority that having gone through this process bestowed upon them. These masculine performances were employed as a way to legitimise participants' masculine identities and establish familiarity with them. Although seemingly counter-intuitive, such performances were the starting point for participants to become comfortable expressing more personal experiences and vulnerabilities. Despite the benefits of this approach, careful consideration should be given to avoiding further entrenching hegemonic masculine gender norms, and to minimising social desirability bias.

Many participants in this sample have demonstrated creativity, agency and resilience in moving through precarious and challenging situations. This experience was evident in the ways that boys navigated health facility attendance and medicine-taking, responded to difficult social and familial situations, and excelled in multiple areas of their lives. At the same time, they faced multiple intersecting challenges and vulnerabilities as (mostly) poor, HIV-positive and 'Black'[26] young people, growing up in contexts of precarity and constraint.

That people have lived experiences that are informed by multiple intersecting privileges and marginalisations (Crenshaw, 1990) is relevant here. By engaging with boys' masculine social

[26] Racial identifiers, when used within this chapter are put within quotation marks ('') to denote that these categories are socially constructed. As much as possible, this work aims to avoid reproducing these categories, while acknowledging these historical and on-going constructs when relevant to this study. We aim to consider race-related power alongside other intersecting factors of power and marginalisation such as class identity, foreign status, language, HIV status and age.

capital[27] as an entry point, Mhlabeni and Mene discussed participants' structural, relational and personal vulnerabilities with them.

A methodological lesson from observing the researchers was that through performing to participants' masculinities (an area where participants held power), an entry point was created to express vulnerability. By engaging participants in a way that made them feel comfortable and validated, the researchers created a starting place to encourage them to speak about more challenging aspects of their identities and lives. This approach fits within a multi-level approach to children and resilience—one which considers social, material and relational factors that may affect their well-being, while also recognising their agency and life skills (Skovdal and Daniel, 2012).

The ways in which male community health workers engage men living with HIV bear some similarity. In a previous study, we observed that male CHWs acted in a warm and informal way towards their clients, and indirectly broached sensitive subjects (Gittings, 2016). In addition to employing these strategies with participants, Mene and Mhlabeni drew on their social capital as 'older' young men, who were employed and 'cool'. They performed to hegemonic masculine norms as a way to gain respect and trust from male participants. This careful strategy, when performed properly, often made boys feel comfortable.

This groundwork, in turn, allowed for expressions of vulnerability and emotion—typically performances associated with alternative masculine norms. Participants spoke extensively about personal issues related to health services engagement and intimate relationships, and expressed opinions that might be seen as controversial. Heartache, anger and fear were present in many participants' narratives. As discussed above, some also asked for advice and help.

While recognising the value of HIV research and programming work with adolescent boys and young men, we must remain mindful of the pull of patriarchy, which privileges the perspectives

[27] Putnam (1993, p. 35) defines social capital as *'features of social organizations such as networks, norms and trust that facilitate action and cooperation for mutual benefit…*'

and the needs of men above women and gender non-conforming people, and of heterosexual men above gay and transgendered men. Meeting men and boys 'where they are at' while, at the same time, not reifying gender binaries, and harmful gender norms, is a challenge. If the goal is healthier individuals and societies and gender transformation, engaging strategies that draw on masculine norms and identities is not an end in itself, but rather a means towards furthering research and programming practice for better health and gender equity outcomes. We explore this in the final section, which focuses on opportunities, pitfalls and challenges of such work. The strategies outlined above engaged aspects of hegemonic masculine identity and drew on their authority and resonance in fostering engagements with greater depth, trust and honesty.

Not all participants felt open to, or comfortable with, Mene and Mhlabeni's strategic performances of masculinity. For example, one participant who Mhlabeni believed to be "gay" (his word) chose not to do a second interview. Another participant whose father was from Ghana openly questioned Xhosa notions of masculinity; Mene responded to this interaction neutrally, but he later disclosed that the experience had bothered him. These situations demonstrate the limitations of gender norms and scripts. In other words, formulaic performances to engage with participants are not always effective, and adolescent boys and young men require engagements that resonate with them.

However, the strategies that Mhlabeni and Mene employed worked relatively well most of the time. Almost all participants were willing to participate in a second and third interview, and some asked, unprompted, for the researchers to come back. In expressing their vulnerabilities, they demonstrated an ability and openness to alternative masculine performances. Their feeling comfortable was in part due to Mene and Mhlabeni's strategies that drew on the authority offered by hegemonic masculine norms in order to acknowledge them as 'men'. This required delicately deploying hegemonic masculine norms without at the same time further entrenching them. In this context, being *indoda* by nature of having completed the process of *ulwaluko*, allowed them to occupy the most honoured type of masculinity (Mfecane, 2016).

Outlined above are considerations of positionality, context and strategies for engaging boys and young men in HIV research and programming. This final section traces the contours of some of

the debates around work with men and boys by drawing on case studies alongside the substantial and growing academic and programmatic literature that interrogates the meanings, benefits and challenges of such work.

Working with adolescent boys and young men – opportunities, pitfalls and challenges

While recruiting research assistants, we asked value-based and situational questions with the aim of determining if the interviewees held gender equitable beliefs. Both researchers responded in a way that was in line with the values and skills we were looking for.

Over the period of a year, Gittings, Mene and Mhlabeni took many long drives together to visit participants, during which they would explore different ideas, happenings and theories together, and co-analyse emergent findings. In conversations about gender, sex and intimacy, they would usually speak indirectly, zig-zagging around the boundaries of the professional and the personal. As they learned more about each other's communication styles, they also began to fill in the spaces of what was not said. After working all together closely over a period of many months, Mene and Mhlabeni started to demonstrate certain gender inequitable beliefs.

One day, ten months into working together, Mhlabeni expressed his belief that women aren't good drivers, which surprised Gittings, because he would often ask her to drive. Mene responded by quipping that he didn't see a difference between men's and women's driving abilities. An animated discussion ensued. Gittings asked Mhlabeni why he asked her to drive if, as a woman, he believed she could not be a good driver. '*It's different with you because I'm used to it*', he answered.

In a team meeting with a group of approximately 15 researchers, Gittings led an activity as an icebreaker where the team was read a list of yes/no/maybe questions about beliefs. 'Yes' was signaled by standing up with their arms above their heads, 'no' by sitting down on their chair, and a 'maybe' was displayed by standing with their arms at their sides.

They started with simple statements such as '*I had a nice weekend'* and '*It is rude not to greet when you see someone'*. After warming up, they engaged with more complex, and potentially

more controversial statements. One such statement was '*Women are responsible for cooking and cleaning*'. Mhlabeni and Mene stood up and stretched their hands over their heads, while the rest of the team sat down. Everyone else looked up at them, chuckling from their seats—partly in discomfort, and partly because of the irony of the only two staff members directly conducting gender research displaying this belief. The idea that women can be responsible for certain activities is not, in itself, gender inequitable. However, the (unequal) burden of labour and value placed on men and women's work, combined with the team's different answers when asked about typical 'masculine' responsibilities, meant that these responses likely drew on a gender inequitable belief about women's labour.

Why had they demonstrated this belief, given their awareness about gender equality and their interview responses a year earlier in which they recounted different perspectives about men and women's roles? Had their work, though aiming to understand boys' and young men's beliefs and actions, somehow cemented hegemonic masculine norms for them? Through being part of a sub-study that allowed the researchers more flexibility and privileges due to its design reinforce patriarchal norms that men and boys are superior, both as researchers and research participants? Or had the comfort, familiarity and trust the team had built created a space in which they felt open to share their gender-inequitable beliefs? And if the latter was the case, was it a 'good' thing, a step towards, or away from, the gender transformative objectives of the research?

While not wanting to over-estimate the role of these interactions and their work as researchers on their belief systems, they had actively and continuously engaged about issues of gender over an extended period of time. Their speaking openly about beliefs that were professionally undesirable, and their sharing opinions that were different to Gittings' suggests that relationships had been built where a certain degree of sharing, comfort and ability to express and manage conflicting beliefs was present.

A few days later Gittings asked Mhlabeni and Mene about the opinions they had shared. They said that they felt comfortable displaying their perspectives because, as a function of having frequent and frank conversations about gender, that they were more comfortable talking about their beliefs than before. By contrast, they suggested that for the others in the room, their lived

practice was also one where women were responsible for domestic work in their homes. They thought that their colleagues may have felt uncomfortable to express their belief that women should be responsible for domestic work in a group setting because they felt it socially unacceptable to do so.

The other potential explanation that Mene and Mhlabeni offered was that their colleagues might hold a different belief in theory, but not in practice, or hold different gendered beliefs for different spheres of their lives—in this case, work and home. This echoes Ratele's (2014b) assertion that people might support gender equality in the abstract, but that this might not translate behaviourally. He posits that gender equality discourse may influence men's support of gender equality '*in the abstract*' but that '*men's positive, but ambivalent and resistant gender attitudes*' prevail (Ratele, 2014b, p. 510). In a review of the evidence on work with men and boys, Gibbs and colleagues (2015) point out that such work does not always lead to behaviour changes that support gender equality. The processes and contexts in which work is implemented play a role in intervention effectiveness (Dworkin, Treves-Kagan and Lippman, 2013).

Were Mene and Mhlabeni's choices to display gender inequitable beliefs in conflict with, ambivalent to, or part of a gender transformative process? Shifting socialised gender norms can be a lengthy and elusive endeavour (Gibbs, Vaughan and Aggleton, 2015). Is performing to socially acceptable gendered beliefs (while not believing them) better than burying gender inequitable beliefs? In terms of Ratele's (2014b) assertion that gender equitable beliefs can exist in the abstract, but not practice, was it possible that Mhlabeni and Mene had 'broken the bubble' of the abstract, but not shifted into practice? And was this the same as going back to explicit gender inequitable beliefs, or towards conscientisation?

These questions and examples are raised as part of broader debates around working with adolescent men and boys for HIV prevention. As described above, gender inequality is a driver of HIV transmission, and ART initiation and retention in care are mediated by hegemonic masculine norms. For these reasons, questions of gender equitable belief and practice are important to research and interventions focusing specifically on HIV and adolescent boys and young men. It has been suggested that it is through practice that new ways of relating are

produced (Sideris, 2004), and that it is necessary to create lived experiences of gender equality through structural and policy approaches as well as programmatic initiatives that change attitudes (Levtov *et al.*, 2014).

As the above case studies and reflections demonstrate, the work of gender transformation is neither straightforward nor formulaic. We suggest that approaches that create space for dialogue and reflection, and that focus on processes (rather than solely end-points) are important components in the often complicated work of exploring and challenging gender norms.

Finally, as highlighted by scholars such as Mfecane (2016), Zungu (2013), Oyěwùmí (1997) and Hodes and Morrell (2018), the broader gendered context in which HIV work with men and boys takes place is important to consider. How do we engage with context-specific gendered constructs to support men's improved health outcomes? And what does it mean to be working with men and boys for HIV prevention in a context where women and girls are more biologically and socially at risk to HIV acquisition? Scholars such as Gupta et al. (2008) have mapped out the importance of multi-layered and systematic approaches in addressing the multiple, overlapping structural and power dynamics that fuel the HIV epidemic. However, work with men and boys may still raise ethical and political considerations, given that it may be seen to compete for resources and attention with work with women and girls. It is therefore critical that gender transformative research and practice with men and boys be able to articulate how its methods and objectives line up with broader feminist principles and goals.

Conclusion

Using case studies of HIV research with adolescent boys and young men, this chapter raises questions about addressing gendered power imbalances and reducing HIV risks and poor health behaviours within this group.

Given the relational nature of gendered power and HIV risk, it is crucial to work with adolescent boys and young men in order to improve population health outcomes (UNAIDS, 2017). Interventions to reduce the material vulnerabilities of adolescents have demonstrated efficacy in reducing HIV risk behaviours among adolescent girls, but not boys, suggesting the differently

gendered relationships between material vulnerability and risky sexual behaviour (Cluver *et al.*, 2013). This is relevant given that HIV risk increases for adolescent boys and young men as they enter their twenties and thirties. Efforts and strategies for working with adolescent boys and young men to prevent them from acquiring HIV, as well as transmitting it onwards, require further elucidation.

In feminist and participatory research, the processes through which evidence is gathered are important. The lessons derived from this research point to the need for consideration of positionality and intersubjectivity, and the importance of considering the unique and intersecting identities, especially for those living in contexts of racialisation and discrimination, precarity and poverty. We suggest that careful consideration of demographic and personal qualities of facilitators, researchers and programme workers are important. Engagements can be radically shaped by elements of 'sameness', 'difference' and geographic proximity. Findings suggest that demographic factors should be carefully considered in deciding 'who' conducts HIV work with adolescent boys and young men, that 'sameness' is not always more effective, and that considerations of positionality are strongly mediated by context. Drawing on the expertise of participants and local researchers and programmers can help navigate these complexities.

Research and programming that aims to conduct in-depth work with adolescent boys and young men must also consider the intersecting vulnerabilities and privileges of participants. The same structural factors that inform HIV risk will be present in aspects of participants' lives. During project development, consideration of how to respond to participant needs and requests for help that are beyond the context of the programme/research are essential—especially in contexts of precarity and constraint.

This chapter has described strategies for working with adolescent boys and young men—including partially leveraging hegemonic masculine interactions—to creating the trusting and open relationships that support in-depth research and interventions to promote health and gender equitable practice. We found that affirming aspects of participant masculine identities can be a starting point for alternative forms of engagement. This process requires delicate consideration of how to make participants feel safe, while not reifying harmful hegemonic masculine norms

and rigid gender binaries. In the complicated work of exploring and challenging gender norms, creating space for dialogue and reflection, and the use of multiple methods to introduce different perspectives may guard against such risks.

Ideally, research and programming should be framed within conducive policy frameworks and a commitment to changing harmful gendered beliefs in practice. The process of meaningfully engaging men for HIV prevention efforts is informed by a variety of factors, including the very gendered power dynamics that are being challenged.

In a context in which little is known about gender transformation, the work of engaging with hegemonic masculine norms is complicated, with 'progress' being difficult to measure. The complexities and dynamics of gender work with adolescent boys and young men are reflective of broader workplace and societal dynamics. Building and documenting relationships over time that allow for ongoing, continuous and non-judgmental engagement may provide some clues as to the pathways towards gender equity.

This chapter has drawn on case studies with qualitative researchers to consider some ethical and methodological aspects of HIV work with adolescent boys and young men. In doing so, it aims to contribute to the movement for engaging men, and to raise some theoretical, ethical and practical questions to add to our notions of young masculinities and HIV risk. The cases studies have aimed to provide a window into how adolescent boys and young men experience, manage and perform masculinity, and ultimately add depth to what we understand about this group.



Figure 49: Ulwazi (13) conducting a pilot life history interview with researcher Zukolwethu Jantjies. 26 November 2016. (Repeat of figure 8[28]).

Acknowledgements:

This evidence was gathered within the auspices of a large, longitudinal study on medicines-taking in the Eastern Cape, the Mzantsi Wakho study. We are grateful to co-Principal Investigators, Professor Lucie Cluver and Dr Elona Toska, study collaborators at the Universities of Cape Town and Oxford, the researchers who supported data collection and analysis and to the research participants for sharing their perspectives and experiences that formed the basis of this research. Thank you also to Mlamli Mayosi for reviewing and providing input into the early drafts of this chapter and to Kaymarlin Govender, Andrew Gibbs and Timothy Quinlan for their detailed review and comments.

[28] This image was included twice because of the requirement to reproduce the publication exactly as it will appear.

Thank you for the financial support provided by Evidence for HIV Prevention in Southern Africa (EHPSA), a DFID programme managed by Mott MacDonald (MM/EHPSA/UCT/05150014). In addition to EHPSA, Lesley Gittings was a supported by the South African National Research Foundation (NRF) Innovation scheme for doctoral student funding, the University of Cape Town AIDS and Society Research Unit (ASRU), the South African Social Science and HIV (SASH) Programme, an initiative funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development of the National Institutes of Health (Award #R24HD077976), the South African National Research Foundation travel funding for postgraduate students, and the University of Cape Town's Max and Lille Sonnenberg Scholarship for international travel.

Christopher Colvin was supported by the US National Institute of Mental Health [#1R01MH106600] and the South African Medical Research Council (SAMRC). This content is solely the responsibility of the authors and does not necessarily represent the official views of the aforementioned funders.

The Mzantsi Wakho Study was funded by the Nuffield Foundation [CPF/41513], but the views expressed are those of the authors and not necessarily those of the Foundation; Evidence for HIV Prevention in Southern Africa (EHPSA), a UK aid programme managed by Mott MacDonald; Janssen Pharmaceutica N.V., part of the Janssen Pharmaceutical Companies of Johnson & Johnson; the Regional Inter-Agency Task Team for Children Affected by AIDS - Eastern and Southern Africa (RIATT-ESA); UNICEF Eastern and Southern Africa Office (UNICEF-ESARO); the International AIDS Society through the CIPHER grant [155-Hod; 2018/625-TOS]. The views expressed in written materials or publications do not necessarily reflect the official policies of the International AIDS society. Further funding provided by: Oxford University Clarendon-Green Templeton College Scholarship; Claude Leon Foundation [F08 559/C]; Oak Foundation [R46194/AA001]; the Leverhulme Trust [PLP-2014-095]. Additional funding was provided for the research team by: the John Fell Fund [103/757; 161/033]; the University of Oxford's ESRC Impact Acceleration Account [IAA-MT13-003; 1602-KEA-189; K1311-KEA-004]; Research England; the European Research Council (ERC) under the European Union's Seventh Framework Programme [FP7/2007-2013]/ ERC grant agreement n°313421, the European Union's Horizon 2020 research and innovation programme/ERC grant agreement n°737476).

Chapter Eight: Discussion and conclusion

Background

The emergence of the HIV epidemic presented a grave and devastating contrast to the celebration and hope of South Africa's historic transition to democracy (Hodes, 2014). While HIV first emerged in South Africa in the 1980s, incidence increased drastically in the 1990s. In 1990, the HIV prevalence of women attending antenatal clinics was 0.7%, and by 1998, it was 22.4% (South African National Department of Health, 2006).

During the height of the epidemic, the government, led by President Thabo Mbeki, alongside Minister of Health Mantombazana Tshabala-Msimang, questioned the causal link between HIV and AIDS, and the efficacy and safety of ART. Instead, they proposed traditional remedies, which created antagonism to traditional approaches amongst many policy makers, programmers and health workers. Although South Africa might have started PMTCT and ART programmes in 1996, when definitive evidence of the efficacy of triple-therapy was published, the state refused to do so. South Africa only began a national PMTCT programme in 2002, after a Constitutional Court ruling which represented the culmination of national and international civil society advocacy (Heywood, 2003).

The delayed implementation of timely, feasible PMTCT and ART programmes resulted in widespread and avoidable transmission of HIV (Abdool Karim *et al.*, 2009; Burton, Giddy and Stinson, 2015), which led to over 330,000 preventable AIDS-related deaths (Chigwedere *et al.*, 2008; Nattrass, 2008a). An estimated 35,000 babies were born with HIV due to the non-implementation of a national PMTCT programme (Chigwedere *et al.*, 2008; Nattrass, 2008a). Once this national programme began, roll-out of PMTCT and ART was slow and uneven across the country (Burton, Giddy and Stinson, 2015), and the Eastern Cape in particular lagged behind.

The participants in this study were born HIV-positive between 1995 and 2004, in large part because of the unavailability of PMTCT or lack of PMTCT provision to their mothers. Many of these participants are also among the millions of South African children born in this period who became orphaned (Burton, Giddy and Stinson, 2015).

Since this time, the public response to HIV has evolved significantly. Although it is tragic that many of these young people contracted HIV avoidably, they are also alive because the HIV treatment landscape has been radically transformed (Burton, Giddy and Stinson, 2015). Because of the availability of ART, AIDS-related deaths have decreased among children and adults.

Despite the successes of ART roll-out, many adolescents living with HIV have poor health outcomes that persist, due to problems adhering to ART and poor retention in HIV care. AIDS-related deaths have tripled amongst adolescents since the year 2000, while declining in all other groups, making AIDS-related illness is the leading cause of death for adolescents in the Eastern and Southern Africa (WHO, 2015).

The adolescent and adult HIV epidemics are gendered. Women and girls are socially and biologically more vulnerable to HIV acquisition, while men have poorer AIDS-related outcomes. Men are less likely to be retained in HIV care and adhere to ART, and are more likely to die of AIDS-related illness (Nattrass, 2008b; Cornell *et al.*, 2010; Cornell, McIntyre and Myer, 2011; Johnson, 2012). The reasons for men's poorer HIV-related health outcomes are twofold. Harmful hegemonic masculine norms place pressure on men to "act tough", and equate biomedical health-seeking with weakness, which deters them from accessing health services (Jewkes *et al.*, 2007; Colvin, Robins and Leavens, 2010; MenEngage, Promundo and Sonke Gender Justice, 2015). It has also been suggested that institutional supply-side barriers, such as the health services offered, and their locations and hours of operation, do not meet men's needs (Dovel *et al.*, 2015). Given the significantly higher HIV prevalence and incidence among adolescent girls and young women, the research and programmatic focus on this group is warranted. However, interventions and research focusing on HIV services and needs of adolescent boys and young men are 'notably absent, except for voluntary male circumcision' (Makusha, 2019).

Ambitious goals have been set to end the HIV epidemic. The 90-90-90 targets, set by UNAIDS and adapted by countries worldwide committed that 90% of people living with HIV know their status, that 90% of this group have sustained access to ART, and that 90% of those on ART be virally suppressed by 2020 (UNAIDS, 2014). The underlying objectives of these targets are to

support the health of people living with HIV, reduce AIDS-related mortality, and to curb new infections. Months away from the deadline of 2020, it is clear that these targets will not be realised. Recent data tracking the progress towards these goals suggests that there are significant gaps that will undermine their success. Specifically, HIV diagnosis and ART coverage in men and in young people under 30 lag behind targets, suggesting that achieving 90-90-90 will require significant additional investments to reach youth and men (Huerga *et al.*, 2018).

This study explored the health practices of adolescent boys and young men living with HIV. It engaged qualitative methods with a group of 36 HIV-positive adolescent boys and young men in the Eastern Cape province of South Africa, as well as 14 traditional and biomedical practitioners. It aimed to gain insight into the health practices of adolescent boys and young men, and to elucidate how health behaviours are formed, reproduced and interrupted during this life phase. In doing so, it also endeavoured to contribute to understandings of the challenges that HIV-positive adolescents face, and how men's (poorer) health behaviours are formed and reproduced. Findings document how male identities and an HIV-positive status shaped participants' lives and practices in separate but interrelated ways. They add to a small literature on children and adolescent boys that documents their vulnerability and uncertainty (such as Govender, 2011; Shefer, Kruger and Schepers, 2015; Hensels *et al.*, 2016), and suggests that it is important to better understand this group on their own, rather than only in relation to adolescent girls and young women.

Key Findings

Pathways to respectable masculinity and personhood

Participants lived in settings where, due to political and health-system histories, they were among the first to grow up with access to ART and democratic freedoms. In a context where HIV-positivity and men's inability to fulfil traditional roles are considered as signs of social and moral decay, they felt pressure to be 'good' HIV-positive patients and respectable adult men, in order to redeem difficult family pasts. Life history narratives included a number of themes, including parental death, HIV disclosure, changing homes and caregivers and absent patrilineal kin.

Participants' HIV-positive status and male gendered identities were central themes to their biosocial lives. They leveraged these as two avenues to redeem challenging family pasts and to imagine new futures. As younger children, performing to norms of HIV-positive patienthood served as an avenue towards parental redemption, to please adult authorities, and to distance themselves from the possibility of dying 'bad' deaths like those of the previous generation of many of their mothers and fathers. As they got older, performances of health citizenship came into conflict with the pressure to perform to norms of adult masculinity. As they came into adulthood, they faced the pressures of achieving what their fathers, most of whom were absent, deceased or poor, were unable to do: to take up the role of a legitimatised patriarch.

It was within this context that participants strived towards certain respectful and respectable masculine norms. These included: (1) engaged fatherhood and provision to children legitimised through marriage; (2) financial security and providing for families; (3) behaviour deemed 'moral', that commands respect; and (4) completing ulwaluko successfully. These avenues were demonstrative of some of the contradictions and complications of masculine norms for participants. They also highlight the pressures that adolescent boys and young men face to perform to certain masculine norms while appearing strong and invulnerable.

Factors at the fore of shaping participant experiences included structural and historical contexts of racialisation, marginalisation and poverty that found unique expression in hegemonic norms of masculinity. Relevant here is Ratele's (2014a) assertion that Black men embody a space of hegemony within marginality, and that the material conditions of poor, Black men are necessary to consider in studying masculinities and health within the South African context. Findings corroborate this assertion, and document the pressures that young men face in performing to certain masculine norms while appearing strong and invulnerable within contexts of poverty and unemployment.

Participants struggled to be seen as respectful and respectable men within contexts characterised by poverty, broken patrilineal relationships and high unemployment rates. The difficulties of achieving such masculinities, and ultimately, adult male personhood, represents a chasm between

the aspirational and achievable. Participants never overtly acknowledged this gap between their current and idealised realities, but expressed their desires to close it by sharing concerns about finding work, making money and acquiring education.

The collective aspirations to manage HIV and achieve better futures sit as parallel weights on the shoulders of young men living with HIV. They aimed to realise the promises of biomedical and democratic citizenship, through avenues available to them: notions of 'good' patienthood as children and younger adolescents, and later, to 'good' masculinity. In these ways, they strived to liberate themselves from the inherited burdens of the past, redeem lost parents and failed patriarchs, and move towards brighter futures.

In striving towards respectable adult masculinity, HIV was an additional burden that made masculine achievement more difficult. Participants juggled the imperative to engage in biomedical care and treatment with attempts to minimise the potential of HIV stigma which may have made them less desirable to potential sexual and romantic partners. HIV may have been seen as a barrier to key elements that mark progression into adult masculinity – such as having sexual relationships, making money and having children. Participants navigated these challenges at the same time as they transitioned into adult manhood, which is a difficulty that men who contract HIV subsequent to sexual debut do not experience. This thesis suggests that their HIV-positive status necessitated an additional aspect of transitioning into manhood, and an added barrier to being legitimised as respectable adult men. This may make other markers of masculinity, such as the successful completion of ulwaluko, more challenging—and also more vital as a prerequisite to participants' legitimisation as adult men.

Ulwaluko

The conflicting expectations of respectable manhood and of 'good' patienthood and retention in HIV care were most apparent during and following ulwaluko. Strong societal norms forbidding initiates from taking pills or accessing health services aggravated challenges to retention in biomedical HIV care. Participants did not openly take pills during the (approximately) four weeks of ulwaluko, nor did they go to the health facility for three months following ulwaluko, for fear of being seen to have had breached the rules of initiation. During this time, initiates'

fears of inadvertently disclosing their HIV-positive status collided with the pressure to successfully complete ulwaluko and be legitimised as men. Participants negotiated health practices against the fear of being said to 'have flown' (as a bat does), which would cast them within a liminal masculine identity that they would carry throughout their whole lives.

The strategies that participants engaged to take their medicine during ulwaluko included hiding pills and taking them in secret, having a trusted person deliver medication discreetly, and stopping medicine-taking altogether. Participants who successfully took medicine during this time had family support and social support stemming from family relationships with amakhankata, private amabhoma, and in a few cases, medical advice. Those who continued taking their medication during the months following ulwaluko organised caregiver pick-ups at the clinic on their behalf.

Findings suggest that a four-month period of disengagement from biomedical care and treatment may have long-lasting implications for participant HIV-related health practices. The difficulties of being seen to conform to 'manhood rules' related to non-engagement with biomedical care and treatment during and following ulwaluko may aggravate other challenges that have been documented as affecting HIV-positive men. These include making money, having children and providing for their families. This dilemma created a potentially long-lasting conflict in relation to biomedical engagements and masculine norms. Baseline data from the quantitative arm of the Mzantsi Wakho study align with this finding, demonstrating that young men who reported that they had a difficult time adhering to treatment during ulwaluko were significantly more likely to be non-adherent to ART afterwards.

However, their medicine-taking strategies during and following ulwaluko also demonstrated that, under seemingly static and dominant norms of masculinities, participants and families were creative and resilient actors that were able to covertly resist and subvert such norms.

Ulwaluko is a critical moment for boys that has been neglected in the HIV response, other than emerging as an opportunity for engaging young men in voluntary medical male circumcision. This is a key personal and social moment in young men's lives that serves to legitimise them as

men. As such, there is a need to better support their health practices during this time, which will require engagement with key stakeholders such as traditional authorities, and to create an effective community health response.

Findings related to ulwaluko demonstrate the importance of context in understanding the relationships between an HIV-positive status and masculine health-related behaviours. They agree with a growing literature which emphasises the importance of context and geography in the production of evidence (Connell, 2007; Morrell, 2016; Hodes and Morrell, 2018). For example, Mfecane (2018b) suggests that gender and health interventions within this region have seen limited success because they are not adequately grounded in local contexts and theories of gender, and Oyěwùmí (1997) stresses the importance of local understandings of gender, language and hierarchy.

Health practices

Another important context-specific consideration within the study site is that of medical pluralism. It has been suggested that men may be more likely to access traditional health services than women (Beck, 2004; Chikovore *et al.*, 2016), and that this is an important area for further enquiry (Colvin, 2019). There is little known evidence on medical pluralism among adolescents living with HIV. This study considered participants' engagements with traditional and biomedical products and services, documenting the presence of both in many of their lives. Although many participants engaged with traditional products and services, they clearly distinguished HIV as requiring ART and biomedical care. This finding differs from the suggestion in much of the preceding literature that medical pluralism is common for HIV-related issues, and especially so for men. Methodological findings demonstrate the value of carefully designed qualitative research which enables open and accurate reporting of medical pluralism, as well as the benefits of triangulating across methods.

This thesis suggests that childhood experiences in navigating a set of biomedical health services, products and relationships influenced participant health practices. Their embodied experiences of the efficacy of ART from getting better after taking it, and the influence of caregivers and health workers shaped health practices in ways that are likely very different from adolescents who are

not living with HIV, or men who acquire HIV later. Given their youth, they have also been subject to the decisions of caregivers, who may have an affinity to biomedicine as a result of first-hand experiences of living with, or caring for someone living with HIV. This finding suggests that participant health-related decisions are mediated by childhood experiences of illness and engagement in biomedical care, as well as by gender. Through experiences of growing up deeply embedded in the health system, they forged additional tools for health seeking, as described below.

Given their extensive engagements with biomedical products and services as children, participants formed biomedical practices before being conditioned into adult masculine norms. In this way, they may have developed some resilience against concerns that adult men who contract HIV later experience, such as concerns over emasculation, stigma and privacy. This suggestion aligns with quantitative findings which demonstrate that children who grow up with HIV have better adherence and retention outcomes that those who contract HIV at a later stage (Sherr *et al.*, 2018).

However, participants' health practices were mediated by many factors that shifted over the life course. During their childhoods, their caregivers' beliefs and practices heavily determined their health practices. As they become older, participants began to test authority, and question information they received about HIV and biomedicine, by not taking ART. Gender-related shifts also began to occur, bringing up a new set of dilemmas for adolescent boys and young men living with HIV. As they moved into adult manhood, despite having developed tools to engage with biomedical health services, masculine norms began to complicate their access of biomedical HIV products and services. Participants began to experience some of the problems and deterrents that men experience with accessing biomedical HIV treatment and care.

Young people may become more vulnerable to disengagement from care when caregivers stop accompanying them to the clinic, and when they have more independence and autonomy to make decisions in relation to their health. Most participants in this sample attended the clinic unaccompanied, and did not have the same caregiver support and instruction to take their ART as they did when they were younger. Findings from the third wave of the Mzantsi Wakho

quantitative dataset suggest that vertically-infected boys over the age of 15 are slightly less likely to be accompanied to the health facility than girls of the same age group and mode of infection[29] (30% of girls and 36% of boys were accompanied to the clinic) (on-going analysis by Zhou and colleagues). Non-accompaniment to health facility and older age in adolescence have been reported as significant factors in ART non-adherence and health facility attendance (Cluver *et al.*, 2018).

Concerns of scolding healthcare workers, stigma, and institutional barriers became more pronounced for participants as they entered adult manhood. The suggestion that older boys and young men begin to reflect gendered adult ART adherence and retention-in-care patterns may also be corroborated through quantitative data analysis within the Mzantsi Wakho study, which is ongoing. Mzantsi Wakho quantitative findings based on ongoing analysis triangulate with the finding that older boys and young men began to demonstrate some gendered adult ART adherence patterns. At the third wave of Mzantsi Wakho follow-up (median age = 17), vertically-infected adolescent males aged 15 and over were more likely to have missed one or more dose of ART in the past week compared to their female peers (43% of vertically infected boys and 33% of vertically infected girls). A year earlier, this gendered difference was not significant. Therefore, this preliminary finding aligns with the argument presented here that as vertically-infected participants get older, gendered differences may emerge in ART adherence patterns. This dovetails with emergent evidence suggesting that, as adolescent boys get older and become young men, their HIV-related treatment outcomes also worsen (Brittain *et al.*, 2017; Denison *et al.*, 2018). Further analysis is needed to better understand this phenomenon.

As participants got older, some also started engaging with traditional health products and services alone, as opposed when they were younger and accessed them with caregivers and family. The reasons for individual traditional practices were related to certain hegemonic masculine performances, such as success in sport and sexual relationships with women.

Although both biomedical and traditional health practices were mediated by gender, they had

[29] Mode of infection in the quantitative dataset is speculative, hypothesised based on a number of factors.

separate motivations and were not always engaged in relation to one another. Traditional health practices offered certain solutions to challenges related to becoming a man and enacting certain norms of masculinity. Masculinity complicated engagements with biomedical practices, but not in a way that was compensated by traditional medicine.

That many participants held traditional beliefs and engaged with traditional products and services suggests that growing up with HIV and in the biomedical health system did not shift their entire belief system. This affirms the syncretic nature of traditional beliefs and document the plural, complementary and creative ways that participants engaged with traditional products and services.

Limitations

The limitations of this research must also be acknowledged. Conceptually, health-seeking behaviour is a concept that considers individual-level behaviours, but not broader societal and health-systems contexts. Global framings of health and adolescence may also not apply completely within the study context, given that dominant notions of childhood and health are often guided by theories developed in the global North (Skovdal and Daniel, 2012). This work has aimed to understand and incorporate local models, but may not have always adequately captured such understandings.

Sampling bias is another limitation of this work. By having tested positive for HIV and initiated onto ART, participants may have been more proactive about their health (or have more proactive caregivers). Participants were also selected based on their interest in taking part in this qualitative research and we may have generated a sampling bias by recruiting participants who may be more open and talkative than their peers. Social desirability bias may also be present in this research, given that it discussed sensitive topics of gender (as discussed in Chapter Seven), ulwaluko (Chapter Four) and traditional health practices (Chapter Six).

Gender is socially constructed, performed, and relational, and this research recognised the presence of multiple dynamic and situational masculinities (Jewkes *et al.*, 2015). Using an intersectional feminist lens as a framework (Crenshaw, 1990), this study considered how the

multiple, intersecting forms of privilege and marginalisation shape lived experiences and embodied realities of participants. Factors that may affect participant experiences of privilege, marginalisation and vulnerability that this study did not have sufficient data to explore included sexual orientation, mental ability, and physical ability, and these bear further elucidation.

Another limitation is language. English was used in the interviews that I conducted with most traditional and biomedical health practitioners. Despite the fact that participants were fluent in English, the interview language may have limited participant expression and meant that important context was missed. Additionally, not being present for isiXhosa-language interviews with adolescent participants meant that I did not have the opportunity to delve deeper with participants into certain topics. This may have limited the data collected, as well as my understanding of it, although it was essential in upholding the norms of privacy and secrecy that characterise ulwaluko.

Despite these limitations, the research design and methods elicited evidence which would have been otherwise difficult to achieve using more traditional public health methods. Findings regarding the methods used in this study are demonstrative of some of the challenges and possibilities for intentional and innovative participant-driven research within vulnerable populations and challenging contexts. Although they are limited, and often resource-intensive, such methods also have value for social science and public health research. The following section reflects on some insights from these methods.

Methodological and Theoretical Insights

In this research, health-focused life history narratives were employed as a tool to understand how individual histories, processes, and contexts are experienced, performed and embodied. Participants told their life histories from their own perspectives using various forms of expression including drawing, writing and speaking. Triangulating analysis of life histories with clinic files and the perspectives of traditional and biomedical health practitioners provided additional insight into young people's health practices from different perspectives. They also demonstrated the tensions of authority and autonomy within the state public health system. Analysing clinic files across time showed how health practices evolved, as well as how family

roles shifted and changed. These files also provided additional insight into the psychosocial, structural and physical challenges faced by young HIV-positive people and their families.

Despite its limitations, this research used the lens of medical pluralism through which to view participant engagements with traditional and biomedical products and services. Exploring the life histories of participants provided insights into how health practices with traditional and biomedical products and services are mediated by age, gender, family beliefs, experience and the messy imprecision of trial and error. Working with various knowledge holders, including those who are the custodians of traditional belief and practice, provided for rich insight that may be missed using solely biomedical frames. Findings affirm the syncretic nature of traditional beliefs within the study site and demonstrate how beliefs and practice inform, and are informed by, embodied experiences and knowledge. Drawing on the knowledge, perspectives and experiences of traditional and biomedical practitioners added detail to these understandings, and showed the possibilities and relevance of engagement within the non-formalised health sectors and the breadth and variety of traditional health practitioner perspectives.

This thesis engaged multiple gender and masculinities concepts to examine how adolescent boys and young men perform to, reconstruct, resist and re-signify health-related masculine norms. Specifically, it employed notions Xhosa masculine identities encapsulated within the terms indoda and inkwenkwe as well as the concept of hegemonic masculinities. The use of multiple masculinities frameworks acknowledges the importance and relevance of engaging local concepts and theories, alongside the potential applicability of the lens of hegemonic masculinities to work alongside local frameworks. Although outside of the scope of this thesis, further theoretical masculinities work could consider the conditions under which the use of local and/or global masculinities theories may be engaged together or independently of one another.

This thesis documented the vast structural, social and health challenges faced by adolescent boys and young men living with HIV in the Eastern Cape. However, it also details the resilience and creativity with which participants navigated such challenges. This was clear in their enactments of certain health and gender performances, and in their work to redeem lost mothers and failed patriarchs of days past. In navigating these forces, participants actively constructed lives and

identities that negotiated, contested, and, at times, reinforced, dominant gender and health norms. This thesis has demonstrated that, far from being a top-down process, young people engage the resources and tools available to them to actively shape their biosocial worlds. It has provided insight into how adolescent boys and young men curate and perform this delicate dance, within the limitations of their structural, health and social environments.

The following table makes recommendations based on this research for policy, practice and further research.

Recommendations table

Ulwaluko
Pre-ulwaluko: Health services could leverage pre-ulwaluko health facility checks, which are legally required to get a certificate to attend ulwaluko. These visits may be a rare time that the health system engages with males of this age group. This is an opportunity to engage adolescent boys and young men in biomedical health services, to encourage health practices and retention in care, for education and linkages to other services.
Pre-ulwaluko: Provide health facility support to initiates and families to plan in advance how initiates with HIV and other chronic conditions will approach medicine-taking during initiation. Findings from this research suggest that discreet daily pill deliveries from amanqalathi or amakhankatha may support initiates to take pills in a way that does not stigmatise them. Another option is organising private amabhoma in non-stigmatising ways for new initiates so they have a private space to take medicine, although this is a more expensive option. Some virally suppressed participants who participated in this research had planned treatment interruptions and reported re-initiating in care easily, although they may already be more likely to be adherent and not representative of others who have more trouble adhering. Regardless of the approach taken, supporting planning with initiates and their families in advance of ulwaluko is crucial for initiates living with chronic conditions to take their medication.
Include information about the needs of boys taking chronic medications, and strategies to support them in training and manuals for amakhankatha and iincgibi, as well with pre-circumcision clinics.
Provide new initiates, in advance of ulwaluko, with information about the potential challenges of chronic medicine-taking and avenues to discuss and plan how to take medicine. Schools offer one forum that could provide a platform to educate boys on this issue before initiation so they can plan.
Post-ulwaluko: Evidence from this study suggests that ulwaluko may be a critical moment where young males disengage from care. Health facility-based follow-up systems to encourage re-engagement in care such as call-backs, or engaging an existing cadre of community health workers, could support new initiates to return to care. Such systems could also be used to engage adolescent boys and young men regardless of their HIV status in health promotion efforts, given their general poor health practices and increasing risk of HIV acquisition and other health issues.
Post-ulwaluko: Ensure that participants can access medications immediately after returning from initiation, either by supported caregiver medication pick-ups, or via clinic or community health worker deliveries.
Engage amakhankatha, and other influential men at ulwaluko, to encourage the use of condoms post-ulwaluko for ‘test-driving’, that is, having sex when they return from initiation as a way to try it out (Hodes and Gittings, 2019). This is a highly risky time for the acquisition and onwards transmission of HIV and other STIs. Findings from this research demonstrate that in some cases, amakhankatha are already doing this, and that this affects new initiates’ sexual practices.

Pre-ulwaluko: Traditional health practitioners are another service that many boys use before ulwaluko. They can also be leveraged to encourage chronic medicine-taking and planning with families. This would require training, input and dialogue, which could be wrapped into already existing trainings and engagements between traditional health practitioners and the Department of Health.
Collaboratively engage the house of traditional leaders, alongside other cultural custodians on the above recommendations.
Traditional health practitioners
This work has shown the value of engaging traditional health practitioners in health and well-being related research and documented some of the rich breadth and variety of traditional health practitioner perspectives. Further work could explore this variety of traditional health practices, and how they interface with the biomedical health system. In addition, considering how plural medical practices overlap or differ for horizontally infected adult men could provide better insight into men's health practices in the age of universal test and treat.
As people who have experience with and a detailed understanding of male clients and the issues facing them, engaging traditional health practitioners on issues related to men and poor health outcomes bears further consideration. Such work should do more than mandate and train traditional health practitioners on referring men to clinic services. Active, meaningful engagement and the co-identification and implementation of solutions is warranted.
Children, adolescents and young people living with HIV
Findings from this study add to a literature that suggests that disclosure of an HIV-positive status, in an appropriate way and by an appropriate age, can have potential long-term implications for ART adherence. Initiatives to encourage timely, appropriate disclosure, including through health workers and social services may support this. Consideration should be given to how to navigate disclosing parental death and a child's HIV-positive status, given how participants often learn about these two things at the same time.
Findings add to a literature documenting the resilience of young people growing up with HIV, as well as the multiple challenges they face. Evidence from this research agrees that greater current social and structural support for adolescents living with HIV and their families is necessary.
Men and health
This research adds to the call for the development and implementation of health systems that better support men to engage with and be retained in biomedical care. Evidence from this thesis demonstrates that as boys become older that they begin to face some of the documented social and institutional barriers that older men face. Further research could explore which interventions support the needs of adolescent boys and young men. These may include sensitisation of health care workers, services provided, the gender of health care workers and the set-up of health facilities. For example, findings in this research aligned with a body of evidence suggesting that being shouted at, fears of gossip, or health facilities that single out chronic medicine-takers are deterrents for young men accessing services.

The provision of differentiated services to adolescent boys and young men, including community-based or peer-led initiatives, may be a way to respond to barriers to engagement in health services. For example, male community health workers may have the potential to provide men with community-based services to support retention in care, as well be transformative to gendered notions of caring (Gittings, 2018).
Findings demonstrate the multiple ways that young people are socialised into gender norms, making a case for further consideration and intervention in communities, families and social services. Encouraging the engaged presence of male role models (Langa, 2010; Stern, 2013; Erasmus, Norins and van der Elst, 2019) in policy and programming may provide an avenue to shift, and deconstruct certain harmful gender norms.
The reflexive co-exploration of the possibilities and limitations of gender-related health research with adolescent boys and young men also bears mentioning. Methodological findings demonstrate the possibilities, and resource intensive nature of participatory, engaged work that acknowledges the knowledge and creativity of adolescent boys and men. Findings demonstrate the opportunities and pitfalls of building relationships which allow for honest, meaningful engagement, and raise questions about what these processes might mean for gender transformative work. Specifically, they demonstrate the importance of time and continued engagement, and question if expressing gender unequal beliefs are a step towards or away from a gender transformative agenda. Important here will be to discern processes that encourage gender equitability in practice for adolescent boys and young men, rather than in abstract terms (Ratele, 2014b). Such processes, alongside a close analysis of power with them, bear further elucidation and focused resource and attention.
Interventions focusing on adolescent boys and young men are notably absent, despite major health-related issues. Other societal issues, including high rates of violence against women and children, although outside of the scope of this thesis, are also indicative of conditioning into harmful gender norms. Participatory initiatives that engage adolescent boys and young men on gender norms that have demonstrated success, such as the Stepping Stones intervention and Grassroots Soccer should be considered for scale-up. A focus on the material conditions of adolescent boys and young men, and creating opportunities and building capacity will be essential parts of such programmes. Unfortunately, the current funding climate may constrain such initiatives.
This research ended as participants entered into young adult manhood, with most being no older than 22 years. Of the older participants, most had recently undergone ulwaluko. Understanding what happens as they incorporate lessons and become older and more established men in relation to their health practices and outcomes could further elucidate pathways to manhood and their impact on health practice and wellbeing. Will they maintain the health practice tools they developed as children via embodied young experiences, or will these shift with age?

Table 4: Recommendations Table

Conclusion

The provision of life-saving HIV medication has changed the course of the HIV epidemic, and has drastically reduced HIV-related mortality. Children and adults die less of AIDS-related illness, and live longer, better quality lives. However, adherence to ART and retention in care for people living with HIV is still highly uneven. Adolescents and men are two populations that perform poorly within the HIV cascade of care, and have poor AIDS-related outcomes.

The findings from this study suggest that there is a need for continued research, policy and programmatic engagement to shift the social, structural and gendered conditions that exacerbate risk and undermine resilience among young people. They call for further contextually-grounded research, policy and programming on issues of health, adolescence and gender.

Through an exploration of the health practices of adolescent boys and young men living with HIV, this thesis has documented both the power and malleability of hegemonic masculine norms. Despite insurmountable challenges faced by participants, their health practices—formed as a result of growing up with HIV and later navigating ulwaluko—demonstrate the pliable nature of health and masculinity-related practice and the agency and resilience of young HIV-positive people.

Despite this, turning the tide on the HIV epidemic to reduce mortality and stem new infections will require more effective responses for adolescent boys and men. This thesis has aimed to provide some insight into the health practices of this group to support such initiatives.

References

Abdool Karim, S. S., Churchyard, G. J., Karim, Q. A. and Lawn, S. D. (2009) 'HIV infection and tuberculosis in South Africa: an urgent need to escalate the public health response', *Lancet*, 374(9693), pp. 921–933. doi: 10.1016/S0140-6736(09)60916-8.

Airhihenbuwa, C. O. (2007) *Healing our differences: The crisis of global health and the politics of identity*. Rowman & Littlefield.

Al-Dakkak, I., Patel, S., McCann, E., Gadkari, A., Prajapati, G. and Maiese, E. M. (2013) 'The impact of specific HIV treatment-related adverse events on adherence to antiretroviral therapy: a systematic review and meta-analysis.', *AIDS care*, 25(4), pp. 400–414. doi: 10.1080/09540121.2012.712667.

Ampofo, A. A. and Boateng, J. (2007) 'Multiple meanings of manhood among boys From boys to men: Social constructions of masculinity in contemporary society', in Shefer, T. et al. (eds). UCT Press, pp. 50–74.

Anderson, K. (2005) 'Relatedness and investment in children in South Africa', *Human Nature*, 16(1), pp. 1–31.

Anthropology Southern Africa (2005) 'Ethical Guidelines and Principles of Good Conduct for Anthropologists', *Anthropology Southern Africa*, 28(3&4), pp. 142–143.

Appelbaum Belisle, H., Hennink, M., Ordóñez, C. E., John, S., Ngubane-Joye, E., Hampton, J., Sunpath, H., Preston-Whyte, E., *et al.* (2015) 'Concurrent use of traditional medicine and ART: Perspectives of patients, providers and traditional healers in Durban, South Africa', *Global Public Health*, 10(1), pp. 71–87. doi: 10.1080/17441692.2014.967709.

Arnfred, Signe (2004) *Re-thinking Sexualities in Africa*. Edited by S. Arnfred. Nordic Africa Institute, Uppsala.

Ashforth, A. (1998) 'Reflections on Spiritual Insecurity in a Modern African City (Soweto)', *African Studies Review*, 41(3), pp. 39–67.

Ashforth, A. (2001) *AIDS, Witchcraft, and the Problem of Power in Post-Apartheid South Africa*. School of Social Science.

Ashforth, A. (2005) 'Muthi, medicine and witchcraft: Regulating "African science" in post-apartheid South Africa?', *Social Dynamics*, 31(2), pp. 211–242.

Asmal, K. and James, W. (2002) 'Education and democracy in South Africa', in Asmal, K. and James, W. (eds) *Spirit of the nation: reflections on South Africa's educational ethos*. New Africa

Education, pp. 174–189.

Atkinson, R. (1998) *The Life Story Interview*. Sage Publications, Thousand Oaks, CA.

Audet, C. M., Blevins, M., Rosenberg, C., Farnsworth, S., Salato, J., Fernandez, J. and Vermund, S. H. (2014) 'Symptomatic HIV-positive persons in rural Mozambique who first consult a traditional healer have delays in HIV testing: a cross-sectional study.', *Journal of acquired immune deficiency syndromes (1999)*, 66(4), p. e80. doi: 10.1097/QAI.0000000000000194.

Audet, C. M., Ngobeni, S. and Wagner, R. G. (2017) 'Traditional healer treatment of HIV persists in the era of ART: a mixed methods study from rural South Africa', *BMC Complementary and Alternative Medicine*, 17(1), p. 434.

Auvert, B., Taljaard, D., Lagarde, E., Sobngwi-Tambekou, J., Sitta, R. and Puren, A. (2005) 'Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk: The ANRS 1265 trial', *PLoS Medicine*, 2(11), p. e298. doi: 10.1371/journal.pmed.0020298.
Baer, H. A. (1995) 'Medical Pluralism in the United States: A Review', *Medical Anthropology Quarterly*, 9(4), pp. 493–502. doi: 10.16373/j.cnki.ahr.150049.

Bakeera-Kitaka, S., Nabukeera-Barungi, N., Nöstlinger, C., Addy, K. and Colebunders, R. (2008) 'Sexual risk reduction needs of adolescents living with HIV in a clinical care setting.', *AIDS care*, 20(4), pp. 426–433. doi: 10.1080/09540120701867099.

Baker, P., Dworkin, S. L., Tong, S., Banks, I., Shand, T. and Yamey, G. (2014) 'The men's health gap: men must be included in the global health equity agenda', *Bulletin of the World Health Organization*, 92, pp. 618–620. doi: 10.2471/BLT.13.132795.

Bank, L. (2001) 'Living together, moving apart: Home-made agendas, identity politics and urban-rural linkages in the Eastern Cape, South Africa.', *Journal of Contemporary African Studies*, 19(1), p. 129.

Barker, R. D., Millard, F. J. C., Malatsi, J., Mkoana, L., Ngoatwana, T., Agarawal, S. and De Valliere, S. (2006) 'Traditional healers, treatment delay, performance status and death from TB in rural South Africa', *International Journal of Tuberculosis and Lung Disease*, 10(6), pp. 670–675.

Barry, A., Osborne, T. and Rose, N. (eds) (1996) *Foucault and Practical Reason: Liberalism, Neo-liberalism and Rationalities of Government*. University College London, London.

Beck, D. (2004) *Men and ARVs: How does being a man affect access to antiretroviral therapy in South Africa? An investigation among Xhosa-speaking men in Khayelitsha*. University of Cape Town, Cape Town.

Becker, F. and Geissler, W. (2009) 'Searching for pathways in a landscape of death: religion and AIDS in Africa', in Becker, F. and Geissler, W. (eds) *Aids and Religious Practice in Africa*.

Kroningklijke Brill BV, Leiden, pp. 1–15.

Beinart, W. (2001) *Twentieth-Century South Africa*. Oxford University Press, Oxford.

Benard, B. (1995) 'Fostering resilience in children'. ERIC Digest. doi: 10.4135/9781452231792.n3.

Bernays, S., Paparini, S., Seeley, J. and Rhodes, T. (2017) '"Not taking it will just be like a sin": Young People Living with HIV and the stigmatization of less-than-perfect adherence to antiretroviral therapy', *Medical Anthropology*, 36(5), pp. 485–499. doi: http://dx.doi.org/10.1080/01459740.2017.1306856.

Betancourt, T. S., Meyers-Ohki, S. E., Charrow, A. and Hansen, N. (2013) 'Mental Health and Resilience in HIV/AIDS Affected Children: A Review of the Literature and Recommendations for Future Research', *The Journal of Child Psychology and Psychiatry*, 54(4), pp. 423–444. doi: 10.1111/j.1469-7610.2012.02613.x.Mental.

Betron, M., Barker, G., Contreras, J. M. and Peacock, D. (2012) *Men, masculinities and HIV/AIDS: Strategies for Action*.

Bhana, D. (2005) 'Violence and the Gendered Negotiation of Masculinity Among Young Black School Boys in South Africa', in Ouzgane, L. and Morrell, R. (eds) *African Masculinities*. Palgrave Macmillan, New York.

Bhana, D. (2008) 'Discourses of childhood innocence in primary school HIV/AIDS education in South Africa', *African Journal of AIDS Research*, 7(1), pp. 149–158. doi: 10.2989/AJAR.2008.7.1.15.443.

Bhana, D., de Lange, N. and Mitchell, C. (2009) 'Male teachers talk about gender violence: "Zulu men demand respect"', *Educational Review*, 61(1), pp. 49–62. doi: 10.1080/00131910802684771.

Bikaako-Kajura, W., Luyirika, E., Purcell, D. W., Downing, J., Kaharuza, F., Mermin, J., Malamba, S. and Bunnell, R. (2006) 'Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda.', *AIDS and Behavior*, 10(1), p. 85. doi: 10.1007/s10461-006-9141-3.

Blackbeard, D. and Lindegger, G. (2015) 'The Value of Participatory Visual Methods in Young Masculinity Research', *Procedia - Social and Behavioral Sciences*, 165, pp. 85–93. doi: https://doi.org/10.1016/j.sbspro.2014.12.608.

Blue, S., Shove, E., Carmona, C. and Kelly, M. P. (2016) 'Theories of practice and public health: understanding (un)healthy practices', *Critical Public Health*, 26(1), pp. 36–50. doi: 10.1080/09581596.2014.980396.

Bogart, L., Kalichan, S. C. and Simbayi, L. C. (2008) 'Endorsement of a genocidal HIV conspiracy as a barrier to HIV testing in South Africa', *Journal of Acquired Immunodeficiency Syndrome*, 49(1), pp. 115–116.

Bogart, L. M., Galvan, F. H., Wagner, G. J. and Klein, D. J. (2011) 'Longitudinal association of HIV conspiracy beliefs with sexual risk among black males living with HIV', *AIDS and Behavior*, 15(6), pp. 1180–1186. doi: 10.1007/s10461-010-9796-7.

Bogopa, D. (2010) 'Health and Ancestors: The Case of South Africa and Beyond', *The Indo-Pacific Journal of Phenomenology*, 10.

Bogopa, D. L. (2007) 'Challenges facing the initiation schools: The case of Nelson Mandela Metropole in the Eastern Cape', *Acta Criminologica: Southern African Journal of Criminology*, 20(4), pp. 55–60.

Bonner, P. (1990) '"Desirable or undesirable Basotho women?" Liquor, prostitution and the migration of Basotho women to the Rand, 1920-194', in Walker, C. (ed.) *Women and gender in Southern Africa 1920 - 1945*. David Philip, Cape Town pp. 221–250.

Boyden, J. (1997) 'Childhood and the policy-makers: a comparative perspective on the globalisation of childhood', in James, A. and Prout, A. (eds) *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood*. 2nd edn. Falmer Press, London.

Bradford, H. (1991) 'Herbs, Knives and Plastic: 150 years of abortion in South Africa', in Meade, T. and Walker, M. (eds) *Science, Medicine and Cultural Imperialism*. Palgrave Macmillan, London, pp. 120–147.

Bradshaw, J. (1994) *Creating Love: The Next Great Stage of Growth*. Bantam, New York.

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3(2), pp. 77–101.

Brittain, K., Asafu-Agyei, N. A., Hoare, J., Bekker, L.-G., Rabie, H., Nuttall, J., Roux, P., Stein, D. J., *et al.* (2017) 'Association of Adolescent- and Caregiver-Reported Antiretroviral Therapy Adherence with HIV Viral Load Among Perinatally-infected South African Adolescents', *AIDS and Behavior*, 22(3), pp. 909–917. doi: 10.1007/s10461-017-2004-2.

Brittijn, M. (2013) '"We're not boys anymore, we need to be courageous": Towards an understanding of what it means to be a man in Lavender Hill', *Agenda*, 27(1), pp. 49–60. doi: 10.1080/10130950.2013.804744.

Burton, R., Giddy, J. and Stinson, K. (2015) 'Prevention of mother-to-child transmission in South Africa: an ever-changing landscape', *Obstetric medicine*, 8(1), pp. 5–12. doi:

10.1177/1753495X15570994.

Butler, J. (1988) 'Performative acts and gender constitution: An essay in phenomenology and feminist theory', *Theatre Journal*, 40(4), pp. 519–531. doi: 10.2307/3207893.

Butler, J. (1993) *Bodies That Matter: On the Discursive Limits of 'Sex'*. Routledge. doi: 10.1177/0306312706056409.

Butler, J. (2004) *Precarious life: the powers of mourning and violence.* Verso, London.

Campbell, C. (1992) 'Learning to kill? Masculinity, the family and violence in Natal', *Journal of Southern African Studies*, 18(3), pp. 614–628. doi: 10.1080/03057079208708328.

Campbell, C., Nair, Y., Maimane, S. and Nicholson, J. (2007) '"Dying twice": a multi-level model of the roots of AIDS stigma in two South African communities.', *Journal of health psychology*, 12, pp. 403–416. doi: 10.1177/1359105307076229.

Campbell, C., Gibbs, A., Maimane, S., Nair, Y. and Sibiya, Z. (2009) 'Youth participation in the fight against AIDS in South Africa: from policy to practice', *Journal of Youth Studies*, 12(1), pp. 93–109. doi: 10.1080/13676260802345757.

Campbell, C., Skovdal, M., Mupambireyi, Z., Madanhire, C., Nyamukapa, C. and Gregson, S. (2012) 'Building adherence-competent communities: factors promoting children's adherence to anti-retroviral HIV/AIDS treatment in rural Zimbabwe', *Health & place*, 18(2), pp. 123–131. doi: 10.1016/j.healthplace.2011.07.008.

Campbell, C., Williams, B. and Gilgen, D. (2010) 'UK AIDS Care : Psychological and Socio-medical Aspects of AIDS / HIV Is social capital a useful conceptual tool for exploring community level influences on HIV infection? An exploratory case study from South Africa', (February 2015), pp. 37–41. doi: 10.1080/09540120220097928.

Casale, D. and Posel, D. (2002) 'The continued feminization of the labor force in South Africa', *South African Journal of Economics*, 70(1), p. 156.

Cattell, V. (2001) 'Poor people, poor places, and poor health: the mediating role of social cohesions and social capital', *Social Science and Medicine*, 52(10), p. 1501.

Chavunduka, G. L. (1999) *Christianity, African religion and African medicine*, *World Council of Churches*. Available at: http://www.wcc-coe.org/wcc/what/interreligious/cd33-02.html.

Chigwedere, P., Seage, G., Gruskin, S., Tun-Hou, L. and Essex, M. (2008) 'Estimating the Lost Benefits of Antiretroviral Drug Use in South Africa', *Journal of Acquired Immune Deficiency Syndromes*, 49(4), pp. 410–415. doi: 10.1097/QAI.0b013e31818a6cd5.

Chikovore, J., Gillespie, N., McGrath, N., Orne-Gliemann, J. and Zuma, T. (2016) 'Men, masculinity, and engagement with treatment as prevention in KwaZulu-Natal, South Africa', *AIDS Care*, 28(sup3), pp. 74–82. doi: 10.1080/09540121.2016.1178953.

Christensen, P. and O'Brien, M. (eds) (2003) *Children in the city: Home, neighbourhood and community*. Routledge Falmer, London.

Cluver, L., Boyes, M., Orkin, M., Pantelic, M., Molwena, T. and Sherr, L. (2013) 'Child-focused state cash transfers and adolescent risk of HIV infection in South Africa: A propensity-score-matched case-control study', *The Lancet Global Health*, 1(6), pp. e362–e370. doi: 10.1016/S2214-109X(13)70115-3.

Cluver, L., Hodes, R., Toska, E., Kidia, K., Orkin, F. M., Sherr, L. and Meinck, F. (2015) '"HIV is like a tsotsi. ARVs are your guns'': associations between HIV-disclosure and adherence to antiretroviral treatment among adolescents in South Africa"', *AIDS*, 29(Suppl 1), pp. S57–S65. doi: 10.1097/QAD.0000000000000695.

Cluver, L., Hodes, R., Sherr, L., Orkin, F. M., Meinck, F., Lim, P. L. A. K., Winder-Rossi, N. E., Wolfe, J., *et al.* (2015) 'Social protection: potential for improving HIV outcomes among adolescents', *Journal of the International AIDS Society*, 18(Suppl 6), p. 20260. doi: http://dx.doi.org/10.7448/IAS.18.7.20260.

Cluver, L., Boyes, M., Bustamam, A., Casale, M., Henderson, K., Kuo, C., Lane, T., Latief, S., *et al.* (2015) 'The cost of action: Large scale, longitudinal quantitative research with AIDS-affected children in South Africa', in Posel, D. and Ross, F. (eds) *Ethical quandaries in social research*. HSRC Press, pp. 41–56.

Cluver, L., Pantelic, M., Toska, E., Orkin, M., Casale, M., Bungane, N. and Sherr, L. (2018) 'STACKing the odds for adolescent survival: health service factors associated with full retention in care and adherence amongst adolescents living with HIV in South Africa', *Journal of the International AIDS Society*, 21(9), p. e25176. doi: 10.1002/jia2.25176.

Cohen, D. W. and Odhiambo, E. S. A. (1989) *Siaya, the historical anthropology of an African landscape*. J. Currey, London.

Colvin, C. J. (2014) 'Evidence and AIDS activism: HIV scale-up and the contemporary politics of knowledge in global public health.', *Global public health*, 9(1–2), pp. 57–72. doi: 10.1080/17441692.2014.881519.

Colvin, C. J. (2019) 'Strategies for engaging men in HIV services', *Lancet HIV*, 6(3), pp. e191–e200.

Colvin, C. J., Robins, S. and Leavens, J. (2010) 'Grounding "responsibilisation talk": masculinities, citizenship and HIV in Cape Town, South Africa', *The Journal of Development Studies*, 46(7), pp. 1179–1195.

Comaroff, Jean and Comaroff, John (2012) *Theory from the South: Or, how Euro-America is evolving toward Africa.* Routledge, London.

Connell, R. (2007) *Southern Theory: The Global Dynamics of Knowledge in Social Science*. Polity, Cambridge.

Connell, R. W. (1995) *Masculinities*. University of California Press, Berkeley.

Connell, R. W. (2005) *Masculinities*. 2nd edn, *Masculinities*. 2nd edn. University of California Press, Berkeley.

Cook, P. A. W. (1931) *Social organization and ceremonial institutions of the Bomvana*. Juta Press, Cape Town.

Cook, P., Ali, S. and Munthali, A. (2000) *Starting from Strengths: Community Care for Orphaned Children in Malawi (unpublished manuscript)*.

Cooper, D., Morroni, C., Orner, P., Moodley, J., Harries, J., Cullingworth, L. and Hoffman, M. (2004) 'Ten Years of Democracy in South Africa: Documenting Transformation in Reproductive Health Policy and Status', *Reproductive Health Matters*, 12(24), pp. 70–85.

Cornell, M., Grimsrud, A., Fairall, L., Fox, M. P., van Cutsem, G., Giddy, J., Wood, R., Prozesky, H., *et al.* (2010) 'Temporal Changes in Programme Outcomes Among Adult Patients Initiating Anti-Retroviral Therapy across South Africa 2002–2007', *AIDS*, 24(14), pp. 2263–2270.

Cornell, M., McIntyre, J. and Myer, L. (2011) 'Men and antiretroviral therapy in Africa: our blind spot', *Tropical Medicine & International Health*, 16(7), pp. 828–829. doi: 10.1111/j.1365-3156.2011.02767.x.

Cornwall, A. (2007) 'Men, masculinity and gender in development', *Gender & Development*, 5(2), pp. 8–13.

Courtenay, W. H. (2000) 'Constructions of masculinity and their influence on men's well-being :a theory of gender and health', *Social Science & Medicine*, 50(10), pp. 1385–1401.

Cowan, P. A., Cowan, C. P. and Schulz, M. S. (1996) 'Thinking about risk and resilience in families', in Hetherington, E. M. and Belchman, E. A. (eds) *Stress, coping, and resiliency in children and families*. Lawrence Erlbaum Associates, Mahwah.

De Craemer, W. (1983) 'A Cross-Cultural Perspective on Personhood', *Millbank Memorial Fund Quarterly/Health and Society*, 61(1), pp. 19–34.

Craffert, P. F. (1997) 'Opposing world-views: The border guards between traditional and

biomedical health care practices', *South African Journal of Ethnology*, 20(1), pp. 1–9.

Crenshaw, K. (1990) 'Mapping the margins: Intersectionality, identity politics, and violence against women of color', *Stan. L. Rev.*, 43, p. 1241.

Cusick, S. and Georgieff, K. (no date) *The First 1,000 Days of life: the brain's window of opportunity*, *UNICEF*. Available at: https://www.unicef-irc.org/article/958-the-first-1000-days-of-life-the-brains-window-of-opportunity.html (Accessed: 28 August 2019).

Dageid, W., Govender, K. and Gordon, S. F. (2012) 'Masculinity and HIV disclosure among heterosexual South African men: implications for HIV/AIDS intervention', *Culture, Health & Sexuality*, 14(8), pp. 925–940. doi: 10.1080/13691058.2012.710337.

Dawes, A., Bray, R., Kvalsvig, J., Kafaar, Z., Rama, S. and Richter, L. M. (2004) *Going Global with Indicators of Child Well-Being: Indicators of South African Children's Psychosocial Development in the Early Childhood Period*. Cape Town, South Africa. Available at: http://www.hsrc.ac.za/en/research-data/view/1783.

Deacon, H. and Stephney, I. (2007) *HIV/AIDS, stigma and children-A literature review*. HSRC Press. Available at: http://kit.nl/-/INS/14224/(57698)-ILS/KIT-ILS-Dossiers.pdf.

Deacon, H. and Thomson, K. (2012) *The Social Penis. Traditional Male Circumcision and Initiation in Southern Africa, 1800-2000: A Literature Review*. 304.

Decoteau, C. L. (2013) *Ancestors and Antiretrovirals: The Biopolitics of HIV/AIDS in post-apartheid*. University of Chicago Press, Chicago.

Delany-Moretlwe, S., Cowan, F. M., Busza, J., Bolton-Moore, C., Kelley, K. and Fairlie, L. (2015) 'Providing comprehensive health services for young key populations: needs, barriers and gaps.', *Journal of the International AIDS Society*, 18(Suppl 1), p. 19833. doi: 10.7448/IAS.18.2.19833.

Dempsey, A. G., MacDonell, K. E., Naar-king, S. and Lau, C.-Y. (2012) 'Patterns of Disclosure among Youth who are HIV Positive: A Multisite Study', *Journal of Adolescent Health*, 50(3), pp. 315–317. doi: 10.1016/j.jadohealth.2011.06.003.Patterns.

Denison, J. A., Packer, C., Stalter, R. M., Banda, H., Mercer, S., Nyambe, N., Katayamoyo, P., Mwansa, J. K., *et al.* (2018) 'Factors related to incomplete adherence to antiretroviral therapy among adolescents attending three HIV clinics in the copperbelt, Zambia', *AIDS and Behavior*, 22(3), pp. 996–1005. doi: 10.1007/s10461-017-1944-x.

Dickson, K. E., Jewkes, R., Brown, H., Levin, J., Rees, H. and Mavuya, L. (2003) 'Abortion service provision in South Africa three years after liberalization of the law', *Studies in Family Planning*, 34(4), pp. 277–284.

Dovel, K., Yeatman, S., Watkins, S. and Poulin, M. (2015) 'Men's heightened risk of AIDS-related death: the legacy of gendered HIV testing and treatment strategies', *AIDS*, 29(10), p. 1123. doi: 10.1097/QAD.0000000000000655.

Dworkin, S. L., Fleming, P. J. and Colvin, C. J. (2015) 'The promises and limitations of gender-transformative health programming with men: critical reflections from the field', *Culture, Health and Sexualityealth & sexuality*, 17(Suppl 2), pp. 128–143. doi: 10.1080/13691058.2015.1035751.

Dworkin, S. L., Treves-Kagan, S. and Lippman, S. A. (2013) 'Gender-transformative interventions to reduce HIV risks and violence with heterosexually-active men: a review of the global evidence', *AIDS and Behavior*, 17(9), pp. 2845–2863.

Edwards, M. (1996) 'New approaches to children and development: Introduction and overview', *Journal of International Development*, 8(6), pp. 813–827.

Epprecht, M. (2004) *Hungochani, Second Edition: The History of a Dissident Sexuality in Southern Africa*. McGill-Queen's University Press.

Erasmus, Y., Norins, J. and van der Elst, L. (2019) *SADC regional study of vulnerability amongst boys (ages 14-20 years) in schools*. Durban, South Africa.

Fassin, D. (2008) 'Suffering children, abused babies and AIDS orphans: the moral construction of childhood in post-apartheid South Africa', in Fassin, D. et al. (eds) *Healing the World's Children: Interdisciplinary Perspectives on Health in the Twentieth Century*. McGill-Queen's University Press, Montreal, pp. 111–124.

Faull, M. (2010) *Does a Male-friendly Health Facility Improve the Uptake of Voluntary Counselling and Testing Services by Men?* Cape Town, South Africa.

Feldacker, C., Ennett, S. T. and Speizer, I. (2011) 'It's not just who you are but where you live: An exploration of community influences on individual HIV status in rural Malawi', *Social Science and Medicine*, 72(5), pp. 717–725. doi: 10.1016/j.socscimed.2011.01.003.

Finlay, L. (2002) 'Negotiating the swamp: the opportunity and challenge of reflexivity in research practice', *Qualitative Research*, 2(2), pp. 209–230.

Finnegan, W. (2001) 'A reporter at large: The poison keeper', *The New Yorker*. Available at: https://www.newyorker.com/magazine/2001/01/15/the-poison-keeper.

Fleck, L. (1935) *Genesis and Development of a Scientific Fact*. University of Chicago Press, Chicago.

Fleming, P. J., Lee, J. G. L. and Dworkin, S. L. (2014) '"Real Men Don't": Constructions of masculinity and inadvertent harm in public health interventions', *American journal of public*

health, 104(6), pp. 1029–1035. doi: 10.2105/AJPH.2013.301820.

Flint, A. and Payne, J. (2013) 'Reconciling the Irreconcilable? HIV/AIDS and the Potential for Middle Ground Between the Traditional and Biomedical Healthcare Sectors in South Africa', *Forum for Development Studies*, 40(1), pp. 47–68. doi: 10.1080/08039410.2012.702681.

Flint, K. E. (2008) *African Medicine, Cultural exchange, and competition in South Africa 1820-1948*. UKZN Press, Durban.

Fonagy, P. and Target, M. (2003) 'Translation towards understanding violence: The use of the body and the role of the father', in Perelberg, R. (ed.) *Psychoanalytic understanding of violence and suicide*. Routledge, pp. 53–72.

Foucault, M. (1978) *The History of Sexuality: Volume I*, *Trans. Robert Hurley*.

Fourie, P. (2006) *The Political Management of HIV and AIDS in South Africa*. Palgrave Macmillan, New York.

Freund, B. (2018) *Twentieth-Century South Africa: A Developmental History*. Cambridge University Press, Cambridge. doi: DOI: 10.1017/9781108604222.

Friend-du Preez, N. and Peltzer, K. (2010) 'HIV symptoms and health-related quality of life prior to initiation of HAART in a sample of HIV-positive South Africans', *AIDS and Behavior*, 14(6), pp. 1437–1447. doi: 10.1007/s10461-009-9566-6.

Frosh, S., Phoenix, A. and Pattman, R. (2001) *Young masculinities: Understanding boys in contemporary society*. Palgrave, London.

Garbarino, J. (1999) *Lost boys: Why our sons turn violent and how we can save them. New York.*

Gardiner, J. (2005) 'Men, masculinities, and feminist theory', in Kimmel, M. S., Hearn, J., and Connell, R. W. (eds) *Handbook of studies on men & masculinities*. SAGE Publications, Thousand Oaks, pp. 35–50. doi: 10.4135/9781452233833.n3.

Gennrich, D. (ed.) (2013) 'Volume 2 Understanding Masculinity in South Africa – Essays and Perspectives', in *Men and masculinities in South Africa (a three-part series)*. PACSA; Sonke Gender Justice.

Germond, P. and Cochrane, J. R. (2010) 'Healthworlds: Conceptualizing Landscapes of Health and Healing', *Sociology*, 44(2), pp. 307–324. doi: 10.1177/0038038509357202.

Giacomet, V., Albano, F., Starace, F., Franciscis, A. de, Giaquinto, C., Gattinara, G. C., Bruzzese, E., Gabiano, C., *et al.* (2003) 'Adherence to antiretroviral therapy and its determinants in children with human immunodeficiency virus infection: a multicentre, national study', *Acta Paediatrica*,

92(12), pp. 1398–1402.

Gibbs, A., Jewkes, R., Sikweyiya, Y. and Willan, S. (2015) 'Reconstructing masculinity? A qualitative evaluation of the Stepping Stones and Creating Futures interventions in urban informal settlements in South Africa', *Culture, Health & Sexuality*, 17(2), pp. 208–222. doi: 10.1080/13691058.2014.966150.

Gibbs, A., Crankshaw, T., Lewinsohn, R., Chirawu, P. and Willan, S. (2017) 'I play with the baby so that people can see that I'm a man: Young fathers' involvement in the first 1 000 days of a child's life in South Africa', *South African Review of Sociology*, 48(1), pp. 67–84. doi: 10.1080/21528586.2016.1204244.

Gibbs, A., Sikweyiya, Y. and Jewkes, R. (2014) '"Men value their dignity": securing respect and identity construction in urban informal settlements in South Africa', *Global health action*, 7, p. 23676. doi: 10.3402/gha.v7.23676.

Gibbs, A., Vaughan, C. and Aggleton, P. (2015) 'Beyond "working with men and boys": (re)defining, challenging and transforming masculinities in sexuality and health programmes and policy', *Culture, Health & Sexuality*, 17(S2), pp. S85–S95. doi: 10.1080/13691058.2015.1092260.

Gibson, D. and Lindegaard, M. R. (2007) 'South African Boys with Plans for the Future: Why a Focus on Dominant Discourses Tells Us Only a Part of the Story', in Shefer, T. et al. (eds) *From Boys to Men: Social Constructions of Masculinity in Contemporary Society*. UCT Press, Cape Town, pp. 116–132.

Gittings, L. (2016) '"When you visit a man you should prepare yourself": male community care worker approaches to working with men living with HIV in Cape Town, South Africa', *Culture, Health & Sexuality*, 18(8), pp. 936–950. doi: 10.1080/13691058.2016.1150513.

Gittings, L. (2018) *Men, Masculinity and Meaning: Engaging men as community health workers for gender transformation*. 411. Cape Town, South Africa.

Gittings, L., Price, J., Cluver, L., Hinton, L., Hodes, R., Moshabela, M., Toska, E., Wilcox, M., *et al.* (2019) 'Medical pluralism among children and adolescents in South Africa: methodological findings from mixed methods research', in *AIDS Impact*. London.

Gitywa, V. Z. (1976) *Male initiation in the Ciskei: formal incorporation into bantu society*. University of Fort Hare, Alice.

Goldstuck, A. (1994) *Ink in the porridge: Urban legends of the South African elections*. Penguin, New York.

Good, C., Hunter, J. M., Katz, S. H. and Katz, S. S. (1979) 'The interface of dual systems of health care in the developing world: toward health policy initiatives in Africa', *Social Science & Medicine*,

13(3), pp. 141–154.

Govender, K. (2011) 'The cool, the bad, the ugly, and the powerful: identity struggles in schoolboy peer culture.', *Culture, Health & Sexualityealth & sexuality*, 13(8), pp. 887–901. doi: 10.1080/13691058.2011.586436.

Gqaleni, N., Moodley, I., Kruger, H., Ntuli, A. and McLeod, H. (2007) 'Traditional and complementary medicine policy', *South African Health Review*, pp. 175–188.

Gray, R. H., Kigozi, G., Serwadda, D., Makumbi, F., Watya, S., Nalugoda, F., Kiwanuka, N., Moulton, L. H., *et al.* (2007) 'Male circumcision for HIV prevention in men in Rakai, Uganda: a randomised trial', *The Lancet*, 369(9562), pp. 657–666. doi: 10.1016/S0140-6736(07)60313-4.

Grebe, E. and Nattrass, N. (2012) 'AIDS Conspiracy beliefs and unsafe sex in Cape Town', *AIDS and Behavior*, 16(3), pp. 761–773. doi: 10.1007/s10461-011-9958-2.

Greef, M. (2015) *Ethics in Health Research: Principles, Processes and Structures*. Pretoria.

Green, L. (2012) 'Beyond South Africa's "indigenous knowledge – science" wars', *South African Journal of Science*, 108(7–8), pp. 44–54. doi: 10.4102/sajs.

Greig, A. (2009) 'Troublesome Masculinities: Masculinities in Trouble', *IDS Bulletin*, 40(1), pp. 69–76.

Gundidza, M. and Kassilo, O. (2015) 'The philosophical underpinnings/basis of African traditional medicine', in *International Conference for AIDS and STIs in Africa (ICASA)*. Harare.

Gupta, G. R., Parkhurst, J. O., Ogden, J. a, Aggleton, P. and Mahal, A. (2008) 'Structural approaches to HIV prevention.', *The Lancet*, 372(9640), pp. 764–775. doi: 10.1016/S0140-6736(08)60887-9.

Hall, K., Richter, L., Mokomana, Z. and Lake, L. (2018) *South African Child Gauge*. Cape Town.

Han, G. S. (2002) 'The myth of medical pluralism: a critical realist perspective', *Sociological Research Online*, 6(4), pp. 1–16.

Hayward, B. (2015) *Eastern Cape AIDS orphan numbers surge drastically*, *Herald Live*. Available at: http://www.heraldlive.co.za/ eastern-cape-aids-orphans-numbers-surge-drastically/.

Van der Heijden, I. and Swartz, S. (2010) 'Bereavement, silence and culture within a peer-led HIV/AIDS-prevention strategy for vulnerable children in South Africa', *African Journal of AIDS Research*, 9(1), pp. 41–50. doi: 10.2989/16085906.2010.484563.

Heller, J. (2015) 'Rumors and realities: Making sense of HIV/AIDS conspiracy narratives and

contemporary legends', *American journal of public health*, 105(1), pp. e43–e50. doi: 10.2105/AJPH.2014.302284.

Henderson, P. (2012) 'Metaphor and ritual: The crafting of care in rural South African childhoods', *Childhood*, 20(1), pp. 1–13.

Hensels, I. S., Sherr, L., Skeen, S., Macedo, A., Roberts, K. J. and Tomlinson, M. (2016) 'Do not forget the boys – gender differences in children living in high HIV-affected communities in South Africa and Malawi in a longitudinal, community-based study', *AIDS Care*, 28(sup2), pp. 100–109. doi: 10.1080/09540121.2016.1176680.

Heywood, M. (2003) 'Preventing Mother-to-Child HIV Transmission in South Africa: Background Strategies and Outcomes of the Treatment Action Campaign Case against the Minister of Health', *South African Journal on Human Rights*, 19(2), pp. 278–315.

Hodes, R., Hatane, L., Gittings, L., Ronan, A., Malunga, S., Cluver, L., Mark, D., Toska, E., Bloch, K., and Haghighat, R. (2018) 'Adherence misfits: Divergent perspectives on ART-defaulting among healthcare providers and HIV-positive adolescents.', in *International AIDS Conference*. Amsterdam.

Hodes, R. (2014) *Broadcasting the pandemic*. HSRC Press.

Hodes, R., Toska, E., Cluver, L. and Vale, E. (2014) 'Mzantsi Wakho Research Protocol - Promoting adolescent ARV adherence and SRH access in South Africa'.

Hodes, R. (2016a) 'The culture of illegal abortion in South Africa.', *Journal of Southern African Studies*, 42(1), pp. 79–93. doi: 10.1080/03057070.2016.1133086.

Hodes, R. (2016b) *Too many rights? Reproductive freedom in post-apartheid South Africa*. 401. Cape Town.

Hodes, Rebecca, Cluver, L., Toska, E. and Vale, B. (2018) 'Pesky metrics: the challenges of measuring ART adherence among HIV-positive adolescents in South Africa', *Critical Public Health*, pp. 1–12. doi: 10.1080/09581596.2018.1550253.

Hodes, R., Doubt, J., Toska, E., Vale, B., Zungu, N. and Cluver, L. (2018) 'The stuff that dreams are made of: HIV-positive adolescents' aspirations for development', *Journal of the International AIDS Society*, 21(S1), p. e25057.

Hodes, R., Vale, B., Toska, E., Cluver, L., Dowse, R. and Ashhorn, M. (2019) 'Yummy or crummy? The multisensory components of medicines-taking among HIV-positive youth', *Global Public Health*, 14(2), pp. 284–299.

Hodes, R. and Gittings, L. (2019) '"Kasi curriculum": what young men learn and teach about sex

in a South African township', *Sex Education*, 19(4), pp. 436–454. doi: 10.1080/14681811.2019.1606792.

Hodes, R. and Morrell, R. (2018) 'Incursions from the epicentre: Southern theory, social science, and the global HIV research domain', *African Journal of AIDS Research*, 17(1), pp. 22–31. doi: 10.2989/16085906.2017.1377267.

Hodes, R., Vale, B. and Toska, E. (no date) 'The misclosure of an adolescent's HIV-status', in Mkhwanazi, N. and Bhana, D. (eds) *Young Families: Gender, Sexuality and Care*. HSRC Press.

Hodgson, J. (1982) *The God of the Xhosa: A study of the origins and development of the traditional concepts of the Supreme Being*. Oxford University Press, Oxford.

Hoekeman, D. A. (2008) 'African Personhood: Morality and Identities in the "Bush Ghost"', *Soundings: An Interdisciplinary Journal*, 91(3 and 4), pp. 255–286.

Holloway, S. L. and Valentine, G. (2000) 'Spatiality and the New Social Studies of Childhood', *Sociology - the Journal of the British Sociological Association*, 34(4), pp. 763–783.

hooks, b. (2004) *The Will to Change: Men, Masculinity and Love*. Atria Press, New York.

HSRC (2018) *The Fifth South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2017: HIV Impact Assessment Summary Report.* Cape Town.

Hudelson, C. and Cluver, L. (2015) 'Factors associated with adherence to antiretroviral therapy among adolescents living with HIV/AIDS in low- and middle-income countries: a systematic review', *AIDS Care*, 27(7), pp. 805–816. doi: 10.1080/09540121.2015.1011073.

Huerga, H., Van Cutsem, G., Ben Farhat, J., Puren, A., Bouhenia, M., Wiesner, L., Dlamini, L., Maman, D., *et al.* (2018) 'Progress towards the UNAIDS 90-90-90 goals by age and gender in a rural area of KwaZulu-Natal, South Africa: a household-based community cross-sectional survey', *BMC public health*, 18(1), p. 303. doi: 10.1186/s12889-018-5208-0.

Hughes, G. D., Puoane, T. R., Clark, B. L., Wondwossen, T. L., Johnson, Q. and Folk, W. (2012) 'Prevalence and predictors of traditional medicine utilization among persons living with AIDS (PLWA) on antiretroviral (ARV) and prophylaxis treatment in both rural and urban areas in South Africa', *African journal of traditional, complementary, and alternative medicines*, 9(4), pp. 470–484. doi: 10.4314/ajtcam.v9i4.4.

Human Research Ethics Committee (2014) 'Informed Consent Standard Operating Procedure'. University of Cape Town, Faculty of Health Sciences. Available at: http://www.health.uct.ac.za/.

Hunter, M. (2005) 'Cultural politics and masculinities: Multiple-partners in historical perspective in KwaZulu-Natal', *Culture, Health & Sexuality*, 7(3), pp. 209–223. doi:

10.1080/13691050412331293458.

Hunter, M. (2006) 'Fathers without amandla: Zulu-speaking men and fatherhood', in Morrell, R. (ed.) *Baba: Men and fatherhood in South Africa*. HSRC Press, Cape Town, pp. 99–117.

Hunter, M. (2010) *Love in the Time of AIDS: Inequality, Gender and Human Rights in South Africa*. Indiana University Press, Bloomington.

Hutchby, I. and Moran-Ellis, J. (2005) *Children and Social Competence: Arenas of Action*. Routledge, London.

Institute for Health Metrics and Evaluation (2014) *Life Expectancy & Probability of Death*, *University of Washington. Seattle, WA.* Available at: http://vizhub.healthdata.org/le/ (Accessed: 23 January 2016).

Iwelunmor, J., Sofolahan-Oladeinde, Y. and Airhihenbuwa, C. (2015) 'Sociocultural factors influencing HIV disclosure among men in South Africa', *American Journal of Men's Health*, 9(3), pp. 193–200.

Jali, M. N. (2009) *Collaboration of indigenous African, Western and European medicine: Policy guidelines.* University of Limpopo.

James, D. (2014) *Money from Nothing: Indebtedness and Aspiration in South Africa*. Stanford University Press, Palo Alto.

Janzen, J. (1978) *The Quest for Therapy in Lower Zaire*. University of California Press, Berkeley.

Jewkes, R., Nduna, M., Levin, J., Jama, N., Dunkle, K., Wood, K., Koss, M., Puren, A., *et al.* (2007) 'Evaluation of stepping stones: A gender transformative HIV prevention intervention.' Medical Research Council. Available at: http://www.mrc.ac.za/policybriefs/stepping stones.

Jewkes, R., Nduna, M., Levin, J., Jama, N., Dunkle, K. L., Puren, A. and Duvvury, N. (2008) 'Impact of stepping stones on incidence of HIV and HSV-2 and sexual behaviour in rural South Africa: cluster randomised controlled trial.', *BMJ (Clinical research ed.)*, 337, p. a506. doi: 10.1136/bmj.a506.

Jewkes, R., Sikweyiya, Y., Morrell, R. and Dunkle, K. (2011) 'Gender Inequitable Masculinity and Sexual Entitlement in Rape Perpetration South Africa: Findings of a Cross-Sectional Study', *PLoS ONE*, 6(12), p. e29590. doi: 10.1371/journal.pone.0029590.

Jewkes, R., Morrell, R., Hearn, J., Lundqvist, E., Blackbeard, D., Lindegger, G., Quayle, M., Sikweyiya, Y., *et al.* (2015) 'Hegemonic masculinity: combining theory and practice in gender interventions.', *Culture, Health & Sexuality*, 17(Sup2), pp. 112–127. doi: 10.1080/13691058.2015.1085094.

Jewkes, R. and Morrell, R. (2010) 'Gender and sexuality: Emerging perspectives from the heterosexual epidemic in South Africa and implications for HIV risk and prevention', *Journal of the International AIDS Society*. doi: 10.1186/1758-2652-13-6.

Jewkes, R. and Morrell, R. (2012) 'Sexuality and the limits of agency among South African teenage women: theorising femininities and their connections to HIV risk practices', *Social Science & Medicine*, 74(11), pp. 1729–1737. doi: 10.1016/j.pestbp.2011.02.012.Investigations.

Joffe, H. (1995) 'Social representations of AIDS: Towards encompassing issue of power', *Papers on Social Representations*, 4(1), pp. 29–40.

Johnson, L. F. (2012) 'Access to Antiretroviral Treatment in South Africa, 2004-2011', *The Southern African Journal of HIV Medicine*, (March), pp. 22–27.

Johnson, L. F., Mossong, J., Dorrington, R. E., Schomaker, M., Hoffmann, C. J., Keiser, O., Fox, M. P., Wood, R., *et al.* (2013) 'Life expectancies of South African adults starting antiretroviral treatment: collaborative analysis of cohort studies', *PLoS Medicine*, 10(4), p. e1001418. doi: 10.1371/journal.pmed.1001418.

Kalichman, S. and Simbayi, L. (2004) 'Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa', *AIDS Care*, 16(5), pp. 572–580.

Kallem, S., Renner, L., Ghebremichael, M. and Al., E. (2010) 'Prevalence and pattern of disclosure of HIV status in HIV-infected children in Ghana', *AIDS and Behavior*, 15(6), pp. 1121–1127.

Kasmir, S. (2018) 'Precarity', *The Cambridge Encylopedia of Anthropology*. The Cambridge Encylopedia of Anthropology. doi: http://doi.org/10.29164/18precarity.

Katz, I., Dietrich, J., Tshabalala, G., Essien, T., Rough, K., Wright, A. A., Bangsberg, D. R., Gray, G. E., *et al.* (2015) 'Understanding Treatment Refusal Among Adults Presenting for HIV-Testing in Soweto, South Africa: A Qualitative Study', *AIDS and behavior*, 19(4), pp. 704–714. doi: doi:10.1007/s10461-014-0920-y.

Kepe, T. (2010) '"Secrets" that kill: Crisis, custodianship and responsibility in ritual male circumcision in the Eastern Cape Province, South Africa', *Social Science & Medicine*, 70(5), pp. 729–735.

Kidia, K., Mupambireyi, Z., Cluver, L., Ndhlovu, C., Borok, M. and Ferrand, R. (2014) 'HIV status disclosure to perinatally-infected adolescents in Zimbabwe: a qualitative study of adolescent and healthcare worker perspectives', *PloS One*, 9(1), p. p.e87322.

King, B. (2017) *States of Disease: Political Environments and Human Health*. University of California Press, Berkeley.

King, R. (2006) *Collaborating with Traditional Healers for HIV Prevention and Care in Sub-Saharan Africa: Suggestions for Program Managers and field Workers*. Geneva.

Kleinman, A. (1980) *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine and psychiatry (Vol. 3)*. University of California Press, Berkeley.

Krieger, N. (2000a) 'Discrimination and health', in Berkman, L. and Kawachi, I. (eds) *Social Epidemiology*. Oxford University Press, New York, pp. 36–75.

Krieger, N. (2000b) 'Epidemiology and Social Sciences : Towards a Critical Reengagement in the 21st Century', *Epidemiology and Social Sciences*, 22(1), pp. 155–163.

Krieger, N. (2000c) 'Refiguring "race": epidemiology, racialized biology, and biological expressions of race relations.', *International Journal of Health Services*, 30(1), pp. 211–216. doi: 10.2190/672J-1PPF-K6QT-9N7U.

Krieger, N. (2001) 'Theories for social epidemiology in the 21st century: an ecosocial perspective.', *International journal of epidemiology*, 30(4), pp. 668–677. doi: 10.1093/ije/30.4.668.

Krieger, N. (2005) 'Embodiment: a conceptual glossary for epidemiology', *Journal of Epidemiology and Community Health*, 59(5), pp. 350–355. doi: 10.1136/jech.2004.024562.

Kuh, D., Ben-Shlomo, Y., Lynch, J., Hallqvist, J. and Power, C. (2003) 'Life course epidemiology.', *Journal of Epidemiology and Community Health*, 57(10), pp. 778–783. doi: 10.1136/jech.57.10.778.

Lam, P. K., Naar-King, S. and Wright, K. (2007) 'Social support and disclosure as predictors of mental health in HIV-positive youth', *AIDS patient care and STDs*, 21(1), pp. 20–29. doi: 10.1089/apc.2006.005.

Lane, T., Mogale, T., Struthers, H., McIntyre, J. and Kegeles, S. M. (2008) '"They see you as a different thing": the experiences of men who have sex with men with healthcare workers in South African township communities.', *Sexually transmitted infections*, 84(6), pp. 430–433. doi: 10.1136/sti.2008.031567.

Langa, M. (2010) 'Adolescent boys' talk about absent fathers', *Journal of Psychology in Africa*, 20(4), pp. 519–526. doi: 10.1080/14330237.2010.10820410.

Langlois-Klassen, D., Kipp, W., Jhangri, G. S. and Rubaale, T. (2007) 'Use of traditional herbal medicine by AIDS patients in Kabarole District, western Uganda.', *The American journal of tropical medicine and hygiene*, 77(4), pp. 757–763.

Lau, R. . (1988) 'Beliefs about control and health behaviour', in Gochman (ed.) *Health Behaviour*. Springer, Boston, pp. 43–63.

Leclerc-Madlala, S., Green, E. and Hallin, M. (2016) 'Traditional healers and the "Fast-Track" HIV response: is success possible without them?', *African Journal of AIDS Research*, 15(2), pp. 185–193. doi: 10.2989/16085906.2016.1204329.

Leichliter, J. S., Paz-Bailey, G., Friedman, A. L., Habel, M. A., Vezi, A., Sello, M., Farirai, T. and Lewis, D. A. (2011) ''Clinics aren't meant for men ': Sexual health care access and seeking behaviours among men in Gauteng province , South Africa', *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 8(2), pp. 82–88.

Lerner, R. (2005) *Promoting positive youth development: Theoretical and empirical bases*. Washington, DC.

Levack, A. (2005) *Understanding Men's Low Utilization of HIV Voluntary Counselling and Testing and Men's Role in Efforts to Prevent Mother-to-Child HIV Transmission in Soweto, South Africa*. University of Washington.

Levins, R. and Lewontin, R. (1985) *The Dialectical Biologist*, *The Dialectical Biologist*. Harvard University Press, Cambridge. doi: 10.2307/2185292.

Levtov, R. G., Barker, G., Contreras-urbina, M., Heilman, B. and Verma, R. (2014) 'Pathways to gender-equitable men: Findings from the International men and gender equality survey in eight countries', *Men and Masculinities*, 17(5), pp. 467–501. doi: 10.1177/1097184X14558234.

Lewis-Beck, M. S., Bryman, A. and Liao, T. F. (2003) *The SAGE Encyclopedia of Social Science Research Methods*. Sage Publications. Available at: http://books.google.com/books?id=xUy-NNnSQIIC.

Li, X., Qiao, S., de Wit, J. and Sherr, L. (2015) 'What's in the telling? Understanding social, psychological and clinical aspects of HIV disclosure', *AIDS Care*, 27(sup1), pp. 1–5. doi: 10.1080/09540121.2015.1102687.

Liddell, C., Barrett, L. and Bydawell, M. (2005) 'Indigenous representations of illness and AIDS in Sub-Saharan Africa', *Social Science and Medicine*, 60(4), pp. 691–700. doi: 10.1016/j.socscimed.2004.06.020.

Lindegger, G. and Quayle, M. (2009) 'Masculinity and HIV/AIDS', in Rohleder, P. et al. (eds) *HIV/AIDS in South Africa 25 Years On: Psychosocial Perspectives*. Springer, New York. doi: 10.1007/978-1-4419-0306-8.

Lowenthal, E. D., Marukutira, T. C., Chapman, J., Mokete, K., Riva, K., Tshume, O., Eby, J.,

Matshaba, M., *et al.* (2014) 'Psychosocial assessments for HIV+ African adolescents: establishing construct validity and exploring under-appreciated correlates of adherence.', *PLoS one*, 9(10), p. e109302.

Lowenthal, E. D. and Marukutira, T. C. (2013) 'Disclosure of HIV Status to HIV-Infected Children in Areas with High HIV Prevalence', *Children and Youth Services Review*, 45, pp. 143–149. doi: 10.1093/jpids/pit026.

Mabuza, G. (2009) 'HIV and AIDS Stigma: Experiences from an HIV and AIDS awareness intervention in Soweto', in *HSRC and Penn State Stigma Capacity Building Project Reunion*. Soweto.

Mackian, S., Bedri, N. and Lovel, H. (2004) 'Up the garden path and over the edge: Where might health-seeking behaviour take us?', *Health Policy and Planning*, pp. 137–146. doi: 10.1093/heapol/czh017.

Maffioli, E. M. (2017) 'Is traditional male circumcision effective as an HIV prevention strategy?', *PLoS one*, 12(5), p. e0177076. doi: https://doi.org/10.1371/journal.pone.0177076.

Mager, A. (1998) 'Youth identities and construction of masculine identities in Ciskei and Transkei, 1945–1960', *Journal of Southern African Studies*, 24(4), pp. 653–667.

Maher, F. A. and Tetreault, M. K. (1993) 'Frames of Positionality: Constructing Meaningful Dialogues about Gender and Race', *Anthropological Quarterly*, 66(3), pp. 118–126.

Mail and Guardian Online (2009) '"Eastern Cape circumcision death toll rises to 44"'. Available at: http://www.mg.co.za/article/2009-07-14-eastern-cape-circumcision-death-toll-rises-to-44.

Makusha, T. (2019) 'Predictors of HIV infection among boys and young men', in *Lunchtime satellite session 'Youth at Risk HSRC', AIDSImpact Conference*. London, United Kingdom.

Malangu, N. (2008) 'Self-reported adverse effects as barriers to adherence to antiretroviral therapy in HIV-infected patients in Pretoria', *SA FamPract.*, 50(5), p. 49.

Mandela, N. (1995) *Long walk to freedom: the autobiography of Nelson Mandela*. Macdonald Purnell, Boston.

Mane, P. and Aggleton, P. (2001) 'Gender and HIV/AIDS: What do men have to do with it?', *Current Sociology*, 49(6), pp. 23–37.

Masten, A. S. and Powell, J. L. (2003) 'A resilience framework for research, policy, and practice', in Luthar, S. S. (ed.) *Resilience and Vulnerability Adaptation in the Context of Childhood Adversities*. Cambridge University Press, Cambridge, pp. 1–25.

Mathews, S., Jewkes, R. and Abrahams, N. (2011) '"I had a Hard Life" Exploring Childhood Adversity in the Shaping of Masculinities among Men Who Killed an Intimate Partner in South Africa', *The British Journal of Criminology*, 51(6), pp. 960–977.

Mathibela, M. K., Egan, B. A., Du Plessis, H. J. and Potgieter, M. J. (2015) 'Socio-cultural profile of Bapedi traditional healers as indigenous knowledge custodians and conservation partners in the Blouberg area, Limpopo Province, South Africa.', *Journal of ethnobiology and ethnomedicine*, 11(1), p. 49. doi: 10.1186/s13002-015-0025-3.

Mattes, D. (2011) 'We are just supposed to be quiet: The production of adherence to antiretroviral treatment in urban Tanzania', *Medical Anthropology*, 30(2), p. 158.

Mattes, D. (2014) '"Life is not a rehearsal, it's a performance": an ethnographic enquiry into the subjectivities of children and adolescents living with antiretroviral treatment in Northeastern Tanzania', *Children and Youth Services Review*, 45, pp. 28–37.

Matthews, H., Limb, M. and Taylor, M. (1998) 'The Geography of Children: Some Ethical and Methodological Considerations for Project and Dissertation Work', *Journal of Geography in Higher Education*, 22(3), pp. 311–324.

Maughan-Brown, B. G. (2006) 'Attitudes towards people with HIV/AIDS: Stigma and its determinants amongst young adults in Cape Town, South Africa', *South African Review of Sociology*, 37(2), pp. 165–188.

Mavundla, T. R., Netswera, F. G., Bottoman, B. and Toth, F. (2009) 'Rationalization of indigenous male circumcision as a Sacred Religious Custom: health beliefs of Xhosa men in South Africa', *Journal of Transcultural Nursing*, 20(4), pp. 395–404. doi: 10.1177/1043659609340801.

Mayer, P. (1971) '"Traditional" manhood initiation in an industrial city. The African view.', in E. J. De jager (ed.) *Man: Anthropological essays presented to OF Raum*. Struik Publishers, Cape Town, pp. 7–18.

Mbisi, T. (2018) *Hidden Sexualities of South African Teachers: Black male educators and same-sex desire*. Routledge.

Mbiti, J. S. (1990) *African Religions and Philosophy*. 2nd edn. Heinemann Educational Publishers, Oxford.

Mburu, G., Ram, M., Oxenham, D., Haamujompa, C., Iorpenda, K. and Ferguson, L. (2014) 'Responding to adolescents living with HIV in Zambia: A social-ecological approach.', *Children and Youth Services Review*, pp. 9–17. Available at: http://ovidsp.ovid.com/ovidweb.cgi?T=JS%7B&%7DPAGE=reference%7B&%7DD=psyc11%7B&%7DNEWS=N%7B&%7DAN=2014-14751-001.

McAllister, P. A. (1989) 'Resistance to "betterment" in the Transkei', *Journal of Southern African Studies*, 15(2), pp. 346–368.

Mchunu, M. (2005) 'Zulu Fathers and Their Sons: Sexual Taboos, Respect, and their Relationship to the HIV/AIDS Pandemic'. Available at: http://hdl.handle.net/2027/spo.4761530.0010.013.

McNeill, F. G. (2009) 'Condoms cause aids': Poison, prevention and denial in Venda, South Africa', *African Affairs*, 108(432), pp. 353–370. doi: 10.1093/afraf/adp020.

Mdleleni-Bookholane, T., Schoeman, W. and Van Der Merwe, I. (2004) 'The development in the understanding of death among black South African learners from the Eastern Cape, South Africa', *Health SA Gesondheid*, 9(4), p. 3.

Mdleleni, T. (1990) 'Amafufunyana spirit possession and faith healing practices: An exploratory study', *University of Zululand Journal of Psychology*, 8, pp. 82–91.

Meinart, L., Morgensen, H. and Twebaze, J. (2009) 'Tests for life chances: CD4 miracles and obstacles in Uganda', *Anthropology & Medicine*, 16(2), p. 195.

Meintjes, G. (1998a) 'Challenge to tradition: Medical complications of traditional Xhosa circumcision', *Indicator South Africa*, 15(3), pp. 67–73.

Meintjes, G. (1998b) 'Manhood at a price: socio-medical perspectives on Xhosa traditional circumcision'. Institute of Social and Economic Research, Rhodes University.

MenEngage, Promundo and Sonke Gender Justice (2015) *MenEngage call for action: Post-2015 agenda*. Available at: https://genderjustice.org.za/publication/menengage-call-for-action-post-2015-agenda/.

Menkiti, I. A. (1979) 'Person and Community in African Traditional Thought', in Wright, R. A. (ed.) *African Philosophy: An Introduction*. University Press of America, Lanham, p. 134.

Menkiti, I. A. (2004) 'On the Normative Conception of a Person', in Wiredu, K. (ed.) *A Companion to African Philosophy*. Blackwell Publishing, Malden, pp. 324–331.

Merriam-Webster Online (2018) 'Merriam-Webster Online, Precarious', *Merriam Webster Online*. Available at: www.merriam-webster.com (Accessed: 30 August 2019).

Messerschmidt, J., 2018. Hegemonic Masculinity: Formulation, Reformulation, and Amplification. Rowman & Littlefield, Lanham, MD.

Mfecane, S. (2004) 'Stigma as a barrier to safe sex practices: A case of Cape Town Township', in *African conference on Social Aspects of HIV/AIDS*. Cape Town.

Mfecane, S. (2008) 'Living with HIV as a man: Implications for masculinity', *Psychology in Society*, 36, pp. 45–59.

Mfecane, S. (2010) *Exploring masculinities in the context of ARV use: A study of men living with HIV in a South African village*. University of Witwatersrand.

Mfecane, S. (2016) '"Ndiyindoda" [I am a man]: theorising Xhosa masculinity', *Anthropology Southern Africa*, 39(3), pp. 204–214. doi: 10.1080/23323256.2016.1208535.

Mfecane, S. (2018a) *(Un)knowing MEN Africanising gender justice programmes for men in South Africa.* Edited by U. of P. Centre for Sexualities, AIDS and Gender. CSA&G Press, Pretoria.

Mfecane, S. (2018b) 'Towards African-centred theories of masculinity', *Social Dynamics*, 44(2), pp. 291–305. doi: 10.1080/02533952.2018.1481683.

Mgqolozana, T. (2009) *A Man Who is Not a Man*. University of KwaZulu Natal Press.

Mhode, M. and Nyamhanga, T. (2016) 'Experiences and impact of stigma and discrimination among people on antiretroviral therapy in Dar es Salaam: A qualitative perspective', *AIDS Research and Treatment, 2016*. doi: https://doi.org/10.1155/2016/7925052.

Miles, M. and Huberman, A. (1994) *Qualitative Data Analysis: An Expanded Sourcebook*. 3rd edn. Sage Publications, Thousand Oaks.

Mills, E. (2005) 'HIV Illness Meanings and Collaborative Healing Strategies in South Africa', *Social Dynamics*, 31(2), pp. 126–160.

Mills, E., de Paoli, M. M. and Grønningsæter, A. B. (2009) *Love in the Time of AIDS: The Relational Gender Dynamics of Prevention, Testing and Treatment*. 252. Cape Town.

Mills, W. G. (1995) 'Missionaries, Xhosa clergy, and the suppression of traditional customs', *Missionaries and Christianity in South Africa History*, pp. 153–171.

Mlisa, L.-R. N. (2009) *Ukuthwasa initiation of Amagqirha: Identity construction and training of Xhosa women as traditional healers*. University of the Free State.

Mokgobi, M. G. (2014) 'Understanding traditional African healing', *African Journal for Physical, Health Education, Recreation, and Dance*, 20(Suppl 2), pp. 24–34.

Morrell, R. (2007) 'Do you want to be a father? Schoolgoing youth in Durban schools at the turn of the 21st century', in Shefer, T. et al. (eds) *From boys to men: Social constructions of masculinity in contemporary society*. UCT Press, pp. 75–93.

Morrell, R. (2016) 'Making Southern theory? Gender researchers in South Africa', *Feminist*

Theory, 17(2), pp. 191–209. doi: 10.1177/1464700116645877.

Morrell, R. (2001). Changing Men in Southern Africa. University of Natal Press/Zed Books, Pietermaritzburg/London.
Morrell, R. (1998). Of Boys and Men: Masculinity and Gender in Southern African Studies. Journal of Southern African Studies, 24, pp. 605–630.

Morrell, R., Jewkes, R. and Lindegger, G. (2012) 'Hegemonic Masculinity/Masculinities in South Africa: Culture, Power, and Gender Politics', *Men and Masculinities*, 15(1), pp. 11–30. doi: 10.1177/1097184X12438001.

Morrow, V. and Richards, M. (1996) 'The Ethics of Social Research with Children: An Overview 1', *Children & Society*, 10(2), pp. 90–105. doi: 10.1002/(SICI)1099-0860(199606)10:2<90::AID-CHI14>3.0.CO;2-Z.

Moshabela, M. (2008) *Reasons given by caregivers for administering African herbal medicine to children at St Rita's hospital in Sekhukhune district of Limpopo Province, South Africa*. University of Limpopo (Medunsa Campus).

Moshabela, M., Pronyk, P., Williams, N., Schneider, H. and Lurie, M. (2011) 'Patterns and implications of medical pluralism among HIV/AIDS patients in rural South Africa', *AIDS and Behavior*, 15(4), pp. 842–852. doi: 10.1007/s10461-010-9747-3.

Moshabela, M., Bukenya, D., Darong, G., Wamoyi, J., McLean, E., Skovdal, M., Ddaaki, W., Ondeng'e, K., *et al.* (2017) 'Traditional healers, faith healers and medical practitioners: the contribution of medical pluralism to bottlenecks along the cascade of care for HIV/AIDS in Eastern and Southern Africa', *Sexually Transmitted Infections*, 93(Suppl 3), p. e052974. doi: 10.1136/sextrans-2016-052974.

Moshabela, M., Zuma, T. and Gaede, B. (2016) 'Bridging the gap between biomedical and traditional health practitioners in South Africa', *South African Health Review*, 1, pp. 83–92.
Msibi, T. (2019) 'Passing through professionalism: South African Black male teachers and same-sex desire', *Sex Education*, 19(4), pp. 389–405. doi: 10.1080/14681811.2019.1612346.

Mtuze, P. T. (2003) *The Essence of Xhosa spirituality and the nuisance of cultural imperialism*. Vivlia.

Muula, A. S., Prozesky, H. W., Mataya, R. H. and Ikechebelu, J. I. (2007) 'Prevalence of complications of male circumcision in Anglophone Africa: a systematic review', *BMC Urology*, 7(1), p. 4.

Mzantsi Wakho (2016) 'Mzantsi Wakho Safety Protocol'.

Nabukeera-Barungi, N., Kalyesubula, I., Kekitiinwa, A., Byakika-Tusiime, J. and Musoke, P. (2007)

'Adherence to antiretroviral therapy in children attending Mulago Hospital, Kampala', *Annals of Tropical Paediatrics*, 27(2), pp. 123–131. doi: 10.1179/146532807X192499.

Nachega, J. B., Hislop, M., Nguyen, H., Dowdy, D. W., Chaisson, R. E., Regensberg, L., Cotton, M. F. and Maartens, G. (2009) 'Antiretroviral Therapy Adherence, Virologic and Immunologic Outcomes in Adolescents Compared With Adults in Southern Africa', *Journal of acquired immune deficiency syndromes*, 51(1), pp. 65–71. doi: 10.1097/QAI.0b013e318199072e.

Nattrass, N. (2005a) 'The quest for healing in South Africa's age of AIDS', *Social Dynamics*, 31(2), pp. 1–23.

Nattrass, N. (2005b) 'Who consults sangomas in Khayelitsha? An exploratory quantitative analysis.', *Social Dynamics*, 31(2), pp. 161 – 182.

Nattrass, N. (2008a) 'AIDS and the Scientific Governance of Medicine in Post-Apartheid South Africa', *African Affairs*, 107(427), pp. 157–176.

Nattrass, N. (2008b) 'Gender and access to antiretroviral treatment in South Africa', *Feminist Economics*, 14(4), pp. 19–36.

Nattrass, N. (2013) 'Understanding the origins and prevalence of AIDS conspiracy beliefs in the United States and South Africa', *Sociology of Health & Illness*, 35(1), pp. 113–129. doi: 10.1111/j.1467-9566.2012.01480.x.

Navario, P. (2009) *Implementation of a novel model to boost routine HIV care and treatment capacity in South Africa: outcomes, costs and cost-effectiveness*. University of Cape Town.

Nduna, M. and Jewkes, R. (2011) 'Undisclosed Paternal Identity in Narratives of Distress among Young People in Eastern Cape, South Africa', *Journal of Child and Family Studies*, 20(3), pp. 303–310.

Nduna, M. and Jewkes, R. (2012) 'Disempowerment and psychological distress in the lives of young people in Eastern Cape, South Africa', *Journal of Child and Family Studies*, 21(6), pp. 1018–1027. doi: 10.1007/s10826-011-9564-y.

Nell, E., Hill, T. and Binns, T. (1997) 'Development from below in the "new" South Africa: The case of Hertzog Eastern Cape', *The Geographical Journal*, 163(1), p. 57.

Ngubane, H. (1977) *Body and mind in Zulu medicine: An ethnography of health and disease in Nyuswa-Zulu thought and practice*. Academic Press, London.

Nguyen, V. (2005) 'Antiretroviral globalism, biopolitics and therapeutic citizenship', in Ong, A. and Collier, S. J. (eds) *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. Blackwell Publishing, pp. 124–144.

Nguyen, V. K. (2013) 'Counselling against HIV in Africa: a genealogy of confessional technologies', *Culture, Health & Sexuality*, 15(sup4), pp. S440–S452. doi: 10.1080/13691058.2013.809146.

Ngxamngxa, A. N. N. (1971) 'The function of circumcision amongst the Xhosa speaking tribes in historical perspective'.

Niehaus, I. (2009) 'Leprosy of a deadlier kind: Christian conceptions of aids in the South African Lowveld', in Becker, F. and Geissler, W. (eds) *Aids and Religious Practice in Africa*. Brill, pp. 307–332.

Niehaus, I. and Jonsson, G. (2005) 'Dr. Wouter Basson, Americans, and wild beats: men's conspiracy theories of HIV/AIDS in the South African Lowveld', *Medical Anthropology*, 24(2), pp. 179–208.

Niehaus, I., Mohlala, E. and Shokaneo, K. (2001) *Witchcraft, Power and Politics: Exploring the Occult in the South African Lowveld*. Pluto Press.

Nigosian, S. A. (2015) *World Faiths*. Springer, New York.

Ntombana, L. (2011) 'Should Xhosa male initiation be abolished?', *International Journal of Cultural Studies*, 14(6), pp. 631–640.

Nxumalo, N., Alaba, O., Harris, B., Chersich, M. and Goudge, J. (2011) 'Utilization of traditional healers in South Africa and costs to patients: findings from a national household survey', *Journal of Public Health Policy*, 32(1), pp. S124–S136. doi: 10.1057/jphp.2011.26.

Olagbuji, B. N. (2017) 'Contraceptive needs of adolescent girls living with HIV in urban townships in Western Cape, South Africa'. Cape Town, South Africa.

Opeodu, O. I. and Ogunrinde, T. J. (2015) 'Mode of transmission of HIV/AIDS: Perception of dental patients in a Nigerian teaching hospital', *Journal of the West African College of Surgeons*, 5(1), pp. 1–19.

Orner, P., Cooper, D., Myer, L., Zweigenthal, V., Bekker, L.-G. and Moodley, J. (2008) 'Clients' perspectives on HIV/AIDS care and treatment and reproductive health services in South Africa', *AIDS care*, 20(10), pp. 1217–1223. doi: 10.1080/09540120701867008.

Oyěwùmí, O. (1997) *The Invention of Women: Making an African Sense of Western Gender Discourses.* University of of Minnesota Press.

Paediatric AIDS Treatment for Africa and World Health Organization (2015) *Adolescent Africa: a situational analysis of adolescent HIV-treatment and care in sub-Saharan Africa*. Cape Town, South Africa.

Pantelic, M., Cluver, L., Boyes, M., Toska, E., Kuo, C. and Moshabela, M. (2015) 'Medical pluralism predicts non-ART use among parents in need of ART: a community survey in KwaZulu-Natal, South Africa', *AIDS and Behavior*, 19(1), pp. 137–144. doi: 10.1007/s10461-014-0852-6.

Parliament of South Africa (2003) *National Health Act of 2003*.

Parliament of South Africa (2005) *Children's Act*.

Parliament of South Africa (2007a) *Children's Amendment Act*.

Parliament of South Africa (2007b) *The Criminal Law (Sexual Offences and Related Matters) Amendment Act*.

Patel, L., Hochfeld, T., Moodley, J. and Mutwali, R. (2012) *The Gender Dynamics and Impact of the Child Support Grant in Doornkop*. Johannesburg, South Africa.

Pattman, R. (2007) 'Researching and working with boys in southern Africa in the context of HIV/AIDS: a radical approach', in Shefer, T. et al. (eds) *From boys to men: social construction of masculinities in contemporary society*. University of Cape Town Press, Cape Town.

Patton, M. Q. (1999) 'Enhancing the quality and credibility of qualitative analysis', *Health Services Reserch*, 34(5 Part II), pp. 1189–1208.

Pease, B. and Flood, M. (2008) 'Rethinking the Significance of "Attitudes" in Challenging Men's Violence Against Women', *Australian Journal of Social Issues*, 43(4), pp. 547–561.

Peltzer, K., & Kanta, X. (2009) 'Medical circumcision and manhood initiation rituals in the Eastern Cape, South Africa: a post intervention evaluation', *Culture, health & Sexuality*, 11(1), pp. 83–97.

Peltzer, K., Preez, N. F., Ramlagan, S. and Fomundam, H. (2008) 'Use of traditional complementary and alternative medicine for HIV patients in KwaZulu-Natal, South Africa', *BMC public health*, 8(1), p. 255. doi: 10.1186/1471-2458-8-255.

Peltzer, K. (2009) 'Traditional health practitioners in South Africa', *Lancet*, 374(9694), pp. 956–957. doi: 10.1016/S0140-6736(09)61261-7.

Peltzer, K., Friend-du Preez, N., Ramlagan, S., Fomundam, H. and Anderson, J. (2010) 'Traditional complementary and alternative medicine and antiretroviral treatment adherence among HIV patients in Kwazulu-Natal, South Africa', *African Journal of Traditional, Complementary and Alternative Medicines*, 7(2), pp. 125–137.

Peltzer, K., Preez, N. F., Ramlagan, S., Fomundam, H., Anderson, J. and Chanetsa, L. (2011) 'Antiretrovirals and the use of traditional, complementary and alternative medicine by HIV

patients in Kwazulu-Natal, South Africa: a longitudinal study', *African journal of traditional, complementary, and alternative medicines*, 8(4), pp. 337–345. doi: 10.4314/ajtcam.v8i4.1.

Peterson, D. and Parker, V. (eds) (1998) *Ecological Scale: Theory and Application*. Columbia University Press New York.

Polisset, J., Ametonou, F., Arrive, E., Aho, A. and Perez, F. (2009) 'Correlates of adherence to antiretroviral therapy in HIV-infected children in Lomé, Togo, West Africa', *AIDS and Behavior*, 13(1), pp. 23–32. doi: 10.1007/s10461-008-9437-6.

Posel, D., Kahn, K. and Walker, L. (2007) 'Living with death in a time of AIDS: a rural South African case study', *Scandinavian Journal of Public Health*, 35(Suppl 69), pp. 138–146. doi: 10.1080/14034950701356443.

Posse, M., Meheus, F., Van Asten, H., Van Der Ven, A. and Baltussen, R. (2008) 'Barriers to access to antiretroviral treatment in developing countries: A review', *Tropical Medicine and International Health*, pp. 904–913. doi: 10.1111/j.1365-3156.2008.02091.x.

Pretorius (1999) 'Traditional healers. In (Eds.), (Vol. 18, pp. 249–56). Durban: Health Systems Trust.', in Crisp, N. and Ntuli, A. (eds) *South African Health Review (Vol 18)*. Health Systems Trust, pp. 249–56.

Puckree, T., Mkhize, M., Mgobhozi, Z. and Lin, J. (2002) 'African traditional healers: what health care professionals need to know', *International Journal of Rehabilitation Research*, 25(4), pp. 247–251. doi: Doi 10.1097/00004356-200212000-00001.

Punch, S. (2002) 'Research with children: the same or different from research with adults?', *Childhood*, 9(3), pp. 321–341.

Puoane, T., Hughes, G., Uwimana, J., Johnson, Q. and Folk, W. (2012) 'Why HIV positive patients on antiretroviral treatment and/or cotrimoxazole prophylaxis use traditional medicine: perceptions of health workers, traditional healers and patients: a study in two provinces of South Africa', *African Journal of Traditional and Complementary Alternative Medicine*, 9(4), pp. 495–502.

Putnam, R. (1993) 'The Prosperous Community', *The American Prospect*, 4(13), pp. 35–42.

Ramose, M. B. (1999) *African philosophy through Ubuntu*. Mond Books, Harare.

Ramphele, M. (2000) 'Teach me how to be a man. An exploration of the definition of masculinity', in Das, V. et al. (eds) *Violence and subjectivity*. University of California Press, pp. 102–119.

Ramphele, M. (2002) *Steering by the stars: Being young in South Africa*. Tafelberg Publishers.

Ratele, K. (2008) 'Analysing Males in Africa: Certain Useful Elements in Considering Ruling Masculinities', *African and Asian Studies*, 7(4), pp. 515–536.

Ratele, K. (2013) 'Masculinities without Tradition', *Politikon*, 40(1), pp. 133–156. doi: 10.1080/02589346.2013.765680.

Ratele, K. (2014a) 'Currents against gender transformation of South African men: relocating marginality to the centre of research and theory of masculinities', *NORMA*, 9(1), pp. 30–44. doi: 10.1080/18902138.2014.892285.

Ratele, K. (2014b) 'Gender Equality in the Abstract and Practice', *Men and Masculinities*, 17(5), pp. 510–514.

Ratele, K., Shefer, T. and Clowes, L. (2012) 'Talking South African fathers: a critical examination of men's constructions and experiences of fatherhood and fatherlessness', *South African Journal of Psychology*, 42(4), pp. 553–563.

Rautenbach, C. (2007) 'Review on a new legislative framework for traditional healers in South Africa', *Obiter*, 28(3), pp. 518–536.

Reed, A. R. (2014) *Inkululeko: Youth, Non-Governmental Organizations, and Discourses of Democracy in Post-Apartheid South Africa*. UCLA. Available at: https://escholarship.org/uc/item/7n75g82z.

Reid, G. and Walker, L. (eds) (2005) *Men behaving differently*. Double Storey Books, Cape Town.

Republic of South Africa (1996) 'Constitution of the Republic of South Africa', *Cape Town*. doi: 10.1017/S0021855300011499.

RIATT-ESA (2016) *Resourcing resilience: The case for social protection for adherence and HIV-related outcomes in children and adolescents in Eastern and Southern Africa*.

Richey, L. (2012) 'Counselling citizens and producing patronage: AIDS treatment in South African and Ugandan clinics', *Development and Change*, 43(4), p. 823.

Richter, L. (2016) 'HIV and early childhood development - new frontiers'. Durban, South Africa.

Richter, L., Manegold, J. and Pather, R. (2004) *Family and Community Interventions for Children Affected by AIDS: Caring for Children Affected by HIV and AIDS*. HSCR Press, Cape Town.

Richter, L. and Morrell, R. (2006) *Baba: Men and Fatherhood in South Africa*. HSRC Press, Cape Town.

Ritchie, J. and Spencer, L. (1994) 'Qualitative data analysis for applied policy research', in

Bryman, A. and Burgess, R. G. (eds) *Analyzing qualitative data*. Routledge, pp. 173–194.

Robins, S. L. (2008) *From Revolution to Rights in South Africa: Social Movements, NGOs and Popular Politics*. Boydell & Brewer Ltd.

Roller, M. (2012) 'Interviewer bias and reflexivity in qualitative research', *Research Design and Review*.

Rosenberg, C. E. and Golden, J. L. (eds) (1992) *Framing Disease: Studies in Cultural History.* Rutgers University Press, New Brunswick.

Ross, E. (2010) 'Inaugural lecture: African spirituality, ethics and traditional healing – implications for indigenous South African social work education and practice', *South African Journal of Bioethics and Law*, 3(1), pp. 44–51.

Roughgarden, J. (1998) *Primer of Ecological Theory*. Prentice Hall, Upper Saddle River.

Rubincam, C. (2014) *Alternative explanations about HIV and AIDS : re-examining distrust among young adults in Cape Town, South Africa*. University of Cape Town, Cape Town.

Rudwick, S. and Posel, D. (2014) 'Contemporary Functions of Ilobolo (Bridewealth) in Urban South African Zulu Society', *Journal of Contemporary African Studies*, 32(1), p. 118.

Sapienza, J. K. and Masten, A. S. (2011) 'Understanding and promoting resilience in children and youth.', *Current opinion in psychiatry*, 24(4), pp. 267–273. doi: 10.1097/YCO.0b013e32834776a8.

Savage, I., Gittings, L., Toska, E., Cluver, L., Hodes, R. and He, E. (2017) 'Changing Homes: Mobility and Well-being for Adolescents Living with HIV', in *South African AIDS Conference*. Durban, South Africa.

Savasta, A. M. (2004) 'HIV: Associated transmission risks in older adults – An integrative review of the literature', *Journal of the Association of Nurses in AIDS Care*, 15(1), pp. 50–59.

Schatz, E. (2007) 'Caring and contributing: The role of rural women in rural South African multi-generational households in the HIV/AIDS era', *World Development*, 35(8), p. 1390.

Schrock, D. and Schwalbe, M. (2009) 'Men, Masculinity, and Manhood Acts', *Annual Review of Sociology, no.*, 35, p. 277.

Semali, L. M. and Kincheloe, J. L. (2002) *What is indigenous knowledge? Voices from the academy*. Routledge.

Sharp, J. (1994) 'A world turned upside down: Households and differentiation in a South African Bantustan in the 1980's', *African studies*, 53(1), pp. 71–88.

Shefer, T., Ratele, K., Strebel, A. and Shabalala, N. (eds) (2007) *From Boys to Men: Social Constructions of Masculinity in Contemporary Society*. Juda and Company Ltd, Cape Town.

Shefer, T., Kruger, L.-M. and Schepers, Y. (2015) 'Masculinity, sexuality and vulnerability in "working" with young men in South African contexts: "you feel like a fool and an idiot … a loser"', *Culture, Health & Sexuality*, 17, pp. 96–111. doi: 10.1080/13691058.2015.1075253.

Shefer, T., Stevens, G. and Clowes, L. (2010) 'Men in Africa: Masculinities, Materiality and Meaning', *Journal of Psychology in Africa*, 20(4), pp. 511–517. doi: 10.1080/14330237.2010.10820409.

Sherr, L., Cluver, L., Betancourt, T., Kellerman, S., Richter, L. and Desmond, C. (2014) 'Evidence of impact: health, psychological and social effects of adult HIV on children', *AIDS*, 28, pp. S251–S259. doi: 10.1097/qad.0000000000000327.

Sherr, L., Cluver, L. D., Toska, E. and He, E. (2018) 'Differing psychological vulnerabilities among behaviourally and perinatally HIV infected adolescents in South Africa – implications for targeted health service provision', *AIDS Care*, 30(sup2), pp. 92–101. doi: 10.1080/09540121.2018.1476664.

Shisana, O., Rehle, T., Simbayi, L., Parker, W., Zuma, K., Bhana, A., Connolly, C., Jooste, S., *et al.* (2005) *South African national HIV prevalence, HIV incidence, behaviour and communication survey, 2005*, *Cape Town: HRSC Press*.

Shisana, O., Rehle, T. M., Simbayi, L. C., Zuma, K., Jooste, S., Pillay-van-Wyk, V., Van Zyl, J., Parker, W., *et al.* (2009) *South African National HIV Prevalence, Incidence, Behaviour and Communication Survey 2008 - A Turning Tide Among Teenagers?* HSRC Press, Cape Town.

Shisana, O., Rehle, T. M., Simbayi, L. C., Zuma, K., Jooste, S., Zungu, N. P., Labadarios, D. and Onoya, D. (2014) *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012*.

Sideris, T. (2004) 'Men, identity and power. A case study of the re-invention of "tradition": implications for involving men in training and education about gender', *Agenda*, 18(60), pp. 88–93. doi: 10.1080/10130950.2004.9674544.

Sideris, T. (2005) 'You have to change and you don't know how! Contesting what it means to be a man in a rural area of South Africa', *African Studies*, 63(1), pp. 29–49.

Siegfried, N., Muller, M., Deeks, J. and Volmink, J. (2010) 'Male circumcision for preventing heterosexual acquisition of HIV in men', *International Journal of Epidemiology*, 39(4), pp. 968–969. doi: 10.1093/ije/dyq108.

Silberschmidt, M. (2001) 'Disempowerment of men in rural and urban East Africa: implications

for male identity and sexual behavior', *World Development*, 29(4), pp. 657–671.

Simbayi, L. C., Kalichman, S. C., Jooste, S., Cherry, C., Mfecane, S. and Cain, D. (2005) 'Risk factors for HIV-AIDS among youth in Cape Town, South Africa', *AIDS and Behavior*, 9(1), pp. 53–61.

Simbayi, L. C., Kalichman, S., Strebel, A., Cloete, A., Henda, N. and Mqeketo, A. (2007) 'Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa', *Social science & medicine*, 64(9), pp. 1823–1831. doi: 10.1016/j.socscimed.2007.01.006.

Simwaka, A., Peltzer, K. and Maluwa-Banda, D. (2007) 'Indigenous healing practices in Malawi', *Journal of Psychology in Africa*, 17(1–2), pp. 155–161. doi: 10.1080/14330237.2007.10820162.

Skovdal, M., and Cornish, F. (2015) *Qualitative research for development: a guide for practitioners*. Practical Action Publishing, Rugby. doi: http://dx.doi.org/10.3362/9781780448534.

Skovdal, M. (2012) 'Pathologising healthy children? A review of the literature exploring the mental health of HIV-affected children in sub-Saharan Africa', *Transcultural Psychiatry*, 49(3–4), pp. 461–491. doi: 10.1177/1363461512448325.

Skovdal, M., Wringe, A., Seeley, J., Renju, J., Paparini, S., Wamoyi, J., Moshabela, M., Ddaaki, W., *et al.* (2017) 'Using theories of practice to understand HIV-positive persons varied engagement with HIV services: a qualitative study in six Sub-Saharan African countries', *Sexually Transmitted Infections*, 93(Suppl 3), p. e052977.

Skovdal, M. and Andreouli, E. (2011) 'Using identity and recognition as a framework to understand and promote the resilience of caregiving children in Western Kenya', *Journal of Social Policy*, 40(3), pp. 613–630. doi: 10.1017/S0047279410000693.

Skovdal, M. and Daniel, M. (2012) 'Resilience through participation and coping-enabling social environments: the case of HIV-affected children in sub-Saharan Africa', *African Journal of AIDS Research*, 11(3), pp. 153–164. doi: 10.2989/16085906.2012.734975.

Smith, C. P. (2000) 'Content analysis and narrative analysis', in Reis, H. T. and Judd, C. M. (eds) *Handbook of Research Methods in Social and Personality Psychology*. Cambridge University Press, New York pp. 313–335.

Sobiecki, J. F. (2014) 'The Intersection of Culture and Science in South African Traditional Medicine', *Indo-Pacific Journal of Phenomenology*, 14(1), pp. 1–11. doi: 10.2989/IPJP.2014.14.1.6.1238.

Soga, J. H. (1931) *The amaXhosa: Life and customs*. Lovedale Press, Lovedale.

Sorsdahl, K., Flisher, A. J., Wilson, Z. and Stein, D. J. (2010) 'Explanatory models of mental

disorders and treatment practices among traditional healers in Mpumulanga, South Africa.', *African Journal of Psychiatry*, 13(4), pp. 284–290. doi: 10.4314/ajpsy.v13i4.61878.

Sorsdahl, K., Ipser, J. C. and Stein, D. J. (2009) 'Interventions for educating traditional healers about STD and HIV medicine', *Cochrane Database of Systematic Reviews*, 4. doi: 10.1002/14651858.CD007190.pub2.

South African National Department of Health (2006) *National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa*. Pretoria.

South African National Department of Health (2016) *Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases*.

Stadler, J. (2003) 'Rumour, gossip and blame: Implications for HIV/AIDS prevention in the South African Lowveld', *AIDS Education & Prevention*, 15(4: Special Issue), pp. 357–368.
Statistics South Africa (2016) *Community Survey 2016: Statistical release P0301*. Pretoria, South Africa.

Statistics South Africa (2018) *Mid-year population estimates 2018*. Available at: https://www.statssa.gov.za/publications/P0302/P03022018.pdf.

Statistics South Africa (2019) *Quarterly Labour Force Survey, Quarter 2*. Pretoria.

Steedman, P. (1991) 'On the relations between seeing, interpreting, and knowing', in *Research and reflexivity*. Sage, London.

Steinberg, J. (2008) *Three letter plague: a young man's journey through a great epidemic*. Jonathan Ball Publishers, Cape Town. Available at: https://books.google.co.za/books?id=Es2IGcCICYoC.

Steinberg, J. (2013) 'Working through a Paradox about Sexual Culture in South Africa: Tough Sex in the Twenty-First Century', *Journal of Southern African Studies*, 39(3), pp. 497–509. doi: 10.1080/03057070.2013.818848.

Steinberg, J. (2017) 'Re-examining the early years of anti-retroviral treatment in South Africa: A taste for medicine', *African Affairs*, 116(462), pp. 60–79. doi: 10.1093/afraf/adw026.

Stern, E. (2013) *Reappraising men's sexual behaviors and gendered attitudes from the sexual-history narratives of South African men and women in a time of HIV/AIDS*. University of Cape Town.

Stern, E., Clarfelt, A. and Buikema, R. (2015) 'The use of sexual history narratives to assess processes of gegemonic masculinity among South African men in the context of HIV/AIDS', *Men and Masculinities*, 18(3), pp. 340–362. doi: 10.1177/1097184X14554950.

Summerton, J. V. (2006) 'Western health practitioners' view about African traditional health practitioners' treatment and care of people living with HIV/AIDS.', *Curationis*, 29(3), pp. 15–23.

Suskin, R. (2014) *Is the increasing initiation of white sangomas into the tradition of Bantu shamanism seen by ritual experts and elders as an adaptation of the cosmology to the changed South African social and political context since the advent of democracy in 1994?* University of Wales Trinity Saint David.

Susser, M. and Susser, E. (1996) 'Choosing a future for epidemiology: II. From black box to Chinese boxes and eco-epidemiology.', *American Journal of Public Health*, 86(5), pp. 674–677.

Tamale, S. (2011) 'Researching and theorising sexualities in Africa', in *African Sexualities: a Reader*. Pambazuka Press, Oxford, pp. 11–36.

Taylor, C. E. (1979) 'Implications for the delivery of health care', *Social Science & Medicine. Part B: Medical Anthropology*, 13(1), pp. 77–84.

Teuton, J., Bentall, R. and Dowrick, C. (2007) 'Conceptualizing Psychosis in Uganda: The Perspective of Indigenous and Religious Healers', *Transcultural Psychiatry*, 44(1), pp. 79–114. doi: 10.1177/1363461507074976.

The World Medical Association (2008) *Declaration of Helsinki, Ethical Principles for Medical Research Involving Human Subjects*.

Toska, E., Cluver, L., Boyes, M. E., Pantelic, M. and Kuo, C. (2015) 'From "sugar daddies" to "sugar babies": Quantitatively testing the pathway between inequitable sexual relationships, condom use, and adolescent pregnancy in South Africa.', *Sexual Health*, 12, pp. 59–66.

Toska, E., Cluver, L., Hodes, R. and Kidia, K. (2015) 'Sex and secrecy: How HIV-status disclosure affects safe sex among HIV-positive adolescents', *AIDS Care*, 27(sup1), pp. 47–58. doi: 10.1080/09540121.2015.1071775.

Toska, E., Gittings, L., Hodes, R., Cluver, L., Govender, K., Chademana, E. and Gutierrez, V. E. (2016) 'Resourcing resilience: social protection for HIV prevention amongst children and adolescents in Eastern and Southern Africa', *African Journal of AIDS Research*, 15(2), pp. 123–140.

Toska, E., Cluver, L., Orkin, M., Bains, A., Sherr, L., Berezin, M. and Gulaid, L. (2019) 'Screening and supporting through schools: educational experiences and needs of adolescents living with HIV in a South African cohort', *BMC Public Health*, 19(1), p. 272. doi: 10.1186/s12889-019-6580-0.

Trengove, J. (2017) *Inxeba (the Wound)*. South Africa.

Ulin, F. R., Robinson, E. T., Tolley, E. E. and McNeill, E. T. (2005) *Qualitative methods in public health: A field guide for applied research in sexual and reproductive health*. John Wiley & Sons, North Carolina.

UNAIDS (2014) *90-90-90 An ambitious treatment target to help end the AIDS epidemic*. Geneva: UNAIDS.

UNAIDS (2017) *Addressing a blind spot: reaching out to men and boys*. Geneva.

UNICEF-ESARO (2015) *Social Cash Transfers and Children's Outcomes: A review of evidence from Africa*. Available at: https://transfer.cpc.unc.edu/wp-content/uploads/2015/12/Social-Cash-Transfer-Publication-ESARO-December-2015.pdf.

UNICEF (2017) *Children and AIDS: Statistical Update*. Available at: https://data.unicef.org/wp-content/uploads/2017/11/HIVAIDS-Statistical-Update-2017.pdf.

United Nations (2011) *Men in Families and Family Policy in a Changing World*. Geneva.

University of Cape Town (2013) 'Research Involving Children Standard Operating Procedure'. Cape Town: Faculty of Health Sciences, University of Cape Town.

University of Cape Town (2018) 'University of Cape Town Code for Research Involving Human Subjects'. University of Cape Town.

Urbasch, M. (2002) 'Bodies and politics: healing rituals in Democratic South Africa', in French Institute of South Africa (ed.) *Representations and restitutions of African traditional healing systems*, Johannesburg, pp. 5–23.

Vale, B., Hodes, R., Cluver, L. and Thabeng, M. (2017) 'Bureaucracies of blood and belonging: what documents tell us about the relationship between HIV-positive youth and the South African State', *Dev Change*, 48(6), pp. 1287–309.

Vale, B., Hodes, R. and Cluver, L. (2017) 'Negotiations of Blame and Care among HIV-positive Mothers and Daughters in South Africa's Eastern Cape', *Medical Anthropology Quarterly*, 31(4), pp. 519–536. doi: 10.1111/maq.12351.

Vale, B. and Thabeng, M. (2015) 'Mobilising AID(S)? Contesting HIV as a social and economic resource among youth in South Africa's Eastern Cape', *Journal of Southern African Studies*, 41(4), pp. 797–813. Available at: http://www.tandfonline.com/loi/cjss20.

Vale, B. and Thabeng, M. (2016) 'Redeeming lost mothers: adolescent antiretroviral treatment and the making of home in South Africa', *Medical Anthropology*, 35(6), pp. 489–502. doi: 10.1080/01459740.2016.1145218.

Varga, C. A. (1997) 'Sexual decision-making and negotiation in the midst of AIDS: Youth in KwaZulu-Natal, South Africa', *Health Transition Review*, 7(3), pp. 45–67. doi: 10.2307/40608688.

Vaz, L. M., Maman, S., Eng, E., Barbarin, O. A., Tshikandu, T. and Behets, F. (2011) 'Patterns of disclosure of HIV status to infected children in a Sub-Saharan African setting', *Journal of Developmental and Behavioral Pediatricsevelopment*, 32(4), pp. 307–315.

Vincent, L. (2008) 'Boys will be boys': traditional Xhosa male circumcision, HIV and sexual socialisation in contemporary South Africa', *Culture, Health & Sexuality*, 10(5), pp. 431–446.

Visagie, J. and Posel, D. (2013) 'A reconsideration of what and who is middle class in South Africa', *Development Southern Africa*, 30(2), pp. 149–167. doi: 10.1080/0376835X.2013.797224.

Visser, M., Zungu, N. and Ndala-Magoro, N. (2015) 'ISIBINDI, creating circles of care for orphans and vulnerable children in South Africa: post-programme outcomes', *AIDS Care*, 27(8), pp. 1014–1019. doi: 10.1080/09540121.2015.1018861.

Waldron, I. (2010) 'Marginalization of African indigenous healing traditions within western medicine: reconciling ideological tensions & contradictions along the epistemological terrain'. Available at: https://tspace.library.utoronto.ca/handle/1807/24423.

Walker, C. (1990) 'Gender and the development of the migrant labour system, 1850-1930: An overview', in Walker, C. (ed.) *Women and gender in Southern Africa*. David Philip, Cape Town, pp. 169–196.

Walker, C. (1995) 'Conceptualising motherhood in twentieth century South Africa', *Journal of Southern African Studies*, 21(3), p. 417.

Walker, L., Reid, G. and Cornell, M. (2004) *Waiting to happen: HIV in South Africa: the bigger picture*. Edited by Lynne Rienner.

Walker, M. (2005) 'Rainbow nation or new racism? Theorizing race and identity formation in South African higher education', *Race Ethnicity and Education*, 8(2), pp. 129–146. doi: 10.1080/13613320500110501.

Watts, J. (2006) '"The outsider within": dilemmas of qualitative feminist research within a culture of resistance', *Qualitative Research*, 6(3), pp. 385–402. doi: 10.1177/1468794106065009.

Werner, E. E. (1989) 'High-risk children in young adulthood: a longitudinal study from birth to 32 years.', *The American Journal of Orthopsychiatry*, 59(1), pp. 72–81. doi: http://dx.doi.org/10.1111/j.1939-0025.1989.tb01636.x.

Wetherell, M. and Edley, N. (2014) 'A discursive psychological framework for analyzing men and

masculinities', *Psychology of Men & Masculinity*, 15(4), p. 355.

White, H. (2001) 'Tempora et mores: Family values and the possessions of a post-Apartheid countryside', *Journal of Religion in Africa*, 31(4), pp. 457–479.

WHO (1946) *Constitution of the World Health Organization*. Geneva.

WHO (1976) *African Traditional Medicine: African Technical Report Series No 1*.

WHO (2000) *General Guidelines for Methodologies on Research and Evaluation of Traditional Medicine*, *World Health Organization (WHO)*. Geneva. doi: WHO/EDM/TRM/2000.1.

WHO (2007) *Engaging Men and Boys in Changing Gender-Based Inequity in Health: Evidence from Program Interventions*. Geneva.

WHO (2015) *Global Health Estimates: Disease burden, 2000–2012*. Geneva.

WHO (2016a) *A framework for voluntary medical male circumcision: effective HIV prevention and a gateway to improved adolescent boys' & men's health in Eastern and Southern Africa by 2021*. Geneva.

WHO (2016b) *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Recommendations for a public health approach.* Geneva.

Wight, D. (1999) 'Cultural factors in young heterosexual men's perception of HIV risk', *Sociology of Health & Illness*, 21(6), pp. 735–758. doi: 10.1111/1467-9566.00181.

Williams, P. L., Storm, D., Montepiedra, G., Nichols, S., Kammerer, B., Sirois, P. A., Farley, J. and Malee, K. (2006) 'Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection.', *Pediatrics*, 118(6), pp. e1745–e1757. doi: 10.1542/peds.2006-0493.

Wilson, M. (1936) *Reaction to Conquest: Effects of Contact with Europeans on the Pondo of South Africa*. Oxford University Press.

Wilson, M. (1978) '*Ritual: Resilience and Obliteration', Social System and Tradition in Southern Africa: Essays in Honour of Eileen Krige*. Edited by J. Argyle and E. Preston-White. Oxford University Press, Cape Town.

Wolfe, R. M. . and Sharp, L. K. (2002) 'Anti-vaccinationists past and present.', *British Medical Journal*, 325(7361), p. 430.

Wood, K., Chase, E. and Aggleton, P. (2006) '"Telling the truth is the best thing'': Teenage orphans' experiences of parental AIDS-related illness and bereavement in Zimbabwe"', *Social*

Science & Medicine, 63(7), pp. 1923–1933. doi: 10.1016/j.socscimed.2006.04.027.

Wood, K. and Jewkes, R. (2006) 'Blood blockages and scolding nurses: barriers to adolescent contraceptive use in South Africa', *Reproductive Health Matters*, 14(27), pp. 109–118.

Worobey, M., Gemmel, M., Teuwen, D. and Haselkorn, T., et al. (2008) 'Direct evidence of extensive diversity of HIV-1 in Kinshasa by 1960', *Nature*, 455(7213), pp. 661–664.

Wreford, J. (2005a) 'Missing Each Other: Problems and Potential for Collaborative Efforts between Biomedicine and Traditional Healers in South Africa in the Time of AIDS', *Social Dynamics*, 31(2), pp. 55–89. doi: 10.1080/02533950508628708.

Wreford, J. (2005b) *Negotiating relationships between biomedicine and Sangoma: Fundamental misunderstandings, avoidable mistakes.* 138. Cape Town: Centre for Social Science Research, University of Cape Town.

Wreford, J. (2008a) *Myths, masks and stark realities: traditional African healers, HIV/Aids narratives and patterns of HIV/Aids avoidance*. 209. Cape Town.

Wreford, J. (2008b) *Shaming and blaming: medical myths, traditional health practitioners and HIV and AIDS in South Africa*. 211. Cape Town.

Wreford, J. and Esser, M. (2008) 'Involving African traditional health practitioners in HIV/ AIDS interventions', *South African Medical Journal*, 98(5), p. 374.

Wringe, A., Renju, J., Seeley, J., Moshabela, M. and Skovdal, M. (2017) 'Bottlenecks to HIV care and treatment in sub-Saharan Africa: a multi-country qualitative study', *Sexually Transmitted Infections*, pp. 1–3. doi: 10.1136/sextrans-2017-053172.

Wyrod, R. (2011) 'Masculinity and the persistence of AIDS stigma', *Culture, Health & Sexuality*, 13(4), pp. 443–456. doi: 10.1080/13691058.2010.542565.

Youde, J. (2005) 'The Development of a Counter-Epistemic Community: AIDS, South Africa, and International Regimes', *International Relations*, 19(4), pp. 421–439. doi: 10.1177/0047117805058533.

Young Carers / Mzantsi Wakho (2016) 'Referrals Guidelines'.

Zamawe, F. C. (2015) 'The implication of using NVivo software in qualitative data analysis: evidence-based reflections', *Malawi Medical Journal*, 27(1), pp. 13–15.

Zuma, K. (2019) 'Dynamics of HIV epidemic in Sub-Saharan Africa: Who are we leaving behind in treatment?', in *AIDSImpact Plenary Presentation*. London, United Kingdom.

Zuma, T., Wight, D., Rochat, T. and Moshabela, M. (2016) 'The role of traditional health practitioners in Rural KwaZulu-Natal, South Africa: generic or mode specific?', *BMC Complementary and Alternative Medicine*, 16(1), p. 304. doi: 10.1186/s12906-016-1293-8.

Zuma, T., Wight, D., Rochat, T. and Moshabela, M. (2018) 'Navigating multiple sources of healing in the context of HIV/AIDS and wide availability of antiretroviral treatment: a qualitative study of community participants' perceptions and experiences in rural South Africa', *Frontiers in Public Health*, 6, p. 73.

Zungu-Dirwayi, N., Shisana, O., Louw, J. and Dana, P. (2007) 'Social determinants for HIV prevalence among South African educators', *AIDS Care*, 19(10), pp. 1296–1303.

Zungu, N. (2013) *Social representations of AIDS and narratives of risk among Xhosa men*. University of Cape Town.

Appendices

Appendix 1: Life history narrative tool (English)

Interview guide

The project is about the health of adolescent boys and young men I am interested to hear about the experiences and health of adolescent boys and young men.

In this interview, I'm going to ask you (or in the case of obtaining guardian consent, your child) to tell me about your life including about your home, health decisions and beliefs. There are no right or wrong answers: I just want to listen to you tell your (their) story.

Sometimes talking about these things can be sensitive; if there is something I ask that makes you (them) uncomfortable or that you (they) don't want to discuss, you (they) will not be pressured to. I hope that this will be a safe space where you can share things that you may not normally speak about.

Your (their) answers will be kept confidential, unless you (they) tell us that you (they) are experiencing a form of violence that hasn't been reported, in which case we will have to report it to someone who can investigate it to keep you (them) safe. Your (their) name will not be written anywhere on this questionnaire. Your experiences might be incredibly helpful to our government and healthcare providers.

If you need a break, just tell the person that is helping you and they will do some activities with you. You can also stop the interview at any time if you are uncomfortable, tired, or for any other reason. This is not a test. There are no right or wrong answers! This research aims to help young people in South Africa. Thank you for taking the time to help.

General information collection

Interview Date: _____
Serial number: _____
How was the participant recruited?
If recommended by another research assistant, who recommended them?
_____

Why was this participant recommended/ selected?
_____

_____

What animal is the participant? _____
(note to examiner– animal types were used to code HIV status so as to avoid inadvertent disclosure.
Giraffe = HIV-positive and disclosed
Elephant =HIV-positive and does not know / has not disclosed
Bear = unknown HIV status)

Details of how you learn which animal they are?

_____

When was the participant born? _____

Thank you for this initial information. Please go through the information and consent form with the participant, and, if under 18 their parent / guardian.

If under 18, did the participants parent / guardian provide consent for them to participate?
- Yes – please continue go through the information and assent form with participant
- No – do not proceed with the interview

Did the participant assent / consent to participate?:
- Yes – please continue (and attach paper consent form)
- No – do not proceed with the interview

Where are you conducting this interview? (e.g. home, clinic, hospital, school, church, community centre, other (please specify and write the address) :
_____
_____

Questions:
We can tell our stories in different ways. 'River of life' is a tool that allows us to tell our stories of the past, the present and the future by drawing and talking. Our river starts with where we have come from, and continues into the future. Let's start by talking about the past, and end with the future.

Step #1
Let's start drawing by drawing your river so far, from the time that you were born until now. (Prompt - ask them to choose a starting point based on their date of birth.)
Questions: **When were you born*?*** Write the year of birth
Where were you born? Write the place of birth.
Let's draw the river of your life up until this point. It can be as straight or winding as you choose. (Prompts – winding can represent difficulties or different event…s)

Step #2
Let's now draw the places where you have lived. Did you ever move from the place where you were born? (Ask them to list the different places they were born and draw them on the river)

For each place that you have lived:
Tell me about the place you lived? Where was it? Who did you live with? What was it like where you live – what did it look like? What is the emotion/feeling in your house?

Separate questions to ask at Step #2.
Do you know your mother? If yes, what is your relationship like? How does she treat you? Please provide an example to explain. (Can draw on the river if they would like)
Do you know your father? If yes, what is your relationship like? How does he treat you? Please provide an example to explain.
Do your parents treat you in the same way they treat the other children? Please provide an example to explain?

Step #3
We would like you to tell us about 3 events from your own life, which you can remember well. Let's start with an important event from your life that you would like to report first.
(For each event:

-Ask them to draw it on the paper (e.g. challenges can be a rock in the river, good events can be flowers by the river)
-**Questions: please tell me about the event?** (Prompts: When did it happen? How did it make you feel? Why was it important in your life? Please provide as much detail as possible)
-**What was the time like between these events? Please explain.**

Step #4
Let's talk now about the journey to being an adult.

Questions:
Please tell me about your journey to learning about being a man/boy. What have you learnt? Who have you learned from? *Can you please tell me a story or draw stories on your river to explain what you mean?* **How has learning these things affected your behaviours?**

Step 5: Health
Now we are going to draw events related to health on your river.

Are there any major health events that you would like to draw on your river? (prompts – have you ever been really sick? Had to stay in the hospital? Have you ever been diagnosed with a lifelong condition?) Draw on map. What happened? How old were you? How has your life changed since then?

When you are sick, where do you go for help? (prompts – clinic / hospital, traditional health practitioner)

Step 6: The future
Now that we have drawn the story of your life to-date, let's draw your future river.
What do you want your future life to be like? Please elaborate.
Imagine yourself 10 years from now. Where do you want to be in the following areas of your life?

In your head? (work, dreams, goals)
In your heart? (relationships, family, friends, children)
In your soul? (beliefs, practices)
In your physical world? (home, health, hobbies)

What are the things that will happen that are related to being an adult man? (e.g. age, circumcision, life experiences, living away from home, etc.)
Do you have children? Please tell me about your experience having children.
Do you want to have (more) children? If yes, why? If not, why not?

If yes: how many children do you want to have?

Who do you want to have children with?

How do you want to be involved in your children's lives?

What do you need to do now in order to achieve your dreams for the future?

Who is the person that you look up to/who is your role model? (Prompts - What are they like? Why are they your role model?)

Thank your sharing your past experiences and future dreams with me. We are almost done, but first is there anything else you'd like to add to your river?

Appendix 2: In-depth, semi-structured interview tool (English)

Interview guide

The project is about the health of adolescent boys and young men I am interested to hear about the experiences and health of adolescent boys and young men.

In this interview, I'm going to ask you (or in the case of obtaining guardian consent, ***your child****) to tell me about your life including about your home, health decisions and beliefs. There are no right or wrong answers: I just want to listen to you tell your (****their****) story.*

*Sometimes talking about these things can be sensitive; if there is something I ask that makes you (****them****) uncomfortable or that you (****they****) don't want to discuss, you* ***(they)*** *will not be pressured to. I hope that this will be a safe space where you can share things that you may not normally speak about.*

*Your (****their****) answers will be kept confidential, unless you (****they****) tell us that you (****they****) are experiencing a form of violence that hasn't been reported, in which case we will have to report it to someone who can investigate it to keep you (****them****) safe. Your (****their****) name will not be written anywhere on this questionnaire. Your experiences might be incredibly helpful to our government and healthcare providers.*

If you need a break, just tell the person that is helping you and they will do some activities with you. You can also stop the interview at any time if you are uncomfortable, tired, or for any other reason. This is not a test. There are no right or wrong answers! This research aims to help young people in South Africa. Thank you for taking the time to help.

General information collection

Interview Date: _____
Serial number: _____
How was the participant recruited?
If recommended by another research assistant, who recommended them?
_____

Why was this participant recommended/ selected?
_____

_____

What animal is the participant? _____
(note to examiner– animal types were used to code HIV status so as to avoid inadvertent disclosure.
Giraffe = HIV-positive and disclosed
Elephant =HIV-positive and does not know / has not disclosed
Bear = unknown HIV status)

Details of how you learn which animal they are?

_____

When was the participant born? _____

Thank you for this initial information. Please go through the information and consent form with the participant, and, if under 18 their parent / guardian.

If under 18, did the participants parent / guardian provide consent for them to participate?
- Yes – please continue go through the information and assent form with participant
- No – do not proceed with the interview

Did the participant assent / consent to participate?:
- Yes – please continue (and attach paper consent form)
- No – do not proceed with the interview

Where are you conducting this interview? (e.g. home, clinic, hospital, school, church, community centre, other (please specify and write the address) :
_____
_____

Gender

Are men and women different from each other? Please explain.

In your opinion, what does it mean to be a man? (How do they act, what do they believe? Please explain, giving an example if possible.)

Are there differences between men? If yes, please describe and explain.

Are you the same as other boys/men? Why or why not?

Is there a difference between the ways that men and women take care of their health? Can you please explain and give an example?

Do men and women have the same health problems? Can you please explain and give an example?

Circumcision

Have you been initiated / circumcised?

If yes – draw the event on the river if not already there.

Where did you go to get circumcised? (e.g. which hospital clinic / or where did you go to initiation camp?)

What made you decide to get circumcised at _____ (insert - the hospital / clinic or initiation camp)?

(If circumcised at the clinic / hospital: Did you go for initiation after being circumcised? If yes, how were you treated there (Prompts: were you treated the same or different as someone who was circumcised traditionally?)

(If went to traditional initiation):

What did you learn during traditional initiation?

Do you feel different after being initiated? (Prompts How did you feel before / how do you feel now? What made the way you feel change?)

Did the way you act change after being circumcised / initiated? (If yes, please explain using an example).

What is the difference between someone who has gone through traditional initiation / circumcision and someone who has not?

Is what you can do different now that you have been circumcised / initiated? (e.g. getting married, performing ceremonies, other?)

Is it possible for someone who has not been circumcised / initiated to become an ancestor? Please explain.

Did your ideas about what it means to be a man change after being circumcised / initiated?

Is it a good thing to have initiation? Please explain.

Did they teach you anything at initiation school about going to the clinic or hospital? (Prompts what did you learn? Did it have any impact on your

behaviours after initiation? If so how? Please give me examples to illustrate what you mean?)

What did you learn about men's health at initiation? Probes: Did it have any impact on your behaviours after initiation? If so how? Give me stories to illustrate what you mean?

Did you learn anything about going to the Sangoma/igqirha at initiation? (Prompts: what did you learn? Did it have any impact on your behaviours after initiation? If so how? Give me stories to illustrate what you mean?)

If you take any medications, did you continue to take them during difficult initiation? (Prompts –
Did you stop taking them / did you continue taking them?
How did you take them?
Did others know you were taking them?
If so, who knew?
What is easy/difficult to take them?
Please tell me a story to explain what you mean.

Did you have any health challenges during initiation/circumcision? If yes, please explain, including how you handled these challenges (for example, did you tell someone? Did you get help?)

If you take any medications, did the way you take your medication change after traditional initiation / circumcision change? (Prompts – do you still take your medication? Do you take your medication as regularly before? Is it easier or harder to take your medication after traditional circumcision/initiation?

If you take any medications, do you pick them up yourself? If yes, could pick up your medication at the clinic / hospital, after traditional initiation / circumcision in the same way as before? Why or why not? Please explain.

<u>If no</u>: Are you going to go in the future for circumcision/initiation?

If yes, why will you go? If no, why not?

Where will you go? (e.g. clinic/hospital, traditional initiation)

When will you go? (Draw on river of life on other side)

Is it a good thing to have initiation? Please explain.

How do you feel about going? (prompts – do you want to go? are you excited to go? Are you afraid)

How will things be different for you after you go? Please explain.

What is the difference between someone who has gone through traditional initiation / circumcision and someone who has not?

Is what you can do different if you have been circumcised / initiated? (Prompts – getting married, performing ceremonies, other?)
Is it possible for someone who has not been circumcised / initiated to become an ancestor (if participant has ancestral beliefs)? Please explain.
If you take any medications, will you continue to take them while you are at initiation? Please explain. (Prompts – what is the way that you will take them? Will you inform others at camp - inkhankatha? Will you take them in public? Private?)

Health Practices

We now have some questions for you about going to the clinic:
Do you ever go to the clinic / hospital?
If yes, how often do you go?
What type of things do you go to the clinic / hospital for? Please explain.
When you go to the clinic / hospital, do you get what you need? Please explain.
Do you like going to the hospital/clinic? Why or why not? Please explain.
Please tell me a story about a time that you went to the clinic. (Prompts - What were the events that made you go? What was your experience like? What did it feel like / look like / sound like? How did it feel when you arrived? How did it feel after you left?)
How do the people working at the clinic/hospital treat you?
Does it make a difference if you see a male or female health care provider?

Which type of clinic / hospital do you go to? (for children, for adults)
If adult clinic – did you used to go to a children's clinic before? (draw on map the different clinics and when they moved)

If yes:

What was it like changing from the children's clinic to the adult clinic?
What are the differences between the children and adult clinic?
Which one did you like better? Why?
Do you always go to the clinic when you are supposed to? If no, why not?
Do you go to the clinic alone or with someone else (e.g. family member, friend)?
If you go with someone, who do you go with? Why do you go with this person?

We now have some questions for you about going to the traditional health practitioner:

Do you ever go to a Sangoma / igqirha, Nyanga/xhwele, and/or faith healer? If yes, which ones?

If yes:
How often do you go? Please explain?
For what reasons do you go? Please explain.
Do you like going? Why or why not?
Please tell me a story about a time that you went to the Sangoma/ igqirha, Nyanga/xhwele or faith healer. What were the events that made you go? What was your experience like? What did it feel like / look like / sound like? How did you feel before going? How did you feel after going?
When you go to the Sangoma/ igqirha, Nyanga / xhwele and/or faith healer, does it help? Please explain.
How are you treated by the Sangoma/ igqirha, Nyanga / xhwele and/or faith healer?
Does it make a difference if you see a male or female Sangoma/ igqirha, Nyanga/ xhwele and/or faith healer?
Do you go to the Sangoma/ igqirha, Nyanga/ xhwele and/or faith healer alone or with someone else (e.g. family member, friend)?
If you go with someone, who do you go with? Why do you go with this person?
How much did you pay them? Where did you get the money to pay them?
Do you ever use traditional medicine?
<u>If yes</u>
What are the ways that you use traditional medicine? (Example drink, put on body, wash in it, cutting).
If yes, for what reason(s) do you use it?
Who else knows that you are taking traditional medicine? (e.g. parents, friends, **nobody). Do they support you taking traditional medicine?** Why or why not?
Do you ever take traditional medicine during the same time that you are taking medicine from the clinic?

<u>Religious and spiritual beliefs</u>
Now we have a few more questions related to beliefs.
What are your religious / spiritual beliefs? (Prompts :Do you believe in God? If yes, please explain to me what you believe. Do you believe in the ancestors? If yes, please explain to me what you believe.)
Is what you believe the same as, or different from what your parents/grandparents believe? (Prompts: How are they different? Why are they different? Please explain how they became different?)

Do Sangomas / igqirha, nyangas / xhwele and/or faith healers have any abilities or powers? <u>If yes</u>, what can they do? (prompts - Can they cure illnesses, if yes, what kinds? Can they help with emotional healing? Can they help with mental healing? Can they help with healing a family or community problem? Can they help with other sorts of problems? If yes, what kinds of problems can they help with?) Please explain or tell me stories to help me understand?
What is the difference between going to the clinic / hospital and traditional health practitioner?
What are the differences between nurses/doctors and Sangomas / igqirha, Nyanga/xhwele?

<u>Beliefs about HIV</u>
Now we have some questions about what you think about HIV
Where do you think HIV comes from?
What are the ways that some people get HIV?
Why do some people get HIV? Please explain, using an example if possible.
(Please prompt for more information here, including if they give an explanation related to supernatural forces – e.g. God, the ancestors, witchcraft, or a conspiracy)

<u>Closing</u>
Considering what we have discussed, what do you think others need to understand about being a boy / man?
What do others need to understand about the health needs of boys & men?
How did you find the interview? Do you have any questions? Do you have any comments on the interview? Are you OK to finish the interview now?

Appendix 3: Interview Guide and Questions – Biomedical Health Worker

Interview guide

The project is about the health of adolescent boys and young men. I am interested to hear about the health of adolescent boys and young men.

(Go through information and ascertain if they would like to participant, including provide informed consent)

We can take a break or stop the interview at any time if you are uncomfortable, tired, or for any other reason. *This is not a test. There are no right or wrong answers! This research aims to help young people in South Africa. Thank you for taking the time to help.*

General information collection

Interview Date: _____
Serial number / pseudonym: _____
How was the participant recruited?

_____

Did the participant consent to participate?:

- Yes – please continue (and attach paper consent form)
- No – do not proceed with the interview

Participant employer (clinic / hospital name):

_____

_____

Location of interview:

_____

_____

Introductions:

(Introduce researcher(s))

Please tell me about yourself?

Please tell me about your work (prompt – what are the types of medical services that you provide?)

Are there any common 'types' of clients that you work with? (e.g. children, women who are pregnant or want to become pregnant, general population, men/women, etc?)

Do you ever see children or adolescents?

If yes, who do they come with? (i.e. alone, with parents, other?)

If yes, what are the common reasons they come? (e.g. parent made them, health issues, etc)

At what age do adolescents come to the clinic / without their caregiver? Is this gendered?

How do adolescents get money to go to the clinic / hospital?

(If hospital clinic with differentiated services or a paediatric unit). What happens when adolescents transition from child to adult care? (prompts – do they come more / less, is it easier / harder for them). How does this affect their medicines taking? Is this gendered? Does transition affect boys and girls differently? Please explain.

What factors determine if an adolescent will go to a traditional health practitioner? (prompts – gender, parent's beliefs?, personal beliefs, urban/rural? HIV status?).

About Adolescents and gender:

Do adolescent girls and boys have the same health problems? Can you please explain and give an example?

Have you noticed that there are differences in what adolescent boys / girls believe about their health? Please explain. If yes, how and when do you believe these beliefs are formed?

Have you noticed that there are differences in the way that adolescent boys / girls take care of their health? Please explain and give an example? If yes, how and when do you believe these behaviours are formed?

Does the gender of the health care make a difference to their client? For example, do boys or men prefer to see a male or female health care worker?

Do men and women have the same health problems? Can you please explain and give an example?

Have you noticed that there are differences in what men and women believe about their health? Please explain.

Have you noticed that there are differences in the ways that men and women take care of their health? Please explain and give an example. If yes, how and when do you believe these behaviours are formed?

Are the reasons that adolescents go to the traditional health practitioner for different than the reasons they go to the clinic? Please explain? Is this different for boys / men and girls/women? For what reasons do adolescent boys going to the traditional health practitioner? Please explain.

In your opinion, what are the biggest challenges facing adolescents today? (Prompts – is this the same for boys and girls?)

Considering what we have discussed, what do you think others need to understand about how adolescent boys / men take care of their health?

About traditional initiation / circumcision:

Is there a difference in the way that men take care of their health after they have been circumcised / initiated? (prompts – are they more /less likely to visit the traditional healer, or clinic/hospital, to take medication?)

In your opinion, what are the most important issues for adolescent boys health? Men's health?

Have you ever been involved in traditional initiation / circumcision? If yes, how? Please explain.

In your opinion, is traditional initiation / circumcision a good thing? Please explain.

Do you think boys living with HIV should go for traditional initiation/circumcision? Why or why not?

Do you have any experience with supporting boys living with HIV to go to traditional initiation/circumcision? Please explain.

Is it possible for boys to take HIV medicines during traditional initiation/circumcision. Please explain.

After returning from traditional initiation / circumcision, is there any difference in how boys living with HIV access biomedical care? (Take their HIV medications? Pick up their medications? (Please explain)

About HIV

What beliefs do your clients hold about HIV? Are these gendered?

On traditional health care:

Do you ever work with traditional health practitioners? If yes – why? How? What was your experience like – please give an example to explain?

What do you think about traditional health practitioners and traditional health care? (prompts - does it work, is it a good thing?)

What role, if any, does traditional health care provide in HIV care? Please explain.

What role, if any, do you believe traditional health care could play in HIV care? Please explain.

What do you think about how traditional and biomedicine work together?

Closing

If you were in a taxi with the Minister of Health, what would you tell him?

Considering what we have discussed, what do you think others need to understand about how adolescent boys / men living with HIV take care of their health?
Is there anyone else that you would recommend that we speak to?
How did you find the interview?
Do you have any questions?
Are you OK to finish the interview now?

Appendix 4: Interview Guide and Questions – Traditional Health Practitioner

Interview guide

The project is about the health of adolescent boys and young men. I am interested to hear about the health of adolescent boys and young men.

(Go through information and ascertain if they would like to participant, including provide informed consent)

We can take a break or stop the interview at any time if you are uncomfortable, tired, or for any other reason. This is not a test. There are no right or wrong answers! This research aims to help young people in South Africa. Thank you for taking the time to help.

General information collection

Interview Date: _____
Serial number / pseudonym: _____
How was the participant recruited?

_____

Did the participant consent to participate?:

- Yes – please continue (and attach paper consent form)
- No – do not proceed with the interview

Location of interview:

_____

_____

Introductions:

(Introduce researcher(s))

Please tell me about yourself?

How long have you been a traditional health practitioner for?

How did you become a traditional health practitioner?

What type(s) of traditional health practices do you provide (e.g. faith healing, mixing and prescribing medicines, prophesizing with bones, prophesizing with candles, ceremonies, etc).

Are there any common 'types' of clients that you work with? (e.g. children, women who are pregnant or want to become pregnant, general population, etc?)

Do you ever see children or adolescents?

If yes, who do they come with? (i.e. alone, with parents, other?)

If yes, what are the common reasons they come? (e.g. parent made them, health issues, etc)

At what age do adolescents come to the traditional health practitioner without their caregiver?

What makes an adolescent start going to the traditional health practitioner without their caregiver? Is this different for boys and girls?

How do adolescents get money to go to the traditional health practitioner?

What factors determine if an adolescent will go to a traditional health practitioner? (prompts – gender, parent's beliefs?, personal beliefs, urban/rural? HIV status?).

About Adolescents and gender:

What types of services do you provide them? (e.g. medicines, counselling and support, etc). Are these services different based on gender?

Do they come alone or with someone? If yes, who do they come with? (i.e. alone, with parents, other?)

If yes, what are the common reasons they come? (e.g. parent made them, health issues, etc)

Do adolescent girls and boys have the same health problems? Can you please explain and give an example?

Have you noticed that there are differences in what adolescent boys / girls believe about their health? Please explain.

Have you noticed that there are differences in the way that adolescent boys / girls take care of their health? Please explain and give an example?

Does the gender of the traditional health practitioner make a difference to their client? For example, do boys or men prefer to see a male or female traditional health practitioner?

Do men and women have the same health problems? Can you please explain and give an example?

Have you noticed that there are differences in what men and women believe about their health? Please explain.

Have you noticed that there are differences in the ways that men and women take care of their health? Please explain and give an example.

Are the reasons that adolescents go to the traditional healer for different than the reasons they go to the clinic? Please explain? Is this different for boys / men and girls/women?

In your opinion, what are the biggest challenges facing adolescents today? (Prompts – is this the same for boys and girls?)

Considering what we have discussed, what do you think others need to understand about how adolescent boys / men take care of their health?

About traditional initiation / circumcision:

What is the difference between someone who has gone through traditional initiation / circumcision and someone who has not?

Is there a difference in the way that men act after they have been circumcised / initiated?

Is there a difference in the way that men take care of their health after they have been circumcised / initiated? (prompts – are they more /less likely to visit the traditional healer, or doctor, to take medication?)

In your opinion, what are the most important issues for adolescent boys health? Men's health?

Have you ever been involved in traditional initiation / circumcision? If yes, how? Please explain.

In your opinion, is traditional initiation / circumcision a good thing? Please explain.

Do you think boys living with HIV should go for traditional initiation/circumcision? Why or why not?

About HIV

In your opinion, where does HIV come from? Please explain.

What are the ways that people get HIV?

In your opinion, why do some people get HIV? Please explain.

Do you take any safety precautions related to HIV? (e.g. wearing gloves, disposing of razors / not sharing after cutting)

Do you have clients with HIV or AIDS?

If yes, do they take anti-retrovirals? Why or why not?

If yes, do they take traditional medicines / muthi? Why or why not?

What types of services do you provide to people living with HIV? (e.g. medicines, counselling and support, etc).

What do you do if a client tells you they have HIV?

Do you have any adolescent clients with HIV? If yes, are they boys, girls, a mixture?)

If yes, do they take anti-retrovirals? Why or why not? Are there gendered differences in the way adolescents boys and girls take this medication?

If yes, do they take traditional medicines / muthi? Why or why not? Are there gendered differences in the way adolescents boys and girls take this medication?

In your opinion, are their traditional medicines that can help people living with HIV? Please explain.

Is HIV related to calling sickness/ ukuthwasa in any way? Please explain.

Is HIV related to bewitchment in any way? Please explain.

Considering what we have discussed, what do you think others need to understand about how adolescent boys / men living with HIV take care of their health?

About becoming an ancestor

Can anyone become an ancestor? Why or why not?

Can a boy or adolescent become an ancestor? Please explain?

Is it important for people to become an ancestor? Why or why not? Please explain.

What is required of a man to become an ancestor? Please explain?

Can a person living with HIV become an ancestor? Why or why not?

If a man lives an unhealthy life, can he still become an ancestor? Will people still perform ceremonies for him? Please explain?

On biomedical care

Do you ever work with clinics or hospitals? If yes –why? How? What was your experience like – please give an example to explain?

What do you think about biomedicine? (prompts does it work, is it a good thing?)

What do you think about how traditional and biomedicine work together?

If you were in a taxi with the Minister of Health, what would you tell him?

Closing

Is there anyone else that you would recommend that we speak to?
How did you find the interview?
Do you have any questions?
Are you OK to finish the interview now?

Appendix 5: Interview Guide and Questions – Key Informant

* Questions will be modified, added or removed based on the age and category of the key informant and their expertise.

The project is about the health of adolescent boys and young men. I am interested to hear about the health of adolescent boys and young men.

(Go through information and ascertain if they would like to participant, including provide informed consent)

We can take a break or stop the interview at any time if you are uncomfortable, tired, or for any other reason. This is not a test. There are no right or wrong answers! This research aims to help young people in South Africa. Thank you for taking the time to help.

General information collection

Interview Date: _____
Serial number / pseudonym: _____
How was the participant recruited?

_____

Did the participant consent to participate?:

- Yes – please continue (and attach paper consent form)
- No – do not proceed with the interview

Participant expertise (e.g. working with boys, involved in traditional circumcision, etc)

_____

_____

Location of interview:

_____

_____

(To select / modify questions based on participant expertise)

Introductions:

(Introduce researcher(s))

Please tell me about yourself?

About adolescents, health and gender

Do adolescent girls and boys have the same health problems? Can you please explain and give an example?

Have you noticed that there are differences in what adolescent boys / girls believe about their health? Please explain. If yes, how and when do you believe these beliefs are formed?

Have you noticed that there are differences in the way that adolescent boys / girls take care of their health? Please explain and give an example? If yes, how and when do you believe these behaviours are formed?

Does the gender of the health care make a difference to their client? For example, do boys or men prefer to see a male or female health care worker?

Do men and women have the same health problems? Can you please explain and give an example?

Have you noticed that there are differences in what men and women believe about their health? Please explain.

Have you noticed that there are differences in the ways that men and women take care of their health? Please explain and give an example. If yes, how and when do you believe these behaviours are formed?

Are the reasons that adolescents go to the traditional health practitioner for different than the reasons they go to the clinic? Please explain? Is this different for boys / men and girls/women? For what reasons do adolescent boys going to the traditional health practitioner? Please explain.

In your opinion, what are the biggest challenges facing adolescents today? (Prompts – is this the same for boys and girls?)

Considering what we have discussed, what do you think others need to understand about how adolescent boys / men take care of their health?

About traditional initiation / circumcision:

What is the difference between someone who has gone through traditional initiation / circumcision and someone who has not?

Is there a difference in the way that men act after they have been circumcised / initiated?

Is there a difference in the way that men take care of their health after they have been circumcised / initiated? (prompts – are they more /less likely to visit the traditional healer, or doctor, to take medication?)

Have you ever been involved in traditional initiation / circumcision? If yes, how? Please explain.

In your opinion, is traditional initiation / circumcision a good thing? Please explain.

Do you think boys living with HIV should go for traditional initiation/circumcision? Why or why not?

Do you have any experience with supporting boys living with HIV to go to traditional initiation/circumcision? Please explain.

Is it possible for boys to take HIV medicines during traditional initiation/circumcision. Please explain.

After returning from traditional initiation / circumcision, is there any difference in how boys living with HIV access biomedical care? (Take their HIV medications? Pick up their medications? (Please explain)

About HIV

In your opinion, where does HIV come from? Please explain.

Is HIV related to calling sickness/ ukuthwasa in any way? Please explain.

Is HIV related to bewitchment in any way? Please explain.

What are the ways that people get HIV?

In your opinion, why do some people get HIV? Please explain.

Do you have any knowledge or experience with adolescents living with HIV?

If yes, do they take anti-retrovirals? Why or why not? Are their biomedicine taking practices gendered?

If yes, do they take traditional medicines / muthi? Why or why not? Are their traditional medicine practices gendered?

In your opinion, are their traditional medicines that can help people living with HIV? Please explain.

About traditional health care:

What factors determine if an adolescent will go to a traditional health practitioner? (prompts – gender, parent's beliefs?, personal beliefs, urban/rural? HIV status?).

What do you think about traditional health practitioners and traditional health care? (prompts - does it work, is it a good thing?)

What role, if any, does traditional health care provide in HIV care? Please explain.

What role, if any, do you believe traditional health care could play in HIV care? Please explain.

What do you think about how traditional and biomedicine work together?

Do adolescents go to traditional health practitioners? If so, for what reasons do

they go, and who do they go with? Is this the same or different for adolescent boys? Is this the same for adolescents / adolescent boys living with HIV? Please explain.

Do they come alone or with someone? If yes, who do they come with? (i.e. alone, with parents, other?)

What makes an adolescent start going to the traditional health practitioner without their caregiver? Is this different for boys and girls?

How do adolescents get money to go to the traditional health practitioner?

What factors determine if an adolescent will go to a traditional health practitioner? (prompts – gender, parent's beliefs?, personal beliefs, urban/rural? HIV status?).

About becoming an ancestor

Can anyone become an ancestor? Why or why not?

Can a boy become an ancestor? Please explain?

Is it important for people to become an ancestor? Why or why not? Please explain.

What is required of a man to become an ancestor? Please explain?

Can a person living with HIV become an ancestor? Why or why not?

If a man lives an unhealthy life, can he still become an ancestor? Will people still perform ceremonies for him? Please explain?

On biomedical care

What happens when adolescents living with HIV transition from child to adult care? (prompts – do they come more / less, is it easier / harder for them). How does this affect their medicines taking? Is this gendered? Does transition affect boys and girls differently? Please explain.

What do you think about how traditional and biomedicine work together?

If you were in a taxi with the Minister of Health, what would you tell him?

Closing

Considering what we have discussed, what do you think others need to understand about how adolescent boys / men living with HIV take care of their health?
If you were in a taxi with the Minister of Health, what would you tell him?

Is there anyone else that you would recommend that we speak to?
How did you find the interview?
Do you have any questions?
Are you OK to finish the interview now?

Appendix 6: Details of the informed consent/assent process, and it's underlying principles

The process of obtaining informed consent, and, in the case of adolescent minors, assent, is guided by the University of Cape Town's Human Research Ethics Committee's standard operating procedures (HREC SOPs) on Research Involving Children (University of Cape Town, 2013) and Informed Consent (Human Research Ethics Committee, 2014), as well as the National Health Act (Parliament of South Africa, 2003) and the National Department of Health's 'Ethics in Health Research: Principals, Process and Structures' guideline (Greef, 2015). It also follows the Mzantsi Wakho protocol (Hodes et al., 2014).

The Children's Act (2005) requires that a parent or legal guardian provide permission for a child (under the age of 18) to participate in research. Similarly, the HREC SOP on Research Involving Children outlines these requirements, stipulating that '*Every person under than the age of 18 years requires a legal guardian to assist with decisions with legal consequences, such as consent to research participation*.' (University of Cape Town, 2013). In the case of this proposed research, some adolescent participants will be under the age of 18 (ages 13-17) and others will be over the age of 18 (18-22). In the cases of those under the age of 18, guardian consent will be obtained prior to the interview, as well as informed assent from the potential participant. No minor will participate in this research before obtaining written and verbal guardian consent, and also providing verbal and written assent themselves. Informed written and verbal consent will be obtained for each adult study participant.

The principles and process for seeking informed consent/assent for minors and their guardians, as well as adult participants are mapped out below.

Principles:

1. Every effort will be taken to ensure that assent/consent is informed and voluntary, and that involvement in the research is a participatory and positive experience, with therapeutic elements where possible (Hodes *et al.*, 2014).
2. Only participants deemed competent and capable of providing assent/consent will be interviewed (Hodes *et al.*, 2014). To this effect, participants with severe cognitive disabilities, and those who are unable to demonstrate comprehension of the information or consent process will not be interviewed. Additionally, in line with the British Psychological Society Guidelines, avoidance of participation or visible signs of discomfort will be taken as non-consent (Hodes *et al.*, 2014).
3. Any participant who declines to participate (regardless of whether they or a guardian have previously consented) at any time before or after beginning the research will not be interviewed, or if an interview has already been conducted, data can be removed and destroyed at any time and not used in analysis.
4. In line the Standard Operating Procedure for Informed Consent (Human Research Ethics Committee, 2014), consent (and in the case of minors under the age of 18, assent) to participate is considered to be a process of interactive communication. Questions from potential participants and participants will be welcomed throughout the research process.
5. As per the Mzantsi Wakho protocol (Hodes et al., 2014), participants will be offered to the choice of consenting or refusing immediately, or to have up to a week to consider consent for a week before interviewers return.

6. Interviewers who participate in recruitment and interviewing of participants will be trained on the principles, process and purpose of informed and voluntary consent.
7. **On language:** For seeking consent of all adolescent participants, and all adult participants who prefer to speak in isiXhosa and/or who not fluent in English, I will work with local research assistants who are fluent in isiXhosa and English and who have in-depth understanding of the study context and content.

Process for seeking informed consent/assent:

1. Interviewers will explain the study to participants and, in the case of minors, their parents/legal guardians, in the language of their choice (English or isiXhosa) and provide them with an information guide (also in the language of their choice) which details information about the study and participation.
2. The information guide will be used to provide information about the research to participants in their language of choice (English or isiXhosa). This guide includes an overview of the purpose of the research, risks and benefits, who is conducting the research, procedures on how the data will be used, information about the ability to refuse participation without any penalty and confidentiality. It also includes a section about what will happen if the participant becomes distressed, the estimated time of the interview, data management/destruction, and the contact details of the lead researcher, the Mzantsi Wakho office, and the University of Cape Town's Faculty of Health Sciences Human Research Ethics Committee in case participants require further information or have concerns or complaints.
3. Confidentiality is bounded by the legal requirement to report cases of maltreatment, neglect, physical abuse causing harm and sexual abuse, and reportable diseases. Participants and their guardians will be informed (verbally and in the information sheet) that what they say in the interview will be confidential, with the exception of the mandatory legal requirement to report such cases to the appropriate authorities. In the case of focus groups and small group interviews, participants will follow the same process of providing informed assent/consent (including guardian consent in the cases of participants under the age of 18), but will be informed that confidentiality cannot be guaranteed as other focus group / small group interview members may disclose information. In the case of interviews with adolescent participants, prior to the interview, the participant will be asked where they would like to conduct the interview. If they wish to be interviewed at home, the participant will be asked if there is a space where they would be comfortable conducting the interview in their home which they believe will be free from interference. In the case of home-based interviews, the participant will also be made aware that we cannot guarantee that interference won't occur in the interview and that this might be a limitation to confidentiality. Participants will also be informed that at any time before or during the interview, we can recommend an alternate, secure space to conduct the interview if they prefer.
4. The informed consent / assent form is attached as the last page of the guide. The guide will be left with participants (given that they desire to keep it), and the consent form after completion will be kept by the research project.

5. The contents of this guide, including implications for participation, will be clearly explained to participants, in accessible language, in the language of their choice (English or isiXhosa) prior to seeking consent. As per the guide, the interviewer will emphasize, in the participant's language of choice, that they can refuse to participate (regardless of whether they or a guardian have previously consented), stop the interview at any time, or later request for data related to them to be excluded from analysis and destroyed and this will not affect any support they receive (e.g. referrals to services). If participants choose not to participate, they will still receive a participant pack and (in the case of adolescent participants), a certificate of participation if they desire.
6. Interviewers will also emphasize that participants can ask questions about the study at any time before, during and after the interview. In cases where I am not conducting the interview and participants or caregivers have any questions, I will make myself available to answer any questions participants or guardians may have, and will also ensure that translation services are available for these conversations to happen in their language of comfort (English or isiXhosa).
7. The interviewers will ensure that participants comprehend the research purpose, the potential risks and benefits of participating, and the limitations of confidentiality (such as when a mandatory report is required or within a focus group / small group interview) before providing consent/assent. Steps to ensure comprehension include:
    1. Ascertaining while introducing the study from verbal and non-verbal cues if the participant seems to be understanding and interested and comfortable to provide assent/consent. If so,
    2. they will test comprehension by going through the tick boxes in the consent form with the participant to see if they understand and agree with each.
    3. In cases where the interviewer has any doubt about the understanding of a potential participant, they will test the participant orally using an adapted list from the Standard Operating Procedure for Informed Consent (Human Research Ethics Committee, 2014). These include, but are not limited to:
        1. What is the purpose of this study?
        2. Why makes you want to consider being in this study?
        3. Do you have to be in this study, even if you do not want to participate?
        4. What can you do if you decide that you no longer want to participate?
        5. If you participate in this study, what are some of the things that you will be asked to do?
        6. Will your answers always be kept confidential? Please explain.
    4. If participants do not understand, these answers can be explained and the participant re-tested, if deemed appropriate and if that the participant has the desire and capacity to understand and provide informed assent/consent.
8. In line with the current Mzantsi Wakho protocol (Hodes *et al.*, 2014) and following British Psychological Society Guidelines, avoidance of participation or any visible signs of discomfort will be taken as failure to consent. Participants with severe cognitive disabilities, and those who are unable to demonstrate comprehension of the information or consent process will not be interviewed.
9. Participants will be asked for consent only after explaining the format and purpose of the data collection, and being provided with, and walked through the information sheet in their language of choice (either English or isiXhosa) (Hodes *et al.*, 2014).

10. The adolescent consent form includes the participant name, preferred pseudonym, date of birth, contact details and Mzantsi Wakho quantitative participant number (if applicable). Consent will also be sought to access Mzantsi Wakho participant data, including school and clinic data collected as part of the Mzantsi Wakho study. This data, if obtained, will be used to compliment qualitative data about the adolescent's health, home and school circumstances, and health behaviours to allow for better insight into the participant's behaviours and experiences. Triangulating this data could be incredibly valuable to gather a more holistic understanding of understanding participant behaviours and experiences. The biomedical healthcare worker, traditional health practitioner and adult key informant consent form includes a space for participant name, chosen pseudonym and signature.
11. In cases where participants assent / consent to participate, we will also ask them if they are open for us contacting them again for an additional interview when we are filling out their contact details. The same process of informed consent will be followed for every subsequent interview.
12. Participants will have reminded not to disclose the identities of other participants using names, and participant names and other identifying details will not be included in transcripts.

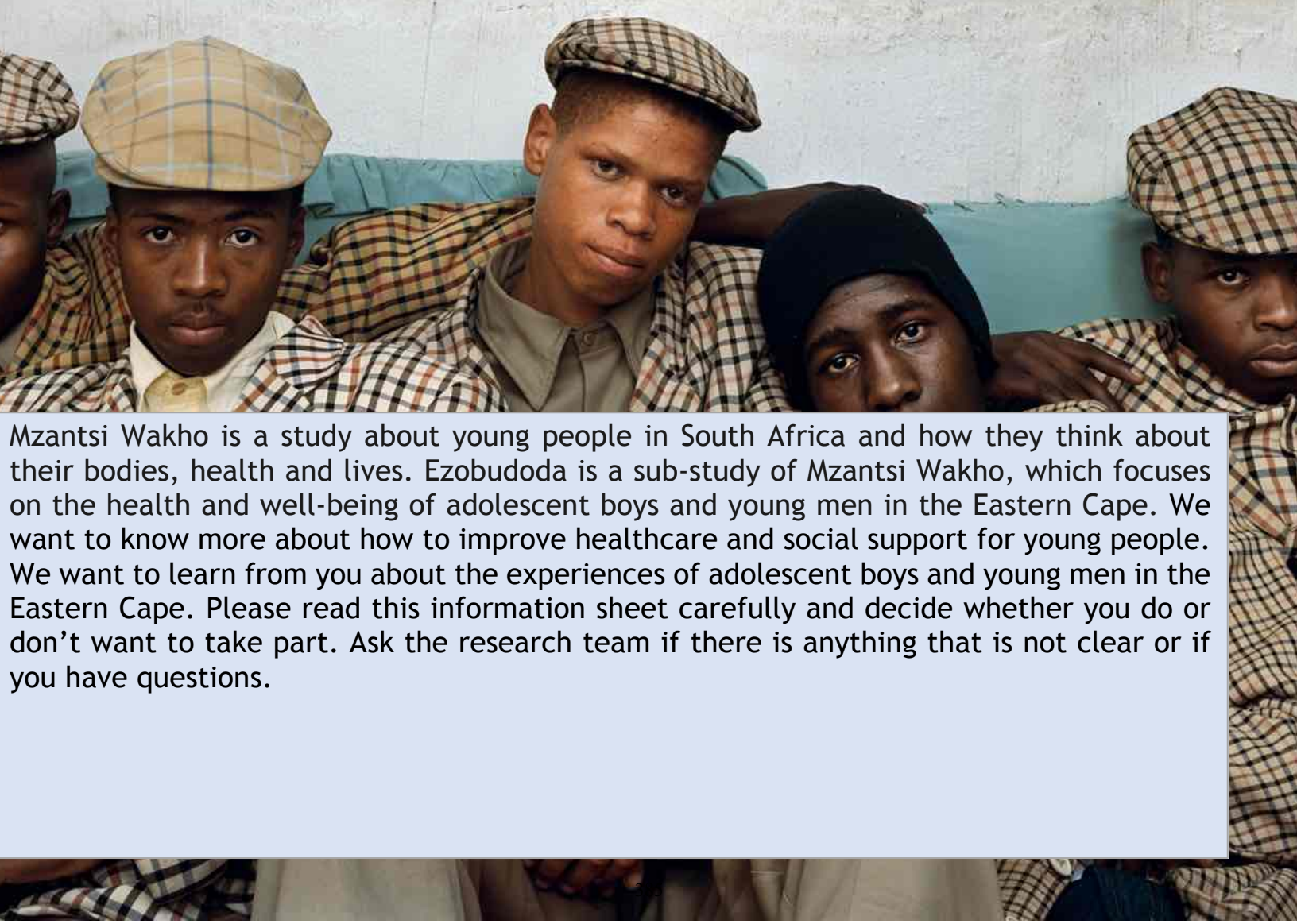
Withholding information

At no stage in the research process, including when introducing the study or seeking informed consent, are participants told that the study focus is on HIV.

Information and assent / consent form

MZANTSI WAKHO

EZOBUDODA



Mzantsi Wakho is a study about young people in South Africa and how they think about their bodies, health and lives. Ezobudoda is a sub-study of Mzantsi Wakho, which focuses on the health and well-being of adolescent boys and young men in the Eastern Cape. We want to know more about how to improve healthcare and social support for young people. We want to learn from you about the experiences of adolescent boys and young men in the Eastern Cape. Please read this information sheet carefully and decide whether you do or don't want to take part. Ask the research team if there is anything that is not clear or if you have questions.

Why have I been invited to take part? You are being invited because we feel that your experiences will help us understand more about adolescent boys' engagement with traditional and biomedical health services. We are inviting adolescent boys and young men between the ages of 13 and 22 to participate in this research study.

Do I have to take part? Not at all. It's up to you whether you want to take part or not. If you don't want to, it won't affect any help you are getting and you won't get into trouble. If you decide to take part, you are still free to stop at any time and you won't have to give a reason. We might visit you again to see how you are doing. You can choose then whether you want to talk to us again?

What will I have to do? If you decide to take part, you will first sign the assent / consent form on pages 4 and 5. If you are under the age of 18, we will seek your parent/guardian's consent to allow you to participate in this research. This means that we will approach your parent/guardian to inform them about the research, provide them with this information sheet and request their written consent (on the form below). You can choose the time and place of the interview, or we can recommend a private place. **If you choose to be interviewed at home, we cannot guarantee that someone will not come into the place where we are conducting the interview. If this is something that you are worried about, you can let us know before the interview, or at any time during the interview and we can recommend a private place to continue the interview.** The interview will take between 45 minutes and 2 hours where you will talk and do activities with a researcher. We will speak about your experiences including going to the clinic or hospital, traditional healer or going to be circumcised (traditionally or at the hospital). We will also speak to you about how you think we can make it easier for young people to take long-term treatment and access health services. Please feel free to expand on the topic or talk about related ideas.
You will be provided with a certificate of participation and a participant pack as a thank-you.
Sometimes we will need to understand things about your health school or other interviews with Mzantsi Wakho. With your permission, we might ask your school and clinic for additional information or look up information about you from interviews with Mzantsi Wakho.
The help that you are getting will not change if you choose not to participate in the interview, decide to stop the interview, or based on any of your answers to interview questions.

What if the questions upset me? If there are any questions you feel you cannot answer or that you do not feel comfortable answering, please indicate and we will move on to the next question. We also offer counselling if you feel like the interview made you feel uncomfortable. You can stop at any point, and you don't have to give a reason. You can also contact the research team at any point and say that you want your answers about certain questions to be removed, which we will do straight away. If you want to talk to someone about anything that has come up from this, you can tell one of the researchers, or contact us by calling us at 0437211716 or sending a 'please call me' to 0617293039.

Will what I say be kept confidential? Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. The interview will not include your name and it will be completely anonymous. But during our chat, it may become clear that you are suffering from serious challenges. If so, our researchers will explain to you, in private, possibilities for further help. If there is a safety issue, we might contact an organization that can help you. But we will talk to you about it first. These safety issues include if we find out or suspect that you have been physically abused causing injury, neglected, maltreated or sexually abused or raped and it has not been reported. If you are under 18 years old, we are required by law to report this information to a child protection agency/child welfare society, the Eastern Cape Department of Social Development, or the police. Someone will then investigate and see what needs to be done to keep you safe. We must also report notifiable diseases, such as tuberculosis.

What will happen to the information I give?

Your answers will be audio recorded, and then written out by a researcher and saved on a password protected computer and in a password protected online folder. If you don't want to be audio recorded, we will take notes during the interview instead. Pictures will be taken of your drawings and also saved in the same password-protected place on the computer and online folder. All interview materials (such as the consent form and your river drawings, if you choose not to keep them) will be stored in a locked filing cabinet or stored in an electronic file that only the research team can access. Consent forms will be destroyed 3 years after the study is finished. Notes and all other written documents will be destroyed at the end of the study. The study began in 2017 and we expect that it will be finished at the end of 2018.

What will happen to information collected from school and clinic records?

If you agree, we might collect information about your health from the clinic or performance or attendance from school. If you agree to allow us to collect this, we will treat this information confidentially. You do not need to agree to allow us to collect this information to continue the interview. It will not be attached to your name in any way, and like the interview materials, this information will be stored in a locked filing cabinet or stored in an electronic file that only the research team can access. We will destroy our copies of the information three years after the study is finished.

What will happen to the results of the study? The results of this study will contribute to a PhD dissertation at the University of Cape Town, and possibly presentations and papers on the same subject. The dissertation will be reviewed be by the University of Cape Town School of Public Health and Family Medicine, and Centre for Social Science Research staff and an external examiner, and then printed and kept in the UCT libraries. This research may also be used to help the government, and health and welfare organizations, to make better policies for young people, their health care providers and their families.

Who is organizing and reviewing the research? This research is being organized by the University of Cape Town.

Who has reviewed and approved this study? This research is being organized by Lesley Gittings, a student at the University of Cape Town. It has been reviewed and approved by the Human Research Ethics Committee at the University of Cape Town (Note to reader/reviewer: I have added this section for completeness. This section is only valid after HREC approval).

What if I have a question or complaint? If there is anything to do with the research that you are unhappy with or have questions about, you can contact Lesley Gittings at the University of Cape Town (Lesley.gittings@gmail.com / 0617293039) or call us on 0437211716 or send a 'please call me' to 0617293039. If you think your concerns are not well addressed, you can report to Human Research Ethics Committee at the Faculty of Health Sciences University of Cape Town at 0214066346.

Thank you for reading this sheet. Please let the research team know if you have any questions or something is not clear. If you feel comfortable with everything, you can fill in the consent form on the next page.



Do I want to take part?

	Agree	Disagree
I have read and understand the information sheet for this study and have had a chance to ask questions.	☐	☐
I understand that I have chosen voluntarily to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting.	☐	☐
I agree to take part in the study.	☐	☐

I agree that information from my school and clinic records can be added to my responses.	☐	☐
I agree that information from other Mzantsi Wakho interviews that I have or will participate in can be added to my responses.	☐	☐
I agree that any words I may say during the interview can be used, without giving my name, in presentation of the research.	☐	☐
I agree to let this interview be recorded and I understand that I can change my mind to stop the recording without getting into trouble.	☐	☐
I don't want to take part in this study.	☐	☐



Filling in your Details:

Name of participant: _____

Signature of participant: _____

Preferred Pseudonym of participant: _____

Age _____ Assent / Consent Date:_____

ID#/Birthday_____



Address:_____

Telephone Number: _____
Can we contact you again to participate further in this study? (Yes/No)
If yes, can we contact you by calling you? (Yes/No)
If yes, can we contact you by going to your home? (Yes/No)
If yes, is there another way you would like us to contact you (Yes/No)? If so, please specify _____

Parent/Guardian Consent (for participants under the age of 18):

I, _____, as the legal guardian/parent have read the above information sheet and give consent for the participant to take part in this study.
Signature of parent/guardian_____
Consent Date:

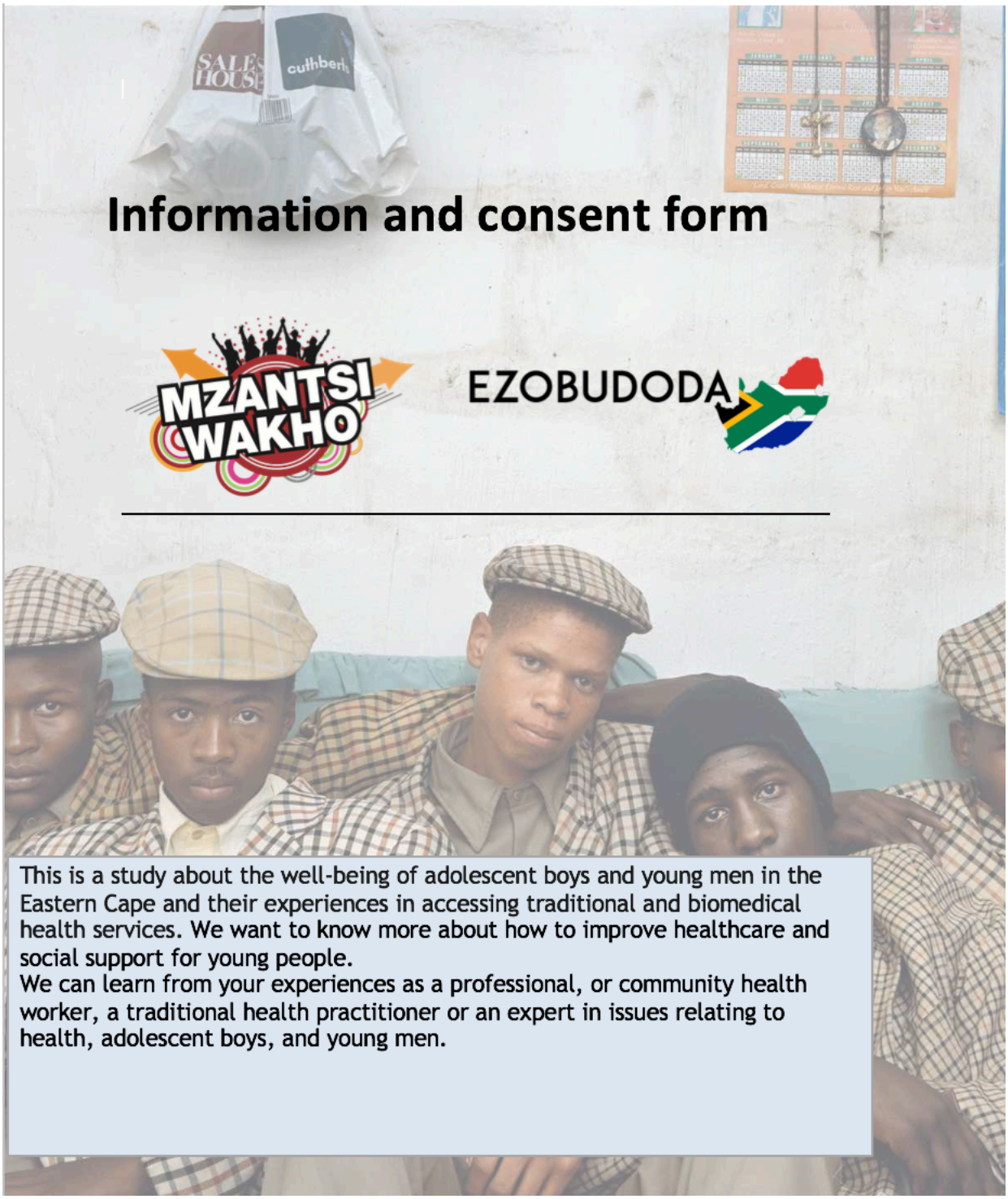
_____



Name of researcher: Date:

_____ _____

Appendix 8: Information guide and informed consent form (English) for traditional and biomedical health workers and key informants.



You are being asked to participate in this research study because we believe you're your experience will help us to understand more about adolescent boys' engagement with traditional and biomedical health services. Please take time to read this carefully and decide whether you do or don't want to take part. Ask the research team if there is anything that is not clear or if you have questions. Thank you for reading this.

Do I have to take part? Not at all. It's up to you whether you want to take part or not. If you don't want to, it won't affect any help you are getting and you won't get into trouble.

What will I need to do if I take part in this research? If you decide to take part, you will first sign a consent form (on page 3), and then spend some time talking together with our researchers. We will speak about your experiences with young male patients, particularly those using sexual and reproductive health services, circumcision services and traditional health services. We will also speak to you about how you think we can make it easier for young people to take long-term treatment and access health services. Please feel free to expand on the topic or talk about related ideas. If there are any questions you feel you cannot answer or that you do not feel comfortable answering, please indicate and we will move on to the next question.

What will happen to the information I give?

If you agree, your answers will be audio recorded, and then written out by a researcher and saved on a password protected computer and in a password protected online folder. If you don't want to be audio recorded, we will take notes during the interview instead. Consent forms will be destroyed 3 years after the study is finished. Notes and all other written documents will be destroyed at the end of the study. The study began in 2017 and we expect that it will be finished at the end of 2018.

What if the questions upset me? If there are any questions you feel you cannot answer or that you do not feel comfortable answering, please indicate and we will move on to the next question. We also offer counselling if you feel like the interview made you feel uncomfortable. You can stop at any point, and you don't have to give a reason. You can also contact the research team at any point and say that you want your answers about certain questions to be removed, which we will do straight away. If you want to talk to someone about anything that has come up from this, you can tell one of the researchers, or contact us by calling us at 0437211716 or sending a 'please call me' to 0617293039.

Will what I say be kept confidential? Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name and address changed so that you cannot be recognised from it. If you share information about a patient or client, please do not use their name or anything that will allow them to be identified. The only cases where information must be shared include child physical or sexual abuse, deliberate neglect, family violence or notifiable diseases such as tuberculosis.

What will happen to the results of the study? The results of this study will contribute to a PhD dissertation at the University of Cape Town, and possibly presentations papers on the same subject. The dissertation will be reviewed be by the University of Cape Town School of Public Health and Family Medicine, and Centre for Social Science Research staff and an external examiner, and then printed and archived in the UCT libraries. This research may also be used to help the government, and health and welfare organizations, to make better policies for young people, their health care providers and their families.

Who has reviewed and approved this study? This research is being organized by Lesley Gittings, a student at the University of Cape Town. It has been reviewed and approved by the Human Research Ethics Committee at the University of Cape Town

What if I have a question or complaint? If there is anything to do with the research that you are unhappy with or have questions about, you can contact Lesley Gittings at the University of Cape Town (Lesley.gittings@gmail.com / 0617293039) or call us on 0437211716 or send a 'please call me' to 0617293039. If you think your concerns are not well addressed, you can report to Human Research Ethics Committee at the Faculty of Health Sciences University of Cape Town at 0214066346.





Do I want to take part?

	Agree	Disagree
I have read and understand the information sheet for this study and have had a chance to ask questions.	☐	☐
My participation in this interview is entirely voluntary and I understand that I will not be reimbursed for participation in the research study.	☐	☐
I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting or affect my job security.	☐	☐
I understand that if I share any information that may be considered confidential, I agree to clearly communicate the confidential nature of this information to the interviewer to prevent it from being included in the final report of research findings.	☐	☐
I agree that any words I may say during the interview can be used, without giving my name, in presentation of the research. My identify and information that I provide will remain anonymous and the transcript of this interview will not be publically available.	☐	☐
I agree to let this interview be recorded and I understand that I can change my mind to stop the recording without any consequence.	☐	☐
I agree to take part in the study.	☐	☐

Name of participant: Signature of participant: Preferred Pseudonym:

_____ _____

_____

Name of researcher: Date:

_____ _____

Appendix 9: Researcher hiring and training criteria

Research Assistant recruitment criteria, responsibilities and training

Recruitment criteria for the research assistant(s) responsible for conducting interviews with adolescent boys living with HIV include:

5) A young man (between the ages of 25-45) who is from the study area, (so as to be older than, but share similar characteristics to participants), fluent in isiXhosa and English, and knowledgeable about social and cultural norms in the study site;
6) Fluent in isiXhosa and English;
7) Has experience working with children/adolescents, and people living with HIV;
8) Qualitative research experience is a strong asset;
9) Non-judgemental;
10) Can work independently;
11) Good attention to detail;
12) Patient; and
13) Sensitive to social and cultural norms, and able to be sensitive to the needs and vulnerabilities of participants.

The research assistant will be trained in the following prior to commencing data collection:

1- Data collection tools to be used, as well as the Mzantsi Wakho and Ezobudoda study designs and content;
2- Quantitative and qualitative data collection methods (basic training);
3- Gender and masculinities theories (basic training);
4- History of HIV, and HIV stigma in South Africa;
5- The principles, purpose and processes of obtaining informed and voluntary participant consent, and in cases of participants under the age of 18, guardian consent, including the criteria for whom can legally provide consent for a minor.
6- The importance and principles of confidentiality, the confidentiality protocol (outlined below in the 'Confidentiality' section, and will have read, understood and signed the confidentiality agreement. He will also be trained in the limitations of confidentiality, namely in cases where a mandatory legal report must be made.
7- Working with vulnerable children, detecting and responding to participant distress.
8- Mandatory reporting & providing referrals to appropriate social services, including the referral protocol and forms are provided later in this document. Specific attention will be paid to training on mandatory reporting requirements, including the conditions under which a mandatory report should be made, and the protocol for making such reports. This training will cover the relevant laws including (1) the Sexual Offences Act of 2007 (including mandatory reporting of sexual offences set out in Section 54) and (2) the Children's Act of 2005 (and the amendment Act of 2007), including Section 110(1) and 110(2) and prescribed forms 22 and 23. The referral and reporting protocols, and the legislative requirements for reporting abuse, maltreatment and neglect are set out the section on legislative requirements for reporting abuse and neglect later in this document.

Appendix 10: HIV status-non disclosure additional information

HIV status non-disclosure

The Ezobudoda study, has put substantial measures in place (modelled on the Mzantsi Wakho study), to reduce the risk of disclosing a participant's HIV status to them (if they are unaware of their own status) or to others. Due to the highly stigmatized nature of HIV, the fact that the Mzantsi Wakho study, and Ezobudoda sub-study focuses on HIV and sexual health will not be disclosed to participants. Instead, the study will be broadly framed as a study about young masculinities and health, including engagement with biomedical and traditional health services. Like the Mzantsi Wakho study, information sheets will not include mention of HIV/AIDS (Hodes et al., 2014). This is an important consideration of stigma mitigation, given that the research is conducted in environments of high surveillance, and the researchers and research project vehicles could be identified and related to an HIV research project. In line with the current Mzantsi Wakho protocol, this study may recruit and interview HIV-status unknown participants from the same household or community (including from the current quantitative or qualitative samples), as a measure of stigma mitigation and confidentiality.

An additional stigma mitigation measure is that participant HIV status is never discussed in plain language within the research project. In line with the Mzantsi Wakho study, animal types (e.g. Giraffe, Elephant, Bear) have been allocated to participants with different HIV statuses or knowledge of their status. For example, the team will not refer to a participant, even within confidential spaces as an HIV-positive adolescent who knows their status. Instead, they will be referred to as 'a Giraffe'. These codes are unknown to participants or others outside of the project, and are never used in the presence of a participant. This sub-study will use the same protocol for discussing participant HIV status.

In acknowledgement of the highly sensitive nature, and potential associated harm of discovering one's HIV-positive status in an inappropriate way, I will approach interviews and approval seeking by caregivers and friends of participants on the assumption that the child and/or caregiver is unaware of the adolescent's HIV-positive status, and will not ask questions that may inadvertently disclose her or his status.

Additionally, in order to minimize the risk of inadvertently disclosing or traumatizing participants, I will work with local male research assistants trained to the complexities and sensitivities of adolescents living with HIV in the Eastern Cape, for whom the hiring and training criteria have been outlined above.

Confidentiality and Privacy

Given the highly personal and sensitive nature of this research, confidentiality is of utmost importance. Participant identifier numbers from participants recruited from the Mzantsi Wakho quantitative cohort will be used, alongside pseudonyms for all participants. All identifiers that can be used to recognize the participant will be removed during analysis and writing and participant details will not be attached to the data in any way that they are identifiable.

A master list which will be password protected and accessible only to myself as the lead researcher will be kept which will contain identifiers as well as linking them to pseudonyms and Mzantsi Wakho participant numbers (when they exist). This information will be obtained from the consent form. Consent forms will be kept locked in a filing cabinet and destroyed 3 years after the completion of the study.

All researchers involved in data collection will be trained on confidentiality, and required to sign the confidentiality agreement (modified from the Mzantsi Wakho Confidentiality Agreement) before beginning the research. Participants' contact details will also be password protected, and those who leave 'please call me' messages will only be contacted by the research team.

Participants will choose the time and location of engagement with the researchers, given that it meets the project's rigorous safety standards (Hodes et al., 2014). For example, participants may choose to be interviewed in a project vehicle, a local park or a community centre in order to ensure that they are comfortable and uphold confidentiality.

As set out in the reporting protocol, confidentiality is bounded by the legal requirement to report cases of maltreatment, neglect, physical abuse causing harm and sexual abuse. As per the principles and process for obtaining informed consent, participants (and in the cases of participants under the age of 18, their guardians as well) will be informed that what they say in the interview will be confidential, except in circumstances where they have been harmed or at risk of harm. This applies in cases of maltreatment, neglect, physical abuse causing harm and sexual abuse as well as when the research team reasonably suspects that a participant has tuberculosis, or another notifiable disease (which are required by law to be reported to a health professional).

Appendix 11: Pre and post interview checklist

Before the interview, please make sure that you have the following:

1) Charged tablets + backup with an audio recording and photography function
2) Paper informed consent forms in English and isiXhosa
3) Paper questionnaire
4) Ezobudoda 'toolkit', including:
    a. Large paper
    b. Markers / coloured pencils
    c. River pictures
    d. Stickers & stones pack
5) Participant packs (pls always carry extras)
6) Make sure car has enough fuel.

While out conducting interviews:

27. When you arrive at an interview site, please send a message to the Ezobudoda whatsapp group, including the participant serial number, and drop a location pin.
28. When you leave an interview site, please send a message to the Ezobudoda whatsapp group.
29. When arriving back in the office, please send a message to the Ezobudoda whatsapp group that you have returned safely.

After leaving the interview, please:

Complete a reflection form.

If the participant disclosed being abused or maltreated, please contact Lesley immediately at 0617293039.

Put the consent form, reflection form and questionnaire form together in the folder.

Write the serial number of the participant on the drawing (if they chose not to keep it).

Take a picture of their drawing on the tablet.

Put the drawing and folder with the forms in 'Ezobudoda' folder in the locked cabinet.

Please do a reflection, responding to the questions on the following page. This can happen in 3 ways:

With Lesley, or another PM or FWC.

By making a voice note on the same tablet that you did the interview on, answering the questions below. Please name the audio file the participant's serial number and date of the interview. E.g. 'March 1 – 987654'

By writing notes on the computer

Upload the audio files, pictures and voice note and upload it to the password-protected dropbox folder.

Lock the tablet and computer, and all paper forms in their place in the filing cabinet.

Ensure the car is re-fueled and the car log has been filled out.

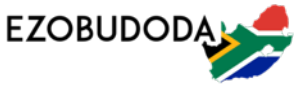
Questions to answer in reflection:

-Overall, how did the interview go?
-What was the feeling in the interview (e.g. relaxed, stressful, sad, etc)
-Was the participant open to talk?
-Were there any challenges with the interview?
-How did the participant feel about the interview?
-Is there anything that you think is important to know about the participant?
-Did the participant disclose that they have been abused or maltreated?
-Are they a good candidate for future qualitative research?
-Is there anything else that is important to know about the interview?
-Did they do the river of life exercise? If so, how did they respond?
-What did you notice about this participant?
-What did you find interesting about this interview?
-What did the participant say about their life events?
-What did they say about masculinit(ies)?
-What did they say about circumcision / initiation?
-What did they say about taking ARVs during initiation?
-What did they say about going to the clinic?
-What did they say about transition from paediatric to adult care (if applicable)
-What did they say about traditional healing?
-What did they say about their beliefs about HIV?
-Anything else you think is interesting to share?

Appendix 12: Reflection form

Ezobudoda Interview Reflection Sheet
Research Assistant Name_____
Participant's identifier number and/or pseudonym
Interview Date _____





Location and Interview Process:

- a)**Where** did you do the interview:

☐ Clinic ☐ Home ☐ Other:

_____

- Did an adult **participate at any point during** the interview?

☐Yes ☐No

If yes, how?

☐Spoke to another RA ☐Commented on questions or answers
☐Spoke to interviewer RA ☐Overheard answers
Other_____

_____
If yes, who? (family member, friends, partner or second RA?)_____
If yes, what actions did you take?

_____

If yes, did the participant want to change location, continue in the same location, or stop the interview? Please explain.

_____

_____

- a) Was another adult **present at any point** during the interview?

☐ Yes ☐ No
If yes, who? (family member, friends, partner or second RA?)_____
b)Was another minor present during the interview?
☐ Yes ☐ No

If yes, who? (family member, friends, or partner?)

_____
c) If a) or b) is yes, how were they involved:

_____

_____

If yes, what actions did you take?

_____

If yes, did the participant want to change location, continue in the same location, or stop the interview? Please explain.

- Was the interview **interrupted** by anything?

☐ Yes ☐ No

If yes, please explain what happened, including actions taken by you to address the interruption?

If yes, did the participant want to change location, continue in the same location, or stop the interview? Please explain.

- What **difficulties**, if any, did the participant have during the interview?
- Did the participant have **trouble understanding** the meaning of the questions?

☐ Yes ☐ No

- Did the participant have **difficulty hearing, seeing and/or any other physical difficulty**?

☐ Yes ☐ No

- Was the participant **distracted/tired/not taking the interview seriously/not concentrating?**

☐ Yes ☐ No

- Did the participant **start crying or became emotional or needed to be cheered up when a sensitive topic was being mentioned**?

☐ Yes ☐ No

If yes, please explain what happened, including actions taken by you to address this situation:

If yes, did the participant want to stop / take a break / continue (please circle which one applies) the interview? Please explain, including your action taken.

- Other difficulties?

☐ Yes ☐ No

If other difficulties then please explain

- a) What **animal** was the participant? *(tick only ONE box)*

☐ Bear ☐ Elephant ☐ Giraffe
☐ Zebra ☐ Cheetah ☐ A Bear turned Giraffe
☐ A Cheetah turned Zebra ☐ Elephant turned Giraffe

b) IF THE PARTICIPANT WAS AN **ELEPHANT**, did they:

(1) Know they were HIV-positive (giraffe) ☐ Yes ☐ No
(2) Know they took ARVs ☐ Yes ☐ No
(3) Know ARVS are for HIV ☐ Yes ☐ No

- a) Did anyone speak with a **caregiver/family member** *before, during or after the interview*?

☐ Yes, before ☐ Yes, during ☐ Yes, after ☐ No

b) **Name** of caregiver/family member spoken to_____

c) **Relationship** of caregiver/family member to participant:

☐ Parent ☐ Grandparent ☐ Aunt/Uncle ☐ Sibling ☐

Other_____

_____

d) **Who spoke with the caregiver**?_____

_

e) Please write a brief summary of points discussed **with the caregiver/Family member**:

_____

_____

- Did the teen tell you anything **that concerned you or requires a referral**? (tick all that apply) If yes, please speak immediately to a project manager so that we can take the necessary steps required by law.

☐ No ☐ Physical abuse ☐ Emotional abuse

☐ Hunger/Lack of food ☐ Needs counselling ☐ Needs medical treatment

☐ Other: _____ (give details)

- Often participants tell us different things at different times and/or the participant and the parents say conflicting things. Were there any **inconsistencies/contradictions** during the interview:

☐ Yes ☐ No

If yes, please provide details: Any other observations, comments etc.

Thank you for completing the reflection form.

Please make sure you have ticked all the appropriate boxes. If you do not know what to answer for any questions ask another RA/Fieldwork Coordinator or Manager for help.

Appendix 13: Confidentiality Agreement

I agree to protect the confidentiality, privacy and security of participants and their families that I come into contact with from any source and in any form (verbal interview / chat, paper, electronic communication).

I understand and acknowledge that:

- During recruitment of participants in communities (home visits, ward counsellor meetings, teachers, home-based carers, traditional health practitioners, etc.), I shall only refer to the research project as an Adolescent Health Research project, and not one that specifically focuses on HIV-positive teens. This will be done to protect the confidentiality of participants and reduce potential stigma associated with participation in the study.
- I shall respect and maintain the confidentiality of all discussions, interviews, patient care records and any other information generated in connection with individual participants. This includes, but is not limited to: HIV Status, Answers to interview questions, Contact details (Phone number, address), Referral information or progress, Any verbal information provided by or about the participant and Family details or information.
- It is my legal and ethical responsibility to protect the privacy, confidentiality and security of all medical records or previous interview data that I access as part of the Mzantsi Wakho study.
- I shall only access or disseminate participant information for the performance of my assigned duties and where required by or permitted by law. I shall make no voluntary disclosure of any discussion, deliberation or records collected by Mzantsi Wakho. I agree to discuss confidential information only in the work place and only for job related purposes and to not discuss such information outside of the work place or within hearing range of other people who do not have a need to know about this information.
- I understand that any and all references to HIV testing and HIV status are specifically protected under law and unauthorized release of confidential information may make me subject to legal and/or disciplinary action. I understand that it is illegal to disclose any minor, adolescent or adult's HIV status to anyone without his or her permission. I understand that it is my responsibility to be discrete and mindful of this in all interactions, discussions, and deliberations with or about a participant.
- I will not take any pictures of participants for personal use with my cell phone or similar methods. I will not post confidential information, including participant pictures on any social media sites without the appropriate participant authorization.
- For participants under the age of 18, I understand that this confidentiality agreement is bounded by the Children's Act 38 of 2005 (as amended by Act 41 of 2007) and Sexual Offences (and Related Matters) Amendment Act of 2007 Acts. The Children's Act requires reporting to authorities if one can conclude on reasonable grounds that a child has been abused in a manner causing physical injury, sexually abused or deliberately neglected to a designated child protection unit or organization, the police or a social worker. The Sexual Offences (and Related Matters) Amendment Act sets out mandatory and immediate reporting by anyone who is aware of a sexual offence committed against a child including rape, statutory rape, child sex work and child pornography. I have been

provided with the protocol and forms for mandatory reporting on the above, and been trained on how to do so.

I hereby acknowledge that I have read and understand the above information and that my signature below signifies my agreement to comply with the above terms. In the event of a breach or threatened breach of this Confidentiality Agreement, I acknowledge that Mzantsi Wakho (including the Ezobudoda sub-study) may, as applicable and as it deems appropriate, pursue disciplinary action up to and including my termination from the project.

Research Assistant: _____ Signature:_____ Date: _____

Project Manager: _____ Signature:_____ Date: _____

Appendix 14: Referrals and legally mandated reporting

The below is an overview of the reporting protocol. The full Mzantsi Wakho/Young Carers referral protocol is over 100 pages and is not attached. It is available on request, alongside the forms, log and list of referral organizations.

Reporting of abuse, maltreatment and neglect

In the course of this research, challenging experiences such as sexual or physical abuse, maltreatment, neglect, psychological challenges, or the inability to meet basic needs may be disclosed or suspected. These may arise due to a high presence of cases of extreme need and abuse within the study sample, or because this may be one of few opportunities that an adolescent has to discuss the details of their lives with a trusted adult (Hodes et al. 2014; Cluver et al. 2015).

Conducting HIV and sexual and reproductive health research with minors is challenging. The law requires reports of violence and maltreatment, non-consensual sexual activity to the South African Police or the Department of Social Development. The below section outlines these mandatory reporting requirements and the processes for reporting and conducting referrals.

Legislation and reporting requirements

The Children's Act includes provisions for young people's rights to SRH services, including that children over the age of 12 can give consent to medical procedures and interventions, as long as they have 'sufficient maturity' and mental capacity to understand the benefits, risks and implications of treatment. Children 12 or over, or who otherwise are considered sufficiently mature to understand the social implications, benefits and risks of an HIV test can also consent to be tested for HIV. In addition, the Act sets out children's rights to contraceptives, such as being provided with/being able to buy condoms, as well other forms of contraceptives if the child has received proper medical advice and a medical examination confirming that there is not a medical condition that would make contraceptive use dangerous to them.

The Children's Act requires reporting to authorities if there is a reasonable suspicion that a child has been abused in a manner causing physical injury, sexually abused or deliberately neglected. Section 110(1) of the Children's Act of 2005 outlines the necessity for reporting when there is a reasonable suspicion that the child is being sexually abused, neglected or abused in a way that causes physical injury if suspected on the part of certain professionals dealing with a child. Section 110(2) of the same act requires that any person suspecting the abuse of a child, or deeming that a child is in need of care or protection, must report to a designated child protection unit or organization, the South African police service, or a social worker.

Section 54 of the Sexual Offences (and Related Matters) Amendment Act sets out mandatory reporting by anyone who is aware of a sexual offence committed against a child including rape, statutory rape, child sex work and child pornography to a police official. It also specifies that reporting must take place immediately, and failing to report renders the person guilty of an offense, and liable on conviction to imprisonment for no longer than 5 years, or a fine, or both

imprisonment and a fine. Further, mandatory immediate reporting to police is required by any person who has knowledge, suspicion or reasonable belief that a mentally disabled person has had a sexual offense committed against them, with the aforementioned terms of punishment for failure to report. It also states that a person reporting in good faith on reasonable belief or suspicion as set out above will not be held liable to criminal nor civil proceedings because they made such a report.

Whereas the Children's Act includes broad provisions for sexual and reproductive health rights and services for children, the Sexual Offences Act is more limiting with regards to children's sexual autonomy and rights. Under the Sexual Offenses Act, a child is a person under the age of 18 years, and in relation to statutory sexual assault and rape, a person 12 years of age or older, but under the age of 16. It also states that children under 12 are incapable of consenting to sex. Statutory rape is defined as all forms of sexual penetration of into/beyond the genital organs, mouth or anus of another person between the ages of 12 and 16, regardless of if they consented or are also within this age group. Sections 15 and 16 of the Act which criminalized consensual sexual acts between adolescents (ages 12-15) including penetrative as well as non-penetrative sexual acts such as hugging, touching and kissing were successfully struck down by the Constitutional Court Judgement of October 2013 of Teddy Bear Clinic for Abused Children and Another v Minister of Justice and Constitutional Development and Another (CCT 12/13 ZACC 35). This case did not address acts non-consensual sex and other forms of sexual violence carried out by children or their reporting.

Circumstances under which a mandatory report will be made

In summary, a mandatory report is required, and will be made in any of the following circumstances:

- A member of project staff (research assistant, myself or another team member) suspects or reasonably believes that a minor (in this case, a participant, under the age of 18) has been emotionally maltreated, deliberately neglected, or sexually abused[30].
- A participant under the age of 18 discloses that they have been or are being abused including in a way that causes emotional ill-being, physical injury or sexual abuse or neglect.
- An adolescent 15 years of age or younger (the youngest participants in this study will be 13 years of age) discloses engaging in a penetrative or non-penetrative act with someone who is (a) older than 18 at the time of the act, or (b) is over two years older at the time of the act and either 16 or 17 years old. This is regardless of whether the participant reports the act as consensual.
- A participant who is under the age of 16 discloses experiencing a non-consensual penetrative or non-penetrative sexual act, in which the perpetrator is 12 years old or older but under the age of 16 at the time of the act.

[30] Here sexual abuse is taken to mean rape/sexual acts where any penetration has occurred including forced anal, vaginal or oral penetration, as well as sexual assault/non-penetrative sexual acts including groping, sexual exploitation, grooming, using children in pornography including photographs.

In cases when myself or anyone working on this study learn of, or have reasonable grounds to suspect maltreatment or abuse of a participant under the age of 18, we will report to a police official (in cases of Sexual Offenses set out under section 54 of the Sexual Offences Act) or designated child protection unit, social worker, or police official (in cases of offenses set out under section 110(1) and 110(2) of the Children's Act).

A Co-PI of the Mzantsi Wakho study is a trained South African social worker. She will provide additional case-specific guidance, including discussing in detail all cases where an adolescent participant is experiencing, or may be at risk of, significant harm (Hodes *et al.*, 2014). Unfortunately, social services are of variable quality and are of low availability in some of the study sites (Hodes et al. 2014). For this reason, the social worker, alongside myself, will closely supervise each case, supportive action and referral taken (Hodes et al., 2014).

In line with Mzantsi Wakho protocol and practice, I will ensure that referrals to necessary services are provided when warranted. A summary protocol is included below. For further in-depth detail of site-specific challenges and case studies, the referral protocol which is used by Mzantsi Wakho (Young Carers / Mzantsi Wakho, 2016), and on which all staff are trained.

Protocol for reporting child maltreatment, abuse or neglect for children under the age of 18:

- During the introduction of the study for the purpose of assent / consent, participants under the age of 18 and their caregivers/guardians will be assured that participant answers will be kept confidential, unless if there is disclosure or reasonable suspicion of maltreatment, abuse and neglect. This is defined as any and all forms of physical ill-treatment causing harm, emotional maltreatment, sexual abuse or neglect resulting in actual or potential harm to the child well-being. These are further set out in Form 22 'Reporting of Abuse or Deliberate Neglect of Child (Regulation 33, Section 110 of the Children's Act 38 of 2005).
- If, during the course of the interview, the participant discloses, or the interviewer suspects that the participant or a member of their household has been maltreated, or is at risk of abuse or neglect (as set out in the above definition), the interviewer will not take any further action without discussing first with the participant. The interviewer will first ask if the abuse has already been reported to a child welfare protection agency, the police or the Department of Social Development. If not, they will discuss possibilities of referral with the participant and then immediately contact me. I will work with the researcher team, including the South African social worker, to determine the course of action, and the strategy to ensure the case gets taken up as effectively and quickly as possible.
- Following this, I will complete and submit the following forms with the Mzantsi Wakho social worker, and the interviewer:
  -Form 22 'Reporting of Abuse or Deliberate Neglect of Child' (Regulation 33, Section 110 of the Children's Act 38 of 2005 - I)

-Form 23 ‘Reporting of Abuse or Deliberate Neglect of Child to Director-General’ (Regulation 33, Section 110(5) of the Children’s Act 38 of 2005). Copies of forms will be kept locked on file and destroyed after 3 years.

As per the Mzantsi Wakho referral guidelines (Young Carers / Mzantsi Wakho, 2016), the following additional actions will be taken in specific cases:

- **In cases of rape within the past 72 hours**, the team will also support the child to immediately access hospital services so that they can access HIV post-exposure prophylaxis, and for female participants, emergency contraception.
- **In cases where a child discloses having attempted suicide recently**, the interviewer will assess if they are still feeling suicidal, and if they are might be, will be taken to the nearest hospital with a request for them to be admitted. (The details of how to navigate these situations are set out in detail in a robust Mzantsi Wakho referral protocol document).
- **In cases of suspicion of participants being infected with a notifiable disease**, such as tuberculosis, pneumonia or another opportunistic infection, they will be referred to a healthcare professional.
- **When participants report non-adherence to HIV and other essential medicines**, the interviewer will discuss the importance of adherence with the participant and also encourage them to consult a healthcare worker or adherence supporter (as per the Mzantsi Wakho protocol - Hodes et al., 2014).
- **For cases that do not meet the criteria of abuse, maltreatment, or neglect but when the child requests psychosocial support or counselling or it becomes apparent that the child could benefit from this type of service**, the child will be provided with contact details of ChildLine, or another relevant and appropriate service. They will also be asked if they would like further support to get in touch with ChildLine or another relevant service, and if so, a plan will be made to link them.
- For any cases where a report is required (and made), I will keep a written record of the reports and actions taken using the template. This table includes details of the name of the reporter, report date, name of the child who disclosed the maltreatment or sexual abuse, summary of the disclosure, the branch and person that the report was made to, and the actions taken in submitting and following up on the report.
- The referral and report tracking log will be used to track and update the status of referrals (including making additional enquiries into the case as necessary).

Appendix 15: Dissemination activities



Figure 50: Mzantsi Wakho team members in abstract development training and mentorship session. 13 April 2017.

Local (Eastern Cape) Findings Dissemination:

Eastern Cape-based dissemination included developing a pamphlet on medicines-taking during ulwaluko to 46 schools by a local NGO, presentations to the two largest public hospitals in Amathole and Buffalo City and presentations to provincial stakeholders including the Eastern Cape AIDS Council and the Eastern Cape Department of Health.

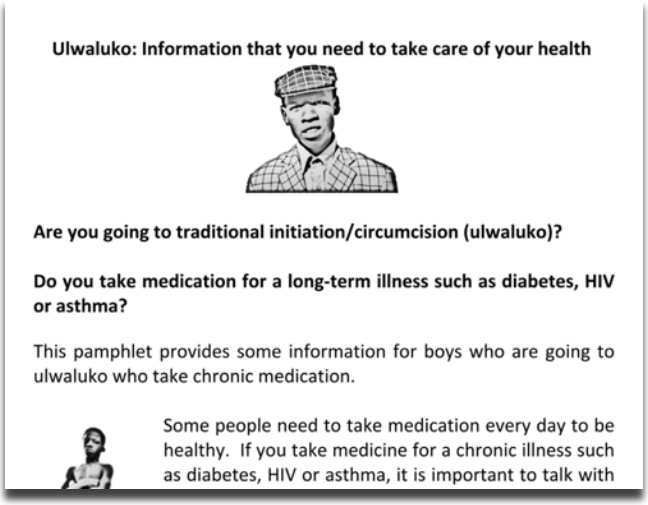


Figure 51: Image of pamphlet on uwaluko and medicine-taking based on Ezobudoda findings, distributed by Eastern Cape non-governmental organisation in schools.

Ezobudoda findings were presented to the following Eastern Cape Based partners. Unless otherwise noted, these were presented as part of the Mzantsi Wakho and HEY BABY research projects:

- 46 schools in East London area. Pamphlet (English version – *shown above*) disseminated by a local NGO partner, Small Projects Foundation.
- ***Eastern Cape AIDS Council***. Barriers to medicines-taking and engagement in biomedical care for adolescent boys and young men living with HIV undertaking traditional initiation/circumcision in the Eastern Cape. February 5, 2019. Presentation to the Eastern Cape AIDS Council. East London, South Africa. (Ezobudoda findings only)
- ***Grey Hospital.*** King Williams Town, Eastern Cape. February 20th 2018. (Ezobudoda findings presented by researchers, PhD candidate prepared materials but was not in attendance).
- ***Secondary School, East London.*** Pre-ulwaluko information event. November 2nd, 2017. (Non-HIV specific Ezobudoda findings presented).
- ***Cecilia Makiwane Hospital.*** Mdantsane, Eastern Cape. September 28th, 2017.
- ***Eastern Cape Department of Health.*** Bisho, Eastern Cape. August 24th, 2017.



Figure 52: Researchers Phakamani Kom and Sinebhongo Mbula discussing circumcision findings with school boys prior to the December circumcision period. 2 November 2017.

National & International Dissemination

The team also endeavored to share findings broadly in domestic and international fora. Findings from this work have been included in a total of 19 presentations, including at the Universities of Cape Town and Oxford, events attended by policy makers and practitioners, with funders, and at conferences (four South African and five international conferences). The candidate also supported six team members to develop abstracts, conduct analysis and deliver presentations at the South African AIDS Conference in Durban in 2017, for five Eastern Cape-based team members for the Public Health Association of South Africa (PHASA) conference in East London in September 2016 and three Eastern Cape-based team members at the PHASA conference in Johannesburg in September 2017. Support and funding for such dissemination was provided from a variety of sources, including the AIDS and Society Research Unit, the Division of Social and Behavioural

Sciences, EHPSA, the SASH programme, the NRF and the University of Cape Town postgraduate funding office among others.

A list of national and international presentations which included findings from this study are included below:

Gittings, L., Price, J., Hodes, R., Cluver, L., Hinton, L., Moshabela, M., Toska, E., Wilcox, M. and Zhou, S. Medical pluralism among children and adolescents in South Africa: methodological findings from mixed methods research. AIDSImpact Conference. London, United Kingdom. July 31st 2019. Oral Presentation.

Gittings, L., Hodes, R. and Colvin, C. 'I used to hate myself when I first knew, but there was a thing that whispered in my ears…': Young HIV-positive masculinities throughout the life course. AIDSImpact Conference. London, United Kingdom. July 30th 2019. Oral Presentation.

Gittings, L., Mbula, S. And Kom., P. "If you are found taking medicine, you will be called names and considered less of a man.": HIV-positive adolescent boys' engagement with HIV treatment and care during and following ulwaluko (traditional initiation/circumcision) in the Eastern Cape Province of South Africa. South African AIDS Conference. Durban, South Africa. June 12, 2019. Oral presentation.

Gittings, L. Devil's medicine or complementary care? Biomedical beliefs and practices amongst traditional health practitioners in South Africa. April 9, 2019. University of Cape Town Centre for Social Science Research lunchtime seminar series. Cape Town, South Africa

Gittings, L. Becoming men: HIV-positive adolescent boys' adherence to antiretroviral therapy in the Eastern Cape Province of South Africa. December 6, 2018. Crossing Boundaries – Global Health Systems Research. The University of Oxford.

Gittings, L. When something else happens…Rich data or inconvenient findings? December 5, 2019. Meeting on health systems in LMIC. The University of Oxford.

Gittings, L. Participatory research with adolescents living with HIV. 9 November 2018. Centre for Evidence-Based Intervention, Department of Social Policy and Intervention, the University of Oxford.

Hodes, R., Hatane, L., Gittings, L., Ronan, A., Malunga, S., Cluver, L., Mark, D., Toska, E., Bloch, K., and Haghighat, R. Adherence misfits: Divergent perspectives on ART-defaulting among healthcare providers and HIV-positive adolescents. 24 July 2018. International AIDS Conference. Amsterdam, the Netherlands. Poster Presentation.

Gittings, L. Devil's medicine or complementary care? Biomedical beliefs and practices amongst traditional health practitioners in South Africa. 23 July 2018. Association for Social Sciences and HIV (ASSHH). Amsterdam, the Netherlands. Oral presentation.

Cluver, L., Toska, E., and Gittings, L. Socio-economic drivers of vulnerability in adolescents and

youth living with HIV in South Africa. Combination prevention for adolescents in Eastern and Southern Africa – evidence from the EHPSA programme. 23 July 2018. International AIDS Conference. Amsterdam, the Netherlands. Satellite presentation.

Gittings, L., Toska, E. Cluver, L. Hodes, R. The case for Social Protection for HIV-Positive Children on Antiretroviral Treatment in Eastern and Southern Africa. 21 July 2018. 90-90-90 Targets Workshop, International AIDS Conference. Amsterdam, the Netherlands. Workshop.

Gittings, L. 'Becoming men: HIV-positive adolescent boys' engagement with traditional and biomedical health services and products'. Centre for Social Science Research Lunchtime Seminar. 22 May, 2018. The University of Cape Town.

Gittings, L., Hodes, R., Toska, E., Cluver, L. Participatory Research with Adolescents Living with HIV. International AIDS Vaccine Initiative #LetsMingle, Wednesday May 9th, Cape Town, South Africa.

Gittings, L., Mbula, S., Kom, P. Becoming Men: HIV-positive adolescent boys' medicines-taking during traditional initiation/circumcision in the Eastern Cape province of South Africa. 13 November 2017. AIDS Impact Conference. Cape Town. Oral poster presentation.

Gittings, L., Mbula, S., Kom, P. Medicines-taking strategies of adolescent boys living with HIV during traditional initiation/circumcision in the Eastern Cape province of South Africa. Gittings, L. 6 September 2017. Public Health Association of South Africa Conference. Johannesburg. Oral presentation.

Gittings, L., Mbula, S., Kom, P. Men, medicines and mystery. Oral Presentation. Men and Masculinities, Policy, Praxis and Practice Conference. 15 June 2017. Orebro, Sweden.
Beyond beanbags and hashtags – adolescent and youth friendly HIV and SRH services beyond the checklist. 7 September 2017. Public Health Association of South Africa. Johannesburg, South Africa. Workshop. (Candidate organized and facilitated this session).

Intersections of HIV and social science research. 19 September, 2016. Public Health Association of South Africa pre-conference workshop. East London, South Africa. (Candidate organized and facilitated this session).

Paediatric Adolescent Africa peer supporter summit for young people living with HIV. July 2016. Dar es Salaam, Tanzania. (Organizer, presenter and facilitator).



Figure 53: Researchers Phakamani Kom and Sinebhongo preparing to deliver an oral poster presentation at the 2017 AIDSImpact Conference. 12 November 2017.

Dissemination for the Mzantsi Wakho study has been a priority to researchers, with the principal investigator team leading the drafting of the South African Adolescent Youth Health Policy as well as providing input into UNAIDS, UNICEF and other international and national policy documents. The study has also conceptualized an 'evidence into action' agenda which includes findings dissemination at the community, clinic, provincial, national levels and through publications and conference presentations.

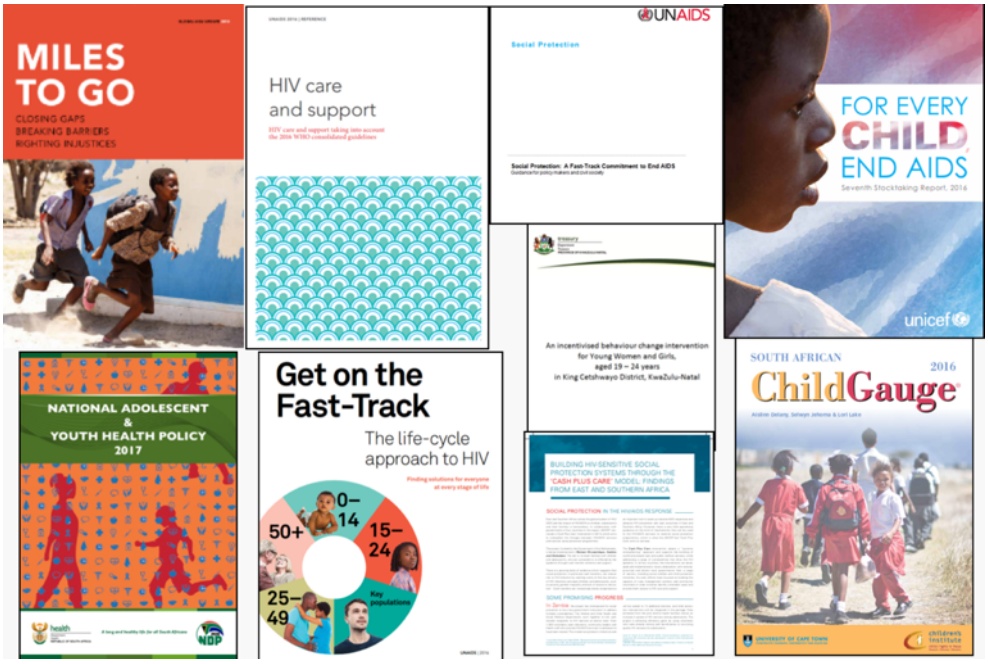


Figure 54: Image of front pages of policy documents including finding from the Mzantsi Wakho study.

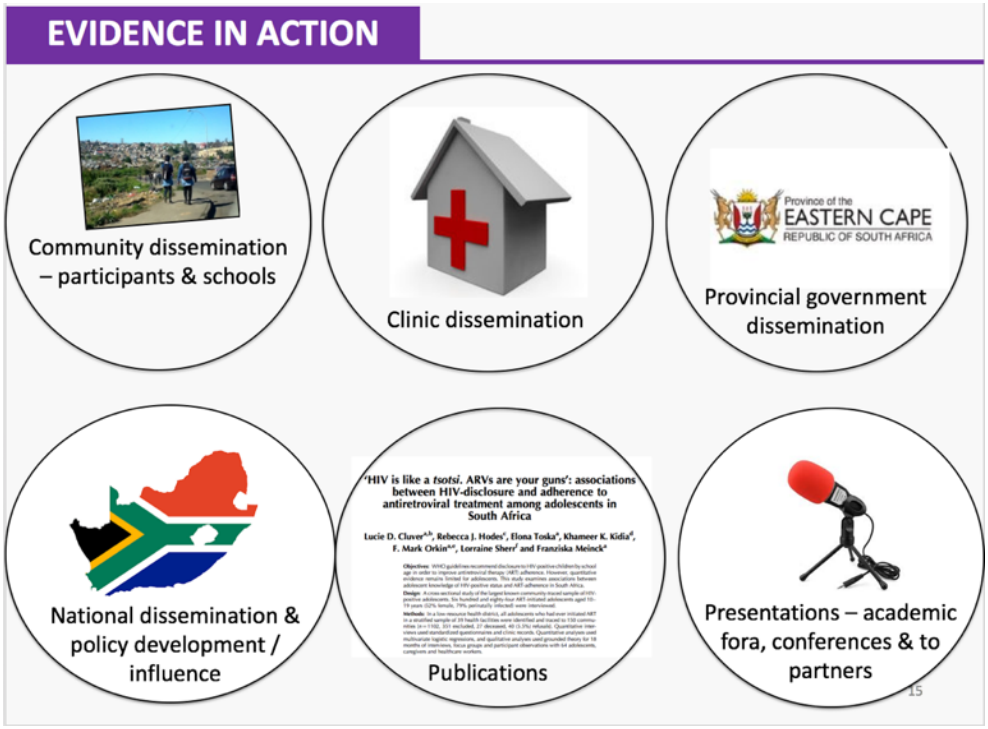


Figure 55: Various forms of evidence dissemination from the Mzantsi Wakho Project.

Appendix 16: UCT HREC Ezobudoda ethics approval & renewals

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6626
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

03 July 2017

HREC REF: 314/2017

A/Prof Chris Colvin
Public Health & Family Medicine
Falmouth Building

Dear A/Prof Colvin

PROJECT TITLE: EZOBUDODA: A QUALITATIVE STUDY OF HIV-POSITIVE ADOLESCENT BOYS' ENGAGEMENT WITH TRADITIONALAND BIOMEDICAL HEALTH SERVICES (Doctorate-candidate-L Gittings)

Thank you for submitting your response to the Faculty of Health Sciences Human Research Ethics Committee received 19 June 2017.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 July 2018.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

The HREC acknowledge that the student, Lesley Gittings will also be involved in this study.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical

Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI),and Declaration of Helsinki (2013) guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Renewal 2019:

UNIVERSITY OF CAPE TOWN
UNIVERSITEIT VAN KAAPSTAD

HUMAN RESEARCH ETHICS COMMITTEE
0 2 SEP 2019
UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938) This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30.09.2020
☐ Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	03/09/2019

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	27 August 2019		
HREC REF Number	314/2017	Current Ethics Approval was granted until	30 September 2019
Protocol title	Ezobudoda: A qualitative study of HIV-positive adolescent boys' engagement with tradtional and biomedical health services.		
Protocol number (if applicable)	N/A		
Are there any sub-studies linked to this study?	☐ Yes ✓ No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Associate Professor Christopher Colvin		
Department / Office Internal Mail Address	Room 3.49, Level 3 Falmouth Building (entrance 5), Division of Social and Behavioral Sciences, School of Pubic Health and Family Medicine, UCT Faculty of Health Sciences		

1.1 Does this protocol receive US Federal funding?	☐ Yes	☐✓ No

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

1.2 If the study receives US Federal Funding, does the annual report require full committee approval? **Note:** Any annual approvals for **Full Committee** review MUST be submitted on the monthly HREC submission dates. (Please send electronic copy for full committee review to hrec-enquiries@uct.ac.za)	☐ Yes	☐ No

If yes in 1.2 please complete section 1.3 below for invoicing purposes	
1.3 Annual Approval for **full committee** review	- R 3450 (inclusive of vat)
For invoicing purposes, please provide:	
Sponsor's name	
Contact person	
Address	
Telephone number	
Email Address	

2. List of documentation for approval

N/A

3. Protocol status (tick ✓)

☐	Open to enrolment
✓	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
✓	Research-related activities are complete, long-term follow-up only
✓	Research-related activities are complete, data analysis only
☐	Main study is complete but sub-study research-related activities are ongoing
☐	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

Number of participants enrolled to date	52
Number of participants enrolled, since last HREC Progress report (continuing review)	N/A
Additional number of participants still required	0

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	0

6. Cumulative summary of participants

Total number of participants who provided consent	52
Number of participants determined to be ineligible (i.e. after screening)	0
Number of participants currently active on the study	0
Number of participants completed study (without events leading to withdrawal)	52
Number of participants withdrawn at participants' request (i.e. changed their mind)	1
Number of participants withdrawn by PI due to toxicity or adverse events	N/A
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	1
Number of participants lost to follow-up. Please comment below on reasons for loss of follow-up.	2
One moved to Cape Town, one untraceable.	
Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	
We have collected all the data needed for the doctorate write up and are now analysing and writing. No active participants.	

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:
Since the last annual report there is nothing new to report, other than that we have been analysing and writing, and have also conducted some dissemination activities. None of these activities identify, or pose a risk to participants. We also received one additional request for support from a participant's family for money to go to initiation (they called the former researcher on the project). In line with the protocol, we did not provide this support. Lesley Gittings will be submitting her doctorate, which is based on this study, this year for examination.

8. Protocol violations and exceptions (tick ✓ all that apply)

✓	No prior violations or exceptions have occurred since the original approval
☐	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved
☐	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

9. Amendments (tick ✓ all that apply)

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

✓	No prior amendments have been made since the original approval
☐	Prior amendments have been reported since the last review and have already been approved
☐	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).
Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.
N/A

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?		
☐ Yes	☐ No	✓ Not applicable
If yes, please describe:		

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. SAHPRA, FDA)?		
☐ Yes	✓ No	☐ Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?		
☐ Yes	✓ No	☐ Not applicable

11.3 If yes, please identify the agency and attach a summary of the findings.					
Agency Name		Report attached	☐ Yes	☐ No	☐ Not applicable
		DSMB report attached	☐ Yes	☐ No	☐ Not applicable

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
☐ Yes	✓ No
If yes, please explain:	

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
☐	Increased
☐	Decreased
✓	Shown no change
If there has been a change, please explain:	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.
N/A

13. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
☐ Yes	✓ No
If yes, please explain and if necessary, attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form FHS013):	

14. Signature

My signature certifies that the above is complete and correct.			
Signature of PI		Date	29 Aug 2019

Renewal 2018:

UNIVERSITY OF CAPE TOWN
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

HUMAN RESEARCH ETHICS COMMITTEE
07 SEP 2018
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938) This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30/09/2019
☐ Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	09/09/2018

Comments to PI from the HREC
09/09/2018 Thank you for the progress report + measures to provide ancillary care + reduce stigma pp ZBurgess

Principal Investigator to complete the following:

1. Protocol information

Date form submitted	24 August, 2018		
HREC REF Number	314/2017	Current Ethics Approval was granted until	30 July, 2018
Protocol title	Ezobudoda: A qualitative study of HIV-positive adolescent boys' engagement with traditional and biomedical health services		
Protocol number (if applicable)	N/A		
Are there any sub-studies linked to this study?	☐ Yes X No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	A/Prof Chris Colvin		
Department / Office Internal Mail Address	Public Health & Family Medicine Falmouth Building		

1.1 Does this protocol receive US Federal funding?	☐ Yes	X No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	☐ Yes	X No

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

1.3 Has sponsorship of this study changed? If yes, please attach a revised summary of the budget.	☐ Yes	X No

2. List of documentation for approval

N/A

3. Protocol status (tick ✓)

☐	Open to enrolment
✓	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
✓	Research-related activities are complete, long-term follow-up only
✓	Research-related activities are complete, data analysis only
☐	Main study is complete but sub-study research-related activities are ongoing
☐	Study is closed → Please submit a Study Closure Form (FHS010)

4. Enrolment

Number of participants enrolled to date	52
Number of participants enrolled, since last HREC Progress report (continuing review)	N/A
Additional number of participants still required	0

5. Refusals

Total number of refusals (participants invited to join the study, but refused to take part)	0

6. Cumulative summary of participants

Total number of participants who provided consent	52
Number of participants determined to be ineligible (i.e. after screening)	0
Number of participants currently active on the study	0
Number of participants completed study (without events leading to withdrawal)	52
Number of participants withdrawn at participants' request (i.e. changed their mind)	1
Number of participants withdrawn by PI due to toxicity or adverse events	N/A
Number of participants withdrawn by PI for other reasons (e.g. pregnancy, poor compliance)	1
Number of participants lost to follow-up (please comment below on reasons for loss of follow-up)	2 (one moved to Cape Town, one untraceable)

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Number of participants no longer taking part for reasons not listed above. Please provide reasons below:	
We have collected all data needed for doctorate write-up and are now analysing and writing. No active participants.	

7. Progress of study

Please provide a brief summary of the research to date including the overall progress and the progress since the last annual report as well as any relevant comments/issues you would like to report to the HREC:

36 adolescent boys and young men living with HIV were interviewed using a life history narrative. Of these, 32 were followed-up with for a semi-structured in depth interview about traditional and biomedical health services engagements. Four were not interviewed again. Of these, one moved out of the study site, and another was untraceable. One refused to participated a second time, and one we chose not to interview as he was engaging but providing information that we believed to be inaccurate.

We visited 22 clinics, and extracted clinic files for 30 of these participants. For the others, we were unable to find files.

In addition, sixteen key informants were interviewed – including traditional and biomedical practitioners and adults with expertise relevant to the project (for example, traditional leaders and people working in traditional initiation/circumcision).

We have completed data collection, and are now analyzing and writing-up.

Despite not facing any serious issues, we found that participants asked for referral support more than we expected, and that we saw within the broader Mzantsi Wakho project. We believe this is due to the methods used, where participants built trust with interviewers and were encouraged to dialogue actively. Some of the referrals that we received were also different in nature – for example, we had disclosures of substance abuse issues and requests for psychosocial support that we did not see in the Mzantsi Wakho study. We believe that, in addition to the methodology, that perhaps the demographic focus on older male participants may be a reason for this. We also had disclosures of food insecurity and requests for support with grant applications. All referrals were followed using the process outline in the protocol. We did not have any cases of participant distress, or disclosures that required mandatory reporting.

In one circumstance we had to engage extra stigma control by sending a less visible project vehicle to meet a participant).

8. Protocol violations and exceptions (tick ✓ all that apply)

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

✓	No prior violations or exceptions have occurred since the original approval
☐	Prior violations or exceptions have been reported since the last review and have already been acknowledged or approved
☐	Unreported minor violations that have occurred since the last review, as well as significant deviations not yet reported, are attached for review

9. Amendments (tick ✓ all that apply)

✓	No prior amendments have been made since the original approval
☐	Prior amendments have been reported since the last review and have already been approved
☐	New protocol changes/ amendments are requested as part of this continuing review (See note below)

Note: If new protocol changes are being requested in this review, please complete an amendment form (FHS006).
Specific changes in the amended protocol and consent/assent forms must be **bolded**, *italicised* or tracked and all changes must include a rationale.

10. Adverse events

10.1 Please provide below or attach a narrative summary of serious adverse events and/ or unanticipated problems since the last progress report. Please indicate changes made to the protocol and informed consent document(s) as a result (if not already reported to the HREC). Please comment on whether causality to any study procedure or intervention could be established.
N/A

10.2 Have participants received appropriate treatment/ follow-up/ referral when indicated (e.g. in the case of abnormal or incidental clinical findings, distress or anxiety)?		
☐ Yes	☐ No	✓ Not applicable
If yes, please describe:		

11. Summary of Monitoring and Audit Activities (tick ✓)

11.1 Was this study monitored or audited by an external agency (e.g. MCC, FDA)?		
☐ Yes	✓ No	☐ Not applicable

11.2 Did a Data and Safety Monitoring Board publish a report?		
☐ Yes	✓ No	☐ Not applicable

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

11.3 If yes, please identify the agency and attach a summary of the findings.					
Agency Name		Report attached	☐ Yes	☐ No	☐ Not applicable
		DSMB report attached	☐ Yes	☐ No	☐ Not applicable

11.4 Has there been any agency, institutional or other inquiry into non-compliance in this study, or any finding of non-compliance concerning a member of the research team?	
☐ Yes	✓ No
If yes, please explain:	

12. Level of risk (tick ✓)

12.1 In light of your experience of this research, please indicate whether the level of risk to participants has:	
☐	Increased
☐	Decreased
✓	Shown no change
If there has been a change, please explain:	

12.2 Please provide a narrative summary of recent relevant literature that may have a bearing on the level of risk.
N/A

13. Statement of conflict of interest

Has there been any change in the conflict of interest status of this protocol since the original approval? (tick ✓)	
☐ Yes	✓ No
If yes, please explain and if necessary attach a revised conflict of interest statement (Section #7 in the New Protocol Application Form (FHS013):	

14. Signature

My signature certifies that the above is comp[illegible]nd correct.			
Signature of PI		Date	4/09/18

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Appendix 17: EC DoH Ezobudoda ethics approval

Proposal Details: EC_201709_013

EASTERN CAPE HEALTH RESEARCH COMMITTEE

APPLICATION DETAILS

TITLE OF RESEARCH PROJECT

Ezobudoda ('manhood things') - A qualitative study of HIV-positive adolescent boys' engagement with traditional and biomedical health services

TYPE OF STUDY

Academic

STATUS OF APPLICATION

Approved

STATUS OF PROJECT

On-Going

Appendix 18: Mzantsi Wakho ethical approvals (UCT Centre for Social Science Research)

CENTRE FOR SOCIAL SCIENCE RESEARCH
University of Cape Town ▪ Private Bag Rondebosch 7701 ▪ South Africa
Tel: 021 650 4656 ▪ Fax: 021 650 4657 ▪ Web: www.cssr.uct.ac.za

TO: Dr Rebecca Hodes
ASRU, CSSR

FROM: Jeremy Seekings
Director, Centre for Social Science Research, UCT

SUBJECT: Research Ethics Review

RESEARCH: Mzantsi Wakho

REFERENCE: CSSR 2017/01

DATE: 6th April 2017

Dear Dr Hodes

The CSSR Research Ethics Committee reviewed in 2013 the original research proposal for Mzantsi Wakho (CSSR 2013/4). On behalf of the Committee I re-approve the revised "Mzantsi Wakho Research Protocol" dated March 2017.

We expect that you will continue to deliberate as necessary over ethical issues that arise in the course of the research, both within the team and with scholars outside of the team as appropriate.

Jeremy Seekings
Professor and Director, Centre for Social Science Research

Appendix 19: Risks and benefits of participation, mitigation procedures

It is important to note the multiple, intersecting power dynamics inherent in this study, especially with adolescent participants. These include age (participants are between the ages of 13 and 22, which is significantly younger than research staff), class, gender, race and language power dynamics between researchers and participants. Additionally, multiple power dynamics and inequalities are inherent with caregiver, biomedical and traditional health worker participants which have the potential to render them more vulnerable. In order to be aware of these inequalities, and avoid harm they may cause, a sensitive, participatory research design and reflexivity throughout all phases of data collection, analysis and presentation are crucial. Research assistants will also be trained on navigating unequal power relations and awareness of roles and social positions (Hodes et al. 2014).

Potential risks and their mitigation measures are summarized below:

Risk: Participant distress
Mitigation measures:

- Interviews with adolescent male minors will be conducted by young male research assistants with in-depth understanding of the potential complexities and sensitivities of adolescents living with HIV in the Eastern Cape.
- Research assistants will be trained in working with vulnerable children, and to identify early signs of participant distress or upset in an interview. In cases where a participant becomes distressed, the person conducting the interview will make themselves available to talk about any issues they have and, where necessary, make referrals (Hodes et al., 2014).
- Referrals to counselling and support services are available to participants who become distressed or who disclose psychological challenges or trauma.
- Interviews will ask each participant at the end if they have felt comfortable and if there is anything further they would like to speak about.
- Each participant is provided with an information sheet with the investigator's contact number if they have any questions or issues post-interview.

- It is an obligation of the research team to support any study participant who may become distressed during or following participation or who reports behaviours requiring follow-up counselling (Hodes et al., 2014).
- If an interviewer has a specific concern, or in cases when participant's case needs further discussion, they will contact the lead researcher telephonically (Hodes et al., 2014).
- *These are mapped out in the consent, mandatory reporting and referral protocol of this document.*

Risk: Stigmatization of participants due to their HIV positive status.
Mitigation measures:

- Due to the highly stigmatized nature of HIV, the fact that the study focuses on HIV and sexual health will not be disclosed to participants. The study will be broadly framed as a study about young masculinities and health, including engagement with biomedical and

traditional health services.

- Where deemed necessary to protect the HIV-positive status of participants, interviews with HIV-status unknown household and neighbourhood members may be conducted so as not to single out one participant.
- Participant HIV status is never discussed in plain language within the research project, rather 'animal types' (e.g. Giraffe, Elephant, Bear) have been allocated to participants with different HIV statuses or knowledge of their status. For example, an HIV-positive adolescent who knows their status will be referred to as 'a Giraffe' rather than by their HIV status. These codes are unknown to participants or others outside of the project, and are never used in the presence of a participant.
- *These measures are described in-depth in the HIV non-disclosure section of this protocol.*

Risk: Confidentiality breaches.

Mitigation measures:

- Participant identifier numbers from participants recruited from the quantitative cohort will be used, alongside pseudonyms for all participants.
- All identifiers that can be used to recognize the participant will be removed from transcripts and during analysis and writing. Participant details will not be attached to the data in any way that they are identifiable.
- A master list which will be password protected and accessible only the lead researcher containing identifiers and linking them to pseudonyms and participant numbers (when they exist) will be kept.
- Consent forms will be kept locked in a filing cabinet and destroyed 3 years after the completion of the study. Electronic information (e.g. audio recordings, typed notes) will be stored in a password protected folder and destroyed at the end of the study.

1) All researchers involved in data collection will be trained on confidentiality, and required to sign the confidentiality forms before beginning the research.

2) Participants' contact details will also be password protected, and those who leave 'please call me' messages will only be contacted by the research team (Hodes et al., 2014).

3) Participants will choose the time and location of engagement with the researchers, given that it meets the project's rigorous safety standards (Hodes et al., 2014).

4) Confidentiality is bounded by the legal requirement to report cases of maltreatment, neglect, physical abuse causing harm and sexual abuse, and reportable diseases. Participants and their guardians will be informed (verbally and in the information sheet) that what they say in the interview will be confidential, with the exception of the mandatory legal requirement to report such cases to the appropriate authorities. For focus groups and small group interviews, despite signing confidentiality forms, participants will be informed that confidentiality cannot be guaranteed as other focus group / small group interview members may disclose information.

5) *These are mapped out in-depth in the confidentiality, data management, and consent sections of this protocol.*

Benefits to participants (direct and indirect):

- The opportunity to interact with adults in a confidential setting and to access information and referrals where necessary (Hodes et al. 2014; Cluver et al. 2015).
- Participation may be therapeutic for participants, as they have the chance to reflect upon their experiences and express their thoughts and feelings in a safer, accountable space, including using novel methods such as drawing or life history narratives.
- Participating organizations, health workers and facilities will receive results and feedback which might positively impact service provision (Hodes et al. 2014).
- Participants can contribute to scientific knowledge that may be used to inform policy and programming to support the well-being of other young people living with HIV.
- The creation of knowledge about the under-researched and crucial public health issues of HIV-positive adolescent masculinities and medical pluralism. There is an ethical imperative to document/record and disseminate findings in a way that accurately and confidentially represents participants. The PhD student endeavour to do so with biomedical and traditional health practitioners, front-line service providers, policy makers and appropriate academic audiences.

Risks to researchers

Every effort will be made to minimize risks to researchers, fieldwork staff and research assistants, including:

- For this study, safety considerations are guided by the Mzantsi Wakho (Mzantsi Wakho, 2016) safety protocol which has been extensively reviewed and considered by Mzantsi Wakho principal investigators, co-investigators and those working at the study sites. In line with the protocol, all staff are trained in safety measures (Hodes et al., 2014) and sign the Mzantsi Wakho safety protocol. All staff are required to read and sign the safety protocol before commencing work.
- Staff (including myself, research assistants and drivers) will not conduct interviews in any situation or location where they feel uncomfortable or safe. In addition, the team frequently monitors safety situations in the locations in which we work. During times of taxi wars, political instability or gang violence, they will not enter into, or conduct research in the site of the instability for research purposes. Additionally, the first Saturday of every month has been deemed additionally risky by the research team, and as a result, research is not conducted on this day.
- Staff will travel in groups of at least two when there is a concern about safety. Additionally, a 'community guide' who knows about the risks of an area will be hired when necessary to support staff safety (Hodes *et al.*, 2014; Young Carers / Mzantsi Wakho, 2016).
- All research vehicles are serviced regularly and properly equipped (Mzantsi Wakho 2016, Hodes et al., 2014)
- Vicarious trauma is also common amongst research assistants and researchers working with adolescents living with HIV. In line with the Mzantsi Wakho referral and safety protocols, which will be followed for this study, team members can access psychosocial support services to help them cope with the vicarious trauma or other psychosocial challenges they may encounter. I will access these services if needed.

- I will conduct frequent check-ins throughout the course of the study, and at its completion with research assistants and provide opportunities to debrief about their work, and its impact on their wellbeing. I will also encourage them to access psychosocial support services provided by the Mzantsi Wakho project if they have are experiencing vicarious trauma or work-related psychosocial challenges.