PROJECT TITLE:

A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE

CLEMENT NHUNZVI

NHNCLE001

SUBMITTED TO THE UNIVERSITY OF CAPE TOWN

in fulfilment of the requirements for the degree of

Doctor of Philosophy in Occupational Therapy

Department of Health and Rehabilitation Sciences

Faculty of Health Sciences

UNIVERSITY OF CAPE TOWN

SUPERVISOR: PROFESSOR ROSHAN GALVAAN

CO-SUPERVISORS: DR LISA LANGHAUG AND PROF RICHARD HARDING

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

Plagiarism Declaration

I, *Clement Nhunzvi*, hereby declare that the work on which this project is based is my original work (except where acknowledgements indicate otherwise) and I have used the APA 7th edition system of referencing. I declare that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

Signature: Signed by candidate

Date: 18/10/2021

Acknowledgements

Firstly, I would like to thank my Lord, God Almighty. Through His grace and mercy, I am included among those who found the strength to pull through the PhD journey.

My wife: Thank you, Pauline, for your love and support and believing that I am an achiever. You are a source of encouragement and a pillar of strength.

My daughters: Thank you Darlene Viola and Daniella Nyasha, the hugs, kisses and merely calling me daddy were the fuel I needed for this journey.

My father, the late Albert Nhunzvi, my mother, Viola Nhunzvi, and my siblings Francis, Dorothy, Lawrence, and Jonathan: Your personal life achievements and being there for one another has always inspired me to want to do exceedingly great things. Your presence in my life motivates me from within. Thank you.

The young adults dually afflicted with SUD and HIV. A special thanks goes to you, you trusted me with your lives, you have anchored this study. Thank you for your time and the experiences you shared in your social inclusion stories, without which this study would not have been possible. My key informants, thank you!

My supervisors: Prof Roshan Galvaan, Dr Lisa Langhaug and Prof Richard Harding, you are more than supervisors. Your time, guidance, mentorship and analytical minds kept this work alive. You believed I was capable and you supported me. You made me realise that you genuinely care for the professional growth of others. Thank you!

My research assistants: Pascal Ndowa, Simba Chigwedere, Clarity Chiadzwa and Davison Samanyada. You have been a pleasure to work with, you demystified data collection. Thank you.

Prof Dixon Chibanda, Dr Walter Mangezi and Prof Midion Chidzonga, thank you for the opportunity, support, and corridor chats checking on my progress. You have been great role models and mentors. Be blessed!

AMARI family, thank you for all the support, encouragement and engagement.

This work was supported through the DELTAS Africa Initiative [DEL-15-01]. The DELTAS Africa Initiative is an independent funding scheme of the African Academy of Sciences (AAS)'s Alliance for Accelerating Excellence in Science in Africa (AESA) and supported by the New Partnership for Africa's Development Planning and Coordinating Agency (NEPAD Agency) with funding from the Wellcome Trust [DEL-15-01] and the UK government. The views expressed in this publication are those of the author(s) and not necessarily those of AAS, NEPAD Agency, Wellcome Trust or the UK government.

Abstract

Background: The vision of the 2030 Agenda for Sustainable Development (2030 Agenda) for a healthy and inclusive society is under threat if adverse social determinants of health are not curtailed. In Zimbabwe, Vision 2030 is under threat from an ever-complicating problem of substance abuse and HIV among young adults, coupled with an evident lack of understanding and application of socially inclusive approaches. Social inclusion is a growing research, policy and practice driver, requiring exploration to inform global health and sustainable development. However, social inclusion as a concept remains unclear and underutilised when considering the plight of marginalised groups in low resource settings like Zimbabwe. It is against this background that this study seeks to explore and understand how dually afflicted young adults with substance use disorders and HIV in Zimbabwe experience and negotiate their social inclusion.

Methods: The researcher uses a qualitative instrumental case study design to describe and explain the ***case of an occupational perspective of social inclusion,*** among dually afflicted young adults in Zimbabwe. This case study involves the collection of multiple sources of evidence, applying both qualitative and quantitative techniques, to develop a thorough understanding of the case. The researcher triangulates four data sources: i) a narrative inquiry with five dually afflicted young adults; ii) in-depth interviews with five key informants; iii) analysis of seven legislative documents and iv) an exploratory cross-sectional survey of social inclusion and associated factors (n=105).

The case study analysis involves a multi-level approach: 1) The first level of analysis involves: narrative analysis of the five young adults' stories, descriptive analysis of key informant interviews and document analysis and descriptive statistical analysis of the cross-sectional survey data. 2) The second level is a thematic case analysis drawing from all four data sources. Further, analysis was applied within and cross-case. 3) The last level theorises around conceptual occupational constructs.

Findings: Five hybrid narratives (Billy, P Jay, Nicky, Mai Ngah, and Mudzvurwa) are presented as they emerged from a rigorous and iterative narrative analysis. The hybrid narrative illustrates how being agentic and occupational choices were central to the young adults` experience and negotiation of social inclusion. The Case is described through one overarching Case theme, "Navigating an already troubled life: Striving for belonging and well-being". This he further explained through three categories: 1) Dealing with a context of mixed realities; 2)

Trying to adjust to new challenges and 3) Life on the margins. These findings posit the complex, dynamic and interconnected processes shaping the everyday social inclusion realities of the dually afflicted young adults in Zimbabwe, heavily influenced by dominant discourses.

Conclusion: The study offers a description and explanation of how dually afflicted young adults experience and negotiate social inclusion in context. The role of agency is reaffirmed and a more critical view of occupational choice in understanding social inclusion proposed. *Activist occupational choice* is an emergent concept from this study, which is proposed to be a category of occupational choices, largely defying the taken-for-granted norms of engagement and aimed at breaking away from oppressive systems and problematic situations.

It is therefore proposed that practitioners working with dually afflicted young adults and other marginalised groups should recognise the multiplicity and diversity with which agency manifests. Practitioners should promote the alternatives for social inclusion. From these, characteristics of resultant occupations like indigeneity, collectivism and resistance arise.

Table of Contents

Plagiarism Declaration 2

Acknowledgements 3

Abstract 4

List of Tables 11

List of Figures 11

Definition of terms 12

Abbreviations 15

Chapter 1. Introduction 16

1.1. Background 16

1.2. The challenge of substance abuse and HIV in Zimbabwe 18

1.3. Social Inclusion for dually afflicted young adults 19

1.4. Occupational therapy and people with SUD and living with HIV in Zimbabwe: Researcher's experiences and reflections 20

1.4.1. Genesis of the study: My journey 21

1.5. Problem Statement 23

1.6. Study Purpose 24

1.7. Research question 25

1.8. Aim 25

1.9. Objectives 25

1.10. Conclusion 25

Chapter 2: A literature review 27

2.1. Introduction 27

2.2. Understanding the value of social inclusion and its historical origins 27

2.3. Defining and conceptualising social inclusion: Multiple perspectives 30

2.3.1. A critical occupational perspective of social inclusion 36

2.3.1.1. Relevance of occupational choice in understanding social inclusion 39

2.4. Factors influencing social inclusion and social exclusion 43

2.4.1 Low income 45

2.4.2. Education 46

2.4.3. Unemployment 48

2.4.4. Ill health 50

2.4.5. Agency/structure as a factor to consider in social inclusion 52

2.5. Conclusion 55

Chapter 3. A Critical Theoretical Perspective 57
3.1. Introduction 57
3.2. A critical and decolonial foundation 57
3.2.1 Critical Social Theory 57
3.2.2. Decolonial Theory 60
3.2.2.1. Understanding coloniality 61
3.3. Capability Approach (CA) 65
3.4. The synthesis of theories 68
3.5. Conclusion 68
Chapter 4. Research design and method 70
4.1. Introduction 70
4.2. Philosophical standpoint 70
4.3. Qualitative research 70
4.3.1. Qualitative Case Study Design 71
4.4. Data generation and collection 75
4.4.1 Data generation with DAYA 76
4.4.1.1 Study population of DAYA recruitment sites 76
4.4.1.2. Selection of participants – DAYA in Narrative inquiry 77
4.4.1.3. Inclusion criteria for DAYA 77
4.4.1.4. Exclusion criteria for DAYA 77
4.4.1.5. Participants sample size DAYA in narrative inquiry data source 78
4.4.1.6. Recruitment of DAYA in narrative inquiry 79
4.4.2.1. Sample size calculation and sampling and for DAYA social inclusion survey 81
4.4.2.2. Social inclusion survey recruitment 81
4.4.3.1. Sample selection for key informants 83
4.4.3.2. Inclusion criteria for key informants 83
4.5. Methods of data generation and collection 85
4.5.1 Narrative inquiry with DAYA 85
4.5.1.1 Narrative interviews with DAYA 85
4.5.2. In-depth interviews with key informants 88
4.5.3. Document Analysis 89
4.3.4 Cross-sectional survey of social inclusion 90
4.6. Data Management and Analysis 92
4.6.1 Qualitative Data Management 92
4.6.2. Narrative Analysis 92

4.6.2.1. The production of hybrid narratives 93
4.6.3. Data analysis of the cross-sectional survey data 96
4.6.4. Analysing documents 96
4.7. Case Study data analysis 97
4.8. The scientific rigour of the study 99
4.8.1. Credibility 100
4.8.2. Transferability 101
4.8.3. Dependability and Confirmability 102
4.8.4. Validation of narratives 103
4.9. Ethical considerations 104
4.9.1. Informed consent 104
4.9.2. Confidentiality 105
4.9.3. Potential for harm and benefits 105
4.10. Conclusion 106
Chapter 5. The hybrid narratives 107
5.1. Introduction 107
5.2. Hybrid Narratives 107
5.2.1. Introducing Billy: Of uncontrolled freedom and swayed choices - a life of blame 108
5.2.2. Introducing P Jay: Inclusion by exclusion – the story of my life 116
5.2.3. Introducing Nicky: Abused, socially excluded and numb. 125
5.2.4. Introducing Mai Ngah: Doing what counts – my survival strategy 133
5.2.5. Introducing Mudzvurwa: A regrettable life: reforming and seeking acceptance. 139
5.3. Conclusion 144
Chapter 6: Navigating an already troubled life: Striving for belonging and well-being. 145
6.1. Introduction 145
6.2. The Case theme 145
6.3. Dealing with a context of mixed realities 148
6.4. Trying to adjust to new challenges 158
6.4.1. Experiencing the health challenges and additional stigmatised identities 160
6.4.2. Rethinking and redefining my ways 167
6.5. Life on the margins 175
6.5.1. Acceptance at all costs 177
6.5.2. Culture of Silence 182
6.5.3. Opportunities' box is dry 184

6.5.4. Experiencing mainstream sanctioned life 190
6.6. Conclusion 196
Chapter 7. Critical discussion of the Case from an occupational perspective 197
7.1. Introduction 197
7.2. Centring agency in seeking social inclusion 198
7.3. The challenge of coloniality, modernity and neo-liberalism in problematic situations 205
7.4. Activist occupational choices 210
7.5. Conclusion. 216
Chapter 8. Recommendations and Conclusion 217
8.1. Introduction 217
8.2. Thesis summary 217
8.3. Strengths and limitations of the study 218
8.3.1. Strengths 218
8.3.2. Limitations 219
8.4. Study recommendations 220
8.4.1. Practice with DAYA 220
8.4.2. Recommendations for research 221
8.4.3. Recommendations for policy 222
8.4.4. Recommendations for training 222
Appendices 223
Appendix A - Information and Consent Sheet -DAYA Narratives. 223
Appendix B - Information and Consent Sheet -DAYA Narratives. Shona 228
Appendix C - Information and Consent Sheet -DAYA Survey. 233
Appendix D - Information and Consent Sheet -DAYA Survey. Shona 238
Appendix E - Information and Consent Sheet -Key Informant 243
Appendix F – Information and Consent Sheet -Key Informant. Shona 248
Appendix G - Interview Questions Guide - DAYA. English 253
Appendix H - Interview Questions Guide - DAYA. Shona 254
Appendix I – Social inclusion Survey Questionnaire 256
Appendix K - Interview Questions Guide Key Informants 257
Appendix L - Interview Questions Guide Key Informants. Shona 258
Appendix M – Study Advert - English 260
Appendix N – Study Advert _ Shona 261
Appendix O - International HIV Dementia Scale (IHDS) 262

Appendix P - International HIV Dementia Scale (IHDS) - Shona 264
Appendix Q – UCT HREC Ethics Approval 266
Appendix R – Harare Central Hospital Ethics Approval 267
Appendix S – JREC Ethics Approval 268
Appendix T – MRCZ Ethics Approval 269
Appendix U1 – Social Inclusion SOP MHOT 270
Appendix U2 - Social Inclusion SOP OI Clinics 284
Appendix V - Social Inclusion Survey Findings 301
References 308

List of Tables

Table 4.1: Common Case Study Definitions.....73
Table 4.2. Stake's Case Study Types 74
Table 4.3. Sociodemographic characteristics of participants in narrative inquiry.....79
Table 4.4 Sociodemographic profile of key informants 85
Table 4.5 Documents included for document analysis 90
Table 6.1. Overall Social Inclusion feeling comparing the two recruitment arms 176
Table 6.2. Feeling left out and ability to change situation 177
Table 6.3. *Social Inclusion domains by participant recruitment arm* 185
Table 6.4. Overall social inclusion against socioeconomic status (n=105) 194

Table 4.1: Common Case Study Definitions.....73
Table 4.2. Stake's Case Study Types 74
Table 4.3. Sociodemographic characteristics of participants in narrative inquiry 79
Table 4.4 Sociodemographic profile of key informants 85
Table 4.5 Documents included for document analysis 90
Table 6.1 Overall Social Inclusion feeling comparing the two recruitment arms 176

List of Figures

Figure 4.1. Case study data sources 76
Figure 4.2. Flow diagram of survey recruitment through Mental Health Units.....82
Figure 4.3. Flow diagram of survey recruitment through OI clinics 83
Figure 4.4. Case study analysis 98
Figure 2-8 Figure 6-4. Perceived HIV Stigma (n=105).....180

Definition of terms

Activist Occupational Choices: a category of occupational choices, largely defying the taken-for-granted norms of engagement and aimed at breaking away from oppressive systems and problematic situations.

Agency: The power or capacity to act independently and make free choices based on one's values and a belief that one can control one's own life (Sen, 1992).

Diagnosis of SUD and HIV: A diagnosis of SUD and HIV/AIDS is one where the SUD diagnosis is made by a qualified health practitioner using the DSM-V criteria and for HIV/AIDS, a confirmed result by laboratory tests is required.

Discourse may also refer to power dynamics in the social field associated with strategies of domination and those of resistance (Diamond et al., 1990).

Discourse: Refers to how knowledge, subjects, objects, behaviour and events are depicted and communicated. Drawing on Faucault, Weedon defines discourse as "…*ways of constituting knowledge, together with the social practices, forms of subjectivity and power relations which inhere in such knowledges and relations between them. Discourses are more than ways of thinking and producing meaning. They constitute the 'nature' of the body, unconscious and conscious mind, and emotional life of the subjects they seek to govern* (Weedon, 1989) p. 108).

Dually Afflicted Young Adult: Young adult with a comorbid diagnosis of a substance use disorder and HIV.

Hybrid narrative: an engaging genre with dual purpose of integrating story and informational text, also serving to gain the reader's attention and inspire curiosity be creative means (Donovan & Smolkin, 2002).

It is, "the extent to which people are able to exercise their rights and participate, by choice in ordinary activities of citizens in the society in which they reside" (Mental Health Commission, 2009.6).

Mental Health: A state of well-being in which individuals can realise their maximum possible potential, can cope with normal life stressors, work fruitfully and are able to make a productive contribution in his or her community (World Health Organization, 2010 p. 1).

Occupation: Everyday actions of people to engage themselves and participate in their environments, or sets of activities performed consistently and regularly, bringing forth structure of time and energy use. Occupations are given value and meaning by individuals and by their culture (Canadian Association of Occupational Therapists, 2002; Chang, 2008).

Occupational Choice: A process and/or an outcome involving the application of choice to participation in everyday activities, where such choices are co-constructed through the person's transactional relationships with their contexts (Galvaan, 2012).

Occupational Injustice: A situation or a process where the individual, groups or communities are denied resources and opportunities in a physical, socioeconomic, cultural and even political sense, to engage and participate in freely chosen healthy, and meaningful occupations (Townsend & Wilcock, 2004).

Occupational Justice: The full enjoyment of occupational rights implying equity and fairness for individuals, groups and communities regarding their engagement in diverse, healthy and meaningful occupations (Durocher et al., 2013; Nilsson & Townsend, 2010)

Occupational Participation: Refers to the performance and subjective experience of occupations that are part of one's sociocultural context and that are desired and /or necessary to one's wellbeing and as vehicles for involvement with one's environment (Kielhofner, 2009; Vessby & Kjellberg, 2010).

Occupational Perspective: "Describes a standpoint whereby the significance of phenomena is described in relation to relational human action as described in the discipline of occupational science. It appreciates that human action is shaped through habit, context and creativity" (Galvaan, 2010, p. 8). An occupational perspective considers issues by applying an occupation-focused philosophical lens and theory (Parnell & Wilding, 2010).

Personal Recovery: Refers to the nonlinear process of changing one's attitudes, values, feelings, goals and skills to live a satisfying life within the limitations provided for by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic limitations of the mental illness (Anthony, 1993).

Social Exclusion: This term describes a multi-dimensional process or state of progressive social rupture, marginalising individuals, groups and communities from social relations and

institutions thereby preventing them from full and active participation in valued activities in the society where they live (Huxley et al., 2016; Rawal, 2008).

Social Inclusion: A multi-dimensional process or state where prevailing conditions enable full and active participation of every member of the society in all aspects of life, including civic, social, economic and political activities, as well as participation in decision-making processes, irrespective of personal characteristic differences (Cobigo & Stuart, 2010).

Stigma: Goffman (1963) defines stigma as "an attribute that is deeply discrediting" and aimed at reducing someone with a perceived negative attribute "from a whole and usual person to a tainted, discounted one" (p. 3).

Substance Use Disorders (SUD): Mental and or behavioural disorders which occur when the recurrent use of alcohol and/or drugs causes clinically and functionally significant impairment, such as health problems, disability and failure to meet major responsibilities at work, school, or home (World Health Organization, 2010). According to the DSM-V, a working diagnosis of SUD is demonstrated by impaired control, social impairment, risky use and pharmacological criteria (American Psychiatric Association, 2013).

Well-being: Well-being involves being happy, feeling satisfied and developing as a person, being fulfilled and making a contribution to the community (Marks & Shah, 2004).

Young Adult: A person aged between 18 – 40 years (Erikson, 1950 accessed from www.dean.usma.edu/ on 23/04/16).

Abbreviations

AIDS: Acquired Immune Deficiency Syndrome

CA: Capability Approach

DAYA: Dually Afflicted Young Adults

HIV: Human Immuno-Deficiency Virus

MoHCC: Ministry of Health and Child Care

MoHTESTD: Ministry of Higher and Tertiary Education, Science and Technology Development

NAC: National AIDS Council

PWDs: Persons with Disabilities

SCOPE: Social and Community Opportunities Profile

STI: Sexually Transmitted Infection

SUD: Substance Use Disorder

WHO: World Health Organization

ZJC: Zimbabwe Junior Certificate

Chapter 1 . Introduction

Chapter one describes the need for this study, emphasising the value of an occupational perspective of social inclusion in the context of substance abuse and HIV among young adults in Zimbabwe. The researcher pays particular attention to the unmet broader health and social care needs and issues of social inclusion and exclusion facing young adults experiencing a dual affliction (referring to the experiences of suffering beyond the medical comorbid diagnosis) of substance abuse disorder(s) and HIV in Zimbabwe. This background offers insight into the rationale for this inquiry and concludes by describing the purpose, research questions, aims and objectives of the study.

1.1. Background

Living with mental illnesses, particularly depression and substance use disorders (SUD) and HIV/AIDS as comorbid conditions is a growing global public health challenge, with even greater challenges in Sub-Saharan Africa (Browne & Wechsberg, 2010; Duffy et al., 2017; Lancaster et al., 2018; Sandfort et al., 2017). The dual affliction of mental illness and HIV does not only mean medical conditions, but has very significant psychosocial, economic and political dimensions (Olley et al., 2016). There is a complex bi-directional relationship between HIV and mental illness which results in persons with severe mental disorders including substance use disorders, being at greater risk of HIV infection, typically being marginalised from education, employment, and conventional prevention and treatment methods (Sin & DiMatteo, 2013).

In Sub-Saharan Africa, those with dual afflictions and their caregivers encounter a broad range of challenges in practical, economic, social, and treatment domains (World Health, 2008). In acknowledging these challenges, the United Nations has proposed more critical and human rights-based approaches to help improve the health, well-being, quality of life and social inclusion of those affected (UNAIDS, 2018). In this quest, the sociocultural and political responses to discrimination, stigmatisation and social marginalisation and exclusion are of paramount importance (Arrey et al., 2017; Dray-Spira et al., 2003; Marsicano et al., 2014; Mavhu et al., 2013; Whetten et al., 2005), as well as the expertise derived from experiential knowledge of those living with the conditions. Substance use disorders and HIV are both stigmatised conditions. Discrimination of dually afflicted young adults usually leads to limited and unequal participation in society (Badahdah, 2016). In most cases, the stigma is associated with poorer health outcomes, health disparities and poor quality of life (Corrigan et al., 2014; Hatzenbuehler et al., 2013). Those who are affected with substance use disorders and HIV are

often marginalised, putting them at risk of life imbalance, marginalisation, alienation and deprivation (Nilsson & Townsend, 2010; Townsend & Wilcock, 2004). Persons experiencing these problems often report challenges, even in accessing medical care (Pickett et al., 2015). Further to this, the lack of comprehensive rehabilitation services, sound community-based mental health practice and the inability of the health system in Zimbabwe to respond to the service users' broader health and social needs (Duffy et al., 2017) presents key challenges to sustainable management of SUD and HIV. These challenges coupled with lack of sound, or under-resourced, public health policies, limit participation in society (Evans-Lacko et al., 2014a; Evans-Lacko et al., 2014b). Despite increasing global research evidence mainly about HIV, there remains a paucity of empirical evidence to direct understanding and management of these problems. From an occupational perspective, it is also not known how best to respond, when resources and opportunities are denied for dually afflicted young adults in low resource settings like Zimbabwe.

Parts of the efforts to mitigate the impact of these conditions are covered in the 2030 Agenda for Sustainable Development (2030 Agenda) which aims "to realize the human rights of all" and is underpinned by a vision for a healthy and inclusive society. This aim entails applying inclusive strategies for meeting all Sustainable Development Goals (SDGs), attending to social determinants of health and well-being, including those driving the substance abuse and HIV global crisis (The United Nations, 2015). However, the social determinants which continue to drive and complicate the substance abuse and HIV crisis in most developing countries, involving poverty, lack of education, unemployment, conflict, political and economic crises and adverse life experiences, are yet to receive the attention they deserve (Lund et al., 2018; Silva et al., 2016; Skeen et al., 2010). The situation is further aggravated by the lack of socially inclusive approaches, which draw on human rights principles (Bekker et al., 2018; Mahomed, 2020; Patel, 2015; Puras & Gooding, 2019; World Health Organization, 2016).

Despite some strides having been made in the management of mental disorders and HIV in Zimbabwe, there remain gaps regarding the social inclusion of those with a dual affliction of HIV and substance use disorders (The study refers to the dually afflicted young adults in this study as DAYA). Moreover, despite marked gains in the fight against HIV, little attention has been paid to the non-medical outcomes associated with SUD and HIV. The emphasis on clinical outcomes may result in service gaps which do not fully support afflicted young adults to live fully productive, inclusive and satisfying lives. Occupation, as conceptualised in occupational therapy and science, is a key component in the quest for social transformation and

empowerment of people who are part of marginalised groups (Hocking & Townsend, 2015). An occupational perspective demands that attention be directed beyond the biomedical gains in the fields of SUD and HIV, and further focus on the person-oriented outcomes like the equitable participation in life, human rights, occupational justice and social inclusion.

1.2. The challenge of substance abuse and HIV in Zimbabwe

Zimbabwe has a high HIV prevalence (12.8%) (UNAIDS, 2019b). HIV in Zimbabwe is mainly driven by poverty and risky sexual practices, chief among them, unprotected heterosexual sex (Gregson, 2006; Mahomva, 2006; Malunguza et al., 2018). A growing mental health problem is adding to the complexity of the epidemic in some population groups, including young people with substance use problems (Madziro-Ruwizhu et al., 2019; C. Rwafa et al., 2019). Gender and power imbalances have also been associated with a disproportionately high prevalence among women, especially adolescent girls, and young women (UNAIDS, 2019b). Despite all this, it is encouraging to note that, of late, Zimbabwe, has reported gains in the management of the HIV pandemic, with the latest adult HIV prevalence now standing at 12.8% (UNAIDS, 2019b), a drop from 25% in 2000. This is mainly attributed to advances in and access to antiretroviral treatments and selected behaviour change.

Substance abuse and depression are known major mental health conditions associated with HIV in Zimbabwe (Duffy et al., 2017), where an institutional prevalence in 2014 of SUD in Harare was as high as 40% (Rwafa, 2014). Given the already high HIV prevalence and restricted opportunities among the economically active age groups in Zimbabwe, there is need for special attention in training, research and practice to address this experience of comorbidity, and even more, the suffering experienced. Chibanda and colleagues report a high prevalence of HIV among mental health service users in Zimbabwe (Chibanda et al., 2011). In their Problem-Solving Therapy trial for common mental disorders, 52% of those who participated in their study treatment sites did so for HIV-related reasons. Mental illness is associated with HIV in multiple and complex ways including as a risk factor for HIV infection, comorbidity with HIV infection, consequence of HIV/AIDS and in influencing the progression to AIDS (Arseniou et al., 2014; Zahari et al., 2010). Risky sexual behaviours are prevalent among persons who abuse substances. There is also poor medication compliance among people living with HIV who are depressed (Duffy et al., 2017).

The reported rise in substance abuse among young adults living with HIV in Zimbabwe is associated with poor coping skills and complicated by a lack of available rehabilitation services

for this group (MoHCC, 2018). Also, despite substance abuse being a factor in the HIV pandemic, it has remained under-explored in Zimbabwe, especially from an occupational perspective. The presence of a well-coordinated HIV antiretroviral therapy programme in Zimbabwe and the progress towards the 90-90-90 target, shows that many people are living longer lives with HIV (UNAIDS, 2019b). With this progress, it has become more reasonable to emphasise productive positive living, empowerment, improved quality of life, occupational justice, and social inclusion as preferred outcomes of interventions. The gains should translate into comprehensive socially inclusive and productive lives. Nevertheless, stigma and poverty continue to negatively impact the lives of those affected. Stigma against HIV has remained high (Zimbabwe National Network of, 2014), while the presence of another stigmatised condition in the form of SUD, leaves many of those afflicted typically being blamed for their conditions.

1.3. Social Inclusion for dually afflicted young adults

Social inclusion has become a prominent concept in global health outcomes (Marmot, 2018; Mayston et al., 2012; van Hees et al., 2019), though it remains unexplored in most low-income contexts especially among dually afflicted young adults with highly stigmatised conditions in Zimbabwe. Despite a considerable amount of literature published on social inclusion in developed countries, the dearth of good quality evidence in low and middle-income countries, especially on equity and the inclusion of specific vulnerable groups, has been noted (van Hees et al., 2019). With the rise in vulnerable and disadvantaged groups, such as those dually afflicted with substance use disorders and HIV, there is an urgent need to assess and address health disparities and to commit to health equity, in terms of social inclusion and human rights (Baumgartner & Burns, 2013; Carter et al., 2013; Mannan et al., 2012). Social inclusion is an important yet complex, multi-dimensional and dynamic outcome and process (Mental Health Commission, 2009), describing "the extent to which people are able to exercise their rights and participate, by choice in ordinary activities of citizens in the society in which they reside" (Mental Health Commission, 2009.6). For dually afflicted young adults, there is a need to rethink and go beyond the clinical severity of these two conditions and examine the social conditions and systems that contribute to people's experiences of social inclusion. Given the limited opportunities and resources for occupational engagement and participation prevalent in low-and middle-income countries (Atkinson & Marlier, 2010; Atkinson et al., 2016; Borrowman & Klasen, 2020), it is also important to explore how the experiences of those affected can inform the drive towards social inclusion. It has been proposed that participation

in a range of freely chosen, healthy and meaningful occupations promotes health, well-being and social inclusion (Harrison & Sellers, 2008; Wilcock, 2006). However, the current understandings remain dominated by insights from the Global North (Nhunzvi et al., 2020; Rawal, 2008).

HIV and substance abuse are linked to social exclusion through economic problems, usually from unemployment and job losses among those infected (Boardman, 2011; Breuer et al., 2011; Chan et al., 2008; Dahlui et al., 2015; Mellins & Malee, 2013). This problem affects working age women in particular (Braveman & Helfrich, 2001; Dray-Spira et al., 2005). Social exclusion of persons with disabilities (PWD), including those with psychiatric disabilities, like substance use disorders, has been explained through the vicious disability poverty cycle (Banks et al., 2017; Bhawuk et al., 2014; Groce et al., 2011). The most recent disability survey carried out in Zimbabwe confirms the presence of income poverty among PWD (Ministry of Health and Child Care & UNICEF, 2013). The survey reports a high rate of unemployment (referring to absence of formal paid work), 90% among those in the economically active age group in Zimbabwe. This was mainly due to their lack of qualifications, inaccessible environments, stigma and discrimination in the workplace (Ministry of Health and Child Care & UNICEF, 2013). Although the rate of unemployment in the domain of paid formal work is equally high for the general population, it is compensated by high informal employment, reported to account for almost 95% of all employment in Zimbabwe (Luebker, 2008; Mujeyi & Sadomba, 2019; Rusvingo, 2015). Amongst the most disadvantaged young adults, few have access to skills' development and other opportunities that would enable them to earn a decent living and thereby experience social inclusion (Islam, 2015). The situation is worse among dually afflicted young adults because of the growing substance use problem, the high HIV prevalence, limited resources to support the marginalised and the stigma and discrimination prevalent against substance abuse and HIV in Zimbabwe (Evangeli, 2018; Madziro-Ruwizhu et al., 2019; C. Rwafa et al., 2019; Sullivan et al., 2020).

1.4. Occupational therapy and people with SUD and living with HIV in Zimbabwe: Researcher's experiences and reflections

In Zimbabwe as in other low- and medium-income countries, people who have mental health problems co-occurring with HIV suffer shame, stigma and discrimination (Schadé et al., 2013). This may have a negative bearing on the way they experience occupation and social inclusion in their lives. Access to health services, including occupational therapy services, is very limited.

During the researcher's ten years of combined clinical, research and teaching experience as an occupational therapist in the field of mental health practice in Zimbabwe, he worked with mental health service users including young adults dually afflicted with substance use disorders and living with HIV. It became apparent to him that one way to sustain the gains being made in HIV management, was to reduce forward transmission of HIV by understanding and empowering dually afflicted young adults and other key populations such as sex workers. However, there is currently a lack of understanding and integrative and social transformational occupational therapy programmes specifically designed for these populations. This situation is compounded by the unavailability of substance abuse rehabilitation centres and occupation-based community mental health practices. While some clinical occupational therapy services are offered for either SUD or HIV, there are none that focus on promoting social inclusion in context. This situation has resulted in the broader health and social care needs of dually afflicted young adults being neglected, a claim supported by current research (Duffy et al., 2017).

Promoting healthy participation in occupations is an important component of occupational therapy, which aims to confront injustice and inequalities while striving for a just society (Hammell & Iwama, 2012). For occupational therapists working with dually afflicted young adults in low resource settings like Zimbabwe, it is important that they identify and address the broader health and social care needs like human rights violations, stigma, discrimination, poverty, unemployment, sexual disempowerment, inadequate housing, lack of socioeconomic empowerment and health services access (Duffy et al., 2017). This could be achieved by increasing their awareness of the occupational perspective of social inclusion and tapping into the life experiences of those worst affected by substance use disorders and living with HIV. However, to do that, social inclusion needs to be explored and more fully understood in this context.

1.4.1. Genesis of the study: My journey

In 2009, the researcher qualified as an occupational therapist and ever since he has worked with different patient populations needing occupational therapy mental health services. What stands out is that this work has always involved marginalised population groups, such as dually afflicted young adults with substance use disorders and living with HIV. Working with young adults from this particular group led him to critique ways of practice that he had taken for granted, generating uncomfortable personal reflective, historical, and futuristic questions.

In his first two years of clinical practice at Zimbabwe's main referral hospital, dually afflicted young adults became an increasingly common feature of his caseload. Despite his inherent desire to see lives being transformed and service users being meaningfully integrated into their communities, the results he was seeing, mainly from what was possible within the system, were disappointing. Instead of the interventions resulting in young adults who were empowered and socially included, they continued to see more relapses and passive service users. Being a young adult like many of the service users and, having emerged from a poor background, he became increasingly hungry for solutions which would see young adults healthy, respected and autonomous members of society. he wanted to see them lead lives they had reason to choose and value. he was also keen to know more about how they could use options available to lead lives resulting in experiences of social inclusion and reduced hospital admissions.

Over time, the dually afflicted young adults became a special group to him. In them, the researcher saw the most complex issues of health and social care, seemingly from the current structuring of the occupational therapy services in Zimbabwe, whose needs were never going to be met. His clinical practice years with these young adults were becoming increasingly frustrating, occupational therapy's moral claim of promoting social inclusion for all, remained elusive. he did not want to surrender and so he started to look for opportunities which would allow him to work collaboratively with the young adults to understand and transform their lives. The researcher also appreciated how limiting his undergraduate training was proving to be; even more so the position he was occupying and the work setting he was operating from. Moreover, he was becoming more conscious of the injustices all this was presenting to these intended beneficiaries of occupational therapy in Zimbabwe.

In addition, he encountered the plight of those who suffer daily injustices because of poverty, health and social status, pushing me to think more deeply about these issues. One encounter was particularly memorable for him. A young lady was admitted to a national referral psychiatry hospital where he was the occupational therapist in charge. She had been brought in by her friends and was admitted with substance induced psychosis. She then tested positive for HIV which seemed to trouble her a great deal. Digging deeper into this, the researcher found that she had suffered inhumane treatment at the hands of her stepmother, who had labelled her the problem and not the substance use challenges she was having, nor the environment around her. When it came to time for her discharge, she had no place she could call home. Going to stay with her stepmother was not an option, especially now that she was living with HIV. Like many, she came back to us with a number of relapses. To the researcher, it became a question

of justice, "Was justice being served here?" What other forces influenced the realities and choices of DAYAs in life? How does one co-construct knowledge with people who are experts through their experience?

All of the above, together with his life journey of starting in a remote, rural and poor background, then "making it" by having a job that is considered prestigious, has influenced his choice of research focus. The researcher's identity, mainly shaped by the then Eurocentric and patriarchal postcolonial context of Zimbabwe and an upbringing grounded in a strict Roman Catholic family, led him to become a keen advocate for those whose circumstances stood as barriers to transformative journeys. The dually afflicted young adults are amongst those struggling, and he wanted to understand their choices and alternatives.

As part of the researcher's masters in Occupational Therapy, he followed-up on some of his burning concerns. He chose naturalistic methods to explore the journey of recovery from substance abuse among young adult men in Zimbabwe (Nhunzvi, Galvaan, et al., 2019). He used narrative inquiry as a means to learn from their life stories. Their hunger to be heard and to be integrated into society and to have access to services reinforced his interest in the co-construction of knowledge and user-led social justice agendas. Noting that there are very few stories and experiences of young adults dually afflicted with HIV and SUD in knowledge construction, the researcher has a deep desire to explore and generate knowledge that may serve to challenge injustices in the status quo.

1.5. Problem Statement

Mental health service user trends in main referral centres show a high prevalence of dually afflicted young adults in Zimbabwe (Duffy et al., 2017; World Health Organization, 2010). A recent study in Zimbabwe reports a high HIV prevalence of 10.8% among adults with substance use disorders in the mental health referral centres (Madziro-Ruwizhu et al., 2019). As observed by other scholars, despite the gains on the biomedical front, a number of broad health, social and occupational needs of this group are not met (Duffy et al., 2017), suggesting that experiences of social exclusion exist. Also of concern, is the fact that the extent of social inclusion of these young adults is not known nor are their experiences. Person-centred interventions could be developed could be developed from this knowledge.

Individuals with chronic, and usually stigmatised and discriminated against, conditions such as substance use disorders and HIV, are being deprived of their full right to participate in their communities (Jackson-Best & Edwards, 2018). Despite the heralded success story in HIV care

in Zimbabwe, it remains concerning that stigma continues to stand as a major barrier in the way of appropriate engagement with HIV care (Nyika et al., 2016). Most barriers to inclusive participation among those facing stigmatised ill health conditions can also be linked to poverty, lack of access to education, lack of suitable housing and unemployment (Bradshaw et al., 2004; Gordon et al., 2017; Nhunzvi et al., 2020). In the face of these challenges, there is a renewed call to take a community-led, equality and social justice approach (UNAIDS, 2018, 2019a) which entails exploring concepts like social inclusion through service user experiences. To this end, Zimbabwe has ratified a legally binding United Nations Convention on the Rights of Persons with Disabilities (UNCRDP), giving a clear mandate to protect the rights of persons with disabilities including the social inclusion of those with psychosocial disabilities (The United Nations, 2006).

However, there are no services designed or being offered from an occupational perspective to promote social inclusion in this population group. This is largely as a result of, a lack of understanding of the concept in context. The lack of emphasis on life after achievement of biomedical outcomes has resulted in high rates of relapse and medication adherence problems, with about 60% of readmissions in some psychiatric institutions being related to relapse and substance abuse problems (PGH Hospital Statistics, 2018). The discharge environment is often unsupportive and most of the substance abuse services in the public sector are poorly resourced and do not respect self-determination among the service users. The two conditions are still disjointly managed in the same ministry of health, with little to no collaboration between the respective units (that is the Opportunistic Infections (OI) unit for HIV and the Mental health unit for SUD). This indicates the clear lack of a holistic and comprehensive approach and has potential to fuel the HIV pandemic and reverse gains achieved to date.

In a move to develop such services, this study is needed to explore how dually afflicted young adults experience and negotiate occupational participation for their social inclusion in everyday life, tapping on experiential knowledge in context.

1.6. Study Purpose

The purpose of this study is to build insight into the way in which social inclusion is experienced and negotiated through occupational participation by dually afflicted young adults in Zimbabwe. The study positions occupational therapy in global mental health and social care practice by exploring the relationship between occupational participation and social inclusion. By exploring participation in occupations, this study has the potential to advance the use of

knowledge of occupation in public health for the social inclusion of disadvantaged and marginalised population groups. It strives to build a foundation for advocacy and critical occupation-based practice to improve the social inclusion of dually afflicted young adults and similarly disadvantaged and marginalised groups.

1.7. Research question

How do dually afflicted young adults in Zimbabwe with substance use disorders and living with HIV, experience and negotiate social inclusion through their participation in occupations?

1.8. Aim

The study aims to explore and understand how young adults in Zimbabwe dually afflicted with SUD and HIV experience and negotiate social inclusion through their everyday occupational participation in context in order to inform critical occupational therapy practice.

1.9. Objectives

- To describe and explain how social inclusion is experienced amongst dually afflicted young adults in Zimbabwe.
- To explore how social inclusion is negotiated through occupational participation by dually afflicted young adults in Zimbabwe.
- To describe possible resources and opportunities that would enable occupational participation.
- To describe potential outcomes for social inclusion through occupational participation.
- To explore the influence that the socio-political context has on the experience and negotiation of social inclusion through participation in occupations by dually afflicted young adults in Zimbabwe.

1.10. Conclusion

This chapter provides a detailed background of and need for the study, aiming to understand the experience and negotiation of social inclusion among dually afflicted young adults in Zimbabwe. The researcher has contextualised the problems of substance use disorders and HIV in Zimbabwe, highlighting their complexity and the fact that they remain a topical issue needing attention from multiple perspectives. He emphasises the lack of a comprehensive approach to address the broad health and social care needs of those affected, especially young adults who are expected to be the economic and developmental backbone of the nation. He positions social inclusion as a worthy concept which, when explored from an occupational perspective, can aid in developing holistic and sustainable care for marginalised groups. He

motivates for the use of service user experiences as part of the initial work needed to generate insights to inform the understanding of this phenomena.

The following chapter considers relevant literature to understand social inclusion and associated occupational constructs.

Chapter 2 : A literature review

2.1. Introduction

This review describes and critiques perspectives on social inclusion in marginalised populations, based on literature drawn from the disciplines of occupational science, occupational therapy, the social sciences and mental health. Two main strategies were used to search the literature. The researcher conducted an extensive literature search[1], paying particular attention to literature concerning those with comorbid substance use disorders and living with HIV in low resource settings. Key search terms included mental health, HIV, substance abuse, social inclusion, social exclusion, occupation, occupational therapy, stigma, young adults and low resource setting. Further, he conducted a scoping review to explore ways in which occupational justice and social inclusion are conceptualised, defined and operationalised in highly stigmatised and chronic conditions of mental illness and HIV https://bmjopen.bmj.com/content/bmjopen/10/8/e036916.full.pdf (Nhunzvi, et al., 2019; Nhunzvi et al., 2020).

With a particular interest in DAYA, the researcher argues for the use of multiple perspectives and experiences of service users outside the dominant geopolitical centres of knowledge production. He also reviews the factors associated with the realisation of social inclusion or lack of it and advocates for attention to be paid to the role of agency in negotiating social inclusion.

2.2. Understanding the value of social inclusion and its historical origins

More fully understanding and appreciating social inclusion has the potential to elicit a new perspective in comprehensively examining and challenging social ills. Understanding social inclusion as it applies to marginalised population groups is necessary since, in the existing narrative, the realities of those disenfranchised by disease and geopolitical forces in the Global South remains underrepresented. A huge moral imperative exists to know more about how to advance social inclusion among historically marginalised population groups. Allman (2013) argues for a social inclusion movement that focuses on greater social justice, equity and collectivism in response to global oppressions which embody and perpetuate social exclusion

[1]The researcher searched for literature through the following databases; MEDLINE, CINAHL, PubMed, Academic Search Premier, ERIC, Psych INFO, Humanities International Complete, Google Scholar, Africa-Wide Information and OT Seeker. Mental health and occupational therapy textbooks and journal publications in the University of Cape Town library were also used as sources of literature. **Search terms:** substance abuse, substance use disorders, drug abuse, HIV/AIDS, HIV, occupation, occupational perspective, occupational science, occupational therapy, occupational choice, social inclusion, social exclusion, stigma, agency, structure, young adults, and low resource setting.

in societies (Allman, 2013). This aligns with the historical trend which proposed social inclusion as offering a valuable way of unpacking the global economic forces driving modernity but, at the same time, influencing how social ties are torn apart, resulting in marginalisation of certain population groups from mainstream society (Reich, 1992; The World Bank, 2013) The argument highlights that investing in processes that enhance social justice and equality for all can limit the growth of the underclass and excluded groups, which, if left unattended, will ultimately put the whole society at risk of social collapse (The World Bank, 2013). Appreciating this understanding offers a foundation for advocating for global equity and self-determination of those marginalised, for a more meaningful and healthy sense of belonging in society to occur.

Internationally, social inclusion and social exclusion have been emphasised as important concepts. With the renewed interest in social determinants of health, social inclusion is a pivotal policy driver providing determined action on unacceptable and unjust health inequalities (Rispel et al., 2009) which are even more pronounced among marginalised population groups, such as the DAYA. Their use as key drivers for developing and implementing policies and services aimed at tackling a range of issues associated with social disadvantage including poverty, youth education, unemployment, fear of crime and homelessness is growing. This is especially evident in Europe, Australia, and North America (Balaj et al., 2017; Dahlgren & Whitehead, 2006; Labonté, 2017; Lui et al., 2011; McDevitt, 2003; Nevile, 2006; Oxfam International, 2015). Although social inclusion as a policy driver is less apparent in regions of South America, Asia and some parts of Southern Africa, there have been promising developments in empirical and exploratory studies (Quinhoes & Fava, 2020; Rispel et al., 2009; Saloojee & Saloojee, 2011). Brazilian occupational therapists and scientists have shown leadership in implementing and advocating for social occupational therapy as a form of critical occupational therapy that attends to the social inclusion needs of both individuals and populations (Malfitano et al., 2014). Social occupational therapy argues that to enable practice that aims for social inclusion, more attention should be given to the social praxis of occupational therapy which entails a critically reflexive approach on cultural issues, context, social policies, social rights and civil rights beyond the traditional constructs of health (Barros et al., 2011b; Esquerdo Lopes et al., 2012; Malfitano, 2005; Malfitano & Lopes, 2018). Despite the growing utility of the concepts of social inclusion and exclusion in policies and research, the difficulty which research and practice have had in trying to understand social inclusion and its associated terms has been identified. The main shortcomings

identified include the lack of universality and the issue that the concepts have remained ambiguous and elastic (Nhunzvi et al., 2020; Rawal, 2008). This has meant that to a greater extent, social inclusion and exclusion are left to mean anything to anyone (Rawal, 2008). The literature to be discussed in this review shows that social inclusion is understood to be inherently political (Pereira & Whiteford, 2013), culturally sensitive and an evolving situated concept (Nhunzvi et al., 2020). It is multidimensional, complex and heavily associated with historical understanding of poverty eradication and welfarism (Cobigo et al., 2012; Le Boutillier & Croucher, 2010; Pereira & Whiteford, 2013).

Part of the complexities in understanding and applying the concepts of social inclusion and exclusion can be traced back to their historical origins and the dominance of the Global North values in their conceptualisation. The history of the concepts of social inclusion and exclusion can be traced back to the writings of Max Weber and social insurance developments in France, where one group was said to be privileged at the expense of the other (Buckmaster & Thomas, 2009). Social inclusion has a further grounding in the functionalist social theory of Emile Durkheim, which strove to maintain social order and stability (O'Brien & Penna, 2008). Dating back to the 1960s, the international disability rights movement, though more pronounced in the Global North, is credited for creating inclusion pathways for people with disabilities and special needs (Grady, 1995), which then influenced social inclusion developments in France. This genesis aligns with the acknowledgement of the inherent political nature of the concept of social inclusion (Pereira & Whiteford, 2013). In France, social inclusion was more to do with groups excluded from social insurance. These included persons with disabilities, single parents and those in informal employment whose experiences were used to help understand social inclusion and exclusion (Rawal, 2008; Silver, 2015). With this foundation, the Global North has led the advancement and utilisation of the concept. In many of the countries, social inclusion has grown to the extent of informing or being a part of mainstream policies (Silver, 2015; Wright & Stickley, 2013). However, the social inclusion goals in the Global North have remained largely about minimising economic exclusion among minority groups, including mental health service users (Wright & Stickley, 2013).

With these roots in the Global North, Eurocentric opinions have dominated the conceptualisation of social inclusion/exclusion (Saloojee & Saloojee, 2011). It is argued that these historical understandings of social inclusion and exclusion may not fully address the needs and realities of experience in the Global South (Rispel et al., 2009; Saloojee & Saloojee, 2011). These conceptualisations, in as much as they have been heralded as progressive, remain

rooted in European and Anglo-Saxon traditions, which are criticised for ignoring contributions made by peoples of Africa, Asia, and Latin America (Saloojee & Saloojee, 2011). Hence, the social inclusion discourse should be context sensitive. Notions of power as central to influencing social relations, social capital and forcing social exclusion of some, is under-represented, as evidenced in limited research on socially constructed exclusionary forces like racism, ableism and sexism in contexts like Zimbabwe (Stienstra & Nyerere, 2016).

2.3. Defining and conceptualising social inclusion: Multiple perspectives

Findings from the scoping review revealed that there are no studies defining social inclusion and exclusion specific for young adults with the dual affliction of HIV and substance use disorders. There are, however, many perspectives informing definitions and conceptualisations in the general population, populations of mental health service users and a few in those living with HIV (Nhunzvi et al., 2020). A geopolitical influence among the definitions applied was evident in that primary research studies included in the scoping review showed that most of the definitions of social inclusion in mental health were from studies conducted in countries in the Global North.

The literature shows great variability and a lack of definitional clarity in defining social inclusion (Cobigo et al., 2012; Nhunzvi et al., 2020; Pereira & Whiteford, 2013; Rawal, 2008). From the scoping review which focused on the conceptualisations and definitions of social inclusion in mental health and HIV, there were only two studies that used the same definition of social inclusion, defining it as a subjective sense of belonging and active citizenship which enhances the individual's social integration (Nieminen et al., 2012; Ramon et al., 2011). The most cited definitions reflect the multidimensional nature by using multiple thematic concepts which include community participation, human rights and relational belonging (Nhunzvi et al., 2020). The emphasis on participation in certain areas of life as a form of inclusion is also reported in the literature (Boardman et al., 2010; Liberman & Kopelowicz, 2002). Most of the definitions of social inclusion in mental health literature include ambiguous terms such as 'community,' 'participation' and 'integration' (Nhunzvi et al., 2020; Rawal, 2008). Some studies define social inclusion in terms of paid work and participation in community events (Killaspy et al., 2014; Mazzi et al., 2018), while others focus on social acceptance and the absence of stigma (Cobigo & Stuart, 2010; Nieminen et al., 2012; Ramon et al., 2011; Turner et al., 2017), while still others emphasise the political discourse (Raitakari et al., 2016). Stain and colleagues aimed to explore the impact of psychosis on an individuals' social and

community participation (Stain et al., 2012). They try to capture the different definitional variations of social inclusion, and define the concept as:

> "the participation of a person in society, evidenced by an individual having the opportunities, resources and abilities to build and maintain relationships, engage in education and employment, and participate in community events and organisations" (p.880).

When considering community participation as a defining marker of social inclusion, most studies emphasise the central importance of paid employment (Evans & Repper, 2000; Lloyd et al., 2006; Nieminen et al., 2012; Salles & Barros, 2013; Stain et al., 2012). This is understandable, given the dominant knowledge systems of capitalism in societies which influenced the genesis of the social inclusion concept (Rawal, 2008). The challenge of such definitions is that they risk leaving out the essence of different communal ways of engagement, especially those outside of a neo-liberal market structure.

Theoretical papers emphasised that the concept of social inclusion has its roots in social justice (Rawal, 2008; Silver, 2015; Wright & Stickley, 2013; Yanicki et al., 2015). In his review of social inclusion and social exclusion, Rawal postulates the theoretical relationship between social justice and social inclusion, emphasising human rights, equality and respect as key ingredients for achieving social inclusion (Rawal, 2008). This social justice orientation in defining social inclusion is important in sustaining the moral imperative of fighting injustice and exclusion faced by those with stigmatised conditions such as substance abuse and HIV. Occupational therapy and science scholars have also extended the social justice orientation of social inclusion by addressing its link to occupational participation and occupational justice (Cobigo et al., 2012; Durocher et al., 2014; Harrison & Sellers, 2008; Malfitano et al., 2014; Pereira & Whiteford, 2013; Townsend & Wilcock, 2004). In addition, a number of definitions still attempt to cover the historical ideals of poverty reduction and a focus on reducing stigma and discrimination (Cáceres et al., 2008; Smyth et al., 2011; Turner et al., 2017).

Some definitions of social inclusion place importance on individual autonomy and independence in participating in life situations (Killaspy et al., 2014; Mazzi et al., 2018; Saavedra et al., 2018). Given that most of the studies defining social inclusion in the scoping review were from Eurocentric communities in high-income regions, it is not surprising that the communal and collective orientations found in indigenous communities and from those in low and middle-income settings remain limited (Nhunzvi et al., 2020). This is however, at the expense of the collective orientations present in societies. Occupational therapy and science

scholars argue for a departure from individualistic approaches in favour of those that address social inclusion as a collective social function, while challenging global inequality and injustice as inhibitors of participation (Dowling & Hutchinson, 2008; Farias & Laliberte Rudman, 2016; Farias & Rudman, 2019; Malfitano, 2005; Malfitano & Lopes, 2018; Malfitano et al., 2021). These scholars take social inclusion to be more fully reflected in collective coexistence, respecting human rights and challenging situations of injustice, difference and privilege of some population groups over others (Malfitano et al., 2021; Muñoz, 2018). This understanding also entails the creation of socially inclusive environments and enabling occupational participation among those facing exclusion, like persons experiencing mental illnesses (Whatley et al., 2015a). The social justice agenda being advocated for by these scholars appears to be a better placed in defining social inclusion from a population level. This may more adequately reflect the broader social determinants of health and well-being as has been found in some studies focusing on developmental and intellectual disabilities (Martin & Cobigo, 2011).

Some definitions of social inclusion emphasise that it is multidimensional (Le Boutillier & Croucher, 2010; Salles & Barros, 2013; Turner et al., 2017), allowing for broad application of the concept, in policy, research and practice. The drawback of the emphasis on adopting multiple perspectives is that, despite the concept of social inclusion having been in use for almost five decades, there remains poor definitional clarity (Rawal, 2008). However, striving for universalism at the expense of diversity will result in negation of the variability embedded in contexts and experienced in multiple ways by individuals and groups (Rawal, 2008; Silver, 2015). Instead, multiple perspectives create room for unrestricted conceptual and theoretical application of the concept, especially in low and middle-income settings, where such research work on social inclusion is still lagging (Rawal, 2008). In the scoping review, the emphasis was on the importance of the variations with clear contextual definitions that reflected diversity and the importance of contexts (Nhunzvi et al., 2020). The authors postulate that the definitions of social inclusion should recognise the different contextual, social, economic, political, cultural and historical realities influencing general life participation and that of those with mental illnesses such as substance use disorders and living with HIV (Nhunzvi et al., 2020). For example, access to and meanings attached to different activities purported to enhance social inclusion in Eurocentric communities like paid employment and leisure engagements, do not hold the same weight in low resource settings. From this position, what remains missing are the conceptualisations and definitions of social inclusion using the realities of traditionally

underrepresented communities, especially from the Global South, such as young adults with a dual affliction of substance use disorders and HIV in Zimbabwe.

The review of literature has also shown that social inclusion has rarely been defined in its own right. In most cases, social inclusion as a concept is kept implicit and unproblematised in social exclusion literature (Cobigo et al., 2012; Martin & Cobigo, 2011; Pereira, 2013; Pereira & Whiteford, 2013; Rawal, 2008). There are many instances where the definition of social inclusion has been implied as the opposite of social exclusion or that the two exist on a continuum with extremes of each at opposing ends (Burchardt & Le Grand, 2002). Rawal argues that when we assume that social inclusion and social exclusion are opposite sides of the same coin, it is problematic because this negates the continuum and fluidity involved and hence the need for separation (Rawal, 2008). In defining social exclusion, some scholars have argued against a binary approach that focuses on actual participation or absence thereof. This is seen as problematic as it risks undermining the hidden social dynamics surrounding the processes and outcomes of the same participation (Davey & Gordon, 2017; Levitas et al., 2007; Rawal, 2008).

A number of paradigms of social exclusion have been suggested by Silver (1994) in an attempt to aid understanding and application of the concept. Silver (1994), proposes three paradigms: i) the solidarity, ii) the specialisation and iii) the monopoly paradigms. These three resonate well with the Eurocentric ideology in explaining the causal pathways of exclusion. Each provides an explanation of multiple forms of social disadvantage - economic, social, political and cultural - and thus encompasses theories of citizenship and racial-ethnic inequality, as well as poverty and long-term unemployment (Silver, 1994). According to the solidarity paradigm, social exclusion arises from the breakdown of social solidarity, which has to do with shared values, beliefs and rights. To oppose such exclusion, there is need for assimilation in to the dominant group, which results in social integration (Silver, 1994). The second paradigm is the specialisation paradigm, which is well situated within Anglo-American liberalism. In this paradigm, exclusion is seen as a result of specialisation:

'*…of social differentiation, the economic division of labour, and the separation of spheres. It assumes that individuals differ, giving rise to specialization in the market and in social groups. It is thus individualist in method, although causation is situated not simply in individual preference but also in the structures created by cooperating and competing individuals markets, associations, and the like'* (Silver, 1994, p. 544).

Of interest to this research is the third paradigm, the monopoly paradigm, which deals with the control of resources and opportunities (Rawal, 2008; Silver, 1994). In this paradigm, social exclusion is said to arise from inequalities in the interplay of class, power, status, even from historical positionings, all serving the interests of the included at the expense of the excluded (Silver, 1994). Combating social exclusion within the monopoly paradigm is achieved through agency, citizenship, equality and facilitation of full community participation of the excluded.

Sen's contribution in the conceptualisation of social exclusion is also noteworthy. He recognises the utility of the social exclusion concept in understanding poverty and the policy and social action for alleviating it (Sen, 2000). Sen uses the Capability Approach (CA) to explain social exclusion and poverty. He asserts that exclusion is about being deprived of your capabilities. According to Sen, social exclusion is an approach that broadens our understanding and tackling of poverty in a multifaceted way (Sen, 2000).

Conceptually, however, social exclusion has been open to criticism and seen as lacking in theoretical rigour, making it open to abuse and continued exploitation. To counter this challenge, Sen suggests that the developing literature of social exclusion should be placed in the broader context of the old concept of poverty as capability deprivation (Sen, 2000). He argues that exclusion from some opportunities like social functioning, can lead to other deprivations, which may be economic in nature, hence the need for a more comprehensive and multidimensional approach as provided by the Capability Approach to social exclusion (Sen, 2000). Another important insight suggested by Sen, which is of interest to this study is that of conceptualising inclusion and exclusion at the level of access to opportunities and the notion of choice. The opportunity to participate should be open to all, but only on equitable and reasonable terms that provide the starting point for what can subsequently constitute social inclusion and exclusion (Davey & Gordon, 2017; Sen, 2000). Sen posits that it is important to retain 'opportunity' in social inclusion and exclusion definitions, as it implies one's choice and the challenges of forced participation, pointing to the need to recognise as problematic both social exclusion and 'unfavourable inclusion' (Sen, 2000).

Hammel and colleagues (2008) found that adults with disabilities referred to the freedom of choice and ability to participate on their own terms rather than following societal norms, as characteristic of their ideal social inclusion (Hammel et al., 2008). This emphasises the importance of having those affected by stigmatised and disabling conditions contributing to what informs definitions of social inclusion. Martin and Cobigo (2011) worked with adults

with disabilities and captured their views about their social inclusion. They report that, to these adults, social inclusion meant being accepted as an individual beyond their disability, having reciprocal relationships, being involved in activities, securing appropriate living accommodations, being employed and receiving formal and informal supports (Martin & Cobigo, 2011). The notions of choice and experience among individuals and groups with substance use disorders and those living with HIV remain unexplored, with most of the dimensions of inclusion being pre-determined from the norms and values of societies in which they live. Even less has been reported from the perspective of people worst affected by social exclusionary forces, such as young adults with stigmatised conditions who are in low-income countries, also experiencing extreme poverty, uneducated, unemployed and affected by many forms of violence (Nhunzvi et al., 2020).

Social inclusion as a lived experience among traditionally marginalised population groups, has gained interest in occupation-based research and practice (Barros et al., 2011b; Davey & Gordon, 2017; Gordon et al., 2017; Malfitano & Lopes, 2018; Martin & Cobigo, 2011; Parvin & Eslamian, 2014; Pereira, 2013; Pereira et al., 2020; Pereira & Whiteford, 2013). The importance of personal experience has been highlighted in trying to go beyond the objective measurement of social inclusion and to capture its subjective dimensions (Nhunzvi et al., 2020). For example, a qualitative study in New Zealand that investigated social inclusion and exclusion from the subjective perspectives of people who were experiencing mental distress found the experiential meaning of social inclusion to be different from that found in the literature (Gordon et al., 2017). Qualitative themes were generated using a hybrid of interpretative phenomenological analysis and thematic analysis, showing that social inclusion was experienced as a 'social mask', where the participants felt pressurised to conform to prescribed normative social behaviours. This calls for a comprehensive examination of the conditions of social inclusion rather than merely labelling individuals as included or not. Some participants experienced social inclusion as an application of agency and self-determination to be their 'true selves', with no need to wear a 'mask' to be included, a function which was largely restricted to everyday living (Gordon et al., 2017). In some situations, people might be content and satisfied with their level of social inclusion, despite not being viewed as typically socially included (Cobigo et al., 2012; Le Boutillier & Croucher, 2010). These experiential realities show the rich understanding gleaned from studying subjective experiences, supporting the need for the current study to explore the concept of social inclusion in DAYA in a low resource setting like Zimbabwe.

Further critical perspectives of social inclusion are slowly increasing, as reflected in the increasing scholarship showing decolonial and critical occupational perspectives. The decolonial perspective has been argued to reveal and challenge the existence of colonial residues that position certain individuals and population groups as peripheral actors in their societies (Behari-Leak & Mokou, 2019; Grosfoguel, 2011; Oxford, 2019). These colonial residues are said to create and perpetuate oppression and multiple exclusion, including racial, religious and gender (Grosfoguel, 2011; Oxford, 2019). Within the decolonial perspective, there are calls to examine and change the complex and historically connected colonial power and social elements that constrain particular actors' participation (Behari-Leak & Mokou, 2019; Oxford, 2019). From a decolonial perspective, scholars and practitioners are encouraged to challenge hegemonies of social inclusion by including traditionally excluded groups in knowledge generation in ways that recognise their agency. Puwar (2004) argues that inclusion should not be based on the ability of the excluded to mimic the norm, whilst the norm itself has never been problematised (Puwar, 2004). In an ethnographic study in Colombia, applying a decolonial perspective to explore female exclusion and inclusion from football, Oxford (2019) reveals the existence of gendered colonial residues perpetuating and reinforcing females as marginalised actors in sport. A decolonial perspective has also been applied in contesting academic development in higher education, showing that the existing elitist and exclusionary ethos can be disrupted so that the normalcy of coloniality in the Global South is questioned (Behari-Leak & Mokou, 2019). Further engagement with decolonial theories as related to issues of social inclusion amongst population groups facing disadvantage in post-colonial settings such as Zimbabwe is needed.

Next, literature positing a critical occupational perspective is reviewed, as another important and growing lens in the exploration of social inclusion.

2.3.1. A critical occupational perspective of social inclusion

The literature on the critical occupational perspective of social inclusion is reviewed using the constructs of occupation and occupational choice as possibilities for understanding and applying social inclusion in traditionally marginalised groups. Occupational therapy and occupational science are premised on the belief that occupation is fundamental to human life and that engagement in meaningful occupations is essential for health and well-being (Wilcock, 2006; Yerxa, 2000). Occupation is foundational for health and also a basic right with the power to transform lives in situations of ill-health or where people's lives are affected by injury (Christiansen & Townsend, 2009; Hammell & Iwama, 2012; Hammell, 2007; G. Kielhofner,

2009). Social inclusion in this field is considered to be the processes and outcomes of addressing inequalities affecting full access to opportunities and participation in key occupations within a certain community, such as education, work and social participation. Social inclusion is achieved and evidenced by participation in occupations and creates a natural synergy with occupational therapy (Harrison & Sellers, 2008). In other words, occupational participation is claimed to be a human right and determinant of health in occupational therapy and science literature (Pereira et al., 2020).

Advancing social inclusion and promoting participation in occupation coalesce to create a strong case for occupational therapists and scientists to apply a critical occupational perspective of social inclusion to their work, seeking social transformation and justice through occupation (Barros et al., 2011a; Farias & Rudman, 2019; Malfitano & Lopes, 2018; Pereira, 2015; Pereira et al., 2020; Whatley et al., 2015a). This perspective has flourished among South American scholars and Brazil, in particular, through the genesis of social occupational therapy (Barros et al., 2011b; Jorge et al., 2017; Malfitano, 2005; Malfitano & Lopes, 2018; Malfitano et al., 2014; Muñoz, 2018; Pereira, 2015; Vinzón et al., 2020). Their work advocates for a socially committed, transformative occupational therapy outside of the health system, designed to examine and address the structural influences of social exclusion and injustice experienced by individuals, groups and communities (Barros et al., 2011b; Malfitano et al., 2014).

While everyday occupations encompass what people need to do, are expected to do and want to do and be in occupying their everyday lives (Harrison & Sellers, 2008), social exclusion segregates people from those everyday occupations. Occupational science and occupational therapy literature argue that these unjust positions which exclude individuals from full participation in the daily lives of their families and communities are a direct or indirect result of the social worlds we live in, manifesting through historical, social, cultural and economic conditions (Barros et al., 2011b; Farias & Rudman, 2019; Kantartzis, 2018; Malfitano & Lopes, 2018; Malfitano et al., 2014; Pereira, 2015; Pereira et al., 2020). Hence, the call for a departure from the individualist, reductionistic focus to more directed attention on the macro factors driving occupational participation (Frank & Muriithi, 2015; Laliberte Rudman, 2013; Malfitano et al., 2021)

The critical occupational perspective argues for a comprehensive focus on systemic and structural influences on occupational participation. Social exclusion is seen in the deprivation of rights to participate in meaningful occupations (Hammell, 2017; Hammell, 2020). To

address this form of social exclusion, the individual or group of persons experiencing difficulties should be capacitated to participate in meaningful and socially inclusive occupations, while, at the same time, efforts to remove participation barriers should be directed at a societal level (Harrison & Sellers, 2008; Kantartzis, 2018). From the critical occupational perspective, addressing participation barriers entails working with the real context (Barros et al., 2011a; Malfitano et al., 2014). The real context is understood as the locus for many sectors of life; it is the context within which occupations are realized, subject to the possibilities and limitations imposed by socioeconomic determinants (Malfitano, 2005). This perspective creates the impetus to push occupational therapy practice for social inclusion outside the illness-health axis to challenge the conflicting power dynamics between biomedical and transformative models of practice (Barros et al., 2005). This perspective is promising for this study, given the dominance of the biomedical disease model and the prevalent systemic and structural factors around the social inclusion of young adults with dual affliction of substance use disorders and HIV in Zimbabwe.

Collective occupations are another way of enabling the social inclusion of all. This has been proposed, though not yet well researched. The importance of collective occupations in challenging injustice and promoting social inclusion among marginalised groups has started to garner attention (Kantartzis, 2018; Kantartzis & Molineux, 2017; Ramugondo & Kronenberg, 2015), something that can be extended to those with stigmatised comorbidities like the DAYA in this study. Kantartzis and Molineux posit that collective occupation is defined "by its unique construction through the numerous people engaged in it and the power that is thereby produced, as well as by its intention or purpose towards the social fabric" (Kantartzis & Molineux, 2017, p.173). Kantartzis suggests that communities can achieve social inclusion through collective occupations which serve as social transformational tools to address the un-just conditions of many people's lives in our societies today (Kantartzis, 2018). The importance of occupations as shared and social is well reflected in collective occupations. There is, however, the possibility that some collective occupations despite bringing people together, may serve to exclude and discriminate against those perceived as different or whose collective occupations are not socially sanctioned. A critical occupational perspective can help gain a collective understanding of social inclusion or exclusion dynamics, thereby making it possible to delineate social interventions related to the rights and justice of population groups (Laliberte Rudman, 2013; Ramugondo & Kronenberg, 2015).

Critical occupational perspectives also bring in the construct of occupational justice as central to understanding social inclusion in occupational science and occupational therapy (Esquerdo Lopes et al., 2012; Muñoz, 2018; Pereira et al., 2020; Serrata Malfitano et al., 2016; Townsend & Wilcock, 2004). Occupational justice is generally accepted as a restorative way of achieving social justice and inclusion by identifying and tackling inequalities in opportunities to participate in occupations. Occupational scientists argue that for occupational justice to be possible, occupation and participation should be treated as human rights and not optional lifestyle choices (Christiansen & Townsend, 2004; Harrison & Sellers, 2008; Kantartzis, 2018). If occupational therapy takes this position, Christiansen and Townsend (2004) posit that it will be possible to pursue the principle of an occupationally just world, a world where everyone can participate fully (Christiansen & Townsend, 2004). Although touted as idealistic, the principle of occupational justice provides a theoretical underpinning for occupational therapists to commit to social inclusion (Corbett & Howe, 2007).

From the occupational perspective, there is call for exploring stigmatised forms of engagement including addictions, substance abuse and impulse control disorders (Kiepek & Magalhães, 2011; Kiepek et al., 2014; Kiepek et al., 2019). In a recent analysis and synthesis of literature, Kiepek & Magalhães (2011) strongly posited that it is important to understand addictions and impulse control disorders as occupations arguing that occupations are neither inherently positive nor negative, but are associated with both positive and negative consequences. Some of the forms of engagements and conditions they listed included pathological gambling, substance use disorders, and eating disorders (Kiepek & Magalhães, 2011). These activities remain underexplored for their social inclusion potential and value, which corresponds with the understanding that occupations hold potential for multiple meanings in different contexts (Kiepek & Magalhães, 2011).

What remains to be understood from the promise of the critical occupational perspective is the role of occupational choice, as a function of occupational engagement and participation, in the face of ill health complicated by stigma and poverty, as is the case for DAYA in this study.

2.3.1.1. Relevance of occupational choice in understanding social inclusion

Through examining occupational science constructs, such as occupational choice, that support the agentic nature of human participation, social inclusion can be further explored. An occupational perspective of social inclusion emphasising occupational choice, has the potential to affirm occupational therapy's role as a profession centring agency and promoting social

transformation for social inclusion, especially for those experiencing multiple forms of disadvantage exacerbated by stigmatised conditions such as substance abuse and HIV. Occupational choice is a key occupational science construct with the promise of promoting agency for occupation-based social inclusion. However, the understanding of it in this way remains limited, and even more so in the context of DAYA with substance use disorders and HIV in Zimbabwe.

Promoting social inclusion through occupation draws attention to the assumption that humans have access to and have the agency to choose their occupations. However, this assumption is being challenged as simplistic and convenient, especially outside developed contexts. Instead, choosing occupations is argued to be a very complex, socio-culturally situated process, influenced by a myriad of factors across societal levels, from individual to society (Galvaan, 2010). Galvaan posits that in order to do justice to the issues surrounding occupational choice, including the understanding of the construct, focus should be directed to broader equity and justice concerns in context (Galvaan, 2010, 2012, 2015).

The early conceptualisation of occupational choice was biased towards the positive health promoting choices and outcomes of occupational participation, a situation which has left occupational choices associated with occupations such as sex work, violence and substance abuse underexplored (Kiepek et al., 2019; Nhunzvi, Galvaan, et al., 2019; Rule & Twinley, 2021; Twinley, 2013; Twinley & Addidle, 2012). Occupational choices have been largely believed to aid individuals' experiences of health, well-being and community membership through creation of habit and structure in people's lives (Minato & Zemke, 2004). Moreover, Pierce posits that the sociocultural aspects of the environment are important in the processes of selecting such occupations (Pierce & Pierce, 2003). However, the dynamics of restricted opportunities for occupational choice processes prevalent in limited resource settings have remained unexamined. This, even though most of social inequalities and injustices faced by marginalised groups are a result of restricted opportunities to make occupational choices that promote wellbeing (Pereira, 2015; Pereira et al., 2020). The ways in which occupational choice might contribute to social exclusion or occupational injustices must be explored. A new perspective to understanding occupational choices in context is indicated, one that recognises the broad role of social context in hindering and facilitating some choices. Galvaan argues that this would be part of the efforts needed in occupational therapy and science to promote social inclusion and community development (Galvaan, 2015).

The growing new perspective considers the complexity and multi-factorial nature of choosing occupations, a view that is coherent with the multidimensional nature of social inclusion. Within this perspective, Galvaan (2012) posits a definition that captures complexities making occupational choices by defining occupational choice as a process and or an outcome involving the application of choice to participate in everyday activities, where such choices are co-constructed through the person's transactional relationships with their societal contexts. She acknowledges the growing need to explore the restrictive and facilitatory nature of the structural factors on choosing occupations (Galvaan, 2012). Within this definition, agency in selecting occupations is recognised as largely informed by a practical sense (habitus), guiding the way people operate as social agents in diverse situations (Galvaan, 2012). From this vantage point, whatever influences people's occupational choices also influences their social inclusion and warrants investigation.

The concept of occupational choice has been studied to some extent, with a focus on understanding how those experiencing disadvantage participate in occupations (Brennan & Gallagher, 2017; Gallagher et al., 2015; Galvaan, 2010; Minato & Zemke, 2004). Minato and Zemke (2004) explore the relationship between occupation and health by examining the occupational choices of persons with schizophrenia. They found that occupational choices were directed towards achieving life satisfaction, managing stress, providing time structure and promoting health and well-being (Minato & Zemke, 2004). However, they only consider positive and socially sanctioned choices. Also emphasising the positive side of occupational choice, Polatajko and colleagues suggest that occupational choice is key in occupational therapy as it influences the therapeutic use of occupation (Polatajko et al., 2007). This, however, assumes that the right and power to make choices is inherent, which is not the case in many situations. for this reason, there is a need to explore and understand contextual barriers, the removal of which will improve opportunities for individual occupational choices.

In 2010, Galvaan conducted a critical ethnographic study to describe young adolescents' occupational choices in a marginalised community in Cape Town, South Africa (Galvaan, 2010). She found that the occupational choices of these young adolescents were heavily influenced by both historical and prevailing intersections of socio-economic and political forces. In this study, the young adolescents were found to make hegemonic occupational choices, resulting in maintenance of historically predictable patterns of occupational participation and occupational injustice (Galvaan, 2010). This study further shows that the constraints of the context affected the possibilities for occupational choices amongst the young

adolescents. Constrained patterns of occupational choices emerged and continued to be reproduced and consequently, led to situations of continued exclusions and occupational injustice (Galvaan, 2010, 2015). This study raises the expectation that contextual factors are likely to influence occupational choices of different population groups in a myriad of ways, either to enable or to constrain occupational participation and consequently, social inclusion. However, this is yet to be examined with regard to the young adults in the current study. From this same critical ethnography, Galvaan emphasises the importance of lived experiences in understanding the historical and socially situated nature of their constructs (Galvaan, 2010, 2015). This is necessary since it is purported that people learn to live based on their experiences of living under the prevalent conditions in their community and focusing on what is reasonable to do there (Galvaan, 2010, 2015). The use of this contextually developed practical sense in making occupational choices when pursuing social inclusion is yet to be explored but may deepen our understanding and utilisation of the constructs among DAYA. We need also to acknowledge the 'normative response' to engaging in risk-taking occupations as a result of the deprivation of socially sanctioned ones.

Using qualitative participatory designs, Gallagher and colleagues challenged the individualistic view of occupational choice and expanded on Galvaan's argument that earlier conceptualisations seemed to neglect the influence of historical and situated context (Gallagher et al., 2015). They worked with nine youths from a disadvantaged community in Ireland using photovoice to elicit stories. When they applied thematic data analysis, they found that occupational choices were contextually informed and constrained. It emerged that the occupational choices of these youths were largely a product of sociocultural and political influences, rather than their internal interests and abilities (Gallagher et al., 2015). They encouraged occupational therapists to pay attention to these external contextual forces which inform people's choices when aiming to improve healthy occupational participation. While acknowledging both intrinsic and extrinsic influences on occupational choice, a study by Brennan and Gallagher (2016) used an exploratory qualitative design to examine the influence of gender as an extrinsic factor in occupational choice. From an occupational justice perspective, they found gender to be a factor which informed occupational choice through multiple mechanisms. Gendered occupational choices emerged as a product of social systems, institutional opportunities, family and friends, as well as expectations of self and others. The occupational choices were also influenced by participants' perceived ease of access to opportunities and resources for participation (Brennan & Gallagher, 2017).

In the literature reviewed on occupational choice, a significant gap was found to still exist pertaining to the understanding of occupational choice and its application among those afflicted by disease and, even more so, in already marginalised contexts. It is arguably possible that social exclusion may arise from restricted access or a lack of exposure to healthy occupational choices in conditions of stigmatised ill health. Hence, an in-depth understanding of occupational choice may reveal ways to understand and promote social inclusion among traditionally disadvantaged and marginalised groups, such as the young adults with stigmatised conditions like substance use disorders also living with HIV. However, a number of other factors need to be explored for a comprehensive understanding of social inclusion in context.

2.4. Factors influencing social inclusion and social exclusion

There is some agreement that personal and systemic factors interact to influence the multidimensional and dynamic processes and outcomes of social inclusion (Allman, 2013; Cobigo et al., 2012; Davey & Gordon, 2017; Le Boutillier & Croucher, 2010; Morgan et al., 2007; Parvin & Eslamian, 2014; Pereira & Whiteford, 2013; Rawal, 2008; Whatley et al., 2015b). Factors influencing social inclusion remain open to critique and exploration as, despite structural factors, they vary between places, situations and times. Hence the call for contextual studies. There remains a paucity of evidence, especially from the Global South, when examining the relationships between these factors and social inclusion. There is even less evidence in populations like those with a dual affliction of substance use disorders and HIV. The World Bank has asserted, in its evidence-driven social inclusion reviews and reports, that the world is in an inclusion crisis influenced by conditions of poverty, injustice, inequity, ethnicity and immigration status, all hinged on access and distribution of resources and opportunities for development (The World Bank, 2013). As argued by the Organisation for Economic Co-operation and Development (Organisation for Economic Co-operation and Development -OECD), social exclusion is considered one of the influencing forces of health inequalities, evidenced by its multidimensional and bidirectional associations with health outcomes (Organisation for Economic Co-operation and Development -OECD, 2021). A systematic review aiming to examine the association between social inclusion/exclusion and health among adults in the EU and OECD countries, found high levels of social exclusion to be associated with adverse health outcomes. This is even more pronounced in mental health (van Bergen et al., 2018). However, causal pathways were not clearly defined and they called for more robust studies (van Bergen et al., 2018). Another comprehensive review of the factors affecting social inclusion was conducted by the Social Exclusion Unit (SEU) in the UK

(Bradshaw et al., 2004). This narrative review explores factors associated with social exclusion and acknowledges the complexity in unpacking the direction of the associations, the overlaps and the underlying causes (Bradshaw et al., 2004). With the aim of establishing factors influencing social exclusion, Bradshaw and colleagues conducted a systematic narrative review of the literature. In their findings, they divide the factors into past and current, with the past factors being grouped into three domains: demographic, labour market and policy factors (Bradshaw et al., 2004). In the past, key demographic factors of social exclusion in the UK included being young, elderly, migrants and single parents. Within labour markets, unemployment and lack of flexibility in the labour markets were key contributing factors. On the part of policy, the team identifies the lack of socially inclusive policies and the failure of existing ones to capture the realities of the excluded (Bradshaw et al., 2004). It is important to note however, that policy remains one key factor which influences all other factors in interventions and preventing social exclusion. In Zimbabwe, there are no specific social inclusion policies to direct the health and social care needs of persons with comorbid substance use disorders and HIV as stigmatised conditions.

The review identifies a number of factors associated with social exclusion: low income, unemployment, lack of education, ill health, poor housing, inadequate transport, social capital, neighbourhood and crime (Bradshaw et al., 2004). Possible factors related to ability, equality of opportunity and resources and human dignity are more prevalent in low-income settings. Inequality, as a factor associated with social exclusion, poses a great challenge to social inclusion in the Global South. Some of the most unequal societies are found in Africa (Beegle et al., 2016). Identity is another factor associated with social exclusion and driving inequality. The World Bank cites identity as central to the social inclusion debate in Africa, with most individuals and groups being excluded or included according to their identity (The World Bank, 2019). Some of the most common group identities associated with social exclusion include gender, race, caste, ethnicity, religion, age, occupational status, location and disability status (The World Bank, 2013, 2019). Factors closely linked to social exclusion for groups with these identities are issues of poverty, unemployment, health and disability status and agency in decision-making (Beegle et al., 2016; Mitra et al., 2013; The World Bank, 2014, 2016, 2019). These factors are further influenced by discourses on health, global power and economic forces, which remain under-explored. In the next part of this review, the focus is on low income, unemployment, education and ill health as factors contributing to social exclusion.

2.4.1 Low income

Low income is globally argued to be one of the key factors associated with social exclusion. Low income, also referred to as income poverty, is also associated with many other factors influencing exclusion, including lack of recovery capital, unemployment and ill health (Beegle et al., 2016; Bradshaw et al., 2004). This factor has remained a concern in the Global South, especially because of its multidimensional nature. For example, Africa alone hosts more than half the world's extreme poor - about 41% of its population experience extreme poverty and exclusion (Beegle et al., 2016; The World Bank, 2016). Poverty reduction has been slower in this region than in other regions and young adults are some of the most affected, an especially worrying situation given the continent's youthful population (Beegle et al., 2016; The World Bank, 2014). Understanding these dynamics through an occupational perspective of social inclusion could help uncover and challenge the perpetuating underlying causes.

Gordon *et al*. used the Poverty and Social Exclusion Survey in the UK and found that households with relative low incomes were more likely to face social exclusion in all dimensions, except isolation and lack of support. In this study, low income was associated with an inability to afford items or to engage in activities that are considered by most of the population to be necessities (Gordon et al., 2000). Moreover, in a review of child poverty and other adverse situations in the UK, there was clear evidence associating child poverty with social exclusion through routes such as poor educational attainment, mental illness, poor environments, crime and suicide (Bradshaw, 2001). In another study, exploring child poverty using the British Household Panel Survey in the UK, the authors found that adolescents who had experienced poverty had higher chances of being excluded through experiencing lower self-esteem, choosing not to marry, believing that their health was a matter of luck, playing truant and dropping out of school (Ermisch et al., 2001). In areas like Sub-Saharan Africa, where the HIV epidemic continues to dominate, income poverty has also been associated with increased vulnerability of young people to further poverty, substance abuse and HIV infection (Mufune, 2015), possibly heightening levels of social exclusion among those affected. In most developing countries, income poverty is associated with disabilities, which are also associated with lower educational attainment, unemployment and higher health expenditures (Mitra et al., 2013). However, social inclusion and exclusion as multidimensional concepts in understanding income poverty, remain underutilised in low-income contexts, with qualitative designs promising to capture the experiential complexities involved.

2.4.2. Education

Globally, access to primary, secondary, tertiary and continuing, lifelong education has been argued to have the potential to reduce social exclusion (Bradshaw et al., 2004; Popay et al., 2008; Rispel et al., 2008; Whiteford, 2017). What remains under- explored is the role played by different types of education, especially Global North-informed curricula in post-colonial settings like Zimbabwe, even more for those whose difficulties are compounded by stigmatised conditions such as substance use disorders and HIV. It is important to acknowledge that the research around education and social inclusion/exclusion has mainly centred around the Western education system, even in regions outside Europe, and is yet to include a critical decolonial analysis. Even so, there are different interlinking processes and factors which influence the relationship between education and social inclusion. These processes are seldom explored in low-income settings such as Zimbabwe.

The formal education system in Zimbabwe still reflects the values of the Global North around competition and devalues indigenous options of education and skill acquisition. Matsika argues that Western colonial education was designed to produce a worker and a consumer of services (Matsika, 2000). This type of education has also been found to be linked to social inclusion via access to paid formal employment, well suited for capitalistic economies (Bradshaw et al., 2004; Sparkes, 1999). The way education influences participation in other domains of social inclusion beyond employment for marginalised population groups, remains unanswered. Furthermore, the question of how the education acquired may be a social inclusion factor in the face of high unemployment in most African countries remains unanswered (The World Bank, 2014).

Educational attainment as defined by years of formal education completed and qualifications held, has been used as the most reliable predictor of social inclusion outcomes, particularly in high-income countries. Bradshaw and colleagues, in their literature review, found that individuals with lower levels of educational attainment were at an increased risk of social exclusion. This was aggravated for those lacking basic literacy and numeracy skills (Bradshaw et al., 2004). Poor educational attainment has also been associated with poor health outcomes and vice versa, with social exclusion being associated with both of these conditions (Jolley et al., 2018; Pufall et al., 2017; Sparkes, 1999; Whiteford, 2017). Both substance abuse and HIV have links to low formal education achievements. For example, a cross-sectional study to investigate the association between HIV and disability, social functioning and school inclusion among HIV-infected children compared with uninfected peers in Zimbabwe, found a higher

prevalence of disabilities among those with HIV (Rukuni et al., 2018). Furthermore, this group was more prone to both social and educational exclusion (Rukuni et al., 2018). In another recent study in Zimbabwe conducted by Pufall et al (2017), among orphaned youths, positive associations between substance abuse and poor educational achievements were found (Pufall et al., 2017). They also found that substance abuse increased risky sexual behaviour that could lead to HIV and recommended a social inclusion approach as a promising way to help address these challenges in schooling programmes (Pufall et al., 2017). The role of education as a social inclusion factor is yet to be elucidated in the context of DAYA in Zimbabwe and other similarly marginalised groups.

Other studies on social inclusion and education have focused on persons with learning disabilities. However, most insights may also apply to various marginalised population groups. Through inclusive education programmes, access to education has been proved to be a key factor in determining the social inclusion of those with learning challenges (Fedulova et al., 2019; Jolley et al., 2018; Koller et al., 2018). Focusing on children with disabilities, studies have shown that inclusive education benefits the affected child and also helps their non-disabled peers to develop attitudes that are more accepting and less stigmatising (Fedulova et al., 2019; Jolley et al., 2018; Koller et al., 2018; Mpofu & Molosiwa, 2017). In a literature review on the impact of education on social inclusion, personal, environmental and policy factors were found to be the factors that influenced 'true' inclusion (Bradshaw et al., 2004). However, the battle over the years has been on implementation, especially in low resource settings, where the adaptations needed to make education more inclusive are usually missing and hence, exclusionary.

Mpofu and Molosiwa (2017) have criticised the education system in Zimbabwe as contributing to social exclusion and have advocated for a democratic human rights approach which would focus more on fostering spaces for learning that are more welcoming to all students and less on a disability label. They posit that this approach would shift the focus from service providers making prescriptive decisions on behalf of the learners to learners exercising their agency in designing how they would participate in their education (Mpofu & Molosiwa, 2017).

In a recent occupational science paper, Whiteford asserts that participation in higher education is a form of social inclusion (Whiteford, 2017). She adds that increasing the representation of disadvantaged groups in higher education enhances their social inclusion through employment, social support and other civil means (Whiteford, 2017). Using an occupational perspective on

a case study of Australia's Bridges to Higher Education, participation in higher education was seen to promote social inclusion by enabling a transformation of identity and socio-economic status, as the individual transitions from the occupation of a student to becoming a worker and professional (Whiteford, 2017). However, she emphasises the need for more critical engagements with the insights in diverse contexts.

Despite growing evidence of the relationship between education and social inclusion, some key questions remain. For example, how do the type of education, its historical positioning and the effectiveness of education at different times in an individual's life affect their social inclusion? It is also still unclear to what extent formal education can counteract multiple co-existing forms of disadvantage, including cases of stigmatised ill health in contexts of high unemployment.

2.4.3. Unemployment

Unemployment emerges from the literature on social inclusion and exclusion as one of the key factors positively associated with social exclusion, especially in already struggling economies (Atkinson & Marlier, 2010; Evans & Repper, 2000; Garrido et al., 2007; Irja Nieminen et al., 2012; Razzano A et al., 2015; Rispel et al., 2008; The World Bank, 2013). Unemployment has been cited as central to the social exclusion dynamics of most Western economies (Bradshaw et al., 2004). This situation has been confirmed to be worse in marginalised population groups, like persons with substance use disorders (Henkel, 2011; Kieselbach, 2003; Nhunzvi, Galvaan, et al., 2019) and those living with HIV (Basavaraj et al., 2010; Duffy et al., 2015). Unemployment is projected to continue to rise as the young population continues to increase in Sub-Saharan Africa (Beegle et al., 2016; The World Bank, 2014, 2016). Despite the increase in educational attainments, most young adults lack the means to translate their education into productive employment, and, as a result, they remain restricted to nonwage jobs on farms and in household enterprises (The World Bank, 2014).

In their review, Bradshaw and colleagues indicate that lack of participation in formal, paid employment is an important indicator of social exclusion. This also influences, directly or indirectly, other aspects of social exclusion, such as poverty, homelessness, health status, substance abuse and access to support and services (Bradshaw et al., 2004). In most economies in the Global North, unemployment has been found to be problematic among certain minority groups. These minority groups have included persons with disabilities, those using substances, ethnic minority groups, the uneducated, people in their fifties and older and those residing in

specific areas known to have low labour demands (Bradshaw et al., 2004). This situation which may be different in Sub-Saharan Africa, where the majority are affected by unemployment.

The experience of social exclusion for many young people faced with multiple disadvantages in the Global North societies has been traced back to their employment status (Lakey et al., 2001). In a qualitative study of the employment difficulties among young people with multiple disadvantages in the UK, it was found that their difficulties made their job prospects worse and also made it difficult for them to retain employment. The multiple difficulties the young people faced in this study include being homeless, having a disability, being in poor mental health, having substance use problems, having poor literacy skills, having a criminal record, having a history of problems with the law, having been in foster care and being young mothers. Most of their work experience was in temporary, casual and part-time jobs (Lakey et al., 2001). What remains to be explored are situations in low-income settings such as Zimbabwe, where the majority of the population is excluded from formal paid employment or where employment is influenced by corrupt practices and engagement in informal types of work is the norm (Njaya, 2015; Rusvingo, 2015).

Unemployment, as a function of social exclusion, has rarely been explored in contexts most affected by HIV and even more seldom in the duality of substance abuse and HIV in Zimbabwe. However, several studies have looked at unemployment in HIV and a significant pool of evidence also exists for the association of unemployment and substance abuse (Henkel, 2011; Liu et al., 2012; Sprague et al., 2011). For example, in a review of unemployment and substance abuse, there is evidence of a vicious cycle between the two, all pathways worsening the affected and their social inclusion (Henkel, 2011). Henkel reviewed 130 studies on substance abuse and unemployment with the aim of understanding the relationship between the two outcomes, including the impact and effects they have on each other. The main results confirm a high prevalence of substance abuse among the unemployed and that substance abuse is associated with an increased likelihood of unemployment and decreased chances of finding and holding a job (Henkel, 2011). Unemployment may be a risk factor for substance abuse and, conversely, substance abuse may make those affected unemployable. This has also been found to be true among some educated and skilled young people in some African countries (Farah & Ali, 2018; Mokwena & Morojele, 2014). However, other contextual factors which may help explain the systemic nature of the procyclical relationship in low resource settings such as Zimbabwe, remain unexamined.

As HIV evolves into a more chronic condition, issues of occupational functioning and employment have been on the rise and considered important in this population group (Basavaraj et al., 2010; Duffy et al., 2015; Liu et al., 2012). Previous research on HIV has demonstrated that unemployment among persons living with HIV results in worse exclusion outcomes through increased experiences of depression, anxiety, social isolation and low self-esteem (Basavaraj et al., 2010; Maulsby et al., 2020; Sprague et al., 2011). Recently, the social determinants of health discussion have gained momentum towards meeting sustainable development goals and, to this effect, employment is maintained as a key social determinant among persons living with HIV (Maulsby et al., 2020). In a recent scoping review on employment and HIV, the literature reviewed suggests that employment status is positively associated with HIV testing, linkage to HIV care, retention in HIV care and HIV medication adherence (Maulsby et al., 2020).

Previously, a South African study acknowledged the complexity of the relationship between unemployment, poverty, substance abuse and HIV, also highlighting the paucity of research evidence in this domain (Kalichman et al., 2006). In this study, surveys were conducted in three South African communities that varied by race and socio-economic conditions. The results showed that the risks of having HIV/AIDS were closely related to experiences of poor education, unemployment, discrimination, violence and crime. The researchers recommended a multisectoral and comprehensive approach to addressing the challenge of HIV and advised against trying to understand or tackle the pandemic as a single social problem, independent of other social ills (Kalichman et al., 2006). Fourteen years later, this call is what the present study aims to achieve by exploring social inclusion from an occupational perspective, with reference to young adults with a dual affliction of substance use disorder and HIV in Zimbabwe.

2.4.4. Ill health

Several health conditions have been associated with more risk for social exclusion. These include mental disorders (Davey & Gordon, 2017; Gordon et al., 2017; Le Boutillier & Croucher, 2010; Morgan et al., 2007; Nhunzvi et al., 2020), substance use disorders (Henkel, 2011; Kalichman et al., 2006; Pufall et al., 2017; Rispel et al., 2008), physical disabilities (Koller et al., 2018), HIV (Liu et al., 2012; Parvin & Eslamian, 2014; Rispel & Popay, 2009; Rukuni et al., 2018; Sprague et al., 2011; Trust., 2001) and other stigmatised conditions. There are multiple and complex ways in which ill health is associated with social exclusion. The health status of an individual or a population group determines their respective social inclusion standing (Bradshaw et al., 2004; Mitra et al., 2013; The World Bank, 2019; van Bergen et al.,

2018). Also, in a variety of ways, people's health status is intrinsically linked to their prevailing social determinants, which may include their social inclusion status.

Most countries report significant progress in the fight against HIV, but the social determinants of health associated with the HIV pandemic remain a cause for concern in most parts of the world (Basavaraj et al., 2010; Popay et al., 2008; Rispel & Popay, 2009; Sprague et al., 2011). However, the longevity that can now be achieved with current prophylactic and therapeutic strategies for persons with HIV infection is a considerable gain. This in turn positions HIV to influence the social inclusion processes and outcomes of those affected more acutely (Basavaraj et al., 2010; Sprague et al., 2011; Trust., 2001). Existing literature posits that HIV can influence social inclusion through the way that the physical manifestation of the disease reduces functionality, through its impact on mental health, the influence of social and cultural belief systems perpetuating stigma and the influence on social support systems, behavioural coping strategies and spiritual well-being (Kalichman et al., 2006; Liu et al., 2012; Parvin & Eslamian, 2014; Pufall et al., 2017; Rispel & Popay, 2009; Rukuni et al., 2018; Sprague et al., 2011). Stigma and discrimination in education, employment and social relationships have also emerged as platforms through which those living with HIV are excluded from society (Liu et al., 2012; Pufall et al., 2017; Rispel & Popay, 2009; Sprague et al., 2011; Trust., 2001). The outlook could be worse for those in multiple situations of disadvantage, like carrying another stigmatised condition, such as a mental disorder, in addition to HIV.

Persons with mental disorders remain among the most socially excluded groups in any society. Several studies, mainly from developed countries, have shown that mental disorders are compounded by stigma and discrimination (Fieldhouse, 2012; Hamer, 2017; Harrison & Sellers, 2008; Le Boutillier & Croucher, 2010; Turner et al., 2017; Wright & Stickley, 2013). Stigma and discrimination are constant features of the social inclusion/exclusion discourse Most domains of social inclusion are directly impacted by mental disorders, including participation in productive activities, social life, relational activities, political activities and accessing services, including health (Cobigo & Stuart, 2010; Hamer, 2017; Harrison & Sellers, 2008; Le Boutillier & Croucher, 2010). However, these may differ from condition to condition and from context to context. Of interest to this study, are the dynamics of social inclusion or exclusion associated with persons with substance use disorders in addition to their positive HIV status.

Substance use disorders may have detrimental impacts on both physical and mental health, as well as influence multiple forms of disadvantage and exclusion. Most people with substance use disorders are reported to experience higher levels of ill-health and social problems, leaving them at an exponentially higher risk of social exclusion (Neale, 2001). There is convincing evidence that substance abuse in any form reflects, causes and reinforces social exclusion (Bradshaw et al., 2004; Mokwena & Morojele, 2014; Neale, 2001). Evidence from existing research highlights the relationship between substance use disorders and important indicators of social exclusion, such as poor physical and mental health, homelessness, unemployment, social deprivation and crime (Bradshaw et al., 2004; Farah & Ali, 2018; Gordon et al., 2017; Henkel, 2011; Kalichman et al., 2006; Lakey et al., 2001; Mokwena & Morojele, 2014; Morgan et al., 2007; Neale, 2001; Popay et al., 2008; Sayce, 2001).

There are many health conditions which remain unexplored regarding their relationship with social inclusion or exclusion, especially in low- and middle-income countries. For example, ill health when persons have a dual affliction of substance use disorders and HIV, as is common amongst young adults in developing contexts like Zimbabwe, is yet to be explored. It is necessary to understand how the affected individual or groups of people negotiate these forces and apply their agency for social inclusion.

2.4.5. Agency/structure as a factor to consider in social inclusion

Agency and structure are central to the function of all the factors discussed above. Anthony Giddens is cited in many sociological studies as an important 20th century thinker whose writings contributed to the structure/agency debate. Giddens' structuration theory (Giddens, 1984) is recognised as his most important contribution to sociology. It is based on the idea that both agency (the ability to deploy a range of causal powers) and structure (identified as rules and resources in society) give rise to people's social practices, consequently making and transforming the world. It has been argued that the most effective way to most health inequalities, including situations of social inclusion and exclusion, would be to attend to both agency and structure. However, there has been a relative bias toward structure - at the expense of agency in most social inclusion studies.

The agency/structure debate is very important in understanding and influencing the degree of control that people have in shaping their own destiny, in contrast to the notion that individuals are constrained by external factors and systems beyond their control (Clifton et al., 2013; Sen, 1992, 2000). When looking at the social determinants of health, social inclusion or exclusion

have long been argued to arise from the interplay of both structure and agency (Frohlich et al., 2001; Sen, 1992; Williams, 2003). Therefore, it is important to ask about the role played by the individual (agent) in order to influence their own social inclusion, with respect to the political, economic, social and cultural environments (structure).

Stemming from an appreciation of the influence of both agency and structure, and embracing an understanding of social inclusion beyond the narrow focus on economic achievements, Sen developed the Capability Approach to argue for a renewed focus on individual agency what individuals are capable of doing and being (Sen, 1992, 2000). A person's capabilities are determined by both agency and structure, as is the case when their abilities are converted into functioning in the context of right and adequate opportunities (Hvinden & Halvorsen, 2014; Sen, 2000; Suzuki, 2017). Agency is informed by lives lived and choices made (Sen, 1992, 2000). The belief that one is not a passive subject but can control one's own life is important when negotiating one's social inclusion. It should be premised on identifying and applying one's agency (Alkire & Deneulin, 2009). Biesta and Tedder (2006) claim that 'true agency' is often misunderstood but can be seen most clearly when people are going through difficulties and they maintain the capacity to be self-directed actors in their responses (Biesta & Tedder, 2006). This suggests that the conditions of DAYA in low resource settings can be a fertile place to contribute to this debate.

Agency is considered an important survival tool when defying oppression and challenging practices of injustice (Gammage et al., 2016; Kiepek et al., 2019; Mondaca, 2021). In disability literature, agency is closely associated with advocacy and activism, from promoting inclusion of persons with disabilities, through service user involvement and the assertion of rights and self-determination (Barnes, 2007).

The relationship between agency, activism and well-being has been partially explored in disability studies (Barnes, 2007), mental health (Gilster, 2012; Montague & Eiroá Orosa, 2017), and HIV (Earnshaw et al., 2016). There is some level of agreement regarding the sense of agency as a key aspect of the human experience of choice and action (Frohlich et al., 2001; Galvaan, 2012; Jay et al., 2018; Malik & Obhi, 2019), which are directly related to processes and outcomes of social inclusion. In this context, if social inclusion is to be meaningful and sustainable, it may be argued that it needs to be done on the terms of those seeking inclusion and not be forced on them. When seen in this light, the failure of the prescriptive approaches in substance abuse management is explained. The prioritisation of self-determination in patient

care is a well-established tenet in occupational therapy, as evidenced by the person-centred recovery models applied in promoting well-being and social inclusion (Jacob, 2015; Law, 1998; Lloyd et al., 2004; McKay & Robinson, 2011). The active engagement of service users and the involvement of their respective communities as equal and agentic beings for desired change, is also emphasised in occupational therapy (Laliberte Rudman et al., 2018; Laliberte Rudman et al., 2019). However, the political self as a function of agency is yet to be covered in complex situations of young adults with dual afflictions of substance abuse and HIV.

The Capability Approach emphasises people-centred, localised processes to increase the capabilities of the marginalised (Alkire, 2008; Frohlich & Potvin, 2010; Suzuki, 2017). Suzuki (2017) advocates that social exclusion implies a denial of social relations leading to serious deprivation of important capabilities. Applying the concept to sport-based social inclusion programmes, he further asserts that at the micro level, agency is most functional but that there has been limited exploration of enabling self-determined social relations. From the analysis, he, however, recommends that more research needs to be done on agency and structure as they apply to the meso and macro levels of social inclusion programmes and alternatives, to facilitate structural transformation towards a more socially inclusive society (Suzuki, 2017).

Limited agency has also been implicated in increasing the vulnerability of women and children to HIV in most sub-Saharan states (Campbell et al., 2015; Rwafa et al., 2019; Sia et al., 2013). The importance of agency when helping people in difficult circumstances has been identified as strategic when working with children and women living with HIV in Zimbabwe (Campbell et al., 2015). Campbell and colleagues drew on Sen′s understandings of agency to raise attention to the negative consequences of many of the choices available to children and the contextual limits on outcomes children themselves would value rather than on what would be prescribed for them (Campbell et al., 2015). Still working within the field of HIV in Zimbabwe, Rwafa and colleagues (2019) found that, despite being in a patriarchal society, women who had agency could negotiate power inequalities and make choices to reduce their vulnerability to HIV and consequently social exclusion (Rwafa et al., 2019). They recommended that notions of agency need to take greater account of service user′s accounts of the outcomes that they value.

Another function of agency as derived from the Capability Approach is that of converting resources and opportunities into valuable functioning (achieved capabilities). However, it remains underexplored in situations of exclusion and ill health. Ingrid Robeyns distinguishes

between three types of conversion factors influencing *the extent to which* a person can transform resources into functioning (Robeyns, 2011, 2016):

- *Personal conversion factors*
- *Social conversion factors*
- *Environmental conversion factors*

Agency is a recognised personal conversion factor, influencing our ability to achieve valued doings and beings (Robeyns, 2016; Sen, 1999). It is possible that the personal, social and environmental conversion factors are likely to interact with each other in diverse ways, depending on context, though the influence of the context for DAYA in Zimbabwe remains unexplored. In this sense, the indicative examples and types of convergence factors proposed by Sen and Robeyns are invitations to sociological theorisation about such interrelationships and not a given list for sorting (Hvinden & Halvorsen, 2017).

In critical occupational therapy, the application of agency as a personal conversion factor is in its infancy but is gaining traction. Pereira developed the Capabilities, Opportunities, Resources and Environments (CORE) approach using the concepts of agency and capabilities for inclusive and occupation-focused practice (Pereira, 2017; Pereira et al., 2020). This approach is considered a practical way of working with service users, applying their agency for capability enablement and social inclusion (Pereira, 2017; Pereira et al., 2020). Proponents of this approach, however, suggest that there is a need for sustained knowledge generation studies on how the approach and concepts involved apply in different contexts.

2.5. Conclusion

This review reaffirms the multiple perspectives needed to further the understanding and promotion of social inclusion. The review reiterates the complexity and dynamic nature of social inclusion which has resulted in the sustained call for continued exploration to seek understanding in diverse settings. The debate about what constitutes social inclusion remains inconclusive, though it continues to expose the paucity of insights from some geopolitical contexts, namely the Global South, and the experiential knowledge of the typically marginalised in these settings.

The gap in knowledge is even more marked when considering the social exclusion of those facing multiple disadvantages in developing countries, as is the case with young adults dually afflicted with substance use disorders and living with HIV in Zimbabwe. Without such evidence, it is very difficult for occupational therapy and other related professions to realise

the social inclusion vision for all. There is, however, the promise of achieving this vision by directing efforts towards the social context and its influence on agency and occupational choice. Exploring the experience of social inclusion through agency and occupational choice among DAYA is yet to be done.

The following chapter builds a theoretical argument to contextualise this exploration.

Chapter 3 . A Critical Theoretical Perspective

3.1. Introduction

This chapter presents the theoretical framework that informs the study. This has been developed through triangulating complementary theories of critical social theory, decolonial theory and the capability approach. Together these three, constitute the critical theoretical perspective of this study. Chapter three introduces the theories and then discusses how selected concepts and principles extracted from these theories aid the understanding of social inclusion among DAYAs.

3.2. A critical and decolonial foundation

3.2.1 Critical Social Theory

Critical Social Theory has its foundation in the Frankfurt School and the work of Habermas (Geuss, 1981; Piccone, 1983; Rush, 2004; Stevens, 1989). The theory is credited for challenging society in totality and advocating for change (Macey, 2000). This theory focuses on the betterment of the human condition by looking for more humane alternatives to prevailing negative social conditions (Ngwenyama, 1991). The primary goal of Critical Social Theory, as explicated by Stevens (1989), is to break the oppressive grip of closed systems of thought and to counter unreflective societal affirmations. A core component of this theory is to challenge the traditional assumptions of what we assume to be 'truth' and 'knowledge' and what we understand to be 'power' (Stevens, 1989). To achieve this, Critical Social Theory brings to the fore hidden oppressive forces and advocates for the emancipation of those experiencing these forms of oppression through social, political and economic forces (Blaikie, 1993; Blaikie, 2007). It calls for uncovering the "…distortions and constraints that impede free, equal and uncoerced participation in society" (Stevens, 1989). Through providing a way to challenge these distortions, Critical Social Theory facilitates the generation of new knowledge, emphasising the primary importance of human subjectivity in challenging established ideologies which are assumed to be serving as oppressive systems (Duchscher, 2000; Stevens, 1989). Social inclusion also challenges the oppressive systems under which marginalised population groups, such as the DAYA, continue to experience stigma and discrimination.

In the current study, Critical Social Theory provides a powerful critique of the systems and situations that perpetuate health inequalities, including restricted participation in occupations, which commonly affect those experiencing injustice. To challenge these societal injustices, the theory helps explain, challenge and change what is unjust with any prevailing situation or system (Phillips, 2009; Piccone, 1983). To achieve justice, the theory prioritises participation

in occupations and social inclusion for all. To understand this, this study uses Critical Social Theory to critique the historical whole and current situatedness of occupation, social inclusion and social structures (Stevens, 1989).

The thrust of Critical Social Theory settles well with the holistic philosophy and an emerging emancipatory agenda in occupational therapy and occupational science. This aims for critically reflexive and socially transformative practice (Farias & Rudman, 2019; Malfitano et al., 2014; Sakellariou & Pollard, 2013). By focusing on the whole or totality of phenomena, one is able to explore their historical positioning (Phillips, 2009). This critical, reflexive and socially responsible inquiry calls for challenging normative expressions and historical positionings of phenomena in order to understand them and to bring about change. With the underlying assumption that the realities faced by those dually afflicted with substance abuse and HIV (DAYA) are stigmatising and discriminating, Critical Social Theory is an asset in unpacking the oppressive forces working against the emancipation of these young adults (Stevens, 1989).

In the application of Critical Social Theory this study explores the six assumptions and seven concepts proposed by Stevens (1989). These are primarily derived from the Frankfurt School but include some tenets of feminist theory. The current methodology (Chapter 4) and discussion (Chapter 7) draw heavily on these assumptions and concepts, which are discussed below. The 6 assumptions are:

1. **Research and theory are socio-political and economic constructions**
   This means that social, economic and political realities are always reflected in research and theory. This assumption allowed the researcher to explore the social, political and economic processes that interact with the everyday social inclusion of the DAYA, as well as the situatedness of these processes within the context of Zimbabwe.
2. **Human societies are inherently oppressive**
   Modern industrialised societies are characterised by embedded oppressive structures that remain unchallenged. These oppressive forces are so naturalised that they are taken for granted. This study looked for the oppressive structural relations assumed by participants to be ‘normal’ and unmasked and challenged them.
3. **All interpretations of society are open to criticism**
   This allows for a critique of the mythical, religious, political and scientific interpretations of all phenomena. From this assumption, the framing and current understandings of the social inclusion realities of the DAYA could be questioned.

4. **Social conditions are a creation of specific historical situations**
   This implies that social conditions are not neutral or constant but emerge as products of dynamic historical happenings. This assumption allowed the examination and contestation of the presumed natural and constant state of social realities for the health, well-being and social inclusion of these young adults.
5. **Conditions of present human hardships can be understood by studying the historical developments of oppressive arrangements in society**
   This allowed the researcher to deliberately explore the historical events - including precolonial, colonial and postcolonial developments - and the way they impacted on the daily realities of Zimbabwean society. The changing conditions of suffering faced by the DAYA could be explored through their historical life journeys as occupational beings. Legislative and policy documents were also reviewed to capture their historical impact on the DAYA's occupational choices over time.
6. **Liberation from oppressive structures is a primary desire for the human condition**
   This assumption frames these young adults as agents in pursuit of freedom and their inherent quest for human potential, completion and authenticity. They might achieve this through occupational choices that challenge hegemonic traditions and exercise agency in nonconformity. One of the concepts proposed by Stevens (1989) which is applied in this study is that of *conscientisation.* This assumes that when individuals learn to perceive social, political, economic and historical contradictions, they can then develop ways to fight their oppressive conditions. Critical understanding of social conditions of inequality and the action taken to change them by the oppressed themselves, is what Freire terms critical consciousness (Freire, 1973). It is through this critical consciousness that those experiencing marginalisation develop human agency against the odds of structural constraints (Diemer et al., 2017; Freire, 1973). This is considered the core work that should take place when working with a traditionally marginalised group (Horkheimer, 1995).

Critical Social Theory also has facets that allow us to understand the constraining contextual factors on these young adults' health and well-being, while simultaneously being positioned to offer transformation for their optimum potential (Stevens, 1989).

Seeing the role played by historical oppressive systems which the Critical Social Theory exposes and challenges, led the researcher to question the implications of colonialism and

coloniality foe social inclusion. He took a decolonial perspective to illuminate usually hidden issues around occupational participation, ill health, stigma, choice, injustice, inclusion and exclusion of young adults in his context in the Global South.

3.2.2. Decolonial Theory

Decolonial Theory is rooted in critical theory, emphasising forms of inter-subjective, social, cultural and political subordination that deny freedom and opportunity to some groups. Decolonial theory seeks to liberate oppressed people by specifically exposing systems of coloniality through thought, language and logic (Mignolo, 2007). Decolonial Theory leads to radical thinking which questions and challenges the colonial aspects of power, knowledge and being, through epistemological shifts from dominant ways of thinking, knowing and doing (Ndlovu-Gatsheni, 2015).

The theory is premised on the view that the primary problem in the present world emanates from colonialism (Maldonado-Torres, 2011), and presents ways of fighting the oppression that emanates from it. Decolonial theory therefore provides processes which allow for the unveiling of places where colonial ideology/assumptions is/are being reproduced and sustained. This in turn, allows for those ideologies and assumptions to be challenged. The theory encourages the emergence of alternative, and usually indigenous, possibilities (Maldonado-Torres, 2007; Ndlovu-Gatsheni, 2015). In other words, Decolonial Theory seeks to liberate the 'other' from oppression by unmasking the ills of coloniality, modernity and neo-liberalism, by advocating for methods that are alternative and self-liberating. In this study, this perspective contributed to conceptualising social inclusion as a multidimensional political construct which is complex and connected to macrolevel social elements.

Decolonial Theory challenges the concept of universality, arguing that diversity should be embraced, for there is no single truth about anything (Grosfoguel, 2011). With this pluriversality of truth, Decolonial Theory is well positioned within the constructivist paradigm, as it challenges a single universal worldview. The theory also contests the notion that those in the Global North produce knowledge and 'others' in the Global South are merely sources of data and consumers of knowledge (Mignolo, 2011). If we assume that knowledge is situated and constructed and then layer this assumption with the understanding that colonial thinking dominated knowledge production (Mignolo, 2009), then a decolonial perspective involves delinking from this notion and a focused critique of the arising modern, colonial, capitalist and patriarchal world-system. By questioning the basis and control of hegemonic knowledge and working to reaffirm the significance of situated knowledge, this study aims to open space to

affirm knowledge produced by people like the DAYA from the Global South, who have been historically excluded from knowledge production because they were treated as subjects (Mignolo, 2009). In this study a decolonial perspective affords the researcher to view the participants as knowers and producers of knowledge. Using Decolonial Theory, the research took heed of the call to acknowledge alternative ways of being, doing and producing knowledge in the world.

Decolonial Theory works to raise awareness and consciousness among the oppressed so that they can work towards their liberation (Ndlovu-Gatsheni, 2015). This awareness is essential in health and social care where Eurocentric concepts around social inclusion are seen as 'the norm'. Instead, Decolonial Theory encourages these systems to benefit from indigenous knowledge systems. A decolonial theoretical lens also helped to explore and explain - with a liberating intention - the complex and intertwined contextual factors constraining decisions about participating in occupations in these young adults' lives. In doing so, Decolonial Theory sanctioned a critical eye that could disrupt the assumptions of exclusionary normalcy that manifest themselves in definitions of stigma and discrimination.

3.2.2.1. Understanding coloniality

Coloniality is different from colonialism. Colonialism refers to the presence of colonial administrations with racialised oppression and exploitation by dominant racial groups in terms of the local's cultural, political, economic, spiritual and sexual systems (Quijano, 2007). The distinct feature of colonialism is that there is domination and exploitation resulting in the sovereignty of the local nation resting on the power of the dominant nation (Maldonado-Torres, 2007, 2011). However, coloniality refers to the "invisible threads of power that emerge in colonial situations but extend well beyond a strictly colonial setting or period" (Giraldo, 2016, p. 161). In other words, coloniality is the continued and pervasive existence of colonial-like power relations or the 'darker side of modernity' (Giraldo, 2016; Maldonado-Torres, 2007), presenting a challenged life for those in zones which experienced settler colonialism (Mignolo, 2005; Quijano, 2007). This understanding helped with the exploration of coloniality as the continued forms of domination and oppression possibly being experienced by the DAYA, making them a powerless marginalised group within the powerful mainstream.

Those affected by coloniality internalise and normalise the extent to which people are able to question and or challenge the rhetoric of modernity. Ndlovu-Gatsheni posits that, with internalised oppression, we strive to be who we are not, and seek to be included on other people's terms, attaching value to everything Western while despising the indigenous (Ndlovu-

Gatsheni, 2013). People are constrained by coloniality when they blindly promote social inclusion through restricted occupational pathways such as formal education and paid employment, instead of using critical methods to expose and challenge these assumed 'universal' inclusion channels.

Decolonial Theory assumes that both historical and current contextual conditions directly and indirectly influence people's everyday lives and their occupational choices (Gallagher et al., 2015; Galvaan, 2015). As a result, people such as the DAYA, are forced to interact with their specific contexts and create their life realities in a prescribed way which might not be in tandem with their indigenous culture (Oxford, 2019; Said, 2003; Santos, 2007; Simaan, 2017).

The historical positioning of life in Zimbabwe can be traced back to the colonial era, where colonial and Eurocentric views of the relationships between power, knowledge and ways of being that dictated how life was to be led. Decolonial Theory allowed the consideration of difficult and complex questions that go beyond the traditional normative ways of understanding social phenomena as this research was pursued. Adopting a decolonial perspective in this study, the researcher asked himself a reflexive question about whether the realities of social inclusion among DAYA in Zimbabwe are a continuation of the structures of domination traceable to the continuation of coloniality. The narrative inquiry and subsequent analysis assumes the existence of hegemonic systems, dominant discourses and colonial residues perpetuating the DAYA's positioning in society and reinforcing their identities as marginalised actors.

Decolonial Theory provided the tools to challenge colonial assumptions by exploring how the status quo of power, knowledge and being in the matrix of the social inclusion of the DAYA occurred. Some major proponents of Decolonial Theory identify with three main units of analysis for understanding coloniality: i) Coloniality of Power; ii) Coloniality of Knowledge; and iii) Coloniality of Being (Grosfoguel, 2007; Maldonado-Torres, 2007; Mignolo, 2009; Ndlovu-Gatsheni, 2013; Ndlovu-Gatsheni, 2015; Quijano, 2007).

A. Coloniality of Power

Coloniality of Power examines how the invisible dominant global political power was constructed and constituted to oppress others. The global asymmetrical and unequal power relations in a capitalistic world economy form the base of Coloniality of Power (Ndlovu-Gatsheni, 2015). The desire is to maintain a global capitalistic order affecting all functions of social existence (Quijano, 2000). This global economic power is reproduced and maintained through knowledge systems and configured into hierarchies

of domination: race, class, gender, sexuality, religious, ethnic, epistemic and linguistic forms (Grosfoguel, 2011). These hierarchies constitute colonial matrixes of power directly influencing the everyday realities, quality and materiality of the lives of citizens (Behari-Leak & Mokou, 2019). This power domination results in inequalities and the systematic exclusion of those not favoured by the modern power structures, as is the case for those with a dual affliction of substance abuse and HIV (Nora D. Volkow & Montaner., 2011; Stockman & Strathdee, 2010). The Decolonising of Power in this study therefore entails realignment of power between the powerful and the powerless in a way that supports the DAYA to change their own lives. Decolonising Power also challenged the researcher to explore social structures working to sustain dominant practices which may have worked to exclude the DAYA from belonging in society. These dominant practices are usually hidden in everyday activities leading to internalised oppression (Behari-Leak & Mokou, 2019).

B. Coloniality of Knowledge

At the centre of Decolonial Theory lies Coloniality of Knowledge which focuses on hegemonic knowledge production. World knowledge systems have a Eurocentric orientation, which are expected to be accepted by Africa and the Global South. which remain defined as subjects and are therefore excluded (Sithole, 2014). In Coloniality of Knowledge, knowledge itself and ways of producing it, are pivotal in maintaining epistemological power at the expense of oppressed groups. De Sousa Santos (2007), talks of epistemicide, which is the erasure of indigenous knowledge, creating the 'Other' and marginalising non-Eurocentric knowledge systems. Decolonial thinkers reject the superior valuing of some knowledges at the expense of others (de Sousa Santos, 2007), hence recognising the value of multiple sources of data, including the DAYA, as valuable knowledge sources.

Therefore, when approaching phenomena like social inclusion in substance abuse and HIV, decolonial theory allowed the study to challenge dominant knowledge systems and promote indigenous and traditional knowledges which are usually silenced or excluded. It is assumed that in doing so understanding of the oppressed lived reality is broadened. Decolonial Theory also helps understand the politics of knowledge generation which define some methods of inquiry as 'less scientific'. Established institutions of learning and worship are used to perpetuate these injustices (Dastile & Ndlovu-Gatsheni, 2013). For example, decolonial thoughts from Africa, point to state-

assisted flourishing of coloniality of knowledge when Dastile and Ndlovu-Gatsheni (2013) claim that; "schools, churches and universities contribute towards the invention of the 'other' as they operate as epistemic sites as well as technologies of subjectivation that make it natural for dominant powers to be universal" (p. 111). In Zimbabwe, Shizha (2006, 2010) has argued for deliberate inclusion of indigenous knowledges in both formal and informal curriculum, so as to de-legitimate Eurocentric hegemonic knowledge systems. He further posits that the promise of indigenous knowledges and practices can be realised through applying decolonial thinking to disrupt dominant Eurocentric views disguised as universal knowledge and questioning the unwarranted devaluation of indigenous practices (Shizha, 2006; Shizha, 2010).

In order to effectively critique dominant knowledge systems, including the way we think about occupational perspectives in relation to social inclusion in marginalised groups, the researcher sought specifically to differentiate between established knowledge systems about social inclusion in substance abuse and HIV and those which had not been given equal value, such as experiential knowledge. For this, he ensured that the primary focus was the DAYA.

C. Coloniality of Being

This concept concerns the way we make modern subjectivities, the nonbeing and ontological negation of the other (Maldonado-Torres, 2007; Ndlovu-Gatsheni, 2015). Coloniality of Being exposes how people's different identities emerge and are then categorised into bipolar binaries (Quijano, 2000). In his writings on coloniality, Quijano further suggests that there are dominant powers behind this:

"World ordering by dominant powers continues to differentiate the global population into bipolar binaries of inferior and superior, irrational and rational, the primitive and civilised, traditional and modern, the black and the white, the civilised and the uncivilised, the powerful and the marginalised, the able and the disabled" (Quijano, 2000).

With this thinking, social inclusion and its opposite, social exclusion, become functions of equality and inequality. Traditionally, those stigmatised for health and social problems like substance abuse and HIV, occupy the inferior and powerless categories (Nora D. Volkow & Montaner., 2011; Stockman & Strathdee, 2010), allowing those fitting the normalcy category, to experience superiority and social inclusion at their expense.

> In this world order, there is a predefined normalcy or gold standard, which serves to deny alternate differences, plurality and other views (Ndlovu-Gatsheni, 2015). In the African context, Ndlovu-Gatsheni (2015), points out how Coloniality of Being serves to question African humanity and feeds into processes that objectify, thingify and commodify Africans. According to Behari-Leak & Mokou (2019), Decoloniality of Being entails, "…reinserting the full humanity of people as thinking, feeling and doing individuals in a collective, irrespective of race, gender, ability, religion and so on" (p. 138). This resonates well with the social inclusion of marginalised groups in this study. To be fully included, one needs to be worthy of human status and to be a benefit to humanity (Behari-Leak & Mokou, 2019).

By framing this study around Decolonial Theory, room was created to question the colonial legacies shaping the development, globalisation and modernity agenda (Asher, 2013), with regard to SUD and HIV. The need to shift perspective and delink from hegemonic knowledge production processes led the researcher to apply a critical, reflexive approach, emerging as a revolutionary scholar through an epistemological critique (de Sousa Santos, 2007; McLaren, 2001). Moreover, the application of Decolonial Theory guided the study to analyse individual experiences of the DAYA within their geopolitical context and to contribute to the broader agenda about equity, choice and inclusion.

3.3. Capability Approach (CA)

The Capability Approach is a theoretical framework that is evolving into a theory of justice. It was proposed by Sen and has been successively developed by other scholars, most notably Martha Nussbaum. From conception, the Capability Approach has been understood to be a flexible and multi-purpose framework about well-being and development, rather than a specific theory (Robeyns, 2011). Sen defines it as a theoretical framework of development and justice that emphasises the examination of inequality found in everyday social arrangements (Sen, 1992). Sen's Capability Approach (1985, 1992) was chosen to inform the current study because it identifies with the paradigm shift towards less and less prioritisation of economic markers of human development and well-being and places the human being at the centre. Using the Capability Approach entails a concerted effort towards social inclusion, health and human development by promoting agency and enlarging people's choices (Hoffman, 2006).

The Capability Approach introduces a multidimensional conceptualisation and measurement of human development and life satisfaction where equality, agency, functioning, and capabilities are central aspects that need to be examined (Alkire, 2005; Gasper, 2007; Sen,

1992). These central elements of satisfaction, equality, agency and capabilities applied in the exploration of social inclusion among the DAYA.

To achieve equality and justice in development, Sen's Capability Approach proposes a focus and examination of *functionings* and *capabilities* (Sen, 1992), in which people have reason to value their personal, social and cultural circumstances (Alkire, 2008; Alkire & Deneulin, 2009). Sen distinguishes between basic functionings (e.g., being nourished, being healthy and avoiding premature mortality) and more complex achievements (being happy, having self-respect and being able to participate in the life of the community [social inclusion]) (Sen, 1992). Related to functionings are capabilities, which are understood as the real opportunities and freedom people have to achieve their valued doing and being, mostly concerned with what is feasible for people to obtain (Sen, 1992). A Capability Approach positions social inclusion as inexplicably linked to justice, which is achieved by expanding the individuals' capabilities (Alkire & Deneulin, 2009; Sen, 2009).

Agency is central to Sen's Capability Approach and he defines it as the individuals' capacity to achieve their own goals and values in life which may not be related to their personal welfare (Sen, 1992). To him, an agent is someone who can act on a situation in order to bring about desired change. In difficult situations, like poverty and other situations that foster exclusion, Sen advocates for the promotion of agency and empowerment to fight them (Sen, 1999). In other words, the concept of agency is an integral component of empowerment (Ibrahim & Alkire, 2007). This empowerment is understood to mean an increment in power, theoretically associated with being autonomous, having self-direction, self-determination, being free or liberated and having self-confidence (Ibrahim & Alkire, 2007). Ibrahim and Alkire (2007) suggest indicators of agency and empowerment that were useful when exploring social inclusion in marginalised groups. These included i) control over personal decisions, ii) power to make autonomous choices, iii) the ability to change aspects in one's life at the individual level and, iv) the ability to generate changes at a communal level. These four indicators formed part of the areas of discussion with the DAYA during the narrative interviews, so that the researcher could better understand what actions they took in their social inclusion circumstances.

The Capability Approach argues that in order for justice and inclusion to occur, individuals need freedom to choose and then achieve valued functionings in life (Nussbaum, 2007; Sen, 1993, 1999). In other words, a person's opportunities or 'capabilities' are more important than

their actual achievements (Sen, 1999). In the process, the focus of justice and social inclusion shifts from meeting the needs of those who are excluded to the expansion of their capabilities (Sen, 1992; Sen, 2009). The goal is to expand and equalise the actual freedom of the marginalised. In this study, the researcher applied these insights to explore the choices made by the DAYA as they sought to achieve valued ways of doing and being on equal terms with others.

People's capabilities are influenced by many conditions, including historical, economic, social and cultural factors. These factors influence people's capabilities at micro-, meso- and macro levels of social processes and need to be investigated at these levels (Suzuki, 2017). More recent work on social inclusion where the Capability Approach was applied has argued that social inclusion outside economic terms can be achieved through capability expansion that focuses on agency and participation in self-selected livelihood opportunities (Suzuki, 2017; Tiwari, 2014).

Occupational therapists and scientists have been attracted to the Capability Approach for some time, they have demonstrated its merit in establishing occupational participation as a human rights issue, focusing attention on equality of opportunities, quality of life, empowerment and justice (Hammell, 2015; Mousavi et al., 2015). The Capability Approach is used to push the socio-political agenda in occupational therapy, aiding occupational therapists to recognise and challenge the inequitable social circumstances, shaping access to occupational resources and opportunities that determine what people can do (Bailliard, 2016; Gallagher et al., 2015; Galvaan, 2015; Hammell, 2019; Pitonyak et al., 2015; Restall et al., 2018; Rudman, 2015). Hammell maintains that occupational therapists and scientists should draw from the Capability Approach as it encourages the consideration of more than the abilities of the people we serve. It includes their opportunities to envision, choose and accomplish what they wish to do and be (Hammell, 2015). Within the Capability Approach, the researcher drew on the focus of addressing the inequitable factors that determine the possibilities and the opportunities available to the DAYA for their social inclusion, development and the exercise of their abilities and the attainment of their occupational rights (Hammell, 2015).

The strength of the approach is that is allows for focus on the ability of people to lead lives they have reasons to value and it prioritises their subjective experiences in informing this. It also resonates with occupational therapy holism philosophy by supporting the use of a wide informational base of understanding health and well-being (Nussbaum & Sen, 1993). The

Capability Approach enabled the study to consider the concept of social inclusion as inherently relational and multidimensional, just as it has been used with regard to the concepts of disability, quality of life and occupational participation, (Hammell, 2015; Terzi, 2005). This entails looking beyond health impairments as causes that explain challenges faced by individuals. A capability perspective makes it possible to identify those religious, cultural and social factors and institutional structures that interact to constrain the opportunities and reduce the quality of life for vulnerable people (Bakhshi & Trani, 2006).

Using the Capability Approach, the study conceptualises the DAYA as people who experience severe deprivation of contextually important capabilities. The DAYA are understood as people with fewer capabilities to achieve their value functionings and are therefore regarded as having more restricted opportunities than others (Sen, 2009). The approach also aided in understanding stigma and discrimination as functions of injustice. In these instances, social exclusion as a function of injustice is understood as the denial of agency, choice and capabilities.

3.4. The synthesis of theories

Critical Social Theory, Decolonial Theory and the Capability Approach have been used conjointly as they complement each other in using a critical and situated understanding of phenomena. All three pay attention to issues of injustice and bring to the fore what is typically hidden and taken for granted. These theories also share an emancipatory focus when dealing with marginalised population groups such as the DAYA. The distinct advantage of using the Decolonial Theory together with the Critical Social Theory for this study is its focus on the Global South and its identifying mechanisms of subordination in Eurocentric scientific and political worldviews on social inclusion. The Capability Approach emphasises the key importance of exploring and questioning systems that influence the participants' freedoms, opportunities and processes (Sen, 1992), something also supported by the critical decolonial lens. In responding to injustice, the Capability Approach weighed in on the importance of agency and participative methods, while the Critical Social Theory and the Decolonial Theory reaffirm the importance of recognising difference and acknowledging indigenous knowledge. The unified theoretical lens suggests the need to strive for more equitable spaces for all. This ensures that the DAYA experience real social inclusion and gain the capabilities to live with dignity.

3.5. Conclusion

This chapter describes the use of a critical and decolonial foundation infused with the Capability Approach to inform understanding of the context and realities of social inclusion

for young adults with a dual affliction of substance use disorders and HIV in Zimbabwe. Drawing on these theoretical frameworks provided a more critical lens through which to view social inclusion, which allowed the researcher to explore the historical positions and use critical naturalistic methodologies and a critical discursive voice.

Chapter 4 . Research design and method

4.1. Introduction

This chapter describes the research design adopted and the methods applied in this study. It begins with explaining the philosophical standpoint, justifying the selection of a qualitative research design, and then discusses why an instrumental case study design was chosen. This is followed by detailed descriptions of the research process, including the four research data sources used. It concludes by discussing measures applied for enhancing methodological rigour and the ethical considerations undertaken throughout the study.

4.2. Philosophical standpoint

This study is informed by constructivist philosophy that posits that knowledge is socially constructed as individuals interact with each other and their environments (Lee, 2012; Murphy, 1997; Prawat & Floden, 1994). In constructivism, truth is considered relative and dependent on the interpreter`s perspective (Baxter & Jack, 2008; Miller & Crabtree, 1999). This paradigm "recognises the importance of the subjective human creation of meaning but doesn't reject outright some notion of objectivity" (Miller & Crabtree, 1999, p. 10).

With respect to the concept of social inclusion, constructivist philosophy argues that experience and reality cannot be objectified but are instead socially constructed as the individual interprets his/her interaction with the environment (Appleton & King, 2002; Fox, 2001; Lee, 2012; Prawat & Floden, 1994). Within this view, there are as many ways to experience and negotiate social inclusion as there are people living through it. Therefore, within this framework, the meaning of experiences and events are a co-construction of reality between the researcher and study participants through a critical reflective relationship (Charmaz, 2006). The qualitative research design in this study reflects the constructivist paradigm's assumption that reality is not absolute but is defined through social interaction and community consensus (Mertens, 2007; Mertens, 2014).

4.3. Qualitative research

In selecting the research design for this inquiry, the researcher was seeking a design that allowed an in-depth understanding of the multifaceted phenomena of social inclusion in DAYA to be revealed. Qualitative research is a multifaceted research method involving a holistic, interpretative and naturalistic approach to its subject matter (Denzin & Lincoln, 2005). The multifaceted nature of qualitative research enables researchers to develop a holistic picture of problems affecting society by exploring human experience in context (Creswell, 2007). This qualitative design was chosen because it could take into account the holism, subjectivism and

pluralism of reality. Specifically, the researcher wanted to take advantage of the utility of qualitative research methods to describe and explain individuals' experiences, behaviours, interactions and social contexts (Corbin & Strauss, 1990). Qualitative research allows for the exploration of the complexity and multidimensional nature of the concept and processes of social inclusion.

The research was guided by the following five principles for choosing qualitative research which Creswell (2007) advocates for. The first principle identifies that qualitative research is best suited for an in-depth exploration of complex issues. This study explores the complexity of social inclusion as it relates to DAYA. The second principle is that the research must aim for a detailed understanding of phenomena. This study presents a detailed description of the experience and negotiation of social inclusion by DAYA. Third, qualitative research allows for participants to share their specific stories and have their voices heard, and, in this study, this was enacted through creating such opportunities during data generation. The fourth principle supports the use of qualitative research where there is a need to minimise power relationships between the researcher and study participants. An approach that enables collaboration with the DAYA in the co-construction of the data has been adopted (see section 4.5.1 below). Finally, Creswell advocates for the use of qualitative research where there is need to explore and understand the broader and naturalist contexts in which events take place. This study explores the DAYA's experience and negotiation of their social inclusion within the context of Zimbabwe.

Moreover, qualitative design is often preferred in research in occupational therapy and occupational science as it focuses on the contexts within which individuals find themselves. Whiteford, an established occupational scientist, argues that "…the unique epistemological foundation of occupation…is best understood through naturalistic means" (Whiteford, 2004, p. 41). This entails studying phenomena using genuine life experiences in the subjects' , social and physical contexts (Frey et al., 1999; Whiteford, 2004). Several specific research designs are supported under naturalistic inquiry, including Grounded Theory, Narrative Inquiry, Ethnography, Phenomenology and Case Study design. Case study design was selected for this study, not only because it is set up to analyse multiple data sources but also because it generates in-depth understandings of phenomena in context.

4.3.1. Qualitative Case Study Design

While there are many definitions of case study research, three main definitions of interest come from Creswell (2007), Stake (2008) and Yin (2009) (Table 1). I chose the case study design to

help me get a gestalt picture of social inclusion as experienced and negotiated by DAYA. I required a design that would allow for multiple perspectives that would in turn help us build a more comprehensive picture that alone those perspectives could not accomplish (Creswell, 2009; Stake, 2008; Yin, 2009). The use of multiple perspectives is well supported in case study research and Creswell (2009) and Merriam (1998) each maintain that all methods of data collection may be used within the qualitative case study design (Creswell, 2009; Merriam, 1998).

Table 4.1: Common Case Study Definitions

Creswell (2007, p. 73)	Stake (2008, p. 121)	Yin (2009, p. 18).
"approach in which the investigator explores a bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information (e.g., observations, interviews, audio visual material and documents and reports) and reports a case description and case-based themes"	"A case study is both a process of inquiry about the case and the product of that inquiry"	"a case study is an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident"

This study draws on each of the theorists' conceptualisations of case study. Those elements of their conceptualisations of case study research that best suit specific needs of the study were used. The researcher mostly drew from Creswell (2007) who focuses on the importance of using in-depth interviews and triangulation of multiple data sources to understand the data.

However, he also found Yin's (2003) guidelines for when to use a case study design particularly useful. He considered a case study design because: (a) the focus of the study was to answer "how", (b) he could not and did not intend to manipulate the behaviour of the participants, (c) he wanted to explore contextual conditions, relevant to the study of social inclusion in DAYA and (d) the boundaries were not clear between the phenomenon of social inclusion and context of Zimbabwe (Yin, 2003).

There are many types of qualitative case study designs (Stake, 1995; Yin, 2009). The researcher was drawn to Stake's (1995) typology as it is extensively applied in research and easily aligned with the constructivist paradigm. This typology is increasingly being applied in critical studies of occupation (Hercegovac et al., 2019; Jónasdóttir et al., 2018). Stake identifies case studies as intrinsic, instrumental or collective. The definitions of these types of case studies are presented in Table 2 below.

Table 4.2. Stake's Case Study Types

Case Study Type	**Definition**
Intrinsic	Used to understand the case itself by a researcher who has a genuine interest in the specific case and not how it applies to similar cases. It is the case itself that is of interest, with all its particularity and ordinariness.
Instrumental	Examines the case in depth, scrutinises its contexts, detailing the ordinary activities involved. It helps the researcher pursue an external interest outside of the chosen case. In an instrumental case study, the case is of secondary interest; it plays a supportive role, facilitating our understanding of something else. It provides insight into an issue or helps to refine a theory beyond the chosen case.
Collective	The collective case study is conducted to provide a general understanding using multiple case studies from either the same site or from multiple sites.

For this research, a single instrumental case study design is used. The researcher chose one issue, an occupational perspective of social inclusion for DAYA, and selected one bounded case to illustrate the issue. He did not want to gain a generalised understanding informed by multiple case studies, which would result in a collective case study, or to conduct an intrinsic case study which would have narrowed the scope. Instead, he was interested in an in-depth understanding of social inclusion from everyday occurrences and in scrutinising the context that situated these activities (Stake, 1995). In this instrumental case study, the DAYA play a supportive role, facilitating understanding of an occupational perspective of social inclusion. They provide insight into social inclusion and even helped further our understanding of it beyond their realities as DAYA. This design was best suited to answer the research question and provide an in-depth understanding of social inclusion, using cases of young adults with SUDs and living with HIV in Zimbabwe. It was thus the design of choice because it allowed for in-depth, multi-faceted explorations of complex issues (Crowe et al., 2011) around an occupational perspective of social inclusion, SUD and HIV/AIDS in real-life settings through the eyes of DAYA.

This study's design also demonstrates the characteristics of an instrumental case study (Stake, 2000; Stake, 1995) in that it explores phenomena beyond the immediate particularities of the situation examined. Here the researcher did not just look at the individual narratives but placed their stories within their historical and legislative contexts. Finally, this study meets the criteria of an instrumental case study design because the case served as an instrument for studying issues related to social inclusion in HIV and substance use.

Boundaries of the case

The main proponents of the case study design advocate for placing boundaries around the case (Stake, 2008; Yin, 2009). The most common ways to create a boundary for the case are to look at its nature or definition, context, activity and time period (Creswell, 2013; Crowe et al., 2011; Miles & Huberman, 1994; Stake, 2008). This assists in avoiding the common pitfall of asking questions that are too broad and setting too many objectives. In this study the case is bounded by definition and by context, activity and time. The "case" is defined as an occupational perspective of social inclusion as experienced and negotiated by DAYA in Harare, Zimbabwe. Study participants had to have been living with the comorbid diagnosis for at least one year, which was deemed sufficient time to have developed an experiential story about their social inclusion. on the focus is on differentiating between what the case was and what it was not when creating its boundaries.

4.4. Data generation and collection

The case study approach usually involves the collection of multiple sources of evidence, using a range of quantitative and more commonly, qualitative techniques, to develop a thorough understanding of the case (Crowe et al., 2011). An underlying assumption is that approaching the study question from different angles can help generate a holistic picture of the phenomenon (Crowe et al., 2011). In data generation and collection for this case study, four data sources were triangulated (Figure 1):

- narrative inquiry with five DAYAs, as the main data source;
- in-depth interviews with five key informants working in the field of mental health, substance abuse and HIV;
- document analysis of seven government Acts, policy, and strategic plan documents that address HIV and mental health;
- an exploratory cross-sectional survey of social inclusion and its associated factors among 105 DAYAs.

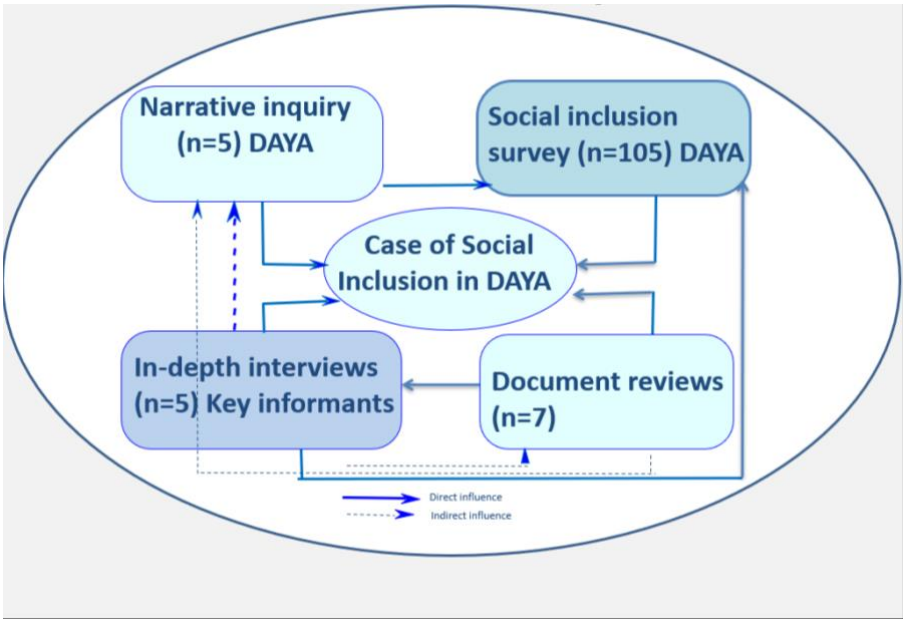


Figure 4.1. Case study data sources

These four data sources were selected based on their ability to answer the research question from multiple perspectives in order to gain an in-depth understanding of social inclusion in relation to DAYAs.

Narrative inquiry with DAYAs was chosen to gain experiential insights. In-depth key informant interviews were used to obtain expert practitioner and government perspectives. Document reviews served to contextualise the case by giving policy and archival descriptions of the context. The cross-sectional survey helped to explore the case by quantifying the extent of social inclusion and associated factors in a larger sample. The data sources at the second level of thematic case analysis were converged with narrative data from DAYA as the main source (Baxter & Jack, 2008; Flyvbjerg, 2006). All of this helped develop a full understanding of social inclusion amongst DAYA.

4.4.1 Data generation with DAYA

4.4.1.1 Study population of DAYA recruitment sites

For the narrative inquiry data source of the study, participants were recruited through three main places/facilities in Harare, Zimbabwe: i) psychiatric units at two main referral hospitals, ii) the corresponding opportunistic infection (OI) clinics at these two main referral hospitals and iii) a support group for young adults living with HIV in one of Harare's high-density suburbs. For the survey data source, only the first two facilities were needed. The OI clinics offered access to those DAYAs primarily defined by their HIV status, while the psychiatric units gave access to those primarily defined by their SUD status.

The researcher received study site permission and ethical clearance (detailed under 4.7. Ethical Considerations) before accessing study participants. This included permission to put up study adverts (Appendix M & N) in strategic points within potential recruitment facilities.

4.4.1.2. Selection of participants – DAYA in Narrative inquiry

A purposive sampling strategy was used for selecting participants (Baxter & Jack, 2008; Palinkas et al., 2015; Palys, 2008). Purposive sampling is a non-probability sampling strategy commonly used in qualitative research. It involves searching for participants who meet a certain criterion which helps answer the objectives of the study (Palys, 2008; Stake, 2008).While using purposive sampling, principles of maximum variation were applied in order to make the sample as heterogenous as possible. This is a technique used in qualitative research sampling to reach a diverse range of participants whose different characteristics are all relevant to the phenomenon under study (Palinkas et al., 2015; Patton, 2005). Using maximum variation sampling allowed for the selection of a small number of participants who maximised the diversity relevant to the research question and the capture of a wide range of DAYA's experiences and their negotiation of social inclusion.

4.4.1.3. Inclusion criteria for DAYA

The following criteria were used to select the DAYAs for narrative inquiry and cross-sectional survey:

1. Young adults between the ages of 18 and 35. This group was chosen because the literature suggests that it is the group most affected by substance use problems, economic challenges and also has one of the highest prevalence rates of HIV (UNAIDS, 2020; Duffy et al., 2017). Moreover, members of this group are key socioeconomic and political players whose social inclusion has far reaching impact.

2. Young adults with a diagnosis of SUD comorbid with HIV (irrespective of whether they were on treatment or not).

3. Participants whose primary language was either English or Shona. This was because participants had to share their stories and complete questionnaires in languages in which they were comfortable and the researcher fluent. fluent.

4.4.1.4. Exclusion criteria for DAYA

I excluded potential participants if they met the above inclusion criteria but had severe intellectual impairment, acute psychosis, or severe HIV/AIDS dementia (screened by using the International HIV Dementia Scale (Sacktor et al., 2005)- See Appendixes O and P. While

acknowledging that these individuals would have rich experiences to share, it was also recognised that their impaired mental state would have rendered it difficult for them to share their stories or to answer the survey questions. Interviews with participants who qualified and had consented to be in the study but were under the influence of substances on the day of the interview were rescheduled and offered counselling support.

The researcher was responsible for the screening of those who met the criteria for participation in narrative interviews. For the cross-sectional survey, a team of research assistants was trained. They screened the participants, obtained written informed consent and administered the questionnaire to the participants.

4.4.1.5. Participants sample size DAYA in narrative inquiry data source

Five young adults were recruited for the narrative inquiry. In both case study and narrative inquiry research, smaller samples are sufficient to produce an in-depth analysis (Creswell, 2013; Guetterman, 2015). The researcher wanted to ensure a diversified sample that differed by age, gender, marital status, duration of living with known dual affliction, substances used/abused, educational level and employment status. to the researcher diversified the sample on these seven primary characteristics as shown in Table 3 below. These sociodemographic characteristics were considered to have the potential to influence the experience and negotiation of social inclusion among young adults in Zimbabwe. This diverse sample makes deeper understanding of an occupational perspective on social inclusion in context, while using a small sample of individuals, possible.

In looking into how to access hard-to-reach or hidden groups like DAYA, snowball sampling was found to be a useful strategy (Browne, 2005). Snowball sampling uses the recommendations of initial participants to find the next round of participants. Its advantage is that it allows one to expand the circle of participants from within groups that are hidden (Browne, 2005; Waters, 2015). Snowball sampling was used specifically with narrative inquiry (see 4.4.1.6).

Table 4.3. Sociodemographic characteristics of participants in narrative inquiry

Characteristics	Billy[2]	P Jay	Nicky	Mai Ngah	Mudzvurwa
Age	35	19	27	35	30
Gender	Male	Male	Female	Female	Male
Marital Status	Divorced	Single	Single	Married	Married
Duration aware of dual affliction (HIV + SUD)	10years	3years	7years	>15years	2years
Substances used	• Alcohol • Illicit drugs • Tobacco • Marijuana	• Alcohol • Marijuana	• Alcohol • Illicit drugs • Tobacco • Marijuana	• Alcohol • Illicit drugs	• Alcohol • Illicit drugs • Tobacco • Marijuana
Level of completed education	O Level	ZJC	O Level	Tertiary level	O Level
Employment status	Unemployed	Unemployed	Unemployed	Self-employed	Self-employed

4.4.1.6. Recruitment of DAYA in narrative inquiry

When recruiting the five participants, he researcher looked for individuals who met the multiple criteria used to diversify my sample. That meant that several characteristics needed to be present in one participant and the next participant sampled needed to have different characteristics from the preceding one (Table 4.3).

The first participant, Billy, was recruited through the patient records of the occupational therapy department at Harare Central Hospital, as their records included user data on both HIV status and substance use disorder. With the help of the occupational therapist in-charge, the researcher contacted Billy. He agreed to meet me at a meeting point in his neighbourhood but away from his house. The aim was to explore his interest in possibly participating in the study. The researcher had to make sure no details of the study were discussed over the phone to ensure that no sensitive and confidential information was disclosed to the wrong person. Billy agreed to be in the researcher's study and they made an appointment for the consenting process and first interview.

After completing the preliminary analysis of the first interview with Billy, the researcher then recruited P Jay as his next participant. he was looking for someone just entering adulthood but

[2] All names used are pseudonyms

still with school-related engagements. A nurse who had seen the study advertisement and was working at Harare Central Hospital psychiatric unit and used to work with a support group in Mufakose, Harare, referred the researcher to P Jay. He suggested they meet in the hospital grounds. After hearing an explanation of the study, P Jay agreed to take part.

After going through the preliminary narrative analysis of the first two participants, the researcher recruited the third participant, Nicky, through occupational therapy department records at the psychiatry unit of the Parirenyatwa Group of Hospitals. The occupational therapist in-charge made an appointment with her and alerted the researcher about the time of her appointment. He contacted her after her OT session and she agreed to be part of the study.

The issues that emerged during the data generation with Nicky prompted the search to better understand the circumstances of a DAYA who was also a married woman. Finding a participant who was married proved more complicated as it emerged that permission from her husband was needed, even though the husband did not participate in the interviews. The researcher initially gained the interest of a potential participant but lost her when her husband refused to grant her permission to participate (although this was not a requirement for participation in the study, the participant wanted her husband's permission). This experience made the researcher even more determined to interview a married woman because he started to wonder about how having a male partner changed women's experience of and ability to negotiate social inclusion. However, the struggle continued as he tried and failed to interview two more participants.

Mai Ngah's participation was finally secured through the Friendship Bench[3] referral. Mai Ngah had been referred by her local clinic to the Friendship Bench for psychosocial support because of her substance abuse which was starting to affect her HIV medication adherence. The researcher's contact at the Friendship Bench had seen his study advertisement and shared it with Mai Ngah who contacted him expressing her interest in participating in his study. They scheduled an appointment, and he was able to successfully recruit her.

Having shared with all his recruited participants that they were free to share the study advertisement with friends who met the inclusion criteria, Mudzvurwa came as a referral from Billy. He arrived at the first appointment drunk, so they rescheduled. He made another appointment with Mudzvurwa in his car at a marketplace in his neighbourhood and he agreed

[3] The Friendship Bench is a community mental health project aiming to reduce the mental health treatment gap by using a cognitive behavioural therapy-based approach delivered by trained community health workers at primary care level to address mild to moderate mental health problems in Zimbabwe.

to participate. He brought along his medical records which were used to confirm that he had the sought comorbid diagnosis of SUD and HIV.

As each participant agreed to participate, an agreement was formalised through written informed consent (Appendix A & B) and initial interview meetings with each participant were set up. The researcher held more than one interview with each participant which allowed him time to conduct a preliminary analysis and draft follow-up questions between the interviews.

4.4.2.1. Sample size calculation and sampling and for DAYA social inclusion survey

Literature recommends that at least 100 participants be used for optimal results (de Winter et al., 2009) in exploratory descriptive studies. The researcher set the sample size at 105 to account for incomplete responses. He used convenience sampling to select the survey participants. This is a nonprobability sampling method, where participants are selected based on their availability (Fowler Jr, 2013). While convenience sampling is less desirable because of the limitations in generalisability and often biased estimates, it is often used in exploratory studies like this one (Daniel, 2012).

4.4.2.2. Social inclusion survey recruitment

It was recognised that there were two main entry points for DAYA into Zimbabwe's health system: i) through the mental health services system and ii) through HIV clinics. The researcher therefore accessed and recruited participants through these two arms. He chose the two main referral hospitals in Zimbabwe and recruited through their mental health units and their corresponding HIV clinics, referred to here as OI (Opportunistic Infection) clinics. By recruiting from both OI clinics and from mental health units, he aimed to increase his chances of obtaining social inclusion perspectives from both those whose primary reason for seeking health services was a substance use disorder or whose primary reason for seeking health services was HIV.

Within mental health institutions, he accessed potential participants using patient records. He followed a detailed Standard Operating Procedures (SOP) (see Appendix U1) in screening for the comorbid diagnosis of SUD and HIV. A team of trained research assistants under his supervision dealt with the participant recruitment for the social inclusion survey. From the two institutions, over a period of two months in October and November 2018, he managed to access 43 potential participants.

These were then screened for severe cognitive impairments using the International HIV Dementia Scale (IHDS) (See Appendix O and P). Three potential participants had severe

impairment and were excluded, judged by an IHDS cut-off score of ≤ 5. It is important to note that he lowered the cut-off score from ≤10 because he wanted to exclude people with severe impairments and not those who may have been at risk of cognitive impairment. He lost eight potential participants, who could not be reached on the planned days for their survey data collection. Following this process, he succeeded in recruiting 32 DAYA into the survey. He recruited the remaining study participants from the OI clinics (Figure 3)

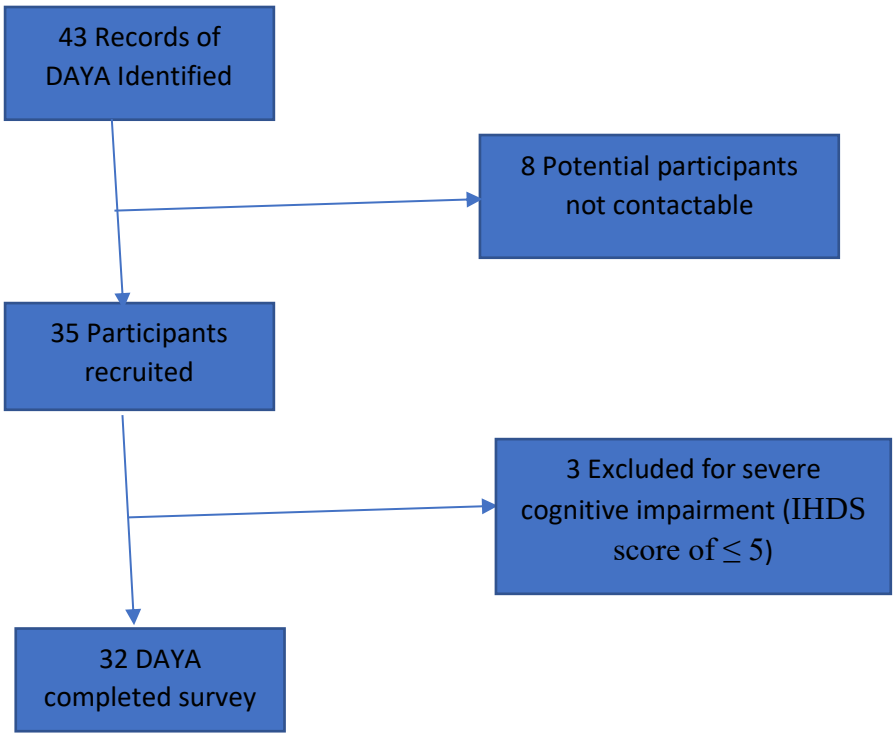


Figure 4.2. Flow diagram of survey recruitment through Mental Health Units

The researcher accessed the remaining participants through OI clinics at the same national referral hospitals. Over a period of five weeks, September to October 2018, He recruited seventy-three (73) participants from the two OI clinics. He worked with his study research assistants who followed a detailed SOP (See Appendix U2). He had to prepare a different SOP from the one he used for mental health units because of the different administrative logistics in the OI clinics. After receiving permission from the respective authorities, he visited visit the clinics early in the morning. Before clinic staff start attending to their patients, they gather them together to give an educational talk. It was during that time that he introduced the study and asked those who fit the study's young adult criteria (18-35years) to volunteer to take an e-ASSIST screen for substance use disorders. Those who qualified on the e-ASSIST screen were then invited to participate in the study. Following written informed consent, the participants

completed a social inclusion questionnaire. Figure 3 below shows the study flow from the OI clinics.

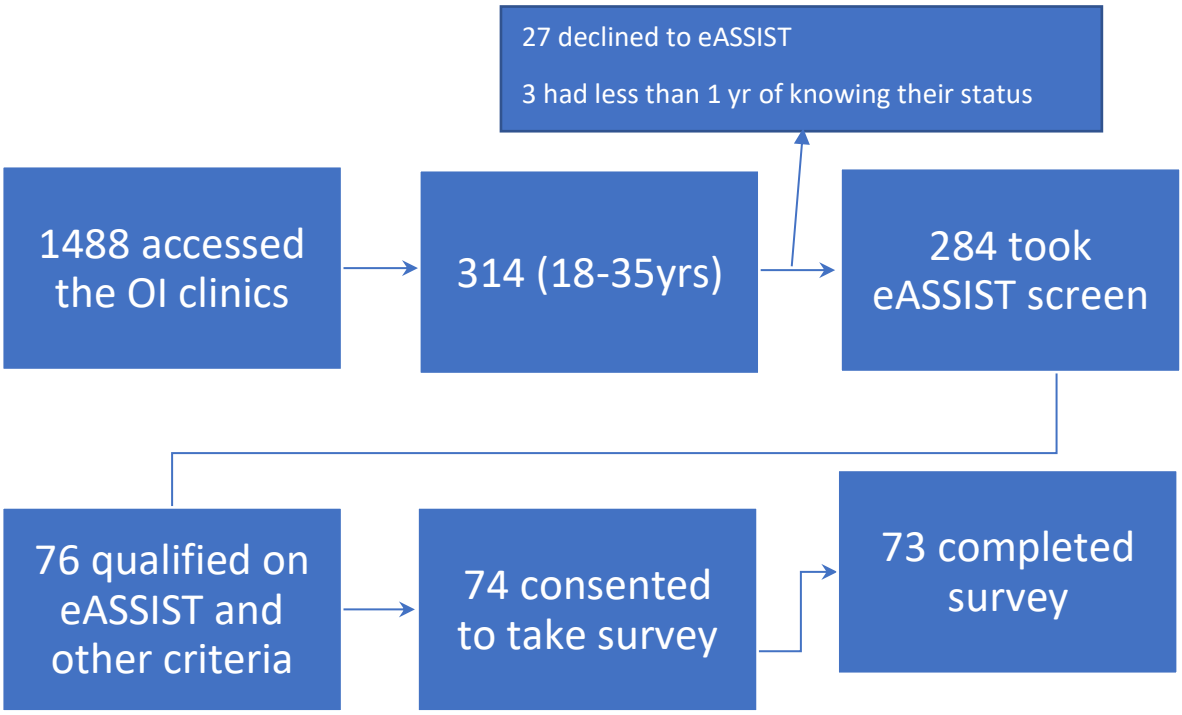


Figure 4.3. Flow diagram of survey recruitment through OI clinics

4.4.3.1. Sample selection for key informants

The approach for selecting key informants involved firstly identifying the key ministries or departments working with the DAYA. The Zimbabwe Ministry of Health and Child Care was one such entity, responsible for the management of all health issues including HIV and SUD. Two key departments within the Ministry of Health and Child Care that were able to provide insight into the research question were the Department of Mental Health Services and the Department of Rehabilitation Services. These two departments also oversee mental health and rehabilitation clinical services in Zimbabwe. Government parastatals and non-governmental organisations provide additional support to this parent ministry. the National AIDS Council, affiliated to the Ministry of Health and Child Care was further identified. The National AIDS Council was established by an Act of Parliament to coordinate the multisectoral and national HIV/AIDS response. Key informants were drawn from these entities.

4.4.3.2. Inclusion criteria for key informants

- key informants had to be senior clinicians or be in managerial/leadership positions within an organisation or department responsible for the care of DAYA or hold

advocacy positions pertaining to the health and social care needs of DAYA in Zimbabwe.

- have a minimum of one-year's experience in the position and work directly with DAYA or on issues pertaining to DAYA.

4.4.3.3. Recruitment of key informants

Through established contacts in the Ministry of Health and Child Care, a database was compiled of key departments, clinicians and organisations working on issues related to HIV and substance use. From that list, the researcher used the strategy of maximum variation to get a diversified sample of persons in positions of clinical practice and policy making. He then approached organisations, departments and persons to explain the study and invited them to participate. Only one organisation he approached refused to participate, as it felt it was not doing enough for the dually afflicted and deemed itself an unsuitable key informant.

The first key informant, an occupational therapist (KI1), was recruited from the national mental health hospital with the largest rehabilitation department. The researcher had worked with him on several DAYA and they still constituted a large part of his caseload. The two deputy directors in the Ministry of Health and Child Care (Mental health – KI2 and Rehabilitation – KI3) were then recruited to have representation at policy governance level. Their two departments are entrusted with overseeing the administrative management of persons with psychosocial disabilities, including young adults with substance use disorders. The fourth key informant was a consultant psychiatrist at a teaching hospital and lecturer at University of Zimbabwe (KI4). He had substantial research and clinical experience working with young adults living with HIV and those with substance use disorders.

During the first four key informant interviews, the National AIDS Council was mentioned repeatedly. So, the researcher sought them out. He wrote to the organisation, was invited for a briefing, and was assigned to work with the deputy director - research, monitoring and evaluation - who also agreed to participate (KI5).

All these eligible participants were contacted, telephonically or in person. Following written informed consent (Appendix E & F), the researcher met with each of them on a date and at avenue most convenient to them. In total, there were five key informants who participated in this data source (Table 4).

Table 4.4 Sociodemographic profile of key informants

Characteristic	KI1	KI2	KI3	KI4	KI5
Gender	Male	Female	Female	Male	Male
Organisation	Ministry of Health & Child Care (MoHCC)	Ministry of Health & Child Care (MoHCC)	Ministry of Health & Child Care (MoHCC)	University of Zimbabwe (UZ) - MoHTESTD	NAC - MoHCC
Position held	Occupational Therapist	Deputy Director – Mental Health	Deputy Director - Rehabilitation	Lecturer and Consultant Psychiatrist	Deputy Director
Years of experience	3-5yrs	>10yrs	>10yrs	>10yrs	>10yrs

4.5. Methods of data generation and collection

4.5.1 Narrative inquiry with DAYA

Narrative inquiry with DAYA was another method of inquiry well-suited to the exploration of complex and context bound phenomena like occupational perspectives of social inclusion in substance use disorders and HIV in Zimbabwe. Narrative inquiry allows for the "study of experience as story" (Connelly & Clandinin, 2006, p. 479). It was recognised that through this data source, by telling their stories, DAYA could reflect on their experiences. Narratives allowed for the understanding of the human world through personal interpretations of events (Connelly & Clandinin, 2006; Lieblich & Josselson, 1994; Polkinghorne, 1988). Using the narrative inquiry, the researcher called on the young adults to reflect on their occupational life experiences and social inclusion in relation to their past, present and future (Polkinghorne, 1998). He used their narratives as tools for examining the complex interlinks between their occupations, their health, justice and sense of inclusion (Wicks & Whiteford, 2006).

4.5.1.1 Narrative interviews with DAYA

When properly applied, narrative interview "envisages a setting which encourages and stimulates interviewees to tell a story about some significant event(s) in the informant's life" (Bauer, 1996). Narrative interviews were used to capture the participants' reflections on their

experiences with reference to them as actors in their contexts. all the interviews were captured using an Olympus VN-541PC password protected digital voice recorder and then the recordings were transcribed verbatim for further analysis.

For the facilitation of the production of rich and meaningful participant stories, the following strategies by Speziale, Streubert and Carpenter (2011) were employed:

- used open-ended questions;
- avoided direct 'why' questions as these are deemed to encourage intellectualism and could be seen as threatening;
- followed up each point made using the respondent's ordering and phrasing in order to ensure they had been correctly understood;
- asked about real-life examples in the young adult's life as a way of eliciting their stories (Speziale et al., 2011).

The basic phases of the narrative interview by Jovchelovitch and Bauer (2000) from Schutze's proposal were followed. These included: i) preparation, ii) initiation, iii) main narration, iv) questioning and, v) a concluding talk (Jovchelovitch & Bauer, 2000). With each participant, two or three interviews were conducted, with each interview lasting on average one and half hours.

The way that Schutze's proposed narrative interview phases were applied are described below:

a) Preparation

The preparation phase starts with critiquing the literature around understanding social inclusion and the social inclusion needs of people with substance use problems who were also living with HIV (Nhunzvi et al., 2020). The researcher's understanding is that social inclusion is both a multidimensional process and outcome that involves active participation in mainstream society and is heavily influenced by both personal and contextual factors (Cobigo & Stuart, 2010; Pereira & Whiteford, 2013; Nhunzvi et al., 2020). This understanding was enhanced through discussions with colleagues working in health and social care to better understand the broader health and social care needs of the participant population in Zimbabwe. Lastly, common rumours and factual accounts of events which emerged in this phase (Jovchelovitch & Bauer, 2000) regarding substance abuse, HIV, and social inclusion in young adults were noted. After gaining basic knowledge around the topic, 'exmanent questions' were developed (Jovchelovitch & Bauer, 2000). These are questions that capture the interest of DAYA and relate to their social inclusion (Appendix G & H).

b) Initiation

The main initial question guiding the narration was: "*Tell me your story of living in everyday life as someone with a SUD and living with HIV.*" (Appendix G & H). Characteristics of the initial question included Jovchelovitch & Bauer's (2000) suggestions:

- The main question focuses on the DAYA's life experiences,
    - helps to build their interest and hence results in a detailed narration;
    - is personally and socially relevant to the young adults;
    - allows development of a full story.

The participants created a timeline around which they mapped their stories, from their childhood to the development of significant health-related challenges of substance use/abuse and getting an HIV positive diagnosis, to the moment when they are telling their story.

c) ***Main Narration***

With natural story tellers like Nicky, P Jay, and Mai Ngah, question prompts and active listening skills were used to facilitate the beginning of their narration. The researcher did not interject or interrupt the flow of the story until such a time when there was a clear 'coda', where the respondent paused and signalled the end of a section in their story (Jovchelovitch & Bauer, 2000). However, with Billy and Mudzvurwa, this was more difficult as they were initially reserved, and the interviewer found that he had to use constant prompting. As the participants were telling their story, he encouraged them to say more and kept the flow by way of non-verbal language to indicate active listening. In the narration process, the researcher made field notes on the key elements emerging from the discussion and possible grey areas that might need further probing. During the interview, he gently probed for more or missing information judged by what was being said and the thrust of the research question and objectives.

d) Question phase

The question phase was used after every coda to fill the gaps in the developing story and to facilitate the participants' sharing of new and additional information beyond the self-generating schema of the story. The three most important guiding principles for asking immanent questions suggested by Jovchelovitch & Bauer were applied (2000).

1. avoiding pressurising the participants for justification and rationalisation of what they had shared;
2. paraphrasing in the participant's own words when asking immanent questions;

3. avoiding a cross-examination climate, highly likely to undo rapport, by carefully handling developing contradictions in the participant's story.

Some participants gave even more detailed narrations in this phase, full of new insights. This indicated that trust had been developed between the researcher as interviewer and the participants as storytellers.

e) Concluding Talk

As happens often in narrative interviews, after the recorder was switched off, interesting discursive small talk frequently ensued (Jovchelovitch & Bauer, 2000). Often this resulted in building a relaxed mood for more free talk and the researcher maximised the climate by throwing in some questions seeking further explanation. These helped contextualise interpretations of some accounts. He continued to take notes so as not to miss emerging important insights.

The researcher's reflections were documented after each interview to capture his immediate interpretations of what the stories were telling him and to make sense of what had transpired during the interview. This included his own emotions as the stories were being told. He documented his subjective views, thoughts, beliefs, assumptions, and uncertainties about what was emerging from the stories, helping him to make sense of the data. This proved important for the follow up interviews. Further, he regularly engaged in peer debriefing with his supervisors after the interviews and before the follow-up interviews. This helped broaden his understanding and to keep my assumptions at bay. Except for the follow-up interview with Billy, all of the interviews with the participants took place in their communities. His interview was on the hospital grounds. When in their communities, participants chose to conduct the interview in the researcher's car, which was parked in an area secluded from public view. Only the follow-up interview with Nicky took place in her one-room rented house. Upon reflection, the researcher took this to show the levels of caution that participants felt that they needed to take in society, and raised his curiosity as to why this was necessary.

4.5.2. In-depth interviews with key informants

Key informants were interviewed to learn more about what was happening at policy, programmatic, and organisational levels. A method was chosen that enabled frank, honest and open responses while safeguarding the respondents' privacy.

The researcher conducted in-depth interviews with five key informants (Table 4). In-depth interviews facilitate face-to-face interaction while learning about participants' behaviours, experiences, opinions, perspectives and or thoughts about phenomena under investigation (Van Esch & Van Esch, 2013). The focus was on capturing their opinions on policy, practice and research regarding the realities of DAYA in Zimbabwe. The goal of generating data from this source was to also provide further context to the study. An interview guide (Appendix K & L) was used and the interviews were audio recorded and transcribed verbatim for further analysis.

4.5.3. Document Analysis

Document analysis can be a rich data source in qualitative research. It involves systematic, usually predefined, procedures to review and evaluate print and/or electronic documents (Bowen, 2009). Document analysis formed a complementary data source to describe the policy context. The document analysis helped the researcher contextualise the DAYAs' narratives, the cross-sectional results and the in-depth interviews and to provide supplementary research data (Bowen, 2009; Eisner, 2017). In this case, he aimed for "a confluence of evidence that breeds credibility" (Eisner, 1991, p. 110) by triangulating the data sources.

Documents for review were purposefully selected to meet the following criteria: i) mental health and HIV policy and ii) legislative and strategic plans covering the study population and period. Some of the documents were mentioned in the research journey by peers and participants. Then I included Acts of Parliament, their respective policies, and strategic plans. A systematic search for these documents was conducted following a search strategy[4]. Seven documents were included documents as data sources. (Table 5). These were the documents deemed relevant to aid the exploration of an occupational perspective of social inclusion in the context of DAYAs.

[4] Documents were searched for using the following search terms: *Young adults* OR Youths OR *Substance abuse* OR *Mental health* OR HIV/AIDS OR *human rights* OR rehabilitation OR *social inclusion* OR *social exclusion* AND Zimbabwe. The researcher also manually searched for hardcopies from respective organisations and softcopies on their websites. Criteria for selecting documents was that they provided historical and current information about social inclusion and related concepts among dually afflicted young adults in Zimbabwe.

Table 4.5 Documents included for document analysis

Document Included	Year	Implementing authority
Mental Health Act	**(1996)**	MoHCC
Mental Health Policy	**(2004)**	MoHCC
Mental Health Strategy	**(2019-23)**	MoHCC
Constitution of Zimbabwe	**(2013)**	Government of Zimbabwe
National AIDS Council of Zimbabwe Act	**(2000)**	National AIDS Council
National Policy on HIV/AIDS for Zimbabwe	**(1999)**	National AIDS Council
Extended Zimbabwe National HIV and AIDS Strategic Plan III	**(2015-2020)**	National AIDS Council

From the documents included, the researcher sought to get historical and policy views of social inclusion in DAYAs. The document analysis also helped generate questions which informed the complementary data generation from the various data sources.

4.3.4 Cross-sectional survey of social inclusion

This case study included an exploratory cross-sectional survey of 105 young adults to help describe the extent of social inclusion and its associated factors. Quantifying was important to establish and monitor the extent of progress toward scalable social inclusion (World Bank, 2013). However, the researcher appreciated that successful measurement of social inclusion could only be drawn from situated conceptualisations of the concept and ways in which other contextual issues were experienced.

To measure social inclusion, he looked for a measure that acknowledged the multi-dimensional nature and complexities. This search led to a review of measures of social inclusion (Coombs et al., 2013) that recommended the Social and Communities Opportunities Profile (SCOPE) short form (Huxley et al., 2012) as a robust measure of social inclusion. The SCOPE short form was rigorously developed, locally validated in several places and found to be suitable for operational use in diverse cultural groups (Coombs et al., 2013).

To ensure that the SCOPE short form reflected the social and cultural context of Zimbabwe, the researcher conducted a concept mapping exercise with three mental health occupational therapists and his supervisors. This involved reviewing the SCOPE short form and its social inclusion concepts. From this process, questions and responses that required local adaptation

were identified and the following adaptations were made: Sociodemographic questions were replaced with questions from the Zimbabwe census questionnaire, questions about socioeconomic status were adapted, as were questions about types of accommodation and income sources, in line with the census questionnaire. Acknowledging the conservative Zimbabwean political climate, politically sensitive questions concerning voting were removed. Following permission from the developers of SCOPE, the researcher concluded by asking two independent bilingual linguists to make a translation of the adapted SCOPE short form into Shona (one of the main local languages).

This adapted SCOPE short form was translated in accordance to the ISPOR- Translation and Cultural Adaptation Group guidelines (Wild et al., 2005). However, due to the significant changes made to the original, a final consultation with the original developers was necessary to further confirm the accuracy of the translation. At this point, insights emerging from the narrative and in-depth interviews with key informants enabled the inclusion of questions coming from the emerging thematic areas (described below).

This process resulted in a master questionnaire (See Appendix I & J) incorporating sociodemographic questions (global and localised), adapted questions from the SCOPE short form, other social inclusion questions and HIV stigma and discrimination questions. From the narrative interviews, it emerged that perceived stigma against substance abuse and feelings of depression were significant issues among DAYAs. Therefore the Perceived Stigma of Substance Abuse Scale (PSAS) (Luoma et al., 2010) and the Shona Symptom Questionnaire (SSQ_14) (Patel et al., 1997) were included to capture these issues. The PSAS had been used in a similar population outside Zimbabwe (Stringer et al., 2015), while the SSQ_14 was developed in Zimbabwe (Patel et al., 1997) and has also been used among young adults (Langhaug et al., 2010; Mavhu et al., 2013).

Thereafter, between January and March 2018, ten young adults were recruited using purposive sampling guided by the inclusion criteria described in 4.2.1.3 to participate in cognitive interviews guided by the developed questionnaire. Among them were the five DAYAs who had participated in the narrative interviews. Cognitive interviewing was used to ensure that the questions were understood by the participants in the way intended (Collins, 2003; Willis, 2004).

Participants were asked to comment on the cultural appropriateness, simplicity of the items and clarity of the scoring instructions (Wild et al., 2005). No major comprehension, applicability

or question wording challenges were reported from the cognitive interviews. Following the cognitive interviews, the forward and back translations between English and Shona were repeated. Another mental health occupational therapist was engaged to proofread the resultant master questionnaire, checking for any grammatical or typing errors before the tool was considered ready for survey administration.

Working with the research assistants, the researcher then administered the developed social inclusion and associated factors master questionnaire (Appendix I & J) in a sample of 105 conveniently selected DAYAs. The questionnaire was administered using a computer-assisted survey instrument (CASI) on tablets by trained research assistants in face-to-face interviews. Each interview took approximately 30 minutes to complete.

4.6. Data Management and Analysis

4.6.1 Qualitative Data Management

Being true to the participants` voices and data is one of the most important parts of qualitative data management and serves to enhance the credibility of the findings (Sutton & Austin, 2015). In this study, qualitative data management involved digital recording of interviews, verbatim transcription of the interview recordings, back and forth translations from Shona to English and anonymising the data transcripts. After successfully recording both the narrative and the in-depth interviews, the interview transcripts were generated as word documents. Qualified linguists transcribed the data verbatim into Shona, and provided forward and backward translations into English. Thereafter the resultant English and Shona transcripts were cross-checked with the audio recordings for accuracy. This task was easy for the researcher as he is fluent in both Shona and English and had carried out the interviews himself. In some instances, during the translation processes, some culture bound phrases and words were not translated into English so as to maintain their original meanings. The DAYAs narrative interview transcripts were subjected to narrative analysis. The key informant interview transcripts were integrated into thematic case analysis using NVivo.

4.6.2. Narrative Analysis

In narrative inquiry, data analysis is carried out using narrative analysis (Haydon et al., 2018; Polkinghorne, 1995b; Riessman, 2008; Wong & Breheny, 2018). There is great diversity in methodological approaches to narrative analysis, though all of them yield to the capacity of the analytic processes to bring understanding to complex human experiences and the way people make sense of their storied lives (Sharp et al., 2019). The major challenge faced by novice researchers in the field is the lack of standardised detailed accounts and techniques showing

how to go about the process. The researcher took advantage of the various approaches and skills described by renowned authors in the field (Polkinghorne, 1995b; Riessman, 2008; Sharp et al., 2019; Wong & Breheny, 2018).

In this study, narrative analysis is defined as the process of making sense of and interpreting the recorded actions, events, and happenings from the gathered data to produce stories following an emerging plot (emplotted narratives) (Polkinghorne, 1995b). In the narrative analysis, the researcher aimed to synthesise the data from narrative interviews into a coherent story (Carter, 1993; Polkinghorne, 1995b). He needed to be prudent in order to apply story recognition, interpretation and understanding (narrative reasoning) and to make meaning of the data. From these processes, it was possible to capture the diverse views of participants comprehensively and to attend to the "richness and the nuances of meaning in human affairs" (Carter, 1993, p 6).

After transcription and translation of the narrative interviews, the researcher spent time becoming intimate with the data. This involved listening to the audio recordings and reading and re-reading the transcripts. The researcher constantly practised reflexivity and kept contact with participants for them to approve translations and preserve intended meaning. He started identifying the meaningful chunks of information which helped discover the plot linking participants' events, actions and happenings. These events, actions and happenings were parts of an "unfolding temporal development culminating in the denouement" (Polkinghorne, 1995, p.15) of the experience and negotiation of social inclusion. A plot is described by Polkinghorne as "a narrative structure through which people understand and describe the relationship amongst the events and choices in their lives" (Polkinghorne, 1995, p.16). The plots developed from summing up relevant life events following the young adults' life trajectories, homing in on the turning points of their health challenges and also emphasising how they negotiated everyday life. This process generated emplotted hybrid narratives of the experience of social inclusion and how the DAYAs negotiated these through their everyday occupational participation. These are presented in Chapter 5. The hybrid narratives became the first level of analysis for the case study working to organise events and meanings the young adults gave to their life situations (Riessman, 2010).

4.6.2.1. The production of hybrid narratives

Polkinghorne's (1995) adaptation of Dollard's (1935) seven criteria for judging a life history served as a guideline for organising the narratives' structure and content.

Criterion 1: Provide thick cultural, socioeconomic and political descriptions of the context

Each of the participants' narratives included descriptions of their contexts, with reference to Harare, Zimbabwe. In producing the narratives, attention was paid to contextual features that gave specific meanings to events and choices made. These included, but were not limited to, economic realities, politics, poverty and social myths about HIV and SUD. Polkinghorne (1995)'s asserts that the context including the "…values, social rules, meaning systems and language conceptual networks…" (p 16), influences the young adults as the protagonists in terms of the choices they make, events and happenings surrounding their dually afflicted lives and how they experience social inclusion. Incorporating context situates the narratives and helps the participants and the reader in meaning-making.

Criterion 2: Attend to the 'embodied nature of the protagonist' (Polkinghorne, 1995, p. 17)

Producing these hybrid narratives, meant attending to the embodied nature of the young adults as protagonists. This helped portray the incarnate nature of human existence thereby locating the young adults spatially and temporally (Polkinghorne, 1995b). Some bodily descriptions of the young adults were included as they are known to influence a person's identity and interactions with the environment (Polkinghorne, 1995b).

Criterion 3: Capture the roles of significant persons in the participants' lives

Recognising that people do not simply live to fulfil personal goals but also to support the goals of significant others (Polkinghorne, 1995b), the roles and relationships of other people were included in each narrative plot. These covered the roles and relations with family and the community, as well as other events between the protagonists and their outer circles. Their family and community were acknowledged as influencers in the experience and negotiation of social inclusion.

Criterion 4: Home in on the participant's life in terms of "…plans, purposes, motivations and interests…" (Polkinghorne, 1995, p.17)

Every story is unique and, to understand it, we need to attend to its personal meanings, its view of the world, the plans and motives and interests and purposes (Polkinghorne, 1995a). It took effort to identify the young adults' choices and actions as they sought social inclusion, experienced it and negotiated it in their life journeys.

Criterion 5: Historical continuity of the characters

In producing the narratives, the personal historical of the DAYAs in important. The plot benefits from past experiences which manifest in the present as habits described in the stories (Polkinghorne, 1995b). Past social, political, economic and even, colonial events were captured as influencing the young adults' occupations and their experience and negotiation of social inclusion.

Criterion 6: Bounded temporal period of the narratives generated

Narrative analysis produces a story with a bounded temporal period, showing the beginning, middle and the end (Polkinghorne, 1995b). The young adults' unique life trajectories needed to be tracked, mostly from childhood, through their health challenges to the they shared their story. Each participant helped to set the bounded temporal period of the story they chose to tell.

Criterion 7: Meaningful explanation of the participants' actions and responses

For this last criterion, the researcher tried to order the data elements into a coherent and meaningful explanatory story. He outlined the contexts in which the stories occurred, the young adults themselves, their choices, actions, and responses (Polkinghorne, 1995b). The aim was to present plausible but original narratives about the experiences and negotiations of social inclusion among DAYAs in Zimbabwe.

The researcher used emplottment (Czarniawska, 2004) to select and transform simple successive events, showing DAYA life trajectory, experience of social inclusion - or lack thereof - its negotiation and the role of occupations, into meaningful stories as guided by the study objectives. In his quest to configure the interview data into a coherent narrative whose goal was to picture the experience and negotiation of social inclusion in everyday circumstances, he continually asked:

- Who were the DAYAs?
- What happened to them?
- How did it happen?
- Why did it come about?
- What does it mean for their futures?

To make sense of the whole story, participant actions, their experiences and their contexts, the researcher kept referring to the raw data, the audio recordings of narrative interviews, the transcripts and his reflective notes. Some data elements became more apparent in this process,

that is to say, the more relevant choices, events, happenings and characters rose to the fore. Instead of dismissing the contradictions, they were used so that each added meaning to the whole narrative.

4.6.3. Data analysis of the cross-sectional survey data

Using ODK Collect, completed survey questionnaires automatically loaded onto an online secure database. Data was moved into an Excel spreadsheet and analysed using Stata 14 (StataCorp, 2015). With help from a statistician, descriptive statistical analysis was applied to this dataset. Measures of central tendency and measures of variability were calculated and the associations and/or correlations between dependent variables and participant sociodemographic characteristics were tested. Detailed survey findings are provided as an appendix (See Appendix V).

The Cronbach's alpha (Cronbach, 1951) was used to determine the reliability of the new master questionnaire, including the embedded sub-scales. Chi-Squared tests were carried out on the independent variables and the outcome of social inclusion to assess the factors associated with social inclusion. Furthermore, independent t-tests on sociodemographic variables and overall social inclusion were performed. Lastly, post hoc Tukey tests to contrast between highest and lowest satisfaction with social inclusion and opportunities for key social participation domains were carried out.

The results of the survey further described and explained an occupational perspective of social inclusion among DAYAs. The findings were integrated during the second phase of thematic case analysis, hence supporting data triangulation by analysing the points of divergence and convergence in explaining the experience of social inclusion.

4.6.4. Analysing documents

An iterative process, involving skimming, reading and then interpretation (Bowen, 2009) was employed to analyse the seven documents included in this case study. This was followed by deductive thematic analysis using predefined codes (Bowen, 2009; Silverman, 2015) in NVivo 12 Pro (QSR International, 2018). Soft copy pdf versions were uploaded into NVivo and the documents were coded by selecting meaningful and relevant passages from the text and adding it into relevant nodes and categories derived from the thematic case analysis described below. Data from the documents review helped to understand the socio-political influences on the experience and negotiation of social inclusion by DAYAs. In a case study, using document

analysis in this way is acceptable, when the document analysis is not the main data source, but a supplementary one (Bowen, 2009).

4.7. Case Study data analysis

An integrated, reflexive and iterative process (Stake, 2008) was followed in collating the different data sources for analysing the case of social inclusion as experienced and negotiated by DAYA through their occupational participation. This meant going back and forth between data sources and fieldnotes, critically deducing what the data was revealing. A multi-level approach (Stake, 2008) was used which included integrating three analysis levels: 1) The first level of analysis is constituted of analysis of the data source. The hybrid narratives that emerged from the narrative analysis of the young adults' stories is reported in chapter 5; 2) secondly, thematic case analysis (integrating all four data sources) and, 3) thirdly, theorising of conceptual constructs (See Figure 4).

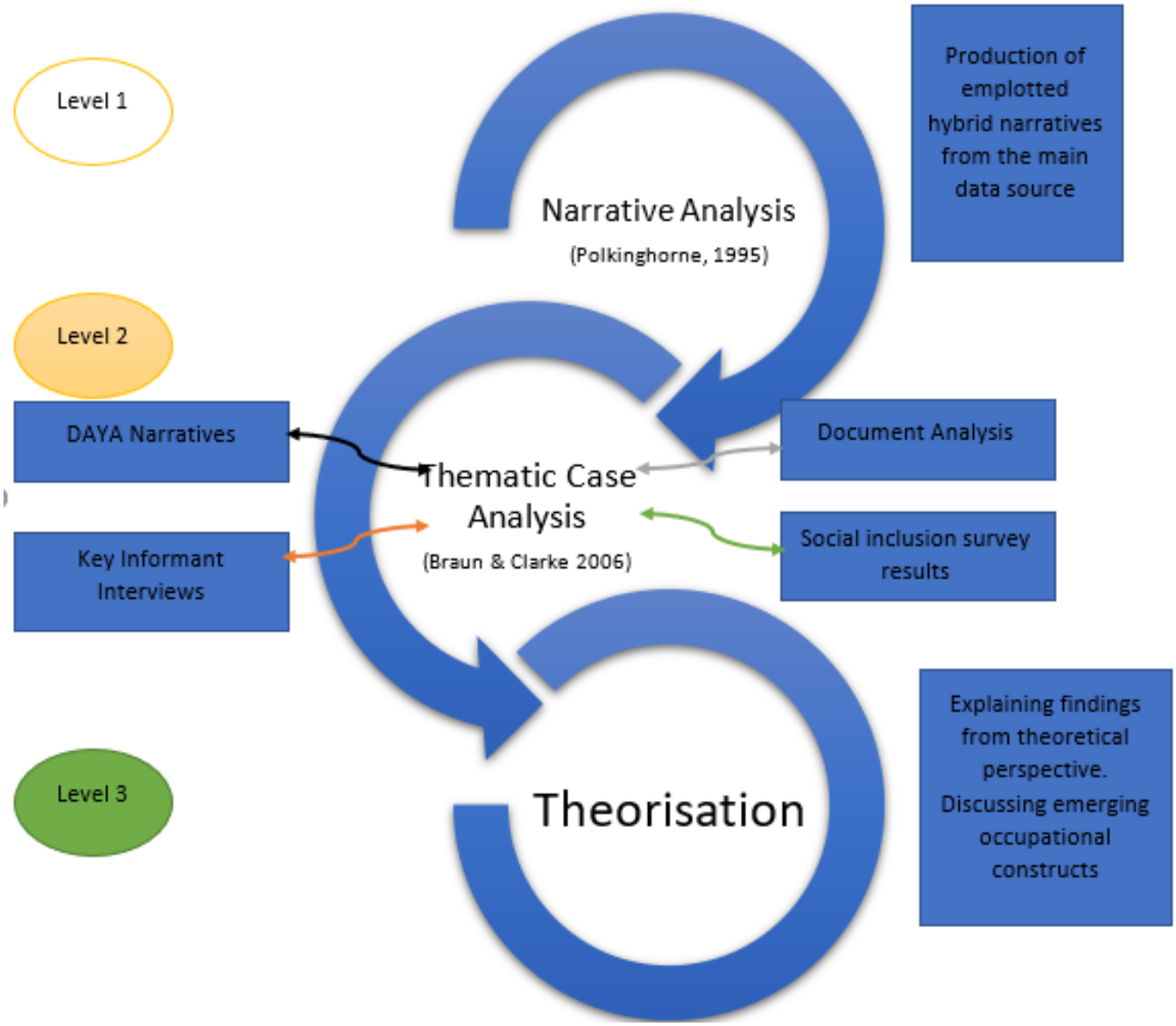


Figure 4.4. Case study analysis

a) Thematic-case analysis

For the second level of analysis, thematic analysis was used (Braun & Clarke, 2006) in all the four data sources. The researcher also applied within-case and cross-case analyses for the emplotted narratives from level one. He started with within-case analysis of the five individual DAYA hybrid narratives. He identified key elements of their experience and negotiation of social inclusion. He then checked for individual examples that he could draw on in answering the objectives in the individual narratives. From there, he engaged in a cross-case analysis, to identify the outstanding features of each DAYA's narrative, and the common as well as the contrasting features across the five narratives. These formed the initial nodes which were as references in coding the other data transcripts and documents.

Using NVivo 12 Pro to manage the data, an inductive and iterative qualitative data analysis was completed to generate codes (meaningful data segments) by grouping together similar statements and topics from transcripts. The codes/nodes were then collapsed into subcategories and categories, from which an overarching theme explaining the case emerged. The researcher kept going back and forth between the four data sources and the hybrid narratives that emerged from the narrative analysis, searching for common elements explaining the experience and negotiation of social inclusion among DAYAs in Zimbabwe. Working with NVivo enabled him to upload all the data and to track the coding. He continued with reflexive and peer debriefing with his primary supervisor throughout this analysis process.

b) Theorisation

The final level of analysis involves interpreting the first and second levels of analysis using critical social theory and the occupational science perspective which forms the conceptual framework for this study. In this way, the relevant conceptual constructs emerged from the data. The researcher aimed to produce a clear picture of an occupational perspective of the case of social inclusion among DAYAs in Zimbabwe. This level of analysis served to link the case to the theoretical constructs that have been established in occupational therapy and occupational science.

4.8. The scientific rigour of the study

The value and significance of qualitative research in health and social sciences is growing, (Houghton et al., 2013) and hence the need to continue to improve its scientific rigour. To achieve this, qualitative researchers have invested considerable time in improving the trustworthiness of their data (Houghton et al., 2013; Lincoln & Guba, 1985; Morrow, 2005; Nowell et al., 2017; Sinkovics & Alfoldi, 2012; Yin, 2003). One key area is being more articulate about the research process (Yin, 2003). This entails having a detailed study protocol so that others can judge the rigour of the work. To that end, this study follows a scientific and ethically approved protocol to ensure that the data is of a rigorous quality and creates standard operating procedures for all the steps in the study.

Qualitative rigour can be assessed in a variety of ways. The most common criteria proposed by Lincoln and Guba (1985), i) credibility, ii) dependability, iii) transferability and iv) confirmability have been applied in the current study. To ensure that the narratives were well-grounded, sound, and correct, Riessman (1993) and Polkinghorne's (1988) guidelines were

used to enhance persuasiveness, coherence and a pragmatic use of the narratives (Polkinghorne, 1988; Riessman, 1993).

4.8.1. Credibility

Lincoln and Guba (1985) describe credibility in qualitative research as the value and believability that the reader finds in the study methods and subsequent findings. Credibility is also defined as a way to determine whether the results can be trusted and if there is congruence between those results and reality regarding establishing the genuineness, reliability or authoritativeness of the research (Carpenter & Suto, 2008; Shenton, 2004). To increase the chances of accurately representing each participant's experiences, prolonged engagement and reflexivity was applied (Carpenter & Suto, 2008) during data collection and analysis by spending time conducting the interviews and undergoing member checks. Prolonged engagement was achieved by not rushing the interview process (Altheide & Johnson, 1994; Lincoln & Guba, 1985) with each participant. Data was generated in the field analysed from July 2017 to November 2019, which facilitated a deeper understanding of the concept of social inclusion as informed by the experiences and negotiations by five DAYAs in Zimbabwe.

Triangulation is another strategy that strengthens credibility (Carpenter & Suto, 2008; Denzin & Lincoln, 2011). By definition, the qualitative instrumental case study design supports methodological triangulation (Stake, 2008; Yin, 2009), ensuring the use of more than one data source. Narrative inquiry with DAYAs was the primary data source, which was then triangulated with in-depth interviews with five key informants, an exploratory social inclusion survey and document analysis from seven key national policy documents. The research was conducted this was way for three main reasons: i) to broaden views on the phenomena; ii) to confirm the data and iii) to ensure data completeness (Casey & Murphy, 2009). Insights from narrative interviews with young adults were largely confirmed by data generated from the in-depth interviews with key informants and the survey findings. During the thematic case analysis, triangulating the four data sources, also confirmed the emerging findings and were consistent in building this Case. The researcher aimed for completeness of the phenomena under study by gathering multiple perspectives from various data sources (Houghton et al., 2013).

Member checking is another strategy used in qualitative research to enhance credibility (Rolfe, 2006; Williams & Morrow, 2009). This is achieved by testing the interpretations and conclusions with the participants to make sure they are credible to them (Houghton et al., 2013;

Stake, 2008). The rigour in qualitative research is improved when participants are given an opportunity to approve or disapprove of elements of what the researcher found in their data (Doyle, 2007). In this study, in addition to the verbatim transcripts, the initial versions of the hybrid narratives from the narrative analysis and excerpts from the case theme were used to conduct the member checking. Hard copies of these were taken to each of the five participants who took part in the narrative interviews. The researcher read them together with the participants and asked them to identify themselves and to query anything they did not agree with regarding the way they were represented. None of the young adults had concerns about the focus and content of their hybrid narratives and core elements of the emerging case theme. They all agreed to have their stories included in the study write up.

Peer debriefing is recommended by Lincoln and Guba (1985) as an important way of making research data analysis explicit and credible. This is achieved when peers can relate to the researcher's interpretations of the data. This validation from other researchers with experience in the same field is meant to bring new perspectives regarding the interpretation of data (Loh, 2013). The researcher worked closely with his supervisors, not to reach exact coding and data interpretation but to achieve a level of agreement on the logic behind hybrid narratives, emerging categories and the case definition (Graneheim & Lundman, 2004). The researcher and his supervisors independently reviewed the study findings and they continually discussed insights and the supporting logic throughout analysis and write up phases. Here, the research supervisors acted as co-researchers by offering feedback and alternative views throughout research process. This made aspects of the research process clearer and facilitated in-depth interpretation that prevented premature closure of the data analysis process.

4.8.2. Transferability

Transferability is the probability that the study findings have the same justifiable application to others in similar situations (Shenton, 2004). To enhance transferability in this case study, a dense description of the research context was given to enable the reader to make informed judgements on the findings and research processes (Koch, 1994). Using the thick descriptions of the study context, the aim was to empower the reader to make informed decisions on applying the findings to their specific contexts similar to Zimbabwe. A lot of detail was included, including descriptions of participants, the places in which the study was conducted, and the analysis processes showing how sense was made of the data. To aid in transferability, extracts of raw data were used as direct supporting quotes so that readers could consider their own interpretations (Tobin & Begley, 2004).

4.8.3. Dependability and Confirmability

Trustworthiness, as encapsulated in dependability and confirmability, is concerned with the degree to which study findings are a true reflection of the respondents' views and not the researcher's views and biases (Lincoln & Guba, 1985). Dependability is often compared to the quantitative notion of reliability, focusing on the stability of the data (Rolfe, 2006). Confirmability implies the neutrality and accuracy of the data (Lincoln & Guba, 1985; Tobin & Begley, 2004). The current study aimed to achieve this by the use of an audit trail and practised reflexivity (Houghton et al., 2013; Lincoln & Guba, 1985). A research protocol with an outline of the decisions and rationale for the methodologies used was followed, to enhance the study's trustworthiness (Lincoln & Guba, 1985). A detailed audit trail was maintained by keeping records of the design, data generation and data analysis decisions as well as the theoretical basis for analytical decisions. By using NVivo 12 Pro, a record of decisions made during the second phase of data analysis was provided. This allows the research decisions to be traced and helps assess their reasonability. These are reported on here, reflecting a thick description.

Reflexivity is another essential component of research rigour applied in this case study. In qualitative research, it is important to engage with ones self-awareness as a research instrument throughout the research process (Mantzoukas, 2005; Rodgers & Cowles, 1993). A reflective diary was maintained throughout the research process as an important measure of reflexivity (Rodgers & Cowles, 1993). Throughout the research process, the researcher acknowledged his personal feelings and experiences which might influence his study views regarding the social inclusion and occupational participation of DAYAs (Carpenter & Suto, 2008; Rolfe, 2006).

It was also important for him to acknowledge the power dynamics inherent in his position as the researcher when constructing knowledge in this case study (Morrow, 2005). He had to acknowledge his own position as a typically socially included young adult in Zimbabwe without the dual affliction of HIV and substance use disorders. He further acknowledged his professional background as a clinical occupational therapist, a mental health researcher, a lecturer and a Christian family man. He continually reflected on these attributes, so as not to impose his own values and beliefs in judging the participants. The primary focus remained the experience and negotiation of social inclusion by DAYAs through their everyday occupational participation. For example, when a DAYA insisted on continuing to take drugs despite the evident health challenges, by default he would have judged them and thought of prescribing

what he deemed was right for them, but instead he silenced those thoughts and continued to listen and probe them to share more.

Throughout the study, personal reflections were recorded in a research journal. During the interviews, the researcher took short notes, reflecting on what he was hearing, and what he was seeing. As soon as he returned to the office from his fieldwork, he completed a detailed field entry, including participant details, date and place of interview and a brief description of the interview setting. He then wrote down detailed reflections of the interview process, his thoughts, perceptions, assumptions, reactions and possible interpretations from the fieldwork experience. Further, he included a section on major highlights emerging from the interview and main follow up points in line with the study research question.

This reflective process helped to minimise bias and to continue to refine the methodological and fieldwork skills. These reflections enabled the follow-up interview questions to be more focused. During data analysis the researcher also applied reflection by way of engaging with the data and taking time to write down the interpretations that came to mind in a diary; further refining them with what was said by the participants.

4.8.4. Validation of narratives

This criterion considers the persuasiveness, coherence and pragmatic use of the narrative (Riessman, 1993). To enhance the value of the narrative, the researcher aimed for a comprehensible, correct, complete and credible evaluation for all parties involved, hence a narrative truth (Polkinghorne, 1988). To achieve this, he shared the narratives and themes with the participants so that they could share their views.

A. **Persuasiveness:** The theoretical claims used in findings are supported by evidence from research data and alternative explanations are considered (Riessman, 1993). The reasoning through which the conclusions were reached is presented (Polkinghorne, 1988).

B. **Coherence:** In narrative inquiry, it is important to work out the fitting together of different parts of the story to form a complete and meaningful picture (Josselson, 1993; Josselson & Lieblich, 2009). The objectives were a guide and the chronology of events made sure that the talk remained focused and existed at global, local and coherent thematic levels (Riessman, 1993).

C. **Pragmatic use:** This criterion refers to the significance of the study and its ability to be a foundation for other studies (Riessman, 1993). The researcher used Riessman (1993)'s advice and produced a clear description which makes the narrative inquiry process visible. He also made the findings available.

4.9. Ethical considerations

To prevent any harm coming to participants based on this case study research, a number of ethical guidelines were followed. The researcher went beyond the standard ethical guidelines and made an extra effort to minimise risks and to maintain an active dialogue with the participants (Stake, 2003). He continually gave participants assurance and feedback and more importantly, "listened well for signs of concern" (Stake, 2003).

This study received ethical clearance from the University of Cape Town's Human Ethics Research Committee (HREC Ref: 340/2017) (Appendix Q), Joint Research Ethics Committee (JREC) for the University of Zimbabwe College of Health Sciences and the Parirenyatwa Group of Hospitals (JREC 160/16) (Appendix S) and the Medical Research Council of Zimbabwe (MRCZ/A/2214) (Appendix R). It also received site permission from Harare Central Hospital (HCHEC 300517/37) (Appendix T). The ways used to ensure ethical practices during the study are described below.

4.9.1. Informed consent

General ethical guidelines for conducting health and social science research including principles of informed consent, confidentiality and beneficence were followed. The access and selection of participants included safeguarding their confidentiality and their right to participate on a voluntary basis. During the recruitment and informed consent processes, a thorough explanation of the study purpose and procedures involved were explained to every potential research participant with respect to the data source they were feeding into.

Eligible participants provided written informed consent before commencing the interviews. Before consenting, potential participants went through study information sheets in their preferred language (Shona or English) (a different sheet for each of the three participant groups, that is the DAYA narrative interviews (Appendix A & B), key informants (Appendix E & F) and DAYA in the survey (Appendix C & D) to read and the researcher was present to explain each aspect of the study in depth. The information explained what the study was about in layman's terms. He ensured that the participants understood the content and what they were consenting to by reading and discussing the study information sheet and consent forms with

them. He emphasised the voluntary nature of the study. To make sure participants had understood what they were consenting to, he had each participant summarise in their own words what they thought the study was about and the meaning of voluntary participation. He emphasised that his intention was not for anyone to feel obliged to participate, highlighting their right to withdraw from the study at any point without negative consequences. Where their information was incorrect or missing, it was corrected or completed. In the cross-sectional survey, research assistants were trained in the study protocol. The researcher made sure that everyone who engaged with participants in the study had successfully completed a human ethics course. During the consenting process, he used simple and appropriate language, communicating in an ethical manner, and inviting questions and clarifications from participants at any stage.

In a case study design, a once-off consent is usually considered insufficient, hence the need for an informed consent process (Polit & Beck, 2006). This allowed the researcher and the participants to continue to engage with the terms of the study and to consider their ethical concerns as they were emerging. He kept reminding the participants of their research rights during the fieldwork. He reiterated the voluntary nature of the study and their ability to withdraw at any stage without any consequences.

4.9.2. Confidentiality

The researcher assured the participants of their confidentiality and privacy (Josselson, 2007). For this, he used pseudonyms which the participants chose and he changed small but obvious identifiers for all participants. He also recognised that for the participants to tell their stories, they had to trust him. He established trust through prolonged engagement, active listening, respect and showing empathy with the participants. Participants became more open and confident to share their stories with every subsequent engagement. He also safeguarded the data by only sharing it with his supervisors over password protected cloud servers. He stored the data in password protected computer folders, and locked hardcopies of transcripts and survey forms securely in his office cabinet. Survey data was collected anonymously. These measures ensured that all participants' privacy and confidentiality was protected at all times.

4.9.3. Potential for harm and benefits

The principle of beneficence asks researchers to continually weigh the benefits of the possible results against the possible risks (Fontes, 2004). Non-maleficence, the researcher's duty to do no harm to the participants (Yick, 2007) was a key ethical consideration when planning and carrying out this study.

Distress is expected when narrating stories of exclusion, hardship and poor health situations which were regular aspects of the primary participants' engagement. The researcher used empathetic listening to help soothe participants during emotional points of their stories. In instances of severe distress, he ensured that interviews could be rescheduled, and referred participants for further psychosocial assistance. He had liaised with local service centres so that he could refer participants to them when there was need. These are free services at mental health referral centres staffed by multidisciplinary teams, including clinical psychologists and occupational therapists. None of the interviews were rescheduled for distress but, following our first interview, Nicky was referred for psychosocial support, a service she said was very helpful.

Possible benefits of being involved in narrative inquiry include increased self-esteem, added meaning making and the promotion of growth through reflection (Atkinson, 2007). In most concluding talks, participants echoed that they felt an increased sense of self-worth from being listened to and having had a chance to introspect. Participation in this study also gave a voice to the typically disadvantaged and marginalised group of DAYAs in Zimbabwe.
Throughout the research process, the researcher regularly consulted the supervisory team who had experience of conducting research with vulnerable groups. He used these engagements to discuss progress and concerns which arose, to ensure the decisions he made remained ethical.

No direct payments to participants for participating in this study were offered. However, participants who took part in the in-depth interviews, were reimbursed US$10 to contribute towards their lunch costs for the day, as a gesture to thank them for their time. Those in the survey received five dollars for transport and breakfast as the time they spent less time completing the survey and also because of the researcher's, budget constraints. He served all participants refreshments during the interviews and after completing the survey questionnaire.

4.10. Conclusion

Chapter four describes the benefits of the qualitative instrumental case study as applied in this research, explaining how it unfolded. It highlights the strengths of using multiple data sources to understand the case of social inclusion of DAYAs in this research.

The next chapter introduces the findings of the Case through the hybrid narratives of Billy, P Jay, Nicky, Mai Ngah and Mudzvurwa. These hybrid narratives are presented as the life stories of young adults in an unsupportive context, where they have developed a dual affliction of two stigmatised conditions of SUD and HIV.

Chapter 5 . The hybrid narratives

5.1. Introduction

This chapter presents the first part of the study findings. The five hybrid narratives which emerged from the narrative analysis as part of the first level of data interpretation are presented. The following chapter presents the case theme and expands on the three categories supporting the findings.

5.2. Hybrid Narratives

The hybrid narratives emerged from rigorous and iterative narrative analysis. The beginning of each narrative presents the young adults' reflective views of their lives and then asks them to journey into their past. The young adults' life stories illustrate the centrality of their personal agency as they experience occupations while navigating towards social inclusion. The experience and negotiation of social inclusion are related to key happenings, actions, events and the role of significant people in the DAYAs' context. For this chapter, the researcher uses the first person while applying creative and fictional writing techniques to make the stories more captivating and keep the participants' voice.

These narratives are presented in the order of participant recruitment, beginning with Billy's story, followed by P Jay, Nicky, Mai Ngah, and lastly Mudzvurwa.

5.2.1. Introducing Billy: Of uncontrolled freedom and swayed choices - a life of blame

A child needs to have its liberty curtailed in some way to have direction and move towards a good future. Too much freedom led me to mess my life in a way that ruined my future. I required hand-holding and shepherding into adulthood. The typical support systems failed, which led to disastrous consequences. I got lost, never recovered, and before I knew it, I found myself mired in the world of alcoholism, drugs and HIV. I am leading a doomed life and I am struggling; I am on my own because I also found myself in an unsupportive setting.

Before I get carried away with my life history, let me begin with a self-introduction. My name is Billy. I was born in Lusaka, Zambia, in 1983. My family moved to Zimbabwe in 1987, settling in the high-density suburb of Mufakose[5] in the capital, Harare. My father had fallen ill in Zambia and, because of this, we relocated to Zimbabwe. Unfortunately, he died the year we moved to Harare. My mother was a nurse and before long, we moved from Harare to the Mashonaland West in Mhondoro Ngezi[6], where she had found a job.

I was a bright student who managed to get eleven units at grade seven, considered a passing result at that stage. When I began high school, my mother transferred to work in Chivhu[7]. She did not move with us this time but instead sent my brother Sam and I back to Harare so we could continue with our education. We started to stay alone, without adult supervision early in life. At this time, Sam was battling teenagerhood and coming to terms with albinism. He constantly had to learn to be different and yet to fit in with other children around.

We were alone, with too much freedom and lacked adult supervision. This happened at a critical developmental period in an unsupportive environment and resulted in the derailing of my life. Staying alone in a hive of activity, high-density suburb of Mufakose without the shepherding touch of our single parent was never a positive setup. They always say your teenage years are very crucial in shaping the destiny of your life and faithful to that word, mine took the wrong turn at that critical stage leading me into the quagmire I find myself in today.

For most of my high school and early adulthood years, I lived unsupervised with my brother. I got hooked up with the wrong company and we turned our house into a brothel where beer binges and sex parties could happen with no restrictions. When my elder brother, whom I

[5] One of the oldest high-density residential suburbs in Harare

[6] A prominent district in Mashonaland West farming region. Serviced by a rural district hospital and a local authority body.

[7] A rural district in Mashonaland East province, housing the Chivhu district hospital. The urban development is about 140km along Harare-Beitbridge highway.

perceived as worse off than me, would try to stop me from doing things, I would quickly dismiss him and tell him he was a child like me who had no moral ground to say to me what to do. We were on the loose.

We were like that until my mother returned to the capital after she retired. When I look back at it now, it was a case of kids blindly leading each other down a path of destruction. We had too many 'bad' friends and our house became the meeting place where boys from the 'hood' would come freely, bringing drugs and girls. Before long, I was deep into these practices. Peer pressure was the major contributing factor that got me into substance abuse and with no one to whip me into line, there was no turning back.

When we started, we never really used to take illegal substances per se but only those alcoholic beverages you could easily find in bottle stores, night clubs and supermarkets. But nowadays because of the hard times we find ourselves in as a country, some cheap but illicit drugs are what is now available, mainly from South Africa, Zambia and Mozambique. Some people import and sell these in the shebeens or even from their houses, which makes it easy to access and use drugs in this community.

In my life, education and substance abuse were like water and oil, they did not mix at all, and so one of them had to give in. Unfortunately for me, it was my education which suffered as I failed ordinary level examinations in 2000. With a habit to sustain, failed O-level marks and no desire to pursue the educational route, I had to adapt quickly to become self-sufficient, at least in as far as satisfying my love for drugs was concerned. All those friends who introduced me to alcohol were not there to help me quench a habit they had helped instigate. But they were very supportive in helping me go deeper. I had one close friend called Takudzwa; we were together in all this.

Around 2002, the country was already facing its fair share of political and economic challenges. We were stuck with the sole importance of formal education and paid employment as pathways for making it in life. Not having these tools for survival was bound to be a nightmare. Even worse, formal employment was now hard to come by, more so without secure connections in the political elite, as corruption took its toll. I started menial jobs, including becoming an assistant in brick moulding. You know, those kinds of jobs that one can do without technical expertise or formal education, just learning on the job. However, you pay dearly with your body and the remuneration is next to nothing. Sometimes they just bought drugs for me as a

reward. But the poverty around me was too much and I had no liberty to choose and at times had to make swayed choices because my body needed drugs to keep going.

When things got harder in the country around 2004, I tried seeking greener pastures in neighbouring Botswana but with no proper immigration papers, I was deported immediately after I set foot in that country. With my partner in this illegal move, Takudzwa (we used to do everything together), we tried again to go back through another unlawful port of entry, and we were nabbed and deported. We gave up and hiked our way back to Harare.

Returning home was a difficult decision to make. My relationships with my mother and other close relatives were growing sour. They detested my drugging and wild life. I had to fend for myself. Mostly, I just got more piecemeal jobs just to keep me going.

With the drugs, I also lost my moral compass regarding my sex life. Later in 2004, I got married, albeit in a polygamous way. I found myself with two wives, Janet and Nakai. A lot was happening and the situation in the country was not helping. Nakai was pregnant already when she ran away to marry me, and she found me already with Janet, who had done the same thing a day earlier. I was still at my mom's place, and she gave us one room we used as our bedroom. This arrangement was unheard of in the community and it drew a lot of criticism. I did not care much but could see the shame in my mother's eyes. Janet also fell pregnant that year and they eventually gave birth to my two sons, Tapiwa and Tinashe.

Misunderstandings arising from my drug life were the constant order of the day. I was becoming an outcast in my own home. My wives and relatives despised me and my drug habits. It was very hard to support two wives and my habit in a collapsed economy. This prompted Nakai, the younger one, to leave as she had countless misunderstandings and fights with Janet. Coupled with the glaring poverty, she had had enough of it, so she left. After that, I stayed with Janet for some time until she also gave up on me. There were just too many misunderstandings and separation became the only option. I was often drunk, at times in a stupor - I would even go to 'work' as a brick moulder drunk.

My identity as a substance abuser pushed me out of any meaningful social roles but instead opened doors for me among the marginalised. Being drunk and high on drugs became a low hanging fruit for many cast blame on and ascribe wrongdoing to me, further making me an outcast. I vividly remember one time I had an altercation with my Janet. I had given her money after doing one of my many piecemeal jobs. The next morning, I asked about the money and she flatly denied that I had given it to her. It was one of the many cases where she took

advantage of my alcoholism to take money from me. Even when I missed my valuables at home, she would claim I had lost them somewhere when I was drunk. Janet would steal from me each time I was drunk taking advantage of my drunkenness. There were many instances like these where I was side-lined and taken advantage of because of my intoxication. There are some issues that I cannot even talk about because I feel they are way too private. Of course, I got denied my conjugal rights: up to now, I still believe someone had replaced me for my husband roles. However, I chose to drug myself and forget for lack of better options.

I engaged in endless fights with Janet. She complained of my drinking habits and eventually, the inevitable happened. We divorced in 2006. Since then, I have never remarried but have had many short-term girlfriends, one of whom I suspect is responsible for infecting me with this virus (HIV).

As if my problems were not enough, I got another punch, further pushing me to the margins of our community. In 2007, I fell while I was drunk, the next thing, I woke up in a Harare Central Hospital orthopaedic ward, with a dislocated shoulder. It had so happened that one of the days, when I was walking back home at night from my regular binges I slipped and fell. The wound I sustained took long to heal, worrying the medical team.

The doctor suggested that I go for an HIV test as a step towards finding out why the wound was not healing, at least in their expected timeframe. I tested positive for HIV. I was subjected to a series of counselling sessions before I started taking the antiretroviral drugs. It was difficult to fathom back then, but as time went on, I have been gradually getting to grips with the new life I have to live now. To me, Billy is a substance abuser living with HIV, I blame my life circumstances on my past, and I am currently leading a life on the margins of my community. I am hustling without any plan in the land of lack. Loads of stigma and exclusion have also been an everyday reality.

Doing my reflections now, I can safely say substance abuse and all this poverty around contributed immensely to me contracting HIV. I drank alcohol often, my decision-making and judgement were highly compromised. I had unprotected sex with my girlfriends. Being fit and ‘curved’ misled me, I thought they were ‘clean’, and now here I am. I strongly feel that there is a lot that needs to be done as far as educating the masses on HIV and its relationship with substance abuse. As they say, when you are drunk, your decision-making is impaired, and I was a victim of that. There are times here in the ghetto when one can easily do HIV diagnosis using one’s eyes to gauge whether their partners are HIV positive or not, which is very rampant

amongst my peers here. This kind of misinformation can only be corrected by further educating and involving the public in all HIV campaigns and fighting stigma.

It has been a rough road to be living with HIV and at the same time being labelled a substance abuser. Especially with HIV, it has not been too good, although many people think it is no longer a topical problem. Discrimination and stigma are still rife out there and I have suffered verbal abuse, even from my family members. My older brother Sam tends to abuse me whenever he is drunk. On one of those days, he came back from his beer binges hurling insults at me.

"You are useless Billy; a 'moving grave' and you are just waiting for your turn to die" – Sam.

That pierced my heart, especially coming from my kith and kin. It made me feel like I was no longer a normal human being like everyone else, his statement was a bitter pill to swallow and up to now, it has not escaped my subconscious. I have always felt like I do not belong to this family.

There was one other incident where I had a misunderstanding with him and we engaged in a heated argument and an exchange of words. Bereft of facts in the argument, he started using my condition as his line of defence. He told me I was sick, waiting to die and had nothing to offer in life and I was not someone to count on. We would disagree on other issues, but he then takes advantage of the fact that I am living with HIV and insults me using that. It is hard to forgive him as my blood brother; it hurts me. This is one of the reasons I feel like leaving home and leading my life among people who understand me. My drinking partners are way better than my family.

As for substance abuse, it is a given that our society loathes substance abusers like me and there is also discrimination around it. Often, substance abuse has led me to misbehave and my community does not tolerate substance abusers. People generally look down on me, and it is effortless to be side-lined. They see nothing coming out of me. The pressure for limited opportunities seemingly makes me an easy target for discrimination. I am a victimised victim, of HIV and substance abuse. Instead of helping, society is more prepared to punish me, arguing I am not doing much about my situation.

There is stereotyping associated with people like me. You are nothing to society when you are a substance abuser, worse when living with HIV - you get the treatment of an outcast, they want to get rid of you. With high unemployment rates in our country, substance abusers are

taken for thieves who steal to satisfy their insatiable desire for alcohol, yet this is not always the case. I work hard and I do not select jobs, I am everywhere doing piecemeal jobs, but I still have people denying me work in those demeaned jobs. We are seen as inferior people and things considered less important are reserved for people like me. Even at essential community gatherings, I am assigned to slaughter goats as others discuss pertinent issues. I have resigned from fighting for my place in this community through the accepted means. I instead go for the alternative means available and usually with less competition.

The feeling of being unwanted, an outcast has the effect of taking us deeper into more undesirable habits. I once got an opportunity to be recruited by the city council some time back, but rumour mongers went and whispered that I am a substance abuser, careless about my HIV status, to my would-be bosses. Negative things like:

"…if you employ him, he would be like a place holder…, a person who will not do anything because of he will be drunk…, after all, he is HIV positive" - Ngoni (pseudonym)

This is not valid; it is just a stereotype that is attached to us because not all of us cannot work. Unfortunately, the company did not hire me; another opportunity to transform my life got stolen.

Even amongst my kith and kin, it is no different, as the tag of being HIV positive and a substance abuser haunts me. They think all energy is exerted towards being loose and 'high' and nothing productive for myself and or the well-being of my two boys. When I ask for help, it is usually not forthcoming. They do not know sometimes I can get drunk without a penny in my pocket; there is a community of drunkards who are always ready to help a craving brother. However, to them, after having seen me drunk the previous day and asking for money the next day, it does not make sense. They think I am valuing my alcoholism at the expense of important needs and my children. Things are tight for everyone, and my family has taken a punitive and exclusionary stance against me. It is a lonely world that most people do not understand but claim to. This side-lining has the opposite effect to what they are pushing for, which is total sobriety.

I vividly recall this incident where I was having problems paying school fees for my children and I sought help from one of my uncles, John, whom I knew could help. He told me off and shouted abusive words. This was his reaction after seeing me drunk and walking with some sex workers the previous week, not knowing someone had bought me the alcohol.

As I alluded to earlier on, there is always money amongst drunkards to satisfy our desire but it ends there. I am always left to be on my own as relatives, like everyone else, view me as irresponsible and undeserving of any kind of help, further alienating me.

The extent of disdain for and trivialisation of substance abusers who live with HIV in the society is deeply entrenched to levels of being a danger to our lives. I remember there was a guy who used to stay in our neighbourhood, Jason. He was always drunk, and yet he was on ART medications. His drinking made me, Billy, with my penchant for alcohol and drugs look like an amateur. He would go for days without food. One day he went to ask for food from the takeaway ladies who brushed him aside because of the drunkard label. Unknown to them, he was in distress with no food for days; he eventually fell and died. Stigma and discrimination can kill. Had he been taken seriously, accepted and helped, he might still be alive today. He died of hunger and an attempt to get food was met with contempt because of the 'careless-drunkard' tag he carried. I am not immune to these realities; one day it could be me.

Some exclusionary challenges I have faced are to do with relationships. This has been mainly because HIV disclosure is still difficult as stigma and discrimination are still rampant in my community. Despite years of education and improvements made in the treatment and management of HIV, I feel like a lot still needs to be done to make people understand the condition. I remember falling in love with this other girl after my divorce. Her name was Esnathy. We dated for some time, and I even introduced her to my relatives. We were in love until I decided to be honest and told her about my HIV status. That marked the death of our relationship as she said, marrying me would be synonymous with choosing to die.

I felt too much pain and anguish in my heart. That incident made me feel I am doomed as a person with HIV. I never heard from Esnathy again as she cut all lines of communication with me. I have given up on my search for a marriage to meet my sexual needs. I now just go for sex workers. I have concluded I will never be accepted in mainstream society.

My sincere desire is to let go of substance abuse and be counted as a worthy, educated, Christian father in paid work, but it is proving difficult. The greatest misunderstanding that society has towards me is the belief that I enjoy this life. I am a prisoner to this life, but that is all I have; I have learnt to live with it. It has so many negative sides to it. Once you get hooked to substance abuse, it is difficult to let go without help from other people; the labels we get do not help us, they further marginalise us. This is where I think society is letting people like me down.

It is my desire to let go of all the 'bad' things I am doing, but it is not easy, it sounds like letting go of myself. I have always found myself back to 'being me'. There are no worthy alternatives or the ones there are played down. Looking back and using myself as a case study, I believe substance abuse is increasing because a lot of young people are idle and drugs become the closest and most readily available escape, which however, comes with risky behaviours. If wishes were horses, I desire a situation where the government and its development partners try to establish running projects to occupy the minds of unemployed young people. That will greatly help as I see most young people in my neighbourhood following the route of drugs because of idleness.

I wish for a day when people like me, despite my substance abuse and HIV, can be viewed as normal people. A day when there is more acceptance and help than there is poverty, stigma and discrimination. I long for a day in a supportive community, where people know the true impact of stigma, that it has the opposite effect of what the community expects. With exclusion and other punitive stances, young people like myself will only sink and decide to live against norms on the margins of society. It is guaranteed, the community will not get what it is expecting by chiding and socially excluding people like me.

My wish is to receive support and opportunities that will aid me and people like me to leave substance abuse and live well with HIV. That would mean contributing to society through working productively, even in traditional or indigenous trades. As I alluded to earlier on, once you get hooked on to substance abuse, it is very difficult to quit on your own. You need the support of people around you and professionals to do so. I have been to Harare Psychiatry Hospital; it did not work for me. They tried to help me quit because I was now defaulting on my ART when drunk. I did not like how I was supposed to be managed as a mentally ill person. It turned out to be a question of me just leaving what I was doing and not being included to share what influenced those doings. In the end, I did not take their advice.

It is my desire and wish for the government to open a realm of choices and possibilities for people like me. I believe this will greatly help towards living an included life. Going forward, I would like to continue to be active and self-determine my life path into a healthy and included life. I want a formal job, to get married and take care of my two boys, Tinashe and Tapiwa. I know it is not going to be easy, but it is a journey I am willing to take. I wish to be seen as a normal person by society not to be segregated and side-lined by the same community that I am

hoping will help my cause. I wish to belong in a community with resources and opportunities to aide everyone in it to realise their maximum possible potential.

5.2.2. Introducing P Jay: Inclusion by exclusion – the story of my life

The quality of one's neighbourhood and childhood have an overwhelming effect on the course of one's adult life. Often, with a closer look at anyone's adult life, we are likely going to get insights into their childhood and the communities they were raised in. Decent shelter, food, education and generally a conducive environment for growth are dreams for every child, but the death of my parents in a poverty-stricken context left me vulnerable and predisposed to injustices and exclusion. For me, seeking a sense of belonging in an unsupportive environment and in the absence of proper parental guidance led me to this marginalised life I live today. It blindly led me to exclusion which I was trying to run away from in the first place. Thus, inclusion by exclusion is the story of my life as a young adult living with HIV and abusing substances.

Born on 20 October 1999, I grew up in Harare's high-density suburb of Mufakose. I once lived a decent and happy life that an average Zimbabwean child would yearn for. An unexpected turn occurred when my parents died one after the other from what we later learnt were HIV related illnesses. I lost my father in 2006, leaving the five of us, my mother, elder brother, myself and my two little sisters, vulnerable to the greed and wickedness of my paternal relatives. I vividly remember how my father's two sisters were a thorn in our lives. You are probably bewildered as to why l am using very strong words against my relatives; it will get clearer soon.

After the death of my dad, his two sisters, who were also struggling to make ends meet, accused my mother of planning to sell their parents' house, the house in which we were staying, it was our home. The accusation did not make sense to me at the time. I wondered how my mother could sell a place which we called home. True to their word, they sent us packing to Chitungwiza, the home of our maternal granny. There were heated arguments and exchanges of words which left both sides bitter and unsupportive of us. My aunts' actions did not sit well with my mother's people who felt their daughter was being abused and taken advantage of after losing her husband, not to mention being left with young children. We stayed in Chitungwiza for about three weeks and the anger induced by my two aunties on my grandparents did not do us any favour, we were sent packing again back to Mufakose.

We went back and forth between Chitungwiza and Mufakose until my mother passed on in 2007, not long after my dad. Only then, did my father's elder sister take us into her custody at the instigation of her husband. People say the move was because the community was now gossiping about how they were neglecting us. We finally had a permanent home, so to speak, at Aunty Mai Matipa in Mufakose, but life became more difficult for us. The change in lifestyle was marked. From getting what we wanted to sometimes going to bed on empty stomachs. This became a stark reminder that indeed my parents were gone, and hard times were with us. I began to see myself as all alone in this brutal world that seemingly has no mercy for the vulnerable. I was growing with little to no options, and no room to make choices, the poverty around us was just too much.

All along, I was oblivious of my HIV status until something happened. The last born in my family, Trish, got sick. She got tested and was found to be HIV positive. Unfortunately, she lost the battle soon after she had been put on medication. This prompted Aunt Mai Matipa to get all of us tested, a decision I did not understand at that time but for which I thank her today. If not for this testing, I probably would have succumbed to the "killer disease" too. I vehemently tried to resist her decision to get us tested; after all, I had never had sexual relationships before. I only yielded after she threatened me with eviction. I had no choice but to give in. When you are a nobody, decisions are made for you and not with you.

My surviving little sister Naomi and I tested positive for the HIV virus and were put on medication. It did not make sense to me, and I developed a negative attitude towards my treatment. I was inconsistent in taking my medication because I was too immature to understand the consequences. The counsellors at the clinic had tried their best to make me come to terms with my developing and newly found identity, but I never listened to a word they said. All I wanted was to leave the counselling sessions as I felt irritated by their long lectures. As I grew up, I started to understand the weight of the condition I was living with, and, even more, how stigmatised and discriminated against it was. I had to find ways to survive this scourge.

None of my friends knew or even know now that I am HIV positive, I give the impression that we are the same. I fear that if I tell someone, especially in our high-density suburbs, they will spread the word throughout Mufakose, exposing me to discrimination because of my HIV status. People still have this belief that HIV is only contracted through promiscuous behaviour. I realised that it is better if people are left in the dark as these days there are no visible marks

indicating that I am living with HIV. I used to be sickly and in and out of hospital. My close relatives are the ones who know of my status, but still, they have been giving me a hard time.

I never loved being at home, in the process loathing my aunt, whom l felt was unfair, cruel, and abusive to me. We used to have endless quarrels. When I look back now, I can see some of them were unnecessary, but anyway, that was my life with Aunt Annah affectionately known as Mai Matipa. We rarely got along, and I found myself away from home often when not at school. I lived a stressful life that made me a cocoon of secrecy. By doing so, I was exposing myself to bad elements that were, unknown to me, going to lead me into an anti-social life, a life where fellow marginalised people would accept me. My aunt never approved of my deeds and the friends I had. I hated that she did not treat me like any other child. She knew I was living with HIV and verbally abused me, discriminated against me on those grounds, in the guise of disciplining me. She insulted me whenever I asked for money to buy things like school stationery. She once said, 'I am not the one who killed your father, and he did not leave anything in his bank account for your upkeep'. Giving me food and shelter was more than enough for her. Those utterances pierced my heart and made me yearn for my deceased parents.

Her reprimands further alienated me from her and the family at large. I guess they meant well, but up to now, I am still convinced it was an unconscious punishment for my HIV status. One day she was really angry at me for coming back home late. She told me had it not been that I was living with HIV, she would have beaten the hell out of me. At eleven, I was already being told to behave or leave her house; I was a burden. From these experiences, I felt alone and an outcast in the family which I called mine. It led me to find solace elsewhere and that is how I joined Nyau dancing and started substance abuse.

I joined Nyau dancing together with my close friends, John whom we called 'Jonso' and Timmy, the 'naughty one'. The Malawian cultural dance practice, answered my need for acceptance, belonging and blended well with my natural love for music and dance. Growing up in the ghetto, I had much respect for the Nyau dancers, my ancestral roots can be traced back to Malawi; and they were feared by the community as they were thought to use juju[8]. They were a family on their own, good at taking care of one another, compared with what I was going through at home.

[8] A traditional spiritual practice associated with magical power, bad spells and witchcraft

I am a natural dancer. After joining, I became so engrossed in the dance that when sent home over unpaid school fees, our first port of call with my friends would be the Nyau dancers' base. It got worse and we would bunk lessons, leaving home clad in school uniforms but spending the whole day with elders of the Nyau dance, doing practices. We were sometimes absent from school for a whole week. The Nyau group became my new family and they introduced me to drugs. It was hard to resist; after all, they had become firmly integrated as my family. Drugs were part of the Nyau practices but also came as solace from my ever complicated and stressful life.

Meanwhile, quarrels with my aunt were getting intense. Saturdays for Nyau dancers was like Sundays are to some Christians. I could not afford to skip my "religious day". At the same time, Saturday, being a weekend, my aunt would require my services for home chores. But this I took as routine punishment to deter me from going out. The Saturday altercations went on, and whenever I would go out against aunt's word, she would not leave food for me. I did not care, after dancing our lungs out, we would get tokens of appreciation from our elders who, despite putting in little or no effort, received the bigger chunk of proceeds from the ecstatic crowd. Chores at home for me were demeaning and unjustified; it was mostly me and not the other kids being sent around. I felt like it was punishment for my status and taking drugs. Against this, Nyau dancing had a pull factor. It gave me belonging, pride and, of course, some monetary reward.

I had a strong feeling that my aunt's mission was to expose and control me. One evening I came back from my Nyau dancing visibly drunk, I found her with visitors, her friends from the hood and I was greeted with the line.

"You are late again, and you haven't taken your tablets, no one will take care of you if you fall sick, I will leave you to die … you naughty boy…" – Aunt Mai Matipa.

I got angry as I felt she was exposing me to her friends, that I was on ART, exposing me to potential stigma and discrimination. How will I be able to walk in the streets, if people got to know I was HIV positive? I had declared it be kept a secret and now she was exposing me to vultures. This incident further weakened the already acrimonious relationship with my aunt. She was going against my fighting strategy. Unknowingly, she was hardening the rebel I was becoming and now I would do anything to get my way.

It became a routine that every time I had a spat with my aunt, I would head straight for the Nyau dancers, where my drug habits were solidified. Drugs, by the way, were part of the

initiation. Nyau dancing and drugs relieved me from stress. Before long, marijuana became part of my life. We believed drugs were a part of being a great Nyau dancer and it made us feel good and forget all troubles.

During my time with the Nyau dancers, drug abuse became the order of the day. My aunt did not give up reprimanding me. She would always point it out that I was risking my health by taking drugs whilst on ART. I did not want to be told this sad truth. For me, the drugs and Nyau dancing were part of my life and a vehicle to belonging. I would sometimes forget to take my medication as I would be high on drugs. I became an outcast in the family, and I went against every advice. My family hated me more for associating with despised people, for the Nyau dancers were regarded as demonic and an excluded group. I did not see any problem with my shameful life and help was far from coming.

I continued the path of drugs and the fruits thereof were beginning to manifest. I became violent and a law unto myself. I developed into this feared young man at school and in my neighbourhood. I became the self-proclaimed security person for some girls at school and chaps from the hood. I had so much courage and no one really dared me. I loved the attention I was getting; it felt good. Fellow students and teachers who noticed I was getting lost reprimanded me, but I never gave them an ear.

Being part of the drug-taking family left me with unwanted labels. If you were to ask anyone from my hood, they tell you suspicion hovers around people who take drugs. The stereotype of substance abusers being thieves followed me. I had to live with it, but I could not care less. The income I got from doing menial jobs was spent on drugs supplementing the supply from the Nyau group.

At school, it was not getting any better. Altercations with teachers being the order of the day. With my crew, we would erase work written on the chalkboard, making us darlings of fellow pupils. They cheered us on for standing up to the teachers, oblivious to the fact that we were ruining our futures. I was eventually expelled from school after beating up a security guard together with my friend, a consequence of the drug life. Meanwhile, my adherence to medication never improved. After the expulsion, my family was not interested in having me back in school and that was the end of it. I left school in form two. After all, I had been a neglected child for a long time, the family could hardly afford to pay my fees and I was always being sent away for unpaid fees; my expulsion was a blessing in disguise.

I loved violence and fighting. I wanted to be feared and was always seeking recognition. Looking back now, I realise, how I did that subconsciously to cope with the misery in my life. For fear of HIV stigma and discrimination, I had to take a pro-fighting stance as a defence. I was more comfortable being on the offensive and controlling my own life than having other people tell me what to do or who to be. I wanted to feel important and I realise now it was in part because I felt rejected at home.

I lost respect for the elders in the community and would verbally insult elderly women and no one crossed my path. These deeds of mine earned a backlash and a label from the community. I could not get any assistance, even when the need was apparent. Substance abuse got me labels, and the respected of our community had no time for me. I did not stop fighting to hide my HIV status, driven by fear of prevalent stigma.

My drug-taking habits continued unabated. Meanwhile, my relationship with my aunt at home did not get better. I turned 18 years (the legal age of majority), and she asked me to look for my own place to stay. With no tangible income of my own, there was no way I could move out. I hated my aunt more, and she seemed to segregate me from the rest of the family. Little did I ascribe that to my delinquent behaviour. The more she tried to be hard on me, the more delinquent I became, we were at crossroads. I was living in my own world, that of ecstasy and drugs.

My close friends were not really from my street. Rarely would you find me with people from there because they turned down my proposal to do things together, they were not willing accomplices to my shenanigans. They also had a tendency of side-lining me for no reason, at least known to me. Who knows, maybe they had heard the news that I was living with HIV and chose to despise me, I thought to myself.

All this time, when the madness was happening, yes, I now see it as madness because that is what it was, my health was unknowingly deteriorating. My adherence to ART was heavily compromised, and at times I would miss my medication for a day or two. I was deep into drugs and alcohol, forgetting my health. It so happened that I had a visit to the hospital for my CD4 count test, recommended by the clinic from where I was getting my ART supply. The results were not pleasing. The doctor called me and told me that I was risking my life. He said my CD4 count was worryingly low. He insinuated I was not taking my medication and I stared him with a bewildered face, wondering how he had come to know. I laughed, which did not go well with the doctor and he sent me home without giving me any medication. They were now

fed up with my poor adherence to treatment. Things were taking a turn for the worst. I met a certain counsellor whom I told what had happened and she advised that I go back and plead with them as I could not survive minus the Anti-Retroviral drugs (ARVs).

I gathered the courage to go back to the hospital and face the very same person who had sent me packing. The reality was gradually dawning on me. Upon my return to the health institution, they enquired if I was now serious about my health. For the first time in a very long time, I felt cornered, someone was whipping me into line, albeit for my own good.

I was referred to the counsellors. They repeated the need for me to religiously take my medication on time every day. They also indicated that drugs and alcohol were not good for a person on ART as they could easily lead to treatment failure. Dire consequences on my health would follow if I failed to follow what they had taught me. Eventually, I got the medication after recounting what I had grasped from the session with the counsellors. This hospital visit had a positive impact on me. It dawned on me: I was risking my life. I could end up dying if I did not adhere to medication. The reality sunk in that I had to shape up and change my ways, or I would die. I got a referral to go and see the mental health team at Harare Psychiatric Hospital but I only went there once. I did not agree with their approach. They concluded I was problematic before listening to my story. I went there with my aunt and it was her account of the story they chose to believe.

On another visit to the hospital, counsellors also asked if I had ever heard of community-based support groups for people living with HIV. They gave me the contact number of the leader of a support group in my community. When I went there (to the support group) for the first time, I saw different age groups represented. I felt better seeing people of the same status. Messages of hope and support shared within the group gave me renewed strength and vigour to religiously take my medication. I thought I had found a new family, a good family.

The familyhood in the support group felt so good. The support group became an eye-opener for me. My interactions there made me realise drugs were not good for me, especially with my condition. It dawned on me, that all along I had been self-destructing. However, the unsupportive environment at home and in our country has continued to stand in my way to a clean and productive life. Stress and lack always take me back to drugs. As I share my story, I have renewed hope of overcoming, but the problems in our country do not allow people like me to escape. I have no means to transform my life or make better choices. If only I could get a formal education and be formally employed.

It has never been a smooth journey for me. I continue to battle relapses now and again. I now feel that I know how drugs will jeopardise my health, but I just cannot quit completely. There is more to these challenges than what rests on me as an individual. The support group and a community church I once went to are trying to turn my life from the mess it is towards a better and positive trajectory. These too are yet to bear tangible positive fruits. Something I have figured along my journey is that if things are really to work out for me, I need to go back to school, then get formal paid employment and be in the church away from drugs. This is what the community recognises as a worthy and respected life. Meanwhile, I take solace in the music and dance group we formed with my friends. We are, at times hired to perform at small functions like parties. People who have seen us perform know that they can count on us. It is however easy to be dismissed on the grounds that some would have seen us drunk. The challenge with the music and dance group comes with the way we are using the proceeds from such. We are always in circles, going back to drugs with every cent.

Doing things which would make me count has always been my dream. I dream of seeing myself away from drugs, going to work and attending church regularly. Where I am healthy, compliant with the medication, speaking openly about my status and encouraging others along the journey without fear of stigma and discrimination. A dream of a life where the church will be an integral part and, where we used to dance to rejection, we would be dancing to acceptance. But in that life, I must be in the driving force for all decisions and choices pertaining to my life. My voice and experience should matter, just as everybody's voice. Our other hustles outside of formal education and paid employment should be counted and valued, giving room for growth of talent and other looked down upon trades. I want to settle the dispute with my aunt and see an improved healthy relationship. I look forward to getting an identity card.

My interaction with the researcher made me feel like human and included, though some memories still haunt me. Often, I find myself yearning for an ear that listens. The researcher gave me an opportunity to tell my story and after numerous engagements with him, I feel like a load has been taken off my shoulders. I am looking forward to a better life and to be counted in a way that counts.

Some of his questions made me realise certain elements of my life I was oblivious to. The conversation I had with him was refreshing. I got some assurance that someone was willing to listen to a ghetto boy like me; it gave me a sense of self-worth. In telling my life story, I realised

that in my quest to seek social inclusion and acceptance in society, I ended up with excluded groups like the Nyau dancers, drug abusers and violent gangs.

5.2.3. Introducing Nicky: Abused, socially excluded and numb.

In many instances, there is an intimate relationship that exists between a mother and a daughter. This close relationship led to the coining of the adage, 'a mother is a daughter's best friend'. I lost my mother at a tender age, worse still in an unsupportive jungle of uncertainties. When I lost my mother, I think I lost a shoulder to cry on, someone to tell all my problems, regrets, failures; and being assured of an attentive ear. I lost someone who could have helped me in the thorny and rocky terrain of my life journey.

My name is Nicky. I was born in 1991 in Zimbabwe's second-largest city. My story is of a child who lost the soft and tender touch of a mother at the tenderest age. I was abused by my own father first, followed by many other waves of abuse as I continued to navigate this unfriendly terrain of the world. I am living on the margins; I am socially excluded but trying to be 'numb' to it.

I have no memories of my mother as I lost her when I was only three months old. Many people say my survival is nothing but a miracle, worse off in our society where supplementary formula milk is a luxury many people cannot afford. I grew up in Bulawayo under the care of my maternal aunt Mai Mako, my mother's elder sister. I stayed with my maternal relatives until the age of eight, when they decided I could start visiting my dad in Harare over school holidays. I barely knew him then, but the opportunity to be with him was one I looked forward to. I could now brag to my friends who trolled me at school for never getting a visit from my dad.

I left Bulawayo for the December 2000 holiday as an innocent little girl relishing the opportunity to reconnect and bond with her father but returned a traumatised child. For all the hype and expectations my journey to the capital carried, it marked a downturn in my life, the genesis of the troubles I am still facing and trying to fight off today. My father was staying alone at that time, and we were to spend the holiday together just the two of us. Instead of seeing a daughter, my father saw a grown woman whom he could be intimate with, at the age of eight, my dad, my own biological father, started being intimate with me. He raped me with no remorse. Was he or is he my father? Why did he do that to his own daughter? I have no sound answers to date. The abuse that was to last for almost five to six years began that fateful holiday.

I went back to Bulawayo, a traumatised child, bewildered, and confused. Something was depressing me and the pressure of it kept piling up inside of me. Anger and bitterness became the order of my day as I failed to cope with the trauma of being sexually abused by my own

father. What made the abuse more hurtful was that I had no one to notice or at least give me a listening ear. Everyone seemed busy with their own lives, trying to make ends meet in the hostile Zimbabwean environment. Instead, I received reprimands and rebukes for trying to open up to those people I trusted.

Growing up with my aunt in Bulawayo, I had this tag of being too clever, a child who always told lies. When I poured my heart out to my aunt, Mai Mako, about what happened to me and would be a routinely exercised each time I went to Harare, she did not believe me at all. Instead of digging to investigate what I was saying, she brushed me aside. I remember eavesdropping on a conversation she had with one of my uncles about the issue. They concluded that I was crafty and lying and that I did not like my father; I wanted to avoid going on holiday where someone would be strict with me. They also agreed that 'Bamunini' (my father), was not that kind of person. From then on, I knew I was on my own.

I was bottling up inside, and gradually I developed a hatred towards all males. I began living in a shell which began to feel like my own world. No one I tried opening up to trusted me, they thought I was trying to frame my father and soil his 'good image' and to be honest, that hurt then and still hurts today. I had nowhere to turn to. There I was alone, young innocent and sexually abused with no one believing me; it took a toll on me. I remember being beaten for repeating the story that my father had indeed abused me.

The abuse continued holiday after holiday, whenever I was taken to Harare to be with my father. The situation became worse, so that, at 15, the piling stress took its toll, and I attempted suicide. I took rat poison and the quick response by the family saved me as I was rushed to the hospital. I had given up living and felt joining my mom was the only option for me. It was now them against me or me against the world. My aunt was angry about my attempted suicide. She feared I was going to die in her custody; she decided she could not stay with me anymore.

That is how I was moved to Harare permanently. I was to be under the same roof as my abusive father. Imagine the trauma. The picture of my father abusing me did not leave my memory, and it was like a horror movie replaying. I was enrolled at Harare's Kambuzuma High 2 to continue with my education. Living under the same roof with him was too much to handle; it led me into drugs seeking comfort from the traumatising experience at home.

At school, I had become friends with Machy, who was into music. He used to play traditional instruments like mbira and marimba. I joined him and he started teaching me how to play some of these. Machy was into drugs. He used to smoke marijuana and was taking ecstasy shots. I

cannot really say he introduced me to drugs per se, as I was already looking for something to soothe my pain or numb me, but being around him most of the time, making music together and seeing how happy he was after taking drugs induced me to try it. This was in the hope of getting relief from the war of rape images and emotions of bitterness and anger. I indeed found comfort in taking marijuana with everything that was happening at home. Machy seemed listening and more understanding, the first person to believe my story. Trouble started at home because of my new habits, but I guess Dad was too tainted to stand on any moral ground to effectively deal with me.

I got hooked into drugs too fast. Before long, I linked up with Machy's associates who sold ecstasy, marijuana and all sorts of drugs. To sustain my newfound habit, I had to find extra money and, without hesitation, I joined the drug-selling gang. I immediately began selling in areas like Chitungwiza and the plush suburb of Avondale. I took all sorts of drugs, marijuana, meth, pills and tablets whose names I cannot even recall. I would inject myself shots of ecstasy and the habit was deepening.

Meanwhile, the effects of drugs began showing. I used to be sociable, but now I was isolating myself from people. I opened up about taking drugs to my cousin, Prim. I told her everything, including how I got hooked into this world. I told her with a strong conviction that I ought to quit the habit, but it was difficult. When my extended family eventually got wind of my drug use, they did not take it lightly. They wanted to beat me out of it and it made me feel like an outcast. I really feel that if they had helped me back then, things might have turned out better for me. They were too harsh on me and failed to comprehend the underlying factors which led me into drugs. It was during this time that my father remarried and I now had a stepmother. She was of no help and she blindly followed whatever she was told by those around me and was too judgemental.

One day my family took me to the police for discipline by caning to take me off drugs. This did not help but strengthened my resolve to continue drugs. I just could not heal from outside when I was injured from within. The real problem was my father abusing me, not the drugs. I tried opening up to the police about the abuse. They too did not take that. They thought I was trying to cover up for my drug abuse.

I became addicted to drugs. When I did not have money to buy my next shot, I would end up engaging in sex work so that I could get money for drugs. At times when I had no money, I would get drugs in exchange for sex from my suppliers. Deep inside, I no longer wanted this,

but when you become a member of a gang, it is difficult to get out. In the mix of all this, my education suffered. When I wrote my Ordinary levels, I managed to pass only three subjects and gave up on school. When I look back, I see myself as an above-average student who should have easily passed her Ordinary level exams, but there were too many forces working against me, my life was just a mess without the right support. I was an abused child suffering the trauma of sexual abuse, and depression was the order of my life. Drugs were the antidote to coping with stress. I totally lost interest in school and I had 'wrong' friends who took me deeper into the drug world.

In 2009, I developed psychiatric issues and my family took me to Annex psychiatry hospital. My dad and stepmother would come to visit me there. At the hospital, I was supposed to be starved of drugs, but my gang friends would smuggle some in for me hidden in food items. This would lead me to relapse again, and the cycle continued. I was not ready for change and so forced rehabilitation failed too. I felt that I was not being listened to and the suggested solutions continued to fail. It was during this period that I tested positive for HIV. Back then, it was not a big issue for me. I just moved on with it as a new background tag.

My family really tried to help me get off drugs. When I looked at them, I would see the agony on their faces as they tried in vain to help me get off drugs. For me, because they were led by my persecutor (my dad), they were never qualified to help me. The withdrawal symptoms and the threat of the gang were punishments I was not willing to endure. I eventually left my home as I felt unsafe. I could not take the reprimanding and close monitoring of my parents anymore. The gang also threatened me because of my family's involvement with the police. I hooked up with some friends and left home to settle in Mufakose. I was moving into independence, staying alone, where there were no rules and laws governing me. I was to become my own person and a law unto myself. I also left home because I could no longer continue facing my primary abuser, pretending to act sincerely.

Meanwhile, in the community where I was now staying, discrimination and stigma against drugs and HIV were rife. Our society loathes drug abusers. An HIV positive young lady who is into drugs automatically takes the tag of a sex worker. Remember, I earlier on highlighted that I would engage in transactional sex to get money for drugs. I slept with men because I needed something. I ended up with no feelings and deep-rooted bitterness towards all males. In the gang, it became a survival engagement as I sought belonging and protection. It is this

hatred that led me to become a homosexual, an unacceptable sexual orientation in my community.

I am unapologetic about my lesbian orientation today. I am in a stay-in type of relationship with Charity, my partner. It really felt better sleeping with a girl than a man. I felt acceptance and power to self-determine, doing it in comparison to heterosexual sex. Bearing in mind that my first sexual encounter was by force and rough and most subsequent sexual encounters had the hallmarks of my first, which was rape, my sexual engagements have all been shaped by that. However, homosexual practices further alienated me from the community in which I lived.

I now carried multiple despised tags, rape survivor, substance abuser living with HIV and a lesbian. These are more life sentences for rejection and victimisation. Homosexual marriages are a crime in Zimbabwe. We once got arrested for a violence case linked to this. One of our female acquaintances sold my partner and me out to the community. Charity and I beat the hell out of her, and we got arrested. Many people came to the police station to see the arrested lesbians (sic). It was embarrassing, but I, for one, did not care that much. Eventually, we were fined and released with warned and cautioned statements, but the event became the talk of the community, further alienating us. Our landlord chucked us out of his house, and we had a torrid time finding accommodation.

That incident was a dent and still has ramifications as I try to progress and turn over a new leaf for myself. Sometimes I hear people gossiping about me. They give me all sorts of derogatory names. They call me names like a sick girl, a 'babe rasta', and a 'homo' (a street name for those in homosexual relationships). Other children are warned against playing with me; I am always used as a bad example, a life not to be lived.

One day I helplessly listened to two ladies talking about me; I could not do anything about it but it did hurt me. I want to be accepted as a normal person, but it is difficult- the tags I have on me are not for that.

I have kept my HIV status a guarded secret and very few people know that I live with the virus. Once the people around me know they would make you feel like a disgrace. For me, just the knowledge that I am HIV positive has led me to subconsciously exclude myself. I sort of isolate and seclude myself from others. Despite all the information and education unleashed on the people about HIV, stigma and discrimination based on one's HIV status is still rife in our communities. This is even worse for me without the means to improve my own life. Without

education, the hope of a job is also dead. It stresses me a lot, but drugs and my partner, Charity's, company soothes.

Disclosure has haunted me big time and I regret telling some people about my status. Once they knew about my status, they gave me my own cup, plate and spoon and did not want to share anything with me. You can imagine the misinformation that is out there. Some people still think one can get HIV from sharing a cup with someone infected. I felt like an outsider amongst some of my friends, even those I was doing drugs with. It happened with my family too. When it happened, I would get comfort in taking drugs again, usually a dose above what I would call the norm.

When I stayed with Charity at their house, her mother was worse. She reprimanded her daughter for being with me, using demeaning and abusive language and gave me my own utensils to use. She would ask Charity if she was sane and said openly that she was ashamed of our relationship, even asking her daughter why she had chosen to associate with a 'moving grave', implying I was dying soon and therefore of no use.

That pierced my heart, but I had nothing else to do nor anywhere to go as I was financially dependent on Charity. That is how Charity and I moved out of their house as she decided to support me at the expense of her family.

My real family was not harsh upon finding out I was HIV positive. They have been supportive on that front but not with substance abuse and homosexual practices. When I look at them, I can see they are deeply hurt by my substance abuse and homosexuality. They are often blamed for not rendering support and helping me out of my situation. But they even asked me to come back home, which I did not feel was the right decision with me still on drugs. Besides, it never really felt like home; the jungle is my home.

Some of my friends enjoy taking drugs and being treated as social outcasts but I do not. It is something I am not proud of but I do not have options. It is very difficult to leave drugs, especially with gangs involved and no viable options to settle for. People who are not hooked, think leaving drugs is easy. I once made up my mind. I wanted to quit and take good care of my health but all hell broke loose. I used to see it happening on other girls in the gang but now I witnessed it first-hand. The rule was that you do not quit drug gangs; they fear you will expose them. They accused me of taking drugs from the base, a false accusation designed to punish me after they got wind that I wanted to quit. I was made to have sex with a dog; it still hurts me even now. I have never told anyone about this, but it happened. Ever since it happened, I

have never felt like I am human. I am ashamed of myself and not worthy of being around others. I did consider reporting it to the police, but I felt it was going to be a futile exercise. These people have connections everywhere, police, politicians and they are always protected. I now realise maybe I should have opened up to other people; I could have been helped, but I kept it to myself, hurting and being further abused.

It is hard to come out with my story because society has all these harsh words waiting for me and I cannot take it. I would love to associate with other people, go to church or even share my story with others as I believe it is part of the process out of this drug conundrum. But I fear being judged, people have stigmatising practices and I have experienced them before. The chances of being rejected once people know about my substance abuse and my HIV status are too high. They will see me as a problem; for this reason I have remained in my cocoon.

Life is tough, generally for everyone but worse for people in my circumstances. I live on piecemeal jobs for those who choose to accept me or who do not know me well; I am into drug dealing, sex work and, at times, some music and night club dancing. At one time, a colleague recommended me for a job at the garage kiosk in my hood. People from the community who got wind of my impending employment went and dissuaded Arnold from hiring me. They told him that it would be of no use employing Nicky, a drug abuser, she will steal from you, she might get drunk at work and your items will be stolen. They even mentioned that I am also on medication (living with HIV), and people would not buy from his store.

That is how I lost the opportunity. I take drugs, yes, but I have never stolen from anyone, but then it is a stereotype attached to drug users and I must live with it. I am living with HIV, yes, but I will not deliberately spread the virus.

It is these kinds of things that make me feel unacceptable in society. Everything is blamed on me despite the problems being bigger than my capacity. People treat and view you as the problem once they know you are a drug addict who is also HIV positive. I always get the notion that I am seen as not willing to change. I have heard some call me demon possessed. Sometimes, I just cannot cope with all that, and I end up feeling it is better to stay away from people and consider alternate ways of making ends meet.

Deep inside my heart, I have this desire to go clean and live a normal life just like any other girl of my age. I yearn for a day when I can quit totally. I understand the process must begin with me but it is hard given the economic problems in our country. My options are restricted,

and drugs offer solace, albeit temporary. The desire is there. There are times are there when I yearn for someone to listen, unpacking the burden inside my heart.

I wish I could get help to go for therapy, I know it will not be easy but I have the desire and conviction that I will do it one day. I hope my family will not tire of helping me in the process of getting clean and being more compliant with my medication, be accepted and productive. I need to change my current environment; it is too hostile and devoid of opportunities for people like myself to transform. I wish to take control of my life path and be accorded more chances and possibilities to better my life.

5.2.4. Introducing Mai Ngah: Doing what counts – my survival strategy

Being a woman in this unequal and patriarchal society comes with its fair share of challenges. Even in similar circumstances as men, women battle to prove their worth. Some refuse to play victim and move to a life they value. However, the world never seems ripe for this. In most instances, they are left bearing the agony of untold stories of resistance which society has normed.

My name is Mai Ngah. I was born in 1983; I am the firstborn in a family of three girls. I did my primary school in the rural areas and my secondary education in Harare. I attended boarding school, Presbyterian Mhondoro for my A' levels. I passed my high school and I wanted to go for nursing, but before I could do that, my father died in 2000. My mother was a housewife, and she could not afford to send me for tertiary education.

By that time, things were starting to go bad economically. Paid employment was hard to secure, more so without corrupt links in high offices. Luckily, I got employed against these odds. I worked for a government parastatal as a fuel attendant for about three years. During this time, I acquired my driver's licence and passport. We were in a hyperinflation period and our earnings were being eroded. I then decided to venture into cross-border trading, going to countries like South Africa, Malawi, Tanzania, Mozambique and the DRC. That is what I am currently doing. It was in this business that I met my husband (Baba Ngah). We dated, did a traditional marriage ceremony and our white wedding.

I had a strong Christian background and at the time of my wedding, I was the church's youth leader. After our wedding, I was appointed to be a youth advisor. Baba Ngah was very supportive although, because of his job, he rarely attended any church services. When he was off from work, he would be drinking at home or hanging out with his friends. We got blessed with three children: two boys and a girl. We were a very happy family.

During our rosy years, all seemed well. However, I was in the dark and Baba Ngah was having an affair with my close friend and neighbour, Mai Elisha. I was too busy with my life and being adventurous in ways to supplement our income. Baba Ngah's salary was not enough for our big extended families, where none of them was gainfully employed. The economic situation was bad but I would not say we were a poor family.

One night, after years of this seemingly rosy marriage, my life turned around. I remember answering a knock around 12 midnight. It was my husband Baba Ngah, *"Open the door,"* he said in a hesitant voice. He asked if I had done laundry. I told him yes and went on to answer

his next questions before he could ask. I had taken his tablets to a friend to ask what they were for and I had been told me everything. Then I went to bed sobbing. That was the longest night I have ever endured. My life was turning for the worst. The loathed virus had visited me; a despised identity was loading. The community was not ready to accept whom I was about to be, based on what I had witnessed with other people living with HIV.

Baba Ngah is a truck driver; I had found tablets I did not know about in his travelling bag. He could not answer any of my questions that night. All he could do was ask me to calm down, saying he would explain everything the following day. The next morning, he called his brother and my aunt, Aunt Chiedza. My aunt was that person who would not usually visit us. When she does, there would be a misunderstanding between my husband and me. She came in, and I prepared tea for her and she had tea with Baba Ngah. I went to the shops to buy something; I think that is when my husband told her why he had called her. When I came back, our uncle (baba Ngah's elder brother) had arrived, and I was asked to join them. My brother-in-law started preaching about forgiveness and that I should accept whatever they were going to tell me because I had vowed in riches and poverty and till death do us part on the altar. I pretended to be a fool, as I struggled to hold back my tears. He then broke the 'news' that the tablets I saw were my husband's and he was sorry for not telling me he was HIV positive. He had been taking them for over a year now. He had not disclosed, fearing that I would leave him. There was cemetery silence in the house, and then I started crying.

I was now recollecting how Baba Ngah used to complain about terrible headaches but was unwilling to seek any medical help. He would downplay it and blame his heavy drinking. Aunt Chiedza asked me to say something but I could not, my tears were shouting the bottling anger. I am short-tempered and, even my husband was expecting more, but the way I reacted shocked him. I guess I was too hurt to act. I felt betrayed.

It took some time for me to get to listen to what was being said. I was subjected to counselling. I still could not believe it. I think it was after a week or so that I slowly coming to my senses, Aunt Chiedza came back and asked me to get tested for HIV. After contemplating for a long time about the idea of getting to know what was to be my new identity, I went there and as expected, HIV positive I was.

I was thinking of my kids. Being a woman of strong faith, I was praying hard that it would not be. I had to take my kids for testing, my firstborn and second born both tested negative but my last-born, Munashe, tested positive and is on medication to date.

God came to my rescue because when I heard this news, I was very depressed though I tried not to show it. At one point, I was contemplating taking my life. I had a lot of unanswered questions. Why am I being punished by God? What did I do wrong? How did Baba Ngah contract it, from who and why did he give it to me? Am I going to die? How is my community going to react? I was very curious to know how my husband had contracted the virus. Many questions would come to mind because he was a truck driver and he would travel across Southern Africa. What was supposed to be closure, was a cut on a fresh wound, Baba Ngah told me he suspected Mai Elisha infected him, my close friend, my neighbour.

I was an established church member, so at some point, I went to church and told my pastor. She asked me to accept my fate because God had allowed it. When my pastor was consoling me, she chose to disclose her status and told me she was also HIV positive. She even showed me her ART medication. I remember I was shocked but did start feeling consoled by that. I had known her for some time, but never suspected she was living with HIV. Maybe I could keep my status secret too; I started to imagine. I was too afraid to face the stigma and discrimination in our communities.

Learning about my HIV status was a significant turn in my life. I had always dreaded the virus growing up; it was traumatic. I never had time to really heal, I tried to play down the impact of my HIV status, but it manifested in another way. As time moved on, I started reflecting deeply about it and imagined the hate and derogatory labels the community was giving to those living with HIV. It caused tension with my husband and after one heated exchange, I packed my bags and went to my parents' place. Baba Ngah had to send his brother to persuade me to return home. I was really hurt, but I loved my family and did not want the divorcee label either. I returned home but continued to stress about it. One day I was home and stressing; I wanted something to soothe me. There was alcohol in the fridge and I said let me try it, the depression will go. This is how it all started; I would initially hide it from the public.

One day my husband returned home to find me drunk. He just asked if that was what I had decided to do with my life, to which I responded that he was the reason and it was my life after all. He would not go beyond that; he was to blame for all this, and I would take advantage of it. He would do and approve everything I wanted. As time went by, he even started buying alcohol to drink together. Initially, I would hide behind destressing but obviously, my drinking habit did not go well with a lot of people, including my late mother-in-law. She used to call me a prostitute because of my drinking. I cannot imagine what would have happened had she had

known I was also living with HIV. She expected my husband to stop me from drinking but that would not happen. She eventually adjusted because she was financially dependent on us and I told her if she continued to persecute me, I would stop supporting her.

My own family members were equally worried when they discovered about my drinking. My own mother also asked and I told her that was what I wanted, I wanted to feel in control of my life. Societally, drinking in marriages is mainly a preserve for men. When a lady drinks alcohol or takes drugs, most people take it that they are of loose morals and even equate it with prostitution. Most women who drink, do not drink in public. Mine was a rare case, to have your husband support your drinking habits - that is a no-no for many.

Living with HIV is not easy against all the stigma and discrimination; worse for me, the diagnosis was just stressful. Of late, I have gone deeper with my drinking. At times being drunk pays off for me. I become more confident as a dancer and a master of ceremonies, my newly found trades of survival. When selling my stuff as a cross-border trader, I am more confident after taking three or four. There are a lot of illegal dealings involved in my line of business. It is not for sober people. I have come to a position of saying, 'those who talk, they are free to do so', and I know people say a lot behind my back. For instance, one day, I was coming out of my gate and two women from my hood were gossiping about me. They implied that I was a disgrace, I was not mindful of my health and not ashamed to be a drunkard who goes to church.

I confronted them and told them to leave me alone. In this jungle, you've got to stand up and fight for your rights. Otherwise, they will send you to live a deprived and marginalised life. I have decided to live life on my own terms.

Our communities are not safe havens and people living with HIV and abusing substances like me, are despised, and mostly deprived of opportunities to turn their lives around. But as for me, I decided to use all my fighting arsenal and take the bull by its horns. I did not sit back and cry, a victim. I decided to do all it took to get a financial voice and be counted. I have told myself, 'I will not wait to be given opportunities but will rather go and find them'.

I am doing all I can and my family is supportive and becoming less judgemental. Despite living with HIV and drinking this much, I have managed to continue with cross-border trading and I am turning my supposed problems into solutions.

I have seen many in my community who are suffering and are despised just because they are having drug problems and are living with HIV. This is one thing I have vowed should not

happen to me. I have decided to take an activist stand about my rights; I cannot be equated to the health problems I have. Of late, I have decided to be open about my HIV status. I am using events platforms where I will be directing functions or am just invited as a guest, to speak out against stigma and discrimination.

I have always been an art person and being a master of ceremonies for parties has always come naturally. Seeing that the odds of getting formal employment are slim, I have turned to the gifts God has blessed me with. I use those to do things that make me count or benefit others. Whenever I am not out of the country with my cross-border hustles, I can be hired for functions. I do all sorts of parties as an MC, from birthdays to weddings. Because I am so good at directing functions and entertaining guests, most people in my community seem to have accepted me the way I am. I seize these opportunities to disclose about my life and challenge people to be less judgemental and more accepting of one another.

Many people in my situation do not set foot in church, but I am different. With all my challenges, I have maintained active participation in the church. I just do not leave room for other people to dictate the pace and direction of my life. I am in charge. My church leadership, especially my pastor, have been very supportive. They did not expel me from the church as others do to their members struggling with substance abuse. I have remained an asset to the church where I teach the youth, women and men at our church about relationships and HIV. I encourage them to get tested, fight stigma and disclose their status to their partners to avoid marital disputes, divorces and heartbreaks. We have had cases of people committing suicide after getting infected when their partners did not disclose their HIV status.

On my quest to be counted and turning my problems to my advantage, I formed an HIV/AIDS and substance use support group. I am proud to have assisted so many young people, especially those who would have been abused. Most of these cases are kept secret by their families because, usually, perpetrators are close relatives. Sometimes it would be because of drug abuse and misconceptions that people have regarding HIV/AIDS. There is a child who we referred to the Musasa Project[9] to take her away from her abusers. Danai was supposed to be doing grade seven, but she did not go to school, she is HIV positive, now using drugs and she is not on medication. Her uncle told her if she wanted to eat, she must have sex with him, which is rape. It is through these goodwill deeds that some community members have accepted me. I have observed that in the current situation in our country one needs to be financially stable to be

[9] A non-governmental women's rights organisation in Harare, Zimbabwe.

respected. People are not concerned about your status if you do not stress them with looking after you. The drugs part just must be moderate and allow you to be participating in key community activities. Another thing I have realised, is that people will first judge you by what they know but they will change their attitude after knowing you more, especially about what you are doing which benefits them.

Times are hard and poverty is rampant. What aided my acceptance despite living with HIV and abusing alcohol was that I remained self-reliant and did not become a burden unto others. I was accepted first by my own family and they set the tone for the community.

Yes, it has not been an easy road for me too, but I just did not choose to have my fate decided by circumstances around me. I had to work hard so that people would perceive me differently. The situation in Zimbabwe needs you to hustle for you to survive. There is no way you can get a job if you do not have relatives to connect you. I remember there was a time when a certain funeral services company was looking for drivers with three years of experience and I had five years of experience, but I was asked to pay $200 to an agent for me to get a job. That is why we turn to illegal trades. At times like these, one must tell oneself that paid employment is not everything and find other ways of making a living.

Currently, I bring Broncleer (cough syrup containing codeine) from Zambia and marijuana from Malawi. It is illegal but it pays. Being financially independent has led us to assist others. My husband and I are doing a lot of philanthropic work at church and in the community. Within our families, nearly everyone is waiting for our hand. I have HIV and I am using substances but that will not be used against me, I am not a problem to anyone; instead, I am solving problems. If you help others, then you get acceptance rather than discrimination.

Life is a journey, filled with uncertainties for many, but most importantly, it has left me with a story to tell. Telling people about my story makes me belong, it makes me feel like I have done my duty to God, for I believe I am in this predicament for a reason. My perfect tomorrow will be to live long and continue with all that I am doing. Doing and being someone who can be counted on. Others may say I am a champion in denial, maybe I will see it one day but for now, my strategy is to do that which counts.

5.2.5. Introducing Mudzvurwa: A regrettable life: reforming and seeking acceptance.

Peer pressure is like a pandemic. This crippling disease has the power to turn people from destined leaders into controlled sheep. It can ruin the lives of whoever is infected, making them commit to actions they did not want to partake in. Some say it has no cure, whilst others say, the cure is the magic word, 'NO'.

It is widespread and I was very unfortunate to be its victim. It started seemingly slowly, just to pass the time and fit in; I then did regrettable things. I am trying to reform; I am seeking acceptance against the odds, into a worthy life.

My name is Mudzvurwa; I am thirty years old, the married father of two. I am living with HIV, and I have some substance use issues. I stay with my family in Harare but I frequently visit my parents' rural home in Chiweshe. I can say I have led a challenged and eventful life in a very short space of time.

I grew up in rural Chiweshe. Ours was a poor polygamous family; we could hardly afford school fees. Consequently, I did not write my final ordinary level exams; my father could not raise money for my exam fees. I was not that good at school, so I did not bother much. After all, this was the trend in the family and the community except for my brother, who had made it into the police force.

It just worked out well for me, that after the academic route was shut, another route opened. My brother, Lameck, took me so I could stay with him in Harare in 2004. His plan was to send me back to school but, before that, I got a job to work as a general hand in his friend's pharmacy. I let my brother down when I refused to go back to school. He battled to explain how the economic outlook was bad for the uneducated and that I needed to aim for paid formal employment. All that was in vain, as I saw myself as accomplished compared with those I had left in the rural areas. Seeing that he was not winning about sending me back to school, Lameck had another plan; he helped me to obtain a class two driver's licence, my most treasured asset.

I left my job at the pharmacy and spent some time at home, doing anything just to keep me engaged. Around 2007, my brother used his connections to get me a job as a driver at a construction company. It was in this company that things started to change towards who I am today. I was very young and innocent but all my workmates were heavy drinkers. We would travel into rural areas and camp there for days or months. I would drive my workmates to and from beer halls and clubs and at times, they would leave me to do the chores like cooking and looking after our wares. I became their cook and chauffeur. This was so boring. They seemed

to enjoy every second of their lives, and I was missing out. I felt pressurised to join them and I eventually did. I wanted to be a true part of the group; I wanted to belong, I wanted to be a man and all that was made possible by doing what 'men' were doing. I started moderately, until today when I am unable to quit even if I must.

From being very shy and reserved about my drinking, especially with my family, I then started to be bullish and unapologetic. Alcohol became my blanket of confidence, and whenever I was drunk, I would joke, laugh with everyone. My workmates nicknamed me Mudzvurwa -one who spends all his money on alcohol without any personal development.

In 2008, I got married to my wife, Ratidzo. It was not a planned marriage; I had impregnated her and was forced to formalise it. We got blessed with two kids, our firstborn, a boy called Tatenda and the last born, Rudo, a girl. We never really enjoyed our marriage; there was a lot of misunderstanding. My wife started getting fed up with me. She would side-line me on issues pertaining to our children and she was financially supported by her parents. At a point, to I was I became a problem that Ratidzo needed to get rid of. However, this position worked out to my advantage because that meant no school fees issues to worry about.

I had many extramarital affairs. Having worked as a truck driver, spending time away from home, drunk most of the time, I found a reason to do what most men in my circles were doing. I was reckless and I would have unprotected sex with different women, mostly 'ladies of the night'.

In the process, I lost my family's respect, and my own family did not want to involve me in vital family gatherings. They complained that I had become verbally abusive and violent. I remember one incident when I was excluded in decision-making because of my drinking. That was when my sister, Spiwe, wanted to remarry before she had gone through a proper divorce. There was a gathering at our rural home to discuss the issue and I was not invited. They did everything in my absence and my sister was married to her new love.

The drinking got so intense that staying in a job for long became impossible as I was usually at crossroads with my supervisors. I once worked at Greenica Construction contracted for Old Mutual work. I was fired for drunk driving. Had I not been drunk, I would have kept my job. I would not be regretting it today. I worked for Mr Right and was fired because of some shady deals. I remember we would have trips to Mt Darwin, where there was illegal gold panning. The gold panners hired us to carry their loads using company trucks. One day, one of my workmates was hired and he was arrested. We ended up confessing at work, leading to

dismissal. That was to be my last formal job in 2014. Zimbabwe had gone past the government of national unity era and was drifting into high unemployment fuelled by political and economic decay.

After losing my job, I also became violent at home. I would steal money from my wife for alcohol. It was during this time that I decided to leave home and stay with one of my girlfriends, Chipo. We (me and Chipo) then decided to go to South Africa, looking for greener pastures. But things did not go according to plan. We illegally crossed into South Africa with no passports. We stayed a bit in Musina but failed to proceed to Johannesburg, our intended destination. We got arrested and deported back to Zimbabwe and headed for Zvimba. My girlfriend's rural home. By this time, I had cut all communication with my wife and family. Chipo's brother, Temba, introduced me to fishing. We needed money for survival. What surprised me was that her family did not have any issues with me staying with them. I guess they knew their daughter. So, we would go fishing with Temba, and Chipo would sell the fish at the growth point. That is how we survived and we would spend most of our money on alcohol and drugs. I got closer to Temba. After some time, I felt like returning to Harare. I felt used in Zvimba and was wasting my life. I did not have any savings; Chipo would use all the money that we were getting from selling fish.

One day I met my uncle who had visited his child at a boarding school close to where we were staying and I asked for a ride to Harare and he agreed. I rushed home, packed my few items and came back to Harare. Literally, I ran away from my girlfriend. That is how I returned to Harare in 2016, after almost two years.

I came back and searched for my family until I found them. Friends helped me to locate the place, but my wife would not take me in. That night I slept outside on the veranda. I was allowed in the following day with many conditions. I continued to sweet talk her until she took me back. Initially, she refused to sleep with me, then gradually, things changed. Life came back to somewhat normal, but I was still struggling with alcohol and drugs.

After a short while, I developed herpes. Because of misconception about these diseases, I was told only traditional medicine could cure it. I developed an eye cataract a few months down the line. I did not go to the clinic I was treated using traditional herbs at my rural homestead where I had moved to because of ill health.

I came back to Harare after recuperating. One afternoon, in August 2016, I was drunk and I was with my friend. We saw a New Start Centre[10] tent, and I wanted to know my HIV status. I had heard people gossiping about me, indicating herpes was linked to HIV. I was starting to worry about it and I wanted closure. Initially, they refused to test us saying we were drunk, but we insisted and they eventually served us. I tested positive for HIV. I was advised to visit the nearest clinic the following day as I was drunk that day. I did visit the said clinic at a later date and I asked to be tested again. The result was the same. I went through post-test counselling and started treatment.

I disclosed my status to my family, that is, my wife and my sister, triggering another rough phase of our marriage. I became a problem, a prodigal burden which had gone out to enjoy only to come back with HIV and in need of care. With the help of my Aunt Thandi who was a counsellor, my wife eventually accepted what had happened and started to be supportive. However, she refused to go for testing. Even now, she has not been tested and she argues that she does not want to know because it will stress her more. However, she has been my pillar of strength. I really want to reform but it is not easy. I think it would be if I find a formal job that could help reorganise my life and I could return to be a valuable breadwinner.

Life is not easy when you are living with HIV and substance abuse, even worse when the odds in life were always against you. HIV is still a despised condition equated with immorality and synonymous with death. The tactic I am using to navigate these muddy waters and fit among my friends is non-disclosure. It is hard to disclose your HIV positive status and it puts you out of the game. You will be an easy target, worse at the bar; everyone would think that you are dying tomorrow.

There are people who happen to know of my HIV status, but I do not remember disclosing to them. Most of them had always had issues with my substance abuse habits and they seem to have found a good reason to further marginalise and mistreat me. This has been the case with other traders at the community market where I, at times, assist my wife with her vegetable sales. These people even try to influence my wife to leave me, saying I am an unrepentant and burdensome husband who did not deserve the love and care she was giving me. They did not even want to see me handling our finances but, to my surprise, she stood with me. I am thankful to God that my wife is a Christian; she understands and encourages me to take my medication.

[10] Non-governmental health facility organisation offering a comprehensive voluntary HIV counselling and testing services.

I personally do not go to church; I have found the environment to be hostile and too judgemental. They want you reformed, especially on my drugs problem, or you are labelled a sinner.

Though we use protection, it is my wish to have a health worker who can talk to her so that she gets tested. Because before I knew of my status, we did not use protection, but she keeps on refusing to get tested. Maybe she is afraid of the stigma around, but she may be killing herself too. I really need help with this. Knowing her status would strengthen our bond and I will have a chance to reform.

At times, my drinking affects my compliance with medication. When drunk, I forget to take my pills. My health has been deteriorating of late but I do not think I have the resources to change on my own in this environment. We are poor and struggling and when I am sober, I stress a lot about what I have brought to my family. I am better off drunk and relieved with friends.

Had I not been into substances, I would be HIV negative and I would have been someone respectable in this community. I could have been a respected church member, owning my own house or a residential stand, I could have gone back to school and been in formal employment. I regret the opportunities I squandered. Now it is against the odds to make it in my current status. I have to settle for whatever is available just to keep me going. That is where my vegetable vending and piecemeal jobs come in.

The other major problem I am facing is mistreatment at the clinic. This is mainly because of my use of substances; the nurses hate that. Even when I have a genuine concern, they never take me seriously. Some of the nurses are too judgemental. They look down upon me because I am a drunkard. My drinking and poor adherence anger them. They once referred me to Harare Psychiatric hospital and I only went there once. I did not like the environment and did not agree with the treatment I received. It was more like I had no plan about my life and was just to follow whatever they told me to do. People need to understand that change comes easier and is sustainable when one is empowered and helped to make informed choices.

Recently, I wanted to go for an interview at Swift. They were looking for a driver but I did not have money for bus fare. I had to ask around. One person I asked for help at the marketplace thought maybe I was just looking for money to buy beer, so he offered to buy me a beer instead of giving me cash. I refused and continued in my quest to look for money. It took time for people to buy my story, even my friends did not trust me, yet it was genuine. By the time I got

the money from a well-wisher, I was already too late for the interview and I lost the opportunity. These are some of my everyday realities; it is more difficult to transform when people have written you off.

Going forward, I want to be seen and treated like everyone else. The best of me will be seen if I get a formal job, leave alcohol and drugs, and live happily with my family. People should not write me off or look down upon my hustles. I am considering going to rural areas and starting farming with my family. Life is cheaper that side and at least accommodation will be free. I long for the day I will be counted as a worthy man in this community. I am still trying to reform and work for my acceptance. Other challenges are beyond us. It is generally hard to make it in Zimbabwe.

5.3. Conclusion

The five hybrid narratives shared above highlight central elements shaping the experience and negotiation of social inclusion when one is dually afflicted with substance use disorder(s) and HIV.

The next chapter presents the case theme: Navigating an already troubled life, striving for belonging and well-being, drawing from all four data sources.

Chapter 6 : Navigating an already troubled life: Striving for belonging and well-being.

6.1. Introduction

This chapter serves to present the second part of the case study findings. The case theme is introduced and explained in three categories: 1.) Dealing with a context of mixed realities, 2.) Trying to adjust to new challenges and 3.) Life on the margins. These categories posit the complex, dynamic and interconnected processes shaping the everyday realities of DAYAs. This Case is illustrated in Figure 5 below as an ongoing process.

6.2. The Case theme

Navigating an already troubled life: striving for belonging and well-being case theme, emerged from the second-level analysis involving a consolidated and iterative thematic analysis. At this level the researcher drew from all four data sources in the case study, after analysing them individually at level one. The case theme is built around the DAYAs' experience of their life journeys as ongoing struggles, in which they had to find ways to make them bearable on their own terms.

"… my life has been a journey full of struggles, even before these illnesses, …I have accepted that this is it for me and I am negotiating each day as it comes…" - Nicky

As shown in the hybrid narratives in the previous chapter, the DAYAs experienced making everyday choices as constrained by their health conditions and the complex entanglements of the historical, socio-economic and political hardships, which were befalling Zimbabwe. The DAYAs' constrained reality of possibilities was made worse by the impact of stigmatised identities leading them to live on marginal spheres of their communities. These challenging life experiences of the DAYAs came out as situations of striving for belonging and well-being, faced with mounting challenges in an already troubled life. There were perpetual contextual hardships they confronted present in their s lives even before the onset of their health-related issues.

The everyday lives of the DAYAs are influenced by micro and macro-level contextual factors, including their health and well-being, poverty, social development and stigma. Zimbabwe, as the context of these challenges, is a post-colonial state, a place of widespread lack of resources and opportunities, corruption and it abounds with uncertainty. Social inclusion becomes hard to negotiate in a shrinking economy with over-dependence on formal education, paid employment and religious participation as the only conventional pathways of achieving

inclusion. Formal, paid employment, formal education, and Christian religious practices emerged as the most valuable adjustment routes towards what most of the young adults longed for. This superiority of mostly Eurocentric forms of participation was usually at the expense of alternatives which were often devalued.

The environmental context shapes the lives of the DAYAs and their ongoing processes of adjusting to challenges and seeking belonging and well-being. The key interpretation given to the young adults' engagements was against what was allowable with the weight of the socio-economic and political challenges, evident but difficult to point out. The social inclusion situation for the young adults in this study was further aggravated by the two chronic and highly stigmatised conditions: substance use disorder and living with HIV.

The pervasive influence of an unsupportive context is what is expanded on in the category 'dealing with a context of mixed realties' (Category 6.3). Here, lacking in resources and opportunities is seen as a pre-existing challenge before the young adults could meet other social and health challenges. The same context highlights the push by others for mandated occupational choices which reinforce the prevailing poverty, stigma and ultimate social exclusion of the young adults. Zimbabwe is portrayed as part of the context characterised by hegemonic systems, with some strong historical legacies impacting the DAYAs' lives.

It is this seemingly inescapable context of challenges that forces the young adults to apply their agency against the odds and continually reposition themselves in their community through the choices they make and their occupations. In this instance, the DAYAs, as occupational beings, espouse their agency and autonomous being in the face of mounting contextual problems, health challenges and the accompanying stigma, by continuing to seek self-determination in everyday activities. In their initial attempts to reposition themselves in the face of stigmatised health challenges and socio-economic hardships, some young adults tried conventional ways. However, stigma in an opportunity-deprived setting hindered their success. They refused to play the victim as passive players but applied their agency in considering alternate ways to similar goals.

The DAYAs face added aggravating health and social issues as their lives unfold. They manage to remain agentic in trying to adjust, explained under "Trying to adjust to new challenges" (category 6.4). Here, the young adults are trying to adjust and reposition themselves so that they can belong and, in the process, meet their subjective well-being goals. But their lives are

further entangled by other critical life changing events which influence their choices. The outcomes of their stories depend on how well they handle the ever-complicating problems at the individual, family and community levels.

At times, the DAYAs experienced some success in negotiating the challenges they faced. These successful negotiations were usually through choices outside modern Western conventional ways like formal education and paid employment. The DAYAs went for alternative, often despised, forms of work, they opted for collective bargaining and went into arts-based occupations. In their reflections, they admit the inferior status carried by the available occupational choices but highlight they were in it for their continued search of the elusive sense of belonging and well-being.

The DAYAs also opted for unsanctioned or informal ways of responding to challenges befalling them to meet their belonging and well-being needs. These ways of responding to challenges were characterised by resistance and social defiance. Some of the occupations some of the DAYAs undertook which were outside conventional means, included piecemeal jobs, peri-urban farming, sex work, drug trade and arts and crafts. Although the DAYAs found value and meaning in these occupations given their circumstances, the mainstream community stigmatised and discriminated against them even more. The result was that the DAYAs ended up leading lives on the margins (category 6.5), where anything was acceptable as long as they experienced some sense of belonging and well-being, even if this was among other excluded groups. In this life of poverty, deprivation, informal engagements and established exclusions, the DAYAs continue to hope for a healthy and socially valued way of existing that is synonymous with sustained recovery, placing importance on participation in formal education, paid employment and Christian religion.

In most instances, life on the margins of mainstream communities ensues from the ongoing negotiation processes. Here, they do whatever it takes to make ends meet, belong and have a sense of well-being. Through the everyday lives of the DAYAs, the ultimate desire remains the need to belong, to be a valuable member of mainstream society and experience well-being. These findings expose the need to challenge taken-for-granted issues and choices, giving rise to and sustaining the DAYAs' marginalised life, including poverty, stigma and lack of diversity in opportunities.

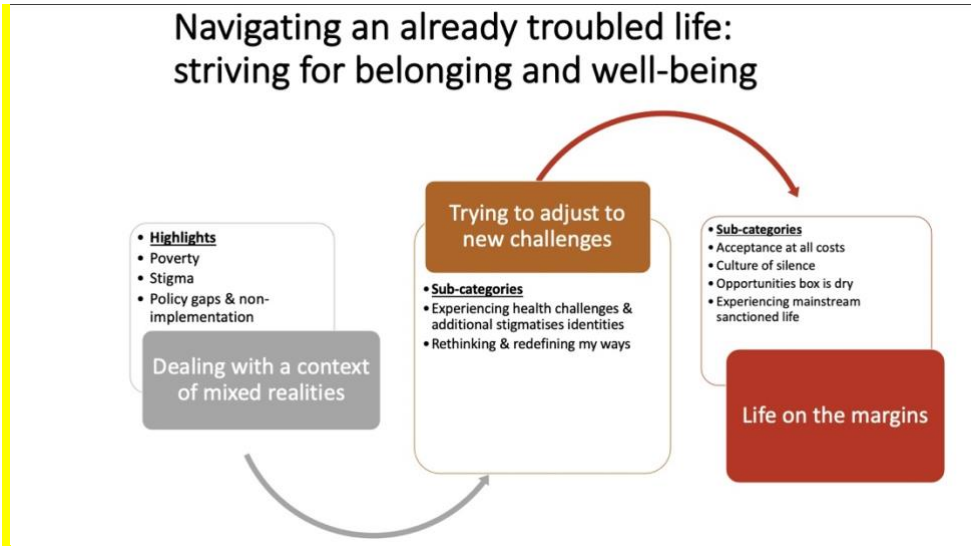


Figure 6-1. Ongoing process of negotiating an already troubled life

6.3. Dealing with a context of mixed realities

This category provides insight into how the DAYAs' life journeys are shaped by the many adversities that they confront in their contexts and how these impact on their life situations. The DAYAs and key informants reflected on the evolving socioeconomic, cultural and political landscape in Zimbabwe, which they argued was jumbled with both adverse and favourable events influencing their everyday lives as ordinary Zimbabweans.

One of the DAYAs, Mudzvurwa, shared:

"When I consider the life I am leading and what I have seen others go through, I would say it is a mixed bag…but life in Zimbabwe is generally tough… it is full of adverse surprises and only a few can make it…"

Similarly, one of the key informants shared the same sentiments and highlighted that:

"… I would consider Zimbabwe to be a context of mixed realities, …some can still make it while the majority are suffering, however, nothing is certain for these young adults…" – KI 5

Within their already disadvantaged family systems, most participants were orphaned, without high levels of education, no formal employment, were unskilled and had no adaptive coping systems at their disposal. Billy captured this position by stating,

"…you see I have no profession of mine… I failed at school…I am unemployed. I am a no one to begin with…I had the wrong foot forward…" – Billy

Most participants echoed the sentiment that by being poor, unskilled and unemployed they had put the 'wrong foot forward'. This restricted their options for making ends meet in their quest for mainstream belonging and well-being.

Acknowledging the harsh realities of an unsupportive context, most young adults saw their personal circumstances, including the family with whom they were living, poverty, stigma and shortcomings in policy and legislature, all setting them up for an intricate and challenged life path. This was aggravated by the presence of their two stigmatised health conditions. They, however, also acknowledged that in the same context, others seemed to make it, but largely by corrupt ways or through political connections.

In this context, a lot was uncertain as their lives continued to change. The ways in which the DAYAs shifted from one way of doing and meaning making to another showed that they had little control over their context, including the timing and quality of these shifts. Billy's hybrid narrative (presented in chapter 5) demonstrates the constant shifting in engagements. He changed from informal trading, piecemeal jobs even to trying to migrate to neighbouring countries. These shifts from one form of engagement to another indicated no established productive routines and identity. The Zimbabwean context presented societal circumstances which influenced the DAYAs' social capital, setting them up for difficult life journeys. All the young adults in this study describe how circumstances at personal levels dictated the possibilities that were accessible for them. Four of the young adults who participated in narrative interviews said they found themselves in disadvantaged positions even before health-related challenges befell them. Formal education emerged as significant social capital they all bemoaned for its absence.

"… to start with, I did not pass my O levels, hence I have no profession I call mine… my challenges are hinged to this to a greater extent …, they are too many to bear …" – Billy.

Capturing her situation before SUD and HIV and spelling the need for education, Nicky shared that:

"Yahh some of the opportunities were already closed for me, …I did not pass at school and that has significantly limited my options…".

Similarly, P Jay reflected on missing formal education and being an orphan:

"…I became an orphan at a tender age, and I did not finish school… that set me up for all these troubles today…"

Data from all the sources corroborated that there was a larger context at play, though it seemed difficult to name these forces. The experiences described by the DAYAs were confirmed at a macro level by policy makers, researchers and clinical service providers. They all resulted in the DAYAs' lives and those of their families playing out to macro the socioeconomic and political dynamics of the context. Whatever was happening in the lives of the DAYAs was a mirror of what was happening in Zimbabwe, though exacerbated by the dual affliction they carried. Drawing from mental health and HIV policies, the key informants echoed that the instability in the DAYAs' lives could partly be explained by the context, including a lack of political will to resource and implement the available legislature and policies. Referring to the macro-level contextual influence of policy and legislation, one of the key informants, a deputy director in the Ministry of Health and Child Care, had this to say:

"… at the root of all this I see a lack of policy to address social inclusion in this population and then a lack of resources …" - KI 3

The narratives in chapter 5 offered insight into the way the young adults viewed their families, and their peers, as primary units of socialisation. To a large extent, the poverty experienced by young adults in this study was generational and, in some instances, situational. Before facing their health challenges, three of the young adults were already in situations of economic and social disadvantage (detailed in chapter 5). This was true for Mudzvurwa, who was part of an impoverished polygamous family and dropped out of school, Billy, who was an unemployed divorcee, without any professional skills and P Jay who was an orphan and school dropout under the care of a financially poor paternal aunt. Notwithstanding, the family was where they derived an initial understanding of connection through blood relations, affinity or co-residence. The DAYAs' lives were influenced by the circumstances which had befallen their families. For many, this negatively positioned them for worse outcomes when they came to face problems which disrupted their health and social well-being. One of the key informants referring to the sociocultural systems which were in place stated that:

"…the family is very important here, and for these young adults I mean the people they are staying with and those in a position to help them… whatever happens to the family will find its way to them as well…" – KI 4

In her narrative (5.2.3. Introducing Nicky), Nicky suggests that her experience as an abused child who lost her mother when she was a toddler opened her up to more adversities in life. She reiterated the discourse on the importance of formal education.

"… my mother had passed away when I was a toddler, my father abused me from around 8 years, I turned to drugs and did not do well in my education, everything was already against me" – Nicky

Whatever negative circumstances were present within the family negatively impacted on the young adults' lives but they kept on trying to find ways for redress. Family units experienced frequent mobility as they changed living spaces in response to socioeconomic challenges. These changes impacted on the DAYAs' life choices, family composition and even changes in values and beliefs in new family units. These changes in environment and familial relationships were apparent in Billy, Nicky and P Jay's families, especially where a significant caregiver moved out of the picture.

"After the death of my mom… I grew up staying with my aunt before coming to stay with my daddy…I didn't have a mother to talk to…" – Nicky

Most of the DAYAs' family situations rendered them vulnerable to less preferred ways of engagement. For example, many of the young adults were members of single-headed families which left them without a stable source providing for their needs.

This circumstantial vulnerability was also illustrated when young adults moved between family members.

"…both my parents were late… we moved between families, finally we were raised by our paternal aunt… things were not easy, lacking basics and the mistreatment…" – P Jay.

In some instances, the service providers identified the absence of adaptive family structures and systems of support as part of the problematic context. A psychiatrist stated that:

"Most of these young adults find themselves in this predicament but they are coming from [struggling] child-headed and single-headed families and some this [challenges befalling them] was bound to happen" – KI 4

Poverty at family level also contributed to their experiences of inequality rather than social inclusion. For example, P Jay dropped out of school before he completed his junior secondary education because his guardians said they could no longer afford to pay his fees and buy his uniforms, even though they continued to afford schooling for their own children.

"I went to Mufakose Mhuriimwe and did form 1 and 2. That is when my aunt said she failed to raise money for my school fees, …they couldn't even buy me a school uniform and I dropped out of school. … but her own kids were in school…" – P Jay.

For Mudzvurwa, his family situation together with the added layer of poverty also meant that he was competing for educational opportunities at home.

"…we were too many in a polygamous marriage and my father could not raise money for some of us including my exam fees, hence I did not write my O levels…" - Mudzvurwa.

Limitations such as this further weakened the foundation from which the young adults were expected to develop.

"… some of it (troubles in young adults' lives) is from the general problems we are facing as a country… the traditional family unit is eroded…it is now rare to have the whole family staying together and speaking with one voice on raising their kids, many are not there and those who are around are too busy chasing livelihoods…we are losing our youths…" – KI 3

In rare instances, the family acted as a protective factor in orienting the young adults to more adaptive and socially valued life choices. Mai Ngah enjoyed being raised in a strong Christian family where she received the love and support that she believed helped her build a morally resilient character. Mai Ngah echoed that while growing up, her character as supported by the Christian grounded family, was the yardstick against which others were judged.

"… I grew up to be a well-groomed girl, my father was a pastor and the family had love and they knew God… this is not found in many families even when everyone aspires to be like that here…it is from this upbringing that I draw my resilience…" – Mai Ngah

On a personal level, factors such as being educated, financially independent and practising a strong religious belief and value system were identified as offering a cushion when one of the young adults come across challenges, such as dealing with having a dual affliction. Mai Ngah reflects on how this positioning acted as a cushion when she became infected with HIV.

"…it was difficult to stigmatise me, I didn't depend on people…if I get a job call, I can apply [because] I went to school up to A level…" – Mai Ngah.

This was not true for the other four DAYAs who participated in this study. Instead, they bemoaned the lack of formal educational qualifications and hence their financial dependency, perpetuated by a lack of paid employment.

"…there is a lot at play for my demise but lack of education and consequently the lack of employment draws me back when I consider my situation…" - Billy

Formal educational achievement and paid work were seen as the main means to satisfying the expectation of making an economic and social contribution in a predominantly capitalistic society. Having an education and a job were valued as indicators of success. Not achieving this contributed to experiences of poverty, shaping the realities of the young adults' experience and negotiation of social inclusion. The historical legacy of colonisation in Zimbabwe contributed to the precariousness of the DAYAs' lives in that Eurocentric values evidenced in practices, such as valuing formal education and paid work, were deemed superior. For these young adults, poverty meant scarcity, dependence on others, deprivation and marginalisation from viable economic activities.

This was most pronounced amongst four of the participants where it was shown to limit their opportunities, resources and restricted their choices for occupational engagement.

"… when you are poor you don't have many options, you go with what's there…" – Billy.

The organising power of poverty was also echoed by one of the key informants who shared that:
"…all these challenges we see may be because of poverty… the youths have no means to functional and economically productive lives…" – KI 1.

Living in poverty meant that these young adults lacked finances and did not have socially acceptable means to meet their basic needs. The poverty situations were frustrating, prompting reactive-responses, including substance/drug use.

The socioeconomic profiles of the young adults who participated in the exploratory social inclusion and associated factors survey (n=105) illustrate the low socioeconomic standing of respondents. Eighty five percent (85%) of the respondents were unemployed, and most of them (83.8%) had not completed tertiary level education, the job market educational attainment in Zimbabwe towards being able to get formal employment. For the young adults in this study, not having education and skills meant they had to resort to work that was risky and demeaning.

"…you know without education you have to do anything… I feel used sometimes, but I have no options…" – Nicky

Reflecting on the forces that pushed her to where she is, Nicky reiterated how being poor limited her options, though it did not take away her agency to act on the situation:

"… poverty was also a factor here, what did you want me to do? … that is why I ended up doing sex work and …selling drugs" – Nicky

The young adults' narratives and insights from the key informants showed that poverty is bad and that it robbed them of education. A lack of formal education bred educational poverty. It was from this deprivation of learning and skill development opportunities, that a lack of life options arose.

"… their fate is always worse when they don't have education…" – KI 3

Some of the harsh realities faced by the young adults in plotting a way through the challenges they faced had to do with the socioeconomic standing of the geographical communities they resided in. The survey data illustrates that 94% of the participants resided in high density suburbs, synonymous with low-income poor neighbourhoods. Living conditions in these high-density suburbs shaped the lives of these young adults by influencing what was possible for and available to them. The two neighbourhoods where the majority of the participants came from are known for poor service delivery, lack of standard institutions of care, population and resources disparity and a crisis of role models necessary for life success.

"…you can see that most of the youths we are talking about come from high density suburbs where the situation is dire. There are just too many problems there… poor services and substance abuse. They also lack role models, those who make it tend to move out of the [high density] suburbs…" – KI 1.

Some of the problems in these communities have been ongoing and have now been accepted.

"… the other problem we have is the communities they are coming from… some of these things like poor service delivery and poverty have become 'normal'…they have been around for too long" KI 5.

The young adults also spoke about people 'stealing their opportunities' and rewarding those who appeared connected in political circles.

"… there is so much corruption out here… we try to make things work but if you are not connected, there is nothing for you…many people work hard but still its only for them to barely survive…" - Mai Ngah.

The key informants re-enforced this sentiment, highlighting it as a governance issue.

"…I for one I see this poverty in our youths as an economic and political issue… we are letting the youths down… they don't have many alternatives, but we are the ones to change this…" - KI 4.

"…the resources we have need to be managed properly. It is a question of accountability and dealing with corruption that I see as much needed to attend to the needs of these young adults…" – KI 5

"… look here the government should improve the economy…end corruption… poverty is a big issue, the economy has to be improved, then at the end opportunities are available for them, I think all young adults should be able to choose whatever works for them…" – KI 4.

Whenever resources and opportunities to meet basic needs are scarce, inequality and injustices in distribution follow. All participants agreed that the scarcity of the perceived primary transformative resource of formal education and paid formal work became a line of exclusion for those considered inferior. This includes the DAYAs and others facing social disadvantage.

With regard to the way that the policy and legislative discourse contribute to the mixed realities experienced, the key informants confirmed that the lack of policy direction weighed heavily on the way that the DAYAs navigated their social inclusion. For example, the lack of targeted policies such as a rehabilitation policy and or social inclusion policy, played a major role influencing the possibilities the DAYAs had in their lives. Without these targeted policies, it became apparent that no targeted interventions were put in place. This left the young adults with little choice but to shift from one occupation to another searching for inclusion. The reviewed documents did not set any clear agenda on the social inclusion needs of DAYAs. There was no promise of well-articulated, resourced or implemented policies. None of the documents analysed included any section on how to improve the social inclusion of young adults living with HIV and SUD. There was also no clear direction on after-care or community

integration, despite the mental health policy stating the need for a comprehensive discharge plan for mental health service users, including those with SUD. Both directors in the Ministry of Health and Child Care concurred that there was nothing specific on the ground regarding the young adults dually afflicted with HIV and substance use disorders. However, their awareness was raised through their participation in this research.

"…we don't have anything specific for that group [DAYA]. As we speak, I am starting to see the need." – KI 2

The document analysis of seven key legislative and policy documents as well as reflections by the key informants highlighted the troubled lives led by the young adults. Although there is acknowledgement of the challenges and intersectional nature of HIV and SUD in the National HIV and Mental Health policies, social inclusion issues of DAYAs are not explicitly covered. The legislative context is also identified with the problem of non-implementation or provision in the Zimbabwe Constitution (2013).

"The greatest legislative tool we have is the constitution and [it] speaks to the very need of providing for all equally and recognition of human rights… The challenge, [is] it is not being followed …" – KI 1

The founding values and principles of the constitution contained in section 3, and applicable to the matter under study, include:

3. Founding values and principles
    c. Fundamental human rights and freedoms;
        e. Recognition of the inherent dignity and worth of each human being;
        f. Recognition of the equality of all human beings;

The broader health and social care needs of DAYAs and other youths in marginalised social positions remain largely uncovered by law and policy. This paucity of coverage of social inclusion matters in policy also presents practice challenges. Practitioners amongst the key informants agree and feel that legislature and policies barely support the needs of DAYAs.

"… at times you don't know what to do with these young adults [DAYAs]… policies that speak to this particular group are disjointed and largely not resourced…" – KI 4.

When the two conditions are approached in silos, the policy environment favours HIV over substance use disorders. This is an unsustainable situation as a comprehensive approach is needed for DAYAs. The laws and policies reaffirm the government's position against discrimination and stigma against people living with HIV, more than they do for those with substance use disorders. On one of its guiding principles, centred on human rights, the National HIV and AIDS policy states:

"*The human rights and dignity of people living with HIV/AIDS should be promoted and protected. Discrimination and stigmatisation should be avoided as far as is consistent with the rights of society and those who are uninfected"* (National HIV and AIDS Policy_1999, p 9).

There are also many NGO activities complementing government efforts in the fight against HIV.

"Zimbabwe has several different organisations involved in HIV/AIDS activities and these include the public sector, private companies, non-governmental organisations, churches and community groups participating actively in HIV/AIDS/STI prevention, control, care and impact mitigation efforts." – (National HIV and AIDS Policy_1999 p iv)

This was echoed by one of the key informants:

"… from the HIV side, I can say we are much better in terms of support by law… there is also a big hand from the NGO sector…the challenge comes when we have duality like what you are presenting, that is not well covered…" – KI 5.

However, the same is not true for substance abuse, where the legislative landscape has been found wanting. There is no specific mention of substance abuse and the duality with HIV. There is only the generalisation of mental disorders, which is reflected in the Mental Health Act (1996) and the Zimbabwe Mental Health Policy (2004). Criminalisation and lack of resources for implementing even the not-so-comprehensive policies have been evident in the fight against substance abuse.

"…the approach we are using with substance abuse is too punitive…criminalising it (substance abuse) has not helped much… mental health is the worst funded again…" – KI 4.

It is in this context of precariousness that the young adults have to respond to the added health and social challenges associated with a dual affliction of SUD and HIV. The following category presents this adjustment process.

6.4. Trying to adjust to new challenges

This section presents the experiences of trying to adjust to having acquired or developed HIV and SUD amongst DAYAs, as added new challenges in an already difficult context. In most instances, the DAYAs experience the dual affliction with HIV and SUD as hurdles which led to or were expected to lead to more undesirable inclusion outcomes, bringing further disruption to their lives. The experiences of turmoil associated with new health and social problems were heavily influenced by dominant contextual situations and prevailing personal and societal conditions for each participant. Their adjustment processes are a function of DAYA and their communities' understanding of the conditions, resources and opportunities available to aid their coping. As their health and social challenges were progressive in nature, so too were their coping methods. Their ability to act on their circumstances was consistent during their life trajectories. This ongoing process of trying to rework their way into mainstream valued life is presented in this category.

The DAYA had to respond and adjust, for a workable and inclusive life as they pursued their quest for survival, belonging and well-being. Limited resources and opportunities had become part of the normal life of the young adults and most Zimbabweans. This made it more challenging for these young adults when they were made aware of their positive HIV statuses and their problematic substance use. In most instances, the DAYAs contracted their HIV positive status as a product of the lives they were leading or had led in the past. This was true for three of those who participated in narrative interviews (Billy, Mudzvurwa and Nicky). These three participants who became HIV infected in horizontal transmission, were already in cycles of substance abuse and facing a measure of stigma. The living out of their lives was an expected outcome of a disadvantaged life in an unsupportive context with high HIV prevalence. Even the key informants, entrusted to lead the change agenda and betterment of the DAYAs' lives, worryingly admitted, and were resigned to not being in control and already being defeated by the situation.

"…it is bound to happen [dual affliction and exclusion] *when they are struggling like that, it is a crisis we await to happen…"* – KI 1.

The DAYAs exhibited agency in their responses to the health challenges that they faced. In all situations, they tried to do something about their problems. The responses differed, based on when they learnt about each condition. If they learnt about their positive HIV status first, more adaptive responses were actioned. When they acquired a SUD diagnosis prior to their HIV positive status, there was delayed professional help seeking. In most situations, substance abuse

was highly rationalised and its real impact on their meaningful and valued participation mostly underestimated.

"… to be frank with you, for most people like me, substance abuse is never seen as a problem, that is why we seek medical help for HIV and rarely for substance abuse. For some, it [substance abuse] is even a way of adjusting to the HIV diagnosis…" – P Jay

Even in its most severe state, substance abuse remained problematic only in retrospect on the part of some young adults.

"… I didn't see how my substance use was the problem… I was just coping; I was going through a lot… I did not identify with the need for treatment, actually it was helping me do what I wanted to do…" – Nicky

These findings are supported by the distribution of participants among the recruitment clinics, with more participants (n=73) being recruited as they sought HIV treatment. These participants identified with HIV as their main diagnosis despite the dual affliction.

The adjustment processes for some DAYAs were dependent on conceptualisation of the dual affliction as an anticipated challenge in their life journey. The DAYAs narrated that they had anticipated having health and social problems, yet when these occurred, they realised they were not prepared for the increased discrimination as a result of the existing stigma.

"…it was difficult realising that I was now HIV positive, … but I saw it coming, I had a lot of unprotected sex in the gang and with my clients…I didn't anticipate this much stigma and being rejected…" – Nicky.

For these young adults, adjusting and repositioning themselves emerged as a process of thoughts and actions where they tried to build variations in their behaviour to achieve harmony with themselves, significant others or their immediate environments. However, the outcomes were heavily dependent on contextual factors beyond the individual.

"… after all that (referring to crisis events) I didn't just sit back, I tried to make things work unfortunately for me it didn't work…" - Nicky

The young adults' choices and actions taken in attempts to adjust to experiences of substance abuse, HIV and stigma, and aiming for inclusion were at times rewarding but for the most part they led to alienation. Also, when strategies introduced by the families to help them cope failed, it led the families to focus on punitive measures.

This category is further discussed below: i) experiencing the health challenges and stigmatised identities (subcategory 6.4.1;) and ii) rethinking and redefining my ways (subcategory 6.4.2).

6.4.1. Experiencing the health challenges and additional stigmatised identities

The DAYAs in this study experienced substance use disorders and living with HIV as stigmatised health challenges that they had to deal with alongside other life challenges. Three significant factors influenced their experiences: historical knowledge about the conditions, past experiences and the state of service provision to ease the challenges. These factors weighed on their positioning in finding ways to remain in control and find belonging in their communities.

Their experience of HIV followed the contextual HIV epidemic developments in the country. One such development was that the fight against HIV in Zimbabwe was praised as a progressive and largely successful fight. The National HIV/AIDS Policy bears testimony that this fight has taken a multisectoral and collaborative approach. And yet, stigma remains a large problem, largely fuelled by myths. The key informant from NAC shared such insights, admitting that there was still work to be done.

"… HIV/AIDS has taken a chronic disease direction with the success of ARVs, prolonging life expectancy of those infected. Stigma and discrimination against HIV are no longer as bad but there is still work to be done with regards to it…" – KI 5.

Other key informants also supported this position, crediting health education and public engagement efforts, which they agreed had made living with HIV more bearable, especially among those who were informed and empowered.

"…health education has to a greater extent demystified HIV/AIDS in Zimbabwe, but some key population groups are still bearing the full burden of stigma… which is affecting disclosure in the process…" – KI 1.

Supporting the key informant's sentiments, the policy and legislative documents on HIV also show that the fight against stigma is ongoing, needing more on the implementation side to sustain this fight. The DAYAs bemoaned the lack of implementation and said they were still experiencing the effects of the stigma.

"… I have heard of the laws but still on the ground we are subjected to stigma and being looked down upon just because you have HIV… I am aware it's not as bad as it was in the past, but something should be done still…" – Mai Ngah.

Some went on to highlight the misunderstandings that they perceived the community to hold about HIV, which in turn influenced their experiences. To them, living with HIV was to live with a feared and an unwanted condition which would invite more challenges when they sought acceptance and belonging.

"…I think the problem is that some people misunderstand the condition and when you get HIV, they think you only got it through being promiscuous… no one wants it and they are afraid of getting it and those of us with it are to blame…" – Mudzvurwa.

Even in the single clear example of vertical transmission, HIV was still experienced as an unfortunate predicament to be feared and where although there was nothing that could have done differently to change it, the participant was just left to struggle and accept it.

For P Jay, HIV was a lifelong condition for which he needed treatment and something he had to keep from his friends for fear of being excluded.

"… I was born with it (HIV), they said my mother gave it to me, it was unfortunate for me… it was beyond my control…I have to live with this, but I have to keep it a secret, even my friends will not accept me…" -P Jay.

The way the DAYAs were informed about their HIV diagnosis and the way they acquired the diagnosis influenced their experience of it. HIV was experienced as a health challenge because of the context in which they were told about the diagnosis. For some, like Billy and Nicky, HIV testing was done when they were admitted to hospital and were already being managed as complex clinical cases. Billy and Nicky's narratives show that they were not responding to treatment as was expected and also that they had sexual histories reflecting risky behaviour. Although these two participants had anticipated the HIV positive diagnosis based on their risky lifestyles, when they actually learnt that they were living with HIV, they thought of the stigma they had seen in their community and became very afraid of what was awaiting them.

Nicky was going through a health scare when she got the news about her HIV positive diagnosis.

"…I tested positive the time I was admitted at Annexe…to me it was just another problem added which I expected would come given what I was going through you see…However when reality kicked in, it meant struggles with all the inhumane treatments I had heard about HIV positive people…" - Nicky

Unlike for Billy and Nicky, the rest of the participants were not sick when they got their HIV diagnosis and even worse, P Jay and Mai Ngah did not anticipate it. This led to their grieving and experiencing denial (P Jay narrative, p. 123; Mai Ngah narrative, p. 139). Theirs were situations of harm minimisation in the experience of HIV. This was brought about by the professional medical testing process. For nearly all young adults, the HIV testing and counselling was done in a health facility by professionals. The news about the HIV positive diagnosis was relayed in an ethical way and treatment options were quickly presented. This may have instilled some hope regarding the medical management of the HIV and consequently the negotiation thereof. However, despite the positive testing experience, the stigmatising messages and myths still dominated and made it difficult for them to accept their status. This often led to poor coping behaviours, including substance abuse.

Also contributing to making HIV a feared and despised condition are issues of non-disclosure, which characterise the victim identity in some young adults' experience of HIV. In some instances, non-disclosure was to avoid stigma and social exclusion. Mai Ngah experienced this from her husband and hence she described the way she got to know about her HIV status as traumatic.

Showing the seriousness of the dreaded nature of HIV which played out in the young adults' lives is highlighted in Mai Ngah's contemplating committing suicide.

"… finding out that I was now HIV positive, it really stressed me, and I almost killed myself… I would ask God, what did I do to deserve this?" – Mai Ngah.

Although HIV was feared, most of the participants in the survey chose to identify themselves with their HIV diagnosis 68% (n=72) rather than substance abuse or the comorbid diagnosis (Figure 6.). The narrative and key informant data confirmed this, saying that the young adults felt HIV was more acceptable and more difficult to discriminate against as it was not easily visible without them disclosing.

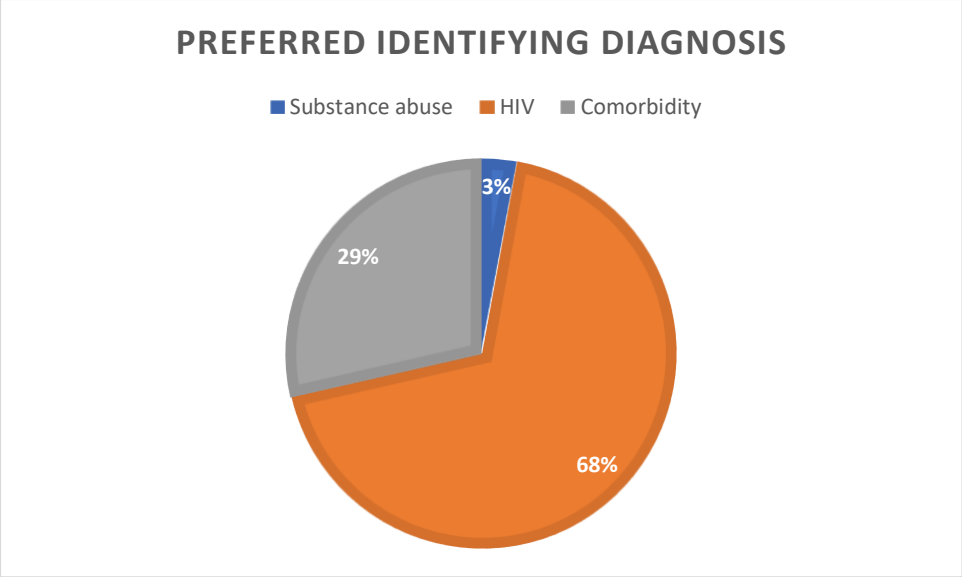


Figure 6.2.The diagnosis the young adults identified with

In its most severe form, substance abuse was considered a worse health and social challenge than HIV, especially when viewed as a contributing factor to poorer prognostic outcomes in HIV. The general stigma associated with mental illness also worsened this experience.

"… most of these young adults with a comorbid diagnosis of HIV and substance abuse, are stigmatised more for substance abuse, maybe because of the prevalent stigma against mental illness which is equated with substance abuse…" – KI 1.

Results of the cross-sectional survey (n=105) also show high levels of perceived stigma against substance abuse. The nested Perceived Stigma of Substance Abuse Scale (PSAS) shows that the PSAS scores were generally high with an average of 25.04 (sd 3.96) for the whole sample, and a range of 15(min) and 32(max)[11]. Comparing the two stigmatised conditions, the participants felt that the discrimination and segregation associated with substance abuse affected their occupational participation more than the stigma associated with HIV.

Insights from the young adult narratives and in-depth interviews bear testimony to a slow and justified course of substance abuse, grounded in experimentation, peer pressure, social acceptance, maladaptive coping mechanisms and the need to belong or fit in.

"… they don't wake up with a substance use disorder, it is something that develops over time and it is nurtured by their life circumstances… in most cases we see, it is teenage

[11] The higher the score, the greater the perception of stigma. 65% of the participants had a score of 20 and above.

experimentation and peer pressure… in some cases it is a coping strategy, like in this case following HIV positive diagnosis…" – KI 1

Delayed help seeking for their substance abuse did not help their situations. For some, the problematic nature of substance abuse was heightened when they had to comply with their HIV medication. Substance abuse with poor medication adherence for HIV was seen as rebellion or resistance against conforming to what was expected of people living with HIV.

"…when you are on our medication for this condition [HIV] people don't expect you to be doing drugs, you get punished for that because they say you don't care about yourself…" - Billy

Substance abuse also became a reasoned coping strategy in response to the challenges that the young adults were already experiencing. In the face of restricted options, to adaptively cope with the challenges including sexual abuse, domestic violence and limited social support, many found comfort in drug circles.

"When I took the rat killer trying to commit suicide, I was transferred to Harare attending school Kambuzuma High 2… I met a friend Machy who used to smoke marijuana and take ecstasy. I can't say she is the one who introduced me to substance abuse but being around her, I got access…I can say I found comfort in that [substances] given what was happening at home…" – Nicky.

Similarly, P Jay said:

"… being told I was HIV positive and what was happening at home stressed me … and I was told taking marijuana helps dealing with stress, that was one of the reasons and how I started…" – P Jay.

Also, from the survey data, more than half of the participants (n=56) concurred that when their substance abuse followed their HIV diagnosis, it was part of a strategy of searching for a way to cope with the stress of the diagnosis.

Stigma then emerged as a powerful factor that affected both their HIV and substance abuse diagnoses. The young adults in this study strongly associated the problematic nature of their HIV and substance abuse, with a stigmatising experience. This was also true when stigmatised conditions prevented them from doing what they wanted to do, to be or to become. For

example, Billy wanted to be a formally employed worker on many occasions but failed because of stigma.

Several stigmatising identities were ascribed to the DAYAs. They were seen as 'the problem'.

"… I came to be called names… beyond the HIV and drugs thing, I was called a prostitute, a thief, and all sorts of evil things and that hurts…" - Nicky

Being a young adult living with HIV and having a substance use disorder became synonymous with being 'the problem' on most occasions. Being reduced to being the problem with no recognition for circumstances, left the DAYAs unsupported. This was aggravated by the fact that the people and structures which could ideally support them, instead tended to blame them. After being reduced to being equated with the problems they were facing, the DAYAs also recounted being treated in a way that led to their exclusion rather than solving the problems they were faced with. At this point in their lives, most DAYAs were seen as disgraceful and unworthy of mainstream belonging. Something they perceived that the community was justifiable in doing.

"… at this time…, I was seen as the problem and a disgrace to the family… distancing themselves from me, became justifiable…" – Nicky.

In some instances, the stigmatised labels were a result of what the DAYAs were doing or had done. Some of the DAYAs' actions while negotiating their lives with the new health-related challenges of comorbid substance abuse and HIV, earned them labels which were then used as grounds for excluding them. These incidences included being in police custody for illegal possession of drugs, domestic violence and even public drinking. These labels would also associate them with thieves, never to be trusted. From the DAYAs' perspective, these labels were internalised and became difficult to challenge. A typical example of such came in Billy's life. He recounts the day he was arrested and spent the night in police custody after a fight with his wife and how, from that day onwards, the neighbours' conduct toward him changed and he started facing discrimination and other derogatory labels, further complicating his life.

"… I was arrested and many people in the hood saw me being taken away by police, they didn't know the issue but I was never to be trusted… started calling me this thief, that's why you were arrested…it happened so often for too long that it ended being a part of me…" - Billy

At times, the labels resulted from things they could not do. When some could not find paid formal employment, and were supported by their families, it became a label. They were lazy,

dull, and not serious about life *(marovha[12])*. Worse still then to be known to be someone living with HIV, seen abusing substances and you were unemployed, the society just wrote them off and dismissed them as unrepentant failures, people who were never serious about life.

It was also clear that the stigmatised labelling did not have the same negative effect on all the DAYAs and that the impact changed at different points in their lives. For some, a position of self-sustenance helped in dealing with derogatory names and labels. One of the DAYAs who was financially independent narrated how she became used to being gossiped about. She was called a loose woman, prostitute and not worthy of being in marriage. She brushed this off and continued with her life. Mai Ngah argued that because she did not depend on thee people who were hurling insults at her, she managed the stigma better:

"…they gossip a lot and call me names, all because I drink, I ignored them and just minded my life, I don't depend on them…" – Mai Ngah

DAYAs were more stigmatised for being substance abusers than for living with HIV. This is because substance abuse was seen as something that could be controlled. However, once their HIV status was known, more stigmatising labels were added. Family expectations also impacted the way the DAYA made sense of the dual affliction and his or her negotiation thereof. In most scenarios, where substance abuse preceded HIV, after testing positive for HIV, the family expected the young adults to do away with substances in an effort to rebuild their lives and, when that did not happen, at least in their expected timeframe, the family started blaming the young adult for all the problems they had and withdrew their support. In common examples of stigma at home, some DAYAs shared what they went through, when they were always drunk and defaulting on their ART. The young adults were relegated to outcast status, but still they had to find a way to cope.

"… to my family and my neighbours, I became a lost soul and a wasted case… I was a moving grave…no one was willing to help me or give me money, they said I would use it on drugs…I didn't sit back and moan, I looked for other ways and means…" - Billy

Some recounted a time when their families went on a punitive drive:

"… I look back at it and it hurts, to them I was the problem and they wanted to beat me out of it…I ended up doing more of that in rebellion…" – P Jay

[12] Irresponsible adults, not employed and loitering waiting to be fed

In some instances, the participants attributed the discrimination at home to a lack of understanding on the part of the family. This led them to rethinking and redefining their ways and further defying the family's moral expectations. When their families labelled them "*possessed and crooked*", they felt that was the signal for a different form of engagement and to be more agentic about their situations.

6.4.2. Rethinking and redefining my ways

The DAYAs' responses to experiences of health and stigma challenges were traceable to their positionality in their contexts. The DAYAs' adjustments can be described as consisting of two overarching responses: agentic responses and resigned helplessness. In some instances, what the DAYAs did entailed choosing societally unsanctioned ways of doing and being to meet their social inclusion and social well-being needs. Being agentic when making choices in the face of challenges, emerged as a widely applied tactic used by the DAYAs to rethink and redefine their ways of engagement and participation, while seeking acceptance and belonging.

"…this is my life, and I should be able to choose what I want…I can't just be there and have everything decided for me because I am facing challenges…" – Mai Ngah.

In the agentic responses, the DAYAs actively engaged with their situations and strove for control in search for solutions. Most utilised their inherent talents, available resources and illegal trades, in resisting succumbing to the challenges they faced.

"…the best way to respond to the challenges we are faced with is to use what you are good at and what is readily available to craft a way to survive… for me I even went on to engage in illegal cross-border trade…" – Mai Ngah.

At times, the DAYAs chose to act on their situations, but went against social norms, trying to challenge the status quo. These mostly came out as radical approaches, where the DAYAs made choices against unquestioned social boundaries in their communities.

"… to respond to the stigma and challenges I was facing, I chose not to comply with narrow options I was presented with… there were no formal jobs to talk about but I did not sit back, so I did a lot of piecemeal jobs and some illegal activities…" - Billy

In the adjustment processes, the DAYAs actively tried to search for ways to be included and what happened most often is that their success was also seen as rebellion. This was because those who included them behaved similarly. Their behaviour was defined as immoral by their families and the larger community.

"… moving away from home was not an acceptable way of handling my situation, … I needed to be with other people who could make me feel accepted and not always judging me…" – Nicky

Seeking inclusion and belonging emerged as a very important need for the participants, so much so that they did anything they thought would afford them that. In as much as it was a radical move to divorce themselves from mainstream society and choose to associate with the excluded, it proved rewarding to them. The young adults in this study talked of appreciating that no preconditions for change were set before acceptance by their friends in similar circumstances. For example, Mudzvurwa talked about being accepted by Billy and other friends and found comfort in being connected with others in similar circumstances, hence forming a collective.

"…as part of my adjustments, being rebuked to change by my sister and my wife… I chose to leave them, and I found new friends who accepted me and had a similar situation with mine… Billy who referred you to me was one such a friend…" – Mudzvurwa

The DAYA in this study described facing segregation and exclusion from the community at large but choosing to focus on ways to belong by whatever means necessary. The findings cement the fact that the DAYAs craved acceptance and belonging at any cost. Some shared how practices considered socially taboo by families, such as drinking with a romantic partner, could still afford them the acceptance and inclusion in the mix of their challenging health and social problems.

"… I don't mind what people say, my husband does not ask or question and he has accepted me…many people expected him to be mad about my drinking but he also drinks a lot and he is also on ART…" – Mai Ngah

The DAYAs' families and their communities also instituted forms of adjustments to the challenges that the DAYAs were facing. Some families chose to withdraw and do away with the DAYA, whom they saw as a disgrace to the family. It emerged that some families did this to protect their family image and integrity, after labelling the DAYA as the 'problem'.

"… after deciding that I was the problem, I think they [her family] left me to be whoever I wanted to be; they had given up on me…I had become a disgrace to the family, and they didn't want anything to do with me…" - Nicky

In the face of family withdrawal, some responded with self-withdrawal from mainstream life. At times, the withdrawal was done to affirm their new stigmatised identities and was seen as an adaptive way of being in control, adjusting and repositioning self in the face of mounting challenges. In order to run away from the change that was being demanded of them by their families, some young adults decided not to change but to discard their families as was described in Billy, Nicky and Mudzvurwa's narratives, when they moved away from home.

Another tactic reflecting agency used by these DAYAs was to take advantage of the non-disclosure of their HIV status to join groups. They did this to protect themselves from stigma and discrimination, minimising judgement based on the dual affliction and its associated problems.

"… my survival tactic was to make sure apart from people at home, no one else knew about my status… that would make me equal with others…" – P Jay

Likewise, Billy used non-disclosure tactics in order to date, a practice very common among young adults living with HIV. Referring to dating, he said:

"… at times I would deliberately not disclose my status… if they know, it's obvious they will leave you…"

However, this tactic might have also meant avoiding seeking necessary help.

In resisting succumbing to the exclusionary effects of their challenges, the DAYAs chose to be proactive about rethinking and redefining their ways of engagement since achieving worthy social identities, acceptance and belonging remained a need for them. These proactive efforts seemed to be based on the establishment of networks with other young adults in similar situations, being creative in art activities, using inherent vocational skills and turning to readily available indigenous occupations like farming. Only Mai Ngah went on to take up an open activist stance to challenge the status quo and to reclaim her space in mainstream community.

With growing challenges at home and pressures to prove his worth, P Jay joined with friends and went into music and dance. Together with his friends, he used his natural talents in music and dance. This was an attempt for a DAYA like P Jay, to develop an identity that was acceptable to others. He shares his experiences of feeling satisfied from such engagements and being able to identify himself with the group as dancers.

"I can say I did something about changing the troublesome label I had acquired… together with my friends, we formed a dance group … I felt equal… I still made sure not to disclose my status… we started as social until we became popular and people were hiring us to dance at parties…music and dance that was who we were…" – P Jay.

Also showing the essence of art as a viable pathway to inclusion, Nicky shares her story of finding acceptance and comfort in the practice of art even though she was not the performer. For her, it was through her newly found friend, Machy, who was into traditional music and playing musical instruments. Nicky found the music and arts' space accepting, consoling and it helped her cope as she was running away from the abuses and segregation at home. Others used their talents to reclaim socially included identities and belonging. Mai Ngah reclaimed part of her socially accepted identity, away from substance abuse and HIV status, by exploring her artistic talents. She managed to create a name for herself around her master of ceremonies' exploits and dancing. To her this was an adaptive way of thinking outside the confines of stigmatised labels.

"Unlike many who are seen as problematic, I chose to act about my situation…I turned to master of ceremonies and I also could dance a lot, people hired me for their functions like kitchen parties… the talk became less on my health issues and more on MC business…" – Mai Ngah

Some DAYAs chose locally available, but looked down upon, occupations, trying to build socially acceptable identities and a sense of belonging. Some settled for piecemeal jobs including general house cleaning, vending and peri-urban farming.

"The good thing is that I am doing something about my situation… there are no formal jobs for people like me, so I do piece jobs to survive, and be seen as a trying father…that is what is available for me..." – Billy

With continued challenges, even in accessing resources and opportunities to participate in the despised occupations, some DAYAs said they were left with no option but to choose illegal trades. For example, Nicky's narrative shows how she made deliberate choices to venture into the illegal drug trade and sex work for both survival and to give her a sense of belonging.

It also happened that, at times the DAYAs and their support systems felt overwhelmed by their situations and accepted the deepening troubled lives as an expected path for them in Zimbabwe. One significant organising force in the adjustment process by the afflicted young adults was

around expectations of negative outcomes and knowledge of restricted options in their communities, leading them to choose maintenance of the status quo versus change.

"… I just accepted what was there…there was nothing much to do other than to live with it [challenges befalling him]…" – Billy

Similarly, others shared how powerless they initially felt when they pondered on their circumstances in the light of the mounting challenges in their lives:

"… at times I felt so grounded because there was nothing I could help myself with. This was more in the first days after I tested positive… I used to see my life's fate as no longer in my hands…" – Mudzvurwa.

At times, some DAYAs seemed to care little about challenging their circumstances, feeling overwhelmed and they just continued with whatever life presented to them, unknowingly normalising their troubled lives.

"…there are things you have to accept as is…it was the new me, so I continued with my life like that with its new provisions…" – Mudzvurwa.

The young adults made default responses, seemingly to accept the "deepening troubles" as the new normal. This was evidenced by how little action was taken by some of them at times to ameliorate the problems they faced within socially acceptable ways. This positioning kept on moving them away from mainstream life, setting them up to be treated as failed young people with no motivation to change.

"Haa my life journey is fine. It is only that when I am drunk, I skip my (HIV) medication, but everything is fine… there is nothing I can change here but then I am blamed for not wanting to change by my family and I get side-lined more…" – Mudzvurwa.

In some instances, the DAYAs' families seemed to give up on them and left them to be whoever they wanted to be. This also happened in the face of other competing needs and challenges befalling the DAYAs' families which meant less attention was placed on the most recent challenges, thought to be exacerbated by the young adults themselves. Departing from the cultural values of Ubuntu[13], most families seemed to take a position where there was no one

[13] Ubuntu is an African culture value system rooted in valuing the other and interdependence, expression of compassion, reciprocity, dignity, humanity, and mutuality in the interests of building and maintaining communities with justice and mutual caring.

willing to take responsibility for the care of the DAYAs, hence the maintenance of the status quo.

"… there were other problems at home… I think that is why they just left me like that…" - Billy

Some of the feelings of helplessness amongst DAYAs may be a result of the lack of services that considered their worsening life situations in a holistic manner. The key informants admitted that the health and social care systems had not done justice to the DAYAs' broader needs. The root causes of the DAYAs' problems remained unattended to as the health and social care system tend to undermine the bigger picture of the true circumstances of the young adults in their contexts. Although all the participants passed through the Zimbabwean health system, as recruitment for this study happened through health centres, the contextual issues feeding their problems never received the attention they deserved. Patients were discharged into the same conditions that had given rise to the problems and relapses continued to be prevalent.

"… part of it is our problem, we discharge them into the same environment having not changed anything about it nor attending to their bread-and-butter issues…" – KI 1.

No framework for community integration, fighting stigma or skills building for these young adults was preferred:

"…I don't think we are doing anything about the issue (broader health and social needs), *so nothing really changes even after the medical treatment…"* – KI 2

This position of not being on an aggressive drive to change the challenged situation was partly a result of the way they viewed themselves. Some already thought of themselves as 'lost' and 'unable' and did not do much to change that. To some, this life was meant to be a life of struggling and full of problems. Hence their adjustment processes became a matter of fitting into that preformed identity. This identity was one where it was meant to be apparent that one had failed in life and where they deserved the hardships that they were going through. The acceptance hence meant the young adults did not question what was considered fate and had to continue to lead difficult lives.

"…when I faced the challenges of being left out because of the conditions I had, …like the case of being rejected because of my HIV… I took it as what was expected for people like me, and I did not question it much…" - Billy

In some rare instances, there was help for the DAYA trying to adjust in the face of his or her problems. In these instances, the challenges befalling some young adults were identified by them and their support systems and help was sought or rendered. However, the help was more often aimed at the HIV related challenges than the substance abuse or the associated stigma. At times, the help was seen as problematic and even complicated their troubled lives. Mai Ngah was one with a better story to tell about receiving help, despite the fact that it was not comprehensive.

"…I would not want to lie, my pastor and my relatives really helped me to accept my HIV status and I commenced treatment on time, which helped me to settle in with others…I only then received some professional help on my substance abuse later on from the Friendship Bench…" – Mai Ngah.

Even in trying to respond to the needs of the DAYA, a holistic approach to combating this dual affliction was difficult to find in both the HIV and mental health settings. People seemed more comfortable to offer help around HIV. For example, despite Nicky's accessing the health system for substance induced psychosis, once she was diagnosed with HIV, attention was shifted to the HIV over the substance abuse and stigma.

"…after the test came out positive, I got commenced on ART and up to now I still go for reviews and to collect my pills…nothing about stigma issues you are talking about…I am also not receiving reviews for substance abuse to check if I am doing well…" - Nicky

The health system seems successful in helping people newly diagnosed with HIV to adjust to lifelong treatment. However, the absence of routine screening for SUD, means that the system fails to attend to substance abuse. This was true for P Jay and Mai Ngah who accessed help for HIV for a long time despite continued struggles with substance abuse. Without employing holistic care and addressing the substance abuse, the substance abuse part of their troubled lives continued to negatively affect the HIV treatment.

"…I was defaulting treatment; I would forget to take my medication when drunk… at times mixing up the times…but it was never picked early that substance abuse was behind it…" – P Jay

Other practices which seemed to maintain or even perpetuate the troubled lives led by the young adults in this study were a lack of comprehensive interventions for health and the social challenges complicating the young adults' lives. Some of the DAYAs who participated in the

narrative interviews bemoaned being let down by the system which they said did not offer tangible help to their real-life circumstances.

"… at times when I look at the challenges I am going through, I feel so hopeless because I don't see the hospital attending to my real needs. I am left with no option but to accept, this is it for me…" – Nicky.

The incompleteness of services also came out in the survey. About a third of the respondents (n=30) were getting both ART and substance abuse treatments which were highly medicalised, and none reported to have received any help directed towards improving their social and community participation (Figure 7).

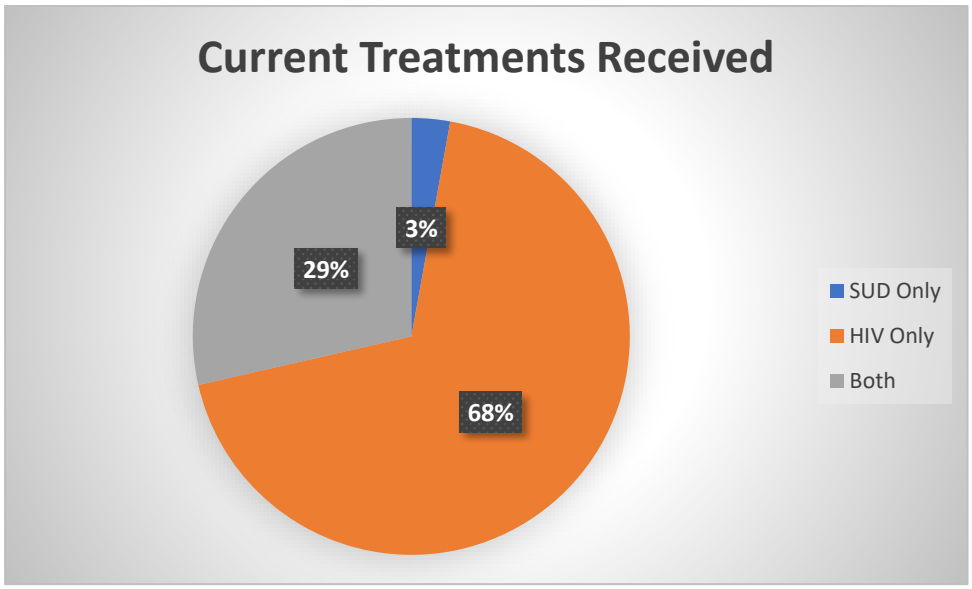


Figure 6-3. Distribution of current treatments received by the young adults

Never was the need for stigma intervention attended to, despite its being highlighted by the key informants and expressed by the DAYAs.

"… stigma is a big issue in this group, but I can't recall anything being done specifically for that in this group…" – KI 5.

At times, the DAYAs' families tried hard to force the DAYA to change but in a stigmatised fashion, this forced change was more pronounced for substance abuse. Some of the strategies that the families tried included approaching law enforcement agents to institute corporal punishment and the prophets to cast out the demons, largely ignoring the autonomy of the

DAYA. Most of these efforts were ineffective and eventually one DAYA ran away from home, to lead a 'life on the margins'.

"… they used to take me to the police to get beaten… they thought I was demon possessed and took me to prophets, … they treated me as a criminal and eventually I ran away from home…" – Nicky

Most of the attempts at adjustment instituted by the DAYA and their support systems landed them to a cyclical life full of deprivation, alienation and disadvantage, when judged against mainstream life expectations.

6.5. Life on the margins

In this last category the outcomes of the adjustment processes which the participants felt resembled a 'life on the margins' are described. Life on the margins emerged as a result of the social exclusions and occupational injustices in the DAYAs' lives. The researcher's aim is to discuss this life as an ongoing journey of navigating the problematic situations in search of belonging and well-being. This life journey is discussed under the following subcategories: i) acceptance at all costs (subcategory 6.5.1), a culture of silence (subcategory 6.5.2), a lack of opportunities (subcategory 6.5.3) and experiencing mainstream sanctioned life (subcategory 6.5.4).

Most of the DAYAs portrayed the developing outcomes of their adjustments as difficult, unvalued, risky and unsanctioned ways of life. However, they continued to apply agency to navigate these in search for mainstream belonging and well-being.

"…so after going through all these challenges and trying to adjust without much success, the first thing was to accept that this is it… it is difficult, a lot of challenges, you are looked down upon, you don't get what you want… you work with what's there, that is my everyday reality…" – Nicky

"… it is a difficult life I admit, but I have to remain in charge of my life to change my situations… it is a battle, and we have to keep fighting to be counted…" – Mai Ngah

Life on the margins captures the everyday realities of the DAYAs and their feelings about their levels of social inclusion, in a context of harsh circumstances, including stigmatised identities from mainstream society. In this everyday life, the DAYAs have to deal with stigma, dominant discourses and deprivation of meaningful occupational opportunities and resources.

"… here [Zimbabwe] mainstream included life for typical young adults is when they are educated, in paid employment and recognised members of the church, which is not the case with these afflicted ones… they are battling stigma and discrimination and the eventual exclusions…" – KI 1.

Despite the odds being against them in most situations, the DAYAs still have to find ways to make ends meet and to belong in certain circles of society, by whatever means it takes. Although the DAYAs constantly try to survive despite their restricted life opportunities, the continued lack of targeted support services was derailing their progress.

"… if I am to sum it up[the life these DAYAs are leading], I would say these young adults are leading troubled lives, carrying two stigmatised conditions, alienated from employment and no sound government initiatives to rescue you is the hallmark of exclusion…" – KI 3

In the cross-sectional survey results, most of the participants said they generally felt excluded and lonely because of their life circumstances. This finding was more pronounced among the DAYAs recruited through mental health facilities. This is shown in the analysis below (Table 6), comparing the two samples (OI Clinic and MH Clinic) in terms of their responses to the overall social inclusion question: "Overall, how do you feel about the extent to which you are included in society?"

Table 6.1 Overall Social Inclusion feeling comparing the two recruitment arms

Sample group	**n**	**mean**	**sd**	**se**	**95% CI**	**P value**
OI Clinic	73	4.37	1.78	0.21	-2.04 – 0.64	<0.001
MH Clinic	32	3.03	1.38	0.24		
Total	105	3.96	1.78	0.17		
Between groups sum of squares =39.87 df 1, mean square =39.87; F=14.26 p=<0.001 Within groups sum of squares =287.98 df 103, mean square =2.80						

The overall social inclusion differed significantly between the two recruitment arms, with those in the OI group feeling more socially included than those in the MH group. Furthermore, a Tukey post-hoc test revealed that overall, feelings of being socially included was significantly higher in the OI Clinic group – accessing health services for HIV compared to the MH Clinic

group – those accessing health services primarily for SUD (1.33 ± .35 units of social inclusion, p = <.001).

This finding is supported by the narratives, where being identified as mental health service users was associated with the everyday reality of stigmatised institutions and being deprived of transformative occupational opportunities.

"… it is like all doors are closed for you just because I have been through a psychiatry facility, I feel like I don't have any options…" – Billy

As shown in Table 7 below, the feeling of being left out of important activities was reported by more than two thirds (69.0%; n=72) of the DAYAs who participated in the cross-sectional survey. More than half of them also felt unable to change their situations to meet mainstream standards.

Table 6.2. Feeling left out and ability to change situation

Feeling left out		**Freq**	**Percentage**
	Yes	72	69
	No	33	31
	Total	105	100
Ability to change situation			
	Yes	34	47
	No	38	53
	Total	72	100

About a third of the participants (n=30) in the cross-sectional survey also reported poor mental health. This was measured using the Shona Symptom Questionnaire with a median score of 9/14 (8 and above suggests poor mental health); about 30% were at risk of depression and anxiety which are also usually missed or under diagnosed and are stigmatised in their communities.

6.5.1. Acceptance at all costs

Life on the margins emerged as an evolving experience of ongoing adjustments to life challenges. One need the DAYAs continued to seek was acceptance. The feelings of being included and belonging in one way or another were so important to the DAYAs that they went

to great lengths to feel included. This meant making some choices despite their perceived consequences, or social desirability, including choosing acceptance and belonging with excluded or other marginalised groups.

"… I had to move out and be with people who at least understood me… the life we are leading here is not restricted… here anything goes, and we have accepted each other…at least I have some sense of belonging among my peers…" - Nicky

As was detailed in the narratives, feeling despised, left out of household plans and other family happenings, were reasons for some participants to move out of their families and find other circles to belong to. Three of the DAYAs had instances of leaving home and joining socially despised groups like drug gangs, where they reported that they found acceptance and belonging. They however, acknowledged how risky these choices were but they felt they led to 'acceptance at all costs'. While they admitted that their new homes were not always ideal and came with their own challenges, their feeling of belonging counterbalanced those emotions. One DAYA reflected and shared that it was not all rosy and that she had to put up with anything to continue to belong and be accepted in the groups she chose outside her family.

"…in the gangs, you do what the gang identifies with… I did everything you may think of; selling drugs, sex in exchange for drugs, … I even had to put up with rape…" – Nicky

Although it seemed she was aware of what she had to put up with, she tolerated different forms of abuse and exploitation in the search for acceptance and a sense of belonging:

Reflecting on the abuse she faced in the gangs and comparing it to what she had been through at the hands of her father, Nicky maintained: "…*it was a different form of abuse, but then I put up with it… I felt accepted and wanted there…"*

In seeking acceptance as they led their marginalised lives, other DAYAs had to join what they deemed 'socially despised groupings'. P Jay joined the Nyau group, while Billy joined the illegal minibus touts. Referring to his membership in the Nyau group, P Jay shared:

"…membership came with strict rules, I had to do everything that was required so I could continue to be part of the group… I knew the Nyau dancers were despised but I longed for acceptance and belonging…"

All five of the DAYAs reported continued substance abuse engagements in the face of health scares as long as they meant acceptance and belonging with their peers.

"…I have been advised to leave drugs [by the counsellors], but I can't… I really need these friends… what keeps us together is the drinking, to be among them means continuing to drink and smoke together…" – Mudzvurwa.

Being sexually active or having a sexual relationship was an important component of acceptance and belonging for all the DAYAs. However, in life on the margins, the DAYAs described experiences of being stigmatised, segregated and excluded from sexual activity. Three of the participants discussed meeting their sexual needs in ways seen as unorthodox by their communities. They resorted to transactional and risky sexual practices. However risky the practices were, the DAYAs thought of them as meeting their sexual needs and their need to belong.

"…I am a man and this has to show among other men… I can't do without sex, so I get it by whatever means… yes at times I pay for sex…" – Billy.

Nicky turned to homosexual practices in her search for unconditional acceptance and love.

"…it is better to have sex with other girls than the abuse I got from men… at least Charity understands and accepts me…" – Nicky.

From the cross-sectional survey, the DAYAs' marital standing also seemed to predispose them to risky sexual practices to meet sexual satisfaction. The demography showed more than half 55% (n=58) of respondents were single and 21%(n=22), were divorced or widowed. Those who were single or divorced, taking part in the, used non-disclosure of their HIV status in order to avoid rejection and meet their sexual needs. This was most common when they were dealing with those they suspected would reject them if they knew they were living with HIV. Billy recounted how he had lost a lover after disclosure, leading to devising new strategies to guarantee acceptance instead,

"…in most cases I now don't disclose because it will mean losing my partner or potential ones…I lost my partner when I thought we were now set to get married, I disclosed and she left me because of my HIV status…" - Billy

For some of the DAYAs, they learnt from their adjustment experiences that there was stigma associated with disclosure. This learning influenced their non-disclosure choices during their life on the margins period. The non-disclosure was part of negotiating social inclusion, as was applied by P Jay and Billy. Non-disclosure was also used when looking to gain acceptance into

other social groups, particularly to do with social engagements, and to protect themselves from stigma which they likened to being a 'second class citizen'.

"… if you disclose, you will be the weak link and seen as second class… no one will want to play with you, people here despise people with HIV and worse off when you use drugs…" – P Jay.

These non-disclosure practices can be partly explained by the high rates of HIV stigma reported in the cross-sectional survey (Figure 8), where more than sixty percent (65%) of the DAYAs perceived HIV as a stigmatised condition, considered shameful, and that those living with HIV should be avoided.

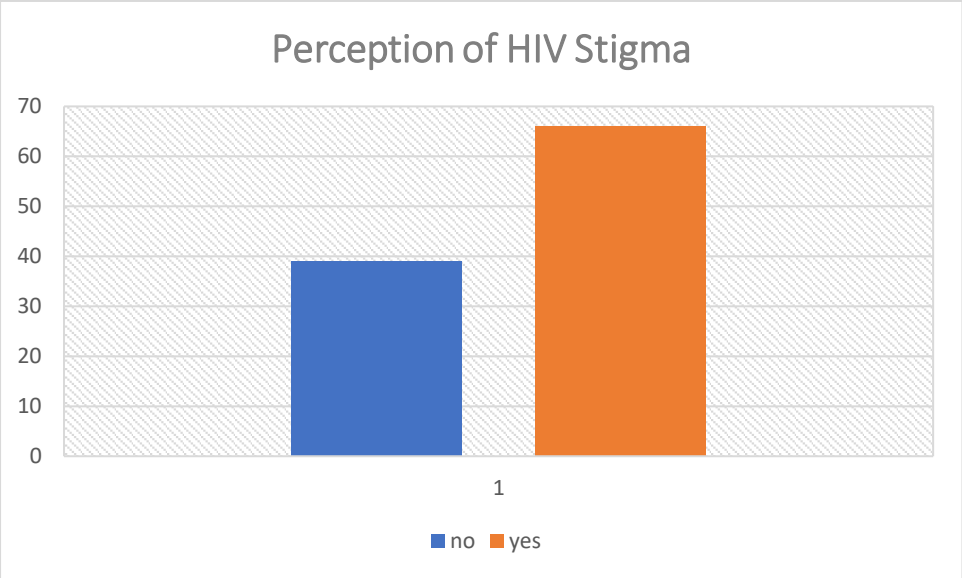


Figure 2-5 Figure 6-4. Perceived HIV Stigma (n=105)

Despite the evidence of internalised fear of stigma against HIV, one DAYA had mastered an advocacy stand for her belonging and acceptance. Mai Ngah decided to provide full disclosure in a non-apologetic stance all the time.

In this continued life on the margins, yearning for acceptance and belonging also played out as the DAYAs sought engagement mimicking paid employment. The DAYAs narrated stories of using whatever was at their disposal to remain in control of their lives, to earn an income and to have a sense of 'valued' worker status. In their marginal lives, most DAYAs continued to engage in looked down upon forms of work: piecemeal jobs, sex work and illegal trades including illegal drug dealing.

"…in trying to be a somebody, in charge of my life and gain a living, I have done sex work… I am doing piecemeal jobs and we also sell drugs just to get money to survive and use with Charity…" – Nicky.

Several activities typically portrayed in negative terms by mainstream society, such as sex work and selling drugs were places where these young people felt accepted. It is important to note that the choice to engage in illegal activities for most of the DAYAs, was as a result of economic pressure, as much as the need for acceptance. Other tactics to improve their economic situations included taking the initiative to cross the borders illegally into neighbouring countries like South Africa and Botswana They ran away from unemployment and widespread poverty which they said was fuelling their difficult lives. This was generally a common practice for DAYAs being autonomous about their life situations. Mudzvurwa described his failed attempt to go to South Africa with his girlfriend as an attempt to escape poverty and the challenges in his marriage as he continued to lead life on the margins and seek acceptance.

"…I decided to leave my family and go to South Africa with my girlfriend, I thought I would get a job and settle there… the challenges were just too much here…we wanted to cross the border without passports and unfortunately we failed for three times…"

To a great extent, the DAYAs' choices were informed by feelings of being excluded and lack of official and ethical opportunities for mainstream acceptance, belonging and inclusion. Data from the cross-sectional survey indicates that most of them felt excluded, with more than two thirds of the participants (68%) reporting that they were dissatisfied with their level of social inclusion in life. The five DAYAs in the narrative interviews, provided vivid descriptions of how they engaged in desperate acts to counter these feelings. However, this way of life resulted in the DAYAs and their associate groups being even more stigmatised, marginalised and excluded.

"… being a respected member of this community is also important to me, I have failed to achieve that through normal ways like being educated, being employed and going to church…society made it difficult for me through stigma. It is out of desperation that you find me doing these piecemeal jobs and continuing to do drugs…" – Billy

The key informants also agreed and acknowledged part of the responsibility:

"… the most unfortunate thing I have seen of which we are partly to blame is that we give them more stigma and exclusion as they are crying to be heard… we see their trying to survive as being uncaring and they end up doing more risky acts…" – KI 2

Despite the moral judgements against the choices by the DAYAs, their stories also showed perseverance and determination in practising agency to change their fortunes.

6.5.2. Culture of Silence

A 'culture of silence' emerged as another significant characteristic of life on the margins. This involved keeping some acts invisible and norming unsanctioned occupations. Some of the young adults had to accept rape, corruption, violence, segregation and illegal drug use and dealings as part of their everyday life realities. In the narrative interviews, some DAYAs shared their experiences of participating in illegal and crime-related acts, which they still downplayed. In most cases, these acts went unreported, and justice was never served.

"… a lot happens here, illegal stuff… you ask what about police, don't you know that here it is these illegal things that make money for us…you survive through it… I smuggle and sell drugs…I bribe my way out and I also use my husband's connections…" – Mai Ngah.

Expanding on the culture of silence, Nicky shared her experience of seeing unsanctioned occupations being normed:

".. in the gang I was raped many times, …I never reported it, even the case of sexual abuse by my father: justice was never served… too much of these things are seen as normal, when directed towards people like me, I think the community see it as a deserved fate…"

Acts of violence also went unchecked and were considered a normal part of the marginalised life the young adults were leading. Some recounted experiences of violence within their families and the verbal abuse that referred to their HIV status and drug life. Some even sustained life-threatening injuries but had to lie to the police to protect their relatives. For Billy, the whole family seemed to protect itself and indirectly kept punishable offences hidden and by virtue of these positions, the unsanctioned occupations continued and were kept in the dark. Despite leaving home and strained relations with their families, as victims, the DAYAs still felt some allegiance to their families. They did not report things that could have got them into trouble.

"…I don't know how he conducts himself (the brother), I don't understand him. Like what happened this year, we were drunk, we were fighting, and he stabbed me with a pair of scissors

on my chest, close to the heart. We had a misunderstanding, and he has tempers. I got admitted to Parirenyatwa and I spent almost three weeks in hospital after that incident. I lied to the police that I had been mugged in order to protect him…" - Billy

Others discussed how abuse at the hands of close relatives was prevalent but kept away from the eyes of law enforcers, who at times were the perpetrators themselves. For example, Nicky suffered this fate from her father and close friends. In these situations, the DAYAs associated the abuse with being taken advantage of as persons living with HIV or seen to be careless with their lives because of substance abuse. Here, one of the DAYA captures these realities in a story of a church member who was a teenager, living with HIV and was abusing substances. In addition, she was being sexually abused by her uncle, yet the matter was never reported to the police. In this situation, the young woman felt helpless and disempowered and accepted the abuse as part of her everyday realities. Only later, did she manage to confide in Mai Ngah with whom she could identify.

"…There is a child from our church being abused by her uncle, because the uncle says' for you to get sadza here you have to have sex with me first.' She is not allowed to go outside - even to do the dishes at the sink outside the house, she is not allowed. She is also not allowed to talk to people. Is this the kind of life she should be living? She is HIV positive and she is not on treatment, she turned to drugs recently. She shared with me when I testified about my status in church… the uncle has sex with her anytime he wants. She is not going to school, she is supposed to be doing grade 7… most of the perpetrators are not strangers but relatives and they [the relatives] agree to keep it a secret so that the perpetrator is not arrested but at the same time destroying the future of the child…" – Mai Ngah.

Experiences of domestic violence were also reported among those who were married or divorced. However, they also shared that the violence rarely was reported to the authorities. Sociocultural mediation practices which should have been the norm were not carried out. It was more often that relatives and religious leaders intervened.

"Yaa, that's why I told you… after being fired from work, I ended up running away from home and abandoning her…we had fights over simple issues… it had become a norm and it never got to the police…" - Mudzvurwa

In the cross sectional-survey, about 72% of the participants who were married reported personal experiences of domestic violence in the past year (Figure 9)

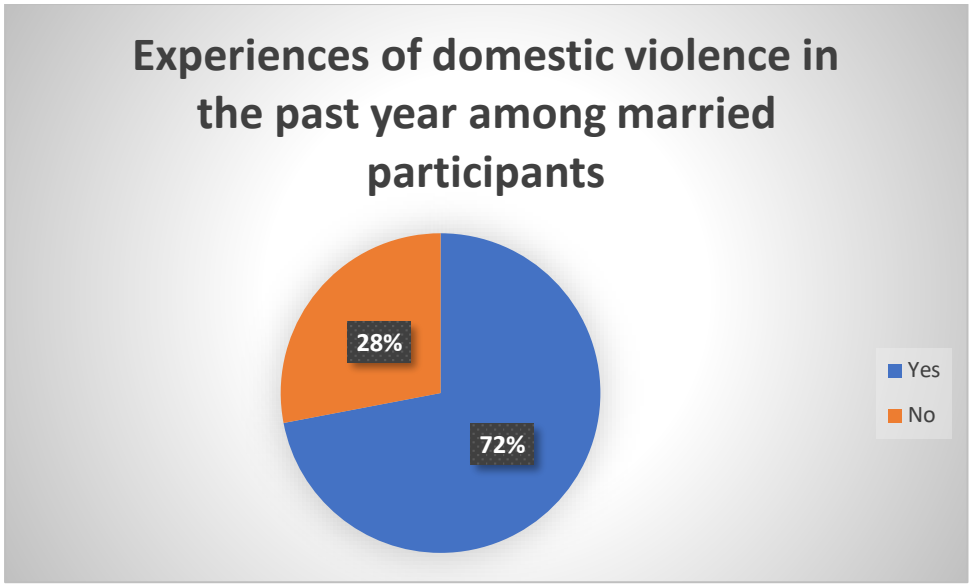


Figure 6.5. Domestic violence experiences among married participants

6.5.3. Opportunities' box is dry

This subcategory describes the resources and opportunities for community and social participation which were available to the DAYAs. These included resources and opportunities for equitable participation in education, formal employment and other economic activities, productive recreational activities, suitable housing, mainstream relationships (marriage/family), religious activities and political life. Particular attention is paid to the way they perceived these resources and opportunities Most of the participants shared experiences of limited access to opportunities and resources to participate in perceived mainstream transformative occupations. The findings also show restricted opportunities to receive the professional help they deemed essential for addressing the multiple challenges in their lives.

"… the opportunities for me to participate in life on equal basis with others of my age without the same problems as mine, are quite limited, I dropped out of school…I don't have a job… I don't even have an identity card… accessing help is also a challenge…" – P Jay

Findings from the cross-sectional survey (n=105), show that more than two thirds of the participants reported dissatisfaction with access to both resources and opportunities, an outcome which was worse in the group recruited through mental health facilities (Table 8). Access to educational opportunities at primary and secondary levels seemed fairly satisfying across the DAYAs in the cross-sectional survey, compared to those who participated in the narrative interviews. About 90% of the participants in the cross-sectional survey had taken part in some secondary education.

Table 6.3. *Social Inclusion domains by participant recruitment arm*

		Leisure and social activities			
Sample group	**n**	**mean**	**range**	**sd**	**p-value**
OI Clinic	73	4.63		1.70	<0.001
MH Clinic	32	3.22		1.58	
Total	105	4.20	1-7	1.77	
		Community Support Groups			
Sample group	**n**	**mean**	**range**	**sd**	**p-value**
OI Clinic	73	3.88		1.82	0.001
MH Clinic	32	2.50		1.19	
Total	105	3.46	1-7	1.81	
		Educational activities/services			
Sample group	**n**	**mean**	**range**	**sd**	**p-value**
OI Clinic	73	4.49		1.83	0.001
MH Clinic	32	3.22		1.64	
Total	105	4.10	1-7	1.87	
		Paid work			
Sample group	**n**	**mean**	**range**	**sd**	**p-value**
OI Clinic	73	3.05		1.96	0.145
MH Clinic	32	2.03		1.61	
Total	105	2.74	1-7	1.62	
		Sociopolitical activities			
Sample group	**n**	**mean**	**range**	**sd**	**p-value**
OI Clinic	73	3.81		1.57	0.292
MH Clinic	32	3.44		1.19	
Total	105	3.70	1-7	1.48	

However, some DAYAs who participated in the narrative interviews experienced limited educational opportunities (as described in P Jay and Mudzvurwa's situation, refer to category 6.3). Reflecting about his educational opportunities, P Jay shared that,

"…you can see I am still young; I could go back to school, but I was told I wasted my chance…that is now a closed chapter for me…I feel sad about that and I think that would have helped me change my life…"

Another characteristic of leading life on the margins among the DAYAs was the experience of restricted access to paid employment opportunities. They believed paid employment was one significant transformative occupational engagement they needed and they continued to look for options to meet this need (refer to category 6.3). However, because of the discriminatory attitudes abounding in their communities, their efforts were in vain. The same discriminatory attitudes made it difficult for them to start up their own businesses. This was made worse by

their not having access to capital. This finding coincided with that of satisfaction with opportunities for work emanating from the survey, where most participants reported feelings of dissatisfaction in that domain with a mean satisfaction score of 2.74 (sd 1.62) (Table 8). Almost half the participants in the survey (50%; n=52), also reported that their opportunities to earn a personal income were severely limited.

Some DAYAs who had been in formal employment reported that their chances of returning to paid employment had dwindled. They recounted experiences of discrimination and stigma as they sought employment. They described being turned away before being given an opportunity to show their abilities and how prospective employers would assume they would steal by virtue of their living with HIV and/or abusing substances. Billy described a job opening in the city council for a general hand for which he met the requirements. However, others working within the council who knew him told the prospective employers that it was a waste of time to employ 'a drunkard.' Nevertheless, he believed that this was the opportunity to 'turn his life around' and by using his time constructively he might be able to stay away from drugs.

"… the job issues are a big problem... at one point I got a chance to be recruited to work for city council but there are people who just went to the bosses and used my condition against me… I am told they told them 'this one you need to leave out because you would have done nothing'… So like that I was told there is no job for you…" – Billy.

Nicky suffered the same ordeal when an opportunity be a shopkeeper at a local tuckshop was offered to her by someone new to the neighbourhood. However, others informed the tuckshop owner he would be making 'a grave mistake by employing an 'HIV positive drug addict', that she would steal from him and so the offer was withdrawn. These experiences reinforced the absence of paid employment opportunities fuelled by stigma among the DAYA.

"… there is a guy who opened a tuckshop by the junction there… he wanted someone to work there and he approached me… I got promised the job but never got it… people went behind my back and told him not to make a mistake of hiring a drug addict and that I was positive this and that, and I would steal from him… that is how I lost it and I think that is how opportunities skip us here…" - Nicky

Repeated failed attempts to get employment by people like Billy, Mudzvurwa, Nicky and Mai Ngah became internalised and some of the DAYAs stopped searching for employment as they settled for available, though despised, options.

"… nothing works here, there are no jobs and I have stopped looking for one… who employs someone like me?…" – Mudzvurwa

The key informants also highlighted the difficult economic circumstances which prevailed in the country as a key driver of the lack of opportunities for all young adults. They talked about the lack of employment opportunities as a national problem, affecting even those who were educated and skilled. They, however, concurred that the situation was worse for the DAYAs who were further disadvantaged by their stigmatising conditions.

"…things are hard…there are no jobs for everyone… you can imagine how bad then it would be for someone with two stigmatised conditions…" – KI 2

In all these struggles of lacking in resources and opportunities to transform their lives, it became apparent that paid employment was dominantly seen as the only viable tool for inclusion. This reflected in the DAYAs' experiences and perception of seeking paid employment. The talk was clear as to paid work being something that the young adults sought and pinned their hopes on as their doorway to social inclusion.

"… I think getting a paid job will help with all I want… If I am a respected worker, people will respect and accept me…" - Nicky

Those who were or had been employed, regardless of the type of employment, also talked highly of paid employment. They shared stories of feeling satisfied and joyful when they were employed and said that it made them feel part of their community life. Irrespective of the type of employment – formal, informal, self-employed – working gave them financial freedom and the ability to build their identity around being a 'worker' and not someone living with HIV or abusing substances. For Mai Ngah, the part time job as a master of ceremonies and her hustles in cross-border trading meant she had something positive to associate with beyond her HIV status and struggles with substance abuse.

"… waking up to something productive to do has helped me a lot…I enjoy it when I meet and work with other people… I do the cross-border business and at times I am hired to be an MC…" – Mai Ngah

The other domain impacted by the life on the margins led by the DAYA, was that of constructive recreational engagements. Without money and creative ideas to navigate the terrain, for the DAYAs like many other young adults in their communities; clubbing, drinking, idleness and generally killing time became synonymous with socialisation, resting and

spending free time. Some bemoaned the non-existent socialising, relaxing and recreational opportunities by highlighting that:

"… there is nothing other than the clubbing and maybe just sitting around to pass time… that is all we do for leisure and taking drugs with friends…" – Nicky

Likewise, others highlighted how their communities only had beerhalls and bottle stores as places for socialisation for people like them.

"… for people like myself we only have easy access to these beerhalls and that is where we hang out…I can say for recreation there is nothing here…" - Billy

In the continuation of life on the margins led by the DAYAs, participation in family and community life was also negatively impacted. The young adults who had opportunities to participate in mainstream social activities and groups in both community and family gatherings, bemoaned being looked down upon and being relegated to take up inferior tasks and roles. Two of the DAYAs, Billy and Mudzvurwa, shared their experiences of being denied the opportunity of meaningful contribution and being restricted to menial tasks at social gatherings, solely because of their stigmatised identities.

"… they[the community] always say you are here for alcohol … they ask you to do degrading stuff like fetching water and cutting firewood whilst they don't…this is my experience with community events…" - Billy

Similarly, Mudzvurwa shared his experiences and added that feeling included includes the notion of being consulted for your input, however this was not happening for him,

"… at family functions I always feel like an outsider… I am not involved… they don't consult me…" – Mudzvurwa

Regarding resources and opportunities for religious activity participation, most of the DAYAs felt satisfied with non-judgemental religious activities. Three of the participants (Billy, P Jay and Mudzvurwa) shared experiences of being accepted. However, because of self-stigma, they felt different and uncomfortable about being in church. Hence their participation was erratic. The DAYAs also took religious participation to mean Christian religion participation, the dominant religion in the community.

"… I never had problems at church, I just felt like I don't belong there… I rarely go to church…" – Billy.

For some, self-stigma made it difficult for them to even consider attending church. They viewed themselves as not worthy of attending church until they had completely recovered, that is, until after they had stopped abusing drugs and could portray a born-again Christian character. For Nicky this came across as a matter of self-stigma but was most probably informed by her past experiences and perceived stigma.

"…I don't think I will be accepted in any church… until I have changed this drugs thing, I will not go to any church…I think they will only accept me as a born-again Christian…" - Nicky

In this continuum of life on the margins, the DAYAs and key informants also bemoaned the death of holistic inclusive services. Both the DAYAs and key informants claimed that accessing stigma free mental health services continued to be a challenge. The utilisation of public mental health facilities for substance use disorders was reserved for severe cases, mainly through involuntary admissions. They also maintained that the lack of community-based rehabilitation services continued and made it difficult to sustain the gains of tertiary services. Because of these challenges, relapses were a common feature of life on the margins. Unfortunately, these relapses were judged harshly by family and community, causing further alienation among the DAYAs. Nicky shares her experience below.

"… my challenge is that there is nothing to support me to stay dry after discharge… to help me fit in with others… I always go back to my drugging friends and I relapse…that is what gets me punished and rejected by my family…they are disappointed with me…" – Nicky

The deputy director for rehabilitation services also bemoaned the situation, saying that integration into community life was difficult for these young adults who had chosen recovery:

"… we don't have a sound plan for this group… we need to consider that their needs are unique… they need help negotiating the stigma in their communities…" – KI 3

Life on the margins, also emerged as a power battle with those in the mainstream. The mainstream community wanted to in charge without consultation with the DAYAs and to make significant life decisions and facilitate their access to opportunities at both family and community level. This situation affected acceptance of the DAYAs and made it difficult for the community to create an environment that would aid the DAYAs resolve their challenges. The National AIDS Council reflected on this and shared:

"…at times I put the blame on us… we don't engage them, and we make it so difficult for them to even see the need to change… we need an environment that is less hostile for these young people…" – KI 5

6.5.4. Experiencing mainstream sanctioned life

In this subcategory, the rare times when DAYAs were able to experience acceptance in their mainstream communities are described. All the DAYAs wished for some change regarding their life circumstances and wanted to be given support and access to resources and opportunities to contribute to the social, economic, religious and political causes of their families and communities. They said that would make them feel a part of the community and be recognised by others as such.

Key informants highlighted the enormous value of feeling socially included in this population. From the key informants' perspectives, a life sanctioned by the mainstream implied a transformed or recovering young adult with adequate and informed support systems in an enabling environment. This life could be initiated from an individual level but needed a collaborative and holistic approach to be sustained. Unfortunately, challenges like poverty and unemployment were cited as factors making it difficult for such a life to be realised.

"… it is possible to have these young adults be fully integrated in their communities… that starts with them taking up treatment…support structures at family and community levels… getting everyone onboard…questioning challenges like poverty and unemployment…" – KI 1

Mainstream community life was understood as a socially and occupationally inclusive life, acknowledging the DAYAs' health challenges and assisting rather than stigmatising them.

"… yes, there are moments when I feel like I am equal and accepted as I am…like when I am with the music group and playing soccer without my status or, when the fact that I use mbanje is not used against me …" – P Jay

Likewise, Nicky shared,

"… in those rare moments when I have felt included and accepted by my community, it is when I am not judged and I am listened to…when I am consulted and I am given a chance to pull shorts on my life choices…. It is also when I feel understood and even the help offered will be relevant… this usually happens when I visit home for a short time, at those times, I feel like I belong…" – Nicky

The hallmark of feeling included in mainstream life discussed here includes experiences and feelings of having a voice, taking control of one's life, being accepted and "treated as equal" in the young adults' communities. Access to one's voice and power to make decisions pertaining self and others was regarded an important marker of integrated mainstream life by the DAYAs. For some, engagement and participation in active family and community life meant utilising their voices and making choices. P Jay referred to the feeling of reclaiming his voice and being heard when he joined the community support group.

"…In the community support group, I felt like I belong…I liked being given a voice and having people who understood me…" – P Jay

The DAYAs described being able to exercise choice over their own lives and being given information to make informed choices as something that resulted in their feeling a part of the community. They despised having decisions made for them and their being forced to conform. This resulted in their non-cooperation, some pointed out the lack of consultation in their treatments, where solutions prescribed were things they did not agree to but were expected to adhere to. To them the acceptance should start with the health personnel listening to them.

"… being able to exercise choice for what works best for me, even with the doctors, would be the start of my inclusion. I need inclusion in my treatment. Unfortunately, they don't listen to me, they brush me off because I am crazy [sic]…" - Nicky

Another critical aspect of acceptance was immediate family support. Inclusion was more meaningful when it happened first within the immediate family which then allowed the person to move more confidently into the community. Mai Ngah recounts that her family understood her, was loving and supportive and they empathised with her, willing to help in all ways they could.

"…for me the difference was that my family embraced me despite my problems early especially about HIV, they didn't push me out or make me feel different…" – Mai Ngah

Having mutual and respectful relationships with others in the community was also an important part of experiencing mainstream life for these young adults. Although their relationships were marred with challenges when they happened the DAYAs really cherished them and felt recognised and accepted. Mudzvurwa describes his relationship with his pastor which made him feel important.

"…I really felt important when my pastor checked on me…she called in asking about my health…it made me feel like I was part of the big family…" – Mudzvurwa

Likewise, P Jay talked about having mutual relationships with other members in the support group and said that made him feel that he belonged to a bigger and important group. Being recognised was synonymous with feeling included and having equal rights.

For some DAYAs, a sense of inclusion in mainstream life meant being in a working marriage associated with adaptive community participation. Being in a marriage had some protective factors for the two who were married during the time of the data generation for this study (Mudzvurwa and Mai Ngah), aiding their experience of mainstream life. The support they received from their spouses was the beginning of more community support, respect and recognition.

"… my wife is always on my side and she defends me… they wanted to segregate me at the market [because of my drugging life], and she stood with me, that was important for me to fit in this community…" - Mudzvurwa

For Mai Ngah, being married and having a husband and family members who helped her take responsibility for her needs, was a marker of adaptive mainstream participation. She reiterated that having the capacity to use community resources and opportunities, coupled with relevant family support, helped her experience life as active mainstream citizenship.

Nevertheless, being in a marriage did not always translate into support, as was the situation with Billy. The quality of participation in the relationship matters too. Billy's polygamous marriage was characterised by violence, separation and, eventually, divorce. Instead of giving him a socially valued identity as a husband and a father, the result was a stigmatised image of failure and as an irresponsible man.

Being resourced and financially independent also emerged as an important catalyst in living an integrated life. In Mai Ngah's situation, the couple's financial standing, which was above average, also cushioned them as they had the resources for self-sustenance and to contribute to the lives of their families and the community. She was included in the family and community, based on the value of her contributions.

"…they cannot exclude me… they (referring to her immediate and extended family) *depend on us… we support them on everything… we donate a lot at church too …"* – Mai Ngah

Access and equal participation in socially valued productive occupations such as paid formal employment was key in the DAYAs' experience and or perception of being integrated in mainstream life. Those who had experienced non-judgemental mainstream paid employment, said they enjoyed the experience and that it made them feel accepted and that they belonged.

"… I miss those days… I really enjoyed going to work and being around other people… even here I was respected as the driver, that would be perfect inclusion to me…" - Mudzvurwa

Likewise, in the cross-sectional survey, those who felt satisfied with their level of inclusion were more likely to have a higher socioeconomic status as determined by their employment status as shown in Table 9 below.

Table 6.4. Overall social inclusion against socioeconomic status (n=105)

		Overall Social Inclusion			
Employment Status		Dissatisfied	Mixed	Satisfied	Total
Unemployed	N	24	6	11	41
	%	51.06	33.33	27.5	39.05
Student	N	8	1	7	16
	%	17.02	5.56	17.5	15.24
Formally employed	N	3	6	12	21
	%	6.38	33.33	30	20
Self employed	N	12	5	10	27
	%	25.53	27.78	25	25.71
Total	N	47	18	40	105
	%	100	100	100	100

Pearson chi2(6) = 12.5901 p=0.05

Leading a past active community life in church and in the family also helped some DAYAs to have moments of integration in the community despite their HIV and substance abuse. In Mai Ngah's story we can see the importance of having had a firm grounding in church and family life before the two diagnoses emerged. As a consequence of this grounding, her community embraced her and remained hopeful and lenient towards her. To enjoy mainstream life, Mai Ngah experienced separation between her person and the problems she was facing and the family and community chose to see the person first and not seeing her as the problem.

"… they didn't treat me as the problem like what I have seen in others…maybe because of my life before all this, I was an active and significant member of the community…" – Mai Ngah.

For some DAYAs, feeling socially included by their families and the general community – even if rare –meant meeting the conditions for socially valued identities which were products of socially approved actions and ways of being. The burden was largely on the DAYAs to prove to their families and communities that they could be different from the reasons for their stigmatisation. The desired identities were developed and sustained through active participation in community life activities outside the routine substance abuse and idleness. To be recognised as productive workers, many went for informal jobs. To be recognised as a worker, Mudzvurwa had to work at the market with his wife. Active church participation resulted in Mai Ngah not feeling different; instead it made her feel like part of her community. Here she referred to herself in terms of her church and what it meant to her.

"…I was a youth advisor at my church… it made me feel like I was serving a purpose and being part of my community…" – Mai Ngah

The traces of mainstream life experience were also made possible by the efforts of others in the young adults' lives. For some, mainstream life participation was a result of the perseverance shown by their caregivers even though they were still struggling with substance abuse (see Mudzvurwa – 5.2.5, and Mai Ngah – 5.2.4 narratives). The effort put in by Nicky's family to try and take her back home and to send her for vocational skills training was commendable and made her feel cared for and allowed her to hope that one day she would be well-integrated in the family and make them proud again (see Nicky's narrative, 5.2.3). Merely being asked about her life plans and being told what the family was thinking about her when she visited them, made her feel like a part of the family.

"… when I went home, they asked me about my plans, how I want them to help me and also told me what they were thinking about my future… I was happy and it made me a part of the family…" – Nicky

Sometimes in life on the margins, the DAYAs felt forced to conform, which they either resisted or the change that came with it was not sustainable. Usually there were continued attempts by relatives to initiate change against the DAYA's will. Two of these young adults, P Jay and Nicky, felt as if they were being pressurised to conform to the ideals and values of their families (see category 6.4). They also felt the options for change were too narrow, as their families believed conforming to mainstream values and norms meant education, paid employment and Christian church participation (see 5.2.2 and 5.2.3). Also, the DAYAs were expected to live like people who aimed recover from substance abuse and who were showing advanced

compliance with their ART - seemingly, continuing to prove themselves to their families. One of them even had conditions for acceptance set out for him at home and his failure to adhere to them would result in renewed segregation and isolation.

"…I felt pressured to do it their (family) *way… when to be home… no drugs… taking my medication on time… being sent to do chores…I was then treated like any other child at home and my aunt liked it that way…"* – P Jay

6.6. Conclusion

This describes and explains how social inclusion was experienced and negotiated by the DAYAs in Zimbabwe through the three categories that emerged from four data sources contributing to this Case. The story that emerges here is one of lives that were marginalised before they were diagnosed with HIV and substance abuse. This resulted in the DAYAs often opting for transgressive and restricted occupational choices to meet their need to feel included. Most of the DAYAs start from positions of disadvantage, have health challenges added to their lives and these are further complicated by stigma. They continue to navigate their way in life through exercising agency in occupational choices against taken-for-granted ways of doing, being and belonging in society. Choices for action inclined to collective participation in dance or art groups and indigenous activities characterised the everyday adjustments of these young adults. In most cases, the negotiation was unsuccessful in yielding successful mainstream life participation and they ended up leading lives on the margins, characterised by dissatisfaction with levels of social inclusion. They navigated lives of poverty where stigma was rife.

Chapter 7 . Critical discussion of the Case from an occupational perspective

7.1. Introduction

The complexities of promoting social inclusion, equality and justice for marginalised people in largely unsupportive contexts, demands critical and reflective approaches. As Zimbabwe pursues its transformative agenda 2030 (Government of Zimbabwe, 2018) to meet the Sustainable Development Goals, inclusive and sustainable options for implementation are imperative. This agenda commits to ending poverty and recognises that a successful economy is dependent on the healthy status of individuals within the nation (Government of Zimbabwe, 2018). To achieve success, this agenda needs to include *everyone*, especially marginalised and disadvantaged population groups such as DAYAs. Within this group, priority should be given to their broader health and social care needs (Duffy et al., 2017). Given that social inclusion processes are an important consideration when addressing the broader health and social care needs of this traditionally marginalised group, this study aimed to explore and understand how social inclusion is experienced and negotiated by DAYAs with an emphasis on their participation in occupations. It revealed three key aspects that contribute to the experiences and negotiation of social inclusion for DAYAs in Zimbabwe: i) the centrality of agency; ii) the influence of dominant contextual discourses and iii) *activist occupational choices*.

The researcher argues that for the DAYAs, participating in ways that demonstrate their agency is essential to their quest for social inclusion. They exercised this agency in response to the problematic situations of the ill health, poverty, stigma, deprivation, exclusion and coloniality, they face in Zimbabwe. They expressed their agency through their participation in occupations which led them to experience social inclusion as a sense of belonging and well-being.

Secondly, he contends that the young adults' agency was shaped through dominant contextual discourses that emerged in relation to conditions of coloniality, modernity and neo-liberalism. These conditions influence the DAYAs' lives and realities of social inclusion through functions of coloniality of knowledge, power and being. In section 7.3, he elaborates on, and discusses, the ways in which these instances of coloniality narrow their pathways to social inclusion.

Lastly, the researcher introduces the concept of *activist occupational choices* to describe the alternate choices which DAYAs could make within the problematic situations that they face. He explains how these activist occupational choices serve as vehicles for breaking away from the narrow confines placed on occupational choices through inscribed dominant discourses. This results in their agency being energised by drawing from indigenous, local, available,

collective and sustainable occupations. He concludes the chapter by highlighting the implications of these insights for occupational therapy in global mental health.

7.2. Centring agency in seeking social inclusion

The DAYAs reflect the common human desire to matter and be agentic in their everyday lives. Their quest to exercise their agency as they go about their lives is central to their experiences of and ways of negotiating social inclusion. As in many studies informed by the capability approach to understanding development and well-being and enabling a holistic look at person-centred outcomes, agency in this study emerged as an expression of the DAYAs' individual choices, reflecting their values and beliefs. Sen (1992) argues that agency is displayed when individuals try to achieve their goals and values on their own terms, while stigma, discrimination and exclusionary situations are acknowledged as limiting one's sense of control and self-determination (Malik & Obhi, 2019; Jay et al., 2018), the DAYAs in this study exercised control and self-determination through their display of agency by making personal choices regardless of the social values associated with these choices. This occurred despite situations that they envisaged as limiting, based on historicity, present occurrences or their imagined futures. Such situations included episodes of ill-health, stigma and exclusion from mainstream communities, which detracted from and constrained the DAYAs' autonomy.

Biesta and Tedder (2006) argue that 'true agency' is seen in difficult circumstances where it points to the capacity of actors to "critically shape their responses to problematic situations" (p. 11). The DAYAs' agency was reflected in their occupational choices and was pivotal to the way they faced challenges that threatened their self-determination for inclusive participation in their communities. Although the situations made the DAYAs' lives difficult, they also pushed for 'true agency'. While recognising that both structure and agency play significant roles in directing the course of one's life (Sen, 2000; Hvinden & Halvorsen, 2014; Suzuki, 2017), people's social inclusion may be obstructed by structures when opportunities for agency are thwarted. As shown in the findings of this study, the agency of each DAYA agency was constrained by dominating structural forces which were aggravated by their ill-health and poor living conditions.

This study findings argue that without self-determination, which is a function of exercising one's agency, meaningful social inclusion remains elusive. The power to participate and even the belief in being able to do so, starts with the understanding that one is not a passive subject but has agency to self-determine and control one's life (Alkire & Deneulin, 2009). The DAYAs' sense of control over their life paths appeared to be the driving force for further action

in pursuit of community participation. They sought social inclusion as a function of belonging and a belief in their ability to self-determine.

In this study, the DAYAs applied their agency in four important functions. First, agency was important in setting personal goals in difficult situations. Although some of the goals pursued were detrimental to their health and well-being, they still felt in charge. Sen' research concurs with this finding, when he posits that it is possible for agency to be used to set and achieve personal goals without particular concern for one's health and well-being (Sen, 1992). Despite the odds being against the DAYAs, they still behaved as people with individual power to influence their destiny. This is the power they applied in influencing their health, well-being and social inclusion goals. These findings suggest that the power to decide on how to participate in occupations should always remain in the hands of the DAYAS to facilitate their sense of agency in goal setting. For example, when accessing health care for substance use disorders, the prescribed treatments for the DAYAs involved surrendering much of their freedom to choose their occupations and pathway towards well-being in that they appeared to feel compelled to accept treatment that they may have disagreed or felt discomfort with. In most situations, the health personnel restricted themselves to what they thought was ideal without co-constructing the options with the DAYA. By not listening to the patients in front of them and taking their actual circumstances into account, the treatment was short lived and had limited sustainability in that it fitted poorly with the DAYA's way of participating in occupations.

When health care workers judged the DAYAs for the lives they were living and negated the DAYAs' agency, it highlights what Sen calls "unfavourable inclusion" (Sen, 2000, p.28). Unfavourable inclusion is where mainstream participation is forced in ways which may be inauspicious for the one primarily affected (Sen, 2000). However, to challenge this practice, health care workers need to take their patients' entire lives into context and not simply bureaucratically prescribe without understanding the whole person. This requires the health care worker to be less judgemental and not to restrict the patient's agency, but to be more understanding of the situation.

When others are prescriptive, they remove the DAYAs' agency, leaving them to deal with the prejudices, stigma and discrimination inflicted when they acted in conflict to those prescriptions. Interventions supporting the DAYAs in exercising their agency through their participation in occupations may contribute to prevent relapses and defaults from prescribed

treatments. This data further supports the fact that treatments for substance abuse and HIV should not only be prescriptive but should also focus on empowerment of the affected to make informed decisions that suit their life situations (Alkire & Deneulin, 2009). An illustration of this was when one of the DAYAs was stigmatised for exercising her agency and asserting a sexual identity that was deemed deviant from the norm. In this example, Nicky had an extremely difficult time asserting her agency because of a dismissed identity. This made it difficult for her to follow treatment advice. These findings support the call for person-centred approaches that centre agency as the thrust of the person-centred recovery model as applied in occupational therapy when promoting social inclusion (Jacob, 2015; McKay & Robinson, 2011; Lloyd et al., 2004). The advantage of promoting DAYAs' agency in their social inclusion is that it empowers them to take responsibility for their problems and goals, it builds self-esteem and increases resilience for future similar problems. Mai Ngah's life exemplifies this, as her sense of belonging and the reported success in negotiating her inclusion was pinned to her ability to exercise agency.

The second function of the DAYAs' agency is as a tool of defiance in oppressive situations working against their belonging and well-being. These young adults confronted their situations by doing the unexpected and at times, unconventional, as concrete examples of their need to assert their ability to determine their course in life, irrespective of the associated consequences. For these young adults, the agency in resistance and non-compliance with prescribed ways of living, emerged as functions of activism. Such agency is understood to work through activism to facilitate service-user involvement, assertion of rights and self-determination (Barnes, 2007). In other words, the DAYAs' agency was instrumental in resisting injustices and seeking change as activists in their lives. For example, Mai Ngah resisted the stigmatised labels and claimed her position is the community, showing that she could still self-determine and influence the terms of her inclusion.

These acts of activism show the ways that the DAYAs challenge the stigma and discrimination that they experience in everyday life. They defy the discrimination meted out to them by continuing to participate in and survive their everyday occupations. In most instances, the young adults have not surrendered in the face of discriminatory practices, but instead have chosen to participate in the next available occupations, remaining defiant in the same space or having found support from like-minded people. In some instances, the DAYAs escalated their activism to institutional and structural levels by being confrontational about it. Similar reports of the relationship between the agency, activism and well-being shown by the DAYA have

been reported in the fields of disability (Barnes, 2007), mental health (Montague & Eiroa-Orosa, 2017) and HIV (Earnshaw, Rosenthal & Lang, 2016). The agency of these DAYAs and the resultant activism appear to serve as vehicles for exerting their political selves in everyday life. Cerulli and Kossak agree that acts in individuals' everyday lives hold political value (Cerulli & Kossak, 2009) and thus the individual small acts of resistance shown by DAYA matter.

In this study, the young adults used their agency to confront situations where opportunities for social inclusion were against them. For example, when Mai Ngah stood her ground against her in-laws, Billy stood up to his brother and P Jay spoke out against his aunt. In those situations, they denied being passive victims and acted to change their circumstances. They believed they could still be agentic although it was with restricted access to opportunities. Unfortunately, the health service sector did not do much good to this cause. The level of control the DAYAs' had in their lives was neglected as is seen by most of them being treated as passive players in their treatment management. However, the principle here should be that DAYAs, and others in similar situations, need not be treated as mere beneficiaries of their treatments, but as true agents who are able to pursue and realise their valued goals.

Although the DAYAs faced many challenges while trying to exercise their autonomy, they did not give up trying to find ways to express themselves through everyday actions. They went for other occupations, though not highly regarded in their communities but still supporting their notion of doing and being, they changed places of engagement, they changed people to associate with, and, in some extreme cases, they turned numb to the injustices.

The avenues that they pursued match a perspective of social inclusion in which the capabilities for doing and being that support development of health and well-being are emphasised (Sen, 1992). This differs from the notion of social inclusion that emphasises participation in certain areas of life such as paid work, education, or social participation as inclusion (Boardman et al., 2010; Liberman & Kopelowicz, 2002). A similar argument has been made about the agency of children with HIV while experiencing extreme hardship in Zimbabwe (Campbell et al., 2015). These children continued exercising agency in their restrictive situations by way of reflecting and acting. However, although they survived, they did so without gaining access to significant power, resources or support, for the outcomes that they would value (Campbell et al., 2015). That the DAYAs were still able to assert their agency during these difficult situations is evidence that they too were able to actively engage in their lives and should not be reduced

to being passive recipients of care needing safeguarding. Instead, the DAYAs should be treated as active doers who can decide and make judgements about their participation in occupations in ways that align with their values and sense of well-being. Sen contends that this could be the foundation of social transformation and effective use of capabilities in one's life (Sen, 1985). This thinking is supported by work on equitable human development where the central goal is to enable people to be active and direct agents in their lives, with the power to determine and make choices (Alkire & Deneulin, 2009; Sen, 1999). In occupational therapy, this active engagement of service users and their communities as agentic beings underlies the growing pursuit for social transformation through occupation (Laliberte Rudman et al., 2019) .

The third function of agency in this study was to convert their limited resources and opportunities into valuable functionings, as the DAYAs negotiated their social inclusion. Robeyns (2011, 2016) claims that three types of conversion factors are required for valued well-being to be achieved: i) personal, ii) social and iii) environmental. These conversion factors create conducive environments for resources and opportunities to be acted upon in order to produce valued doings and beings (Robeyns, 2016). Agency is recognised as a significant personal conversion factor that people are able to draw on in difficult situations (Robeyns, 2016). Having agency was crucial for the DAYAs' capabilities, in that it provided them with a way to examine the extent to which contextual barriers affected their ability to pursue valued doings and beings (Sen, 1999). Agency as a personal conversion factor shown by the DAYAs should be a primary focus of interventions designed for capability enablement and social inclusion. For application of similar insights, the Capabilities, Opportunities, Resources and Environments (CORE) Approach has been proposed (Pereira, 2017). This approach allows for working with the service user as an agentic being in inclusive occupation-based practice, enabling occupation and social inclusion (Pereira, 2017).

Despite their agency, some of the DAYAs still struggled to access suitable resources and opportunities. If the application of agency as a personal conversion factor is to be maximised, then the DAYAs' access to resources and opportunities needs to be enhanced. For example, if P Jay had had access to diverse opportunities for education and skills development, then his agency as a personal conversion factor could have nurtured his musical and dance talents. This is supported by the belief that in situations of exclusion and injustice, such as those faced by the DAYAs, resources and opportunities should be distributed in a way that favours the marginalised for inclusion, equality and justice to be restored (Suzuki, 2017; Sen, 1992). In this study, the DAYAs needed more suggestions of opportunities and resources rather

reprimands The DAYAs did not have a favourable distribution of resources and opportunities emerging from policy and service provisions, despite being disadvantaged and limited in capabilities. What they were left with was to create a new order for themselves, including having to create room to access available occupations by first forming relationships with their peers and moving towards functioning as a collective. For example, the music and dance group which P Jay formed with his friends and Nicky's relationship with Charity.

In the DAYAs' situation, their agency emerged as a personal conversion factor which they used against their restricted opportunities for social inclusion. In essence, respecting and nurturing a DAYA's agency as a significant personal conversion factor would mean that the DAYA would be able to take the lead in negotiating access to available resources and activating the social and environmental conversion factors. For example, when Mai Ngah's agency was respected, she was able to use her public speaking skills and dance talents to act on her environment and influence her social inclusion, consequently improving her health and well-being.

The final function of the DAYAs' agency was shown in the way in which it allowed for self-organisation to challenge societal norms related to employment, education and religious participation. Through their participation in occupations (see findings section 6.3.2), the DAYAs demonstrated that they reclaimed control by setting their own standards for participation and inclusion in the community. For example, when Billy could not make it into formal paid employment, he opted for informal piecemeal jobs in the real estate trade, an area where he felt in control in setting his goals. In setting their own standards, they exercised self-determination and a sense of empowerment which did not concede to mainstream expectations and standards of being empowered. The positive feedback that the DAYAs received following their intuitive responses to their difficult situations (see findings adjusting to new challenges and life on the margins), led them to see themselves as self-determining. An example of this is the reception Mudzvurwa and Nicky received after leaving home and going to stay with their dismissed partner. Although their families despised the moves, the DAYAs felt in control despite their issues. Their feeling of success worked to sustain and amplify their further actions in trying to resolve their situations. For example, venturing into new relationships and family relationships which they had previously thought to be the preserve of healthy people, allowed them to feel accepted and gave them a sense of belonging.

This sense of agency enabled the DAYAs to be constructive in shaping their important engagements, that is, the way they related to others, and this led to feelings of satisfaction. This way of applying their agency, exemplifies expression of interest and self-determination in a purposive and proactive manner focused on actual things that people can do and possibly be. Agency in self-determination is also emphasised in the Capability Approach, where social inclusion is thought about in terms of the actual activities the DAYAs are capable of taking part in to experience inclusion (Sen, 1985; Robeyns, 2005; Alkire & Deneulin, 2009; Robeyns, 2016). Going forward, the DAYAs should be assisted to realise that to become agents, they do not have to wait for society to treat them as actors, they can instead create those circumstances for themselves.

The implications of the outlined experiences of DAYA agency challenges the existing view of DAYAs as being passive players. This is a dominant view in the biomedical approach (Anderson & McCleary, 2015). The importance of this understanding is supported by Sen's view that, inherently, humans are responsible agents, and that this should be the baseline of all engagements (Sen, 1985). Interventions which are person-centred, holistic and less judgemental, can promote agency in marginalised groups such as the DAYAs. These interventions should aim to create enabling spaces for developing agency rather than focusing predominantly on changes in behaviour. When the focus is on on self-determination and empowerment and less on prescribing behaviour changes, the change we seek may be easier to obtain and more sustainable. Alkire and Deneulin's principle of sustainable and participative empowerment may be useful to consider here since it advocates for people actively participating and leading in key decisions about their lives. This includes being part of policy making and implementation (Alkire & Deneulin, 2009). Recognising the DAYAs' agency should emphasise everyone's role in society and the essential contribution of community building in promoting social inclusion, irrespective of the prevailing circumstances. Moreover, when agency is seen as central to social inclusion, it allows us to recognise DAYAs on equal terms with everyone else in society. When this happens, their rights to participation in democratic, social and economic decisions are respected and upheld (Gould, 1988).

Creating reasonable opportunities for DAYAs to achieve their desired functions and feel more responsible for contributing to their communities becomes the thrust of social inclusion. DAYAs should be assisted to understand that being able to contribute to their communities would also strengthen their agency during ongoing participation, making whatever gains they

achieve more sustainable. All this is, however, not in a vacuum, as the dominant discourses which are discussed below also have an impact.

7.3. The challenge of coloniality, modernity and neo-liberalism in problematic situations

Section 7.1 and 7.2 discuss the significance of the agency among the DAYAs and, as is acknowledged in literature, structure has a bearing. Their actions are influenced by dominant discourses of expected pathways to social inclusion. While many sociologists argue that the line between structure and agency is complex (Archer, 1995; Berger et al., 1966; Giddens, 1984), the main point remains that the boundary between them is far from immutable. The main point that remains is that social inclusion is not only a question of adapting people to structures, but also to a large extent a question of continuous re-creation and transformation of structures (Rasmussen, 2002). The researcher contends that while agency is still a central component, the role of dominant discourses can still be critiqued.

The findings of this study affirm the critical and decolonial viewpoint that social phenomena, such as social inclusion, should be understood with a critique of its historical and current power (Stevens, 1989), and contextual situatedness (Grosfoguel, 2009). This has the advantage of eliciting new and alternative forms of knowing and seeing to dominant worldviews. The conditions of coloniality, modernity and neo-liberalism are apparent in influencing the way that DAYAs thought about their participation in occupations, their agency and the actual nature of their participation. For example, in accessing and making choices about participation in most sanctioned occupations (see findings chapter 5 and 6). This was evident in three major areas of their occupational engagement, namely, formal education, paid employment and religious participation. These areas are also understood to be the main routes to and outcomes of social inclusion (Nhunzvi et al., 2020). However, according to literature reviewed, this is heavily influenced by the global north normative value systems (Nhunzvi et al., 2020; Saloojee & Saloojee, 2011). This is reflected in the dichotomies created between a DAYA being formally educated, in paid employment and practising Christianity, the dominant religion in Zimbabwe.

The study findings identify an imagined typical profile of a DAYA as someone who underperforms by failing to achieve the dominantly held expectations of completing formal education, being active in paid employment and practising an established monotheistic religion. When the community prioritises these elements, then they define the DAYA as not performing and as inferior. This in turn creates an obstacle for the DAYAs who have difficulty accessing these perceived socially inclusive occupations. Their communities see them as without agency

and deserving stigma and exclusion. This viewpoint makes it difficult for social inclusion and change to happen, as the community's definition of reality is seen as normal and so is not questioned.

In this study, coloniality, modernity and neo-liberalism shape the contextual understanding of social inclusion. This was evidenced by the ways in which these conditions resulted in the high value attached to the attainment of formal education, paid employment and the practice of the Christian religion. The highly valued perception of these occupational areas was heavily influenced by Western value systems embedded in the dominant discourses. The findings of this study show that by idealising Western notions of valued participation, the DAYAs, as people falling outside the standard mainstream mold, are stigmatised and made to feel inferior and shameful about their conditions and participation. For example, not being formally educated, employed, or practising Christianity, made Billy and Nicky easier to dismiss in their quest for agency and inclusion. The idealising of Western valued ways of social inclusion implies acceptance of Eurocentric dominance in knowledge, power and being. Believing that for DAYAs, social inclusion can only be by participation in dominant occupational areas shows lack of contestation of dominant hegemonies, underlying notions of universal reason and scientific knowledge (Quijano, 2007). From this, occupational therapists risk assisting in the creation of dehumanised beings who serve at the mercy of the included. If the dominant discourses influencing the DAYAs' participation is not considered and challenged, their agency and potential to engage in alternative occupations like arts, risks being destroyed as they expect to be accommodated, saved and emancipated by the powerful, healthy, and civilized (Grosfoguel, 2014). When this happens, the DAYAs, like any marginalised group, are prone to other forms of domination and exploitation including, sexual, political, epistemic, economic and spiritual (Oxford, 2019; Grosfoguel, 2009). However, part of the status quo can be traced back to the Eurocentric origins of the concept of social inclusion, in which the individual excluded should be helped to fit in by participation in work, education and social life, without changing what they are fitting into (Saloojee & Saloojee, 2011).

The dominant notions are embedded in the everyday running of health and social care services. The notions, informed by conditions of coloniality, modernity and neo-liberalism, can be argued to be invisible, influential parts of the context, both in historical and present terms (Said, 2003). Asher (2013), points out that these dominant discourses shaping participation, development and modern subjectivity in most parts of the developing world, can be understood as colonial legacies. If occupational therapy is going to do justice to the agency and diversity

among DAYAs, it needs to make a deliberate effort to engage with these and to accept the existence of others pertaining to the occupational choices of the DAYAs.

The dominant contextual assumptions frame those with formal education as included or with the capacity to negotiate their social inclusion more than those with informal, traditional and indigenous forms of knowledge and skill. In this context of postcolonial Zimbabwe, there is continued domination by Eurocentric knowledge systems in schools at the expense of indigenous and traditional knowledge, which is seen as problematic (Shizha, 2006). In most situations, the postcolonial education provided through formal education, is seen as superior to indigenous methods and serves to redefine and reproduce hegemonic structures of the global north defined knowledge (Shizha, 2006). This may be viewed as a continuation of the colonial legacies which devalue indigenous knowledge as inferior, intuitive, superstitious and awaiting scientific inquiry (Maldonado-Torres, 2017; Santos, 2007). The legacy of coloniality, disguised as modernity, contributes to preventing the construction of alternative routes of education and skill acquisition for mainstream social inclusion of the DAYA. For example, despite being good in Nyau dance, P Jay was still condemned for not making it through the formal education system. This legacy serves as a barrier to alternatives by framing them as non-existent or ineffective. This Eurocentric understanding of knowledge and skill acquisition routes as the only viable routes, impacted the young adults' agency, as they too had internalised this position. This was common when the DAYA did not always meet the implied expectations or participate in formal education as an occupation within the confines of mainstream participation. Matsika (2000), argues that formal education in Zimbabwe reflects the global north value system which, for example, is diametrically opposite to the devalued traditional Shona indigenous education, where diversity and collective belonging are rewarded. He further asserts that, there is a need to bridge the two worlds to give value to traditional and indigenous education, by providing a hybrid curriculum that incorporates highly valued experiences from the traditional home environment (Matsika, 2000). Valuing indigenous knowledge may be a vehicle for promoting agency on the part of those like DAYAs, who find themselves without formal education, in other words, organised and institution-based learning. For example, most of the DAYAs did not hold formal educational qualifications but that did not mean they did not have intuitive knowledge and skills (shown in their narratives), only that it was not formally identified and nurtured.

The DAYAs' agency in social inclusion experience and negotiation was also influenced by the dominant discourses regarding perception and participation in paid employment. Similarly, to

many marginalised groups, such as homeless persons, persons with disabilities and persons with psychosocial disabilities, DAYAs also report low rates of paid employment (Conover et al., 2006; Cramm et al., 2013; Laudet, 2012; Olmsted, 2005). Being out of paid employment is associated with feeling excluded from society. Their unemployment status affected their self-perception and how they were perceived. The capitalistic society in which the DAYAs live, despised unemployment, the DAYAs internalised this and perceived themselves as having limited options for social integration. This affected their life satisfaction, access to other resources and opportunities and their quality of life. These effects of unemployment on social inclusion have been documented for similar population groups elsewhere (European Commission, 2010; Pohlan, 2019; The World Bank, 2013). In the current dominant capitalistic economy in Zimbabwe, unemployment among the DAYAs led to greater vulnerability, exploitation and decreased agency.

With dominant contexts of coloniality, modernity and neo-liberalism influencing perception and participation of DAYAs in paid employment, other forms of participation which resemble inclusion in work occupations are usually undervalued and despised. In this study, most of the undervalued and despised work occupations are also those engagements one could do without proof of any formal education or training, such as talent-based occupations like arts, informal trade, piecemeal jobs, cross-border trade, vending and drug peddling. To the DAYAs, these constituted work in the absence of formal paid employment, however it was considered inferior and was despised. This superiority of paid employment as a marker of success correlated with the expectation of acquiring formal education. This is another sign of the modernity and the neo-liberal ideas that drive global economic policies from the global north. However, this understanding should be contested or broadened. The dominant and taken-for-granted Eurocentric epistemologies are not exhaustive (Ndlovu-Gatsheni, 2015). Although the findings of this study suggest that equitable access and participation in paid employment may create more inclusive participation opportunities to DAYAs, the researcher argues that the dominant discourses should be challenged so that they do not portray paid employment as the only option because then failure to access it becomes synonymous with limited agency, social exclusion and other injustices.

Lastly, coloniality, modernity and neo-liberalism, as connected to the Christian religion, influence participation in spiritual activities, including religion. The domination of the Eurocentric Christian beliefs and values makes it difficult for some of the DAYAs to negotiate their inclusion in religious occupations. In most instances, they were labelled sinners who

needed to be ‘saved’ (life on the margins). In this, the dominant discourses of coloniality, modernity and neo-liberalism, framed the DAYAs’ perception and participation in religious occupations. It is possible that Christianity became dominant in all its variants because of its forceful introduction in that it is still considered the religion of civilization and development (Okon, 2014). The missionaries and colonialists are known to have aided each other, resulting in the replacement of most of the traditional indigenous religions value systems around 1800AD (L'Abbe, 2005). Therefore, to promote social inclusion through religious participation, it is important to critique the historical divisive introduction of Eurocentric Christianity in Zimbabwe and African society in general.

Although there are many variants of Christianity practised in Zimbabwe, the Eurocentric Christian beliefs and values are taken to resemble ideal religious practices, evidenced by about 84% of the Zimbabwean population claiming their affiliation with protestant and Roman Catholic churches (Central Intelligence Agency -CIA, 2018). In terms of religious participation, the DAYAs expressed that the ideal and inclusive religious participation designed to gain them mainstream inclusion was Christianity. Their participation in Christian church activities was highly regarded as progressive and even the DAYAs themselves longed for such participation. For them, it would be a marker of mainstream integration. This superiority of Christianity over traditional spiritual engagements has been a familiar phenomenon in most colonial societies. Ramugondo (2009), in her work on occupational consciousness, also outlines the problematic reconstitution of meaning and ways of participation that came with Western cultures embedded in Christianity (Ramugondo, 2009). In the current study, Christianity is portrayed as the ideal for social inclusion. Since most of the DAYAs who participated in the narrative inquiry data source, typically did not subscribe to Christianity, they experienced limited agency, and even self-exclusion. Social exclusion and discrimination have always been ways of handling those who fell outside of hegemonic religions, including exclusion by excommunication and even expulsion (Kirkaldy, 2005). Moreover, those who see themselves as not fitting the criterion, self-exclude as was the case with Nicky, unlike Mai Ngah who went into church and actively influenced her inclusion terms, Nicky had internalised ideas of rejection and never attempted going to church saying it was a place for the sober and recovered. On the other hand, Mai Ngah’s experiences showed that even in the presence of highly stigmatised dual afflictions, being an active member of a Christian religion denomination served as social inclusion capital.

Furthermore, misconceptions (sic) held by some defined the DAYAs as having loose morals, engaging in sinful acts and deserving of exclusion from church. This positioning made it even harder for the DAYAs to exercise their agency in mainstream engagements. The dominance of Christianity, aided by the colonial past of the society, may be problematic if those who work with groups such as the DAYAs do not facilitate empowered choices. Christianity might be unjustifiably used to dictate what should be done and who people should be, for them to be included in society. This consequently narrows people's options and choices when pursuing social inclusion.

This critique on historical and colonial assumptions about certain forms of engagement is also growing in South America, challenging the negative framing of certain occupations and assumed positive value of paid work and productivity (Sy et al., 2020). Sy and colleagues drew on occupational justice principles to explore Philippine War on Drugs political rhetoric. Looking at drug use as a non-sanctioned occupation, they contend that, contrary to government claims, the War on Drugs was contributing to occupational injustices, particularly occupational apartheid and occupational marginalization. These insights can also inform understanding of indigenous occupations and engagements labelled problematic among DAYA, generating culture-specific understanding of those occupations to include considerations of spiritual health, occupational justice, and occupational rights. Re-examination of drug use policies and practices in drug rehabilitation through an occupational lens may contribute to occupationally just possibilities and social inclusion (Sy et al., 2020).

7.4. Activist occupational choices

In the face of difficulty, the DAYAs continue to strive for a sense of belonging and well-being. They do this by exerting their agency to find and participate in available occupations outside of the dominant occupational areas of formal education, paid employment and Christian religious participation. This signals that, although they face many restrictions, they have remained active agents in their lives. Their well-being and belonging are integral elements of their social inclusion and are promoted through purposeful and meaningful everyday choices about what to do and who to be (Townsend & Wilcock, 2004) For example, the decisions to engage in piecemeal jobs, doing drugs, illegal trade business, sex work, collective engagement with peers are basic and instrumental activities of daily living. These daily decisions manifest as occupational choices, defined as the "…selection of occupations as co-constructed through an individual, group and community's transactional relationship with the context" (Galvaan, 2012 p. 174).

Through their ongoing occupational engagement, the DAYAs recognised that they faced a hostile environment for the realisation of their social inclusion needs. This was characterised by restricted options for occupational participation and occupational choice, related to their limited agency. It is from this background that the DAYAs' occupational choices emerged as inextricably linked to a context characterised by dominant beliefs related to poverty, stigma and discrimination. This understanding of occupational choice is similar to that recently proposed by occupational therapists and scientists, whereby occupational choice is said to involve a process of co-construction between the agency of the individual and their contexts. This results in occupational participation and engagement (Galvaan, 2010, 2014; Gallagher et al., 2015; Brennan & Gallagher, 2016). Engagement in socially valued and meaningful occupations has always been heralded as an important component of the promotion of health, well-being and feelings of social inclusion by occupational therapists. However, this assumption has been aided by a biased notion of occupation as inherently health enhancing. The occupational choices of the DAYAs in this study challenge this position.

Faced with situations and experiences of poverty, stigma, oppression and exclusion, the DAYAs had to make choices about how and what to engage in; these were based on what they deemed local, available, indigenous and sustainable choices. The researcher terms these ***'activist occupational choices'***, a category of occupational choices aimed at breaking away from oppressive systems and problematic situations, irrespective of the health and well-being outcomes or the social rightness of them. He takes activism to mean behaviours of resistance, advocacy and seeking the change aligned with particular political and justice causes and expressed through a variety of means which may include individual resistance, collective action, institutional acts, such as petitioning, and unconventional acts, such as civic disobedience (Klar & Kasser, 2009). For these DAYAs, their occupational choices had the activist hallmark of seeking change, finding alternatives, and asserting the right to define their realities in situations of injustice (Bartlett, 2014; Brough & Shresthova, 2012; Traustadóttir, 2008). In their activist occupational choices, the DAYAs also used their agency in emancipatory doings (Dobson et al., 2012). For example, practising social disobedience by leaving their families in search of personal 'freedom' and belonging.

The activism in these occupational choices was underwritten by a need for change by claiming control of their lives and rights through acts of resistance, collectivism and indigeneity. The DAYAs made activist occupational choices as they sought belonging and well-being through active means. For example, when they all went through life on the margins, it was a life of

active engagement, though not a typically socially sanctioned one. In these activist occupational choices, the DAYAs started using their agency to delink from the taken-for-granted ways of living prescribed for them. Through continual processes, they delinked from thinking, doing and being what the dominant discourses espoused in terms of the coloniality, modernity and neo-liberalism. They actively engaged outside formal education and paid employment. They delinked by going beyond the provided options and showing the possibility of other ways of succeeding (Mignolo, 2011). For example, when Mai Ngah thrived through her art-based talents and P Jay could realise something meaningful through music and dance group. From this standpoint, activist occupational choices were made beyond what the DAYAs had been socialised to believe as the only options in their lives. Some of the DAYAs even went against the social rules and norms known to shape occupational choices (Galvaan, 2010). An example of this is when Nicky went for trades such as drug trade and sex work. This calls for the occupational therapist to be less judgemental and to minimise the extremes of activist occupational choices which may have negative health and social outcomes.

In some circumstances, activist occupational choices serve a decolonial delinking process to dismantle the colonial matrix disguised as modernity (Mignolo, 2005, 2011). The DAYAs had to fight through their everyday occupational participation, resisting the prioritisation of formal education, paid employment and Christian religious participation. In rare instances, some DAYAs took active advocacy and activist stances against the prescribed ways of participation and resisted the accompanied injustices. For example, the advocacy work done by Mai Ngah in her church and community and the resistance to being sidelined and dismissed at the marketplace by Mudzvurwa. Applying these insights and free participation and enabling the imagining of alternative ways for all, indicates a need for all individuals and societies affected by dominant discourses to consider these activist delinking exercises (Mignolo, 2011), actioned as activist occupational choices.

Activist occupational choices also emerged as the young adults' efforts to redeem their agency and dignity from the shaming stigma and discrimination haunted them. With stigma and discrimination serving to restrict the DAYAs' occupational choices in the dominant areas of formal education, paid employment and Christian religious participation, they had to choose available occupations where they would experience less stigma and discrimination. Different to Minato and Zemke's (2004) findings about the occupational choices of persons with schizophrenia, the DAYAs' activist occupational choices were born out of conditions of lack, that is, lack of opportunities for personal development or opportunities to be part of the

mainstream. However, their occupational choices still served the function of enhancing their well-being, patterned time use and offering a sense of belonging (Minato & Zemke, 2004). the findings of the current study support the recommendation of Galvaan (2015), that we should not only talk about occupational choice if there is variety of occupations to choose from. In other words, when a range of meaningful and socially sanctioned occupations are accessible. However, this study shows that it is equally important to engage with the choices made when the conditions are least conducive, as they tap into creativity, resilience and survival. Through activist occupational choices, occupational therapists have room to further the understanding and promotion of resilience in marginalised groups such as the DAYAs.

In these activist occupational choices, the DAYAs felt they had the control and freedom to decide how to lead their lives despite difficult situations. It is from these experiences of freedom and self-determination in doing activities of value to themselves that they start to develop self-respect, diminished shame and decreased self-discrimination. When Nicky left home and entered into her relationship with Charity, she felt free, independent, accepted and belonging. The sense of self-respect further creates consciousness of the respect and honour they deserve from other people, further assisting them to fight stigma, discrimination and social exclusion in their everyday lives.

The DAYAs' activist occupational choices reflect that they were able to reshape what was available when navigating the ongoing problematic situations that they faced (see findings 'adjusting to new challenges'). These ways of adapting their occupational choices, through creating opportunities for themselves, contributed to experiences of agency and ownership of their lives. Through this, they were able add activist occupational choices as alternative routes to achieving valued basic functioning, including being a friend, a worker and experiencing nurturing in supportive social networks outside of the provisions of mainstream society. The DAYAs thus used their agency to make occupational choices that led to everyday occupations enriching their lives without changing the social, institutional and structural systems creating their problematic situations. They did this while remaining excluded from mainstream life. The DAYAs' experiences of intra group inclusion, despite being excluded from mainstream society was described in chapter six (category 6.4, life on the margins). For example, when Billy and Mudzvurwa lamented how easy it was to belong and be heard among fellow drunkards and when P Jay shared his experiences of acceptance and belonging among the Nyau dancers. However, mainstream community remained exclusionary. This may have remained as it was

because the primary causes of injustice and exclusion such as the dominant discourses, remained unchallenged.

The ways in which the DAYAs opted to move on with their lives without seeking significant structural changes to their situations could also be explained through the finding in this study that show that existing policies placed little importance on the broader health and social care needs of this group. The poor implementation of interventions, as reported by key informants, and the internalisation of feelings of being neglected on the part of the DAYAs in the findings (category 6.2) reflect this. It appears that these policy gaps contribute to the ongoing occupational injustices, stigma and social exclusion, leaving the DAYAs to resist the normative practices which continue to marginalise them.

The context the DAYAs are in is unsupportive and largely restrictive, many decisions are made which lead to negative engagements and consequently, more social exclusion from mainstream, something confirmed among disadvantaged youths in Ireland (Gallagher et al., 2015). It is important to reconsider the overall judgemental stance adopted when working with people from such settings. Some of the activist occupational choices made by the DAYAs, have led to participation in, or exposure to, health risks. It is known that exposure to risk-taking occupations may further influence successive occupational choices in similar occupations (Galvaan, 2012; Ramafikeng et al., 2019). When life is lived on the margins, the occupations of substance abuse, sex work and drug dealing continue despite their negative outcomes, because to the DAYAs, these become viable alternative occupational choices for inclusion in their situations. Although it seemed to work for the well-being and belonging needs of the DAYAs, Gallagher et al (2015), argue that these situations of marginalisation should be challenged as restrictions from positive occupational choices. However, according to this study the devaluing of alternatives, will result in further occupational injustices.

Despite the efforts of the DAYAs to seek alternatives to adjust to their difficult situations, macro-level, coloniality, modernity and neoliberal forces continued to impact on their available choices. The young adults and those significant in their lives also internalised the inferiority of the indigenous alternatives and still longed for formalised educational qualifications, paid employment and Christian religious participation as the ultimate solutions to their feelings of worth. These forces defined their indigenous occupations resulting from activist occupational choices, as inferior alternatives and hence, the production and reproduction of injustice, exclusion and marginalisation of the DAYAs. Thus, the promise of the alternative as found in

activist occupational choices needs to be supported if we are to see a context that allows delinking from Eurocentric dominant knowledge systems that play down the available indigenous alternatives for social inclusion.

The DAYAs also saw activist occupational choices as processes leading to occupational engagement that had the hallmark of nonconformity and offering ways to resist subjecthood by drawing from precolonial principles of engagement. This yielded new possibilities for social inclusion, belonging and well-being in their marginalised groups. Through using their indigenous knowledge to counter dominant hegemonies about preferred occupational choices and social inclusion, the DAYAs could contest coloniality, modernity and neoliberalism. This contestation of dominant hegemonies through the creation of an alternative, usually indigenous, is central in decolonial thinking (Mignolo, 2009; de Souza Santos, 2013). The DAYAs did this by exploring and embracing the multiple perspectives of thinking, doing and being to meet their inclusion needs.

The occupations which resulted from these activist occupational choices included, but were not limited to, traditional creative arts, dialogue, agricultural family activities, cooperatives, networking, talent-based trades, illegal trades and traditional spiritual occupations (see findings categories 6.3 and 6.4). These occupations represented workable ways of meeting The DAYAs' needs for belonging and well-being within the constraints of their limited range of resources and opportunities. The attraction of occupations emerging from activist occupational choices appeared to be that they were available, promoted agentic participation, promoted resilience, provided quick wins, utilised talent more than skill, helped in meeting basic survival needs and aided in resisting dominance and conformity.

In rare situations, the activist occupational choices resulted in some DAYAs engaging in confrontational and self-advocacy occupations to claim mainstream inclusion. This involved publicly speaking out against stigma and discrimination, educating those in mainstream about their challenges and playing active societal roles (see findings category 6.4). In these instances, some DAYAs managed to access opportunities for participation in mainstream society and life. In the traces of mainstream inclusion experienced by DAYAs, it was evident that they had to challenge internalised stigma, exclusions and feelings of inferiority and to refuse to accept the sick role born of the dominant disease model. As much as this points to the DAYAs' resilience, initiative and agency, it also points to a society with transformative potential that could be realised through occupation (Laliberte Rudman et al., 2019). Enabling the social inclusion of

DAYAs through activist occupational choices could be part of the social transformation required to address the problematic and unjust situations they continue to face, applied in the same way that collective occupations have been suggested for social change (Kantartzis, 2018).

7.5. Conclusion.

Chapter 7 provides a critical perspective of the discussion on how the DAYAs experience and negotiate social inclusion through occupational participation. The DAYAs experienced this as an ongoing process of navigating an already troubled life while seeking belonging and well-being. It is evident that central to this process is the DAYAs' agency, which forms the basis of all efforts to thrive under difficult circumstances. Befitting the agency/structure sociological discussion, the DAYAs' agency was influenced by the dominant discourses espoused in the conditions of coloniality, modernity and neo-liberalism. These conditions create problematic situations which resulted in overreliance on Eurocentric occupational engagement, such as formal education, paid employment and Christian religious practices as superior occupational routes for social inclusion. The participants had to respond to these problematic situations, complicated by stigmatised conditions, by enacting activist occupational choices. Reflecting on the DAYAs' social inclusion, the use of activist occupational choices can be understood as a critical and decolonial process of resisting oppression and injustice while applying agency for a sense of belonging and well-being in unsupportive contexts.

Chapter 8 . Recommendations and Conclusion

8.1. Introduction

Chapter eight summarises this thesis and reflects on the strengths and the limitations of the qualitative instrumental case study methodology as applied here Recommendations resulting from the study are made as it relates to practice, research, training and policy; a dissemination plan for the findings is also suggested.

8.2. Thesis summary

This study sought to explore and understand how dually afflicted young adults (DAYAs) in Zimbabwe experience and negotiate social inclusion in everyday life. A qualitative instrumental case study design was used, informed by a critical theoretical framework drawing from the Critical Social Theory, Decolonial Theory and the Capability Approach. The case was investigated through triangulating four data sources, namely a narrative inquiry with five DAYAs. in-depth interviews with five key informants, analysis of seven policy and legislative documents and a cross-sectional survey of social inclusion and associated factors (n=105). The case study analysis involved a multi-level approach: 1) narrative analysis of DAYA stories, 2) thematic case analysis drawing from survey data, narratives, in-depth interviews with key informants and document analysis and 3) theorising of conceptual constructs.

One theme (Navigating an already troubled life: seeking belonging and well-being) and three categories emerged from the analysis. The key finding is that the experience and negotiation of social inclusion is a complex and dynamic situated process, with both internal and external influences. This process resides in a context largely unsupportive, influenced by stigma and hegemonies which the DAYAs experienced as oppressive, restrictive and dehumanising. The dual affliction of substance use disorders and HIV emerged as added health and social challenges working against the occupational choices, resources and opportunities for social inclusion. The situation is further compromised by policy gaps and lack of resourced strategic plans to pursue the broader health and social needs of DAYAs and other similarly marginalised groups. All this leads to an ongoing difficult life on the margins of mainstream society, characterised by continual processes of fighting stigma, oppression and injustice in everyday life.

The thesis discusses the way agency, context and occupational choices are intertwined and pivotal in influencing the social inclusion of typically marginalised population groups like DAYAs. It further contends that, to promote social inclusion so that it reflects a sense of belonging and well-being, is to take cognisance of and challenge problematic situations arising

from dominant discourses sustained through conditions of coloniality, modernity and neo-liberalism. To respond to these problematic situations, agency is central. The DAYAs' exercise of agency plays a fundamental role for developing self-consciousness, self-determination and meaningful involvement in life choices.

The conditions of coloniality, modernity and neo-liberalism are apparent in influencing the way that DAYAs conceptualise and apply their agency, make choices and participate in occupations. The DAYAs' marginal lives lie within limited participation in three major occupational areas of Eurocentric value, namely: formal education, paid employment and Christian religious participation. The resultant response to these situations, similarly to occupational injustice, were acts of resistance through maintaining agency and *activist occupational choices*.

Activist occupational choice is a concept emerging from this study, which is proposed as a category of occupational choices, largely defying the taken-for-granted norms of engagement, aimed at breaking away from oppressive systems and problematic situations. These were alternate ways of seeking belonging and well-being in many problematic situations faced by the DAYAs. These *activist occupational choices* were central in the DAYAs' ongoing processes of (re)claiming control over their lives and rights through acts of resistance, collectivism and indigeneity. The DAYAs also at times employed some unconventional and transgressive acts and choices embedded in their everyday doing, as ways of disrupting oppressive and exclusionary contextual systems and asserting their agency.

These findings add to the body of knowledge in theorising occupational participation and social inclusion, by recognising the value of agency in restrictive contexts. The potential of alternate ways of engaging, usually local, available, indigenous and collective, when working with traditionally disadvantaged and marginalised population groups in post-colonial settings like Zimbabwe is emphasised.

8.3. Strengths and limitations of the study

8.3.1. Strengths

- The in-depth investigation of a single case using an exploratory design allowed for new knowledge about social inclusion to be generated from multiple perspectives, including people typically marginalised within Zimbabwe, voicing the reality experienced within their contexts. Anchoring the study in real-life situations as captured in the DAYAs'

hybrid narratives, gave room to build a rich and holistic account of the experience and negotiation of social inclusion.

- Positioning the instrumental qualitative design as the methodology, allowed for triangulation between four data sources. With the narrative inquiry as the main data source, supported by three complementary data sources, allowing for a mix of archival, qualitative and quantitative approaches, means the findings are not just limited to the experiences of the primary participants.
- The use of the narrative format in the findings makes complex social constructs accessible to many audiences, as stories are known to appeal even to lay consumers of research. These narratives stand as a resource that the researcher plans to disseminate more widely, collaborating with the participants, through lay public platforms such as blogs.
- The findings are presented with illuminating meanings to aid understanding and application in similar contexts. The colourful and detailed descriptions used for the two findings chapters help create a vivid portrait of the way the DAYAs experience and negotiate social inclusion, making learnings transferrable to other similar situations.
- Th researcher was reflexive throughout the research process and gave detailed and reasoned descriptions of the methods and findings, to allow the reader to follow the research audit trail closely in order to be able to consider how the study may be useful elsewhere.
- The insights from this study may inform future research on social inclusion among marginalised population groups, hence advancing the occupational therapy and science knowledge base.

8.3.2. Limitations

- This case study focuses on a single unit and thus is not generalisable to all DAYAs. However, it allows for an in-depth learning from this case study.
- The study participants were recruited through the country's main referral centres in Harare and thus may have been mainly from urban and peri-urban, rather than rural, areas. Given that rural areas are known for communal living situations, low literacy levels and limited access to information, distinct experiences of social inclusion may have emerged from them. While this may be addressed through future research, in this study the DAYAs shared some of their experiences derived from their time in rural areas and key informants also reflected on rural life complexities.

- Data gathering mainly relied on interviews. The experiences and insights shared are based on the subjective memories of the participants and what they chose to share. It is possible that in the process, critical information might have been omitted, deliberately or not, in telling. The omitted insights might have aided in gaining a deeper understanding, or an alternative understanding, of social inclusion in DAYAs.
- This study does not explore the neuropsychiatric complications of SUD and HIV on executive functioning, including decision-making. Despite screening for severe HIV dementia and active psychosis, it is possible that there were executive functioning impacts, warranting investigation in future studies to improve the social inclusion of DAYAs.
- The adoption of a survey to support the selection of the participants might have silenced some individuals with interesting accounts, however, the narrative inquiry data source specifically targeted these information rich cases.

8.4. Study recommendations

8.4.1. Practice with DAYA

The insights shared from this study present an opportunity for reflection on the way occupational therapy and other services for DAYAs are currently structured and resourced, and how this influences the social inclusion goals of this particular group, and others in similar precarious conditions.

For social inclusion, the practitioners are called to reprioritise agency, thereby facilitating self-determination among service users like DAYAs, usually relegated to being passive consumers of ascribed services. The Capability Approach can be used as a guiding framework for promoting agency and the realisation of meaningful social inclusion. The argument is that agency is a prerequisite for people-centred inclusive development which leads to the promotion and protection of all human rights, based on non-discrimination, respect for diversity, equality of opportunity and the equal participation of all people, including the marginalised and vulnerable population groups like the DAYAs.

Practitioners and services should recognise the multiplicity and diversity with which agency manifests and should promote the alternate, particularly activist occupational, choices. To this end, occupational therapists should depart from a narrow and positivist view of occupational choices and embrace other forms, like activist occupational choices, from which the characteristics of resultant occupations like indigeneity, collectivism and resistance can be used

to direct sustained engagement in occupation. This calls on practitioners to embrace indigenous occupational forms of achieving social inclusion. Such forms may include traditional arts and crafts, talent-based engagements, group projects, peasant farming, dialogue and cooperatives.

When working with DAYAs and other similarly marginalised groups, practitioners should act as advocates for change, by advocating for systemic change that leads to more attention being paid to the broader health and social care needs of the DAYA. This should include going on to challenge the status quo and aiming beyond the individual circumstances of the people they serve to make social inclusion a primary goal. To this effect, a critical and decolonial approach to address the contextual influences (inclusive of dominant discourses) on health, well-being and social inclusion is called for.

Opportunities for dialogue within global health practitioners to raise consciousness and break away from ways of thinking, knowledge and being associated with injustice and colonial systems are presented. For example, occupational therapists, psychiatrists, psychologists, nurses and occupational scientists should seek to understand stigma and exclusion as tools linked to global power and knowledge structures which result in loss of humanity, rights, freedom and opportunities to the benefit of those in mainstream positions of advantage.

8.4.2. Recommendations for research

To my knowledge and following a search of literature on Zimbabwe, this study is an index study exploring social inclusion in DAYAs. It is therefore recommended that this field of research be expanded to grow a research database on social inclusion, including its measurement and interventions to promote it in DAYAs and to generalise this to marginalised groups such as mental health service users and persons with disabilities.

It is suggested from the findings of this study that there is a relationship between agency and activist occupational choices when negotiating for social inclusion in problematic situations as with the DAYAs. This relationship could be further investigated using quantitative longitudinal studies to ascertain the associations.

A deepened awareness raising and conscientisation ongoing programme within departments and organisations from which the key informants were drawn (MoHCC, NAC and University of Zimbabwe) is further recommended. Those in strategic positions to influence the care directed toward the social inclusion of DAYAs should be aware of and keen to attend to both contextual and historical hegemonies influencing the lives of marginalised groups.

Drawing from the exploratory cross-sectional survey, more attention should be directed towards complicating factors such as stigma, common mental disorders and social support. However, the need for more robust qualitative and analytical studies to measure variables such as prevalence of common mental disorders, stigma, and level of social inclusion and their relationships with sociodemographic characteristics of the DAYA is recommended.

8.4.3. Recommendations for policy

A review of the current Mental Health and the National HIV policies to include social inclusion as a key element, thereby giving policy direction on promoting inclusive development and equitable participation for all in a just society, is recommended. The role of rehabilitation services is scantly captured and should be revisited with a critical social inclusion focus. The goal for rehabilitation should be encapsulated as that of promoting social inclusion, especially for the most marginalised groups like the DAYAs.

In fighting stigma and discrimination, social and community resources and opportunities which include sensitisation of communities on tolerance and diversity, should be central in strategies to implement socially inclusive policies. There is a need to explicitly state the role of occupational therapy in these policies. The approach to these policy revisions should be participatory and should include input from all key stakeholders, including DAYAs as experts through their experience.

8.4.4. Recommendations for training

The University of Zimbabwe, College of Health Sciences, is repackaging and restructuring its curriculum for Health Sciences degrees in line with Education 5.0, paying special attention to indigeneity, innovation and industrialisation. It is recommended that their curriculum should adopt a critical theoretical and decolonial perspective in order to prepare graduates to be reflexive practitioners who can attend to the complexities of the broader health and social care needs of their patient populations, like DAYAs. Attending to the health and social care dominant discourses in post-colonial Zimbabwe is key. For this epistemological shift to happen, insights from this study may be used to raise awareness among academics regarding the hegemonies, contextual and historical forces which influence the social inclusion, health and social well-being narrative of population groups such as the DAYA. These hegemonies are, however, taken for granted and remain unchallenged in the current, largely biomedical, curriculum. This broadening of scope could be furthered through research theoretical frameworks in postgraduate studies, departmental seminars and faculty discussions.

Appendices

Chapter 3 Appendix A - Information and Consent Sheet -DAYA Narratives.

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Study Title	**A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**
Activity	Narrative interviews
Participants	Young Adults
Principle Investigator:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com

You are invited to take part in a research study. Before you decide whether to participate, you need to understand why the research is being done and what it would involve. Please take the time to read or to listen as I read the following information. You may talk to others about the study if you wish. Please ask me if there is anything that is not clear, or if you would like more information. When all your questions have been answered and you feel that you understand this study, you will be asked if you wish to participate in the study, and if yes, to sign this Informed Consent form. You will be given a signed copy to keep.

Purpose of the Study and Study Requirements

What is the study?
The purpose of the study is to gain a better understanding of how young adults with both a substance use disorder and HIV/AIDS participate in everyday life. The study also aims to gain a better understanding between participation in everyday life activities and the level of being included in society and community life. We know little about the experiences of this population and we are using this study to learn more. By learning more about these experiences, we hope to help service providers like occupational therapists and other mental health practitioners to better support young adults with substance use disorders and HIV/AIDS.

Why have I been invited to take part? You have been invited to take part because you are a young adult living with a substance use disorder and HIV/AIDS in Harare, Zimbabwe.

What will happen if I take part? If you agree to take part in the study. You will be invited to take part in three or four interview sessions. These will be in a private and confidential place most convenient to you. During the interview, you will be asked to talk about your everyday life activities. You will be asked about your thoughts about everyday happenings around you. These interviews will be audio recorded.

How long will the study last? Each interview will last about 1-2 hours.

Risks/Benefits

What are the risks of the study? We do not anticipate that there will be any other major risks associated with your participation. It is possible that the stories you share may cause you some distress. Measures will be taken to help you if this happens. You will be given opportunity to speak with a counsellor if you need to and there will be referral to our mental health team for further support if necessary. However, through the interviews, you will be in charge of the stories that you tell, so can choose not to share things that cause you distress. All questions will focus on your life experiences as a young adult dually afflicted with substance use disorders and HIV/AIDS, in Zimbabwe. If you are asked about something that you do not want to discuss, you can say so and we will move on.

What are the benefits of participating? Information from this study will be used to advise the development of better and effective occupational therapy rehabilitation programs and or treatments to help address the broader health and social care needs of young adults who have both a substance use disorder and HIV/AIDS and others like them.

Confidentiality

Will my participation in the study be kept confidential? Every effort will be made to protect your privacy and maintain the confidentiality of all the information that you provide to the extent permitted by law. This includes audio recordings of our interviews and any notes taken. When the interview is over, the information on the audio recording will be typed up so that the entire conversation is captured accurately. Your name will be removed from this transcript. Once the audio recording has been typed up accurately, it will be destroyed. The only way that you will be linked to the documents will be through an ID code that only the researchers will know. Once the study is over, this ID code will be removed permanently so that your name will no longer be linked to the transcript file. Your name will never be used in the PhD thesis or reports that come from this study. Throughout the study, the transcripts will be stored and transferred in a manner that our institutions have approved for studies like this one.

This study is being regulated by the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee, Joint Research Ethics Committee for the University of Zimbabwe, College of Health Sciences, and Parirenyatwa Group of Hospitals (JREC), Harare Central Hospital Ethics Committee and the Medical Research Council of Zimbabwe (MRCZ). All these organizations adhere to rules of keeping secret information in performing their responsibilities.

Voluntariness

What are my rights as a research participant/subject? You do not have to take part in this study if you do not want to. You can also stop at any time. Even if you say yes now and then you change your mind later, that will be OK. If you say no to the research or stop, it will not affect anything about your relationship with the researcher, and or any support groups or organizations you are part of. If you decide to stop taking part in the research, I will stop using the information you have given me for the research, and I will remove any information that I would have not used yet for the research or reports.

Other Information

What will I receive for participating?

There will be no direct payment for participating in this study. However, should transport be required, it will be reimbursed. In addition, lunch costs incurred on the day of data collection from the part of the participant will be reimbursed to a maximum of $10. Light refreshments will be provided during the interview.

Contacts and Questions:

Before you sign this form, please ask any questions you have about the study that are unclear to you. If you have any questions about this study now or in the future, you may contact Mr. Clement Nhunzvi on 0775814587 or clemynhu@gmail.com. If you have any questions concerning this study or consent form beyond those answered by the principal investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Chair of the Human Research Ethics Committee (UCT): Professor M. Blockman, Health Sciences Faculty Human Research Ethics Committee, Room E52-24. Groote Schuur Hospital. Old Main Building. Observatory 7925, University of Cape Town. South Africa. Tel: +27 21 406 6338 or Medical Research Council of Zimbabwe (MRCZ) on telephone (04) 791792 or (04) 791193 and cell phone lines 0772 433 166 or 0779 439 564. The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Principle Investigator:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Title of the Research	**A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

YOUNG ADULT NARRATIVE INTERVIEW CONSENT

PARTICIPANT INFORMATION SHEET:

1. Make sure that you read the Information Sheet carefully, or that it has been explained to you to your satisfaction.
2. Your participation in this research is entirely voluntary, i.e. you do not have to participate if you do not wish to.
3. Refusal to take part will not affect your participation in any of your work or community activities.
4. If you decide to take part, you are still free to withdraw at any time without penalty services and without giving a reason for your withdrawal.
5. You may choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.
6. The information collected will be kept strictly confidential.
7. If you choose to participate in this research study, your signed consent is required below.

Statement of Consent:
I have read (or have had read to me) the contents of this consent form. I agree to take part in the study and understand that this is my choice and that I can stop at any time.

I agree to participate in the in-depth interviews ☐ Yes ☐ No

I agree to the audio recording being used during the interviews ☐ Yes ☐ No

_____

Full Name of Young Adult *(first name, last name)*

Date: _____ / _____ / 2017
day *month* *year*

_____
Signature of Young Adult

_____ Time AM PM

Person obtaining informed consent:

I confirm that I have personally explained the nature and extent of the planned research, study procedures, potential risks and benefits, and confidentiality of personal information.

Name of person obtaining consent *(first name, last name)*	Signature of person obtaining consent
Position of person obtaining consent	Date: _____ / _____ / 2017 *day* *month* *year*

Independent Witness:

If the young adult cannot sign for himself or herself, a witness to the consent process may sign on his or her behalf

Full Name of Witness *(first name, last name)*	Date: _____ / _____ / 2017 *day* *month* *year*
Signature of Witness	_____ Time AM PM

Relationship of Witness to young adult

Chapter 4 Appendix B - Information and Consent Sheet -DAYA Narratives. Shona

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Musoro wetsvakiridzo	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**
Chiitiko	Hurukuro dzakadzama
Vari mutsvakiridzo	Vabvezera
Mukuru wetsvakiridzo	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com

Munokokwa kuva mutsvakiridzo ino. Musati matenderana nekupinda mutsvakiridzo, munofanira kunzwisisa sei tsvakiridzo iyi irikuitwa uye kuti zvinyi zvichaitwa pamuri. Tinokumbira muvane nguva yekuverenga kana kutetekera muchiverengerwa zviri pamusoro petsvakiridzo zvinotevera. Kana muchida, munogona kukurukura nevamwe pamusoro pezvetsvakiridzo ino. Bvunzai zvenyu kana paine pamusiri kunzwisisa, uye kana muchida kunzwa zvimwe zvakadzika pamusoro petsvakiridzo. Kana mibvunzo yenyu yose yapindurikauye makunzwa kuti manyatsonzwisisa nezve tsvakiridzo, muchabvunzwazve muchikumbirwa kana muchida kupinda muneino tsvakiridzo. Kana mhinduro yenyu iri hongu, munokumbirwa kusaina bepa rebvumo iro muchazopiwawo renyu rakadaro rekuti muchengete.

Chinangwa chetsvakiridzo uye zvinotarisirwa kwamuri

Tsvakiridzo ndeyei/yakanangei? Chinangwa cheino tsvakiridzo ndechekuti tiwane kunzwisisa kwakadzika uye kuri nani pamusoro peraramo yevechidiki vari pakati pemakore gumi nepfemba kusvika makumi matatu anemashanu, varikurarama nezvirwere zvekushandisa zvinodhaka pamwe neche HIV/AIDS. Tsvakiridzo ino irikuda kunzwisisa zvinosanganikwa nazvo nevechidiki ava mukurarama kwakamanikidzika uye zvavanoitawo kuyedza kuzvisunungura pakurarama kwezuva nezuva. Ino tsvakiridzo irikuyedzazve kuwana kunzwisisa kuri nani pakati peiyo raramo yakamanikidzika nepanozvikwa nevechidiki ava pakupiwa chikamu muupenyu munzvimo dzavagere. Parizvino zvationoziva zvishomasa pamusoro penyaya dzakaita seiri mutsvakiridzo ino, saka tichashandisa uno mukana kudziidza zvakawanda. Mukudziidza zvakawanda panezvinosanganikwa nazvo, tinotarisira kubatsira vanorapa vanonzi ma occupational therapists nevamwe vanoshanda navo muboka rekurapwa kwechirwere chepfungwa kuti vanatso bastsira zvakanaka vanokanganiswa nekushandisa zvinodhaka uye chirwere che HIV ne AIDS.

Sei ndakumbirwa kupinda mutsvakiridzo? Makumbirwa kupinda mutsvakiridzo nekuda kwekuti muri mumwe wevabvezera vari kurarama nechirwere chekushandisazvinodhaka pawe neutchiwana hweHIV ne AIDS muchigara muHarare, muZimbabwe.

Chii chinoitika kana ndikapinda mutsvakiridzo? Kana mukatenderana nekuva mutsvakiridzo ino, muchakokwa kutora chikamu muhurukuro dzakadzika dzingaita nhatu kana ina munzvimbo isina kufumuka yamunoona ichikuitirai zvakanaka. Muhurukuro idzi mubvunzwa kuti mutaurenyaya nezveupenyu hwenyu hwamazuva ose uyewo zvamunofunga nezvazvo. Hurukuro idzi dzichatapwa netepirekodha kuitira kuti tizonatso kwanisa kuinyora yose zvakanaka.

Tsvakiridzo ichatora nguva yakadii? Hurukuro imwe neimwe ichatora nguva ingangoita awa rimwe kusvika maawa maviri.

Njodzi/Zvaungangowane

Ndedzipi njodzi dzakarerekera kutsvakiridzo ino?
Hazvitarisirwe kuti kuva kwenyu mutsvakiridzo ino kungakodzera njodzi huru. Zvinogona kudaro kuti pahurukuro idzi munogona kutaura zvinokusuwisai. Pane matanho achatorwa kuitira zvakadaro zvichinge zvaitika. Muchapihwa mukana wekukurukura nevakadzidza kubatsira pakadai kana muchida uye munogona kukumbirirwa kuonekwa pachena nevanorapa matambudziko echirwere chepfungwa. Zvisinei hazvo, muhurukuro idzi, ndimi muchange muchitungamirira kutaurwa kwenyaya naizvozvo munogona kusataura zvamuona zvichizikukanganisai kana kukusuwisai. Mibvunzo ichanangana nezvamakasangana nzvo semunhu abvezera arikurarama nezvirwere zvekushandisa zvinodhaka pamwe ne HIV/AIDS. Pamusoro pazvo, mukabvunzwa zvamusingafare nekupindura, munataura tinobva tapfuurira mberi pane zvimwe.

Ndezvipi zvaungawane patsvakiridzo ino? Zvichawanikwa kubva mutsvakiridzo ino zvichashandiswa kuumba nekurairidza kurapwa kwakazara kuchibva kuboka re occupational therapy. Kubatsira uku kwakanangana nezvingadiwa pautano nemagariro evabvezera vane dambudziko rezvirwere zvekushandisa zvinodhaka uye utachiona hweHIV pamwe nemukondombera, nevamwewo vanematambudziko akadaro.

Zvakavanzika
Kupinda kwangu muchirongwa kuchachengetedzwa zvakavanzika here? Mukuedza kwose, tichachengetedza zvakavanzika zvenyu nezvamuchatipa pahurukuro dzatichaita, zvichiteedzera mitemo yenyika**.** Izvi zvinosanganisira hurukuro dzatichataita dzichatapwa patepi nezvatinenge tichinyora. Kana hurukuro yapera, tichanyora pasi humbowo hwunenge hwatapwa patepi. Tichabvisa zita rako nezvakanangana nemhuri yako pagwaro iri. Kana taona kuti zvanyorwa pasi zvinoenderana nezvepatepi, tichaparadza matepi aya. Chinhu chega chichange chakanangana newe pahumbowo uhwu inhamba yakavanzika ichange ichizivikanwa nevashandi vetsvakiridzo chete. Kana tsvakiridzo yapera, nhamba iyi ichabiswa zvachose. Hatizoshandise kana nguva ipi zita rako kana zvinechekuita newe mumagwaro achabuda mutsvakiridzo ino. Panguva yese yatinenge tichiita tsvakiridzo, tichachengetedza nekutransfeya humbowo zvinoenderana nezvinotarisirwa neboka retsvakiridzo dzakadai seino.

Tsvakiridzo ino irikuongororwa neve University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee, Joint Research Ethics Committee ye University of Zimbabwe, College of Health Sciences, pamwe neParirenyatwa Group of Hospitals (JREC), veHarare Central Hospital Ethics Committee uye neve Medical Research Council of Zimbabwe (MRCZ). Masangano ose aya anotevedza mitemo inoona nezvekuchengetedzwa kwezvakavanzika mukuita mabasa avo.

Kushanda pasina kubhadharwa kana kumanikidzwa

Ndedzipi kodzero dzangu semunhu arikupinda mutsvakiridzo? Hamumanikidzwe kupinda mutsvakiridzo kana musingade. Munokwanisa kubuda pane chero ipi nguva. Chero mukabvuma kupinda panguva ino, mozochinja pfungwa pamberi munogona kubuda. Mukati hamudi nezvetsvakiridzo ino, hazvizokanganise ukama hwenyu nemukuru wetsvakiridzo, uye masangano amunoshandira. Kana mukasarudza kusave mutsvakiridzo ino, tichamira kushandisa humbowo hwamunenge matipa mutsvakiridzo, uye tinobva tabisa humbowo hwese hwatinenge tisati tashandisa kunyora gwaro.

Rumwe Ruzivo

Ndezvipi zvandinowana pakuve mutsvakiridzo? Pachange pasina mubhadharo wakanangana nekuva kwenyu mutsvakiridzo. Zvisinei, mari yamuchashandisa pakufamba nemichovha yeruzvinji, muchaidzorerwa. Tinofarawo kukuudzai kuti mari yekudya kwamasikati kwezuva rehurukuro, muchairipirwa, zvichibatanidzwa kuita mari isingadariki gumi ramadhora ekuAmerika. Panguva yehurukuro, muchapihwawo twekudya nekumwira twakareruka.

Vekutaura navo kana waita mibvunzo:

Musati masaina gwaro iri, ndapota bvunzai mibvunzo pamusoro pezvamunenge musina kunzwisisa pamusoro petsvakiridzo ino. Kana muine mibvunzo pamusoro petsvakiridzo ino parizvino kana zvepamberi, munokwanisa kutaura Mr. Clement Nhunzvi panhare dzinoti 0775814587 kana petsamba mbozha clemynhu@gmail.com. Kana muine mibvunzo pamusoro petsvakiridzo ino kana gwaro retenderano rino, inodarika yapindurwa nemuridzi wetsvakiridzo, zvinosanganisira kodzero dzanyu semunhu arimutsvakiridzo kana kukuvara uri mutsvakiridzo, kana mukaona kunge musina kubatwa zvakanaka muchida mumwe munhu wekutaura naye asiri mushandi wetsvakiridzo, ndapota fonai kumukuru we Human Research Ethics Committee (UCT): Professor M. Blockman, Health Sciences Faculty Human Research Ethics Committee, Room E52-24. Groote Schuur Hospital. Old Main Building. Observatory 7925, University of Cape Town. South Africa. Tel: +27 21 406 6338 kana kuMedical Research Council of Zimbabwe (MRCZ) pa (04) 791792 kana (04) 791193 kana pa 0772 433 166 kana 0779 439 564. Mahofisi anowanikwa paNational Institute of Health Research panosangana mugwagwa unonzi Josiah Tongogara naMazowe Avenue muHarare.

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Mukuru wetsvakiridzo:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Musoro wetsvakiridzo	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

TENDERANO NEVAKURU/VAZIVI VEZVIRIMUTSVAKIRIDZO VACHAPINDURA MIBVUNZO

8. Ivai nechokwadi kuti manyatsoverenga zvizere, mukanzwisisa Information sheet iri, uye kuti matsanangurirwa mukagutsikana zvizere.
9. Kuve kwenyu mutsvakiridzo ino isarudzo yanyu, zvichireva kuti hamumanikidzwi kuvemo kana musingade.
10. Kuramba kwenyu kuve mutsvakiridzo ino hakukutadzise kuti mupinde munezvimwe zvirongwa zvemunharaunda menyu.
11. Kana mukasarudza kuve mutsvakiridzo, makasununguka kubuda pane chero ipi nguva pasina kuripiswa kana kurasikirwa nezvamunofanira kuwana uye pasina kupa chikonzero chekubuda mutsvakiridzo.
12. Munogona kusarudza kusapindura mimwe mibvunzo yamunobvunzwa mutsvakiridzo ino. Kana pane chamusina kugadzikana kutaura nezvacho, ndapota sunungukai kutaura.
13. Humbowo hwese huchatorwa huchachengetedzwa zvakavanzika.
14. Kana mukasarudza kupinda mutsvakiridzo ino, sainecha yenyu inodiwa pagwaro riripazasi.

TENDERANO

Ndaverenga (kana ndaverengerwa) zvirimugwaro retenderano. Ndinotenderana nekuve mutsvakiridzo ino uye ndanzwisisa kuti isarudzo yangu uye ndinogona kubuda pane chero ipi nguva.

Ndinobvuma kupinda muhurukuro ☐ Hongu ☐ Kwete

Ndinopa tenderano yekutapwa patepi panguva yehurukuro ☐ Hongu ☐ Kwete

_____ Date: _____ / _____ / 2017
Zita remurume kana mukadzi abvezera *(rekupiwa, remhuri)* *Zuva* *Mwedzi* *Gore*

_____ _____ AM
Sainecha yemurume kana mukadzi abvezera Time PM

Munhu arikupa tenderano:

Ndinobvuma kuti ndapa humbowo hwakazara pamusoro petsvakiridzo, zvichange zvichiitwa, njodzi dzakarerekera kutsvakiridzo, zvaangangowane, uye zvakavanzika zvaanenge atipa mutsvakiridzo.

Munhu arikupa tenederano *(rekupiwa, remhuri))*	Sainecha yearikupa tenderano
	/ / 2017
Chinzvimbo chearikupa tenderano	Date: *Zuva* *Mwedzi* *Gore*

Witinesi

Kana uyo abvezera asingakwanise kusaina ega, witinesi atsanangurirwa gwaro iri anokwanisa kusaina akamumiririra

Zita raWitinesi *(rekupiwa, remhuri)*	/ / 2017 Date: *Zuva* *Mwedzi* *Gore*
Ukama hwewitinesi neuyo arikupinda mutsvakiridzo	Nguva AM PM

Chapter 5 Appendix C - Information and Consent Sheet -DAYA Survey.

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:26347**97800**/724912/335249/79195
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Study Title	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**
Activity	Survey
Participants	Young Adults
Principle Investigator:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com

You are invited to take part in a research study. Before you decide whether to participate, you need to understand why the research is being done and what it would involve. Please take the time to read or to listen as I read the following information. You may talk to others about the study if you wish. Please ask me if there is anything that is not clear, or if you would like more information. When all your questions have been answered and you feel that you understand this study, you will be asked if you wish to participate in the study, and if yes to sign this Informed Consent form. You will be given a signed copy to keep.

Purpose of the Study and Study Requirements

What is the study?
The purpose of the study is to gain a better understanding of how young adults with a dual diagnosis of a substance use disorder and HIV/AIDS go through and cope with opportunities for participation in everyday life. The study also aims to gain a better understanding of the relationship between their participation opportunities in everyday life activities and their level of being included in society and community life. We know little about the experiences of this population and we are using this study to learn more. By learning more about these experiences, we hope to help service providers like occupational therapists and other mental health practitioners to better support young adults with substance use disorders and HIV/AIDS.

Why have I been invited to take part? You have been invited to take part because you are a young adult living with a substance use disorder and HIV/AIDS in Harare, Zimbabwe.

What will happen if I take part? If you agree to take part in the study, we will invite you to participate in a short survey. You will be asked questions from a Social and Community Opportunities Profile (SCOPE) short form by a trained research assistant in an interview format. You will be asked questions about your daily life experiences and your opinions about things that have happened to you. It will ask you questions about your work life, your social life, and your experiences in your community.
How long will the study last? Each survey interview should take about 40

minutes to complete.

Risks/Benefits

What are the risks of the study? It is possible that some survey questions or topics will make you feel unhappy. If we ask you a question that you do not want to answer, you can just say that you do not want to answer, and we will move over that one.

What are the benefits of participating? Information from this study will be used to inform the development of better and effective occupational therapy rehabilitation programs and or treatments to help address the broader health and social care needs of young adults dually afflicted with substance use disorders and HIV/AIDS and other similar disadvantaged groups.

Confidentiality

Will my participation in the study be kept confidential? The study team will make every effort to protect your privacy and maintain the confidentiality of all the information that you provide to the extent permitted by law. There is no way the study team can link your name with the data provided. We will never use your name or other identifiers in the PhD thesis or reports from this study. Throughout the study, we will store and transfer all documents in a manner that our institutions have approved for studies like this one.

This study is being regulated by the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee, Joint Research Ethics Committee for the University of Zimbabwe, College of Health Sciences, and Parirenyatwa Group of Hospitals (JREC), Harare Central Hospital Ethics Committee and the Medical Research Council of Zimbabwe (MRCZ). All these organizations adhere to rules of keeping secret information in performing their responsibilities.

Voluntariness

What are my rights as a research participant/subject? You do not have to take part in this study if you do not want to. You can also stop at any time. Even if you say yes now, and then you change your mind later, that will be OK. If you say no to the research or stop, it will not affect anything about your relationship with the researcher, and other organizations you are associated with. If you decide to stop taking part in the research, we will stop using the information you have given us for the research.

Other Information

What will I receive for participating? There will be no direct payment for participating in this study. However, we will give you a small gift as a token of our appreciation for the time you have given us to complete this survey. Your transport costs incurred on the day of data collection from the part of the participant will be reimbursed to a maximum of $5. You will also be given some light refreshments soon after completing the survey interview.

Contacts and Questions:
Before you sign this form, please ask any questions you have about the study that are unclear to you. If you have any questions about this study now or in the future, you may contact Mr. Clement Nhunzvi on 0775814587 or clemynhu@gmail.com. If you have any questions concerning this study or consent form beyond those answered by the principle investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Chair of the Human Research Ethics Committee (UCT): Professor M. Blockman, Health Sciences Faculty Human Research Ethics Committee, Room E52-24. Groote Schuur Hospital. Old Main Building. Observatory 7925, University of Cape Town. South Africa. Tel: +27 21 406 6338 or

Medical Research Council of Zimbabwe (MRCZ) on telephone (04) 791792 or (04) 791193 and cell phone lines 0772 433 166 or 0779 439 564. The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263**797800**/724912/335249/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Principle Investigator:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Title of the Research	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

YOUNG ADULT CONSENT – SOCIAL INCLUSION SURVEY

PARTICIPANT INFORMATION SHEET:

15. Make sure that you read the Information Sheet carefully, or that it has been explained to you to your satisfaction.
16. Your participation in this research is entirely voluntary, that is you do not have to participate if you do not wish to.
17. Refusal to take part will not affect your participation in any community activities.
18. If you decide to take part, you are still free to withdraw at any time without penalty or loss of services and without giving a reason for your withdrawal.
19. You may choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.
20. The information collected will be kept strictly confidential.
21. If you choose to participate in this research study, your signed consent is required below.

Statement of Consent:
I have read (or have had read to me) the contents of this consent form. I agree to take part in the study and understand that this is my choice and that I can stop at any time.

I agree to participate in this survey ☐ Yes ☐ No

_____ Date: _____ / _____ / 2018
Full Name of Participant *(first name, last name)* *day* *month* *year*

_____ _____ AM PM
Signature of participant Time

Person obtaining informed consent:
I confirm that I have personally explained the nature and extent of the planned research, study procedures, potential risks and benefits, and confidentiality of personal information.

_____ _____
Name of person obtaining consent *(first name, last name)* Signature of person obtaining consent

_____ Date: _____ / _____ / 2018
Position of person obtaining consent *day* *month* *year*

Independent Witness:

If the young adult cannot sign for himself or herself, a witness to the consent process may sign on his or her behalf

_____ Date: _____ / _____ / 2018
Full Name of Witness *(first name, last name)* *day* *month* *year*

_____ _____ AM PM
Signature of Witness Time

_____
Relationship of Witness to young adult

Chapter 6 Appendix D - Information and Consent Sheet -DAYA Survey. Shona

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-
7**97800**/724912/335249/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Musoro wetsvakiridzo	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**
Chiitiko	Hurukuro dzakadzama
Vari mutsvakiridzo	Varume nevakadzi Vabvezera
Mukuru wetsvakiridzo	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com

Munokokwa kuva mutsvakiridzo ino. Musati matenderana nekupinda mutsvakiridzo, munofanira kunzwisisa sei tsvakiridzo iyi irikuitwa uye kuti zvinyi zvichaitwa pamuri. Tinokumbira muvane nguva yekuverenga kana kutetekera muchiverengerwa zviri pamusoro petsvakiridzo zvinotevera. Kana muchida, munogona kukurukura nevamwe pamusoro pezvetsvakiridzo ino. Bvunzai zvenyu kana paine pamusiri kunzwisisa, uye kana muchida kunzwa zvimwe zvakadzika pamusoro petsvakiridzo. Kana mibvunzo yenyu yose yapindurikauye makunzwa kuti manyatsonzwisisa nezve tsvakiridzo, muchabvunzwazve muchikumbirwa kana muchida kupinda muneino tsvakiridzo. Kana mhinduro yenyu iri hongu, munokumbirwa kusaina bepa rebvumo iro muchazopiwawo renyu rakadaro rekuti muchengete.

Chinangwa chetsvakiridzo uye zvinotarisirwa kwamuri

Tsvakiridzo ndeyei/yakanangei? Chinangwa cheino tsvakiridzo ndechekuti tiwane kunzwisisa kwakadzika uye kuri nani pamusoro peraramo yevechidiki vari pakati pemakore gumi nepfemba kusvika makumi matatu anemashanu, varikurarama nezvirwere zvekushandisa zvinodhaka pamwe neche HIV/AIDS. Tsvakiridzo ino irikuda kunzwisisa zvinosanganikwa nazvo nevechidiki ava mukurarama kwakamanikidzika uye zvavanoitawo kuyedza kuzvisunungura pakurarama kwezuva nezuva. Ino tsvakiridzo irikuyedzazve kuwana kunzwisisa kuri nani pakati peiyo raramo yakamanikidzika nepanozvikwa nevechidiki ava pakupiwa chikamu muupenyu munzvimo dzavagere. Parizvino zvationoziva zvishomasa pamusoro penyaya dzakaita seiri mutsvakiridzo ino, saka tichashandisa uno mukana kudziidza zvakawanda. Mukudziidza zvakawanda panezvinosanganikwa nazvo, tinotarisira kubatsira vanorapa vanonzi ma occupational therapists nevamwe vanoshanda navo muboka rekurapwa kwechirwere chepfungwa kuti vanatso bastsira zvakanaka vanokanganiswa nekushandisa zvinodhaka uye chirwere che HIV ne AIDS.

Sei ndakumbirwa kupinda mutsvakiridzo? Makumbirwa kupinda mutsvakiridzo nekuda kwekuti muri mumwe wevabvezera vari kurarama nechirwere chekushandisazvinodhaka pawe neutchiwana hweHIV ne AIDS muchigara muHarare, muZimbabwe.

Chii chinoitika kana ndikapinda mutsvakiridzo? Kana mukatenderana nekupinda mutsvakiridzo ino, tichakukumbirai kuti mutore chikamu muongororo pfupi. Muchabvunzwamibvunzo ichibva pa Social and Community Opportunities Profile (SCOPE) short form nemumwe wewakadzidzira basa rekuva mutsvakiridzi zvichiitwa sehurukuro. Muchabvunzwa mibvunzo inechekuita

nezvamunosangana nazvo mukurarama uye zvamunofungawo nezvirikuitika munharaunda dzamugere. Mubvunzo ichava yezveupenyu maringe nekubasa, matandariro namagariro uye hupenyu munharaunda navamwe.

Tsvakiridzo ichatora nguva yakadii? Hurukuro yeongororo imwe ichatora maminitsi angangosvika makumi mana.

Njodzi/Zvaungangowane

Ndedzipi njodzi dzakarerekera kutsvakiridzo ino? Zvinogona kudaro kuti mimwe mibvunzo muongororo ino ingangokutsamwisei. Kana paine yamusingafari kupindura makasununguka kureva, tinogona kuisiya todarikira panemimwe yepamberi. Zvisinei zvazvo,vakambopinduri mibvunzo yakaita seino Havana kuita dambudziko nazvo.

Ndezvipi zvaungawane patsvakiridzo ino? Zvichawanikwa kubva mutsvakiridzo ino zvichashandiswa kuumba nekurairidza kurapwa kwakazara kuchibva kuboka re occupational therapy. Kubatsira uku kwakanangana nezvingadiwa pautano nemagariro evabvezera vane dambudziko rezvirwere zvekushandisa zvinodhaka uye utachiona hweHIV pamwe nemukondombera, nevamwewo vanematambudziko akadaro.

Zvakavanzika

Kupinda kwangu muchirongwa kuchachengetedzwa zvakavanzika here? Mukuedza kwose, tichachengetedza zvakavanzika zvenyu nezvamuchatipa pahurukuro dzatichaita, zvichiteedzera mitemo yenyika**.** Hakuna nzira dzingashandiswa nevetsvakiridzo kunanganidza zita renyu nezvichatorwa paongororo. Hatisi kuzoshandisazve zita renyu chero paneripi gwaro richabuda mutsvakiridzo ino. Panguva yese yatinenge tichiita tsvakiridzo, tichachengetedza nekutransfeya humbowo zvinoenderana nezvinotarisirwa neboka retsvakiridzo dzakadai seino.

Tsvakiridzo ino irikuongororwa neve University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee, Joint Research Ethics Committee ye University of Zimbabwe, College of Health Sciences, pamwe neParirenyatwa Group of Hospitals (JREC), veHarare Central Hospital Ethics Committee uye neve Medical Research Council of Zimbabwe (MRCZ). Masangano ose aya anotevedza mitemo inoona nezvekuchengetedzwa kwezvakavanzika mukuita mabasa avo.

Kushanda pasina kubhadharwa kana kumanikidzwa

Ndedzipi kodzero dzangu semunhu arikupinda mutsvakiridzo? Hamumanikidzwe kupinda mutsvakiridzo kana musingade. Munokwanisa kubuda pane chero ipi nguva. Chero mukabvuma kupinda panguva ino, mozochinja pfungwa pamberi munogona kubuda. Mukati hamudi nezvetsvakiridzo ino, hazvizokanganise ukama hwenyu nemukuru wetsvakiridzo, uye masangano amunoshandira. Kana mukasarudza kusave mutsvakiridzo ino, tichamira kushandisa humbowo hwamunenge matipa mutsvakiridzo, uye tinobva tabisa humbowo hwese hwatinenge tisati tashandisa kunyora gwaro kana tisati taisanganisa nezvimwe zvinozotitadzisa kudzipatsanura.

Rumwe Ruzivo

Ndezvipi zvandinowana pakuve mutsvakiridzo? Pachange pasina mubhadharo wakanangana nekuva kwenyu mutsvakiridzo. Zvisinei, tichakupaiwo kachipo kaduku kekutenda nekuda kwenguva yenyu yamuchatipa kupindura ongororo ino. Mari yamuchashandisa pakufamba nemichovha yeruzvinji, muchaidzorerwa isingadariki madhora mashanu ekuAmerika. Muchangopedza kupindura hurukuro yeongororo, muchapihwawo twekudya nekumwira twakareruka.

Vekutaura navo kana waita mibvunzo:

Musati masaina gwaro iri, ndapota bvunzai mibvunzo pamusoro pezvamunenge musina kunzwisisa pamusoro petsvakiridzo ino. Kana muine mibvunzo pamusoro petsvakiridzo ino parizvino kana

zvepamberi, munokwanisa kutaura naMr. Clement Nhunzvi panhare dzinoti 0775814587 kana petsamba mbozha clemynhu@gmail.com. Kana muine mibvunzo pamusoro petsvakiridzo ino kana gwaro retenderano rino, inodarika yapindurwa nemuridzi wetsvakiridzo, zvinosanganisira kodzero dzanyu semunhu arimutsvakiridzo kana kukuvara uri mutsvakiridzo, kana mukaona kunge musina kubatwa zvakanaka muchida mumwe munhu wekutaura naye asiri mushandi wetsvakiridzo, ndapota fonai kumukuru we Human Research Ethics Committee (UCT): Professor M. Blockman, Health Sciences Faculty Human Research Ethics Committee, Room E52-24. Groote Schuur Hospital. Old Main Building. Observatory 7925, University of Cape Town. South Africa. Tel: +27 21 406 6338 kana kuMedical Research Council of Zimbabwe (MRCZ) pa (04) 791792 kana (04) 791193 kana pa 0772 433 166 kana 0779 439 564. Mahofisi anowanikwa paNational Institute of Health Research panosangana mugwagwa unonzi Josiah Tongogara naMazowe Avenue muHarare.

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe

Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/335249/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Mukuru wetsvakiridzo:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Musoro wetsvakiridzo	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

TENDERANO NEVAKURU/VAZIVI VEZVIRIMUTSVAKIRIDZO VACHAPINDURA MIBVUNZO

22. Ivai nechokwadi kuti manyatsoverenga zvizere, mukanzwisisa Information sheet iri, uye kuti matsananguriwa mukagutsikana zvizere.
23. Kuve kwenyu mutsvakiridzo ino isarudzo yanyu, zvichireva kuti hamumanikidzwi kuvemo kana musingade.
24. Kuramba kwenyu kuve mutsvakiridzo ino hakukutadzise kuti mupinde munezvimwe zvirongwa zvemunharaunda menyu.
25. Kana mukasarudza kuve mutsvakiridzo, makasununguka kubuda pane chero ipi nguva pasina kuripiswa kana kurasikirwa nezvamunofanira kuwana uye pasina kupa chikonzero chekubuda mutsvakiridzo.
26. Munogona kusarudza kusapindura mimwe mibvunzo yamunobvunzwa mutsvakiridzo ino. Kana pane chamusina kugadzikana kutaura nezvacho, ndapota sununguka kutaura.
27. Humbowo hwese huchatorwa huchachengetedzwa zvakavanzika.
28. Kana mukasarudza kupinda mutsvakiridzo ino, sainecha yenyu inodiwa pagwaro riripazasi.

TENDERANO

Ndaverenga (kana ndaverengerwa) zvirimugwaro retenderano. Ndinotenderana nekuve mutsvakiridzo ino uye ndanzwisisa kuti isarudzo yangu uye ndinogona kubuda pane chero ipi nguva.

Ndinobvuma kupinda muhurukuro dzeongororo ☐ Hongu ☐ Kwete

_____ Date: _____ / _____ / 2018
Zita remurume kana mukadzi abvezera *(rekupiwa, remhuri)* *Zuva* *Mwedzi* *Gore*

_____ Time : _____ AM PM
Sainecha yemurume kana mukadzi abvezera

Munhu arikupa tenderano:

Ndinobvuma kuti ndapa humbowo hwakazara pamusoro petsvakiridzo, zvichange zvichiitwa, njodzi dzakarerekera kutsvakiridzo, zvaangangowane, uye zvakavanzika zvaanenge atipa mutsvakiridzo.

_____ Date: _____ / _____ / 2018
Munhu arikupa tenederano *(rekupiwa, remhuri)* *Zuva* *Mwedzi* *Gore*

_____ : _____

Chinzvimbo chearikupa tenderano	Sainecha yearikupa tenderano

Witinesi

Kana uyo abvezera asingakwanise kusaina ega, witinesi atsanangurirwa gwaro iri anokwanisa kusaina akamumiririra

Zita raWitinesi *(rekupiwa, remhuri)*	Date:	*Zuva* /	*Mwedzi* /	2018 *Gore*

Ukama hwewitinesi neuyo arikupinda mutsvakiridzo	Nguva	AM PM

Chapter 7 Appendix E - Information and Consent Sheet -Key Informant

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912//791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Study Title	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**
Activity	In-depth interviews
Participants	Key informants
Principle Investigator:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com

You are invited to take part in a research study. Before you decide whether to participate, you need to understand why the research is being done and what it will involve. Please take the time to read or to listen as I read the following information. You may talk to others about this study if you wish. Please ask me if there is anything that is not clear, or if you would like more information. When all your questions have been answered and you feel that you understand this study, you will be asked if you wish to participate in the study, and if yes, to sign this Informed Consent form. You will be given a signed copy to keep.

Purpose of the Study and Study Requirements

What is the study? The purpose of the study is to gain a better understanding of how young adults with a dual diagnosis of a substance use disorder and HIV/AIDS go through and cope with opportunities for participation in everyday life. The study also aims to gain a better understanding of the relationship between their participation opportunities in everyday life activities and their level of being included in society and community life. We know little about the experiences of this population and we are using this study to learn more. By learning more about these experiences, we hope to help service providers like occupational therapists and other mental health practitioners to better support young adults with substance use disorders and HIV/AIDS.

Why have I been invited to take part? You have been invited to take part because your work involves working with young adults with a dual diagnosis of substance use disorder and HIV/AIDS.

What will happen if I take part? If you agree to take part in the study, you will be invited to take part in an in-depth interview in a private and confidential place most convenient to you. The interview will be recorded so that a full transcript of the conversation can be created.

How long will the study last? The interview will last about 1-2 hours.

Risks/Benefits

What are the risks of the study? There are no anticipated risks associated with your participation in this study. Questions will focus on your experience of serving or working with young adults dually afflicted with substance use disorders and HIV/AIDS. It is possible that in sharing your experience, you may experience some distress. If that happens, the interview will be stopped or paused until you are ready to continue. In addition, if you are asked something that you do not want to discuss, you can say so and we will move on.

What are the benefits of participating? Information from this study will be used to inform the development of comprehensive-occupational therapy rehabilitation programs or interventions to help address the broader health and social care needs of young adults dually afflicted with substance use disorders and HIV/AIDS and other similar groups.

Confidentiality

Will my participation in the study be kept confidential? Every effort will be made to protect your privacy and maintain the confidentiality of all the information that you provide to the extent permitted by law. This includes audio recordings of our interviews and any notes taken. When the interview is over, the information on the audio recording will be typed up so that the entire conversation is captured accurately. Your name will be removed from this transcript. Once the audio recording has been typed up accurately, it will be destroyed. The only way that you will be linked to the documents will be through an ID code that only the researchers will know. Once the study is over, this ID code will be removed permanently so that your name will no longer be linked to the transcript file. Your name will never be used in the PhD thesis or reports that come from this study. Throughout the study, the transcripts will be stored and transferred in a manner that our institutions have approved for studies like this one.

This study is being regulated by the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee, Joint Research Ethics Committee for the University of Zimbabwe, College of Health Sciences, and Parirenyatwa Group of Hospitals (JREC), Harare Central Hospital Ethics Committee and the Medical Research Council of Zimbabwe (MRCZ). All these organizations adhere to confidentiality rules in performing their responsibilities.

Voluntariness

What are my rights as a research participant/subject? You do not have to take part in this study if you do not want to. You can also stop at any time. Even if you say yes now and then you change your mind later, that will be OK. If you say no to participating in the research or stop, it will not affect anything about your relationship with the researcher, University of Zimbabwe, or University of Cape Town or the organization for which you work. If you decide to stop taking part in the research, we will stop using the information you have given us for the research, and we will remove any information that has not yet been used.

Other Information

What will I receive for participating? There will be no direct payment for participating in this study. However, should transport be required, it will be reimbursed. In addition, lunch costs incurred on the day of data collection from the part of the participant will be reimbursed to a maximum of $10.
Light refreshments will be provided during the interview.

Contacts and Questions:
Before you sign this form, please ask any questions you have about the study that are unclear to you. If you have any questions about this study now or in the future, you may contact Mr. Clement Nhunzvi on 0775814587 or clemynhu@gmail.com. If you have any questions concerning this study or consent form beyond those answered by the principal investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated

unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Chair of the Human Research Ethics Committee (UCT): Professor M. Blockman, Health Sciences Faculty Human Research Ethics Committee, Room E52-24. Groote Schuur Hospital. Old Main Building. Observatory 7925, University of Cape Town. South Africa. Tel: +27 21 406 6338 or the Medical Research Council of Zimbabwe (MRCZ) on telephone (04) 791792 or (04) 791193 and cell phone lines 0772 433 166 or 0779 439 564. The MRCZ Offices are located at the National Institute of Health Research premises at Corner Josiah Tongogara and Mazowe Avenue in Harare.

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Principle Investigator:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Title of the Research	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

KEY INFORMANT CONSENT

PARTICIPANT INFORMATION SHEET:

29. Make sure that you read the Information Sheet carefully, or that it has been explained to you to your satisfaction.
30. Your participation in this research is entirely voluntary, i.e. you do not have to participate if you do not wish to.
31. Refusal to take part will not affect your participation in any of your work or community activities.
32. If you decide to take part, you are still free to withdraw at any time without penalty services and without giving a reason for your withdrawal.
33. You may choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.
34. The information collected will be kept strictly confidential.
35. If you choose to participate in this research study, your signed consent is required below.

Statement of Consent:
I have read (or have had read to me) the contents of this consent form. I agree to take part in the study and understand that this is my choice and that I can stop at any time.

I agree to participate in the in-depth interview ☐ Yes ☐ No

I agree to the audio recording being used during the interview ☐ Yes ☐ No

_____

_____ Date: _____ / _____ / 2017
Full Name of Key Informant *(first name, last name)* *day* *month* *year*

_____ _____ AM PM
Signature of Key Informant Time

Person obtaining informed consent:
I confirm that I have personally explained the nature and extent of the planned research, study procedures, potential risks and benefits, and confidentiality of personal information.

Name of person obtaining consent *(first name, last name)*	Signature of person obtaining consent
Position of person obtaining consent	Date: _____ / _____ / 2017 *day* *month* *year*

Chapter 8 Appendix F – Information and Consent Sheet -Key Informant. Shona

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Musoro wetsvakiridzo	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**
Chiitiko	Hurukuro dzakadzama
Vari mutsvakiridzo	Vakuru navazivi vezvirimutsvakiridzo
Mukuru wetsvakiridzo	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com

Munokokwa kuva mutsvakiridzo ino. Musati matenderana nekupinda mutsvakiridzo, munofanira kunzwisisa sei tsvakiridzo iyi irikuitwa uye kuti zvinyi zvichaitwa pamuri. Tinokumbira muvane nguva yekuverenga kana kutetekera muchiverengerwa zviri pamusoro petsvakiridzo zvinotevera. Kana muchida, munogona kukurukura nevamwe pamusoro pezvetsvakiridzo ino. Bvunzai zvenyu kana paine pamusiri kunzwisisa, uye kana muchida kunzwa zvimwe zvakadzika pamusoro petsvakiridzo. Kana mibvunzo yenyu yose yapindurikauye makunzwa kuti manyatsonzwisisa nezve tsvakiridzo, muchabvunzwazve muchikumbirwa kana muchida kupinda muneino tsvakiridzo. Kana mhinduro yenyu iri hongu, munokumbirwa kusaina bepa rebvumo iro muchazopiwawo renyu rakadaro rekuti muchengete.

Chinangwa chetsvakiridzo uye zvinotarisirwa kwamuri

Tsvakiridzo ndeyei/yakanangei? Chinangwa cheino tsvakiridzo ndechekuti tiwane kunzwisisa kwakadzika uye kuri nani pamusoro peraramo yevechidiki vari pakati pemakore gumi nepfemba kusvika makumi matatu anemashanu, varikurarama nezvirwere zvekushandisa zvinodhaka pamwe neche HIV/AIDS. Tsvakiridzo ino irikuda kunzwisisa zvinosanganikwa nazvo nevechidiki ava mukurarama kwakamanikidzika uye zvavanoitawo kuyedza kuzvisunungura pakurarama kwezuva nezuva. Ino tsvakiridzo irikuyedzazve kuwana kunzwisisa kuri nani pakati peiyo raramo yakamanikidzika nepanozvikwa nevechidiki ava pakupiwa chikamu muupenyu munzvimo dzavagere. Parizvino zvationoziva zvishomasa pamusoro penyaya dzakaita seiri mutsvakiridzo ino, saka tichashandisa uno mukana kudziidza zvakawanda. Mukudziidza zvakawanda panezvinosanganikwa nazvo, tinotarisira kubatsira vanorapa vanonzi ma occupational therapists nevamwe vanoshanda navo muboka rekurapwa kwechirwere chepfungwa kuti vanatso bastsira zvakanaka vanokanganiswa nekushandisa zvinodhaka uye chirwere che HIV ne AIDS.

Sei ndakumbirwa kupinda mutsvakiridzo? Makumbirwa kupinda mutsvakiridzo nekuda kwekuti mashando enyu anosanganisira kushanda nevechidiki vari kurarama nezvirwere zvekushandisa zvinodhaka uye cheHIV/AIDS.

Chii chinoitika kana ndikapinda mutsvakiridzo? Kana mukatenderana nekuva mutsvakiridzo ino, muchakokwa kutora chikamu muhurukuro dzakadzika munzvimbo isina kufumuka yamunoona ichikuitirai zvakanaka. Hurukuro iyi ichatapwa netepirekodha kuitira kuti tizonatso kwanisa kuinyora yose zvakanaka.

Tsvakiridzo ichatora nguva yakadii? Hurukuro imwe neimwe ichatora nguva ingangoita awa rimwe kusvika maawa maviri.

Njodzi/Zvaungangowane

Ndedzipi njodzi dzakarerekera kutsvakiridzo ino?
Hazvitarisirwe kuti kuva kwenyu mutsvakiridzo ino kungakodzera njodzi. Mibvunzo ichanangana nezvamakasangana nzvo mukushanda nevakuru vechidiki vanematambudziko ezvinodhaka uye chirwere che HIV/AIDS. Zvinogona kudaro kuti pahurukuro idzi munogona kutaura zvinokusuwisai. Kana zvakadaro zvaitika, hurukuro ichamiswa kuzvika magadzikana zvekukwanisa kuenderera mberi. Pamusoro pazvo, mukabvunzwa zvamusingafare nekupindura, munataura tinobva tapfuurira mberi pane zvimwe.

Ndezvipi zvaungawane patsvakiridzo ino? Zvichawanikwa kubva mutsvakiridzo ino zvichashandiswa kuumba nekurairidza kurapwa kwakazara kuchibva kuboka re occupational therapy. Kubatsira uku kwakanangana nezvingadiwa pautano nemagariro evakuru vechidiki vane dambudziko rezvirwere zvekushandisa zvinodhaka uye utachiona hweHIV pmwe nemukondombera, nevamwewo vanematambudziko akadaro.

Zvakavanzika
Kupinda kwangu muchirongwa kuchachengetedzwa zvakavanzika here?? Mukuedza kwose, tichachengetedzazvakavanzika zvenyu nezvamuchatipa pahurukuro dzatichaita, zvichiteedzera mitemo yenyika**.** Izvi zvinosanganisira hurukuro dzatichataita dzichatapwa patepi nezvatinenge tichinyora. Kana hurukuro yapera, tichanyora pasi humbowo hwunenge hwatapwa patepi. Tichabvisa zita rako nezvakanangana nemhuri yako pagwaro iri. Kana taona kuti zvanyorwa pasi zvinoenderana nezvepatepi, tichaparadza matepi aya. Chinhu chega chichange chakanangana newe pahumbowo uhwu inhamba yakavanzika ichange ichizivikanwa nevashandi vetsvakiridzo chete. Kana tsvakiridzo yapera, nhamba iyi ichabiswa zvachose. Hatizoshandise kana nguva ipi zita rako kana zvinechekuita newe mumagwaro achabuda mutsvakiridzo ino. Panguva yese yatinenge tichiita tsvakiridzo, tichachengetedza nekutransfeya humbowo zvinoenderana nezvinotarisirwa neboka retsvakiridzo dzakadai seino.

Tsvakiridzo ino irikuongororwa neve University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee, Joint Research Ethics Committee ye University of Zimbabwe, College of Health Sciences, pamwe neParirenyatwa Group of Hospitals (JREC), Harare Central Hospital Ethics Committee uye neve Medical Research Council of Zimbabwe (MRCZ). Masangano ose aya anotevedza mitemo inoona nezvekuchengetedzwa kwezvakavanzika mukuita mabasa avo.

Kushanda pasina kubhadharwa kana kumanikidzwa

Ndedzipi kodzero dzangu semunhu arikupinda mutsvakiridzo? Hamumanikidzwe kupinda mutsvakiridzo kana musingade. Munokwanisa kubuda pane chero ipi nguva. Chero mukabvuma kupinda panguva ino, mozochinja pfungwa pamberi munogona kubuda. Mukati hamudi nezvetsvakiridzo ino, hazvizokanganise ukama hwenyu nemukuru wetsvakiridzo, University of Zimbabwe kana University of Cape Town uye masangano amunoshandira. Kana mukasarudza kusave mutsvakiridzo ino, tichamira kushandisa humbowo hwamunenge matipa mutsvakiridzo, uye tinobva tabisa humbowo hwese hwatinenge tisati tashandisa kunyora gwaro.

Rumwe Ruzivo

Ndezvipi zvandinowana pakuve mutsvakiridzo? Pachange pasina mubhadharo wakanangana nekuva mkwenyu mutsvakiridzo. Zvisinei, mari yamuchashandisa pakufamba nemichovha yeruzvinji, muchaidzorerwa. Tinofarawo kukuudzai kuti mari yekudya kwamasikati kwezuva rehurukuro, muchairipirwa, zvichibatanidzwa kuita mari isingadariki gumi ramadhora ekuAmerika. Panguva yehurukuro, muchapihwawo twekudya nekumwira twakareruka.

Vekutaura navo kana waita mibvunzo:
Musati masaina gwaro iri, ndapota bvunzai mibvunzo pamusoro pezvamunenge musina kunzwisisa pamusoro petsvakiridzo ino. Kana muine mibvunzo pamusoro petsvakiridzo ino parizvino kana zvepamberi, munokwanisa kutaura Mr. Clement Nhunzvi panhare dzinoti 0775814587 kana petsamba mbozha clemynhu@gmail.com. Kana muine mibvunzo pamusoro petsvakiridzo ino kana gwaro retenderano rino, inodarika yapindurwa nemuridzi wetsvakiridzo, zvinosanganisira kodzero dzanyu semunhu arimutsvakiridzo kana kukuvara uri mutsvakiridzo, kana mukaona kunge musina kubatwa zvakanaka muchida mumwe munhu wekutaura naye asiri mushandi wetsvakiridzo, ndapota fonai kumukuru we Human Research Ethics Committee (UCT): Professor M. Blockman, Health Sciences Faculty Human Research Ethics Committee, Room E52-24. Groote Schuur Hospital. Old Main Building. Observatory 7925, University of Cape Town. South Africa. Tel: +27 21 406 6338 kana kuMedical Research Council of Zimbabwe (MRCZ) pa (04) 791792 kana (04) 791193 kana pa 0772 433 166 kana 0779 439 564. Mahofisi anowanikwa paNational Institute of Health Research panosangana mugwagwa unonzi Josiah Tongogara naMazowe Avenue muHarare.

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Mukuru wetsvakiridzo:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Musoro wetsvakiridzo	**A CASE STUDY EXPLORING OCCUPATIONAL INJUSTICE AMONG YOUNG ADULTS WITH A DUAL DIAGNOSIS OF A SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

TENDERANO NEVAKURU/VAZIVI VEZVIRIMUTSVAKIRIDZO VACHAPINDURA MIBVUNZO

36. Ivai nechokwadi kuti manyatsoverenga zvizere, mukanzwisisa Information sheet iri, uye kuti matsananguriwa mukagutsikana zvizere.
37. Kuve kwenyu mutsvakiridzo ino isarudzo yanyu, zvichireva kuti hamumanikidzwi kuvemo kana musingade.
38. Kuramba kwenyu kuve mutsvakiridzo ino hakukutadzise kuti mupinde munezvimwe zvirongwa zvemunharaunda menyu.
39. Kana mukasarudza kuve mutsvakiridzo, makasununguka kubuda pane chero ipi nguva pasina kuripiswa kana kurasikirwa nezvamunofanira kuwana uye pasina kupa chikonzero chekubuda mutsvakiridzo.
40. Munogona kusarudza kusapindura mimwe mibvunzo yamunobvunzwa mutsvakiridzo ino. Kana pane chamusina kugadzikana kutaura nezvacho, ndapota sunungukai kutaura.
41. Humbowo hwese huchatorwa huchachengetedzwa zvakavanzika.
42. Kana mukasarudza kupinda mutsvakiridzo ino, sainecha yenyu inodiwa pagwaro riripazasi.

TENDERANO

Ndaverenga (kana ndaverengerwa) zvirimugwaro retenderano. Ndinotenderana nekuve mutsvakiridzo ino uye ndanzwisisa kuti isarudzo yangu uye ndinogona kubuda pane chero ipi nguva.

Ndinobvuma kupinda muhurukuro ☐ Hongu ☐ Kwete

Ndinopa tenderano yekutapwa patepi panguva yehurukuro ☐ Hongu ☐ Kwete

_____ Date: _____ / _____ / 2017
Zita remukuru/muzivi vezvirimutsvakiridzo *(rekupiwa, remhuri)* *Zuva* *Mwedzi* *Gore*

_____ _____ AM
Sainecha yemukuru/muzivi vezvirimutsvakiridzo Time PM

Munhu arikupa tenderano:

Ndinobvuma kuti ndapa humbowo hwakazara pamusoro petsvakiridzo, zvichange zvichiitwa, njodzi dzakarerekera kutsvakiridzo, zvaangangowane, uye zvakavanzika zvaanenge atipa mutsvakiridzo.

Munhu arikupa tenederano *(rekupiwa, remhuri))*	Sainecha yearikupa tenderano
	/ / 2017
Chinzvimbo chearikupa tenderano	Date: *Zuva* *Mwedzi* *Gore*

Chapter 9 Appendix G - Interview Questions Guide - DAYA. English

Study title: A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE

Date: **Time of interview:**

Place: **Participant ID/Pseudonym:**

Main question: Tell me your story of living in everyday life as someone with a substance use disorder and who is living with HIV?

Guide questions *(not in order of questioning, but as possible prompts)*

1. What was happening just before you started using substances or you learnt of your HIV status?
2. Tell me about your life as someone with a SUD cooccurring with HIV/AIDS? Can you share any examples of life experiences?
3. How do you respond to the challenges, where you are denied access to meaningful and of value everyday doings of your society? Can you share any examples where you had to respond?
4. Tell me about the resources and opportunities in your life pertaining your health and social care needs? Are there any specific examples of these earmarked for young adults like you?
5. What can you say about your experience of social inclusion? Can you tell me of an example where you felt included or excluded?
6. How has your community at large contributed to your experiences of everyday living in light with your diagnosis which you have just shared with me?
7. Is there anything else you would like to share with me?

Conclusion: Can you tell me how you felt telling me about your life story?

Thank you.

Chapter 10 Appendix H - Interview Questions Guide - DAYA. Shona

Musoro wetsvakiridzo: A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE

Musi: **Nguva yehurukuro:**

Nzvimbo: **Zita rekuzvipa:**

Chitangiso: Ndiudzewo nezvechinhu chakakunakidza chakaitika nguva pfupi yadarika?

Nhanga nyaya: Ndiudzeiwo nezvenyaya yeupenyu hwenyu hwamazuvaose. Ndinochanyoda kunzwa maererano nekurarama kwenyu semunhu ane nechirwere chekushandisa zvinodhaka pamwe neutachiona hwe HIV?

Mibvunzo yekutungamirira hurukuro *(kwete semabvunzirwo aachaitwa*

1. Ndiudzeiwo muchidimbu kuti ndimi ani?
2. Chinyi chaimboitika muupenyu hwenyu musati matanga kushandisa zvinodhaka kana kuti musati maziva kuti mave neutachiona hwe HIV?
3. Panenguva yamungati yakashandiswa urwere hwenyu pamabatirwo amakaitwa navanhu here? Mungandiudze zvizere here nekuti chii chakaitika?
4. Mungati panenguva yamakamboshaiswa mukana wekuita mabasa amazuva ose zvichibva pakuti munoshandisa zvinodhaka kana kuti mune HIV? Mungandipa muennzaniso kana zviripo?
5. Ndiudzeiwo muchiisa nemienzaniso, zveupenyu hwenyu semunhu ane urwere hwezvinodhaka uye utachiona hwe HIV?
6. Munoita sei kana muchisangana nematambudziko ekutadza kana kutadziswa kuita kana kuwana mukana yekuita zvinokosha mamugere? Mungadipowo mienzaniso yepazvakamboitika?
7. Ko zvinyi zvirimowo mamugere kana mikana yekuva kana kuita zvinechekuita neutato kana zvinodiwa pamagariro? Mungaitawo mienzaniso yezvakadaro uye zvakanangana nevabvezera semi?
8. Mungati vanhu vakawanda zvakadii munharaunda yenyu vanoziva nezveurwere henyu? Vanhu ava vakaziva sei kana kuziviswa nani?

9. Munoti kudii neraramo yenyu maringe nekuwana kana kuita zvakaenzana navamwe munharaunda yamugere? Mungapewo miendzaniso panyaya iyi, zvichibva panezvamakasangana nazvo pakusarira kunze kana kuve pana vamwe?
10. Koiyo nharamunda kana vamakagarisana navo vane chikamu chipi kana kuti chakadii pararamo yenyu yamazuva ose, semunhu arikurarama nechirwere chezvinodhaka pamwe neutachiona hwe HIV?
11. Ko pane zvimwe here zvamungada kundiudza pamusoro penyaya yatange tichikurukura nezvayo?

Mhendero: Mungandiudzawo here kuti manzwa sei kana kuti murikunzwa sei muchindiudza nezvenyaya iyi yeupenyu hwenyu?

Tinotenda

Chapter 11 Appendix I – Social inclusion Survey Questionnaire

Master Questionnaire

Master Questionnaire

Interview date

yyyy-mm-dd

Clinician ID

Clinic Name

- Harare OI
- Pari OI
- Pari OT
- Harare OT

Participant Identity(PID) Number: Please note site name and client number (01000)

Please confirm PID number on the following radio button
If the Participant ID "" is not listed below, please verify against PID list.

Participant Identity(PID) Number: Please note site name and client number (02000)

Please confirm PID number on the following radio button
If the Participant ID "" is not listed below, please verify against PID list.

Participant Identity(PID) Number: Please note site name and client number (03000)

Please confirm PID number on the following radio button
If the Participant ID "" is not listed below, please verify against PID list.

Participant Identity(PID) Number: Please note site name and client number (04000)

Please confirm PID number on the following radio button
If the Participant ID "" is not listed below, please verify against PID list.

Chapter 12 Appendix K - Interview Questions Guide Key Informants

Study title: A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE

Date: **Time of interview:** **Participant ID/Pseudonym:**

Place:

Warm-up: Can you share with me one interesting thing that happened to you of late?

Main question: Tell me about your experiences and views as someone working with young adults dually afflicted with SUD and HIV/AIDS?

Guide questions *(not in order of questioning)*

1. Tell me about your job?
2. What do you make of the everyday life of young adults with SUD and HIV/AIDS in Zimbabwe?
3. Tell me about the challenges in meeting their broad health and social care needs in context?
4. Can you give me examples of cases you have worked with? What was outstanding about these cases?
5. Tell me about the support systems or services in place for this group?
6. Do you know of any legislative frameworks that are in place for this group? - what are your thoughts and or experiences regarding these?
7. What can you say about how they respond to the restricted participation, limited citizenship and social exclusion in Zimbabwe?
8. What can you say about their history and current state of social inclusion? - do you think things have changed for this population? If so, in what ways?
9. What can you say about the way forward in addressing the restricted participation, limited citizenship, and social exclusion of these dually afflicted young adults in Zimbabwe?
10. If you could change three things in Zimbabwe to help this group, what would that be?
11. Any other information you would like to share with me regarding the everyday lives of these dually afflicted young adults?

Conclusion: Can you tell me how you felt sharing this information with me?

Thank you.

Chapter 13 Appendix L - Interview Questions Guide Key Informants. Shona

Musoro wetsvakiridzo: **A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

Musi: **Nguva yehurukuro:**

Nzvimbo: **Zita rekuzvipa/Nhamba yearimutsvakiridzo:**

Chitangiso: Ndiudzewo nezvechinhu chimwe chakakunakidzai chakaitika munguva pfupi yadarika?

Nhanga nyaya: Mungandiudzewo nezve zvamakasangana nazvo, zvamunoziva, kana maonero enyu pakushanda kwenyu nevabvezera varikurarama neurwerwe hwezvinodhaka pamwe neutachiona hwe HIV?

Mibvunzo yekutungamirira hurukuro *(kwete semabvunzirwo aachaitwa*

1. Ndiudzeiwo nezvebasa renyu?
2. Mungatiwo kudii nezveupenyu hwamazuva ose kune avo vabvezera varikurarama neurwerwe hwezvinodhaka pamwe neutachiona hwe HIV muZimbabwe?
3. Mungandiudzewo nezvematambudziko anosanganikwa nawo pakuda kusazikisa zvinodikwa panezveutano kana magariro evabvezera ava munyika ino?
4. Mungandiudzewo here nezvevamwe vaneurwere hwakadai vamakambooshanda nawo? Chii chamunonyanyo rangarira nezvawo?
5. Ndiudzeiwo nezve nzira dzekubatsira kana maservices akaiswa panzvimbo kubatsira vabvezera ava?
6. Mungazivewo here nezve mitemo kana magwaro akaiswa panzvimbo kuitira boka irori? Ndedzipi pfungwa dzenyu kana maexperience enyu maringe nemitemo kanamagwaro aya?
7. Mungati kudiniwo nezvavanoita ivo vabvezera ava, kana vachisangana namatambudziko mukurarama kwavo muZimbabwe?
8. Mungati kudiniwo nemamiriro avo pakupinda munezveraramo yamazuva ose munharaunda dzavagere, tichitarisa kubva kare naparizvino? – Mungati pane zvashanduka here, uye kana zviripo zvasanduka sei?
9. Ko zvingafambiswawo sei kugadzirisa nhuna namatambudziko anosangana nevabvezera vane urwerwe hwezvinodhaka pamwe neutachiona hwe HIV muZimbabwe?

10. Kuri kunzi mungachinja zvinhu zvitatu muZimbabwe kuitira kubatsira boka iri, chingava chii?
11. Mungaitawo zvimwe here zvamungada kundiudza maringe neraramo yamazuva ose yevabvezera ava vane urwerwe hwezvinidhaka pamwe neutachiona hwe HIV?

Mhendero: Mungandiudzawo here kuti manzwa sei kana kuti murikunzwa sei muchindiudza nezvenyaya iyi

Tinotenda.

Chapter 14 Appendix M – Study Advert - English

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/335249/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Principle Investigator:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Title of the Research	**A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

Are you a young adult (19-35yrs) living with a substance use disorder and you are also HIV positive, and has lived with these two conditions for at least one year? An occupational therapist and lecturer at the University of Zimbabwe who is doing his PhD studies in the Health Sciences Faculty of the University of Cape Town is interested in interviewing anyone like that. If you are such a person, I believe you can provide me and the occupational therapy-mental health field with valuable information that could help improve existing treatments for solving problems around the broader health and social care needs of these young adults and similar groups. Total confidentiality is guaranteed.

If you are such a person and interested in participating, you can leave your contact details with the principal researcher (Mr Clement Nhunzvi), office number 40, Department of Rehabilitation, College of Health Sciences, University of Zimbabwe. Alternatively, you can contact me on 0775 814 587.

Thank you.

Chapter 15 Appendix N – Study Advert _ Shona

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-797800/724912/335249/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Mukuru wetsvakiridzo:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Musoro wetsvakiridzo	**A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

Muri munwe wevabvezera here, uye mune makore ari pakati peguni nepfumbamwe kusvika pamakore makumi matatu nemashanu, uyezvi muchirarama neutachiona kweHIV pamwe nechirwere chekushandisa zvinodhaka kwe gore kana kudarika here? Murapi uye mudzidzisi wezve occupational therapy ari paUniversity of Zimbabwe uye achiita zvidzidzo zvake zvePhD ne University of Cape Town, anodawo kuzokurukura nemi kana vamwe vakaita sekudaro. Ndinokutenda kwekuti munogona kupa humbowo maringe neraramo yenyu zvinobatsiridza pakurapwa nepakuzadzikiswa kwezve utano pamwe nekugara kwakanaka kwevabvezera vakadai. Zvakawanzika zvose zvichachengetedzwa nenzira kwadzo musingazofumurwa.

Kana muri munwe wevakadaro, uye muchida kupinda mutsvakiridzo ino, munogona kusiya manyoresa nzira dzekukuwanai nadzo kumukuru wetsvakiridzo (Mr Clement Nhunzvi), muhofisi 40, Department of Rehabilitation, College of Health Sciences, University of Zimbabwe. Munogona kundibatawo panhare dzinoti: 0775 814 587.

Ndatenda.

Chapter 16 Appendix O - International HIV Dementia Scale (IHDS)

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/335249/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Principal Investigator:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Study Title:	**A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

International HIV Dementia Scale (IHDS)

Memory-Registration – Give four words to recall (dog, hat, bean, red) – 1 second to say each. Then ask the patient all four words after you have said them. Repeat the words if the patient does not recall them all immediately. Tell the patient you will ask for recall of the words again a bit later.

1. Motor Speed: Have the patient tap the first two fingers of the non-dominant hand as widely and as quickly as possible.

4 = 15 in 5 seconds 3 = 11-14 in 5 seconds 2 = 7-10 in 5 seconds 1 = 3-6 in 5 seconds 0 = 0-2 in 5 seconds

_____

2. *Psychomotor Speed*: Have the patient perform the following movements with the non-dominant hand as quickly as possible: 1) Clench hand in fist on flat surface. 2) Put hand flat on surface with palm down. 3) Put perpendicular to flat surface on the side of the 5th digit. Demonstrate and have the patient perform twice for practice.

4 = 4 sequences in 10 seconds 3 = 3 sequences in 10 seconds 2 = 2 sequences in 10 seconds 1 = 1 sequence in 10 seconds 0 = unable to perform

_____

3. *Memory-Recall:* Ask the patient to recall the four words. For words not recalled, prompt with a semantic clue as follows: animal (dog); piece of clothing (hat); vegetable (bean); color

(red).

Give 1 point for each word spontaneously recalled Give 0.5 point for each correct answer after prompting Maximum – 4 points

_____

Total International HIV Dementia Scale Score: This is the sum of the scores on items 1–3. The maximum possible score is 12. A patient with a score of ≤10 should be evaluated further for possible dementia.

_____

Reprinted from Sacktor NC, Wong M, Nakasujja N, et al. The International HIV Dementia Scale: A new rapid screening test for HIV dementia. *AIDS* 2005;19:1367-1374 with permission from Wolters Kluwer Health.

New York State Department of Health AIDS Institute: www.hivguidelines.org

Chapter 17 Appendix P - International HIV Dementia Scale (IHDS) - Shona

DEPARTMENT OF REHABILITATION

HARARE, Zimbabwe
Telephone:263-4-791631 Ext 2175/6
Fax:263-4-**797800**/724912/335249/791995
Telex: 26580 UNIVZ ZW
Telegrams: UNIVERSITY
E-mail: rehab@medsch.uz.ac.zw

COLLEGE OF HEALTH SCIENCES **UNIVERSITY OF ZIMBABWE**

Mukuru wetsvakiridzo:	Mr. Clement Nhunzvi, Dept of Rehabilitation, College of Health Sciences, University of Zimbabwe, +263 (0) 775814587, clemynhu@gmail.com
Musoro wetsvakiridzo	**A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

International HIV Dementia Scale (IHDS)

Kurangarira – Taurwa mazwi mana ekuti murwere ari mutsvakiridzo iyi azorangarira (imbwa, ngowani, bhinzi, ruvara rutsvuku). Kumbira murwere uyu kuti adzokorore mazwi aya mushure mekunge maataura. Kana asina kunge amabata pekutanga, dzokororai mazwi aya zvakare. Tsanangurai kuti muchange muchida kuti azorangarira mazwi aya mushure mekanguva.

1. *Motor Speed*: munhu ngaarovanise zvigunwe zvake zvekutanga zveruoko rwaasingashandise zvakanyanya nekukasika.

4 = 15 mumas*econds* mashanu 3 = 11-14 mumas*econds* mashanu

2 = 7-10 mumas*econds* mashanu 1 = 3-6 mumas*econds* mashanu

0 = 0-2 mumas*econds* mashanu

---

2. *Psychomotor Speed*: Itai kuti murwere aita zvinotevera neruoko rwake rwaasingashandise achikurumidz: 1) Pfumba chibhakera woisa patafura *(flat surface*). 2) Isa ruoko rwako patafura iyi chanza chakatarisa pasi. 3) Isa ruoko rwako rwakamira patafura iyi, chigunwe chekupedzisira chakarara patafura, chigunwe chihombe *(thumb*) chiri mudenga.

Muratidzei kuti zvinoitwa sei iye obva aitawo kaviri kuti muone uti anzwisisa.

4 = 4 sequences mumas*econds* gumi

3 = 3 sequences mumas*econds* gumi

2 = 2 sequences mumas*econds* gumi

1 = 1 sequence sequence mumas*econds* gumi

0 = atadza kuita

_____

3. *Kurangarira:* Kumbirai murwere kuti adzokorore mazwi mana amambotaura kwekutanga. Kana vari kunetsekana nekurangarira, vapei mazwi anoenderana nemazwi iwayo ekuvabtsira kurangarira sokuti mhuka (imbwa); chinhu chekupfeka (ngowani); chekudya (bhinzi); ruvara (chitsvuku).

Mupei chibodzwa chimwe chete kana aching arangarira ega, 0.5 kana aching arangarira achiwana rubatsiro. Munhu anogona kuwana zvibodzwa zvinosvika zvina (4). _____

Total International HIV Dementia Scale Score: sanganisai zvibodzwa zvese zvaawana. Munhu anogona kuwana zvibodzwa zvinosvika gumi nemaviri (12). Munhu anowana zvibodzwa zvishoma pana gumi (10) anofana kuongororwa pfungwa (dementia.)

_____

Reprinted from Sacktor NC, Wong M, Nakasujja N, et al. The International HIV Dementia Scale: A new rapid screening test for HIV dementia. *AIDS* 2005;19:1367-1374 with permission from Wolters Kluwer Health.

New York State Department of Health AIDS Institute: www.hivguidelines.org

Chapter 18 Appendix Q – UCT HREC Ethics Approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7935
Telephone (021) 406 6492
Email: [illegible]
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

03 July 2017

HREC REF: 340/2017

A/Prof R Galvaan
Division of Occupational Therapy
Health & Rehab Sciences
OMB

Dear A/Prof Galvaan

PROJECT TITLE: A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE (PhD candidate Clement Nhunzvi)

Thank you for your response letter dated 23 June 2017, addressing the issues raised by the Human Research Ethics Committee (HREC).

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)

We acknowledge that the student, C Nhunzvi will also be involved in this study.

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.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 340/2017

Chapter 19 Appendix R – Harare Central Hospital Ethics Approval

Telephone: 621100-19
Fax: 621157

ZIMBABWE

Reference: HCHEC 300517/37

HARARE CENTRAL HOSPITAL
P. O. Box ST 14
SOUTHERTON
Harare

05 June 2017

Mr. Clement Nhunzvi
University of Zimbabwe
College of Health Sciences
Department of Rehabilitation
Harare

Dear Mr. Nhunzvi,

REF: A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE

I am glad to advise you that your application to conduct a study Entitled: **A Case Study Exploring an Occupational Perspective of Social inclusion Among Young Adults Dually Afflicted with Substance Use Disorder and HIV/AIDS in Zimbabwe (Ref: HCHEC 300517/37)**, has been approved by the Harare Hospital Ethics Committee.

This approval is premised on the submitted protocol. Should you decide to vary your protocol in any material way please submit these for further approval.

You are advised to avail the results of your study whether positive or negative to the hospital through the committee for our information.

Yours sincerely,

HARARE CENTRAL HOSPITAL
DEPARTMENT OF MEDICINE
05 JUN 2017
P. O. BOX ST14, SOUTHERTON
HARARE, ZIMBABWE

DR. C. Pasi
Chairman Harare Central Hospital Ethics Committee

Chapter 20 Appendix S – JREC Ethics Approval

Joint Research Ethics Committee
For The University of Zimbabwe,
College of Health Sciences and
Parirenyatwa Group of Hospitals

Parirenyatwa
Group of Hospitals

University of Zimbabwe
College of Health Sciences

JREC Office No. 4, 5th Floor College of Health Sciences Building
Telephone: +263 4 708140/ 791631 Exts 2241/2242
Email:jrec.office@gmail.com/jrec@medsch.uz.ac.zw, website:www.jrec.uz.ac.zw

APPROVAL LETTER

JREC Ref: 160/16

Date: 13th June 2017

Names of Researcher: Mr. Clement Nhunzvi
Address: **Department of Rehabilitation**

RE: **A CASE STUDY EXPLORING AN OCCUPATIONAL PERSPECTIVE OF SOCIAL INCLUSION AMONG YOUNG ADULTS DUALLY AFFLICTED WITH SUBSTANCE USE DISORDER AND HIV/AIDS IN ZIMBABWE**

Thank you for your application for ethical review of the above mentioned research to the Joint Research Ethics Committee. Please be advised that the Joint Research Ethics Committee has reviewed and approved your application to conduct the above named study. You are still required to obtain MRCZ and RCZ approval before you commence the study if required by the nature of your study.

- **APPROVAL NUMBER:** JREC/160/17
- **APPROVAL DATE:** 13th June 2017
- **EXPIRY DATE:** 12th June 2018

This approval is based on the review and approval of the following documents that were submitted to the Joint Ethics Committee:

a) Completed Application Form
b) Full Study Protocol
c) Informed Consent in English and/or appropriate local language
d) Data Collection Tool version

After this date the study may only continue upon renewal. For purposes of renewal please submit a completed renewal form (obtainable from the JREC office) and the following documents before the expiry date:

OHRP IRB Number: IORG 00008914
PARIRENYATWA GROUP OF HOSPITALS FWA: 00019350

Chapter 21 Appendix T – MRCZ Ethics Approval

Telephone: 791792/791193
Telefax: (263) - 4 – 790715
E-mail: mrcz@mrcz.org.zw
Website: http://www.mrcz.org.zw

Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

REF: MRCZ/A/2214

APPROVAL

8 September, 2017

Clement Nhunzvi
UZ-CHS
Rehabilitation Department
P.O Box A 178
Avondale
Harare

RE:- A Case Study Exploring An Occupational Perspective Of Social Inclusion Among Young Adults Dually Afflicted With Substance Use Disorder And HIV/AIDS In Zimbabwe

Thank you for the application for review of Research Activity that you submitted to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study.

This approval is based on the review and approval of the following documents that were submitted to MRCZ for review:-

1. Study Protocol dated18 September, 2017
2. Study summary
3. Informed Consent Form for Young Adults Narrative Interviews version 1.1 dated 18 September, 2017 (English, and Shona)
4. Informed Consent Form for Key Informant Interviews, version 3.1 dated 18 September, 2017 (English)
5. Informed Consent Form for Key Informant Interviews, version 1.1 dated 18 September, 2017 (Shona)
6. Informed Consent Form for Young Adults SCOPE Survey version 1.1 dated 18 September, 2017 (English, and Shona)
7. Interview Questions Guide Key Informants version 1.0 dated 18 September, 2017 (English and Shona)
8. Interview Questions Guide Key Young adults, version 1.0 dated 18 September, 2017 (English and Shona)
9. Study Advert version 1.0 dated 18 September 2017 (English and Shona)
10. HIV Dementia Scales

- **APPROVAL NUMBER** : **MRCZ/A/2214**

This number should be used on all correspondence, consent forms and documents as appropriate.

- **TYPE OF MEETING** : **Normal review**
- **EFFECTIVE APPROVAL DATE** : **08 September, 2017**
- **EXPIRATION DATE:-** : **07 September , 2018**

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted three months before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices or website.
- **MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices or website.
- **QUESTIONS**: Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw

Other

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

Bwtare

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

MEDICAL RESEARCH COUNCIL OF ZIMBABWE
2017 -09- 08
APPROVED
P.O. BOX CY 573 CAUSEWAY, HARARE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

Chapter 22 Appendix U1 – Social Inclusion SOP MHOT

SOP FOR THE SOCIAL INCLUSION SURVEY

COLLECTING DATA ON SOCIAL INCLUSION ISSUES FROM YOUNG ADULTS (18-35) DUALLY AFFLICTED WITH SUD AND HIV

Background

Mental illness and HIV are prevalent and interwoven contributing to health and social problems particularly in Sub-Saharan Africa, including Zimbabwe. Substance use disorders (SUD) are on the rise among young adults in Zimbabwe, a case which is more complex among those living with HIV. SUD and HIV are both associated with poor coping skills and complicated by lack of sound rehabilitation services in Zimbabwe.

Despite recent gains made in the management of HIV and substance use disorders in Zimbabwe, there remain gaps regarding the unmet broader health and social care needs of young adults who are dually afflicted with substance use disorders and HIV. This vulnerable group is highly likely to experience social exclusion. Moreover, little attention has been given to the non-biomedical outcomes of substance use disorders and HIV resulting in an incomplete service which does not always translate into opportunities for dually affected young adults to live fully productive, inclusive, and satisfying lives. By understanding and responding to their broader health and social care needs, otherwise known as 'social inclusion issues', occupational therapy rehabilitation is better positioned to move their human rights agenda forward within this field. Their participation in a range of freely chosen, healthy and meaningful occupations will promote health, well-being, and social inclusion. However, in order to assist them in this, we need to better understand their experiences and the barriers they face. This study comprises three aspects: i) narrative interviews with dually afflicted young adults and in-depth interviews with key informants; ii) document analysis; and, iii) a cross sectional survey of social inclusion issues among dually afflicted young adults accessing mental health services and or ART at the two referral institutions in Zimbabwe.

With respect to the survey (iii), we are aiming to recruit a minimum of 100 dually afflicted young adults, aged 18-35 years. We aim to recruit them from two state referral centres for opportunistic infections (OI clinics) and their corresponding mental health units in Harare, Zimbabwe:

i) Parirenyatwa OI Clinic
ii) Parirenyatwa Psychiatry Unit
iii) Harare Central OI Clinic
iv) Harare Psychiatry Unit.

By recruiting from both OI clinics and from mental health centres we are able to obtain perspectives from both those whose primary reason for seeking health services is either substance use disorders or whose primary reason for seeking health services is that they live with HIV.

This protocol focuses on the recruitment and survey administration from the two mental health/psychiatry units.

Key personnel:

Clement Nhunzvi	Principle Investigator	0775814587
Simba Chigwedere	Survey Team Leader	0773711231
Pascal Ndowa	Senior surveyor	0774086648
Davison Samanyada	Surveyor	0777331655
Clarity Chiadzwa	Surveyor	0718594668

Survey administration- an overview

Depending on the turnover of potential participants at the unit, the survey team will be at each unit every Friday of the week over a period of one month. Participants will be recruited by means of a convenient consecutive sampling, targeting a minimum of twenty participants per unit. (This is because we hope to recruit 70 participants from the two OI clinics listed above)

Introduction of the Survey Team

In the months prior to the survey, we have been working with the occupational therapists from the two respective mental health units. It was anticipated that it would take a few months to recruit the 100 participants for the survey. As such, we decided to begin the process of identifying potential participants ahead of the survey which was scheduled to begin in September. This planning allowed us to create a detailed database of potential participants for the cross-sectional survey. Information was extracted from the patient notes using a form entitled *"Survey Sample Recruitment Form."* This protocol describes the specific process of recruitment from the existing database of young adults with a comorbid diagnosis of substance use disorder and HIV.

At each of the mental health units, they have also agreed to provide us with a private room which we can use for questionnaire administration. Our research team comprises of well-trained occupational therapists, certified in ethics of conducting health research.

Accessing completed survey Sample recruitment forms

On the Friday preceding the targeted Friday as day of appointment, retrieve the accessible file labelled "Social inclusion: DAYA" from your locked cabinet. In that file you will have access to the completed and filed "Survey Sample Recruitment Forms". Retrieve these and proceed to check the stated review schedule.

Checking review schedule and making OT appointment

From the completed survey sample recruitment forms, take down the patient's phone number and check their stated review schedule. Make a phone call to this number and tell them about their OT appointment which you are asking them to come for on the following Friday. Tell them you shall call again toward the date just to remind them. If you are not successful after three attempts, you are to call on the caregiver number also found on the form. You are expected to talk about the OT appointment only over this call.

Sending reminders for OT appointment

On the Thursday, a day before the agreed appointment, call the patient reminding them of their appointment. The morning of the appointment call them again to confirm they are coming and to remind them of their appointment.

Step 1: Introduction on appointment day

On the appointment day, the survey team will arrive at the respective mental health units at 0730hrs, the prospective participants would have been booked from 0800hrs. As the patients arrive and waits for their OT appointments, the survey team will be introduced to patients by the OT-in-charge at the centre. The PI or survey team leader will then introduce the study briefly and outline study eligibility (see

Appendix A). Young adults aged 18-35 years, have a substance use disorder and have known their HIV status for at least one year, and are Shona/English speaking.

Step 2: Obtain consent to be in the survey

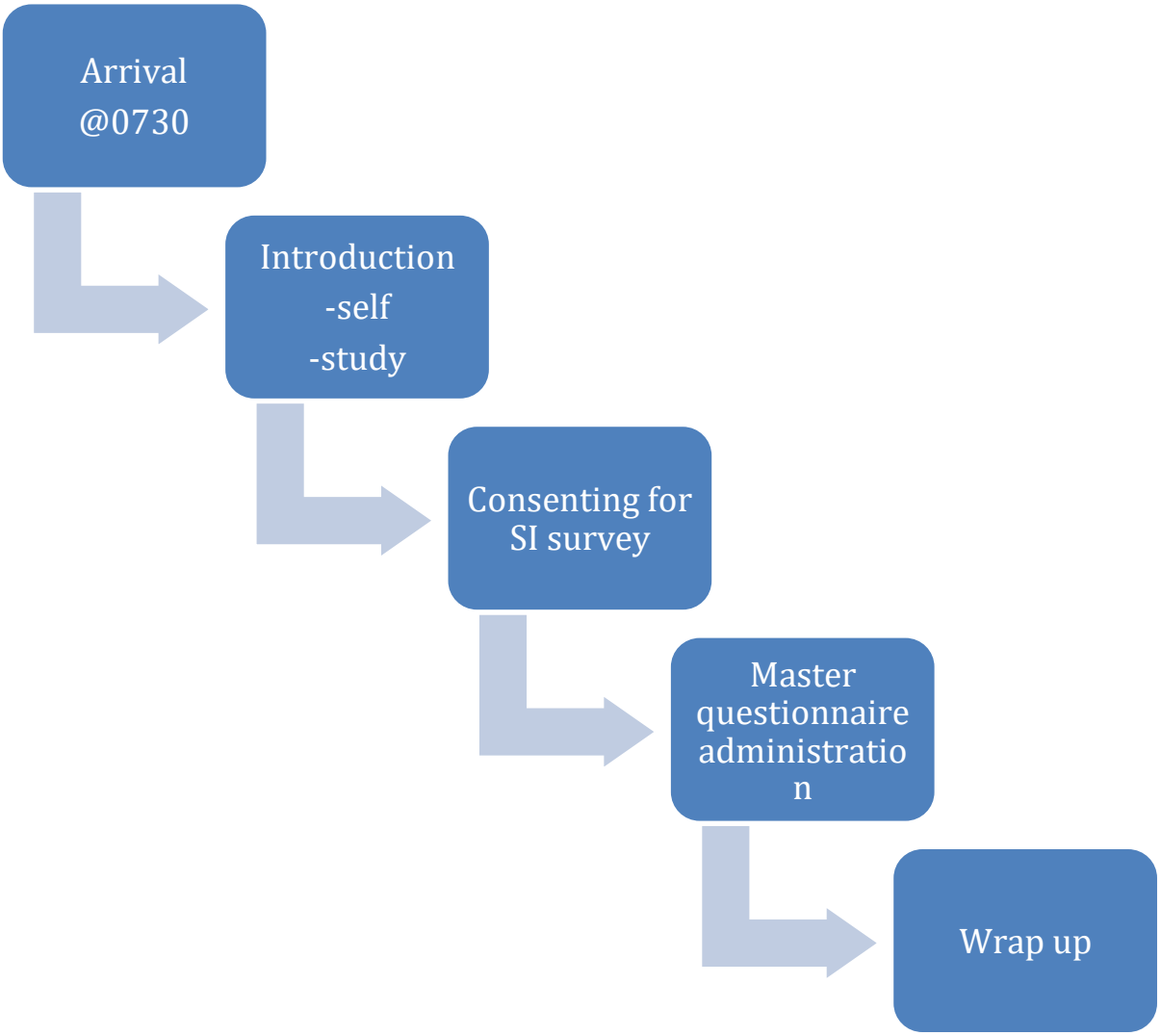
Patients who meet the inclusion criteria will be invited to learn more about the study and provide written informed consent.

Step 3: Questionnaire administration – Dually afflicted young adults

Following an affirmative consent, each young adult with a comorbid diagnosis of substance use disorder and HIV, will be asked to complete an interviewer-administered questionnaire. As the surveyor you will read the questions and responses aloud while the young adult will choose the response option(s) that is most true for them. It is anticipated that questionnaire administration will take about 30-40 minutes.

Step 4: Wrap up

Following questionnaire completion, the participant will be offered a small gift as a token of our appreciation for the time they took in answering our questions. This gift is comprised of toothpaste, toothbrush, face towel, a pen and bathing soap. Once they have received their gift, the team will escort them back to the OT office and work with the OT team to ensure they are served for their appointment.



ON THE DAY SURVEY FLOW DIAGRAM

Before You Begin

The successful implementation of any survey is dependent on careful planning. It is very important that the team is properly prepared and equipped before they begin. Every form has an important function and it is critical that nothing is forgotten. For this reason, checklists have been devised which detail each piece of required equipment.

All supplies are carried out into the field in folders and tablet bags. They are returned to Mr Clement Nhunzvi's office at UZCHS, Harare (Room 40) and will be checked by Mr Clement Nhunzvi on a daily basis. This section lists everything that you will need to collect data for this survey.

Item	Per group	Comments
Information Sheet & Consent forms	2 per targeted participant at the OTMH Unit	Office copy is filed in a lever arch file labelled 'Consent Forms"
Tablets	5 tablets	They should be fully charged from the night before. There is an extra tablet for the team, in case one of them temporarily malfunctions
Pens - Blue	Enough for each young adult and the survey team	Blue pens are used to complete all forms.
Pens - Red	1 for each member of the survey team	Red pens used by the survey team when they are checking someone else's work.
Consent Check & Gift Form (Appendix D)	2 per clinic	It is to be administered before handing over the gifts to the participant after they have completed the survey questionnaire
Gift package ● Face towel (1) ● Bath soap (1) ● Colgate toothpaste (1) ● Toothbrush (1) ● Pen (1)	40 sets per clinic	The pen is the one used by the participant to sign the consent form.
Refreshments ● Cascade/Pepsi soft drinks ● Biscuits	1 soft drink per participant 5 biscuits per young adult (estimated from the packet)	

1. HOW YOU WILL INTRODUCE THE SURVEY

How to obtain written informed consent

Making sure the participant is informed

For those participants who qualify to be in the survey, you will first need to explain the survey. It is important that you highlight that you are interested in getting to understand their life more broadly, especially in terms of their community interactions. Once you have explained the survey, and have answered their questions, you can proceed with obtaining consent.

Keep your earlier seating arrangement – so that you can have a short private conversation.

Hand out a copy of the information/consent form. Explain to them that you will go through this together so want them to have a copy. However, they must not complete the form at this time (therefore do not give them a pen just yet).

Content of the introduction: Welcome the young adult again and thank them for their time they are giving you to consider if they would like to join the study. Then summarize the survey outlining that we would like to ask them questions about their daily life at the moment, learning about how they are treated within their community. Let them know that this questionnaire will take approximately 40 minutes to complete. We will only ask them to complete the questionnaire today.

Then go through the information sheet. Read each section aloud and then explain it. After each section, ask if there are any questions.

Emphasize that if they do not want to participate in the survey, this will not affect any of their care at the clinic or elsewhere in the community.

Obtaining Consent

Once you have gone through the entire information sheet step by step, you will now ask the young adult to let you know their decision regarding their willingness to participate in the survey.

You, as the surveyor, should start by asking the participant to summarize, in their own words, what they understand is happening in this survey. If they cannot fully answer how they will participate in the survey, then you, as the surveyor, need to go through it with them again. Answering 'this is research about social inclusion' is not sufficient; participants must be able to outline what will happen to them and why.

Participants should be able to mention the following points in their summary:

- **That this questionnaire will be asking them questions about their daily life, in particular about their opportunities for leisure and community participation, their health status, and their experiences with stigma and discrimination around HIV and substance abuse.**
- The information that we collect from them is anonymous. This means that their name is NOT linked to the information they share with us in the questionnaire. The unique identifier listed in the questionnaire will NOT be linked to their name. The only place where we have a copy of their name is on the consent form and that form is NOT linked to the questionnaire. (It is just a written record of their agreement to participate in the study).
- That they do not have to participate if they don't want to. And, if they choose not to participate, they will still be able to access services from the clinic and the community as they were able to in the past.
- That they can stop participating at any time.
    - It is very important that they understand that if they decide to withdraw from the survey after they have participated, that we cannot remove their information from the database because we will not know which questionnaire was theirs. This is because

the data we are collecting is anonymous which means that there is NO way that anyone – not even the research team – can connect their name to the data once it has been completed.

After you are satisfied that they have understood the purpose of the survey, and are 'well informed,' you can complete the consent form together.

If, at any time during the summary process, they miss out on something, you will need to remind them of this information.

Completing the Consent Form

There are four parts to completing the consent form

- The consent itself
- Participant information
- Surveyor information
- Independent witness information

The Consent Itself

The statement that is followed by two boxes is the consent itself:

I agree to participate in this survey ☐ Yes ☐ No

It is the participant's responsibility to complete this section. They will put an "X" in either the "yes" box or the "no" box.

Participant Information

This is the participant's full name and signature. It is important that you, as the surveyor, print their name, but that the young adult sign their own name. Even if their 'signature' is just their name being printed again, as long as they are the one holding the pen, the process is legitimate.

_____		__ /	_____ /	20….
Full name of Participant (first name, last name)	*Date*	*day*	*month*	*year*
_____			_____	*AM*
Signature of Participant			*Time*	*PM*

If the participant is actually unable to write their name at all, see the section below under 'Independent Witness.'

Surveyor Information

Person obtaining informed consent: That is YOU! – and you must complete the following sections of the Consent Form:

Name of person obtaining consent:	Print your first name and then your last name. PRINT IT CLEARLY.
Signature of person obtaining consent:	Place your signature here
Date:	Complete the day as a two-digit number. Complete the month as a 3-4 letter word. So June will be JUNE and July will be JULY and August will be AUG.
Time:	Complete the hour and the minutes and circle AM or PM to indicate time of day.

_____		___ /	_____ /	20…
Full name of person obtaining consent (first name, last name)	*Date*	*Day*	*month*	*year*
_____			_____	*AM*

Position of person obtaining consent	*Time*	*PM*

Independent Witness

The role and use of a witness in the consent process:

- The role of the witness is NOT to sign on behalf of the participant but to witness the participant putting their mark. They are witnessing that the process the participant went through was not coercive in any way and that the participant is making their decision freely.
- If a participant is unable to sign their own name, then the witness they have nominated should be called in. If they have not nominated a witness then it is preferable to find someone independent of the survey team who can act as their witness, preferably one of the participants at the site. This person should listen to the survey team member go through the consent process with the participant and should witness the individual marking their cross and/or giving their thumbprint and the printing of the participant's name by the surveyor. The witness should sign the witness box at the bottom of the form and give their position or relationship to the participant as independent witness (e.g. sister or friend) on both copies of the consent form. Note: The witness must be over 18 years old and able to sign their own name.
- If no independent witness is available, the next best choice is to ask a member of staff at the clinic. If this occurs, print the following at the bottom of the consent form "no individual witness was available, so a member of staff was used."

- The independent witness will print their name in FULL: first name followed by last name.
- They will sign their name.
- They will indicate their relationship to the participant.

_____		___ /	____ /	*20….*
Full name of Witness (first name, last name)	*Date*	*day*	*month*	*year*
_____			____	*AM*
Signature of Witness			*Time*	*PM*
_____				
Relationship of Witness to Participant				

Young Adult Consent Process

When speaking with the young adult, you will ask them to complete two consent forms:

a) one for themselves
b) one for our files

Do's and Don'ts for completing the consent form

- ☐ DO NOT complete the form in advance.
- ☐ DO ensure the participant completes the form first.
- ☐ DO make sure that two copies are completed.
- ☐ DO make sure that ONE copy goes to the participant and ONE copy is kept with you.

Completing the Survey Register

Any participant who agrees to complete the Master questionnaire will be recorded on the *Survey Register*.

Complete it as follows:

Column	Options	Instructions
Date	__ __ / _____/ 2018	Enter the date as a two-digit number Enter the month as a three-letter abbreviation. For example, September, will be written as 'SEP'
Consent		
Consent Status	☐ Yes ☐ No	Look at the box that has been marked on the Consent Form. If they marked the 'Yes' box, then mark an X in the box 'yes.' If they marked the 'No box, then mark an X in the box 'no.'
Surveyor Initials		Enter your initials here. This is because you are the surveyor who is taking this participant through the survey administration.
Questionnaire Administration		
Study ID	Pre-printed	The Study ID is comprised of two parts: The Clinic ID The Participant ID These are pre-printed on the Register. When prompted on the tablet, enter the Study ID into the questionnaire system.
Completed	☐ Yes ☐ No	If the participant completes the entire questionnaire, mark an X in the box 'Yes' If the participant does not complete the questionnaire, mark an X in the box 'No.'
Saved	☐ Yes ☐ No	Check to see that the questionnaire has been saved. The screen should read "Form successfully saved" If it has been saved (and you see the above message) mark an X in the box 'Yes.'

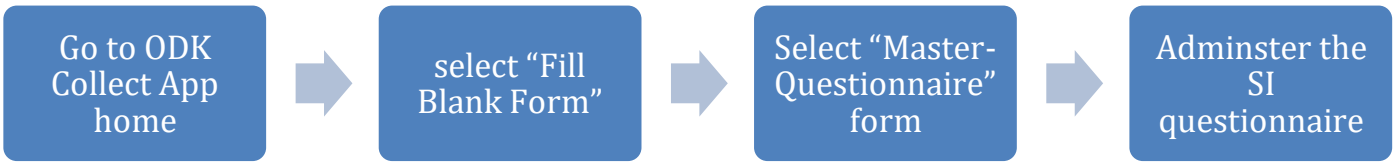
Once the participant has completed the TWO consent forms (one copy remains with the survey team and the other copy is for the participant), their consent status needs to be recorded on the *Survey Register*.

Administering the questionnaire

You will be administering the questionnaire as a face to face interview.

Explain to the young adult that you will read each question aloud, just like you did in the eASSIST survey. You will then read each possible response. Ask the young adult to choose the answer that is MOST true about them. Emphasize that this is **not** a test and that there are no right or wrong answers to these questions. The 'right answer' is the one that is most true for them. At several points during the questionnaire, remind them of this fact (that there are no right or wrong answers). If they are able to enter their own responses allow them to do this.

The social inclusion questionnaire will be assessed through the ODK Collect App on your tablet.



Start the interview. Go through each question on the questionnaire. Read the question, the instruction, and each answer. Ask them to choose from the responses given for their most appropriate response.

When you have read out all the questions, save the completed questionnaire on the tablet. You will know that you have successfully saved the completed questionnaire when you see this message on your screen:
"Form successfully saved"

Wrapping up with the young adult

After you have completed the questionnaire with the young adult, thank them for their time. Explain and complete the mental health referral form. First explain to them about need to get expert help about their substance use/abuse. Tell them about the free mental health services at Parirenyatwa and Harare hospitals. Assure them of a quality service they will get and that the PI is willing to facilitate this including giving them a referral. Now ask them if they would like to have this referral? If yes, complete their "Mental Health Referral Form" as follows:

Section	Options	Instructions
Date		Enter the date as a two-digit number Enter the month as a three-letter abbreviation. For example, September, will be written as 'SEP'
Name		Write down their first name followed by their surname
DOB		Write down their date of birth as dd/mm/yyyy e.g. 17/09/1986
Preferred mental health facility	☐ Harare Psychiatry Unit ☐ Parirenyatwa Psychiatry Unit	Ask them their preferred mental health facility and put an X in the relevant corresponding box

Put the completed referral form in an envelope and hand it over to them, encouraging them to seek help in time.

Direct them to serve themselves from the refreshment table and to be given their 'thank you' gift:

- 1 face towel
- 1 bath soap
- 1 tube of Colgate toothpaste
- 1 tooth brush
- 1 pen

Note that there should be a different team member staffing the refreshments and gifts table. This team member will check your consent form, file it, offer the participant refreshments, give them their gift, and ask them to write down their details on the *Consent Check & Gifts Form*

Here is how you complete the *Consent Check & Gifts Form.*

Column	Options	Instructions
Consent Form Checked	☐ Yes ☐ No	Check the consent form (see instructions below). If there are errors, work with the surveyor to correct them – this may require completing a new form. Once it has been checked, mark your initials in red on the bottom right hand corner of the form. Include a date with your initials. Mark an X in the 'Yes' box
Assessor Initials		Print your initials here.
Participant Details		
First Name		Look at their consent form and print their first name as it appears on the consent form.
Last Name		Look at their consent form and print their last name as it appears on the consent form.
Gift received	☐ Yes ☐ No	Once you have handed over the gift package, let the participant put an X in the 'Yes' box.
Date	___ ___ / _____ 2018	Enter the date as a two-digit number Enter the month as a three-letter abbreviation. For example, September, will be written as 'SEP'
Participant National ID		Enter the participant's National ID number
Participant Signature		Ask the participant to sign here as acknowledgement of receiving their gift
Assessor's Signature		Sign here if you have done all checks and tasks

At this time, ask them if they incurred any transport expenses coming to the clinic today. If so, ask them how much and give them these funds. If they receive funds from you, they will need to complete the *'Transport reimbursement form'* (Appendix E).

Column	Options	Instructions
Participant Details		
First Name		Look at their consent form and print their first name as it appears on the consent form.
Last Name		Look at their consent form and print their last name as it appears on the consent form.
Participant National ID		Enter the participant's National ID number
Phone Number		Write the participant's phone number preferably mobile number as they give it to you
Amount		Write down the amount you have given them for their transport cost according to what they told you their trip to and from clinic costs.
Date	___ ___ / _____ 2018	Enter the date as a two-digit number Enter the month as a three-letter abbreviation. For example, September, will be written as 'SEP'
Participant Signature		Ask the participant to sign here as acknowledgement of receiving their transport money
Surveyor's Signature		Sign here if you have done all checks and tasks

Wrapping up

Except for this training folder, all other study documentation will need to be returned to the office upon completion of each exercise.

- Blank Consent Forms – to be filed in "Blank Consent Forms Flat File"
- Completed Consent Forms –to be filed in "Completed Consent Forms Flat File".
- Completed eASSIST and Survey Register Forms – to be filed in "Completed Registers Flat File"
- Completed Gift Forms – to be filed in "Completed Gifts Flat File"
- Unused gifts – to be stored

Appendices

Appendix A – Inclusion Criteria

- 18-35yrs
- Living with HIV for at least 1 year
- Scored moderate or high on at least one substance covered in the eASSIST
- Shona/English speaking

Appendix B – eASSIST Scoring

Interpreting Scores			
RISK	Low – Drugs (0-4), Alcohol (0-10)	Moderate – Drugs (5-26), Alcohol (11-26)	High – (27 or above)
TREATMENT	Not required	Further assessment and treatment by mental health team	Further assessment and treatment by mental health team
REFERRAL	No referral	Referral	Urgent Referral

Appendix C1 – CLINIC REGISTER & eASSIST CONSENT FORM

Appendix C2 – eASSIST & SURVEY REGISTER

Appendix D – CONSENT CHECK & GIFTS FORM

Appendix E – TRANSPORT REIMBURSEMENT FORM

Appendix F – MENTAL HEALTH REFERRAL FORM

Chapter 23 Appendix U2 - Social Inclusion SOP OI Clinics

SOP for the SOCIAL INCLUSION survey

collecting data on SOCIAL INCLUSION ISSUES from YOUNG ADULTS (18-35) DUALLY AFFLICTED WITH SUD AND HIV

Background

Mental illness and HIV are prevalent and interwoven contributing to health and social problems particularly in Sub-Saharan Africa, including Zimbabwe. Substance use disorders (SUD) are on the rise among young adults in Zimbabwe, a case which is more complex among those living with HIV. SUD and HIV are both associated with poor coping skills and complicated by lack of sound rehabilitation services in Zimbabwe.

Despite recent gains made in the management of HIV and substance use disorders in Zimbabwe, there remain gaps regarding the unmet broader health and social care needs of young adults who are dually afflicted with substance use disorders and HIV. This vulnerable group is highly likely to experience social exclusion. Moreover, little attention has been given to the non-biomedical outcomes of substance use disorders and HIV resulting in an incomplete service which does not always translate into opportunities for dually affected young adults to live fully productive, inclusive, and satisfying lives. By understanding and responding to their broader health and social care needs, otherwise known as 'social inclusion issues', occupational therapy rehabilitation is better positioned to move their human rights agenda forward within this field. Their participation in a range of freely chosen, healthy and meaningful occupations will promote health, well-being, and social inclusion. However, in order to assist them in this, we need to better understand their experiences and the barriers they face. This study comprises three aspects: i) narrative interviews with dually afflicted young adults and in-depth interviews with key informants; ii) document analysis; and, iii) a cross sectional survey of social inclusion issues among dually afflicted young adults accessing mental health services and or ART at the two referral institutions in Zimbabwe.

With respect to the survey (iii), we are aiming to recruit a minimum of 100 dually afflicted young adults, aged 18-35 years. We aim to recruit them from two state referral centres for opportunistic infections (OI clinics) and their corresponding mental health units in Harare, Zimbabwe:

v) Parirenyatwa OI Clinic
vi) Parirenyatwa Psychiatry Unit
vii) Harare Central OI Clinic
viii) Harare Psychiatry Unit.

By recruiting from both OI clinics and from mental health centres we are able to obtain perspectives from both those whose primary reason for seeking health services is either substance use disorders or whose primary reason for seeking health services is that they live with HIV.

This protocol focuses on the recruitment and survey administration from the two OI clinics.

Key personnel:

Clement Nhunzvi	Principle Investigator	0775814587

Simba Chigwedere	Survey Team Leader	0773711231
Pascal Ndowa	Senior surveyor	0774086648
Davison Samanyada	Surveyor	0777331655
Clarity Chiadzwa	Surveyor	0718594668

Survey administration- an overview

Depending on the turnover of potential participants at the clinic, the survey team will be at each clinic for four days a week over a period of 3 months. Participants will be recruited by means of a convenient consecutive sampling, targeting a minimum of forty participants per clinic. (This is because we hope to recruit 35 participants from the two psychiatric units listed above)

Step 1: Introduction of the Survey Team

In the month prior to the survey, we have been working with the medical staff from the two respective OI clinics. The staff have agreed to assist us by introducing us to patients, allowing us to address the potential participants and facilitating that they get their routine services with minimum disruptions. They have also agreed to provide us with a private room which we can use for questionnaire administration. Our research team comprises of well-trained occupational therapists, certified in ethics of conducting health research.

Step 2: Introduction

The survey team will arrive at the respective OI clinic at 0700hrs, as this is when patients first begin to arrive for their ART care appointments. The young adults (18-35years) will be part of this group of patients. The survey team will be introduced to patients in the morning address by the sister-in-charge at 0730hrs. The PI or survey team leader will then introduce the study briefly and outline study eligibility (see Appendix A). Young adults aged 18-35 years, who have known their HIV status for at least one year, and are Shona/English speaking, will be asked to complete a short screening tool to assess their substance use: the Alcohol, Smoking and Substance Involvement Screening Test (eASSIST). Those who volunteer to take the eASSIST, will be asked to follow the survey team to their private work station where the eASSIST will be interviewer-administered by a trained surveyor. It is anticipated that the screening questions will take between 1 to 5 minutes.

Step 3: Screening for substance use using eASSIST.

We need to screen for alcohol, smoking and substance involvement as part of the inclusion criterion. Following the administration of the eASSIST, a score will be created. Patients who score 'moderate' or 'high' will be informed that they qualify to be a part of the study. See Appendix B for eASSIST scoring.

Step 4: Obtain consent to be in the survey from those who screen positive on the eASSIST

Patients who scored 'moderate' or 'high' on the eASSIST will be invited to learn more about the study and provide written informed consent.

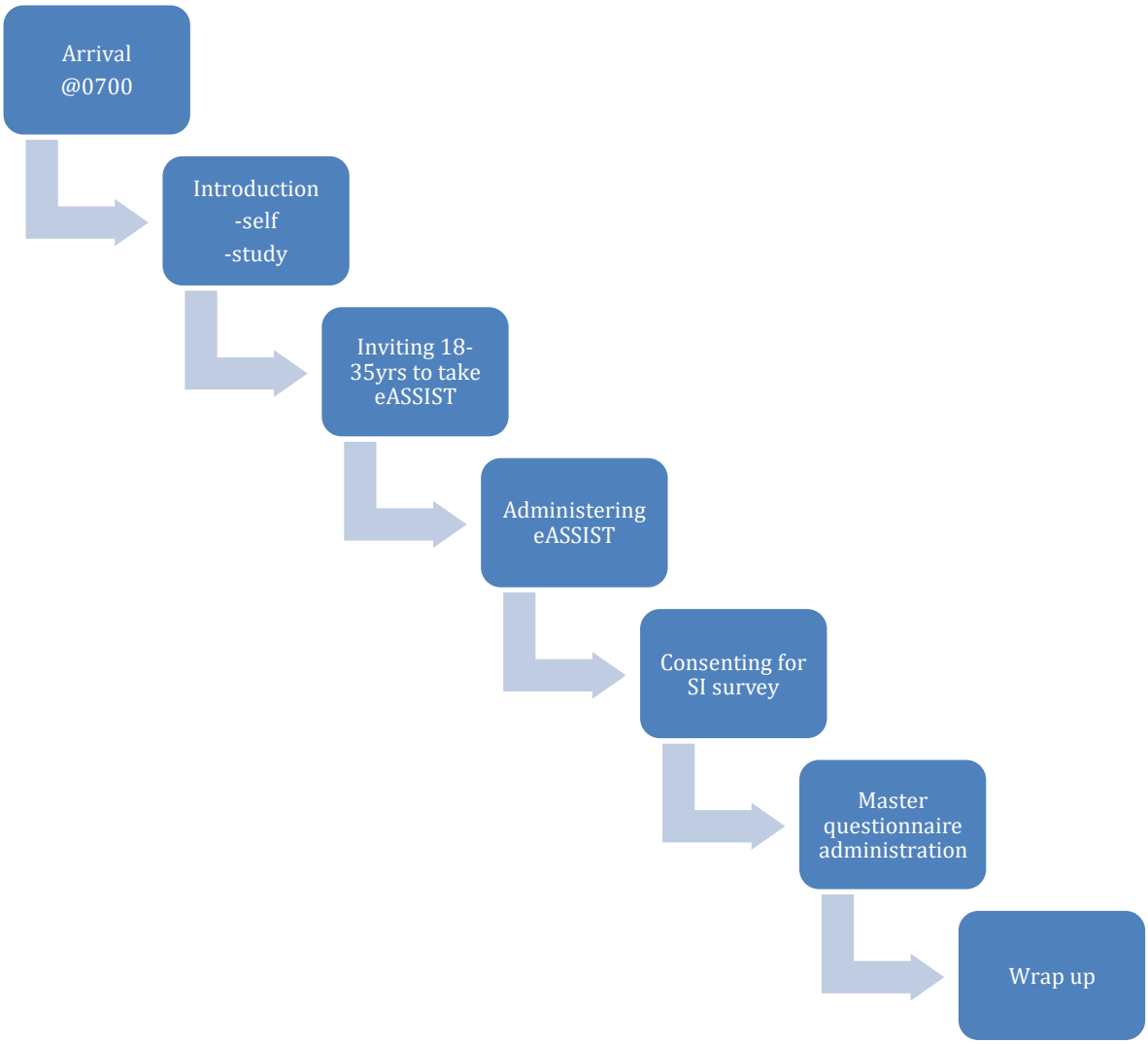
Step 5: Questionnaire administration – Dually afflicted young adults

Following an affirmative consent, each young adult with a comorbid diagnosis of substance use disorder and HIV, will be asked to complete an interviewer-administered questionnaire. As the surveyor you will read the questions and responses aloud while the young adult will choose the response option(s) that is most true for them. It is anticipated that questionnaire administration will take about 30-40 minutes.

Step 6: Wrap up

Following questionnaire completion, the participant will be offered a small gift as a token of our appreciation for the time they took in answering our questions. This gift is comprised of toothpaste, toothbrush, Vaseline, a pen and bathing soap. Once they have received their gift, the team will escort

them back to the OI Clinic system and work with the clinic team to ensure they are back in the queue and have not lost any time in the queue.



SURVEY FLOW DIAGRAM

Before You Begin

The successful implementation of any survey is dependent on careful planning. It is very important that the team is properly prepared and equipped before they begin. Every form has an important function and it is critical that nothing is forgotten. For this reason, checklists have been devised which detail each piece of required equipment.

All supplies are carried out into the field in folders and tablet bags. They are returned to Mr Clement Nhunzvi's office at UZCHS, Harare (Room 40) and will be checked by Mr Clement Nhunzvi on a daily basis. This section lists everything that you will need to collect data for this survey.

Item	Per group	Comments
Information Sheet & Consent forms	2 per targeted participant at the OI clinic	Office copy is filed in a lever arch file labelled 'Consent Forms"
Tablets	5 tablets	They should be fully charged from the night before. There is an extra tablet for the team, in case one of them temporarily malfunctions
Pens - Blue	Enough for each young adult and the survey team	Blue pens are used to complete all forms.
Pens - Red	1 for each member of the survey team	Red pens used by the survey team when they are checking someone else's work.
eASSIST & Survey Registers (Appendix C)	1 per clinic	The eASSIST & Survey *Register* is unique to each clinic. It has the name of the clinic and clinic-based study IDs.
Consent Check & Gift Form (Appendix D)	2 per clinic	It is to be administered before handing over the gifts to the participant after they have completed the survey questionnaire
Mental Health Referral Forms (Appendix F)	1 booklet per clinic	For writing referrals to mental health team for those needing this service.
Gift package • Face towel (1) • Bath soap (1) • Colgate toothpaste (1) • Toothbrush (1) • Pen (1)	40 sets per clinic	The pen is the one used by the participant to sign the consent form.
Refreshments • Cascade/Pepsi soft drinks • Biscuits	1 soft drink per participant 5 biscuits per young adult (estimated from the packet)	

2. HOW YOU WILL INTRODUCE THE SURVEY AND ASK YOUNG ADULTS TO TAKE THE eASSIST.

When you first arrive, patients will be in the waiting area waiting to be served. Your first task is to work with the nurse on duty to introduce yourself and the study. At this point, the goal is to provide a very general overview of the study: that you are looking to better understand the whole person's experience which you know is influenced by many factors. This study is specifically focussed on people aged 18 to 35 years. So, the first step is to ask those people who are 18-35 to step forward. You will need to reassure them that they will not lose their place in the queue by stepping forward.

Once you have the group of patients who are 18-35, you need to explain that this study is looking at individuals who are struggling with multiple health and social concerns. So, the first step is for them to take a very short survey that will take no more than 9 minutes to establish if their other health concerns fit/match the needs in this study. Reassure the patients that the information collected is anonymous – their name will not be connected to the data. Let them also know that if they meet the criteria, then they will be given time to more fully understand the study and make a decision as to whether or not they want to join it.

Invite each of them to take part in the screening test.

Invite young adults aged 18 to 35 years

Record the total number of patients at the clinic, 18-35years who come forward and the total number of those who agree or refuse to take eASSIST on "Clinic Register & eASSIST Consent Form" (Appendix C1)

Complete it as follows:

Column	Options	Instructions
Date	__ __ / _____/ 2018	Enter the date as a two-digit number Enter the month as a three-letter abbreviation. For example, September, will be written as 'SEP'
Clinic Attendees		
Total		Record the total number of patients at the clinic as you address them in the morning. Write the total number as a digit like 25
18-35 Age group		Record the total number of those who step forward when you call for the 18-35yrs age group. Write the total number as a digit like 15
Agreeing to take eASSIST		
Green (Agreed)		Among the 18-35yrs age group, record the total number of those who agree to take eASSIST. Write the total number as a digit like 10
Red (Refused)		Among the 18-35yrs age group, record the total number of those who refuse to take eASSIST. Write the total number as a digit like 5
Surveyor Initials		Enter your initials here. E.g. CN

3. eASSIST administration

The eASSIST is an 8-item interviewer administered tablet-based questionnaire, which screens for the use of a variety of substances including: tobacco products, alcohol, cannabis, cocaine, amphetamine-type stimulants (ATS), sedatives and sleeping pills, hallucinogens, inhalants, and opioids. The eASSIST takes around 5 to 9 minutes to administer. Scoring is programmed to take place automatically on the tablet. Respondents' answers to items on the eASSIST are entered by a trained healthcare professional, and a results table of risk scores is automatically generated. Risk scores (ie. 'lower', 'moderate' or 'high' risk'), determine who qualifies to be invited to take part in the social inclusion questionnaire. If

a respondent has a 'moderate' or 'high' risk score on one of the substances screened for, they are eligible to take part in the survey.

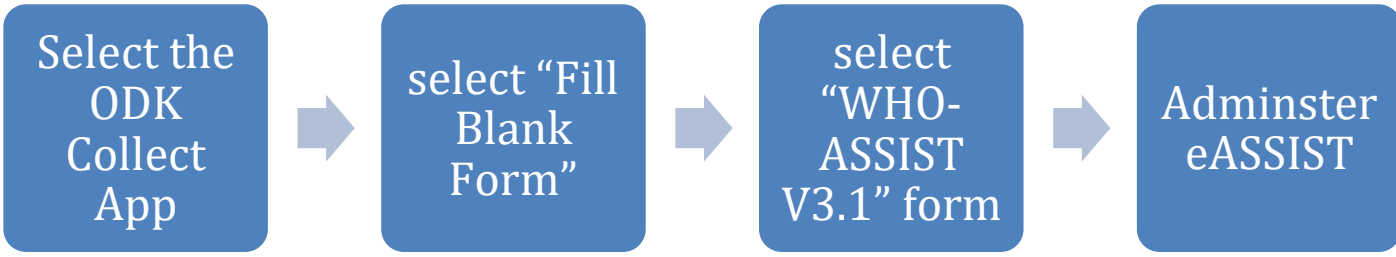
For those respondents with moderate or high-risk scores who decide **not** to take part in the study, you will alert them to their condition and provide a referral the psychologists, psychiatrists and rehabilitation team at Parirenyatwa Psychiatry Unit or Harare Psychiatry Unit (depending on which hospital you are at). A list of their contact details will be provided to the participant as a referral form for mental health services.

Interpreting Scores			
RISK	**Low** Drugs:0-4 Alcohol:0-10	**Moderate** Drugs: 5-26 Alcohol: 11-26	**High** All: 27 or above
TREATMENT	Not required	Further assessment and treatment by mental health team	Further assessment and treatment by mental health team
REFERRAL	No referral	Referral	Urgent Referral

After receiving the participant from the morning address, set your chair apart and get one more chair for the participant. Place it in front of you or to the side – so that you can have a short conversation. Explain to them the importance of holistic healthcare and knowing both one's mental and physical health status. Focus on one dimension that can affect the health of this population group, which is substance use. Explain why it is helpful to have a routine screening for this. Explain that the screening tool helps to identify those people who are in need of additional help and care around substance use. Reassure the participant that proper care is available at this hospital and that the information they share here in the screening tool is anonymous. This means that it is impossible to trace their answers back to them as the system does not record their name. Now explain what the eASSIST is all about and how it is being used in this study. Assure them of the anonymity of the data and that the information is being used only to help see if they qualify to enter the study.

- If they do not agree to proceed, thank them for considering your request. Make a note of their refusal on Clinic Register & eASSIST Consent Sheet in the "Red Refused" column. By putting a small x in the box.
- If they do agree to proceed, administer the eASSIST following the prompts on the tablet. When the system asks you to enter their Study ID, look at the *eASSIST & Survey Register* (Appendix C2). Their Study ID will be in the next blank row that you find on the *eASSIST & Survey Register*. It will be listed under the column labelled 'Study ID.'

The eASSIST will be assessed through the ODK Collect App on your tablet. Switch on the tablet. You will be prompted to enter a password, which you will be furnished with. Follow the following guide from tablet screen:



Complete the administrative questions first. Be sure to look at your *eASSIST & Survey Register* to locate the next correct Study ID.
Once the administrative questions are completed, begin the interview with your participant. Sit beside the participant so that both of you can see the screen. Go through each question. For each question, read the question aloud and then all of the response options. Wait for the participant to choose their response and then select this response on the tablet. If they are able to select their response, let them do this.

When you have completed all of the questions, a results table will be displayed with risk scores for each substance in which the young adult has engaged. For those who score 'moderate' or 'high' on any of the substances, there will be a **QUALIFIES** note next to each substance they qualify with. Invite them to participate in the social inclusion survey.

For those who do not score 'moderate' or high' on *any* of the substances, tell them that they are not currently at risk of substance abuse and do not qualify to participate in your survey. Thank them for their time and willingness to complete the eASSIST screening tool.
Mark the status of their score on the *eASSIST & Survey Register* under the column labelled "eASSIST Inclusion Outcome" by putting an X in the box corresponding to Yes for those who qualify and, in the box, corresponding with No, for those who do not qualify. For those who do not qualify, escort them back to the ART queue and work with the nurses to get them back in the queue such that they have not lost their place.

For those that do qualify, tell them they qualify to take part and invite them to learn more about the study and decide if they want to join.

How to obtain written informed consent

Making sure the participant is informed

For those participants who qualify to be in the survey, you will first need to explain the survey. It is important that you highlight that you are interested in getting to understand their life more broadly, especially in terms of their community interactions. Once you have explained the survey, and have answered their questions, you can proceed with obtaining consent.

Keep your earlier seating arrangement – so that you can have a short private conversation.

Hand out a copy of the information/consent form. Explain to them that you will go through this together so want them to have a copy. However, they must not complete the form at this time (therefore do not give them a pen just yet).

Content of the introduction: Welcome the young adult again and thank them for their time they are giving you to consider if they would like to join the study. Then summarize the survey outlining that we would like to ask them questions about their daily life at the moment, learning about how they are treated within their community. Let them know that this questionnaire will take approximately 40 minutes to complete. We will only ask them to complete the questionnaire today.

Then go through the information sheet. Read each section aloud and then explain it. After each section, ask if there are any questions.

Emphasize that if they do not want to participate in the survey, this will not affect any of their care at the clinic or elsewhere in the community.

Obtaining Consent

Once you have gone through the entire information sheet step by step, you will now ask the young adult to let you know their decision regarding their willingness to participate in the survey.

You, as the surveyor, should start by asking the participant to summarize, in their own words, what they understand is happening in this survey. If they cannot fully answer how they will participate in the survey, then you, as the surveyor, need to go through it with them again. Answering 'this is research about social inclusion' is not sufficient; participants must be able to outline what will happen to them and why.

Participants should be able to mention the following points in their summary:

- **That this questionnaire will be asking them questions about their daily life, in particular about their opportunities for leisure and community participation, their health status, and their experiences with stigma and discrimination around HIV and substance abuse.**
- The information that we collect from them is anonymous. This means that their name is NOT linked to the information they share with us in the questionnaire. The unique identifier listed in the questionnaire will NOT be linked to their name. The only place where we have a copy of their name is on the consent form and that form is NOT linked to the questionnaire. (It is just a written record of their agreement to participate in the study).
- That they do not have to participate if they don't want to. And, if they choose not to participate, they will still be able to access services from the clinic and the community as they were able to in the past.
- That they can stop participating at any time.
    - It is very important that they understand that if they decide to withdraw from the survey after they have participated, that we cannot remove their information from the database because we will not know which questionnaire was theirs. This is because the data we are collecting is anonymous which means that there is NO way that anyone – not even the research team – can connect their name to the data once it has been completed.

After you are satisfied that they have understood the purpose of the survey, and are 'well informed,' you can complete the consent form together.

If, at any time during the summary process, they miss out on something, you will need to remind them of this information.

Completing the Consent Form

There are four parts to completing the consent form

- The consent itself
- Participant information
- Surveyor information
- Independent witness information

The Consent Itself

The statement that is followed by two boxes is the consent itself:

I agree to participate in this survey ☐ Yes ☐ No

It is the participant's responsibility to complete this section. They will put an "X" in either the "yes" box or the "no" box.

Participant Information

This is the participant's full name and signature. It is important that you, as the surveyor, print their name, but that the young adult sign their own name. Even if their 'signature' is just their name being printed again, as long as they are the one holding the pen, the process is legitimate.

_____		___ /	_____ /	*20….*
Full name of Participant (first name, last name)	*Date*	*day*	*month*	*year*
_____			_____	*AM*
Signature of Participant			*Time*	*PM*

If the participant is actually unable to write their name at all, see the section below under 'Independent Witness.'

Surveyor Information

Person obtaining informed consent: That is YOU! – and you must complete the following sections of the Consent Form:

Name of person obtaining consent:	Print your first name and then your last name. PRINT IT CLEARLY.
Signature of person obtaining consent:	Place your signature here
Date:	Complete the day as a two-digit number. Complete the month as a 3-4 letter word. So June will be JUNE and July will be JULY and August will be AUG.
Time:	Complete the hour and the minutes and circle AM or PM to indicate time of day.

_____		___ /	_____ /	*20…*
Full name of person obtaining consent (first name, last name)	*Date*	*Day*	*month*	*year*
_____			_____	*AM*
Position of person obtaining consent			*Time*	*PM*

Independent Witness

<u>The role and use of a witness in the consent process:</u>

- The role of the witness is NOT to sign on behalf of the participant but to witness the participant putting their mark. They are witnessing that the process the participant went through was not coercive in any way and that the participant is making their decision freely.
- If a participant is unable to sign their own name, then the witness they have nominated should be called in. If they have not nominated a witness then it is preferable to find someone independent of the survey team who can act as their witness, preferably one of

the participants at the site. This person should listen to the survey team member go through the consent process with the participant and should witness the individual marking their cross and/or giving their thumbprint and the printing of the participant's name by the surveyor. The witness should sign the witness box at the bottom of the form and give their position or relationship to the participant as independent witness (e.g. sister or friend) on both copies of the consent form. Note: The witness must be over 18 years old and able to sign their own name.

- If no independent witness is available, the next best choice is to ask a member of staff at the clinic. If this occurs, print the following at the bottom of the consent form "no individual witness was available, so a member of staff was used."

- The independent witness will print their name in FULL: first name followed by last name.
- They will sign their name.
- They will indicate their relationship to the participant.

_____		___ /	____ /	20….
Full name of Witness (first name, last name)	***Date***	***day***	***month***	***year***
_____			____	***AM***
Signature of Witness			***Time***	***PM***
_____				
Relationship of Witness to Participant				

Young Adult Consent Process

When speaking with the young adult, you will ask them to complete two consent forms:

c) one for themselves
d) one for our files

Do's and Don'ts for completing the consent form

- ☐ DO NOT complete the form in advance.
- ☐ DO ensure the participant completes the form first.
- ☐ DO make sure that two copies are completed.
- ☐ DO make sure that ONE copy goes to the participant and ONE copy is kept with you.

Completing the eASSISIT & Survey Register

Any participant who agrees to complete the eASSIST will be recorded on the *eASSIST & Survey Register*.

Complete it as follows:

Column	Options	Instructions
Date	__ __ / _____/ 2018	Enter the date as a two-digit number Enter the month as a three-letter abbreviation. For example, September, will be written as 'SEP'
Study ID	Pre-printed	The Study ID is comprised of two parts: The Clinic ID The Participant ID These are pre-printed on the Register. When prompted on the tablet, enter the Study ID into the eASSIST system.
eASSIST inclusion outcome	☐ Yes ☐ No	If the participant scores 'moderate' or 'high' on any of the substances, they qualify to be a participant in the study. Mark an X in the box 'Yes'. If the participant does not score 'moderate' or 'high' on any of the substances, then they do not qualify to be a participant in the study. Mark an X in the box 'No'.
Consent		
Consent Status	☐ Yes ☐ No	Look at the box that has been marked on the Consent Form. If they marked the 'Yes' box, then mark an X in the box 'yes.' If they marked the 'No box, then mark an X in the box 'no.'
Surveyor Initials		Enter your initials here. This is because you are the surveyor who is taking this participant through the survey administration.
Questionnaire Administration		
Study ID	Pre-printed	The Study ID is comprised of two parts: The Clinic ID The Participant ID These are pre-printed on the Register. When prompted on the tablet, enter the Study ID into the questionnaire system.
Completed	☐ Yes ☐ No	If the participant completes the entire questionnaire, mark an X in the box 'Yes' If the participant does not complete the questionnaire, mark an X in the box 'No.'
Saved	☐ Yes ☐ No	Check to see that the questionnaire has been saved. The screen should read "Form successfully saved" If it has been saved (and you see the above message) mark an X in the box 'Yes.'

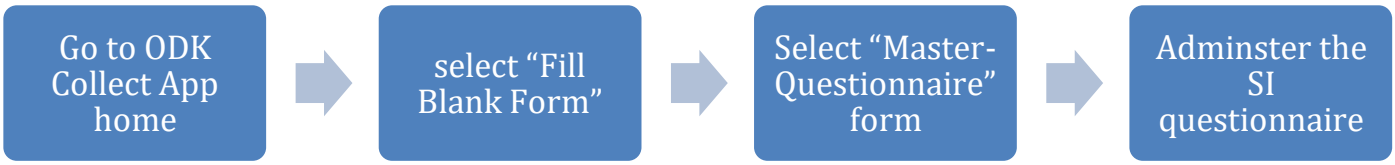
Once the participant has completed the TWO consent forms (one copy remains with the survey team and the other copy is for the participant), their consent status needs to be recorded on the *eASSIST & Survey Register*.

Administering the questionnaire

You will be administering the questionnaire as a face to face interview.

Explain to the young adult that you will read each question aloud, just like you did in the eASSIST survey. You will then read each possible response. Ask the young adult to choose the answer that is MOST true about them. Emphasize that this is **not** a test and that there are no right or wrong answers to these questions. The 'right answer' is the one that is most true for them. At several points during the questionnaire, remind them of this fact (that there are no right or wrong answers). If they are able to enter their own responses allow them to do this.

The social inclusion questionnaire will be assessed through the ODK Collect App on your tablet.



Start the interview. Go through each question on the questionnaire. Read the question, the instruction, and each answer. Ask them to choose from the responses given for their most appropriate response.

When you have read out all the questions, save the completed questionnaire on the tablet. You will know that you have successfully saved the completed questionnaire when you see this message on your screen:
"Form successfully saved"

Wrapping up with the young adult

After you have completed the questionnaire with the young adult, thank them for their time. Explain and complete the mental health referral form. First explain to them about need to get expert help about their substance use/abuse. Tell them about the free mental health services at Parirenyatwa and Harare hospitals. Assure them of a quality service they will get and that the PI is willing to facilitate this including giving them a referral. Now ask them if they would like to have this referral? If yes, complete their "Mental Health Referral Form" as follows:

Section	**Options**	**Instructions**
Date		Enter the date as a two-digit number Enter the month as a three-letter abbreviation. For example, September, will be written as 'SEP'
Name		Write down their first name followed by their surname
DOB		Write down their date of birth as dd/mm/yyyy e.g. 17/09/1986
Preferred mental health facility	☐ Harare Psychiatry Unit ☐ Parirenyatwa Psychiatry Unit	Ask them their preferred mental health facility and put an X in the relevant corresponding box

Put the completed referral form in an envelope and hand it over to them, encouraging them to seek help in time.

Direct them to serve themselves from the refreshment table and to be given their 'thank you' gift:

- 1 face towel
- 1 bath soap
- 1 tube of Colgate toothpaste
- 1 tooth brush
- 1 pen

Note that there should be a different team member staffing the refreshments and gifts table. This team member will check your consent form, file it, offer the participant refreshments, give them their gift, and ask them to write down their details on the *Consent Check & Gifts Form*

Here is how you complete the *Consent Check & Gifts Form.*

Column	**Options**	**Instructions**
Consent Form Checked	☐ Yes ☐ No	Check the consent form (see instructions below). If there are errors, work with the surveyor to correct them – this may require completing a new form. Once it has been checked, mark your initials in red on the bottom right hand corner of the form. Include a date with your initials. Mark an X in the 'Yes' box
Assessor Initials		Print your initials here.
Participant Details		
First Name		Look at their consent form and print their first name as it appears on the consent form.
Last Name		Look at their consent form and print their last name as it appears on the consent form.
Gift received	☐ Yes ☐ No	Once you have handed over the gift package, let the participant put an X in the 'Yes' box.
Date	___ ___ / _____ 2018	Enter the date as a two-digit number Enter the month as a three-letter abbreviation. For example, September, will be written as 'SEP'
Participant National ID		Enter the participant's National ID number
Participant Signature		Ask the participant to sign here as acknowledgement of receiving their gift
Assessor's Signature		Sign here if you have done all checks and tasks

At this time, ask them if they incurred any transport expenses coming to the clinic today. If so, ask them how much and give them these funds. If they receive funds from you, they will need to complete the *'Transport reimbursement form'* (Appendix E).

Column	Options	Instructions
Participant Details		
First Name		Look at their consent form and print their first name as it appears on the consent form.
Last Name		Look at their consent form and print their last name as it appears on the consent form.
Participant National ID		Enter the participant's National ID number
Phone Number		Write the participant's phone number preferably mobile number as they give it to you
Amount		Write down the amount you have given them for their transport cost according to what they told you their trip to and from clinic costs.
Date	___ ___ / _____ 2018	Enter the date as a two-digit number Enter the month as a three-letter abbreviation. For example, September, will be written as 'SEP'
Participant Signature		Ask the participant to sign here as acknowledgement of receiving their transport money
Surveyor's Signature		Sign here if you have done all checks and tasks

Wrapping up

Except for this training folder, all other study documentation will need to be returned to the office upon completion of each exercise.

- Blank Consent Forms – to be filed in "Blank Consent Forms Flat File"
- Completed Consent Forms –to be filed in "Completed Consent Forms Flat File".
- Completed eASSIST and Survey Register Forms – to be filed in "Completed Registers Flat File"
- Completed Gift Forms – to be filed in "Completed Gifts Flat File"
- Unused gifts – to be stored

Appendices

Appendix A – Inclusion Criteria

- 18-35yrs
- Living with HIV for at least 1 year
- Scored moderate or high on at least one substance covered in the eASSIST
- Shona/English speaking

Appendix B – eASSIST Scoring

Interpreting Scores			
RISK	**Low** – Drugs (0-4), Alcohol (0-10)	**Moderate** – Drugs (5-26), Alcohol (11-26)	**High** – (27 or above)
TREATMENT	Not required	Further assessment and treatment by mental health team	Further assessment and treatment by mental health team
REFERRAL	No referral	Referral	Urgent Referral

Appendix C1 – CLINIC REGISTER & eASSIST CONSENT FORM

Appendix C2 – eASSIST & SURVEY REGISTER

Appendix D – CONSENT CHECK & GIFTS FORM

Appendix E – TRANSPORT REIMBURSEMENT FORM

Appendix F – MENTAL HEALTH REFERRAL FORM

Chapter 24 Appendix V - Social Inclusion Survey Findings

Social Inclusion Survey Findings

This section serves to present part of the results from social inclusion exploratory cross-sectional survey data source. A sample of 105 young adults dually afflicted with HIV and SUD were recruited from two service ends (OI n=73) (MH n=32).

Major insights from narrative interviews, key informant interviews and document analysis which the survey sought to explore and describe using a larger sample included: Sociodemographic characteristics of the DAYA, feelings and thoughts regarding engagement and participation in key occupational areas (leisure, education, work, socialisation), health state especially depression, stigma, discrimination, and socioeconomic status. The cross-sectional survey also generated a baseline measurement of the level of social inclusion for further exploration and or reference point for progress in promoting social inclusion.

Descriptive analyses were conducted for sociodemographic variables and for the social inclusion variables. The sociodemographic findings revealed some important characteristics of the sample. Most of the participants (n=59 (56.2%)) said their HIV diagnosis preceded the development of substance use challenged. More than sixty per cent were male and majority were single (n=58 (55.2%)). Only twenty per cent (20%) said they were in formal paid employment and the largest number were unemployed (n=41(43.1%)), despite majority (n=84(80%)) having acquired at least secondary education (Table 1).

Table 1: Baseline sociodemographic variables of the whole sample

Characteristics	DAYA (n=105)	
	N	%
Primary diagnosis trend		
hiv	59	56.2%
sud	46	43.8%
Gender		
male	67	63.8%
female	38	36.2%
Age group		
<25	45	42.9%
>=25<30	23	21.9%
>=30<=35	37	35.2%
Marital status		
single	58	55.2%
married	25	23.8%
divorced/widowed	22	21.0%
Highest Education		
primary	4	3.8%
secondary	84	80.0%
tertiary	17	16.2%
Current employment status		
unemployed	41	43.1%
student	16	15.2%
formally employed	21	20.0%
self-employed	27	25.7%
Depression status		
no depression	75	71.4%
depression	30	28.6%
Loneliness		
no	65	61.9%
yes	40	38.1%
Current Treatment		
SUD only	3	2.9%
HIV only	72	68.6%
Both	30	28.6%
Overall Social Inclusion		
Satisfied	40	38.1%
Mixed	18	17.1%
Dissatisfied	47	44.8%

There were statistically significant differences between the two recruitment arms (OI clinic participants and MH clinic participants) in major sociodemographic variables and the overall social inclusion feeling outcome (Table 2).

Table 2: Baseline sociodemographic variables in the two recruitment arms, HIV arm (OI) and SUD arm (MH)

Characteristics	OI Clinic (n=73)		MH Clinic (n=32)		χ^2 p-value
	N	%	N	%	
Primary diagnosis trend					0.033
hiv	46	63.0%	13	40.6%	
sud	27	37.0%	19	59.4%	
Gender					0.798
male	46	63.0%	21	65.6%	
female	27	37.0%	11	34.4%	
Age group					0.481
<25	33	45.2%	12	37.5%	
>=25<30	17	23.3%	6	18.8%	
>=30<=35	23	31.5%	14	43.7%	
Marital status					0.020
single	45	61.6%	13	40.6%	
married	18	24.7%	7	21.9%	
divorced/widowed	10	13.7%	12	37.5%	
Education					0.012
primary	1	1.4%	3	9.4%	
secondary	56	76.7%	28	87.5%	
tertiary	16	21.9%	1	3.2%	
Current employment status					0.044
unemployed	23	31.5%	18	56.3%	
student	12	16.4%	4	12.5%	
formally employed	19	26.0%	2	6.3%	
self-employed	19	26.0%	8	25.0%	
Depression status					<0.001
no depression	62	84.9%	13	40.6%	
depression	11	15.1%	19	59.4%	
Loneliness					0.096
no	49	67.1%	16	50.0%	
yes	24	32.9%	16	50.0%	
Current Treatment					<0.001
SUD only	0	0.0%	3	9.4%	
HIV only	70	95.9%	2	6.3%	
Both	3	4.1%	27	84.4%	
Overall Social Inclusion					<0.001
Satisfied	36	49.3%	4	12.5%	
Mixed	13	17.8%	5	15.6%	
Dissatisfied	24	32.9%	23	71.9%	

When we described the sample by the primary outcome of social inclusion, lower educational level, unemployment, having depression feelings and feeling lonely, were all significantly associated with feeling socially excluded in society.

The following analysis compares the two samples (OI Clinic and MH Clinic) in terms of their responses to the overall inclusion question: "overall, how do you feel about the extent to which you are included in society?" (Table 3).

Table 3: Sociodemographic variables and overall social inclusion

Characteristics	Socially Included (N=40)		Mixed (N=18)		Socially Excluded (N=47)		χ^2 p-value
	N	%	N	%	N	%	
Primary diagnosis trend							0.310
hiv	21	52.5%	8	44.4%	30	63.8%	
sud	19	47.5%	10	55.6%	17	36.2%	
Gender							0.332
male	29	72.5%	10	55.6%	28	59.6%	
female	11	27.5%	8	44.4%	19	40.4%	
Age group							0.737
<25	18	45.0%	6	33.3%	21	44.7%	
>=25<30	7	17.5%	6	33.3%	10	21.2%	
>=30<=35	15	37.5%	6	33.3%	16	34.0%	
Marital status							0.443
single	24	60.0%	8	44.4%	26	55.3%	
married	11	27.5%	4	22.2%	10	21.3%	
divorced/widowed	5	12.5%	6	33.3%	11	23.4%	
Education							0.063
primary	1	2.5%	2	11.1%	1	2.1%	
secondary	33	82.5%	10	55.6%	41	87.2%	
tertiary	6	15.0%	6	33.3%	5	10.7%	
Current employment status							0.050
unemployed	11	27.5%	6	33.3%	24	51.1%	
student	7	17.5%	1	5.6%	8	17.0%	
formally employed	12	30.0%	6	33.3%	3	6.4%	
self-employed	10	25.0%	5	27.8%	12	25.5%	
Depression status							0.014
no depression	34	85.0%	14	77.8%	27	57.5%	
depression	6	15.0%	4	22.2%	20	42.5%	
Loneliness							0.001
no	32	80.0%	13	72.2%	20	42.6%	
yes	8	20.0%	5	27.8%	27	57.5%	

The overall social inclusion differs significantly between the two sample groups, with those in the OI group feeling more socially included than those in the MH group. A Tukey post-hoc test revealed that overall social inclusion was statistically significantly higher in the OI Clinic group – assessing health service for HIV compared to the MH Clinic group – those assessing health service primarily for SUD (1.33 ± .35 units of social inclusion, p = <.001) (Table 4).

Table 4: ANOVA

Sample group	n	mean	sd	se	95% CI	P value
OI Clinic	73	4.37	1.78	0.21	-2.04 – 0.64	<0.001
MH Clinic	32	3.03	1.38	0.24		
Total	105	3.96	1.78	0.17		
Between groups sum of squares =39.87 df 1, mean square =39.87; F=14.26 p=<0.001 Within groups sum of squares =287.98 df 103, mean square =2.80						

The MH clinic group had greater levels of perceived stigma against substance abuse than the OI clinic group. The PSAS scores are generally high with an average of 25.04(3.96) for the whole sample, and a range of 15(min) and 32(max) (Table 5).

Table 5: Summary of PSAS by sample group

Sample group	n	mean	sd	χ^2 p-value
OI Clinic	73	24.47	3.48	0.054
MH Clinic	32	26.34	4.68	
Total	105	25.04	3.96	

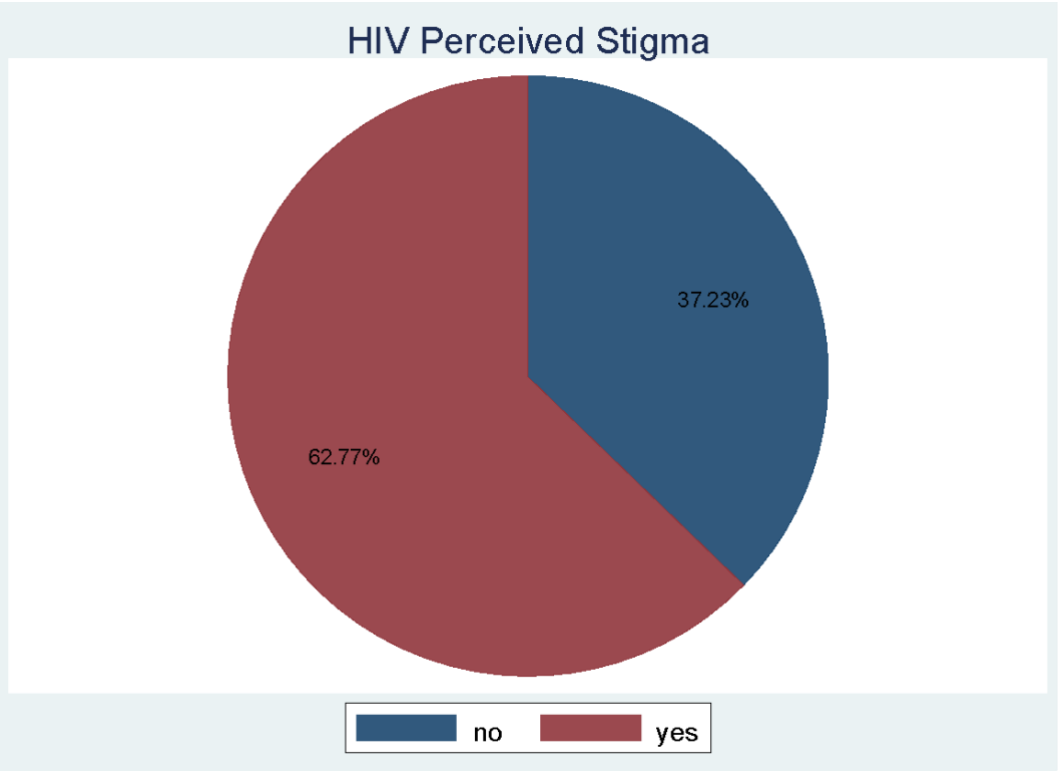


Figure 2: HIV Stigma perception among dually afflicted young adults (n=105)

About 63% of the dually afflicted young adults perceived HIV as a stigmatised condition in which people think it is shameful and those infected should be avoided.

Perceiving HIV as a stigmatised condition was also significantly associated with dissatisfaction with overall social inclusion. As shown in table 6 below.

Table 6: Overall Social inclusion by HIV stigma

Sample group	n	mean	sd	χ^2 p-value
No HIV Stigma	39	4.69	1.54	0.010
HIV Stigma	66	3.53	1.77	
Total	105	3.96	1.78	

The two samples were compared for major social inclusion domains derived from SCOPE. The social inclusion mean scores were lowest in the domains of participation in community groups or clubs (3.46 sd 1.81), and paid work (2.74 sd 1.62). Statistically significant differences between the OI clinic and MH clinic groups, with the MH clinic group feeling more socially excluded, were found in leisure and social activities (<0.001), community groups (0.001) and educational activities (0.001) (Table 7).

Table 7: Social Inclusion domains by recruitment arm

	Leisure and social activities			
Sample group	**n**	**mean**	**sd**	**χ^2 p-value**
OI Clinic	73	4.63	1.70	<0.001
MH Clinic	32	3.22	1.58	
Total	105	4.20	1.77	
	Community Support Groups			
Sample group	**n**	**mean**	**sd**	**χ^2 p-value**
OI Clinic	73	3.88	1.82	0.001
MH Clinic	32	2.50	1.19	
Total	105	3.46	1.81	
	Educational activities/services			
Sample group	**n**	**mean**	**sd**	**χ^2 p-value**
OI Clinic	73	4.49	1.83	0.001
MH Clinic	32	3.22	1.64	
Total	105	4.10	1.87	
	Paid work			
Sample group	**n**	**mean**	**sd**	**χ^2 p-value**
OI Clinic	73	3.05	1.96	0.145
MH Clinic	32	2.03	1.61	
Total	105	2.74	1.62	
	Sociopolitical activities			
Sample group	**n**	**mean**	**sd**	**χ^2 p-value**
OI Clinic	73	3.81	1.57	0.292
MH Clinic	32	3.44	1.19	
Total	105	3.70	1.48	

Chapter 25 References

Alkire, D. S. (2008). *Concepts and measures of agency*. Oxford Poverty & Human Development Initiative (OPHI).

Alkire, S. (2005). Why the Capability Approach? *Journal of Human Development*, *6*(1), 115-135. https://doi.org/10.1080/146498805200034275

Alkire, S., & Deneulin, S. (2009). Introducing the human development and capability approach. *An introduction to the human development and capability approach. London: Earthscan*.

Allman, D. (2013). The Sociology of Social Inclusion. *SAGE Open*, *3*(1), 2158244012471957. https://doi.org/10.1177/2158244012471957

Altheide, D. L., & Johnson, J. M. (1994). Criteria for assessing interpretive validity in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research.* (pp. 485-499). Sage Publications, Inc.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.

Anderson, M., & McCleary, K. K. (2015). From passengers to co-pilots: Patient roles expand. *Science Translational Medicine*, *7*(291), 291fs225-291fs225. https://doi.org/10.1126/scitranslmed.aac6023

Anthony, W. A. (1993). Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial rehabilitation journal*, *16*(4), 11-23. https://doi.org/https://doi.org/10.1037/h0095655

Appleton, J. V., & King, L. (2002). Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing*, *40*(6), 641-648. https://doi.org/https://doi.org/10.1046/j.1365-2648.2002.02424.x

Archer, M. S. (1995). *Realist Social Theory: The Morphogenetic Approach* Cambridge UniversityPress.

Arrey, A. E., Bilsen, J., Lacor, P., & Deschepper, R. (2017). Perceptions Of Stigma And Discrimination In Health Care Settings Towards Sub-Saharan African Migrant Women Living With Hiv/Aids In Belgium: A Qualitative Study. *Journal of Biosocial Science*, *49*(5), 578-596. https://doi.org/10.1017/S0021932016000468

Arseniou, S., Arvaniti, A., & Samakouri, M. (2014). HIV infection and depression [https://doi.org/10.1111/pcn.12097]. *Psychiatry and Clinical Neurosciences*, *68*(2), 96-109. https://doi.org/https://doi.org/10.1111/pcn.12097

Asher, K. (2013). Latin American Decolonial Thought, or Making the Subaltern Speak. *Geography Compass*, *7*(12), 832-842. https://doi.org/https://doi.org/10.1111/gec3.12102

Atkinson, A. B., & Marlier, E. (2010). *Analysing and measuring social inclusion in a global context*. http://www.un.org/esa/socdev/

Atkinson, K., Lowe, S., & Moore, S. (2016). Human development, occupational structure and physical inactivity among 47 low and middle income countries. *Preventive Medicine Reports*, *3*, 40-45. https://doi.org/https://doi.org/10.1016/j.pmedr.2015.11.009

Atkinson, R. (2007). The life story interview as a bridge in narrative inquiry. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology,* (pp. 224-245.). Sage Publications.

Badahdah, A. M. (2016). Attitudes Toward Restricting the Sexual and Reproductive Rights of Women Living With HIV Infection in Yemen. *Journal of the Association of Nurses in AIDS Care*, *27*(2), 180-187. https://doi.org/https://doi.org/10.1016/j.jana.2015.10.006

Bailliard, A. (2016). Justice, Difference, and the Capability to Function. *Journal of Occupational Science*, *23*(1), 3-16. https://doi.org/10.1080/14427591.2014.957886

Bakhshi, P., & Trani, J. F. (2006). The capability approach to understanding disability: Increasing comparability, defining efficient programs. *Capabilities and Public Policies, French Agency for Development, Paris*, 1-14.

Balaj, M., McNamara, C. L., Eikemo, T. A., & Bambra, C. (2017). The social determinants of inequalities in self-reported health in Europe: findings from the European social survey (2014) special

module on the social determinants of health. *European Journal of Public Health*, *27*(suppl_1), 107-114. https://doi.org/10.1093/eurpub/ckw217

Banks, L. M., Kuper, H., & Polack, S. (2017). Poverty and disability in low- and middle-income countries: A systematic review. *PLoS ONE*, *12*(12), e0189996. https://doi.org/10.1371/journal.pone.0189996

Barnes, C. (2007). disability activism and the struggle for change: disability, policy and politics in the UK. *Education, Citizenship and Social Justice*, *2*(3), 203-221. https://doi.org/10.1177/1746197907081259

Barros, D. D., Ghirardi, M. I. G., & Lopes, R. E. (2005). Social occupational therapy: A socio-historical perspective. In F. Kronenberg, S. S. Algado, & N. Pollard (Eds.), *Occupational therapy without borders: Learning from the spirit of survivors* (pp. 1140–1151). Elsevier Science/Churchill Livingstone.

Barros, D. D., Ghirardi, M. I. G., Lopes, R. E., & Galheigo, S. M. (2011). Brazilian experiences in social occupational therapy. Elsevier. In F. Kronenberg, N. Pollard, & D. Sakellariou (Eds.), *Occupational therapy without borders. Towards an ecology of occupation-based practices* (Vol. 2, pp. 209–215). Edinburgh.

Bartlett, R. (2014). Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. *Disability & Society*, *29*(8), 1291-1304. https://doi.org/10.1080/09687599.2014.924905

Basavaraj, K. H., Navya, M. A., & Rashmi, R. (2010). Quality of life in HIV/AIDS. *Indian journal of sexually transmitted diseases and AIDS*, *31*(2), 75-80. https://doi.org/10.4103/0253-7184.74971

Baumgartner, J. N., & Burns, J. K. (2013). Measuring social inclusion—a key outcome in global mental health. *International Journal of Epidemiology*, *43*(2), 354-364. https://doi.org/10.1093/ije/dyt224

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, *13*(4), 544-559. https://doi.org/https://doi.org/citeulike-article-id:6670384

Beegle, K., Christiaensen, L., Dabalen, A., & Gaddis, I. (2016). *Poverty in a rising Africa*. The World Bank.

Behari-Leak, K., & Mokou, G. (2019). Disrupting metaphors of coloniality to mediate social inclusion in the global South. *International Journal for Academic Development*, *24*(2), 135-147. https://doi.org/10.1080/1360144X.2019.1594236

Bekker, L.-G., Alleyne, G., Baral, S., Cepeda, J., Daskalakis, D., Dowdy, D., Dybul, M., Eholie, S., Esom, K., Garnett, G., Grimsrud, A., Hakim, J., Havlir, D., Isbell, M. T., Johnson, L., Kamarulzaman, A., Kasaie, P., Kazatchkine, M., Kilonzo, N., Klag, M., Klein, M., Lewin, S. R., Luo, C., Makofane, K., Martin, N. K., Mayer, K., Millett, G., Ntusi, N., Pace, L., Pike, C., Piot, P., Pozniak, A., Quinn, T. C., Rockstroh, J., Ratevosian, J., Ryan, O., Sippel, S., Spire, B., Soucat, A., Starrs, A., Strathdee, S. A., Thomson, N., Vella, S., Schechter, M., Vickerman, P., Weir, B., & Beyrer, C. (2018). Advancing global health and strengthening the HIV response in the era of the Sustainable Development Goals: the International AIDS Society—Lancet Commission. *The Lancet*, *392*(10144), 312-358. https://doi.org/10.1016/S0140-6736(18)31070-5

Berger, P. L., Berger, P. L., & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. Anchor.

Bhawuk, D. P., Carr, S. C., Gloss, A. E., & Thompson, L. F. (2014). Poverty reduction through positive work cycles: Exploring the role of information about work, culture and diversity, and organizational justice. *Barriers to and Opportunities for Poverty Reduction*, 63.

Biesta, G., & Tedder, M. (2006). How is agency possible? Towards an ecological understanding of agency-as-achievement. *Learning lives: Learning, identity, and agency in the life course*.

Blaikie, N. (1993). *Approaches to Social Inquiry.* Polity Press.

Blaikie, N. (2007). *Approaches to social enquiry: Advancing knowledge*. Polity Press.

Boardman, J. (2011). Social exclusion and mental health - how people with mental health problems are disadvantaged: an overview. *Mental Health and Social Inclusion*, *15*(3), 112-121. https://doi.org/10.1108/20428301111165690

Boardman, J., Killaspy, H., & Mezey, G. (2010). *Social inclusion and mental health*. RCPsych Publications.

Borrowman, M., & Klasen, S. (2020). Drivers of Gendered Sectoral and Occupational Segregation in Developing Countries. *Feminist Economics*, *26*(2), 62-94. https://doi.org/10.1080/13545701.2019.1649708

Bowen, G. A. (2009). Document Analysis as a Qualitative Research Method. *Qualitative Research Journal*, *9*(2), 27-40. https://doi.org/10.3316/QRJ0902027

Bradshaw, J. (2001). *Poverty: the outcomes for children* (Vol. 26). Family Policy Studies Centre London.

Bradshaw, J., Kemp, P., Baldwin, S., & Rowe, A. (2004). The drivers of social exclusion. *London: Social Exclusion Unit*.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Braveman, B., & Helfrich, C. A. (2001). Occupational Identity: Exploring the Narratives of Three Men Living with AIDS. *Journal of Occupational Science*, *8*(2), 25-31. https://doi.org/10.1080/14427591.2001.9686486

Brennan, G. J., & Gallagher, M. (2017). Expectations of choice: an exploration of how social context informs gendered occupation. *Irish Journal of Occupational Therapy*, *45*(1), 15-27. https://doi.org/10.1108/IJOT-01-2017-0003

Breuer, E., Myer, L., Struthers, H., & Joska, J. a. (2011). HIV/AIDS and mental health research in sub-Saharan Africa: a systematic review. *African Journal of AIDS Research*, *10*(2), 101-122. https://doi.org/10.2989/16085906.2011.593373

Brough, M. M., & Shresthova, S. (2012). Fandom meets activism: Rethinking civic and political participation. *Transformative Works and Cultures*, *10*.

Browne, F. A., & Wechsberg, W. M. (2010). The intersecting risks of substance use and HIV risk among substance-using South African men and women. *Current opinion in psychiatry*, *23*(3), 205-209. https://doi.org/10.1097/YCO.0b013e32833864eb

Browne, K. (2005). Snowball sampling: using social networks to research non-heterosexual women. *International Journal of Social Research Methodology*, *8*(1), 47-60. https://doi.org/10.1080/1364557032000081663

Buckmaster, L., & Thomas, M. (2009). *Social inclusion and social citizenship: towards a truly inclusive society*. Parliamentary Library Canberra.

Burchardt, T., & Le Grand, J. (2002). Degrees of Exclusion: Developing a Dynamic, Multidimensional. *Understanding social exclusion*, 30.

Cáceres, C. F., Aggleton, P., & Galea, J. T. (2008). Sexual diversity, social inclusion and HIV/AIDS

AIDS, *22*(Suppl2), S45-S55. http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2008-10658-008&site=ehost-live

Campbell, C., Andersen, L., Mutsikiwa, A., Madanhire, C., Skovdal, M., Nyamukapa, C., & Gregson, S. (2015). Re-thinking children's agency in extreme hardship: Zimbabwean children's draw-and-write about their HIV-affected peers. *Health Place*, *31*, 54-64. https://doi.org/https://doi.org/10.1016/j.healthplace.2014.09.008

Canadian Association of Occupational Therapists. (2002). *Enabling occupation: An occupational therapy perspective.* CAOT Publications ACE.

Carpenter, C. M., & Suto, M. (2008). *Qualitative research for occupational and physical therapists: A practical guide*. Wiley.

Carter, K. (1993). The Place of Story in the Study of Teaching and Teacher Education. *Educational Researcher*, *22*(1), 5-18. https://doi.org/10.3102/0013189X022001005

Carter, R., Satcher, D., & Coelho, T. (2013). Addressing stigma through social inclusion. *American Journal of Public Health*, *103*(5), 773. https://doi.org/10.2105/ajph.2012.301167

Casey, D., & Murphy, K. (2009). Issues in using methodological triangulation in research. *Nurse Researcher*, *16*(4).

Central Intelligence Agency -CIA. (2018). *The World Factbook on Zimbabwe [online]* https://www.cia.gov/library/publications/the-world-factbook/geos/zi.html

Cerulli, C., & Kossak, F. (2009). Agency and the praxis of activism (Special issue: Agency and the praxis of activism). . *Field: A Free Journal of Architecture*, *3*(1), 1–4.

Chan, K., Stoové, M. A., & Reidpath, D. D. (2008). Stigma, social reciprocity and exclusion of HIV/AIDS patients with illicit drug histories: A study of Thai nurses' attitudes. *Harm Reduction Journal*, *5*(1), 28-28. https://doi.org/10.1186/1477-7517-5-28

Chang, E. (2008). Drug use as an occupation: Reflecting on Insite, Vancouver's supervised injection site. *OT Now*, *10*(3), 21-23.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. sage.

Chibanda, D., Mesu, P., Kajawu, L., Cowan, F., Araya, R., & Abas, M. A. (2011). Problem-solving therapy for depression and common mental disorders in Zimbabwe: piloting a task-shifting primary mental health care intervention in a population with a high prevalence of people living with HIV. *BMC Public Health*, *11*(1), 828. https://doi.org/10.1186/1471-2458-11-828

Christiansen, C., & Townsend, E. (2004). The occupational nature of communities. *Introduction to occupation: The art and science of living*, 141-172.

Christiansen, C., & Townsend, E. A. (2009). *Introduction to Occupation: The art of science and living* (2nd ed.). Prentice Hall.

Clifton, A., Repper, J., Banks, D., & Remnat, J. (2013). Co-producing social inclusion: the structure/agency conundrum. *Journal of Psychiatric and Mental Health Nursing*, *20*(6), 514-524. https://doi.org/https://doi.org/10.1111/j.1365-2850.2012.01953.x

Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma research and action*, *2*(2).

Cobigo, V., & Stuart, H. (2010). Social inclusion and mental health. *Current opinion in psychiatry*, *23*(5), 453-457. https://doi.org/10.1097/YCO.0b013e32833bb305

Collins, D. (2003). Pretesting survey instruments: An overview of cognitive methods. *Quality of Life Research*, *12*(3), 229-238. https://doi.org/10.1023/A:1023254226592

Connelly, F. M., & Clandinin, D. J. (2006). Narrative inquiry. In J. Green, G. Camilli, & P. Elmore (Eds.), *Handbook of complementary methods in education research* (Vol. 3, pp. 477-487). Lawrence Erlbaum.

Conover, C. J., Arno, P., Weaver, M., Ang, A., & Ettner, S. L. (2006). Income and employment of people living with combined HIV/AIDS, chronic mental illness, and substance abuse disorders. *The journal of mental health policy and economics*, *9*(2), 71-86. http://europepmc.org/abstract/MED/17007485

Coombs, T., Nicholas, A., & Pirkis, J. (2013). A review of social inclusion measures. *Australian & New Zealand Journal of Psychiatry*, *47*(10), 906-919. https://doi.org/10.1177/0004867413491161

Corbett, P., & Howe, H. (2007). Bridge building in mental health. *Occupational Therapy News*, *15*(1), 24-25.

Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology*, *13*(1), 3-21. https://doi.org/10.1007/BF00988593

Corrigan, P. W., Druss, B. G., & Perlick, D. A. (2014). The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care. *Psychological Science in the Public Interest*, *15*(2), 37-70. https://doi.org/10.1177/1529100614531398

Cramm, J. M., Nieboer, A. P., Finkenflügel, H., & Lorenzo, T. (2013). Comparison of barriers to employment among youth with and without disabilities in South Africa. *Work*, *46*, 19-24. https://doi.org/10.3233/WOR-121521

Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2 ed.). Sage.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Sage publications.

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Sage.

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, *16*(3), 297-334.

Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., & Sheikh, A. (2011). The case study approach. *BMC Medical Research Methodology*, *11*(1), 100. https://doi.org/10.1186/1471-2288-11-100

Czarniawska, B. (2004). *Narratives in social science research*. Sage.

Dahlui, M., Azahar, N., Bulgiba, A., Zaki, R., Oche, O. M., Adekunjo, F. O., & Chinna, K. (2015). HIV/AIDS related stigma and discrimination against PLWHA in Nigerian population. *PLoS ONE*, *10*(12), 1-12. https://doi.org/10.1371/journal.pone.0143749

Daniel, J. C. (2012). Choosing the type of probability sampling. In *Sampling essentials: Practical guidelines for making sampling choices* (pp. 125-174). SAGE Publications, Inc. https://doi.org/10.4135/9781452272047

Dastile, N. P., & Ndlovu-Gatsheni, S. J. (2013). Power, knowledge and being: Decolonial combative discourse as a survival kit for Pan-Africanists in the 21st century. *Alternation*, *20*(1), 105-134.

Davey, S., & Gordon, S. (2017). Definitions of social inclusion and social exclusion: the invisibility of mental illness and the social conditions of participation. *International Journal of Culture and Mental Health*, *10*(3), 229-237. https://doi.org/10.1080/17542863.2017.1295091

de Sousa Santos, B. (2007). Beyond abyssal thinking: From global lines to ecologies of knowledges. *Review (Fernand Braudel Center)*, 45-89.

de Winter, J. C. F., Dodou, D., & Wieringa, P. A. (2009). Exploratory Factor Analysis With Small Sample Sizes With Small Sample Sizes. *Multivariate Behavioral Research*, *44*(April), 147-181. https://doi.org/10.1080/00273170902794206

Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The Discipline and Practice of Qualitative Research. In *The Sage handbook of qualitative research, 3rd ed.* (pp. 1-32). Sage Publications Ltd.

Denzin, N. K., & Lincoln, Y. S. (2011). *The Sage handbook of qualitative research*. sage.

Diamond, I., Quinby, L., Benhabib, S., & Cornell, D. (1990). Feminism and Foucault: Reflections on Resistance. *Hypatia*, *5*(3), 118-124.

Diemer, M. A., Rapa, L. J., Park, C. J., & Perry, J. C. (2017). Development and Validation of the Critical Consciousness Scale. *Youth & Society*, *49*(4), 461-483. https://doi.org/10.1177/0044118X14538289

Dobson, S., Voyer, S., & Regehr, G. (2012). Perspective: Agency and Activism: Rethinking Health Advocacy in the Medical Profession. *Academic Medicine*, *87*(9). https://journals.lww.com/academicmedicine/Fulltext/2012/09000/Perspective__Agency_and_Activism__Rethinking.12.aspx

Dowling, H., & Hutchinson, A. (2008). Occupational therapy - its contribution to social inclusion and recovery. *A Life in the Day*, *12*(3), 11-14. https://doi.org/10.1108/13666282200800023

Doyle, S. (2007). Member Checking With Older Women: A Framework for Negotiating Meaning. *Health care for women international*, *28*(10), 888-908. https://doi.org/10.1080/07399330701615325

Dray-Spira, R., Lert, F., Marimoutou, C., Bouhnik, A. D., & Obadia, Y. (2003). Socio-economic conditions, health status and employment among persons living with HIV/AIDS in France in 2001. *AIDS Care*, *15*(6), 739-748. https://doi.org/10.1080/09540120310001618595

Dray-Spira, R., Persoz, A., Boufassa, F., Gueguen, A., Lert, F., Allegre, T., Goujard, C., Meyer, L., & Group, T. P. C. S. (2005). Employment loss following HIV infection in the era of highly active antiretroviral therapies. *European Journal of Public Health*, *16*(1), 89-95. https://doi.org/10.1093/eurpub/cki153

Duchscher, J. E. B. (2000). Bending a habit: critical social theory as a framework for humanistic nursing education. *Nurse Education Today*, *20*(6), 453-462. https://doi.org/https://doi.org/10.1054/nedt.2000.0492

Duffy, M., Sharer, M., Cornman, H., Pearson, J., Pitorak, H., & Fullem, A. (2017). Integrating Mental Health and HIV Services in Zimbabwean Communities: A Nurse and Community-led Approach to Reach the Most Vulnerable. *Journal of the Association of Nurses in AIDS Care*, *28*(2), 186-198. https://doi.org/https://doi.org/10.1016/j.jana.2015.09.003

Durocher, E., Gibson, B. E., & Rappolt, S. (2014). Occupational Justice: A Conceptual Review. *Journal of Occupational Science*, *21*(4), 418-430. https://doi.org/10.1080/14427591.2013.775692

Durocher, E., Rappolt, S., & Gibson, B. E. (2013). Occupational Justice: Future Directions. *Journal of Occupational Science*, *21*(4), 431-442. https://doi.org/10.1080/14427591.2013.775693

Earnshaw, V. A., Rosenthal, L., & Lang, S. M. (2016). Stigma, activism, and well-being among people living with HIV. *AIDS Care*, *28*(6), 717-721. https://doi.org/10.1080/09540121.2015.1124978

Eisner, E. W. (2017). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice*. Teachers College Press.

Ermisch, J., Francesconi, M., & Pevalin, D. J. (2001). *Outcomes for children of poverty*. Corporate Document Services Leeds.

Esquerdo Lopes, R., Paula Serrata Malfitano, A., Regina Silva, C., Leme de Oliveira Borba, P., & Selma Hahn, M. (2012). Occupational therapy professional education and research in the social field. *World Federation of Occupational Therapists Bulletin*, *66*(1), 52-57.

European Commission. (2010). *Combating poverty and social exclusion: a statistical portrait of the European Union 2010*. Office for official publications of the European Communities.

Evangeli, M. (2018). Mental health and substance use in HIV-infected adolescents. *Current Opinion in HIV and AIDS*, *13*(3), 204-211. https://doi.org/10.1097/COH.0000000000000451

Evans-Lacko, S., Corker, E., Williams, P., Henderson, C., & Thornicroft, G. (2014a). Effect of the Time to Change anti-stigma campaign on trends in mental-illness-related public stigma among the English population in 2003–13: an analysis of survey data. *The Lancet Psychiatry*, *1*(2), 121-128. https://doi.org/https://doi.org/10.1016/S2215-0366(14)70243-3

Evans-Lacko, S., Courtin, E., Fiorillo, A., Knapp, M., Luciano, M., Park, A. L., Brunn, M., Byford, S., Chevreul, K., Forsman, A. K., Gulacsi, L., Haro, J. M., Kennelly, B., Knappe, S., Lai, T., Lasalvia, A., Miret, M., O'Sullivan, C., Obradors-Tarragó, C., Rüsch, N., Sartorius, N., Švab, V., van Weeghel, J., Van Audenhove, C., Wahlbeck, K., Zlati, A., McDaid, D., & Thornicroft, G. (2014b). The state of the art in European research on reducing social exclusion and stigma related to mental health: A systematic mapping of the literature. *European Psychiatry*, *29*(6), 381-389. https://doi.org/10.1016/j.eurpsy.2014.02.007

Evans, J., & Repper, J. (2000). Employment, social inclusion and mental health [Article]. *Journal of Psychiatric and Mental Health Nursing*, *7*(1), 15-24. https://doi.org/10.1046/j.1365-2850.2000.00260.x

Farah, S. A., & Ali, H. A. (2018). A Study on the Causes of Unemployment among University Graduates in Kenya: A Case of Garissa County, Kenya. *European Journal of Social Sciences Studies*.

Farias, L., & Laliberte Rudman, D. (2016). A Critical Interpretive Synthesis of the Uptake of Critical Perspectives in Occupational Science. *Journal of Occupational Science*, *23*(1), 33-50. https://doi.org/10.1080/14427591.2014.989893

Farias, L., & Rudman, D. L. (2019). Challenges in enacting occupation-based social transformative practices: A critical dialogical study. *Canadian Journal of Occupational Therapy*, *86*(3), 243-252. https://doi.org/10.1177/0008417419828798

Fedulova, I., Ivanova, V., Atyukova, O., & Nosov, V. (2019). Inclusive Education as a Basis for Sustainable Development of Society. *Journal of Social Studies Education Research*, *10*(3), 118-135.

Fieldhouse, J. (2012). Mental health, social inclusion, and community development: lessons from Bristol. *Community Development Journal*, *47*(4), 571-587. https://doi.org/10.1093/cdj/bss028

Flyvbjerg, B. (2006). Five Misunderstandings About Case-Study Research. *Qualitative Inquiry*, *12*(2), 219-245. https://doi.org/10.1177/1077800405284363

Fontes, L. A. (2004). Ethics in Violence Against Women Research: The Sensitive, the Dangerous, and the Overlooked. *Ethics & Behavior*, *14*(2), 141-174. https://doi.org/10.1207/s15327019eb1402_4

Fowler Jr, F. J. (2013). *Survey research methods*. Sage publications.

Fox, R. (2001). Constructivism Examined. *Oxford Review of Education*, *27*(1), 23-35. https://doi.org/10.1080/03054980125310

Frank, G., & Muriithi, B. A. K. (2015). Theorising social transformation in occupational science: The American Civil Rights Movement and South African struggle against apartheid as 'Occupational Reconstructions'. *South African Journal of Occupational Therapy*, *45*, 11-19. http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S2310-38332015000100003&nrm=iso

Freire, P. (1973). *Education for critical consciousness* (Vol. 1). Bloomsbury Publishing.

Frey, L., Botan, C. H., & Kreps, G. (1999). Investigating communication. *NY: Allyn & Bacon*.

Frohlich, K., & Potvin, L. (2010). Commentary: Structure or agency? The importance of both for addressing social inequalities in health. *International Journal of Epidemiology*, *39*, 378-379. https://doi.org/10.1093/ije/dyp372

Frohlich, K. L., Corin, E., & Potvin, L. (2001). A theoretical proposal for the relationship between context and disease. *Sociology of Health & Illness*, *23*(6), 776-797. https://doi.org/https://doi.org/10.1111/1467-9566.00275

Gallagher, M., Pettigrew, J., & Muldoon, O. (2015). Occupational choice of youth in a disadvantaged community. *British Journal of Occupational Therapy*, *78*(10), 622-629. https://doi.org/10.1177/0308022615583065

Galvaan, R. (2010). *A critical ethnography of young adolescents' occupational choices in a community in post-apartheid South Africa* University of Cape Town]. Cape Town.

Galvaan, R. (2012). Occupational choice: The significance of socio-economic and political factors. In W. Gail E. & H. Clare (Eds.), *Occupational science: Society, inclusion, participation* (pp. 152-162). Blackwell Publishing Ltd. https://doi.org/10.1002/9781118281581

Galvaan, R. (2015). The Contextually Situated Nature of Occupational Choice: Marginalised Young Adolescents' Experiences in South Africa. *Journal of Occupational Science*, *22*(1), 39-53. https://doi.org/10.1080/14427591.2014.912124

Gammage, S., Kabeer, N., & Van Der Meulen Rodgers, Y. (2016). Voice and Agency: Where Are We Now? *Feminist Economics*, *22*(1), 1-29. https://doi.org/10.1080/13545701.2015.1101308

Garrido, P. B., Paiva, V., do Nascimento, V. L. V., Sousa, J. B., & Santos, N. J. S. (2007). AIDS, stigma and unemployment: Implications for health services [Article]. *Revista de Saude Publica*, *41*(SUPPL. 2), 72-79. https://www.scopus.com/inward/record.uri?eid=2-s2.0-38049177674&partnerID=40&md5=d81fb616ce5e0ee8b799fc9cb099f016

Gasper, D. (2007). What is the capability approach?: Its core, rationale, partners and dangers. *The Journal of Socio-Economics*, *36*(3), 335-359. https://doi.org/https://doi.org/10.1016/j.socec.2006.12.001

Geuss, R. (1981). *The idea of a critical theory: Habermas and the Frankfurt School*. Cambridge University Press.

Giddens, A. (1984). *The Constitution of Society.* Cambridge: Polity Press.

Gilster, M. E. (2012). Comparing neighborhood-focused activism and volunteerism: psychological well-being and social connectedness. *Journal of Community Psychology*, *40*(7), 769-784. https://doi.org/https://doi.org/10.1002/jcop.20528

Giraldo, I. (2016). Coloniality at work: Decolonial critique and the postfeminist regime. *Feminist Theory*, *17*(2), 157-173. https://doi.org/10.1177/1464700116652835

Gordon, D., Adelman, L., Ashworth, K., Bradshaw, J., Levitas, R., Middleton, S., Pantazis, C., Patsios, D., Payne, S., Townsend, P., & Williams, J. (2000). *Poverty and Social Exclusion in Britain*. Joseph Rowntree Foundation.

Gordon, S., Davey, S., Waa, A., Tiatia, R., & Waaka, T. (2017). Social inclusion and exclusion, stigma and discrimination, and the experience of mental distress. *Auckland: Mental Health Foundation of New Zealand*.

Gould, S. J. (1988). Consumer Attitudes Toward Health and Health Care: A Differential Perspective. *Journal of Consumer Affairs*, *22*(1), 96-118. https://doi.org/https://doi.org/10.1111/j.1745-6606.1988.tb00215.x

Grady, A. P. (1995). Building Inclusive Community: A Challenge for Occupational Therapy. *American Journal of Occupational Therapy*, *49*(4), 300-310. https://doi.org/10.5014/ajot.49.4.300

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105-112. https://doi.org/https://doi.org/10.1016/j.nedt.2003.10.001

Gregson, S. (2006). HIV Decline Associated with Behavior Change in Eastern Zimbabwe. *Science*, *311*(5761), 664-666. https://doi.org/10.1126/science.1121054

Groce, N., Kembhavi, G., Wirz, S., Lang, R., Trani, J.-F., & Kett, M. (2011). Poverty and disability–a critical review of the literature in low and middle-income countries. *Leonard Cheshire Research Centre Working Paper Series*(16).

Grosfoguel, R. (2007). THE EPISTEMIC DECOLONIAL TURN. *Cultural Studies*, *21*(2-3), 211-223. https://doi.org/10.1080/09502380601162514

Grosfoguel, R. (2009). A decolonial approach to political-economy: Transmodernity, border thinking and global coloniality. *Kult*, *6*(1), 10-38.

Grosfoguel, R. (2011). Decolonizing post-colonial studies and paradigms of political-economy: Transmodernity, decolonial thinking, and global coloniality. *Transmodernity: Journal of peripheral cultural production of the Luso-Hispanic world*, *1*(1).

Guetterman, T. (2015). Descriptions of sampling practices within five approaches to qualitative research in education and the health sciences. *Educational Psychology Papers and Publications.*, *263*.

Hamer, H. (2017). Returning citizens: Social inclusion and occupational justice for mental health service users. *Cadernos Brasileiros de Saúde Mental/Brazilian Journal of Mental Health*, *9*(21), 89-113.

Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, *30*(19), 1445-1460. https://doi.org/10.1080/09638280701625534

Hammell, K. R. W. (2017). Critical reflections on occupational justice: Toward a rights-based approach to occupational opportunities. *Canadian Journal of Occupational Therapy*, *84*(1), 47-57. https://doi.org/10.1177/0008417416654501

Hammell, K. R. W., & Iwama, M. K. (2012). Well-being and occupational rights: An imperative for critical occupational therapy. *Scandinavian Journal of Occupational Therapy*, *19*(5), 385-394. https://doi.org/10.3109/11038128.2011.611821

Hammell, K. W. (2007). Reflections on … Well-Being and Occupational Rights. *Canadian Journal of Occupational Therapy*, *75*(1), 61-64. https://doi.org/10.2182/cjot.07.007

Hammell, K. W. (2015). Quality of life, participation and occupational rights: A capabilities perspective. *Australian Occupational Therapy Journal*, *62*(2), 78-85. https://doi.org/10.1111/1440-1630.12183

Hammell, K. W. (2019). Building globally relevant occupational therapy from the strength of our diversity. *World Federation of Occupational Therapists Bulletin*, *75*(1), 13-26. https://doi.org/10.1080/14473828.2018.1529480

Hammell, K. W. (2020). Action on the social determinants of health: Advancing occupational equity and occupational rights. *Cadernos Brasileiros de Terapia Ocupacional*, *28*(1), 387-400. https://doi.org/10.4322/2526-8910.ctoarf2052

Harrison, D., & Sellers, A. (2008). Occupation for mental health and social inclusion. *British Journal of Occupational Therapy*, *71*(5), 216-219.

Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a Fundamental Cause of Population Health Inequalities. *American Journal of Public Health*, *103*(5), 813-821. https://doi.org/10.2105/AJPH.2012.301069

Haydon, G., Browne, G., & van der Riet, P. (2018). Narrative inquiry as a research methodology exploring person centred care in nursing. *Collegian*, *25*(1), 125-129. https://doi.org/https://doi.org/10.1016/j.colegn.2017.03.001

Henkel, D. (2011). Unemployment and Substance Use: A Review of the Literature (1990-2010). *Current drug abuse reviews*, *4*(1), 4-27. https://www.ingentaconnect.com/content/ben/cdar/2011/00000004/00000001/art00002

Hercegovac, S., Kernot, J., & Stanley, M. (2019). How Qualitative Case Study Methodology Informs Occupational Therapy Practice: A Scoping Review. *OTJR: Occupation, Participation and Health*, *40*(1), 6-16. https://doi.org/10.1177/1539449219850123

Hocking, C., & Townsend, E. (2015). Driving social change: Occupational therapists' contributions to occupational justice. *World Federation of Occupational Therapists Bulletin*, *71*(2), 68-71. https://doi.org/10.1179/2056607715Y.0000000002

Hoffman, A. (2006). The Capability Approach and educational policies and strategies: Effective life skills education for sustainable development. *AFD, Paris*.

Horkheimer, M. (1995). Materialism and Morality. In M. Horkheimer (Ed.), *Between Philosophy and Social Science, Selected Early Writing*. Massachusetts Institute of Technology Press.

Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher*, *20*(4).

Huxley, P., Evans, S., Madge, S., Webber, M., Burchardt, T., McDaid, D., & Knapp, M. (2012). Development of a social inclusion index to capture subjective and objective life domains (Phase II): psychometric development study. *Health Technology Assessment*, *16*(1), iii-vii, ix-xii, -1-241. https://doi.org/10.3310/hta16010

Huxley, P. J., Chan, K., Chiu, M., Ma, Y., Gaze, S., & Evans, S. (2016). The social and community opportunities profile social inclusion measure: Structural equivalence and differential item functioning in community mental health residents in Hong Kong and the United Kingdom. *Int J Soc Psychiatry*, *62*(2), 133-140. https://doi.org/10.1177/0020764015607550

Hvinden, B., & Halvorsen, R. (2014). The Capability Approach and the Agency/Structure Discussion in Sociology: Understanding Social Exclusion and Inclusion as Empirical Case.

Hvinden, B., & Halvorsen, R. (2017). Mediating Agency and Structure in Sociology: What Role for Conversion Factors? *Critical Sociology*, *44*(6), 865-881. https://doi.org/10.1177/0896920516684541

Ibrahim, S., & Alkire, S. (2007). Agency and Empowerment: A Proposal for Internationally Comparable Indicators. *Oxford Development Studies*, *35*(4), 379-403. https://doi.org/10.1080/13600810701701897

Islam, M. R. (2015). Rights of the people with disabilities and social exclusion in Malaysia. *International Journal of Social Science and Humanity*, *5*(3), 299.

Jackson-Best, F., & Edwards, N. (2018). Stigma and intersectionality: a systematic review of systematic reviews across HIV/AIDS, mental illness, and physical disability. *BMC Public Health*, *18*(1), 919. https://doi.org/10.1186/s12889-018-5861-3

Jacob, K. S. (2015). Recovery model of mental illness: a complementary approach to psychiatric care. *Indian Journal of Psychological Medicine*, *37*(2), 117-119. https://doi.org/10.4103/0253-7176.155605

Jay, S., Muldoon, O., & Howarth, C. (2018). Connecting social exclusion and agency: social class matters. *Political Psychology: A Social Psychological Approach*, 134-151.

Jolley, E., Lynch, P., Virendrakumar, B., Rowe, S., & Schmidt, E. (2018). Education and social inclusion of people with disabilities in five countries in West Africa: a literature review. *Disability and Rehabilitation*, *40*(22), 2704-2712. https://doi.org/10.1080/09638288.2017.1353649

Jónasdóttir, S. K., Hand, C., Misener, L., & Polgar, J. (2018). Applying case study methodology to occupational science research. *Journal of Occupational Science*, *25*(3), 393-407. https://doi.org/10.1080/14427591.2018.1480409

Jorge, C., Debra, R. W., James, G. L., & Emanuel, A. (2017). The role of the family in defining and managing disability of persons with schizophrenia in Chile: Meeting objective and subjective criteria of social inclusion. *International Journal of Sociology and Anthropology*, *9*(12), 166-172. https://doi.org/10.5897/ijsa2017.0742

Josselson, R. (1993). A narrative introduction. *The narrative study of lives*, *1*.

Josselson, R. (2007). The ethical attitude in narrative research: principles and practicalities. In D. Jean Clandinin (Ed.), *Handbook of Narrative Inquiry: Mapping a Methodology* (pp. 537-566). SAGE Publications, Inc. https://doi.org/10.4135/9781452226552

Josselson, R., & Lieblich, A. (2009). Reflections on The Narrative Study of Lives. *Narrative Inquiry*, *19*(1), 183-198. https://doi.org/10.1075/ni.19.1.10jos

Jovchelovitch, S., & Bauer, M. W. (2000). Narrative interviewing. *Qualitative researching with text, image and sound*, 57-74.

Kalichman, S. C., Simbayi, L. C., Kagee, A., Toefy, Y., Jooste, S., Cain, D., & Cherry, C. (2006). Associations of poverty, substance use, and HIV transmission risk behaviors in three South African communities. *Social Science & Medicine*, *62*(7), 1641-1649. https://doi.org/https://doi.org/10.1016/j.socscimed.2005.08.021

Kantartzis, S. (2018). Perspectives on occupation-based social inclusion: Collective occupation in the local, social world. *Japanese Journal of Occupational Science*, *12*(1), 14-37.

Kantartzis, S., & Molineux, M. (2017). Collective occupation in public spaces and the construction of the social fabric: L'occupation collective dans les espaces publics et la construction du tissu social. *Canadian Journal of Occupational Therapy*, *84*(3), 168-177. https://doi.org/10.1177/0008417417701936

Kielhofner, G. (2009). *Conceptual foundations of occupational therapy practice*. FA Davis.

Kielhofner, G. (2009). Emergence of the contemporary paradigm: A return to occupation. . In G. Kielhofner (Ed.), *Conceptual foundations of occupational therapy practice* (pp. 41–55). PA: F.A. Davis Company.

Kiepek, N. C., Beagan, B., Rudman, D. L., & Phelan, S. (2019). Silences around occupations framed as unhealthy, illegal, and deviant. *Journal of Occupational Science*, *26*(3), 341-353. https://doi.org/10.1080/14427591.2018.1499123

Kieselbach, T. (2003). Long-Term Unemployment Among Young People: The Risk of Social Exclusion. *American Journal of Community Psychology*, *32*(1-2), 69-76. https://doi.org/https://doi.org/10.1023/A:1025694823396

Killaspy, H., White, S., Lalvani, N., Berg, R., Thachil, A., Kallumpuram, S., Nasiruddin, O., Wright, C., & Mezey, G. (2014). The impact of psychosis on social inclusion and associated factors [Article]. *International Journal of Social Psychiatry*, *60*(2), 148-154. https://doi.org/10.1177/0020764012471918

Kirkaldy, A. (2005). *Capturing the soul: the Vhavenda and the missionaries [1870-1900]*. Protea.

Klar, M., & Kasser, T. (2009). Some Benefits of Being an Activist: Measuring Activism and Its Role in Psychological Well-Being. *Political Psychology*, *30*(5), 755-777. https://doi.org/https://doi.org/10.1111/j.1467-9221.2009.00724.x

Koch, T. (1994). Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing*, *19*(5), 976-986. https://doi.org/https://doi.org/10.1111/j.1365-2648.1994.tb01177.x

Koller, D., Pouesard, M. L., & Rummens, J. A. (2018). Defining Social Inclusion for Children with Disabilities: A Critical Literature Review. *Children & Society*, *32*(1), 1-13. https://doi.org/https://doi.org/10.1111/chso.12223

L'Abbe, E. N. (2005). *A palaeodemographic, palaeopathologic and morphologic study of the 20th century Venda* University of Pretoria]. Pretoria.

Labonté, R. (2017). Global Finance's Impacts on Social Determinants of Health and Health Equity. *Population Health in Canada: Issues, Research, and Action*, 137.

Lakey, J., Barnes, H., & Parry, J. (2001). *Getting a Chance: Employment Service Support for Young People with Multiple Disadvantages*. Joseph Rowntree Foundation.

Laliberte Rudman, D. (2013). Enacting the Critical Potential of Occupational Science: Problematizing the 'Individualizing of Occupation'. *Journal of Occupational Science*, *20*(4), 298-313. https://doi.org/10.1080/14427591.2013.803434

Laliberte Rudman, D., Pollard, N., Craig, C., Kantartzis, S., Piskur, B., Algado, S., van Bruggen, H., & Schiller, S. (2018). Contributing to social transformation through occupation: Experiences from a think tank. *Journal of Occupational Science*, *26*, 1-7. https://doi.org/10.1080/14427591.2018.1538898

Laliberte Rudman, D., Pollard, N., Craig, C., Kantartzis, S., Piškur, B., Algado Simó, S., Van Bruggen, H., & Schiller, S. (2019). Contributing to social transformation through occupation: Experiences from a think tank. *Journal of Occupational Science*, *26*(2), 316-322. https://doi.org/10.1080/14427591.2018.1538898

Lancaster, K. E., Hetrick, A., Jaquet, A., Adedimeji, A., Atwoli, L., Colby, D. J., Mayor, A. M., Parcesepe, A., & Syvertsen, J. (2018). Substance use and universal access to HIV testing and treatment in sub-Saharan Africa: implications and research priorities. *Journal of Virus Eradication*, *4*, 26-32. https://doi.org/https://doi.org/10.1016/S2055-6640(20)30342-3

Langhaug, L. F., Pascoe, S. J., Mavhu, W., Woelk, G., Sherr, L., Hayes, R. J., & Cowan, F. M. (2010). High prevalence of affective disorders among adolescents living in Rural Zimbabwe. *Journal of Community Health*, *35*(4), 355-364.

Laudet, A. B. (2012). Rate and Predictors of Employment Among Formerly Polysubstance Dependent Urban Individuals in Recovery. *Journal of Addictive Diseases*, *31*(3), 288-302. https://doi.org/10.1080/10550887.2012.694604

Law, M. (1998). Client-centered occupational therapy. *Slack*.

Le Boutillier, C., & Croucher, A. (2010). Social inclusion and mental health. *British Journal of Occupational Therapy*, *73*(3), 136-139.

Lee, C. J. G. (2012). Reconsidering Constructivism in Qualitative Research. *Educational Philosophy and Theory*, *44*(4), 403-412. https://doi.org/10.1111/j.1469-5812.2010.00720.x

Levitas, R., Pantazis, C., Fahmy, E., Gordon, D., Lloyd, E., & Patsios, D. (2007). *The multi-dimensional analysis of social exclusion*. University of Bristol.

Liberman, R. P., & Kopelowicz, A. (2002). Recovery from schizophrenia: a challenge for the 21st century. *International Review of Psychiatry*, *14*(4), 245-255. https://doi.org/10.1080/0954026021000016897

Lieblich, A., & Josselson, R. (1994). *Exploring identity and gender: The narrative study of lives* (Vol. 2). SAGE Publications, Incorporated.

Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic inquiry*, *289*(331), 289-327.

Liu, Y., Canada, K., Shi, K., & Corrigan, P. (2012). HIV-related stigma acting as predictors of unemployment of people living with HIV/AIDS. *AIDS Care*, *24*(1), 129-135. https://doi.org/10.1080/09540121.2011.596512

Lloyd, C., Tse, S., & Bassett, H. (2004). Mental health recovery and occupational therapy in Australia and New Zealand. *International Journal of Therapy and Rehabilitation*, *11*(2), 64-70. https://doi.org/10.12968/ijtr.2004.11.2.13392

Lloyd, C., Tse, S., & Deane, F. P. (2006). Community participation and social inclusion: How practitioners can make a difference. *AeJAMH (Australian e-Journal for the Advancement of Mental Health)*, *5*(3), 1-10. https://doi.org/10.5172/jamh.5.3.185

Loh, J. (2013). Inquiry into issues of trustworthiness and quality in narrative studies: A perspective. *The Qualitative Report*, *18*(33), 1.

Luebker, M. (2008). Employment, unemployment and informality in Zimbabwe: Concepts and data for coherent policy-making.

Lui, C.-W., Warburton, J., Winterton, R., & Bartlett, H. (2011). Critical Reflections on a Social Inclusion Approach for an Ageing Australia. *Australian Social Work*, *64*(3), 266-282. https://doi.org/10.1080/0312407X.2011.573860

Lund, C., Brooke-Sumner, C., Baingana, F., Baron, E. C., Breuer, E., Chandra, P., Haushofer, J., Herrman, H., Jordans, M., Kieling, C., Medina-Mora, M. E., Morgan, E., Omigbodun, O., Tol, W., Patel, V., & Saxena, S. (2018). Social determinants of mental disorders and the Sustainable Development Goals: a systematic review of reviews. *The Lancet Psychiatry*, *5*(4), 357-369. https://doi.org/10.1016/S2215-0366(18)30060-9

Luoma, J. B., O'Hair, A. K., Kohlenberg, B. S., Hayes, S. C., & Fletcher, L. (2010). The Development and Psychometric Properties of a New Measure of Perceived Stigma Toward Substance Users. *Substance Use & Misuse*, *45*(1-2), 47-57. https://doi.org/10.3109/10826080902864712

Macey, D. (2000). *The Penguin dictionary of critical theory*. Penguin London.

Madziro-Ruwizhu, T. B., Nyagura, T., Takarinda, K., Jack, H. E., Kajawu, L., & Mangezi, W. (2019). HIV Infection in Attendees of Psychiatric Clinics in Harare, Zimbabwe; Prevalence, Associated Factors and HIV Care Uptake. *AIDS and Behavior*, *23*(12), 3471-3481. https://doi.org/10.1007/s10461-019-02633-2

Mahomed, F. (2020). Addressing the Problem of Severe Underinvestment in Mental Health and Well-Being from a Human Rights Perspective. *Health and Human Rights*, *22*(1), 35-49. https://pubmed.ncbi.nlm.nih.gov/32669787

Mahomva, A. (2006). HIV prevalence and trends from data in Zimbabwe, 1997-2004. *Sexually transmitted infections*, *82*(suppl_1), i42-i47. https://doi.org/10.1136/sti.2005.019174

Maldonado-Torres, N. (2007). ON THE COLONIALITY OF BEING. *Cultural Studies*, *21*(2-3), 240-270. https://doi.org/10.1080/09502380601162548

Maldonado-Torres, N. (2011). Thinking through the decolonial turn: Post-continental interventions in theory, philosophy, and critique—An introduction. *Transmodernity: Journal of peripheral cultural production of the Luso-Hispanic world*, *1*(2).

Maldonado-Torres, N. (2017). On the Coloniality of Human Rights. *Revista Crítica de Ciências Sociais*(114), 117-136. https://doi.org/10.4000/rccs.6793

Malfitano, A. P. S. (2005). Intervention fields and centers in social occupational therapy. *Journal of Occupational Therapy, University of São Paulo*, *16*(1), 1-8. https://doi.org/10.11606/issn.2238-6149.v16i1p1-8

Malfitano, A. P. S., & Lopes, R. E. (2018). Social occupational therapy: Committing to social change. *New Zealand Journal of Occupational Therapy*, *65*(1), 20–26. https://doi.org/10.3316/informit.779763971754213

Malfitano, A. P. S., Lopes, R. E., Magalhães, L., & Townsend, E. A. (2014). Social occupational therapy: Conversations about a Brazilian experience. *Canadian Journal of Occupational Therapy*, *81*(5), 298-307. https://doi.org/10.1177/0008417414536712

Malfitano, A. P. S., Whiteford, G., & Molineux, M. (2021). Transcending the individual: The promise and potential of collectivist approaches in occupational therapy. *Scandinavian Journal of Occupational Therapy*, *28*(3), 188-200. https://doi.org/10.1080/11038128.2019.1693627

Malik, R. A., & Obhi, S. S. (2019). Social exclusion reduces the sense of agency: Evidence from intentional binding. *Consciousness and Cognition*, *71*, 30-38. https://doi.org/https://doi.org/10.1016/j.concog.2019.03.004

Malunguza, N. J., Hove-Musekwa, S. D., & Mukandavire, Z. (2018). Projecting the impact of anal intercourse on HIV transmission among heterosexuals in high HIV prevalence settings. *Journal of Theoretical Biology*, *437*, 163-178. https://doi.org/https://doi.org/10.1016/j.jtbi.2017.10.020

Mannan, H., Amin, M., & MacLachlan, M. (2012). Non-communicable disease priority actions and social inclusion. *The Lancet*, *379*(9812), e17-e18. https://doi.org/10.1016/S0140-6736(12)60106-8

Mantzoukas, S. (2005). The inclusion of bias in reflective and reflexive research: A necessary prerequisite for securing validity. *Journal of Research in Nursing*, *10*(3), 279-295. https://doi.org/10.1177/174498710501000305

Marks, N., & Shah, H. (2004). A well-being manifesto for a flourishing society. *Journal of Public Mental Health*, *3*(4), 9-15. https://doi.org/10.1108/17465729200400023

Marmot, M. (2018). Inclusion health: addressing the causes of the causes. *The Lancet*, *391*(10117), 186-188. https://doi.org/10.1016/S0140-6736(17)32848-9

Marsicano, E., Dray-Spira, R., Lert, F., Aubrière, C., Spire, B., & Hamelin, C. (2014). Multiple discriminations experienced by people living with HIV in France: results from the ANRS-Vespa2 study. *AIDS Care*, *26*(sup1), S97-S106. https://doi.org/10.1080/09540121.2014.907385

Martin, L., & Cobigo, V. (2011). Definitions matter in understanding social inclusion. *Journal of Policy and Practice in Intellectual Disabilities*, *8*(4), 276-282.

Matsika, C. (2000). *Traditional African education: its significance to current educational practices with special reference to Zimbabwe* (Publication Number 5394) [Doctoral Thesis, University of Massachusetts Amherst]. Massachusetts.

Maulsby, C. H., Ratnayake, A., Hesson, D., Mugavero, M. J., & Latkin, C. A. (2020). A Scoping Review of Employment and HIV. *AIDS and Behavior*, *24*(10), 2942-2955. https://doi.org/10.1007/s10461-020-02845-x

Mavhu, W., Berwick, J., Chirawu, P., Makamba, M., Copas, A., Dirawo, J., Willis, N., Araya, R., Abas, M. A., Corbett, E. L., Mungofa, S., Laver, S. M., & Cowan, F. M. (2013). Enhancing Psychosocial Support for HIV Positive Adolescents in Harare, Zimbabwe. *PLoS ONE*, *8*(7), e70254. https://doi.org/10.1371/journal.pone.0070254

Mayston, R., Kinyanda, E., Chishinga, N., Prince, M., & Patel, V. (2012). Mental disorder and the outcome of HIV/AIDS in low-income and middle-income countries: a systematic review. *AIDS*, *26*, S117-S135. https://doi.org/10.1097/QAD.0b013e32835bde0f

Mazzi, F., Baccari, F., Mungai, F., Ciambellini, M., Brescancin, L., & Starace, F. (2018). Effectiveness of a social inclusion program in people with non-affective psychosis [Article]. *BMC psychiatry*, *18*(1), Article 179. https://doi.org/10.1186/s12888-018-1728-5

McDevitt, S. (2003). Social Exclusion in the European Union. *The Social Policy Journal*, *2*(4), 3-18. https://doi.org/10.1300/J185v02n04_02

McKay, E. A., & Robinson, K. (2011). Creating Occupational Engagement to Maximise Recovery in Mental Health. In L. Mackenzie & G. O'Toole (Eds.), *Occupation Analysis in Practice* (pp. 217-231). Blackwell Publishing Ltd. https://doi.org/https://doi.org/10.1002/9781118786604.ch15

McLaren, P. (2001). Che Guevara, Paulo Freire, and the Politics of Hope: Reclaiming Critical Pedagogy. *Cultural Studies ↔ Critical Methodologies*, *1*(1), 108-131. https://doi.org/10.1177/153270860100100112

Mellins, C. A., & Malee, K. M. (2013). Understanding the mental health of youth living with perinatal HIV infection: Lessons learned and current challenges. *Journal of the International AIDS Society*, *16*(Lmic). https://doi.org/10.7448/IAS.16.1.18593

Mental Health Commission. (2009). *Mental health and social inclusion concepts and measurements.* . https://ndhadeliver.natlib.govt.nz/view/action/ieViewer.do?metadata=xsl&is_mobile=false&is_rtl=false&dps_dvs=1613465847510~312&dps_pid=IE1711144&inst=CRS00.INS00#

Merriam, S. B. (1998). *Qualitative Research and Case Study Applications in Education. Revised and Expanded from" Case Study Research in Education.*". ERIC.

Mertens, D. M. (2007). Transformative Paradigm: Mixed Methods and Social Justice. *Journal of Mixed Methods Research*, *1*(3), 212-225. https://doi.org/10.1177/1558689807302811

Mertens, D. M. (2014). *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods*. Sage publications.

Mignolo, W. D. (2005). *The idea of latin america*. John Wiley & Sons.

Mignolo, W. D. (2007). INTRODUCTION. Coloniality of power and de-colonial thinking. *Cultural Studies*, *21*(2-3), 155-167. https://doi.org/10.1080/09502380601162498

Mignolo, W. D. (2009). Epistemic Disobedience, Independent Thought and Decolonial Freedom. *Theory, Culture & Society*, *26*(7-8), 159-181. https://doi.org/10.1177/0263276409349275

Mignolo, W. D. (2011). Geopolitics of sensing and knowing: on (de)coloniality, border thinking and epistemic disobedience. *Postcolonial Studies*, *14*(3), 273-283. https://doi.org/10.1080/13688790.2011.613105

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. sage.

Miller, W., & Crabtree, B. (1999). Depth interviewing., edn. In B.F. CRABTREE & W.L. MILLER (Eds.), *Doing qualitative research* (2 ed.). Sage.

Minato, M., & Zemke, R. (2004). Occupational Choices of Persons with Schizophrenia Living in the Community. *Journal of Occupational Science*, *11*(1), 31-39. https://doi.org/10.1080/14427591.2004.9686529

Ministry of Health and Child Care & UNICEF. (2013). *Zimbabwe: Living Conditions Among Persons with Disability Survey*. UNICEF. https://www.unicef.org/zimbabwe/National_Survey_on_Disability_2013(1).pdf

Mitra, S., Posarac, A., & Vick, B. (2013). Disability and Poverty in Developing Countries: A Multidimensional Study. *World Development*, *41*, 1-18. https://doi.org/10.1016/j.worlddev.2012.05.024

Mokwena, K., & Morojele, N. (2014). Unemployment and unfavourable social environment as contributory factors to nyaope use in three provinces of South Africa: substance abuse. *African Journal for Physical Health Education, Recreation and Dance*, *20*(sup-1), 374-384. https://doi.org/doi:10.10520/EJC162262

Mondaca, M. (2021). "Doing hope" as a possible way towards a responsive occupational science. *Journal of Occupational Science*, *28*(1), 19-28. https://doi.org/10.1080/14427591.2020.1797858

Montague, A. C., & Eiroá Orosa, F. J. (2017). Exploring the role of engagement on well-being and personal development: A review of adolescent and mental health activism. In Nicholas JL Brown, Tim Lomas, & F. J. Eiroa-Orosa (Eds.), *The Routledge International Handbook of Critical Positive Psychology*. Routledge.

Morgan, C., Burns, T., Fitzpatrick, R., Pinfold, V., & Priebe, S. (2007). Social exclusion and mental health: Conceptual and methodological review. *British Journal of Psychiatry*, *191*(6), 477-483. https://doi.org/10.1192/bjp.bp.106.034942

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, *52*(2), 250.

Mousavi, T., Forwell, S., Dharamsi, S., & Dean, E. (2015). The historical shift towards human rights in occupational therapy with special reference to the Capabilities Approach and its implications. *World Federation of Occupational Therapists Bulletin*, *71*, 81-87. https://doi.org/10.1179/2056607715Y.0000000005

Mpofu, J., & Molosiwa, S. (2017). Disability and Inclusive Education in Zimbabwe. In P. Nareadi, M. Dikeledi, & G. J. S. Dei (Eds.), *Disability and Inclusive Education in Zimbabwe* (pp. 49-63). Brill | Sense. https://brill.com/view/book/edcoll/9789463008037/BP000005.xml

Mufune, P. (2015). Poverty and HIV/AIDS in Africa: Specifying the connections. *Social Theory & Health*, *13*(1), 1-29. https://doi.org/10.1057/sth.2014.14

Mujeyi, K., & Sadomba, W. Z. (2019). Unemployment and informal entrepreneurship in Zimbabwe: Implications for regional integration. In *Innovation, regional integration, and development in Africa* (pp. 251-266). Springer.

Muñoz, C. G. (2018). Challenges in occupational justice and social inclusion: Selected experiences within Valdivia's civil society. *Journal of Occupational Science*, *25*(4), 486-496. https://doi.org/10.1080/14427591.2018.1517404

Murphy, E. (1997). *Constructivism: From Philosophy to Practice*. http://files.eric.ed.gov/fulltext/ED444966.pdf

Ndlovu-Gatsheni, S. J. (2013). Why decoloniality in the 21st century. *The thinker*, *48*(10), 5-9.

Ndlovu-Gatsheni, S. J. (2015). Decoloniality as the Future of Africa. *History Compass*, *13*(10), 485-496. https://doi.org/https://doi.org/10.1111/hic3.12264

Neale, J. (2001). *Drug users in society*. Springer.

Nevile, A. (2006). *Is Social Exclusion a Useful Concept for Policy-Makers in Australia?* (Vol. 1). Curtin University of Technology. https://doi.org/10.3316/informit.767007035620049

Ngwenyama, O. K. (1991). The critical social theory approach to information systems: problems and challenges. *Information systems research: Contemporary approaches and emergent traditions*, 267-280.

Nhunzvi, C., Galvaan, R., & Peters, L. (2019). Recovery From Substance Abuse Among Zimbabwean Men: An Occupational Transition. *OTJR: Occupation, Participation and Health*, *39*(1), 14-22.

Nhunzvi, C., Langhaug, L., Mavindidze, E., Harding, R., & Galvaan, R. (2019). Occupational justice and social inclusion in mental illness and HIV: a scoping review protocol. *BMJ Open*, *9*(3), e024049. https://doi.org/10.1136/bmjopen-2018-024049

Nhunzvi, C., Langhaug, L., Mavindidze, E., Harding, R., & Galvaan, R. (2020). Occupational justice and social inclusion among people living with HIV and people with mental illness: a scoping review. *BMJ Open*, *10*(8), e036916. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7418773/pdf/bmjopen-2020-036916.pdf

Nieminen, I., Ramon, S., Dawson, I., Flores, P., Leahy, E., Pedersen, M., & Kaunonen, M. (2012). Experiences of social inclusion and employment of mental health service users in a european union project [Article]. *International Journal of Mental Health*, *41*(4), 3-23. https://doi.org/10.2753/IMH0020-7411410401

Nieminen, I., Ramon, S., Dawson, I., Flores, P., Leahy, E., Pedersen, M. L., & Kaunonen, M. (2012). Experiences of Social Inclusion and Employment of Mental Health Service Users in a European Union Project [Article]. *International Journal of Mental Health*, *41*(4), 3-23. https://doi.org/10.2753/IMH0020-7411410401

Nilsson, I., & Townsend, E. (2010). Occupational Justice—Bridging theory and practice. *Scandinavian Journal of Occupational Therapy*, *17*(1), 57-63. https://doi.org/10.3109/11038120903287182

Njaya, T. (2015). Informal sector, Panacea to the high unemployment in Zimbabwe? Case of informal sector enterprises of Harare Metropolitan. *International Journal of Research in Humanities and social studies*, *2*(2).

Nora D. Volkow, & Montaner., J. (2011). The Urgency Of Providing Comprehensive And Integrated Treatment For Substance Abusers With HIV. *Health Affairs*, *30*(8), 1411-1419. https://doi.org/10.1377/hlthaff.2011.0663

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*, *16*(1), 1609406917733847. https://doi.org/10.1177/1609406917733847

Nussbaum, M. (2007). Human Rights and Human Capabilities *Harvard Human Rights Journal*, *20*, 21-24.

Nussbaum, M., & Sen, A. (1993). *The quality of life*. Clarendon Press.

Nyika, H., Mugurungi, O., Shambira, G., Gombe, N. T., Bangure, D., Mungati, M., & Tshimanga, M. (2016). Factors associated with late presentation for HIV/AIDS care in Harare City, Zimbabwe, 2015. *BMC Public Health*, *16*, 369. https://doi.org/10.1186/s12889-016-3044-7

O'Brien, M., & Penna, S. (2008). Social exclusion in Europe: some conceptual issues. *International Journal of Social Welfare*, *17*(1), 84-92. https://doi.org/10.1111/j.1468-2397.2006.00478.x

Okon, E. E. (2014). Christian missions and colonial rule in Africa: Objective and contemporary analysis. *European Scientific Journal*, *10*(17).

Olley, B. O., Ogunde, M. J., Oso, P. O., & Ishola, A. (2016). HIV-related stigma and self-disclosure: the mediating and moderating role of anticipated discrimination among people living with HIV/AIDS in Akure Nigeria. *AIDS Care*, *28*(6), 726-730. https://doi.org/10.1080/09540121.2016.1140894

Olmsted, J. C. (2005). Is paid work the (only) answer? Neoliberalism, Arab women's well-being, and the social contract. *Journal of Middle East Women's Studies*, *1*(2), 112-139.

Organisation for Economic Co-operation and Development -OECD. (2021). *Improving social inclusion at the local level through the social economy*. Retrieved 6/05/2021 from https://www.oecd.org/cfe/leed/improvingsocialinclusionatthelocallevelthroughthesocialeconomy.htm

Oxfam International. (2015). *A Europe For the Many, Not the Few: Time to reverse the course of inequality and poverty in Europe* (1780778988). https://www-cdn.oxfam.org/s3fs-public/file_attachments/bp206-europe-for-many-not-few-090915-en.pdf

Oxford, S. (2019). 'You look like a machito!': a decolonial analysis of the social in/exclusion of female participants in a Colombian sport for development and peace organization. *Sport in Society*, *22*(6), 1025-1042. https://doi.org/10.1080/17430437.2019.1565389

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533-544. https://doi.org/10.1007/s10488-013-0528-y

Palys, T. (2008). Purposive sampling. *The Sage Encyclopedia of Qualitative Research Methods*, *2*(1), 697-698.

Parnell, T., & Wilding, C. (2010). Where can an occupation-focussed philosophy take occupational therapy? *Australian Occupational Therapy Journal*, *57*(5), 345. https://doi.org/10.1111/j.1440-1630.2010.00860.x

Parvin, S., & Eslamian, A. (2014). The Lived Experience of Social Relations in Women Living with HIV. *Women in Development & Politics*, *12*(2), 207-228. https://doi.org/10.22059/jwdp.2014.52356

Patel, V. (2015). Addressing social injustice: a key public mental health strategy. *World psychiatry: official journal of the World Psychiatric Association (WPA)*, *14*(1), 43-44. https://doi.org/10.1002/wps.20179

Patel, V., Simunyu, E., Gwanzura, F., Lewis, G., & Mann, A. (1997). The Shona Symptom Questionnaire: the development of an indigenous measure of common mental disorders in Harare. *Acta Psychiatrica Scandinavica*, *95*(6), 469-475. https://doi.org/https://doi.org/10.1111/j.1600-0447.1997.tb10134.x

Patton, M. Q. (2005). Qualitative Research. In *Encyclopedia of Statistics in Behavioral Science*. https://doi.org/https://doi.org/10.1002/0470013192.bsa514

Pereira, R. (2015). Enabling social transformation through occupation for citizens living with mental illness.

Pereira, R. B. (2013). *The politics of participation: A critical occupational science analysis of social inclusion policy and entrenched disadvantage* Macquarie University].

Pereira, R. B. (2017). Towards inclusive occupational therapy: Introducing the CORE approach for inclusive and occupation-focused practice. *Australian Occupational Therapy Journal*, *64*(6), 429-435. https://doi.org/10.1111/1440-1630.12394

Pereira, R. B., Whiteford, G., Hyett, N., Weekes, G., Di Tommaso, A., & Naismith, J. (2020). Capabilities, Opportunities, Resources and Environments (CORE): Using the CORE approach for inclusive,

occupation-centred practice. *Australian Occupational Therapy Journal*, *67*(2), 162-171. https://doi.org/https://doi.org/10.1111/1440-1630.12642

Pereira, R. B., & Whiteford, G. E. (2013). Understanding social inclusion as an international discourse: Implications for enabling participation. *British Journal of Occupational Therapy*, *76*(2), 112-115.

Phillips, M. (2009). Critical Theory (after Habermas). In *International Encyclopaedia of Human Geography* (pp. 385-397). https://doi.org/10.1016/B978-008044910-4.00673-8

Pickett, S. A., Luther, S., Stellon, E., & Batia, K. (2015). Making Integrated Care a Reality: Lessons Learned From Heartland Health Outreach's Integration Implementation. *American Journal of Psychiatric Rehabilitation*, *18*(1), 87-104. https://doi.org/10.1080/15487768.2015.1001698

Pierce, D. E., & Pierce, D. (2003). *Occupation by design: Building therapeutic power*. FA Davis company Philadelphia.

Pitonyak, J. S., Mroz, T. M., & Fogelberg, D. (2015). Expanding client-centred thinking to include social determinants: a practical scenario based on the occupation of breastfeeding. *Scandinavian Journal of Occupational Therapy*, *22*(4), 277-282. https://doi.org/10.3109/11038128.2015.1020865

Pohlan, L. (2019). Unemployment and social exclusion. *Journal of Economic Behavior & Organization*, *164*, 273-299. https://doi.org/10.1016/j.jebo.2019.06.006

Polatajko, H. J., Molke, D., Baptiste, S., Doble, S., Santha, J., & Kirsh, B. (2007). Occupational science: Imperatives for occupational therapy. In EA Townsen & HJ Polatajko (Eds.), *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, and justice through occupation* (Vol. 2, pp. 63-81). Canadian Association of Occupational Therapists.

Polit, D. F., & Beck, C. T. (2006). The content validity index: Are you sure you know what's being reported? critique and recommendations. *Research in Nursing & Health*, *29*(5), 489-497. https://doi.org/https://doi.org/10.1002/nur.20147

Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences*. Suny Press.

Polkinghorne, D. E. (1995a). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*, *8*(October), 5-23. https://doi.org/10.1080/0951839950080103

Polkinghorne, D. E. (1995b). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*, *8*(1), 5-23. https://doi.org/10.1080/0951839950080103

Polkinghorne, D. E. (1998). *Narrative Knowing and the Human Sciences*. State University of New York Press.

Popay, J., Escorel, S., Hernandez, M., Johnson, H., Mathieson, J., & Rispel, L. (2008). *'Understanding and tackling social exclusion'. Final report to the World Health. Organisation's Commission on Social Determinants of Health* (Vol. null).

Prawat, R. S., & Floden, R. E. (1994). Philosophical perspectives on constructivist views of learning. *Educational Psychologist*, *29*(1), 37-48. https://doi.org/10.1207/s15326985ep2901_4

Pufall, E. L., Eaton, J. W., Robertson, L., Mushati, P., Nyamukapa, C., & Gregson, S. (2017). Education, substance use, and HIV risk among orphaned adolescents in Eastern Zimbabwe. *Vulnerable children and youth studies*, *12*(4), 360-374. https://doi.org/10.1080/17450128.2017.1332398

Puras, D., & Gooding, P. (2019). Mental health and human rights in the 21st century. *World Psychiatry*, *18*(1), 42-43. https://doi.org/10.1002/wps.20599

Puwar, N. (2004). *Space invaders: Race, gender and bodies out of place*. Berg.

QSR International, P. L. (2018). *NVivo qualitative data analysis software. Version 12* (USA Patent No. https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home/

Quijano, A. (2000). Coloniality of Power and Eurocentrism in Latin America. *International Sociology*, *15*(2), 215-232. https://doi.org/10.1177/0268580900015002005

Quijano, A. (2007). COLONIALITY AND MODERNITY/RATIONALITY. *Cultural Studies*, *21*(2-3), 168-178. https://doi.org/10.1080/09502380601164353

Quinhoes, T. A. T., & Fava, V. M. D. (2020). Social Inclusion in Brazil from 2003 to 2014: Insights of Bolsa Família Program and the Brasil Sem Miséria Plan. *Journal of Iberian and Latin American Research*, *26*(1), 34-53. https://doi.org/10.1080/13260219.2020.1778766

Raitakari, S., Haahtela, R., & Juhila, K. (2016). Tackling community integration in mental health home visit integration in Finland. *Health & Social Care in the Community*, *24*(5), E53-E62. https://doi.org/10.1111/hsc.12246

Ramafikeng, M. C., Roshan, G., & Amesun, S. L. (2019). Tobacco use and concurrent engagement in other risk behaviours: A public health challenge for occupational therapists. *South African Journal of Occupational Therapy*, *49*, 26-35. http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S2310-38332019000100005&nrm=iso

Ramon, S., Griffiths, C. A., Nieminen, I., Pedersen, M., & Dawson, I. (2011). Towards social inclusion through lifelong learning in mental health: Analysis of change in the lives of the EMILIA project service users. *International Journal of Social Psychiatry*, *57*(3), 211-223. https://doi.org/10.1177/0020764009354943

Ramugondo, E. (2009). *Intergenerational shifts and continuities in children's play within a rural Venda family in the early 20th and 21st centuries* University of Cape Town]. OpenUCT. Cape Town. http://hdl.handle.net/11427/12113

Ramugondo, E. L., & Kronenberg, F. (2015). Explaining Collective Occupations from a Human Relations Perspective: Bridging the Individual-Collective Dichotomy. *Journal of Occupational Science*, *22*(1), 3-16. https://doi.org/10.1080/14427591.2013.781920

Rawal, N. (2008). Social inclusion and exclusion: A review. *Dhaulagiri Journal of Sociology and Anthropology*, *2*, 161-180.

Razzano A, L., Hamilton M, M., Yost, C., Pashka J, N., & Perloff K, J. (2015). Employment Outcomes for Individuals With HIV/AIDS and Co-Occurring Mental Health Factors. *American Journal of Psychiatric Rehabilitation*, *18*(1), 19-41. https://doi.org/10.1080/15487768.2015.1001700

Reich, R. B. (1992). *The work of nations: Preparing ourselves for 21st century capitalis*. Vintage.

Restall, G. J., MacLeod Schroeder, N. J., & Dubé, C. D. (2018). The Equity Lens for Occupational Therapy: A program development and evaluation tool: L'Equity Lens for Occupational Therapy: un outil pour le développement et l'évaluation de programme. *Canadian Journal of Occupational Therapy*, *85*(3), 185-195. https://doi.org/10.1177/0008417418756421

Riessman, C. K. (1993). *Narrative analysis* (Vol. 30). Sage.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage.

Riessman, C. K. (2010). What's different about narrative inquiry? Cases, categories and contexts. In D. Silverman (Ed.), *Qualitative research* (3rd ed., pp. 310-330). Sage.

Rispel, L., Molomo, B., & Dumela, S. (2008). *South African case study on social exclusion*. http://www.hsrcpress.ac.za/downloadpdf.php?pdffile=files/PDF/2235/exclusion_pr.pdf&downloadfilename=South African case study on social exclusion

Rispel, L., & Popay, J. (2009). Confronting social exclusion, HIV and gender inequalities in South Africa. *Agenda*, *23*(81), 90-100. https://doi.org/10.1080/10130950.2009.9676257

Rispel, L. C., de Sousa, C. A. D. P., & Molomo, B. G. (2009). Can social inclusion policies reduce health inequalities in sub-Saharan Africa?--A rapid policy appraisal. *Journal of health, population, and nutrition*, *27*(4), 492-504. https://doi.org/10.3329/jhpn.v27i4.3392

Robeyns, I. (2011). The capability approach. *Stanford*.

Robeyns, I. (2016). Capabilitarianism. *Journal of Human Development and Capabilities*, *17*(3), 397-414. https://doi.org/10.1080/19452829.2016.1145631

Rodgers, B. L., & Cowles, K. V. (1993). The qualitative research audit trail: A complex collection of documentation. *Research in Nursing & Health*, *16*(3), 219-226. https://doi.org/https://doi.org/10.1002/nur.4770160309

Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, *53*(3), 304-310. https://doi.org/https://doi.org/10.1111/j.1365-2648.2006.03727.x

Rudman, D. L. (2015). Situating occupation in social relations of power: Occupational possibilities, ageism and the retirement 'choice'. *South African Journal of Occupational Therapy*, *45*, 27-33. http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S2310-38332015000100005&nrm=iso

Rukuni, R., McHugh, G., Majonga, E., Kranzer, K., Mujuru, H., Munyati, S., Nathoo, K., Gregson, C. L., Kuper, H., & Ferrand, R. A. (2018). Disability, social functioning and school inclusion among older children and adolescents living with HIV in Zimbabwe. *Tropical Medicine & International Health*, *23*(2), 149-155. https://doi.org/https://doi.org/10.1111/tmi.13012

Rule, R., & Twinley, R. (2021). Developing an occupational perspective of women involved in sex work: A discussion paper. *Journal of Occupational Science*, *28*(1), 133-143. https://doi.org/10.1080/14427591.2020.1739552

Rush, F. (2004). Conceptual foundations of early Critical Theory. In F. L. Rush (Ed.), *The Cambridge Companion to Critical Theory* (pp. 6--39). Cambridge University Press.

Rusvingo, S. L. (2015). The Zimbabwe soaring unemployment rate of 85%: A ticking time bomb not only for Zimbabwe but the entire SADC region (2014). *Global Journal of Management and Business Research*.

Rwafa, C. (2014). *The prevalence of substance use disorders among adult mental health service users admitted in psychiatry hospitals in Harare, Zimbabwe.* University of Zimbabwe.]. Harare.

Rwafa, C., Mangezi, W. O., & Madhombiro, M. (2019). Substance Use Among Patients Admitted to Psychiatric Units in Harare, Zimbabwe. *The Lancet Psychiatry*.

Rwafa, T., Shamu, S., & Christofides, N. (2019). Relationship power and HIV sero-status: an analysis of their relationship among low-income urban Zimbabwean postpartum women. *BMC Public Health*, *19*(1), 792. https://doi.org/10.1186/s12889-019-7137-y

Saavedra, J., Pérez, E., Crawford, P., & Arias, S. (2018). Recovery and creative practices in people with severe mental illness: evaluating well-being and social inclusion [Article]. *Disability and Rehabilitation*, *40*(8), 905-911. https://doi.org/10.1080/09638288.2017.1278797

Sacktor, N. C., Wong, M., Nakasujja, N., Skolasky, R. L., Selnes, O. A., Musisi, S., Robertson, K., McArthur, J. C., Ronald, A., & Katabira, E. (2005). The International HIV Dementia Scale: a new rapid screening test for HIV dementia. *AIDS*, *19*(13), 1367-1374. https://doi.org/10.1097/01.aids.0000180790.77379.3a

Said, W. E. (2003). *Orientalism* (3rd ed.). Penguin.

Sakellariou, D., & Pollard, N. (2013). A commentary on the social responsibility of occupational therapy education. *Journal of Further and Higher Education*, *37*(3), 416-430. https://doi.org/10.1080/0309877X.2011.645459

Salles, M. M., & Barros, S. (2013). Social representation of users of a Psychosocial Care Center and those in their social network on mental illness and social inclusion. *Saude e Sociedade*, *22*(4), 1059-1071. https://doi.org/10.1590/s0104-12902013000400009

Saloojee, A., & Saloojee, N. (2011). From Social Exclusion to Social Inclusion Theory and Practice over Two Continents. *African Journal of Public Affairs*, *4*(2), 1-17.

Sandfort, T. G. M., Knox, J. R., Alcala, C., El-Bassel, N., Kuo, I., & Smith, L. R. (2017). Substance Use and HIV Risk Among Men Who Have Sex With Men in Africa: A Systematic Review. *Journal of acquired immune deficiency syndromes (1999)*, *76*(2), e34-e46. https://doi.org/10.1097/QAI.0000000000001462

Santos, B. (2007). Beyond abyssal thinking: From global lines to ecologies of knowledges. *Review (Fernand Braudel Center)*, 45-89.

Sayce, L. (2001). Social inclusion and mental health. *Psychiatric Bulletin*, *25*(4), 121-123. https://doi.org/10.1192/pb.25.4.121

Schadé, A., van Grootheest, G., & Smit, J. H. (2013). HIV-infected mental health patients: characteristics and comparison with HIV-infected patients from the general population and non-infected mental health patients. *BMC psychiatry*, *13*(1), 35. https://doi.org/10.1186/1471-244X-13-35

Scope, O. T., Therapy, O., Ot, T., Board, L., Therapy, O., Rules, O. A., & Therapy, O. (2008). Oregon OT Licensing Board " Scope of Practice ". *210*(3).

Sen, A. (1992). *Inequality reexamined*. Oxford University Press.

Sen, A. (1993). Capability and well-being. In Nussbaum & Sen (Eds.), *The quality of life* (Vol. 30, pp. 270-293).

Sen, A. (1999). *Development as freedom*. Oxford Paperbacks.

Sen, A. (2000). *Social Exclusion: Concept, Application, and Scrutiny*. http://hdl.handle.net/11540/2339

Sen, A. K. (2009). *The idea of justice*. Harvard University Press.

Serrata Malfitano, A. P., Gomes da Mota de Souza, R., & Esquerdo Lopes, R. (2016). Occupational Justice and Its Related Concepts: An Historical and Thematic Scoping Review. *OTJR (Thorofare N J)*, *36*(4), 167-178. https://doi.org/10.1177/1539449216669133

Sharp, N. L., Bye, R. A., & Cusick, A. (2019). Narrative inquiry and narrative analysis: practical application of techniques for occupational therapy research. Australian Occupational Therapy Journal, Vol. 66, Suppl. 1: Occupational Therapy Australia 28th National Conference and Exhibition, 10-12 July 2019, International Convention Centre, Sydney,

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*, 63-75. https://doi.org/10.3233/EFI-2004-22201

Shizha, E. (2006). Legitimizing indigenous knowledge in Zimbabwe: A theoretical analysis of postcolonial school knowledge and its colonial legacy. *Youth and Children's Studies*, *2*. http://scholars.wlu.ca/brantford_yc/2

Shizha, E. (2010). Rethinking and Reconstituting Indigenous Knowledge and Voices in the Academy in Zimbabwe: A Decolonization Process. In D. Kapoor & E. Shizha (Eds.), *Indigenous Knowledge and Learning in Asia/Pacific and Africa.* (pp. 115-129). Palgrave Macmillan. https://doi.org/ https://doi.org/10.1057/9780230111813_8

Sia, D., Onadja, Y., Nandi, A., Foro, A., & Brewer, T. (2013). What lies behind gender inequalities in HIV/AIDS in sub-Saharan African countries: evidence from Kenya, Lesotho and Tanzania. *Health Policy and Planning*, *29*(7), 938-949. https://doi.org/10.1093/heapol/czt075

Silva, M., Loureiro, A., & Cardoso, G. (2016). Social determinants of mental health: a review of the evidence. *The European Journal of Psychiatry*, *30*, 259-292. http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S0213-61632016000400004&nrm=iso

Silver, H. (1994). Social exclusion and social solidarity: Three paradigms. *International Labour Review*, *133*(5-6), 531-578.

Silver, H. (2015). The contexts of social inclusion.

Silverman, D. (2015). *Interpreting qualitative data*. Sage.

Simaan, J. (2017). Olive growing in Palestine: A decolonial ethnographic study of collective daily-forms-of-resistance. *Journal of Occupational Science*, *24*(4), 510-523. https://doi.org/10.1080/14427591.2017.1378119

Sin, N. L., & DiMatteo, M. R. (2013). Depression Treatment Enhances Adherence to Antiretroviral Therapy: a Meta-Analysis. *Annals of Behavioral Medicine*, *47*(3), 259-269. https://doi.org/10.1007/s12160-013-9559-6

Sinkovics, R. R., & Alfoldi, E. A. (2012). Progressive Focusing and Trustworthiness in Qualitative Research. *Management International Review*, *52*(6), 817-845. https://doi.org/10.1007/s11575-012-0140-5

Sithole, T. (2014). *Achille Mbembe: Subject, subjection, and subjectivity* University of South Africa Pretoria].

Skeen, S., Kleintjes, S., Lund, C., Petersen, I., Bhana, A., & Flisher, A. J. (2010). 'Mental health is everybody's business': roles for an intersectoral approach in South Africa. *International Review of Psychiatry*, *22*(6), 611-623. https://doi.org/10.3109/09540261.2010.535510

Smyth, G., Harries, P., & Dorer, G. (2011). Exploring mental health service users' experiences of social inclusion in their community occupations. *British Journal of Occupational Therapy*, *74*(7), 323-331. https://doi.org/10.4276/030802211X13099513661072

Sparkes, J. (1999). *Schools, education and social exclusion* (LSE STICERD Research Paper No. CASE029, Issue. https://ssrn.com/abstract=1158920

Speziale, H. S., Streubert, H. J., & Carpenter, D. R. (2011). *Qualitative research in nursing: Advancing the humanistic imperative*. Lippincott Williams & Wilkins.

Sprague, L., Simon, S., & Sprague, C. (2011). Employment discrimination and HIV stigma: survey results from civil society organisations and people living with HIV in Africa. *African Journal of AIDS Research*, *10*(sup1), 311-324. https://doi.org/10.2989/16085906.2011.637730

Stain, H. J., Galletly, C. A., Clark, S., Wilson, J., Killen, E. A., Anthes, L., Campbell, L. E., Hanlon, M.-C., & Harvey, C. (2012). Understanding the social costs of psychosis: The experience of adults affected by psychosis identified within the second Australian national survey of psychosis. *Australian and New Zealand Journal of Psychiatry*, *46*(9), 879-889. https://doi.org/10.1177/0004867412449060

Stake, R. (2000). Case studies. In NK Denzin & YS Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 435-454). Sage.

Stake, R. (2003). Responsive evaluation. In *International handbook of educational evaluation* (pp. 63-68). Springer.

Stake, R. E. (1995). *The art of case study research*. Sage.

Stake, R. E. (2008). Qualitative case studies. In *Strategies of qualitative inquiry, 3rd ed.* (pp. 119-149). Sage Publications, Inc.

StataCorp, L. (2015). *Stata statistical software (version release 14)*.

Stevens, P. E. (1989). A critical social reconceptualization of environment in nursing: implications for methodology. *ANS. Advances in Nursing Science*, *11*(4), 56-68. https://doi.org/10.1097/00012272-198907000-00009

Stienstra, D., & Nyerere, L. (2016). Race, Ethnicity and Disability: Charting Complex and Intersectional Terrains. In S. Grech & K. Soldatic (Eds.), *Disability in the Global South. International Perspectives on Social Policy, Administration, and Practice.* Springer. https://doi.org/ https://doi.org/10.1007/978-3-319-42488-0_16

Stockman, J. K., & Strathdee, S. A. (2010). HIV among people who use drugs: a global perspective of populations at risk. *Journal of acquired immune deficiency syndromes (1999)*, *55 Suppl 1*(Suppl 1), S17-S22. https://doi.org/10.1097/QAI.0b013e3181f9c04c

Stringer, K., Schumacher, J. E., Turan, J. M., Mugavero, M., Kempf, M. C., & Baker, E. (2015). The perceived stigma of substance abuse scale: Reliability and validity with substance using people living with HIV. *Drug and Alcohol Dependence*, *100*(156), e215. https://doi.org/10.1016/j.drugalcdep.2015.07.579

Sullivan, M. C., Rosen, A. O., Allen, A., Benbella, D., Camacho, G., Cortopassi, A. C., Driver, R., Ssenyonjo, J., Eaton, L. A., & Kalichman, S. C. (2020). Falling Short of the First 90: HIV Stigma and HIV Testing Research in the 90–90–90 Era. *AIDS and Behavior*, *24*(2), 357-362. https://doi.org/10.1007/s10461-019-02771-7

Sutton, J., & Austin, Z. (2015). Qualitative Research: Data Collection, Analysis, and Management. *The Canadian journal of hospital pharmacy*, *68*(3), 226-231. https://doi.org/10.4212/cjhp.v68i3.1456

Suzuki, N. (2017). A Capability Approach to Understanding Sport for Social Inclusion: Agency, Structure and Organisations. *Social Inclusion*, *5*(2), 150-158. https://doi.org/doi:http://dx.doi.org/10.17645/si.v5i2.905

Terzi, L. (2005). A capability perspective on impairment, disability and special needs: Towards social justice in education. *Theory and Research in Education*, *3*(2), 197-223. https://doi.org/10.1177/1477878505053301

The World Bank. (2014). *Youth employment in sub-Saharan Africa*. The World Bank.

The World Bank. (2016). *Poverty and Shared Prosperity 2016: Taking on Inequality*. The World Bank. https://doi.org/10.1596/978-1-4648-0958-3

The World Bank. (2019). *Inclusion Matters in Africa*. The World Bank. https://doi.org/10.1596/32528

Tiwari, M. (2014). Capability Approach, Livelihoods and Social Inclusion: Agents of Change in Rural India. In S. Ibrahim & M. Tiwari (Eds.), *The Capability Approach: From Theory to Practice* (pp. 29-51). Palgrave Macmillan UK. https://doi.org/10.1057/9781137001436_2

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4), 388-396. https://doi.org/https://doi.org/10.1111/j.1365-2648.2004.03207.x

Townsend, E., & A.Wilcock, A. (2004). Occupationaljustice and Client-Centred Practice: A Dialogue in Progress. *Canadian Journal of Occupational Therapy*, *71*(2), 75-87. https://doi.org/10.1177/000841740407100203

Townsend, E., & Wilcock, A. A. (2004). Occupational justice and client-centred practice: a dialogue in progress. *Canadian Journal of Occupational Therapy. Revue Canadienne D'Ergothérapie*, *71*(2), 75-87. https://doi.org/10.1177/000841740407100203

Traustadóttir, R. (2008). Work, Disability, and Social Inclusion. In M. L. DeVoult (Ed.), *People at work: life, power, and social inclusion in the new economy* (pp. 74–96). New York University Press.

Trust., T. H. (2001). *Social exclusion and HIV* (Vol. null).

Turner, N., Ferguson, L., Hill, M., Nesbitt, T., O'Callaghan, E., O'Mahony, P., & Clarke, M. (2017). An exploratory study of the extent of social inclusion among people with psychosis and psychotic-related conditions. *International Journal of Social Psychiatry*, *63*(3), 195-202. https://doi.org/10.1177/0020764017691551

Twinley, R. (2013). The dark side of occupation: A concept for consideration. *Australian Occupational Therapy Journal*, *60*(4), 301-303.

Twinley, R., & Addidle, G. (2012). Considering Violence: The Dark Side of Occupation. *British Journal of Occupational Therapy*, *75*(4), 202-204. https://doi.org/10.4276/030802212x13336366278257

UNAIDS. (2018). *THEMATIC SEGMENT: MENTAL HEALTH AND HIV/AIDS PROMOTING HUMAN RIGHTS, AN INTEGRATED AND PERSON-CENTRED APPROACH TO IMPROVING ART ADHERENCE, WELL-BEING AND QUALITY OF LIFE.* https://www.unaids.org/sites/default/files/media_asset/20181203_UNAIDS_PCB43_BN_thematic-segment-mental-health-and-HIV_EN.pdf

UNAIDS. (2019a). *Global AIDS update 2019 — Communities at the centre — Defending rights, breaking barriers, reaching people with HIV services*. https://www.unaids.org/sites/default/files/media_asset/2019-global-AIDS-update_en.pdf

UNAIDS. (2019b). *UNAIDS data 2019*. https://www.unaids.org/sites/default/files/media_asset/2019-UNAIDS-data_en.pdf

van Bergen, A. P. L., Wolf, J. R. L. M., Badou, M., de Wilde-Schutten, K., IJzelenberg, W., Schreurs, H., Carlier, B., Hoff, S. J. M., & van Hemert, A. M. (2018). The association between social exclusion or inclusion and health in EU and OECD countries: a systematic review. *European Journal of Public Health*, *29*(3), 575-582. https://doi.org/10.1093/eurpub/cky143

Van Esch, P., & Van Esch, L. (2013). Justification of a qualitative methodology to investigate the emerging concept: The dimensions of religion as underpinning constructs for mass media social marketing campaigns. *Journal of Business Theory and Practice*, *1*(2), 214-243.

van Hees, S. G. M., O'Fallon, T., Hofker, M., Dekker, M., Polack, S., Banks, L. M., & Spaan, E. J. A. M. (2019). Leaving no one behind? Social inclusion of health insurance in low- and middle-income

countries: a systematic review. *International Journal for Equity in Health*, *18*(1), 134. https://doi.org/10.1186/s12939-019-1040-0

Vessby, K., & Kjellberg, A. (2010). Participation in Occupational Therapy Research: A Literature Review. *British Journal of Occupational Therapy*, *73*(7), 319-326. https://doi.org/10.4276/030802210x12759925544380

Vinzón, V., Allegretti, M., & Magalhães, L. (2020). An overview of occupational therapy community practices in Latin America [Um panorama das práticas comunitarias da terapia ocupacional na América Latina]. *Cadernos de Terapia Ocupacional da UFSCar*, *28*(2), 600-620. https://doi.org/http://dx.doi.org/10.4322/2526-8910.ctoAR1891

Waters, J. (2015). Snowball sampling: a cautionary tale involving a study of older drug users. *International Journal of Social Research Methodology*, *18*(4), 367-380. https://doi.org/10.1080/13645579.2014.953316

Weedon, C. (1989). *Feminist Practice and Poststructuralist Theory*.

Whatley, E., Fortune, T., & Williams, A. E. (2015a). Enabling occupational participation and social inclusion for people recovering from mental ill-health through community gardening. *Australian Occupational Therapy Journal*, *62*(6), 428-437. https://doi.org/https://doi.org/10.1111/1440-1630.12240

Whatley, E., Fortune, T., & Williams, A. E. (2015b). Enabling occupational participation and social inclusion for people recovering from mental ill-health through community gardening. *Australian Occupational Therapy Journal*, *62*(6), 428-437. https://onlinelibrary.wiley.com/doi/abs/10.1111/1440-1630.12240

Whetten, K., Reif, S. S., Napravnik, S., Swartz, M. S., Thielman, N. M., Eron, J. J., Jr., Lowe, K., & Soto, T. (2005, 2005/01//). Substance abuse and symptoms of mental illness among HIV-positive persons in the Southeast. *Southern medical journal*, *98*(1), 9+.

Whiteford, G. (2004). When people can't participate: Occupational Deprivation. In *Introduction to occupation: The art and science of living* (pp. 221-242). Prentice Hall.

Whiteford, G. (2017). Participation in higher education as social inclusion: An occupational perspective. *Journal of Occupational Science*, *24*(1), 54-63. https://doi.org/10.1080/14427591.2017.1284151

Wicks, A., & Whiteford, G. (2006). Conceptual and practical issues in qualitative research: Reflections on a life-history study. *Scandinavian Journal of Occupational Therapy*, *13*(2), 94-100. https://doi.org/10.1080/11038120600654676

Wilcock, A. A. (2006). *An occupational perspective of health*. Slack Incorporated.

Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., & Erikson, P. (2005). Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: Report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value in Health*, *8*(2), 94-104. https://doi.org/https://doi.org/10.1111/j.1524-4733.2005.04054.x

Williams, E. N., & Morrow, S. L. (2009). Achieving trustworthiness in qualitative research: A pan-paradigmatic perspective. *Psychotherapy Research*, *19*(4-5), 576-582. https://doi.org/10.1080/10503300802702113

Williams, G. H. (2003). The determinants of health: structure, context and agency. *Sociology of Health & Illness*, *25*(3), 131-154. https://doi.org/https://doi.org/10.1111/1467-9566.00344

Willis, G. B. (2004). *Cognitive interviewing: A tool for improving questionnaire design*. sage publications.

Wong, G., & Breheny, M. (2018). Narrative analysis in health psychology: a guide for analysis. *Health psychology and behavioral medicine*, *6*(1), 245-261. https://doi.org/10.1080/21642850.2018.1515017

World Bank. (2013). *Inclusion matters: The foundation for shared prosperity.*

World Health, O. (2008). *The Global Burden of Disease: 2004 update* (9789241563710). http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/index.html

World Health Organization. (2010). Mental health: Strengthening our response (Fact Sheet 220). . http://www.who.int/mediacentre/factsheets/fs220/en/

World Health Organization. (2016). *World health statistics 2016: monitoring health for the SDGs sustainable development goals*. World Health Organization.

Wright, N., & Stickley, T. (2013). Concepts of social inclusion, exclusion and mental health: a review of the international literature. *Journal of Psychiatric and Mental Health Nursing*, *20*(1), 71-81.

Yanicki, S. M., Kushner, K. E., & Reutter, L. (2015). Social inclusion/exclusion as matters of social (in)justice: a call for nursing action. *Nursing Inquiry*, *22*(2), 121-133. https://doi.org/https://doi.org/10.1111/nin.12076

Yerxa, E. J. (2000). Occupational science: a renaissance of service to humankind through knowledge [https://doi.org/10.1002/oti.109]. *Occupational Therapy International*, *7*(2), 87-98. https://doi.org/https://doi.org/10.1002/oti.109

Yick, A. G. (2007). Role of Culture and Context: Ethical Issues in Research with Asian Americans and Immigrants in Intimate Violence. *Journal of Family Violence*, *22*(5), 277. https://doi.org/10.1007/s10896-007-9079-x

Yin, R. (2003). *Case Study Research: Designs and Methods.* (3rd ed.). Sage Publications.

Yin, R. K. (2009). *Case study research: Design and methods (applied social research methods)*. Sage publications Thousand Oaks, CA.

Zahari, M. M., Hwan Bae, W., Zainal, N. Z., Habil, H., Kamarulzaman, A., & Altice, F. L. (2010). Psychiatric and Substance Abuse Comorbidity among HIV Seropositive and HIV Seronegative Prisoners in Malaysia. *The American Journal of Drug and Alcohol Abuse*, *36*(1), 31-38. https://doi.org/10.3109/00952990903544828

Central Intelligence Agency -CIA. (2018). *The World Factbook on Zimbabwe [online]* https://www.cia.gov/library/publications/the-world-factbook/geos/zi.html

de Sousa Santos, B. (2007). Beyond abyssal thinking: From global lines to ecologies of knowledges. *Review (Fernand Braudel Center)*, 45-89.

Gould, S. J. (1988). Consumer Attitudes Toward Health and Health Care: A Differential Perspective. *Journal of Consumer Affairs*, *22*(1), 96-118. https://doi.org/https://doi.org/10.1111/j.1745-6606.1988.tb00215.x

Grosfoguel, R. (2009). A decolonial approach to political-economy: Transmodernity, border thinking and global coloniality. *Kult*, *6*(1), 10-38.

Kiepek, N., & Magalhães, L. (2011). Addictions and Impulse-Control Disorders as Occupation: A Selected Literature Review and Synthesis. *Journal of Occupational Science*, *18*(3), 254-276. https://doi.org/10.1080/14427591.2011.581628

Kiepek, N., Phelan, S. K., & Magalhães, L. (2014). Introducing a Critical Analysis of the Figured World of Occupation. *Journal of Occupational Science*, *21*(4). https://doi.org/10.1080/14427591.2013.816998

Kiepek, N. C., Beagan, B., Rudman, D. L., & Phelan, S. (2019). Silences around occupations framed as unhealthy, illegal, and deviant. *Journal of Occupational Science*, *26*(3), 341-353. https://doi.org/10.1080/14427591.2018.1499123

Kirkaldy, A. (2005). *Capturing the soul: the Vhavenda and the missionaries [1870-1900]*. Protea.

L'Abbe, E. N. (2005). *A palaeodemographic, palaeopathologic and morphologic study of the 20th century Venda* University of Pretoria]. Pretoria.

Okon, E. E. (2014). Christian missions and colonial rule in Africa: Objective and contemporary analysis. *European Scientific Journal*, *10*(17).

Ramugondo, E. (2009). *Intergenerational shifts and continuities in children's play within a rural Venda family in the early 20th and 21st centuries* University of Cape Town]. OpenUCT. Cape Town. http://hdl.handle.net/11427/12113

Said, W. E. (2003). *Orientalism* (3rd ed.). Penguin.

Shizha, E. (2006). Legitimizing indigenous knowledge in Zimbabwe: A theoretical analysis of postcolonial school knowledge and its colonial legacy. *Youth and Children's Studies*, *2*. http://scholars.wlu.ca/brantford_yc/2

Shizha, E. (2010). Rethinking and Reconstituting Indigenous Knowledge and Voices in the Academy in Zimbabwe: A Decolonization Process. In D. Kapoor & E. Shizha (Eds.), *Indigenous Knowledge and Learning in Asia/Pacific and Africa.* (pp. 115-129). Palgrave Macmillan. https://doi.org/https://doi.org/10.1057/9780230111813_8

Sin, N. L., & DiMatteo, M. R. (2013). Depression Treatment Enhances Adherence to Antiretroviral Therapy: a Meta-Analysis. *Annals of Behavioral Medicine*, *47*(3), 259-269. https://doi.org/10.1007/s12160-013-9559-6

Sy, M. P., Bontje, P., Ohshima, N., & Kiepek, N. (2020). Articulating the form, function, and meaning of drug using in the Philippines from the lens of morality and work ethics. *Journal of Occupational Science*, *27*(1), 12-21. https://doi.org/10.1080/14427591.2019.1644662