
**Exploring how a Genetic Attribution to disease relates to
Internalised Stigma experiences of Xhosa people with
Schizophrenia and Rheumatic Heart Disease in South Africa**

Olivia Precious Matshabane



**Dissertation presented in fulfilment of the requirements for the degree of
Doctor of Philosophy in the Faculty of Health Science (Medicine)**

University of Cape Town

Supervisor: Dr J. de Vries

Co-supervisor: Dr M.M. Campbell

Date: JULY 2019

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.

DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof and that I have not previously in its entirety or in part, submitted it for obtaining any qualification.

Signed by candidate

Signed: O.P. Matshabane

Date: July 2019

ABSTRACT

Advances in genomics research have brought forth a number of psychosocial concerns. In Africa, in particular, one of the concerns relates to the potential impact of genomics research on stigma experienced by specific population groups. Using a mixed-methods approach, this study sought to explore how genetic causal explanation relates to the internalised stigma experiences of a sample of South African Xhosa people with schizophrenia (n= 36) and rheumatic heart disease (n= 46). Additionally, a pilot study was conducted with another sample of schizophrenia (n= 65) and rheumatic heart disease (n= 55) patients to translate and adapt an internalised stigma of mental illness scale into isiXhosa. The aim of the study was operationalised into three research questions, namely; 1. What causal attribution models do Xhosa people with schizophrenia and rheumatic heart disease employ to explain their illness and to what extent do genetic explanations play a role in these causal models? 2. What are the internalised stigma experiences of Xhosa people with schizophrenia and rheumatic heart disease? 3. How do the genetic causal explanations of Xhosa people with schizophrenia and rheumatic heart relate to their internalised stigma experiences, if at all? Through focus-group discussions participants were introduced to non-genetic and genetic causal explanations and then asked a series of open-ended questions eliciting their perceptions of disease causation, genetic causation and the possible implications these perceptions may have on internalised stigma they may have experienced. Next, an internalised stigma of mental illness scale (ISMI) was translated through a mixed-methods translation approach into Xhosa and adapted for use in both disease groups. Insights from this translation were used to gain an understanding of how the Xhosa language supports particular descriptions and conceptualisations of stigma experiences. Psychometric results provided further insights into particularly relevant internalised stigma items for each disease group. Findings from the FGDs and translation process suggested that firstly Xhosa people with schizophrenia and those with rheumatic heart

disease have a general understanding of genetics and genetic attribution to disease. Secondly, and not withstanding this knowledge, these participants hold a multitude of disease explanations. In consideration of the alternative causal explanations, and the factors these participants are exposed to, the genetic explanation did not appear to relate to their internalised stigma. While there was evidence of stigma in the two disease groups – schizophrenia patients reporting more stigma than the rheumatic heart disease sample – this stigma was not often related to a genetic attribution of disease. Findings suggest that the link between genetic attribution and stigma is complex. Due to the variable nature of the evidence derived from the study we cannot conclude that a genetic attribution is not related to stigma, however the findings provide clues as to why this is an unlikely implication for Xhosa people in these disease groups. This finding is different to empirical research which has been conducted in North American and European contexts. Although research in Western and European contexts suggests that attributing a disease to genetics may have an impact on disease-stigma, there have been minimal efforts to explore that assumption in the African context. This study, being one of the first to explore that assumption in an African population group, did not find consistent evidence to support it.

ISISHWANKATHELO

Ukukhula kwamanyathelo athe athatyathwa ngocwaningo ngezofuzo kuye kwazisa ngaphambili inxalabo malunga nemo yokuziphatha. Kwilizwekazi iAfrika ingakumbi, ezinxalabo zinxulumene kakhulu negalelo lophando kwezofuzo kwakunye nechaphaza abanye abantu ekuhlaleni abaye bazifumane benalo. Ngokusetyenziswa kweendlela ezixubeneyo, olucwaningo luzama ukuqwalasela ngokubanzi ukuba ingaba lengcaciso inxulumene njani na nechaphaza elithi libe ngaphakathi kulowo uziva enalo kwiqela labantu boMzantsi Afrika kubantu abangamaXhosa abanesifo sengqondo (aba=36) kwakunye nabanesifo sentliziyo (abanga=46). Ukongeza kolucwaningo, kuthe kwenziwa izifundo zokugelesha (pilot study) kwelinye iqela labantu abagula ngengqondo (abayi=65) kwakunye nabanesifo sentliziyo (abayi=55) ukuze kucaciswe ngokubanzi ukuba ingaba londele kangakanani na ichaphaza elingaphakathi kubantu besiXhosa abanezizifo. Injongo zolucwaningo zithe zohlulwa-hlulwa kwimibuzo emithathu eyile: 1. Ingaba abantu besiXhosa abanesifo sengqondo nesentliziyo basebenzisa eyiphi na imifanekiso ukuze bacacise izigulo zabo kwaye ingaba ingakanani indima edlalwa lufuzo kwezingcaciso? 2. Ngawaphi amava echaphaza elingaphakathi abantu abangamaXhosa abanesifo sengqondo nesentliziyo abanawo? 3. Ingaba ingcaciso zofuzo kubantu besiXhosa abanesifo sengqondo kwakunye nesentliziyo zinxulumana luhlobo luni na nechaza elithi libe ngaphakathi, ukuba kukhona ukunxulumana? Ngokusetyenziswa kweengxoxo zamaqela akhethiweyo abathabatha inxaxheba kolucwaningo bathe bachazelwa ngengcaciso zofuzo kwakunye nezo zingezizo ezofuzo bandula ukubuzwa imibuzo evulekileyo esiphelweni khonukuze kulandelwe eyabo imicamango ngabona bonobangela bezizifo, negalelo lofuzo, kwakunye nendima enokuthi lemicabango ithi ibenayo kwichaphaza elingaphakathi abaye bazive benalo. Ukusukela apho kuyekwathatyathwa isikali sesifo sengqondo (ISMI) sacalucalulwa ngeendlela ezixubeneyo siguqulelwa esiXhoseni ukuze kulungiselelwe ukusetyenziswa kwaso ngamaqela anazo zombini ezizifo. Imibono ethe

yafunyaniswa kulenguqulelo ithe yasetyenziswa ukuze kulandeleke ukuba ingaba ulwimi lwesiXhosa luzixhasa kangakanani na ezingcaciso kwakunye neengcaciso-banzi ngamava abanawo ngokuba nechaphaza. Iziphumo zengqondo ziye zanika ingcaciso ngokubanzi ngechaphaza elingaphakathi kubantu besifo ngasinye. Iziphumo ezifunyenweyo kolucwaningo (FGDs) kwakunye nenguqulelo zithe zabonakalisa okokuqala ukuba amaXhosa anesifo sengqondo nalawo anesifo sentliziyo anenkolo yawo ngezofuzo kwakunye nezinto ezibalelwa kwezizifo. Okwesibini, lungajongelwanga phantsi njalo olulwazi, abathabathe inxaxheba banengcaciso eziliqela ngezizifo. Xa kuqwalaselwa ezinye ingcaciso kwakunye nezinye izinto (abo bathe bathabatha inxaxheba badlula kuzo ebomini), ezingcaciso ngezofuzo azikhange zibonakalise kunxulumana nechaphaza elithi libe ngaphakathi kubo. Njengokuba kuye kwafumaneka ubungqina bechaphaza kwezizifo zombini, izigulana zesifo sengqondo zibe zezona zichatshazelwa ngakumbi lichaphaza kunezigulana zesifo sentliziyo kwaye elichaphaza alibonwanga linxulumene nofuzo lwezizifo. Iziphumo zibonakalisa ukuba unxulumano phakathi kofuzo nechaphaza yinto enobuzaza kakhulu. Ngoko ke ngenxa ye- antlukwano yobungqina obuthe bafunyaniswa kolucwaningo kunzima kakhulu ukugqiba ngokupheleleyo ukuba ufuzo lungabalelwa ekubeni lube kanti lunegalelo kwichaphaza, kodwa ke iziphumo zisinika umkhondo wokuba kungokuba kutheni lombono uphikisana namaXhosa akwezi zifo. Eziziphumo zahlukile kucwaningo oluthe lwagqitywa kuMantla Melika kwakunye neYurophu Njengokuba ucwaningo eNtshona kwakunye naseYurophu lubonakalisa ukuba ukubalela ezizizifo kufuzo kungaba negalelo kwisifo nechaphaza, imbalwa kakhulu imizamo ethatyathiweyo ukuqwalasela lombono kwizwekazi laseAfrika. Olucwaningo njengokuba ilolokuqala ukuqwalasela lengqikelelo kumaqela oluntu lwezwekazi laseAfrika alukhange lufumane bungqina buphangaleleyo bokuluxhasa.

ACKNOWLEDGEMENTS

"It takes a village to raise a child"- African proverb

This journey would not have been possible without the almighty Allah, following which, an army of phenomenal human beings who supported me. First, I would like to acknowledge A/Prof Jantina de Vries. Jantina, you have taught me how to rise with grace after a fall. Your grit and good humour have made this journey all the better. Dr Megan Campbell, you have taught me the power of kindness, patience and empathy to myself first, and then to others I have encountered on this journey. I have the deepest respect for you both. It has been an honour to be your student. The most important thing I thank you both for is believing in me.

It is that belief that bolstered me to believe in myself and my academic abilities.

While pursuing a PhD, I am told, is often a lonely journey, I can honestly say, to me, it did not once feel lonely, as I had so many individuals to lean on throughout this process. In particular, I was based in a research team at the Department of Medicine at UCT (the Mayosi Research Group) which consists of phenomenal staff, researchers and postgraduate students. While so many individuals within the team have shared kind words with me which I am truly grateful for, I would specifically like to acknowledge Mrs Peggy Kraba. Your warm welcome, consistent enthusiasm and support made all the difference during this journey.

Next, I would like to thank my family, starting with my son, Siphosethu Ali Matshabane. When I felt low, he would always say to me, *"Mommy I'm so proud of you"* and those words alone kept me going. I thank my mother and my grandmother for stepping in on various occasions when I could not be there for him because of my academics. When I think of these two women, I can not help but think how selfless they have been. I think of the words, they *"sacrificed their dreams so I could dream"*- rupi kaur. These words are without a doubt true to the very nature that these women have been. I would also like to mention a few other special individuals, my two brothers and fathers, who have also both supported me in numerous ways through this journey. *Kuni nonke, ndiyabulela, ngakho konke.*

Next, I would like to thank other individuals who have played salient roles in my journey; Mrs Thembelihle Dube-Addae, thank you for mentoring me, Prof. Tony Naidoo, following your much appreciated guidance as my Master's thesis supervisor, thank you for pushing me

to remain authentic in my academic journey and continuing to remain supportive of my career development. Ms Nokwanda Khumalo, I appreciate the fact that you created and nurtured a non-judgemental space where I could always come and process everything. My friends and family members who accepted my absence for long periods and instead of being upset, you prayed for me, I thank you. Prof Paul Appelbaum, I am grateful to you for your kindness in hosting me for a month at Columbia University and for always commenting on work I sent you efficiently. Prof Ezra Susser, you have been and continue to be incredibly generous to me, thank you. Prof Dan Stein, I am truly appreciative of your support in numerous ways.

The last six months of this journey were the most difficult for me as it was also the time when I stepped into the role of being a lecturer for Psychology second year students at UCT. I would therefore also like to thank the students who motivated me and continuously shared words of encouragement.

Finally, I am extremely indebted to the individuals who participated as research participants in this study. I am incredibly thankful to them for being open to sharing and trusting me with their narratives. In the same breath I am eternally grateful to the individuals who took time over weekends and after working hours to assist in the development of the materials used in this study.

This study received funding from the National Institutes of Health, the National Research Foundation and the Harry Crossley Research Fellowship at UCT. I am grateful for the financial support which made this work possible. Furthermore, I am appreciative of the opportunities I received during the course of the degree to present parts of this research at the 5th World Congress of Cultural Psychiatry meeting in New York City, USA; the 7th World Congress of Paediatric Cardiology & Cardiac Surgery in Barcelona, Spain; the 8th Human Heredity and Health in Africa Consortium Meeting and the 9th African Society of Human Genetics Meeting both in Dakar, Senegal; the Global Mental Health T32 Programme meeting and the Psychiatric Epidemiology training programme meeting both in New York City, USA; the Global Initiative in Neuropsychiatric GenEthics, Africa Ethics Working Group meeting and the Developing Genomic Medicine between Africa and the UK meetings in Cape Town;

as well as the 22nd Psychological Society of South Africa Congress meeting in Johannesburg, South Africa.

I am also particularly grateful to the diverse community of people who have spared some time to listen, read, critically review and reflect on my work. I have no doubt that the engagements, lessons learnt and networks fostered through this journey will remain valuable to me throughout my academic career. I close this chapter with excitement to see how my future unfolds. More so, I look forward to uncovering what this PhD journey will mean, for myself, my family, my community and my country.

DEDICATION

I dedicate this dissertation to three individuals: first, my late maternal grandfather, Simon Phillip Kungune and second, my grandmother, Nomalungelo Grace Kungune. These individuals spent most of their adult years working - as a security guard and a food stall vendor respectively - at a university in South Africa, yet were never afforded the opportunity to navigate the space as a student much less an academic. Their firm belief in the value of education and their own sacrificed aspirations have contributed not only to how I have progressed in my career development but also to how I will ultimately use this degree in service to my country. I do not take for granted that reaching this milestone must be the realisation of theirs (and all my ancestors) wildest dream come true.

Third, the late Prof Bongani Mayosi. Your very being served as confirmation to me, and many others that absolutely anything you put your mind to is possible. I believe that completing this dissertation contributes to your dream of achieving '1000 PhDs' who will take the baton forward and serve the country. Your passion to '*lift as you rise*' as well as your legacy of excellence and humility will continue to be inspiration for generations to come.

"I come as one, but stand as ten thousand" - Maya Angelou

Table of Contents

DECLARATION	ii
ABSTRACT.....	iii
ISISHWANKATHELO.....	v
ACKNOWLEDGEMENTS.....	vii
DEDICATION.....	ix
LIST OF FIGURES.....	xiv
LIST OF TABLES.....	xv
LIST OF GRAPHS	xvi
LIST OF APPENDICES	xvii
ABBREVIATIONS AND ACRONYMS.....	xviii
CHAPTER 1: INTRODUCTION.....	1
1.1. Background	1
1.2. Genomics in Africa: Human Heredity and Health in Africa.....	3
1.3. Thesis outline	4
CHAPTER 2: DISEASE CAUSAL ATTRIBUTIONS.....	7
2.1. Introduction	7
2.2. Causal attributions.....	7
2.3. Causal attributions for mental illness and cardiovascular disease globally.....	8
2.4. African cultural beliefs	13
2.4.1. The Xhosa culture	16
2.5. South African context	19
2.5.1. Access to healthcare in South Africa.....	22
2.6. Language and biomedical information	25
2.7. Chapter summary.....	27
CHAPTER 3: GENOMICS RESEARCH	28
3.1. Introduction	28
3.2. Genetic attribution.....	28
3.3. Concerns regarding genomics research.....	31
3.4. Discussions in the global context.....	36
3.4.1. How people utilise genomic information	36
3.4.1.1. Individual (Micro-level)	36
3.4.1.2. Family, Community and Public (Macro-level).....	37
3.5. Chapter summary	40

CHAPTER 4: STIGMA	41
4.1. Introduction	41
4.2. Defining stigma	41
4.3. Stigma Theory conceptual framework.....	45
4.4. The effects of stigma.....	50
4.5. Mental illness and stigma	51
4.6. Cardiovascular disease and stigma	53
4.7. How genetics may relate to stigma	56
4.8. How genetics may relate to stigma in SCZ and RHD genomics research.....	57
4.9. Chapter summary	58
CHAPTER 5: THEORETICAL FRAMEWORKS	59
5.1. Introduction	59
5.2. The Attribution Theory	59
5.3. The Modified Labelling Theory	61
5.4. Chapter summary	63
CHAPTER 6: RESEARCH METHODOLOGY	64
6.1. Introduction	64
6.2. Problem area and focus	64
6.3. Research aims	65
6.4. Research questions	65
6.5. Research design	66
6.6. Sampling strategy and gaining access to the study sample.....	68
6.6.1. The Genetics of Rheumatic Heart Disease (RHD Gen) Project	69
6.6.2. Genomics of Schizophrenia in the South African Xhosa people (SAX) Project	70
6.6.3. Focussing on RHD and SCZ	70
6.6.4. Focusing on the Xhosa-speaking patient population	70
6.6.5. Study sites	71
6.6.6. Recruitment process	71
6.7. Procedure.....	71
6.7.1. Phase 1: Obtain permission and ethical clearance	72
6.7.2. Phase 2: Translation of the ISMI scale	72
6.7.3. Phase 3: Focus group discussions	73
6.8. Development of the vignettes	78
6.9. Demographics of Study Sample	78
6.10. Data Analysis.....	80

6.10.1. Qualitative Analysis: Transcribing and coding of FGD data	80
6.10.2 Analysis of data from the translation of the internalised stigma scales.....	81
6.11. Role of the researcher	82
6.12. RHD Data collection	84
6.13. SCZ Data collection	84
6.14. FGD Data collection – General observations	86
6.15. Ethical considerations	87
6.16. Chapter summary	88
CHAPTER 7: DISEASE CAUSAL ATTRIBUTIONS.....	90
7.1. Introduction	90
7.2. Demographic details of FGD participants	90
7.3. Disease causal attributions	97
7.3.1. Genetic attribution	99
7.3.1. Knowledge about genetics.....	99
7.4. Alternative causal explanations.....	108
7.4.1. Psychosocial explanations.....	109
7.4.1.1. Environmental explanations	109
7.4.1.2. Psychological explanations	113
7.4.1.3. Personal lifestyle choices	117
7.4.2 Cultural explanations	121
7.4.2.1. Bewitchment/Supernatural causation.....	121
7.5. Chapter summary	125
CHAPTER 8: EXPERIENCES OF STIGMA	126
8.1. Introduction	126
8.2. Knowledge about the disease.....	127
8.3. Experiences of stigma	134
8.3.1. Family and community.....	134
8.3.2. Marriage.....	141
8.3.3. Having children	146
8.3.4. Ability to earn an income/work.....	150
8.4. Coping Strategies	156
8.4.1. Social support.....	156
8.4.2. Acceptance, openness and transparency	161
8.4.3. Sense of purpose.....	167
8.4.4. Health knowledge	169
8.5. Chapter summary	171

CHAPTER 9: INTERNALISED STIGMA SCALE	173
9.1. Introduction	173
9.2. Approaches to understanding culture and health.....	179
9.3. Internalised stigma and disease.....	181
9.3.1. The Measure: Internalised Stigma of Mental illness scale.....	184
9.3.2. Structure scoring and psychometric properties of the ISMI scale.....	188
9.4. Translation Method	190
9.4.1. The selection of the translation team.....	191
9.4.2. Translation design	193
9.5. Psychometric properties	204
9.6. Summary of the main findings of the study.....	236
9.7. Chapter summary	238
CHAPTER 10: DISCUSSION, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS.....	239
10.1. Introduction	239
10.2. Causal models of Xhosa people with SCZ and RHD	240
10.2.1 Genetic Attribution	241
10.2.2. Psychosocial Explanations.....	242
10.2.3. Cultural Explanations.....	246
10.3. Genetic causation vs other Causal Models.....	249
10.4. Internalised stigma experiences of Xhosa people with SCZ and RHD	253
10.5. How genetic attribution may relate to stigma.....	262
10.6. Conclusion.....	267
10.7. Strengths and Limitations	271
10.8. Recommendations	276
REFERENCES	280

LIST OF FIGURES

Figure 1: Stigma Framework.....	45
Figure 2: Participants completing consent and demographic form.....	73
Figure 3: Participants watching vignette of Andile.....	74
Figure 4: Schematic representation of FGD process.....	75

LIST OF TABLES

Table 1: Theoretical building blocks of stigma research.....	43
Table 2: Socio-demographics of participants enrolled in study.....	78
Table 4: Distribution of participants' age categories.....	89
Table 5: Distribution of participants' sex.....	91
Table 6: Employment status of participants.....	92
Table 7: Participants highest level of education.....	93
Table 9: Disease causal attribution themes	97
Table 10: Stigma categories and themes	125
Table 11: Examples of back-translation ISMI review.....	195
Table 12: Demographics of RHD and SCZ pilot samples.....	202
Table 13: Utility of RHD and SCZ ISMI-X scales.....	204
Table 14: Internal consistency coefficients reported for the ISMI-X scales.....	206
Table 15: Within-scale correlations RHD sample.....	209
Table 16: Within-scale correlations SCZ sample.....	210
Table 17: Demographics of SCZ sample who completed ISMI and DISC scales.....	212
Table 18: Results for correlations with the ISMIS-X and DISC.....	214
Table 19: Summary of the psychometric properties of the ISMI-X scales.....	224

LIST OF GRAPHS

Graph 1: Age of participants.....	90
Graph 2: Sex of participants.....	92
Graph 3: Distribution of participants employment status.....	93
Graph 4: Distribution of participants' receiving social grant.....	94
Graph 5: Participants highest level of education.....	95
Graph 6: Alienation subscale (pilot).....	216
Graph 7: Stereotype Endorsement subscale (pilot).....	217
Graph 8: Discrimination experience subscale (pilot).....	218
Graph 9: Social withdrawal subscale (pilot).....	219
Graph 10: Stigma resistance (pilot).....	221
Graph 11: Abuse subscale (pilot).....	222

LIST OF APPENDICES

Appendix A: HREC Ethics Approval Letter

Appendix B: ISMI Translation Permission Email

Appendix C: Information sheet for RHD & SCZ participants

Appendix D: Consent form for RHD & SCZ participants

Appendix E: Demographic form

Appendix F: FGD Process

Appendix G & H: FGD Topic guides & vignettes RHD & SCZ samples

Appendix I: ISMI/ISRHD-X scales

Appendix J: Back-translation of the ISMI/ISRHD-X

ABBREVIATIONS AND ACRONYMS

ELSI: Ethical, Legal and Social Implications

H3Africa: Human Heredity and Health in Africa

LMIC: Low and Middle Income Countries

NCD: Non-communicable disease

RDP: Reconstruction and Development Programme

RF: Rheumatic Fever

RHD: Rheumatic Heart Disease

RHD Gen: Genetics of Rheumatic Heart Disease Project

SSA: sub-Saharan Africa

SAX: Genomics of Schizophrenia in South African Xhosa People Study

SCID: Structured Diagnostic Interview for DSM-IV Axis I Disorders (SCID-I)

SCZ: Schizophrenia

UBACC: The University of California, San Diego Brief Assessment of Capacity to Consent

WHO: World Health Organization

CHAPTER 1: INTRODUCTION

1.1. Background

The adoption of the Human Genome Project (HGP) in 1990 has led to an increasing interest in genomics research with the hope that it may positively influence the advancement of treatments for diseases across the globe (Flowers, Froelicher & Aouizerat, 2012). Increased funding available for genomics research has meant an upsurge of studies conducted in this field. However, advancements in the field have raised awareness of associated ethical, legal and social implications (ELSI) which need to be addressed.

Considering the expectations that genomics research could possibly reduce global health inequalities, it is concerning to consider that population groups from the African continent have minimally been represented in the genomics arena (Munung, Mayosi & de Vries, 2018; Popejoy & Fullerton, 2016). Over the past few years there has been a push towards enabling genomics science to expand on the African continent and involving different population groups in order to better understand disease causes in diverse groups. This is partly motivated by Africa's rich genetic diversity and the increased disease burden on the continent (Munung, et al., 2018).

With the introduction of genomics research in Africa, a particular concern arises as to whether it is possible that receiving genetic information about disease may cause any harm to African population groups (de Vries et al., 2012). This concern was first raised soon after the inception of the HGP by researchers in the United States of America (USA) who questioned the possibility of stigma as a consequence of obtaining genetic information (Beckwith, 1991). More than 15 years later, USA researchers Khoury, Gwinn, Burke, Bowen and Zimmern (2007) postulate that this concern is still important to investigate as it is not yet clearly understood.

Most of the research on this topic has been conducted in North American and European contexts and has revealed conflicting evidence of whether genomics could create or increase stigma for individuals who have diseases with a known genetic or hereditary basis (Sankar, Cho, Wolpe & Schairer, 2006). Currently, there is limited literature exploring this concern in genomics research conducted in non-Western countries.

In Africa, ELSI researchers and ethics committees have questioned whether harm in the form of stigma may be a consequence of genomics research (de Vries et al., 2012). This assumption is made routinely for all genomics research studies and is raised particularly often in research that focusses on either (1) a known stigmatised population group, or (2) when conducting research with a population that has been marginalised or discriminated against (de Vries et al., 2012). Since genomics research is only just advancing on the African continent, it is pertinent to explore how African population groups understand genomics and whether or how a genetic disease causal explanation may relate to their stigma experiences. Importantly, the concern that genomics research could increase stigma is made regardless of whether the condition under study is stigmatised.

This study involves Xhosa patients with schizophrenia (a known stigmatised population group) and Xhosa patients with rheumatic heart disease (a group which has experienced marginalisation and discrimination). The goal of this study is to explore what causal attributions are held by Xhosa people with SCZ or RHD, how genetic explanations are understood by these population groups and whether a genetic attribution may relate to their internalised stigma experiences.

1.2. Genomics in Africa: Human Heredity and Health in Africa

Genomics research has recently been introduced in Africa. Despite the increased burden of infectious diseases, along with non-communicable diseases (WHO, 2002), Africans have participated minimally in genomics research (H3Africa, 2014; Munung et al., 2018; Popejoy & Fullerton, 2016). Thus, most of what is known in relation to genetics is based on individuals from European ancestry, e.g. in 2016 over 80% of participants in genome-wide association studies (GWAS) were from Europe and North America (Popejoy & Fullerton, 2016).

One of the first group of scientists to conduct genomics research in Africa fall under the Human Heredity and Health in Africa (H3Africa) Consortium which was established less than a decade ago, in the year 2010 (Adebamowo et al., 2017). The H3Africa Consortium aims to investigate genomic and environmental determinants on common diseases relevant to African populations through African leadership. With funding received from the National Institutes of Health in the USA and the Wellcome Trust in the United Kingdom (UK), the consortium aims to facilitate the advancement of genomics research on the continent (H3Africa Consortium, 2014). This initiative supports a wide range of genomics projects as well as four biobanks, a bioinformatics network, as well as a series of ELSI projects (one of which this research project falls under). The purpose of the establishment of the ELSI projects is to address the aforementioned potential ethical, legal and social implications arising from genomics research. Notably, the H3Africa Consortium has also collaborated with another group of genomics researchers, namely the African Society of Human Genomics group (AfSHG) that was founded in 2003. The aim of the AfSHG group is to equip the African scientific community and policy-makers with information and practical knowledge to contribute to the field of genomics research. Furthermore, it also aims to attract global attention to the efforts of African scientists (Diallo et al., 2017). When conducting genomics research in Africa, it is pertinent to consider the

possible implications of this work on the lives of Africans living with the diseases investigated through a genomics methodology.

This research is part of a larger H3Africa ELSI project entitled “Stigma in African genomics research on Schizophrenia and Rheumatic Heart Disease”. It was a three-year collaborative study between investigators in South Africa and the USA, funded by the National Institutes of Health (NIH) under Grant number: 5U01HG008226-03. That project had two phases. Through the use of Focus Group Discussions (FGDs), phase one aimed to explore the possible relation between a genetic attribution and disease stigma within SCZ and RHD patient population samples. Through the use of semi-structured interviews with caregivers or family members of patients with SCZ and RHD, phase two explored the effects of disease-related stigma on caregivers or family members and the likely effect of genetic attribution on stigma experienced by these stakeholders.

1.3. Thesis outline

This thesis is structured as follows:

- *Chapter 1* serves as an introductory orientation by providing a brief contextual background to genomics research and ELSI concerns that arise in it. The chapter then introduces the reader to genomics research in Africa. This chapter also describes the broader project which this study falls under and concludes with a presentation of the structure of the thesis.
- *Chapter 2* discusses what causal attributions are. This is followed by a discussion on causal attributions held globally and in Africa. A discussion on how which causal

models African cultural groups attribute to disease are discussed. Then I provide a background on the Xhosa culture, language and translation of biomedical terminology.

- *Chapter 3* starts by defining genetics and genomics as it is understood in this study. The chapter also describes the concept of a genetic causal attribution. The concerns highlighted in the global context in relation to how genetic information may influence individuals, family and community relationships as well as having serious possible future planning implications are presented.
- *Chapter 4* describes the concept of stigma, the stigma conceptual framework applied in this thesis and the possible effects of stigma, as cited in the literature. Next, literature on mental illness and stigma as well as cardiovascular disease and stigma are discussed. The chapter ends with a discussion on how genetics may relate to stigma experienced by people with SCZ and RHD.
- *Chapter 5* describes the theoretical frameworks employed in this study, namely the Attribution Theory (AT) and the Modified Labelling Theory (MLT). The chapter ends with a summary of how these frameworks are integrated in this study to inform the epistemological underpinnings.
- *Chapter 6* outlines the research methodology employed in this research. It contains the problem statement, research aim and research questions guiding the study. The chapter documents the data collection methods followed and provides a description of the participants enrolled. The chapter also contains a discussion on the data analytical framework employed in this study, as well as a reflection on the process of data collection and my role as a researcher in this process. Lastly, I discuss the ethical considerations.

- *Chapter 7* presents the socio-demographic characteristics of the participants. It then provides a description of the qualitative data that articulates the participants' disease causal explanations.
- *Chapter 8* documents the qualitative data that presents evidence of stigma experiences and the coping mechanisms employed to mitigate the stigma in the two disease groups investigated in this study.
- *Chapter 9* describes the translation and adaptation of a psychometric tool to measure internalised stigma, the Internalised Stigma of Mental Illness scale in isiXhosa (ISMI/ISRHD-X). I also discuss insights of the items which were most relevant for the two disease groups based on the endorsement rates. I also discuss the limitations of the translations and end the chapter with a summary of the overall findings in this study.
- *Chapter 10* provides a discussion on the findings of the research in relation to the conceptual and theoretical frameworks employed. It also discusses how the results emanating from this study add value to the genomics ELSI literature and can inform arguments about the possibility of genomics research playing a role in increasing stigma among people from a South African population group. The chapter also includes some considerations researchers ought to make when conducting genomics research with African populations. The chapter concludes with an outline of the limitations of the study and some recommendations for future research.

CHAPTER 2: DISEASE CAUSAL ATTRIBUTIONS

2.1. Introduction

As described in the previous chapter, this thesis focusses on exploring the causal attributions held by Xhosa people with schizophrenia (SCZ) and rheumatic heart disease (RHD) and specifically sought to understand the possibility of a genetic attribution influencing their internalised stigma experiences. An important starting point for this work is to explore what causal attributions are. Therefore, I begin the chapter by describing causal attributions. This is followed by a discussion on generally held causal attributions for mental illness and cardiovascular disease. I then discuss disease causal models held globally and in African cultures, with a specific focus on the Xhosa culture and language. The challenges of language and the use of biomedical terminology are also discussed. Lastly the background of the social context - South Africa - of the research participants is discussed.

2.2. Causal attributions

Generally speaking, people tend to understand illness in a variety of ways. In social science research, the term for how people understand illness is “causal attribution”. A number of causal models of disease have been proposed and previous research suggests that people generally perceive the causes of their disease to be multifactorial (Condit et al., 2009; Davison, Davey, Smith & Frankel, 1991). The causal attributions people make about a disease may be shaped by their culture and/or experience of living or caring for an individual with that disease. Moreover, societies may differ in the way in which individuals from different cultural groups, with differing sensitivities or historical backgrounds, make attributions to illness (Gaskell, Bauer, Durant & Allum, 1999). Broadly, disease causal attributions may be influenced by biomedical, environmental, psychological, behavioural and cultural factors (Swartz, 1998). In many instances, individuals may hold a number of these explanations simultaneously. This

study seeks to understand what causal models Xhosa people with either SCZ or RHD hold, as well as how a genetic model may play a role in their understanding of disease causation, and in turn their internalised stigma experiences.

2.3. Causal attributions for mental illness and cardiovascular disease globally

As is true for other conditions, mental disorders are also often attributed to a range of causes including, biological, psychological and cultural. For instance, medical professionals variably attribute the cause of mental illness to be biological, psychological or both. Luhrmann (2000) articulates the two perspectives eloquently by saying:

“Sometimes [psychiatrists] talk about mental anguish as if it were cardiac disease: you treat it with medication, rest, and advice about the right way to eat and live... Sometimes, though, psychiatrists talk about distress as something... that involves the kind of person you are: your intentions, your loves and hates, your messy, and complicated past” (p. 6)

Beliefs around a variety of causes for mental illness may suggest that researchers – including genomics researchers – ought to prioritise gaining an understanding of these causal beliefs, many of which may vary across different contexts and cultural groups (Radua et al. 2018). In a recent review of the literature, Radua et al. (2018) report that there is mixed evidence on the aetiology of SCZ. These researchers document that a model which has gained much traction recently for the cause is the genetic and environmental risk factors interaction (van Os, Rutten & Poulton, 2008). While other scholars such as Howes and Murray (2014) denote that the influence of social factors on causing SCZ is also been well supported in the literature. In Brazil, with first year college students, Gericke, Carver, Castéra, Evangelista, Marre & El-Hani

(2017) for instance investigated the relationships among belief in genetic determinism, genetic knowledge and social factors for various diseases, and found evidence for SCZ being largely equated to genetics. These authors found that the association between knowledge of genetics or genomics and genetic determinism (i.e. the belief that a disease is primarily caused as a result of genetics despite what scientific evidence suggests) was low. This could also be understood as evidence that higher knowledge of genetics may counteract genetic determinism.

In Greece, Economou, Richardson, Gramandani, Stalikas and Stefanis (2009) conducted a study with patients who have SCZ, investigating their causal disease models. Eighty percent of their sample reported their causal explanations. Of those who indicated a cause, 18.5% identified biological and genetic causes, while the most common attribution cited by these participants was psychosocial-environmental explanations with 34%, and the rest (27.7%) attributed their disease to a combination of psychosocial, genetic and environmental factors (Economou et al., 2009). This study also found that the attribution of SCZ only to biogenetic causes increased with socioeconomic status (SES) and education level, which is in contrast to Gericke et al. (2017). Therefore, individuals who had a higher SES and education level were more likely to attribute their disease to a biogenetic cause, than those who had lower education levels (Economou et al., 2009). This explanation is in support of Naanyu (2009) who found evidence that black South African males with low-levels of education held non-biological causes for mental illness.

Shifting to Africa, there is a robust amount of research on the causal attributions of mental illness (Adewuya & Makanjuola, 2005; Adewuya & Oguntade, 2007; Patel, 1995; Seedat, et al., 2002). Much of the mental illness literature - documenting the perspectives of the general public, traditional healers, health care practitioners, patient carers and some

patients - suggests that individuals from a variety of African cultural groups primarily attribute their disease to cultural or supernatural causes (Bantjes, Swartz, Cembali, 2017; Cheetham & Cheetham, 1976; Mbanga, 2002; Motlana, Sokudela, Moraka, Roos & Snyman, 2004, Naanyu, 2009; Ngobe, 2015; Sorshdahl et al., 2010). This is similar to the findings by scholars in other LMICs such as India (Saravanan et al., 2007) and Malaysia (Thornicroft et al., 2009).

From the perspective of patient relatives in the South African context, Mbanga et al. (2002) conducted research with 100 relatives of Xhosa patients diagnosed with SCZ. Essentially, the findings of their study indicate that caregivers of patients with SCZ tend to more commonly attribute mental disorder to a complex variety of causes, many of which are related to psychosocial stresses, as opposed to a biomedical explanation. When symptoms are obvious and observable, as in psychotic symptoms of SCZ, this behaviour tends to be commonly attributed to witchcraft or possession by evil spirits (Mbanga et al., 2002). Naanyu (2009) reiterates this finding in her research by reporting that in South Africa and most African communities in general, magical aetiologies are regularly cited causal models for mental illness.

Shifting to cardiovascular disease global beliefs of causes, in the US, Bates et al. (2003) conducted research among the general public to understand how individuals understood a genetic explanation to heart disease. Through the use of FGDs with participants from rural, sub rural and urban areas, the scholars sought responses to the question “what does a gene for heart disease mean?”. They found that participants understood a gene for heart disease to mean that genetics and the environment both played a role in the onset of heart disease. This interpretation by the lay public is supported in other international studies (Davidson et al., 1989; Hunt et al.,

2000 & Ponder et al., 1996) that have found that individuals in the US general public consistently understand heart disease to be caused by behavioural, environmental and genetic (in relation to family history) factors. In the US, heart disease is recorded as the second highest preventable cause of death, and it affects ethnic minorities disproportionately (National Heart Lung and Blood institute, 2000 as cited in Bates et al., 2003; Smedly et al., 2000). African Americans have been found to provide different estimates for the role of genetics in causing heart disease (Bates et al., 2003). Again, this is in support of a robust amount of literature, suggesting that people may hold multi-causal models for disease (Senior, Mateau & Weinman, 2000). With growing evidence, these multi-causal explanations held by people with disease may provide valuable insights into treatment acceptance and adherence. Given that genomics research aims to provide advanced treatments for genetically affiliated diseases, these causal beliefs may be pertinent to consider in the process.

Cardiovascular disease (including heart disease and stroke), type 2 diabetes, cancer, chronic lung disease, depression and schizophrenia are some of the major documented non-communicable diseases (NCDs) in low and middle-income countries (LMIC) of the world (Daar Singer, Persad et al., 2007; Sorshdahl, Flisher, Wilson & Stein, 2010). Mayosi, Flisher, Lalloo, Sitas, Tollman and Bradshaw (2009) postulate that in present day South Africa, NCDs are increasingly common in both rural and urban areas of the country. In poorer areas of South Africa, these scholars predict the burden of NCDs to increase substantially (Mayosi et al., 2009) and the same is predicted for the broader sub-Saharan Africa (SSA) (Dalal, Beunza, Volmink et al., 2011). In their systematic review of common diseases in SSA, Dalal et al. (2011) found that external factors, including environmental factors such as polluted air, may play a role in cardiovascular disease onset. Other factors cited were diet, lack of exercise, alcohol use, psychological and physical abuse.

Although these are the cited general possible causes of heart disease in African contexts, it is not yet well understood what individuals in local societies believe to be the cause of their cardiovascular disease (Mshana et al., 2008). In a study investigating the explanatory models held and treatment seeking attitudes by patients with stroke in Tanzania, Mshana et al. (2008) found that the attribution of illness in African aetiologies can be characterised by biomedical explanations and/or spiritual explanations. In the South African context Hundt, Stuttaford and Ngoma (2004) investigated the conceptualisations of illness causation held by individuals with stroke-like symptoms in a rural population in the Limpopo province and found that patients cited both physical environment and social causes. Bham and Ross (2005) found cultural explanations a strong focus among South African Indian Muslims, hence their conclusion that faith and religion feature strongly in the aetiology beliefs held by Muslim patients with cardiovascular disease. A pertinent reason for understanding the explanations held by patients is the concern that the explanations may fuel stigma which could negatively inform their help-seeking practices, selection of pathways to care and adherence to treatment.

In Africa, and many non-Western cultures, causal attributions for illness are often also understood in relation to traditional cultural belief systems (Alem, Jacobsson, Araya, Kebede, & Kullgren, 1999; Mshana, Hampshire, Panter-Brick, & Walker, 2008; Saravanan, Jacob, Johnson, Prince, Bhugra & David, 2007; Swartz, 1998). The African belief system often informs the manner in which many Africans perceive their world and impacts their understanding of illness (Matoane, 2012). It is difficult to speak of a single African viewpoint, since many Africans have shifted to establishing a variety of belief systems influenced by different cultures including Western views. Mkhize (2003) suggests that cultural groups in SSA may hold similar beliefs and a unique consciousness about the world. In addition to biological explanations to illness, which are often cited as dominant causal models in European

population groups (Jayaratne et al., 2009), Africans generally also emphasise external factors such as relationships with family, the environment, sorcery, bewitchment, ancestors and ancestral spirits (Mkhize, 2003; Naanyu, 2009; Nwoye, 2015).

2.4. African cultural beliefs

In many traditional belief systems in Africa, including South Africa, mental health problems may be attributed to the influence of the aforementioned ancestors or bewitchment factors (Sorsdahl, Flisher, Wilson & Stein, 2009). The “Africentric approach” to research is documented by authors such as Bangura (2012) and Mazama (2001), who posit that this paradigm relates to an ideology that guides the essence of research and practice in contemporary African-centred scholarship. Crossman (2004) postulates that the principal message of this paradigm is that research conducted in the African context should take into account the worldview and philosophical assumptions held by people in Africa. More specifically, in the context of mental illness, Nwoye (2015) describes the difference between biomedical and biogenetic models of illness in Africa, which tend to see an illness in relation to the abnormality of a patient’s anatomy, genetics and nervous systems, and the African paradigm which sees an illness as “symbolic” with a hidden message from external spiritual forces (i.e. ancestors). For instance, some Africans go beyond the clinical information provided by a clinician, and seek to find “who” is speaking through the patient’s physical manifestations (Nyowe, 2015). The differences between the biomedical understanding of illness and the African paradigm undoubtedly influences treatment and help-seeking behaviour. While belief in the aforementioned results in patients seeking help from Western medicine practices, the latter for instance results in a patient and their family seeking guidance from traditional healers to provide clarity on what they should do in

order to determine “who” is speaking through the illness and what is expected of them in order to effect healing for the patient (Bantjes et al., 2017; Mzimkulu & Simbayi 2006; Nwoye, 2015). Other scholars such as Connell et al. (2015) and Campbell et al. (2017) attest that Xhosa people often hold a diverse range of spiritual beliefs, including African traditional healing systems, traditional medicine, ancestral worship, magic and witchcraft, along with Christian, Islamic, atheist and agnostic beliefs. With the presence of a multitude of disease causal explanations often held in conjunction with one another, scholars such as Kabir, Iliyasu, Abubakar & Aliyu (2004) suggest that many Africans have poor knowledge, understanding and acceptance of a biomedical explanation to disease. Moreover, in relation to mental illness, Ilechukwu (1998) proposes that a large number of African people do not know the cause of their illness. Overall however, cultural aetiologies are highly prevalent in African cultural groups, even though individuals also consider other potential factors, including biomedical and genetic explanations to illness.

Kleinman et al. (1978) propose that cultural beliefs are prominent in the development of individuals’ causal models for disease. There are many definitions for the term “culture”. In this study culture is understood as defined by Mkhize (2003:6), stating “culture refers to meanings, values and behavioural norms that are learned and transmitted in the dominant society and within its social groups”. He further describes culture as a complex system of symbols which include values, feelings and ideals as well as beliefs, traditions and behaviours governed by societal laws and rituals. Scholars such as Vaughn, Jacquez and Baker (2009) and Swartz (1998) also attest that people’s beliefs about disease causation, treatment and health practices are influenced by their culture. Globally, there is much debate about the influence of culture on the biomedical explanatory models for illness. Authors such as Kohrt et al. (2014) express concerns with not considering culture in biomedical research. For instance, where

many studies have been conducted on schizophrenia, very little has been done to alter conceptualisations or treatments of this disorder in consideration of the commonly held cultural beliefs.

A particular question to investigate is whether it is possible that a disease (presenting with similar symptoms across different contexts) is understood in the same way by people in different contexts. An African psychiatrist, T. Adeoye Lambo, (who joined international psychiatry research networks in the 1950s and 60s) expressed that the content of the symptoms of mental illness presented differ cross-culturally. Furthermore, T. Adeoye Lambo believed that it is critical for psychiatrists to be sensitive to the cultures they worked with, in order to make accurate judgements on illness. The same argument can be made for physical diseases and physicians treating physical diseases among African population groups. In the South African context, scholars such as Drennan, Levett and Swartz (1991) and Swartz (1998) have raised important questions about the transportability and relevance of western biomedical constructs of disease in African settings.

Typically, in the 21st century, research indicates that attributional styles differ cross-culturally. However, the argument holds that most studies have been aligned to the World Health Organisation (WHO) and World Mental Health tools, which are mostly conducted based on Western culturally developed biomedical diagnoses that lack the inclusion of cultural concepts (Kohrt et al., 2014). Vaughn et al. (2009) asserts that individuals from diverse cultural backgrounds typically make different attributions of illness, health, disease, symptoms and treatment.

In the US for example, African Americans are reported to more likely attribute a disease to external factors such as destiny or the will of God, along with a firm belief in the healing power of prayer (Landrine & Klonoff, 1994). Moreover, ethnic minorities in the US (i.e. Anglo Americans) are more likely to hold traditional Western health beliefs involving individual responsibility for health and illness (Landrine & Klonoff, 1992; 1994), as well as more “empirical” explanations of illness. These authors explain that because of the emphasis on micro-level and natural causes of illness, many Caucasian Americans believe that illness can be treated without reference to family, community or deities, as it holds an intrinsic element.

According to the Western biomedical model, a disease originates inside the body due to a specific, identifiable “medical” cause or pathogen (viral, bacterial, etc.). Yet, whilst people in Western countries tend to attribute the cause of illness to the individual or the natural world, individuals from non-Western or European countries are more likely to explain illness as a result of social and supernatural causes (Naanyu, 2009; Vaughn et al., 2009). These findings are consistent with another study by McCabe and Priebe (2004) who investigated the exploratory models of illness among people with schizophrenia in the UK by comparing four ethnic groups (Caucasian, Bangladeshi, African Caribbean and West African). These scholars found that the white population cited genetic causes more prominently, while the three non-white groups cited supernatural causes as being more prominent.

2.4.1. The Xhosa culture

For the purposes of this thesis (involving Xhosa people with SCZ and RHD) it is critical to provide some information about the Xhosa people (amaXhosa) and their culture. Hence, it is vital to have some knowledge of their culture, customs, language, as well as their worldview and philosophy of life. This is especially relevant as Emsley et al. (2001) point out that thus far

health researchers have paid scant consideration to the ways in which the cultural norms of the Xhosa people may inform opinions on disease and the politics about causation. Although culture can be a complex arena that constantly changes over time, there is reported value in explaining the cultural backgrounds of individuals involved in a study.

The Xhosa people fall within the previously racially segregated populations stipulated during the apartheid era in South Africa (Buhrmann, 1977). This group was restricted to the Eastern Cape Province of South Africa, thus the majority of Xhosa people continue to reside in the Eastern Cape (Steele & Edwards, 2008). In 2008, Steele and Edwards reported that over 90% of the population in the Eastern Cape Province are isiXhosa-speaking. The Xhosa language is associated with the Nguni group of African languages, which encompasses isiXhosa, SiSwati and isiZulu (Buhrmann, 1977). Xhosa people are divided into various clan groups (the clan group name which one belongs to is called *isiduko*). These clan groups derive from the patrilineal lineage of an individual and are very crucial for the individual's identity. They are unchangeable, and exclude a number of potential marriage and sexual partners (namely, those who belong to the clan groups of all four grandparents) (Hirst, 2005).

The Xhosa cultural belief system places great value on the role of the ancestors in individuals' health and wellness (Hirst, 2005). It is the ancestors who are believed to either expose individuals to witchcraft and possession by evil spirits or protect them from these sources (Buhrmann, 1984; Connell et al., 2015; Hirst, 2005; Mbanga et al., 2002). In order to treat illnesses that may arise based on the presumption of bewitchment, Xhosa people often consult "traditional doctors (*inyanga*), diviners (*izangoma*), faith healers (*umprofiti* or *umthandazi*) or a birth attendant" (Sodi et al. 2011; p. 102). Although terms for the healers do vary across different ethnic groups, they are often similar in many African cultural groups (Truter, 2007).

Healers and practicing herbalists are often skilled to provide natural herbs as treatment, however no amount of treatment can be efficacious if appropriate traditional life-cycle rituals are neglected. Healers also provide some guidance on the particular rituals that ought to be performed by the ill individual and/or their family in order to appease the ancestors so that they can provide protection (Hirst, 2005). The main source of guidance from the ancestors is through dreams. Most Xhosa people follow the Christian religion. They believe that the ancestors play a mediatory role between living beings and the Christian God (named, uThixo), therefore the cultural and religious beliefs are held alongside one another.

In particular, many Xhosa individuals have upheld purity of the language and traditional practices, including ancestor worship and traditional treatment (Buhrmann, 1977; Buhrmann, 1984). It is important to note however that there are subtle differences to the beliefs upheld by Xhosa people in the Eastern Cape Province – province which most Xhosa people reside in rural villages - and Xhosa people in the Western Cape Province where most Xhosa people reside in townships.

Generally, in the Xhosa culture, Hirst (2005) emphasises that the nosology of diseases is often believed to be linked to witchcraft, ancestors or both. Overall, Xhosa people often focus on dual systems of illness causal explanations (where their relationships with ancestors, family and environment are all connected) therefore understanding of illness causation takes all of them into consideration in addition to other explanations (Mkhize, 2003; Nwoye, 2015). This finding is of particular relevance because African cultures typically do not consider the individual in isolation, but in the context of a greater collective of factors (Mkhize, 2003; Nwoye, 2015). The cultural beliefs of African people are often underappreciated in genomics studies (Adebamowo et al., 2017). The limited consideration

of cultural norms may in itself have implications for stigma. Botha, Koen and Niehaus (2016) provide preliminary evidence that cultural differences contribute to the way in which disease causation beliefs manifest and how a disease is stigmatised. Cultural awareness is one strategy which has been proposed by African genomics researchers, in order to efficiently conduct genomics research with African population groups (Munung et al., 2018).

2.5. South African context

South Africa is a middle-income country, yet there are large disparities in access to resources (Petersen et al., 2016). South African cities and towns have been shaped by a range of discriminatory laws following the apartheid era (Nqwela & Lewis, 2012), which has resulted in persisting inequalities (Mayosi & Benatar, 2014). Considering that apartheid intentionally promoted separate and unequal development of the different racial groups in South Africa, there are many people, particularly black African people still living in poverty with limited access and barriers to healthcare and education. These communities are similar to the communities of African American participants in the study by Collins et al. (1998), which are unfavourable in terms of safety, friendliness, delivery of facilities such as health, education and municipal services. These areas are also often loud, unclean and distanced from cities and may also be called townships.

Since 1994 there have been significant advances in primary healthcare initiatives and a stern focus on improved healthcare delivery (Mayosi, van Niekerk, Bradshaw, Karim & Coocadia, 2012). Low-income communities in underdeveloped areas of the country, however, are still largely occupied by black African people who, alongside other population groups that are poor in the country, suffer the most in terms of accessing adequate healthcare and other resources

(Vergunst, Swartz, Mji, MacLachlan & Mannan, 2015). Most of the participants in this study come from these communities. These low-income communities are challenged with a high rate of crime and poverty (Ngqela & Lewis, 2012). This contextual background is important to acknowledge, as Lund et al. (2018) maintains, that poverty is consistently related to increased prevalence of disease in low-income, middle-income and high income countries. Other scholars, such as Folb et al. (2015), conclude that socioeconomic disadvantage among mental health patients in the Western Cape province of South Africa, may not only be a cause of depression, but also a barrier to accessing treatment. Lund et al. (2010) extensively reports on the implications of poverty in exacerbating the presence of mental health conditions in low-income communities, with some of his research conducted in the context of South African townships. It is not uncommon for individuals in these areas to witness or experience violent behaviour such as stabbings, assaults or gunshot encounters. Nqwela and Lewis (2012) maintain that tensions from the experience of poverty are part of the reasons for the internal violence in these communities.

Growing global evidence indicates that health, poverty and stigma are intertwined in a negative cycle (Lund et al., 2010; Turan et al., 2019). These elements are all intertwined in the concept “intersectional stigma” (Turan et al., 2019). While disease causes may vary, the social circumstances of individuals in low-income communities in South Africa may certainly account for their residents being the most vulnerable to disease onset. Zuhlke (2015) supports the above by stating that the inequalities in these communities translate into continued high prevalence of diseases of poverty in the population, mentioning RHD and tuberculosis. This view was extended by Vergunst et al. (2015) and more recently, supported by Lund et al. (2018), who included the increased vulnerability to mental illness onset among individuals in these communities.

Employment is seen as a protective factor for acquiring disease. For example, having financial income provides one with greater opportunities to have access to better health care, such as access to good hospitals and clinics, healthier food and exercise facilities, safer neighbourhoods to live and work in (i.e. suburban areas with less crime, pollution and noise), as well as increased access to education facilities. Unfortunately, unemployment in South Africa is a huge burden, especially among black South Africans (Statistics South Africa, 2013). Notably, the Stats SA 2018 report documents that unemployment in black African population groups is extraordinary high at 30.5% (2018). Stats SA (2013) reported that black South Africans constitute 80% of the population. However, the majority of blacks continue to experience poverty, homelessness and unemployment (Statistics South Africa, 2013). This is a concern, considering researchers such as Lund et al. (2018) report that employment is also associated with better social functioning, less severe symptoms and a higher quality of life for people living with a physical or mental disease.

In low-income communities in South Africa the transportation system is a challenge. Lucas (2011) documents that the majority of South African families do not have steady access to any form of transport, which impacts on their capability to contribute to important financial and societal activities (Vergunst, Swartz, Mji, MacLachlan & Mannan, 2015). The lack of transport experienced by South Africa's low-income populations has been a persistent and prominent problem in both its pre-and post-apartheid eras (Khosa & Zwane, 1995). Thus, the people who comprise the vast majority of South Africa's urban population struggle to access reliable, safe transport in order to reach employment or even health facilities. This is critical to highlight as Potgieter, Pillay and Rama et al. (2006) indicate that transport has been recognised as a main factor in the monetary and societal growth process because it facilitates the movement of individuals and goods, thereby encouraging trade and improved standards of living through

access to employment, health, education and communal facilities. Also, Potgieter et al. (2006) emphasis the concept of transport poverty (which is associated with a lack of provision of transport infrastructure and motorised services), the monetary cost of travel and the amount of time people spend accessing and waiting for transportation, which all serve as barriers to accessing the aforementioned services. The lack of transport may also be the reason why many individuals in rural areas go to local traditional healers as first point-of-care when they become ill (Ngobe, 2015). These transportation barriers often shape the reality of outpatients in low-income communities who attend health facilities in urban areas. The challenges to access safe, reliable and convenient transportation not only affects their ability to hold and maintain jobs in urban areas but also affects their ability to seek help and treatment from health facilities.

Evidence reports that many Xhosa people are juggling the combined effects of transgenerational poverty, inequality and discrimination. The realities of many individuals residing in low-income communities in South Africa are extremely difficult, even more so for people living with a disease. As a result, these factors cannot be overlooked when considering disease causal explanations and stigma.

2.5.1. Access to healthcare in South Africa

In the South African constitution, section 27 documents the right to access health care for all South Africans. In reality the country's healthcare is divided between private and public healthcare. Private healthcare is payed for by individuals who can afford it (servicing only 16% of the population). Public healthcare thus holds the responsibility of servicing the remaining 84% of the population. This heavy burden on the system has resulted in challenges to access adequate healthcare in the country (Petersen et al., 2016). Challenges to access health care

remain a huge problem for many South Africans, one reason being the distribution of resources and staff in different facilities (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009).

Many people living in low-income communities in South Africa increased barriers to accessing adequate healthcare. Their challenges to accessing health care are fuelled by the inadequate infrastructure, housing and limited access to basic services in township communities. Access to health care is therefore affected by these notable barriers: (i) poverty and inequality, (ii) transport and distance to travel to access a clinic/hospital, (iii) resources and staff capacity of the health facility, and (iv) traditional beliefs regarding illness held by members of different cultures (v) violence in their communities and (vi) stigma and discrimination (Coovadia et al., 2009).

Issues related to accessing health care are especially important to highlight for SCZ and RHD patients, who need to frequently collect medication for their illness. In terms of minimising stigma and discrimination, Zuhlke (2015) explains that patients with physical and psychological diseases prefer going for treatment in cities as this maintains a sense of privacy and anonymity. It distances them from the stigma experienced when attending local community-based healthcare facilities because frequent visits to the clinic are often associated with the collection of HIV treatment, which is a highly stigmatised disease in these communities (Stein, 2003; Vincent, 2008).

Another challenge is the limited available resources at local clinics. For instance, in one township in Cape Town, individuals queue for 6 hours before getting medical attention (Nteta, Mokgatle-Nthabu & Oguntibeju, 2010; Zuhlke, 2015). This is due to the high volume of people who visit these facilities on a day-to-day basis. It is not uncommon for people to return home

without having been attended to and having to return to the clinic the following day to queue again in the hope that they will be attended to. Their necessary periodic visits to the health facilities, which take a significant amount of time, are a further reason why many people living with disease experience barriers to accessing healthcare (Nteta, Mokgatle-Nthabu & Oguntibeju, 2010; Vergunst et al., 2015), subsequently exerting further pressure on the costs incurred by the state if or when they are admitted to hospitals for disease complications (Zuhlke, 2015).

Furthermore, another barrier to accessing healthcare for people in low-income communities is the influence of the cultural belief systems held by people of the community. Cultural causal attributions may influence pathway to care in various ways (Burns, Jhazbhay & Emsley, 2010). Many Africans consult alternative healers in their communities who provide traditional medication (Bantjes et al., 2017; Mzimkulu & Simbayi, 2006; Sorsdahl et al., 2009). Generally, these healers have varied levels of experience and avail their services to the tradition-bound members of the community (Bantjes et al., 2017; Mzimkulu & Simbayi, 2006; Vergunst et al., 2015). This could also pose various problems, as in many cases this leads to the late detection or diagnosis of diseases in health facilities, which can result in further complications (Zuhlke, 2015). Burns et al. (2010) indicate that for patients with a first episode psychosis who first consult traditional healers, there is a longer duration of medically untreated psychosis, thereby negatively impacting prognosis of the mental condition. Based on these barriers, among others, it is evident that contextual factors may influence causal explanations of individuals with physical or mental diseases.

2.6. Language and biomedical information

South Africa currently has 11 official languages. The Xhosa people are the second largest population group in South Africa (Steele & Edwards, 2008). As it has been found in other African contexts, having population groups who speak various local languages can create a language barrier between the patients and health professionals (Drennan & Swartz, 2002; Swartz, Kilian, Twesigye, Attah & Chiliza, 2014). Tindana et al. (2012) document that in a genomics study conducted in Ghana, research staff clearly struggled to explain scientific terms to participants in their local languages. This challenge is echoed by South African scholars (see, Campbell & Young, 2016; Drennan & Swartz, 2002; Levin, 2016; Swartz et al., 2014) stating that amongst the general public, there is often difficulty understanding and interpreting biomedical information and constructs, which is particularly challenging for black Africans as this information is predominantly communicated to them in English and not their home language. The primary reason that communication is conducted predominantly in English and sometimes Afrikaans is the historical and current realities of the country having mostly only white healthcare practitioners (with the exception of black nurses) who relay health information (Drennan & Swartz, 2002). Secondly, very few of the white general practitioners can speak any black African language (Drennan & Swartz, 2002)

Because of the past discriminatory system in South Africa, a large majority of black Africans in the general public have low levels of education, which means that receiving genetic information (often communicated by the available medical practitioners in English/Afrikaans) can be even more difficult to comprehend (Drennan & Swartz, 2002; Levin, 2016; Steele & Edwards, 2008). In addition, Levin (2016) maintains that the general practitioners themselves often have limited training and knowledge of genetics, which makes it even more difficult for them to relay the information to patients.

The difficulty for practitioners to find isiXhosa words to describe genetics aggravates the challenge for health staff or researchers in relaying genomics and biomedical information to many black African people. This is elaborated on by Levin (2016) who investigated misunderstandings encountered by doctors communicating with Xhosa-speaking patients in the Western Cape, South Africa. In his research Levin (2016) revealed gaps in communication and discovered that most isiXhosa words were not in the doctors' vocabulary and some common English words were not in patients' vocabulary. Additionally, in situations where words were common to the vocabulary of both groups, significant differences existed in the number and range of definitions, with many significantly different interpretations being apparent. Hence, for Africans, in addition to the complexity of the scientific terms, a further layer of challenge in conveying this explanation is the language barrier between healthcare practitioners and patients. The continuing institutional failures to adequately bridge the language gap in healthcare systems in South Africa fuels the stereotypes held about certain diseases and disregards the importance of all people understanding the health information provided to them (Drennan & Swartz, 2002).

That said, it is of no surprise that experts in the social sciences and humanities fields in Africa are concerned about ordinary people having misconceptions and misunderstandings about genetics. One particular misconception which may occur is the reported belief that an individual acquires an illness solely as a result of their genes. Furthermore, people may be more prone to believe that one is defined by their genes in the present and future, thus making it predictable and unchangeable – even by health promoting behaviour – which can result in increased stigma and discrimination (Lynch et al., 2008). This may relate to what King et al. (2002) calls “genetic illiteracy”. Given the lack of knowledge on what Xhosa people with SCZ

and RHD understand about genetics, this study hopes to better understand their genetic literacy and how it may influence stigma.

2.7. Chapter summary

This chapter provided a discussion on what causal attributions are. It also provides a brief description of disease causes often cited globally and in African literature. The chapter ends with a general background of the culture of the research participants (the Xhosa culture and language), the South African context, as well as how language informs the understanding of genomics research information among African participants.

CHAPTER 3: GENOMICS RESEARCH

3.1. Introduction

Interest in genomics research has increased substantially in the past three decades. The enthusiasm of the possibilities of genomics providing tangible improvement in diagnosis, treatment and prevention of disease can not be ignored. Alongside the enthusiasm, there are also real ethical, legal and social implications which have been highlighted for consideration by researchers (Catz et al., 2005). Genetic explanations have long held a strong view of being a dominant explanatory model for human characteristics in Eurocentric contexts (Garrison, Brothers, Goldenberg & Lynch, 2019). The field has moved from focussing on genetics, to genomics. In this chapter I start by defining the difference between genetics and genomics. I then discuss the concerns raised by ELSI researchers regarding genomics research. I explain how genomics information can influence individuals and communities, as well as future prospects. The discussion in this chapter is helpful in drawing out the main assumptions guiding the backdrop of the research questions explored in this thesis. I end the chapter with a summary.

3.2. Genetic attribution

The field of genetics largely focusses on single genes, genomics describes the study of the entirety of an individual's genetic material (the genome) which includes interactions of the genes with each other and the individual's environment (non-genetic factors) (Flowers et al., 2012). Genetic attribution (Tygart, 2000) refers to a perceived genetic cause of a trait or behaviour and is related to deterministic thinking (Dar-Nimrod & Heine, 2011). Deterministic thinking attests to the idea or belief that differences in people (such as physical appearance, health outcomes, characteristics and life experiences, etc.) are largely due to genetics and therefore can never be changed. According to Phelan, Cruz-Rojas and Reiff (2002), when an

individual believes an illness is genetic, then s/he may be more likely to believe that the disease cannot be avoided through a change in behaviour or environment.

Tygart (2000) suggest that genetic attribution, how people perceive the influence of genetics on an individual trait, depends on the types of traits. Therefore, as emphasised by Gericke et al. (2017) it is important to explore how this perception may influence a diversity of traits. Given the concern of a pessimistic attitude to disease onset or prognosis, holding solely a genetic explanation to a disease trait raises some serious questions around how it may fuel consequences which may influence stigma for different diseases. How genetic attribution impacts the lives of various people with different diseases, and from different social contexts and cultural groups is yet to be discovered (Catz et al., 2005).

Data from multiple studies using different methodologies and focussing on different traits revealed results suggesting that individuals understand that even if genetics may play a role in disease causation, it is not an overwhelming role and there may be other factors which influence disease onset (Condit et al., 2018). For instance, Parrott, Silk and Condit (2003) who conducted FGDs investigating genetic attribution for traits such as talents, mental abilities, lung/prostate cancer, weight and height, found that individuals believe that whilst genes do play a role in most of these traits, the effect is not overwhelming.

In the US, Jayaratne et al. (2009) asked individuals what they think about genetics, environment and choice, which allowed for a comparison across the causal models. In their study, black and white Americans indicated their beliefs in attributions for athleticism, intelligence, tendency towards violence, drive to succeed, and sexual orientation. For most of the traits individuals were below the midpoint (less than 2 in a 1-4 point Likert scale), with white respondents

reporting a little higher genetic score for intelligence and athleticism both at 2.3, which was the highest traits reported closer to genetics. As Condit (2018) suggests, individuals vary in how they think about disease causation (which may be different for physical and mental diseases) and often hold a multifactorial causal model, rather than just a genetic deterministic perspective.

Condit et al. (2009) conducted a study with individuals who have physical and mental conditions. Through the use of interviews, these researchers asked participants what they think causes their disease? Then they prompted individuals with other causes not mentioned (i.e. behaviour and personal choice). Additionally, they provided vignettes with causal models (including genetics and gene-environment causes). These scholars found that individuals provided a variety of responses and in some instances these responses seemed contradictory. During the discussions individuals changed, adapted or modified their causal models to include factors not previously mentioned. In another study in the US, Parrott et al. (2004) found that there was uncertainty about the role of personal behaviours, social environments, and religious faith on genes' impact for human health. In their study, some participants reported believing that God plays a critical role in how genes are expressed and impact health. This provides further evidence that individuals may attribute the cause of their disease to multiple factors simultaneously. It also may suggest that introducing participants to particular causes may be likely to shift their original beliefs to some extent accommodate the new information they receive to their disease model.

Globally, there is robust evidence reported over the past 20 years, suggesting that individuals from different contexts have complex causal accounts for disease and genetic explanations are just one of them (Condit, 2018). Most people seem to fluctuate between causal models based

on genetics, the environment (including physical, social and cultural), supernatural factors, individual will and chance.

3.3. Concerns regarding genomics research

Clinical and research institutions around the globe are generating enormous amount of genetic and genomic data through enrolling thousands of patients in large-scale studies (Garrison et al., 2019). Accompanying this increased interest in the field, Kong, Dunn and Parker (2017) propose that, it is critical to investigate the possible ethical, legal and social issues that such research raises. Scholars such as Munung et al. (2015); Marshall et al. (2014) and Tindana et al. (2012) comment on some of the important considerations when conducting this research in Africa. Munung et al. (2015) for instance discusses issues relating to the difficulty that genomics research participants (across numerous countries and cultural groups on the African continent) may experience in understanding genomics informed consent documents. Marshall et al. (2014) also highlights (in the context of Nigeria) the importance of investigating the comprehension of informed consent documents utilised for genomics research among African cultural groups. These authors suggest that it is important for researchers to consider various qualitative (Catz et al., 2005; Kinney, DeVellis, Skrzywnia & Millikan, 2001) and quantitative (Bottorff et al., 2002) strategies to examine the knowledge of research participants in genomics research, particularly because biomedical studies often employ complex terminology (Catz et al., 2005; Levin, 2016).

In Ghana, Tindana et al. (2012) refers to the challenges of comprehending the implications of participating in genomics research (specifically in terms of long-term storage, sharing and re-using of data and samples). These authors urge researchers to consider guidelines for the

protection of participants who may not fully understand the implications of genomics research and what it would reveal in relation to their personal genetic make-up as well as that of their family or community members. Situated amongst these ethical considerations is a concern about potential stigma arising from genomics research. De Vries et al. (2012) and Tekola et al. (2009) describe the potential of ethnic stigmatisation among African population groups enrolled in genomics research. The most pertinent issue they raise is the potential for genomics research to highlight particular cultural groups as being more susceptible to particular diseases.

More importantly, Sabatello and Juengst (2018) report that a critical concern in genomic information about specific populations, is that it may trigger a negative response in societies. As mentioned before, this is especially pertinent when conducting research with already stigmatised or marginalised population groups (de Vries et al., 2012). In relation to the latter, there is a concern that a genetic focus on disease could increase stigma relating to the disease (Kong et al., 2017). This concern is arguably rooted in concerns over eugenics (Savulescu, & Kerin, 1999) and in early experiences with genetic screening for conditions such as sickle cell disease in the US (Duster, 2003; Phelan, 2002). Taking a closer look at the concerns of stigma and genomic research, this phenomenon could run two ways: genetic information could reduce stigma by reducing some degree of personal responsibility for developing the condition (Angermeyer et al., 2011; Mehta & Farina, 1997; Phelan, 2005; Phelan, Cruz-Rojaz & Reiff, 2011), or it could increase stigma by placing emphasis on conditions perceived to be fundamental and unchangeable, with little possibility for recovery or treatment (Angermeyer et al. 2011; Kong et al., 2017). In the context of mental illness, Kong et al. (2017) put forward that an increased focus on genetic causes for disease may contribute to deterministic thinking and essentialist views, which may increase the already present stigma of mental illness. Furthermore, these authors also postulate that a focus on genetic causes may distract

researchers from attending to nonbiological causes. Contrastingly, Appelbaum (2017) attests that while this is possible, genomic research is not likely to be the main cause for increased stigma experienced by people with mental diseases.

The hypothesis that genetic information may increase stigma is built on the Attribution Theory for stigma, which hypothesises that disease-related stigma and associated characteristics like blame, rejection and anger are greater if the person suffering from the condition carries greater personal responsibility (Phelan, 2005; Phelan, 2006). This hypothesis has been empirically tested only relatively recently, with some of the first studies conducted just over a decade ago (Phelan, 2006; Rusch et al., 2010). The most systematic attempts at understanding the implications of genetic attribution on disease stigma have been made in the context of mental health research (Kvaale et al., 2013(1); Kvaale et al., 2013(2); Phelan, 2005; Sabatello et al., 2015; Shostak et al., 2009). In the US, Phelan (2005) examined how attributing SCZ to a genetic cause affects stigma (for this condition) in a series of quantitative and qualitative projects (Meiser et al., 2005; Shostak et al., 2009). It was found that while respondents were less likely to attribute blame for their condition to patients when a genetic cause was known – which could reduce stigma – they were less likely to think that the person's condition could improve with treatment. These findings were echoed by Kvaale et al. (2013) in a meta-analysis of studies on the effect of genetic attribution on disease stigma (Laegsgaard et al., 2010). Phelan and colleagues also found some evidence that the social status of participants could be important in understanding the perceived importance of genetic information in understanding health outcomes (Meiser, Mitchell, McGirr, Van Herte & Schofield, 2005). Furthermore it was suggested that stigma may be extended to family members where a disease is attributed to a genetic factor (Shostak et al., 2009).

A US-based study investigating this relation on physical diseases included people with either breast cancer, deafness, cystic fibrosis or sickle cell disease (Sankar et al., 2006). These authors found that identifying a genetic cause for a disease or condition does not in itself increase or decrease stigma associated with a particular disease. Rather, they suggest that a genetic cause is interpreted in the context of patients' "lived experiences with a particular condition" (Sankar et al., 2006). Based on their research in Brazil, Gericke et al. (2017) extend this suggestion and state that genetic attribution is influenced by education and personal experience. In New Zealand Breheny (2007) investigated genetic attribution and social distance (as a measure of stigma) in relation to schizophrenia, depression and skin cancer, and she also found no main effect for genetic attribution in relation to participants' willingness to interact with an individual who has one of the three diseases. Hence, de Vries et al. (2012:11) suggests that genomics research may not cause stigma, however it may "feed into stigma where it is already present". Furthermore, it could enhance other forms of harm (i.e. disadvantages from the family, community or governmental structures) to participants enrolled in this kind of research.

Contrastingly, in the context of the US, Lebowitz and Ahn's (2012) study involving patients experiencing depression found that a biogenetic attribution could help alleviate some of the guilt and shame associated with this mental illness. Another US-based qualitative study involving family members of people with bipolar disorder found that family members thought that genetic information could reduce stigma by taking away personal responsibility (Meiser et al., 2005). Phelan et al. (2006) also put forward the hope that genetic explanations of illness may influence public perceptions, which may decrease stigma and increase help-seeking behaviour among mentally ill patients. In contrast Sabatello et al. (2015), investigating the effects of genetic attribution on stigma related to epilepsy in a US sample, found that 22% of

their recruited participants (who were outpatients) reported an increase in stigma related to having received genetic information about their illness. Also, scores were increased among those who were unemployed, older, and who reported discrimination related to their disease (Sabatello et al., 2015).

Shifting from the US context, a qualitative study in Denmark involving people diagnosed with depression found that patients had an expectation that genetic information about their disease may decrease stigma (McGregor, 2010). On the other hand, having a biomedical attribution of the disease could remove personal blame for patients. Kvaale et al. (2013), who compared attitudes to genetic attribution between mental health patients and members of the general public, found that the former tended to assume greater personal responsibility for their condition. Dietrich et al. (2006) found evidence that attributing mental illness to genetics may reduce desire for social contact from the general public towards the individual living with the disease. While in the review by Angermeyer et al. (2011) it was found that a biogenetic explanation has a positive association with stigma in relation to SCZ, but not necessarily other diseases.

In summary, studies conducted on various diseases, mostly mental illness, present inconsistent evidence of whether or not genetic attribution to disease may increase or decrease stigma (Tekola et al., 2009). Because of the uncertainty of this possible implication on African populations and given the increase in genomics research in Africa, it is pertinent to at least explore whether there is a possibility that this kind of research may influence disease-related stigma experiences of Africans.

3.4. Discussions in the global context

3.4.1. How people utilise genomic information

3.4.1.1. Individual (Micro-level)

In North American and European contexts - where much of the genomics research has been conducted - the implications of genomic information have been proposed to influence each level of society, including the individual, family, community and future social categories. At the individual level/micro-level (particularly for young people who are still developing their identity), the concern is that informing individuals about a genetic predisposition for a particular disease, may result in them developing fatalistic views about the onset of the disease. Concurrently, Sabatello and Juengst (2018) explain that this may impact on their beliefs of identity, self-worth, current and future plans in terms of career aspirations and having children of their own. Furthermore, Sabatello and Appelbaum (2016) attest that the distribution of adolescents' genomic information may lead to personal and social consequences (including stigma and discrimination). Anderlik and Rothstein (2001) describe this as a violation of a child's "open future". These scholars further suggest that relaying information about a predisposition for a disease may also influence an individual's subsequent behaviour (i.e. some may part-take in risky behaviour based on fatalistic views), in addition to it influencing their views on self-blame.

One of the assumptions of genomics research, is that genetics informs on who we are, and who we can be. This idea that biology ultimately rules our individual fates (Petersen, 1998) remains a dominant understanding today, despite the greater acknowledgement from many geneticists in the 21st century that environmental and social factors may act as "triggers" that influence the manifestation of a genetically related disease. Based on the abovementioned assumption that genetics determines one's 'fate' or future, scholars such as Anderlik & Rothstein (2001) and

Bates et al., (2005) report that some researchers' express concerns in relation to the use of genetic information for genetic stigmatisation and discrimination; e.g. when obtaining medical insurance (by insurance companies who may access their genetic information) and employment (if employers access their genetic information). In the US, it is this fear which lead to the implementation of the Genetic Information Non-discrimination Act (GINA), which became effective in 2008 (Department of Health and Human Services, 2009). This act was established to protect Americans from discrimination based on their genetic information when accessing health insurance and employment. The NIH reported that GINA also has implications for individuals participating in genomics research. Hence, Hellman (2003) argues that genetic information is special, and warrants special protection for discrimination. Therefore, in the US, genomic research projects are scrutinized by ethics review boards to ensure that researchers have considered the guidelines outlined by this act when designing their studies (Department of Health and Human Services, 2009). Aside from GINA there are other laws focussing on protecting US citizens from discrimination based on genetic information. On the African continent no known similar laws exist yet for the protection of Africans, although South Africa has very robust discrimination legislation that equally prevents discrimination on genetic grounds.

3.4.1.2. Family, Community and Public (Macro-level)

Revealing a genetic predisposition to an individual often goes beyond the individual, as it also provides information about people they may share genetic ties with (e.g. biological relatives). The NIH National Human Genome Research Institute explains that genetic information includes; family history, the manifestation of a disease in a family member and information regarding individuals and family genetic tests (Department of Health and Human Services, 2009). Thus, if there are any possible implications based on the disclosure of genetic

information, there may be implications at the family and community level. Sharing genomic information may have implications on family dynamics (including fuelling tensions between parents, parent-child relationships and sibling-sibling relationships) (Anderlik & Rothstein, 2001; Sabatello & Juengst, 2018). For instance, Sabatello and Juengst, (2018) maintain that blame may be shifted between the parents on who is responsible for causing the disease in the offspring or within parent-child relationships, there may be favouritism, or treating children differently (i.e. treating the child with a genetic predisposition more kindly, being overprotective over them or “labelling them” as the child with the gene to the disease). This may create conflict among the siblings as feelings of “othering” may emerge.

Additionally, the psychosocial consequences of providing genetic information to an individual may shift from the individual to extended family members (i.e. through ‘associative/courtesy stigma’), further complicating the family dynamics and processes of blame, discrimination and stigma within families and communities. Revealing this information to the individual, family or community directly impacts the level of privacy (about one’s own genetic-make-up) that individuals have. Anderlik and Rothstein (2001) and Bates, Lynch, Bevan and Condit (2005) support the above by reporting that some US citizens who participated in their research were concerned that divulging genomic information may impact society as a whole. Anderlik and Rothstein (2001) elaborated that genetic information is connected to the individual and their population group’s identity. It may be easier to anonymise individual data, however it may be trickier to anonymise population groups. Therefore, protecting their privacy (by not sharing genetic information) may be as important for the individual as it is for their population group.

In the media – which is a source often used to share genetic information - Bates et al. (2005) and Lynch et al. (2008) also indicate that, among others, concerns of the psychosocial

implications of genomics research include increased determinism and discrimination, positioning their argument particularly in relation to the public. It is important to note that projects such as the HGP and those employed by other health researchers have used media platforms to engage the public on human genetics. The impact of this type of broadcasting has also raised concerns among ELSI researchers. One reason for this concern being around the kind of platforms on which genetic information is relayed, as well as the content, as it can create a negative shift in how ordinary people may use genetic explanations to justify discrimination and determinism (Condit, 2010; Lynch et al., 2008). The definition of genetic determinism employed in this study is, “genetic determinism identifies genes as the sole relevant causal feature of an individual’s characteristics and life courses” (Condit, Parrott, & O’Grady, 2000, p. 558)

Reydon, Kampourakis and Patrinos (2012) and Sabatello and Juengst (2018) note that the manner in which genomics research is communicated to the general public (which often consists of people who typically have a poor understanding of genetics, genomics and its impact in society) creates distinct differences to what lay people know about genetics (Condit, 2010). Which is understandable given Kerr, Cunningham-Burley and Amos’ (1998) view that the general public’s involvement in dialogues about genetic research is skewed, as these conversations are often controlled by more educated individuals who have been exposed to contexts where genetic attribution to disease may have been discussed. This is not common for many black South Africans, as many of them reside in small townships away from cities or rural areas and a smaller number in urban areas. Most of them have no access to an easy exchange of genomic information and education resources.

3.5. Chapter summary

This introduced genomics research. It provides a short, yet valuable discussion on the concerns raised by scholars, primarily ELSI researchers, regarding the potential psychosocial implications of genomics research. The chapter describes how people may use genomic information, and how the information may affect the individual, family and community levels. The next chapter describes the concept of the stigma construct, the stigma theory framework used in this study and how genetics may influence disease related stigma.

CHAPTER 4: STIGMA

4.1. Introduction

Stigma is a concept which is understood in different ways in different studies. This chapter provides an overview of stigma research, how it has evolved and describes the common concepts related to stigma which are discussed in the literature. The chapter also describes the stigma theory conceptual framework applied in this study. It also discusses mental illness and stigma, cardiovascular disease and stigma and concludes by considering how genetics may relate to stigma among African people with SCZ and RHD.

4.2. Defining stigma

Stigma, and later the concept of prejudice that has been incorporated into stigma research, stem from the works of Goffman (1963) and Allport (1954) who are pioneering authors in the field. Initially, the concept of stigma was associated with diseases such as mental disorders and later HIV, and the concept of prejudice and discrimination to status characteristics such as race, gender, poverty or sexual orientation (Pescosolido & Martin, 2015). In contemporary literature, scholars have begun to merge these concepts into one stream of stigma research due to the overlap of the conceptualisations (Phelan, Link & Dovidio, 2008). Dembling, Chen and Vachon (1999) note that there is, however, variation in the use of terms often discussing the same social phenomena.

According to Goffman (1963), stigma is a mark, condition or status that is likely to lead to devaluation. Phelan et al. (2014) attest that primary consequences of stigma include status loss and discrimination, which often result in long-term social and economic inequality between those who stigmatise and those who are stigmatised. Although the majority of stigma research focuses on stigma in illness (Cocker, Bown & Henderson, 2016), disability or behaviour

(Phelan et al., 2005), there has been some work focusing on conditions, traits or situations such as poverty, sexual orientation and ethnicity (dos Santos, Kruger, Mellors, Wolvaardt & van der Ryst, 2014; Parker & Aggeleton, 2003; Simbayi et al., 2007). A more nuanced conceptual definition of stigma is provided by Link and Phelan (2001) as well as Byrne (2000).

Stigmatisation is the social process whereby the mark affects the lives of those associated with that mark, condition or status (Link & Phelan, 2001). In their recent research, Link and Phelan (2014) propose a concept they identify as “stigma power”. This concept suggests that stigma is a process where stigmatisers aim to keep others (the stigmatised) down or away. This aim is often achieved by processes which are indirect, generally effective and disguised as taken-for-granted cultural circumstances (Link & Phelan, 2014). These authors drew on the work of Bourdieu (1987) and Phelan et al (2008) to describe “stigma power” as the disguised, taken-for-granted cultural circumstances that enforce or reinforce stigma processes.

The “stigma power” process is the transference of particular characteristics through a social process. This process builds on existing social and power relations and dominant cultural beliefs about similarity and difference (Link & Phelan, 2001; Yang et al., 2007). According to these scholars, the stigmatisation process requires four aspects (a) distinguishing and labelling differences, (b) associating human differences with negative attributions or stereotypes, (c) separating “us” from “them,” and (d) experiencing status loss and discrimination. Pescosolido and Martin (2015) postulate that stigmas is “shaped and reshaped in particular cultural configurations that arise in social context, i.e., depending on time and place” (p. 91).

Contemporary research differentiates between perceived stigma, endorsed stigma, anticipated stigma, felt/received stigma and enacted stigma. Perceived stigma is the belief that “most

people” will devalue or discriminate against the stigmatised (Pescosolido & Martin, 2015). It has been associated with a lower quality of life, low self-esteem, low quality of work or role functioning, as well as a decreased uptake of social activities (Alonso et al., 2009). Endorsed stigma can be understood as the agreement with commonly held stereotypes about the condition or disease. According to Pescosolido (2013) this is the most researched type of stigma. Anticipated stigma is defined as an individual or group expecting that others will devalue or stigmatise them (Pescosolido & Martin, 2015). Felt/Received stigma focusses on the stigmatised individuals, establishing their recollections of discriminatory or stigmatised behaviour acted towards them (Pescosolido & Martin, 2015). Enacted stigma refers to the experience of discrimination that a stigmatised individual is subjected to by others (i.e. members of the family or community) (Gray, 2002).

The action-oriented stigma concepts often cited are internalised/self-stigma, courtesy/associative stigma, public stigma and structural stigma. Internalised/self-stigma involves an individual experiencing shame and an expectation of discrimination when being open about living with a condition that is vulnerable to stigma (Corrigan & Watson, 2002; Gray, 2002; Lee, 2002; Livingston & Boyd, 2010). Therefore, it can be viewed as the internalisation of negative attitudes, stereotypes and perceptions of people who belong to a devalued social group (Corrigan, Markowitz & Watson, 2004). Associative/courtesy stigma relates to the stigma experienced by caregivers or family members of an individual with a particular disease (Cathoor, Schrijvers, Hutsebaut et al., 2014). Public stigma refers to the reaction that individuals in the general public have to persons with an illness (Corrigan & Watson, 2002). Structural or institutional stigma, refers to the policies of private and governmental institutions that intentionally or unintentionally restrict opportunities available to people who have a particular disease (Corrigan et al., 2004; Lukachko et al., 2014).

Table 1 below lists the most commonly used terms in stigma research, many of which are used in this thesis (adapted from Pescosolido & Martin, 2015). This list is not exhaustive, however, to better understand how stigma is described in the literature, it tries to provide the conceptual definitions often used in stigma research.

Table 1: Theoretical building blocks of stigma research

Basic concepts	
Stigma	A deeply discrediting attribute; “mark of shame”; “mark of oppression”; devalued social identity
Stigmatisation	A social process embedded in social relationships that devalues through conferring labels and stereotyping
Labels	Officially sanctioned terms applied to conditions, individual, groups, places, organizations, institutions, or other social entities
Stereotypes	Negative beliefs and attitudes assigned to labelled social entities
Prejudice	Endorsement of negative beliefs and attitudes in stereotypes
Discrimination	Behaviours that act to endorse and reinforce stereotypes, and disadvantage those labelled
Target variants	
Perceived	Belief that “most people” will devalue, discriminate the stigmatised
Endorsed	Expressed agreement with stereotypes, prejudice, and discrimination
Anticipated	Expectations of experiencing prejudice and discrimination among the stigmatised
Received/felt	Overt behaviours of rejection and devaluation experiences of negative interactions
Enacted	Behaviours of differential treatment by stigmatisers
Action-oriented	
Internalised/self-stigma	Internalised acceptance of stereotypes and prejudice
Courtesy/associative stigma	Stereotypes, prejudice, and discrimination by association with marked groups
Public stigma	Stereotypes, prejudice, and discrimination endorsed by the general population

Structural stigma	Prejudice and discrimination by policies, laws, and constitutional practice; also called institutionalized Stigma
-------------------	---

Table 1 adapted from Pescosolido & Martin (2015)

4.3. Stigma Theory conceptual framework

This study is guided by the Stigma Theory conceptual framework of mental illness stigma, which is used in this research to position the discussion of internalised stigma and attribution. Exploring whether internalised stigma related to disease is particularly prevalent within certain populations is an important consideration for health promotion and prevention strategies (Livingston & Boyd, 2010). For this study, internalised stigma is the focus because it is a risk for increasing negative outcomes for persons living with a physical or psychological disease. These outcomes may include non-adherence to medication and decreased help-seeking. Theorists Corrigan and Watson (2002) distinguish between public and internalised stigma. These two types of stigma have three components, namely: (1) negative associations with particular human characteristics or disease (stereotypes), (2) beliefs in the negative associations (prejudice) and (3) the social consequences of these negative associations (discrimination) (Corrigan & Watson, 2002). Thornicroft, Rose, Assam and Sartorius (2007) and Thornicroft, Brohan, Kassam, Lewis-Holmes (2008) propose that the first is related to problems of knowledge or misinformation (ignorance), the second is about attitudes (prejudice) and the third is associated with action or behaviour (discrimination). The concepts of stereotypes, prejudice and discrimination have been used by various other authors (e.g. Heatherton, Klerk, Helb & Hull, 2000; Levin & Laar, 2006). Whilst Corrigan and Watson (2002) apply these concepts to the context of mental illness, other scholars such as Parker and Aggleton (2003) have applied this framework to stigma research on other diseases like HIV for example.

For this particular study, this framework was selected to position the discussion for three reasons: (1) this is the framework which is most cited in mental health stigma research (which is where a robust amount of research has been conducted on disease stigma), (2) this framework closely relates to the concepts of stigma described by the well-established stigma theorist Thornicroft in the area of stigma research, and (3) this framework has been applied to studies involving both mental illness and ones focussing on physical diseases. Figure 1 below presents the schematic presentation of the conceptual framework.

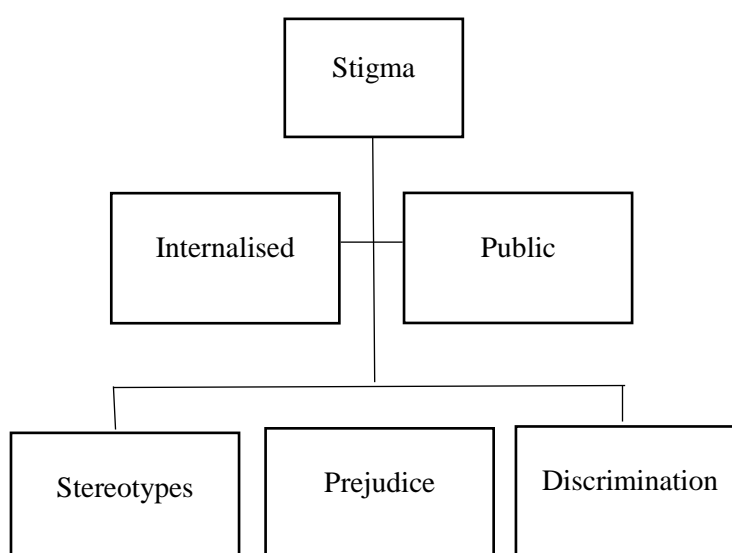


Figure 1: Stigma's two dimensions (Internalised and Public) and three components (Stereotypes, Prejudice and Discrimination) (Corrigan & Watson, 2002; Corrigan et al., 2004).

3.2.1. Components of Stigma Theory: Stereotypes, prejudice and discrimination

Stereotypes

Angermeyer and Dietrich (2006) describe stereotypes as commonly held beliefs about a group of people that are used to categorise the group members and anticipate their behaviour. In relation to internalised stigma (which this study focusses on), negative stereotypes are

internalised by individuals belonging to the “categorised” or “devalued” group. This means that the individual believes the negative stereotypes to be true of themselves and others who have the same condition (Quinn, Williams & Weisz, 2015). Corrigan and Rao (2012) describe the consequences of the internalisation of stereotypes as leading to fears of rejection, discrimination and a lowered self-concept experienced by individuals living with the disease. For example, much research has reported people with SCZ to be more dangerous, unpredictable and weak (Angermeyer & Dietrich, 2006). These beliefs about people with SCZ may lead to particular stereotypes. People with RHD have in some form or another been suggested to be weak, especially women because they are viewed as having fewer chances to obtain employment (Faure, 2018) or bearing their own children (Chang et al., 2018). These negative beliefs or stereotypes have been reported to have an impact on self-concept and self-esteem. Thachuc (2011) for example reports that stereotypes can be more disabling than the illness itself because they create a set of held beliefs which influences action/behaviour. For instance, negative stereotypes held by health professionals (see Adewuya & Oguntade, 2007; Li, Li, Thornicroft, & Huang, 2014; Thornicroft, Rose & Kassam, 2007) may prevent people with SCZ from seeking medical treatment for their disease (Angermeyer & Dietrich, 2006; Boyd, Katz, Link & Phelan, 2010; Rusch, Angermeyer & Corrigan, 2006; Pescosolido et al., 2010). Furthermore, Chang et al. (2018) report that women with RHD not only often refrain from consulting with health professionals about their reproductive decisions, but many of them ignore the opinions of health professionals and take “risks” by becoming pregnant without consultation because of the negative or judgemental responses they receive from health professionals when they articulate their desire to bear children. Not being children results in judgement from members in their family and community (Chang et al., 2018), which can further fuel internalised stigma.

Prejudice

Corrigan and Watson (2002) describe that a person is prejudiced when they believe a stereotype or perception. Thornicroft et al. (2007) describe that prejudice is more likely to lead to discrimination than stereotypes themselves. This is based on the knowledge that prejudice does not only result in negative thoughts about the stigmatised persons, but also results in negative emotions towards them, such as anxiety, anger, disgust, resentment, distaste or hostility, which may all influence behaviour (Corrigan & Watson, 2002; Thornicroft et al., 2007; Phelan et al., 2008). Experiencing emotions of disgust for instance, may result in the action of social distancing from a person forming part of a “devalued” group. If individuals are prejudiced about people who have a particular disease, they tend to endorse actions that discriminate against those people (Phelan et al., 2008). It is worth noting here that prejudice is often cited as a common concept in research related to race and racism, and similarly so, the action of discrimination is also often associated with issues of race and racism (Dovidio, 2001). This may be because these issues relate to the internalisation of negative beliefs (prejudice) and the actions linked to them (discrimination).

Discrimination

Discrimination is described as a behavioural response to the negative stereotypes and prejudice described above (Corrigan & Watson, 2002). Discrimination can result in the “harm” or oppression of a stigmatised group of people. For example, discriminatory behaviour toward people who have SCZ would be to refuse them employment opportunities, decent healthcare, housing and sometimes falsely accusing them of violent crimes (Corrigan & Watson, 2002; Phelan & Link, 2005). For instance, in a study done in the UK, black Caribbeans and mixed ethnicity patients who had a mental illness reported higher rates of discrimination than their white counterparts (Hatch et al., 2016). Similarly, in a study measuring anticipated and

experienced discrimination among people with schizophrenia, bipolar and depression in the UK, it was found that 87% experienced discrimination. In that study, higher levels of experienced discrimination were reported by individuals belonging to ethnic minority groups (Farely et al., 2014). A multi-centre study in 27 countries found high experiences of discrimination among patients with a mental illness (Thornicroft et al., 2009).

Du Plessis et al. (2004) refers to research by Zerwech (2000: 54) and Mhaule & Ntswane-Lebang (2009) who describe the experiences of Xhosa people with SCZ with a mental illness. These authors suggest that this group of people maintain a level of secrecy about a mental condition of a family member. These authors also highlight that the individual with the illness themselves, are often encouraged to or choose to isolate themselves from social engagements, leading to limited exposure to situations where they may experience discrimination. Hence, Zerwech (2000: 54) comments that the consequence of a lack of understanding and support from family and community members results in self-isolation by the person with a mental illness.

In Uganda, women with RHD reported being discriminated against in obtaining employment and anticipated of discrimination regarding their reproductive prospects (Chang et al., 2018). Faure (2018) found that mixed-ancestry RHD patients in the Western Cape reported discrimination experienced by women because of not being able to do as many household chores or engage in physical activities as they did prior to their diagnosis, which sometimes resulted in being excluded from community activities which were meaningful to them. An anticipation of discrimination can also result in people not participating fully in certain aspects of their lives, which can create negative feelings and reactions.

Jones (1997) defines discrimination as repeated indignities that deny people in the stigmatised group benefits that are available to those who do not fall part of that group. The nature and expression of prejudice and racism, however, depends on a number of dynamic processes closely relate to structural stigma (Dovidio, 2001). The Xhosa population enrolled in this study may therefore experience layers of discrimination based on: (1) racial categorisation, (2) disease label, and (3) socioeconomic status. Because of the possible real-life consequences of stigma, if there is any possibility that genomics research could increase the stigma they experience, then it is essential to understand better when and how this may occur and could be prevented.

4.4. The implications of stigma

Stigma has a significant negative impact on individuals living with disease, consequently affecting many aspects of their external lives, including relations with friends, family, communities, employers, healthcare services and the justice system (Mental Health Commission of Canada, 2009, p.90). Internalised stigma has been found in people with mental diseases, however research investigating internalised stigma in people with physical diseases is rare (Corker et al., 2016). Ritcher, Otilingam and Grajales (2003) conclude that internalised stigma impacts the self-esteem of people with the illness. Individuals labelled with a disease label who live in a culture with dominant stereotypes about the disease may anticipate and internalise attitudes that are based on the discrimination they have received (Corrigan, Larson, & Ruesch, 2009). Corrigan et al. (2009). Ritcher et al. (2003) and Link, Struening, Neese-Todd, Asmussen & Phelan (2001) demonstrated the relationship between internalised stigma and low self-esteem. Low self-esteem may prevent individuals from seeking relationships, employment, decent housing and even healthcare services for the fear of rejection or being viewed as weak. The hesitancy to seek healthcare for the fear of being associated with the

disease label – i.e. in the public hospitals in South Africa where there are clear signs of wards for patients with mental illness – may influence adherence to medication and ultimately the recovery process.

4.5. Mental illness and stigma

SCZ is a highly stigmatised condition and has been defined as a psychiatric disease for over a century, but despite decades of research, a definitive set of biological markers for the disorder is still not available, nor are there any existing preventative or curable treatments (Abayomi et al., 2014). Despite the fact that this disease is not curable, there are potential ways to improve lived experiences of people with a SCZ diagnosis with the help of pharmaceutical and psychotherapeutic interventions. However, in the South African context, as is reported in other LMIC, the majority of people living with mental diseases do not have access to adequate mental healthcare services (Lund et al., 2012).

Lund and Fisher (2009) point out that many of the facilities providing mental healthcare in South Africa are chronically under-resourced. Barriers to accessing mental healthcare include among others: poverty, poor mental health literacy, stigma and the influence of cultural beliefs (Naanyu, 2009). Furthermore, due to the fact that mental healthcare services are mostly integrated into primary healthcare (i.e. the community clinics with clearly marked labels of the psychiatric sections), patients are potentially exposed to public scrutiny (Botha et al., 2006; Swartz, 1998). With the exception of Botha et al. (2006) and Sorsdahl, Kakuma, Wilson, & Stein (2012), minimal research has been documented on the topic of internalised stigma in relation to mental illness (from the perceptions of patients) in South Africa. In their study, Botha et al. (2006) found a high level overall degree of perceived stigma reported by schizophrenia patients. Additionally, these authors suggest that their stigma may also be

influenced by contextual and cultural factors. As described by Satorius (2005) different fears and prejudicial judgments may be prevalent in relation to stigma in different cultural groups. Physical abuse as a demonstration of stigma due to having a mental illness was highly reported by male Xhosa-speaking patients who had frequent hospitalisations for longer periods in Botha et al's (2006) study. Sorsdahl et al. (2012) found that internalised stigma is not always a consequence for people with depression. However, where it is present, it is significantly related to social withdrawal and discrimination.

Generally, the South African public tends to be more stigmatising towards patients diagnosed with SCZ in comparison with patients diagnosed with other mental disorders (Mbanga et al., 2002). In addition, caregivers and family members of patients with SCZ have demonstrated a tendency to perceive these patients as dirtier, weaker, more unpredictable, worthless, delicate, slow, foolish and more dangerous than the average person (Hughes & Huby, 2002; Mbanga et al., 2002; Sorsdahl et al. 2012). Anecdotal reports from traditional healers suggest that these patients are rejected and ridiculed by their communities (Pain, 2012). Hence their life opportunities are decreased and employment, suitable accommodation and suitable life care of people with SCZ may be negatively affected.

There is much research on stigma and mental illness on African population groups (Adewuya & Makanjuola, 2005; Adewuya & Oguntade, 2007; Patel, 1995; Seedat, Stein, Berk, & Wilson, 2002). While evidence suggests that African people with SCZ are stigmatised (Naanyu, 2009), a gap in this literature is that the perceptions of the people living with SCZ themselves have been largely ignored. Much of the available research has included members of the general public, family members or traditional healers to the exclusion of patients themselves. This study is unique in that it explores the SCZ patients' own perceptions.

Following Naanyu's (2009) research on social context, attribution and stigma in South Africa, this study is one of the first to explore the possibility of a genetic explanation to disease influencing internalised stigma experienced by a South African patient population group.

4.6. Cardiovascular disease and stigma

The second disease focussed on in this study is RHD. This population group was selected for inclusion in this study for three reasons. Firstly, as mentioned before, ethics committees often highlight stigma as a potential concern when considering genomics research projects for all disease groups (de Vries et al., 2012; WHO, 2002). It is thus important to better understand whether this is a valid concern, and if so, how genetic attribution of physical, non-stigmatised conditions could possibly influence stigma. Secondly, this disease group was deemed suitable for inclusion due to fact that during the time when the study was developed, the Faculty of Health Sciences at UCT conducted the largest ongoing genomics project in Africa that enrolled patients with RHD (the Genetics of Rheumatic Heart Disease study). This provided a unique opportunity to recruit patients who had been involved in a genomics study, to enrol in this particular study that investigates a potential ethical or social implication of genomics research. Furthermore, in similar ELSI genomics studies in the context of the USA for instance (see Condit et al. 2009) researchers have investigated the psychosocial implications of genomics research across very different diseases (e.g. Condit et al., 2009 focussed on heart disease, lung cancer and depression). Thirdly, focussing on a mental illness (which may be perceived as more stigmatised) and a physical disease (which may be perceived to be generally less stigmatised) may reduce the chances of mistakenly suggesting general conclusions relating to the concern that genetic attributions may influence stigma in similar ways across mental and physical disease groups based on the findings of one disease group, which is known from the literature to already be vulnerable to stigma.

RHD is a chronic heart condition caused by untreated infection with *Streptococcus* pharyngitis, also known as Strep A (Carapetis, McDonald & Wilson, 2005). In some patients, untreated Strep A sore throat can cause rheumatic fever, which in turn can cause an autoimmune reaction that attacks the tissue of heart valves. Repeated infection with Strep A can cause cumulative damage to the heart valves, leading to serious and potentially lethal heart damage (Carapetis et al., 2005) that can only be effectively mediated with surgery. Globally, RHD remains the most common cause of heart disease in children and young adults (Robertson, Volmink & Mayosi, 2006) with about 30 in 1000 schoolchildren affected in Sub-Saharan Africa (Robertson & Mayosi, 2008).

RHD has been described as a disease of poverty that largely affects marginalised population groups (Barth, 2013; Chang et al., 2018; Engel et al., 2011; French & Poppas, 2018; Zuhlke, 2015). It is a rare phenomenon in wealthy countries with incidences increasing under the influence of poverty (Robertson & Mayosi, 2008). In South Africa for instance, the prevalence of RHD runs parallel with a host of variables indicating poverty, such as crowded housing, poor nutrition and low levels of education (Barth, 2013).

In a systematic review of published twin studies, Engel et al. (2011) estimated the heritability for developing rheumatic fever to be 60%. Ironically, the prevention of RHD is both affordable and effective (Irlam, Mayosi, Engel & Gaziano, 2013), as primary care treatment of sore throat infections with penicillin prevents the development of RHD, whilst prophylactic use of penicillin in RHD patients prevents recurrent infections and further damage to heart valves. Concerning estimates suggest that there are 15.6 million prevalent cases of RHD worldwide, with 282,000 new cases and over 233,000 deaths per year (Zuhlke & Steer, 2013).

RHD is often detected at higher rates in women than men due to the physiological changes experienced by women during pregnancy, which includes increased blood volume and heart rates (French & Poppas, 2018). RHD may often only be diagnosed in pregnancy. If RHD is diagnosed at a young age, then women are usually discouraged from getting pregnant, because of the possible complications which may arise (Zuhlke, 2011). Due to the risks of complications for the mother and offspring (French & Poppas, 2018), women with RHD are often discouraged by medical practitioners to bear children. The social consequences of not bearing children, however, are often a cause for stigma among women in Africa living with RHD (Chang et al., 2018).

The only other two known studies that explored the stigma experiences of people with RHD in an African population group (Chang et al., 2018 & Faure, 2018) used a similar methodological approach to the present study. Chang et al. (2018) conducted FGDs with 75 women living with RHD in Uganda (Chang et al., 2018). Fifty out of the seventy-five women completed a stigma questionnaire designed by the authors. Participants in their study reported considerable stigma in the domains of reproduction and financial limitations (Chang et al., 2018). The authors found that the stigma reported by the participants was often worse than the stigma reported by patients with HIV in their context (Chang et al., 2018). Faure's (2018) study explored the impact of genetic attribution on stigma associated with RHD among mixed-ancestry patients in the Western Cape, South Africa. Eleven FGDs were conducted with 52 mixed-ancestry patients with RHD, 70% of which were women. Findings from that study suggest that RHD stigma is impacted by various contextual realities that are largely shaped by the historical racialised nature of marginalisation and structural inequality of the South African context (Faure, 2018). Despite the limited number of studies involving RHD patients and exploring stigma, we anticipated that Xhosa people with RHD would share similar disease stigma experiences,

particularly given that it is a disease of poverty, and in conjunction with the other stigmatising factors they face (i.e. social inequality, low-levels of education, lack of adequate healthcare services, high unemployment rates etc.).

4.7. How genetics may relate to stigma

DiMillo et al. (2015) define the concept of genetic stigmatisation as a negative label by virtue of membership to a particular group that has been described as being genetically deviant. These authors identify three types of stigmatisation associated with genetics, namely; (1) stigmatisation through anticipation, (2) stigmatisation through rejection, and (3) stigmatisation by affiliation (DiMillo et al., 2015).

Reasons for genetic stigmatisation have been discussed as firstly, genetic illiteracy among health professionals, the public and policy-makers (King et al., 2002). One example is the genetic testing of African Americans for sickle cell disease in the US in the 1970s. During that time there was confusion among physicians, and subsequently the general public, in understanding the results between carriers of the disease and people who actually had the disease. The second reason may be what Markel et al. (1992) describe as the “quarantine mentality”, which refers to society attempting to keep people who carry specific genes “out” or “away” from the general or “normal” population who do not have those genes, as Link and Phelan (2014) allude to in their conceptualisation of the “stigma power” concept. These individuals are seen as inferior and “different” (i.e. othering). This may be done as an attempt to prevent the genes from being passed down to the next generation or as an attempt to keep the “normal” people “pure” (Sabatello & Juengst, 2018). Similarly, ethics committees often raise concerns about stigma as a result of genomics research, regardless of the disease under investigation.

The WHO (2002) report suggests that genetic stigmatisation can occur for any disease. In this research we enrolled participants who either had SCZ or RHD and were participants in one of the ongoing genomics studies in the Faculty of Health Sciences at UCT. These two parent projects are discussed in Chapter 6, section 6.6.

4.8. How genetics may relate to stigma in SCZ and RHD genomics research

Rotimi and Marshall (2010) propose a list of ten cultural and social factors to consider when compiling informed consent forms for conducting any genomics research in Africa. One of these ten factors is the potential for stigmatisation of specific population groups. These authors attest that the social and cultural meanings of disease held by the people in the population group under investigation should be considered with sensitivity prior to highlighting genetic attributions about their disease. A physical disease named Podoconiosis – a disease resulting in the swelling of the lower limbs of the legs of people exposed to red soil – is highly prevalent in some regions of Africa, such as in Ethiopia for instance. It is a physical disease that is highly stigmatised (Rotimi & Marshall, 2010). Researchers engaging in a genomics study focussing on Podoconiosis (Tekola et al., 2009) found that participants were afraid to participate in the research because they were fearful that receiving information about the genetic nature of the disease may contribute to an increase in social stigma.

While this is a physical disease, and considering that genomics research on African populations has only just started over the past few years, it is unclear whether Xhosa people involved in schizophrenia and rheumatic heart disease genomics research may feel that genomic information about their disease in any way relates to their internalised stigma experiences. While we know that SCZ is a stigmatised condition, and there has been some stigma reported on RHD, if there is a possibility that providing genetic information as a cause may increase

internalised stigma, it is important to explore how that may be possible. This possibility is important to consider because, as Rotimi and Marshall (2010) propose, genomics researchers have a responsibility to investigate whether stigma is a potential risk for African population groups involved in genomics research. This study may contribute to gaining an understanding of the relevance of this concern amongst the Xhosa people with SCZ and RHD enrolled in this study. It may help the continuously evolving field of genomics and ELSI research to consider the ways in which genomics research could potentially relate to stigma of common physical and mental diseases in Africa, and thus insert measures to protect against that in future study designs.

4.9. Chapter summary

There is a robust amount of literature related to mental illness and stigma. However, there is not much literature focussing on cardiovascular disease and stigma, both globally and in Africa. Most research on stigma and disease has been conducted in North American and European context. This chapter provides a description of the concepts often used in the literature to explore stigma. Given that Africa has a unique context with diverse population groups, these concepts are applied in this study with caution and openness to the conceptualisations of stigma that may emanate from this African population group.

CHAPTER 5: THEORETICAL FRAMEWORKS

5.1. Introduction

In this chapter I discuss the theoretical frameworks that are utilised in the current study. The research in this thesis is guided by the Attribution Theory (Weiner, 1986) and the Modified Labelling Theory (Link & Phelan, 2001). The constructs of the theories, synergies between the constructs and how they could relate to the research findings are explored.

5.2. The Attribution Theory

The first theory this study employs is the Attribution Theory (Weiner, 1986; 1995). Attribution Theory (Weiner, 1986; 1995) refers to a collection of models and theories that focus on creating an understanding of the process that involves people forming inferences about the cause of events or disease (i.e. causal attributions) and the consequences of these causal explanations (Fiske & Taylor, 1991). Attribution Theory was selected as one of the suitable theoretical frameworks for this research for two reasons. First, this theoretical framework is useful because it specifically focusses on perceptions of causation rather than the actual cause or the accuracy of these causal beliefs. Dovidio, Major and Crocker (2000) articulate that attributions typically involve explanations about beliefs on causes, actions, or conditions. Perceptions of causes of disease are thought to influence subsequent cognitive, affective and behavioural responses.

Secondly, we found the Attribution Theory a suitable model to guide this research because, in his later work Weiner (1995; 1998) suggests that the Attribution Theory can also be used to describe whether or not an attribution can lead to stigmatised perceptions and discriminatory behaviours. Concurringly, Corrigan (2000) describes attribution theory as a cognitive emotional process whereby individuals make attributions about the cause and controllability of the individual's disease.

Many attribution theories report that people are motivated to make causal attributes in order to firstly, gain an understanding of their world and past events, and secondly, to guide future behaviour and enable greater predictability and control over their environments (Harvey & Weary, 1984). Weiner (1986; 1998) puts forward that by identifying the cause of the disease, an individual may have the ability to assess which actions may be taken, if any, to minimise the reoccurrence of negative outcomes in the future, as well as maximise the probability of a desirable outcome.

Being one of the first theorists to classify Attribution Theory and coin the attribution theory of motivation and emotion, Weiner (1986) identified three main dimensions, namely locus, stability and controllability. Each of the dimensions has predictable psychological and behavioural consequences (Corrigan, 2000). An internal locus of causality suggests that the disease onset is a result of dispositional factors originating from the individual, while an external locus of causality implies that contextual factors constrained the individual to the extent that they developed the illness. Furthermore, where there is an internal locus of causality, it is not always under the individual's control. An example of this might be that while an individual's genetics can be considered to be internal, genetic composition is not considered as being within the individual's control. Also, Weiner (1986) defines stability and controllability by proposing that the stability of a cause refers to its perceived degree of permanence over time (some illnesses remain stable over time, while others increase or decrease), as opposed to controllability, which refers to the degree the cause is believed to be under the individual's control. An example of controllability may be an individual choosing to abuse substances, eat unhealthy food and not exercise, which may influence the onset and stability of a disease. On the contrary, one cannot control something like blindness.

Essentially, it is possible that there is more than one factor that makes one susceptible to developing a disease. These factors may be located differently in terms of Weiner's (1986) three dimensions. Furthermore, perceived causality may vary between individuals living with the same disease diagnosis. It may also vary within a single individual at different times, both for the cause and the location of the cause on the three dimensions. Hence Weiner (1986) suggested that each causal dimension is related to a specific set of emotions that emanated or is enhanced because of the disease onset.

Fundamentally this study draws on the Attribution Theory's process to associate causal attributions and likely responses to the disease onset. Corrigan and Watson's (2002) conceptual framework of stigma (as described in Chapter 4, section 4.3) and Weiner's (1986) Attribution Theory have been used in this study in order to better understand the process of a potential genetic attribution to disease and its potential influence on stigma experienced by SCZ and RHD Xhosa patients. Next, the Modified Labelling Theory will be discussed, which is also used in this study to inform the epistemological underpinnings (Link, Cullen, Stuenkel, Shrout & Dohrenwend, 1989).

5.3. The Modified Labelling Theory

The Labelling Theory views the label, rather than the outcomes of having the label as shaping the fate of mentally ill persons (Rosenfield, 1997). A label of a mental illness is believed to create negative attitudes (held by others and the person with the illness) (Link, 1987; Link et al., 1989). This theory maintains that the label creates a state of chronic illness through compromising the opportunities afforded to the person with the label (Scheff, 1966; as cited in Rosenfield, 1997).

The theory has received considerable critiques from the medical model of mental health due to the disagreement between the importance of the behaviour and the label assigned to it resulting in the negative social response (Link et al., 1989). One of the main criticisms being that the Labelling Theory places less importance on factors such as stigma and stereotyping. Link et al. (1989) therefore draw on the Labelling Theory (Scheff, 1966) and extend it into what they call a Modified Labelling Theory (MLT). Like Scheff (1966), step one of their proposed theory lies in that individuals internalise social conceptions of stereotypes related to having a mental illness. This is when individuals begin to distinguish and assign labels to individuals with a stigmatisable attribute or disease (Link & Phelan, 2001). These conceptions are guided by two elements: first, the extent to which people (with and without the label) believe that persons will be devalued, and second, their perceptions of these individuals experiencing discrimination. Step two involves official labelling through treatment contact, for instance in whether or not people maintain social distance from a person with an illness. An example of this component is described by Link and Phelan (2001) regarding a vignette experiment conducted by Link (1987) where when the vignette described a person with mental illness, the response from participants in general were “dangerous” and an increased desire for social distance, while when it described a person with back pain the participants did not express a relation to dangerousness and/or an emphasis on social distancing. Step three focusses on patients’ responses to their stigmatisation process. Link and Phelan (2001) describe the labels to connote a separation between “us” and “them”. These authors maintain that in extreme cases, individuals falling in the “them” group are treated horrifically. Step four includes the consequences of stigma process on the patients’ lives. At this stage, individuals with the label experience consequences of status loss and discrimination (Link & Phelan, 2001). Using the Modified Labelling Theory together with the Attribution Theory, this study aims to understand the relation between attributing a labelled disease (in this case SCZ and RHD) to a particular

causational model and how that could influence the stigmatisation process experienced by individuals with that disease. This study applies these theories bearing in mind that they were developed in very different contexts and that different cultures have been reported to assign a variety of attributions to disease onset (Naanyu, 2009).

5.4. Chapter summary

This chapter outlined the theoretical paradigms used in this study. These theoretical frameworks were used in the research with the hope to elucidate the relation or association between attributions, disease labels and stigma experienced by Xhosa people with SCZ and RHD. The Attribution Theory and the Modified Labelling Theory are integrated in the study in order to better understand the constructs they explore. In support of Phelan et al.'s (2008) position that stigma is contextual and the unique social milieus important when trying to understand the stigma process of different population groups, the research methodology employed in this thesis will be discussed in the next chapter.

CHAPTER 6: RESEARCH METHODOLOGY

6.1. Introduction

In this chapter I will first outline the problem statement and the focus of the study. I then provide an explanation of the research aims and research design. I also provide an overview of sampling strategies, the study setting, samples, data collection and data analysis. Furthermore, I detail the development of the research instruments and how they were utilised in the study. In the chapter I provide a detailed account of the development use of the instruments used in the FGD process. I also briefly mention the translation of the Internalised Stigma scale (an extensive elaboration of which is discussed in Chapter 9 of this thesis). In this section, I also reflect on my own position as researcher. The chapter concludes with a discussion of the ethical considerations pertinent to the study and a chapter summary.

6.2. Problem area and focus

Problem area: The adoption of the Human Genome Project, the increasing interest in genomics research and associated increase in funding this research agenda led to a number of ethical and social concerns. Implications of genomics research, particularly within specific population groups, need to be taken into account by researchers. One concern is that the results of genomics research could create or increase stigma for individuals who have diseases that are known to have a genetic or a hereditary basis (Sankar et al., 2006). Although the concern about stigma is identified broadly for all medical genomic projects including those investigating illnesses that do not have a clear genetic basis (WHO, 2002; Yakubu, Tindana, Matimba, Littler, Munung, Madden ... de Vries, 2018). The concern of stigma has been identified as particularly important because genomics research is only just advancing on the African continent, and it is important to recognise that studies may involve participants who have different language and cultural backgrounds governed by different belief systems. Some

participants may be from populations which are marginalised or already stigmatised (Yakubu et al., 2018). These nuances ought to be considered sensitively. Much of the research investigating this potential implication has been conducted in North American and European contexts on diseases that are already stigmatised like schizophrenia. Whether or not the same risk of stigmatisation is apparent in an African contexts and with populations which are not yet known to experience disease-related stigma remains unexplored to date.

Focus: The general aim of this study is to explore how genetic attribution of disease may relate to the internalised stigma experiences of South African Xhosa people with schizophrenia and people with rheumatic heart disease.

This research project focussed on exploring how a genetic attribution to disease relates to internalised stigma experiences of South African Xhosa people with schizophrenia and people with rheumatic heart disease.

6.3. Research aims

This study aims to explore how genetic attribution to disease relates to the internalised stigma experiences of South African Xhosa people with schizophrenia or rheumatic heart disease.

6.4. Research questions

1. What causal models are employed by Xhosa people with schizophrenia and people with rheumatic heart disease to explain their illness, and to what extent do genetic explanations play a role in these causal models?
2. What are the internalised stigma experiences of Xhosa people with schizophrenia and rheumatic heart disease?

3. How do the genetic disease causal explanations of Xhosa people with schizophrenia and rheumatic heart relate to their internalised stigma experiences, if at all?

6.5. Research design

The research design is one of the most important aspects of a research study as it provides guidance for the research process, and the interpretation of the results (Gobo, 2008). The present research is explorative and descriptive in nature and through the use of focus-group discussions (FGDs) a mixed-methods (inclusive of a qualitative and a quantitative component) approach was utilised. We chose this method to elicit thorough and nuanced information from our participants. This method has also been used in previous studies investigating stigma and RHD (Chang et al., 2018) and stigma and SCZ (Atkins, 2016). Furthermore, a mixed-methods approach has also been employed in studies investigating ethical and social implications of genomics research (i.e. Sabatello et al., 2015 in the context of mental illness and Condit et al., 2009 across physical and mental diseases). As found in previous ELSI genomics studies (Condit et al., 2009), a focus-group format allowed us an opportunity to engage with participants to explore and probe on their perceptions around genetics as disease causation and how it may relate to any stigma experiences they may have. Conducting FGDs has been reported as an effective method to explore disease causal attributions (see Condit et al. 2009 and Sankar et al. 1999 for example). Condit et al. (2009) conducted focus-group discussions with eighty participants from the US, Australia and Europe. During their FGDs, individuals answered questions like (what do they know about their illness and about genetics) and completed questionnaires to indicate estimates of genetic influence on their disease.

The first component of this study sought to translate and adapt the ISMI scale into isiXhosa for use among both SCZ and RHD participants. For use among RHD participants, the term ‘mental illness’ was replaced with ‘heart disease’. This was a specific methodological decision informed by previous adaptations of the ISMI for use in other disease groups in health-related research, and correspondence with the ISMI scale developer about the extent of adaptation of the scale for use in the RHD sample. A discussion of the advantages and disadvantages of this decision, and the resultant limitations of the Xhosa scales that were ultimately produced are presented in Chapter 9, section 9.5. In the context of FGDs (7 for RHD patients and 6 for SCZ patients), I hoped to use the newly translated and adapted scale to quantify some of the internalised stigma experiences of the Xhosa samples with RHD and SCZ. However important limitations within the translated scales were revealed during the investigation of psychometric properties which made the use of the data generated from the scales problematic. Instead important insights about the conceptualisation of internalised stigma in the Xhosa language and particularly relevant internalised stigma items identified in each disease group from the translation design of the study were used to inform the second research question: *What are the internalised stigma experiences of Xhosa people with schizophrenia and rheumatic heart disease?* Additionally, I qualitatively explored what disease causal models these individuals hold and how a genetic explanation may influence any potential disease stigma. I used the context of FGDs based on the guidance of Liamputtong (2011) who describes that, “focus groups involve 6-8 people who come from similar social and cultural backgrounds or who have similar experiences or concerns” (Liamputtong, 2011, p. 3). Morgan (2002) on the other hand reports that FGDs may even have a minimum of 5 people.

Following a mixed methods approach, data collection took place in one session for each group (Creswell, 2009; Collins, Onwuegbuzie, & Johnson, 2012). Not only was that efficient, but it

also ensured that all the data for each participant was collected without the threat of difficulty in follow-up. A series of 13 focus group discussions were held. This process allowed participants' to articulate themselves and explain their perceptions, while I as the researcher had an opportunity to listen and gain an understanding of their viewpoints (Cresswell & Plano Clark, 2011). A mixed method approach to translation of the internalised stigma scale component was preliminary to the focus groups and involved an investigation of psychometric properties of the translated internalised stigma scales in Xhosa, to inform understandings of how the constructs of internalised stigma (i.e. alienation, social withdrawal, discrimination experiences and stereotype endorsement) were supported in the Xhosa language in these two population groups.

Each FGD was roughly 90 minutes long. Interviews took place at a boardroom in a public or psychiatric hospital that participants were outpatients to and thus were familiar with because they received their treatments at these facilities. Upon completion of the FGD questions, participants were thoroughly debriefed to ensure that they understood that the FGD videos involved hypothetical scenarios, and that at present there were no existing evidence for exclusive genetic attribution for these two diseases. As the researcher, I conducted these FGDs in isiXhosa alongside the recruited home-language isiXhosa-speaking co-facilitator (who at the time, was pursuing a Master's degree in Medical Anthropology) who had some experience in conducting empirical research. During the first FGDs with each disease group, one of my supervisors was present to assist and provide guidance where necessary.

6.6. Sampling strategy and gaining access to the study sample

Onwuegbuzie and Collins (2007) view sampling which involves selecting a portion or segment representative of a whole, as an important part of the research process. The authors explain that

this is because careful sampling informs the quality of the conclusions made by the researcher based on the research findings. For the purpose of this research, purposive sampling was used (Bryman, 2012). The research sample was based on people living with RHD and those with SCZ who were available and willing to participate in the study and who had met the inclusion criteria. The inclusion criteria for this study was that prospective participants had to have been enrolled (as patients) in one of two ongoing genomics research projects, namely the “Genetics of Rheumatic Heart Disease project” also referred to as the RHD Gen project (FHS016/2013, PI: Bongani Mayosi, Grant number: WT ME060838MA) and the “Genomics of Schizophrenia in Xhosa-speaking South Africans project” (FHS049/2013, PIs: Dan Stein; Ezra Susser & Mary-Claire King, Grant number: NIH1U01MH096754-01A1). At the time, these studies were both ongoing in the Faculty of Health Sciences at UCT. Because the latter study only enrolled individuals of Xhosa origin, in order to ensure an adequate comparative sample, we decided to include a second inclusion criterion which was that we would only enrol patients of Xhosa origin. The two parent genomic studies provided a unique opportunity to engage with research participants who had enrolled in those genomic studies.

6.6.1. The Genetics of Rheumatic Heart Disease (RHD Gen) Project

The RHD Gen project aims to build a clinical and laboratory network for the phenotyping of RHD patients and controls in Africa; identify genes affecting susceptibility and resistance to RHD as well as train scientists and clinicians in genomics research while also addressing ELSI issues relevant to Africa (*h3africa.org*). The RHD Gen study enrolls participants irrespective of their ethnic background, but due to factors stemming from South Africa’s apartheid legacy which created significant differences in socio-economic levels (RHD being a disease affecting mostly the poor) in the RHD Gen study sites in South Africa, research participants are either of mixed-ancestry or Xhosa background.

6.6.2. Genomics of Schizophrenia in the South African Xhosa people (SAX) Project

The SAX project is a multisite project, which aims to identify gene mutations associated with SCZ in Xhosa people in South Africa. This study is the first of its kind to investigate genomics of SCZ in specifically Xhosa-speaking people (*h3africa.org*).

6.6.3. Focussing on RHD and SCZ

We chose to focus on RHD and SCZ for a two reasons. Firstly, the fact that these diseases are distinctly different (i.e. a physical disease vs a mental disease) provides an opportunity to explore how disease stigma may be influenced in a condition which is not currently known to carry much stigma (RHD) and one which is well-known to carry stigma (SCZ). This was important because concerns around stigma in African genomics arise regardless of whether the disease under investigation carries stigma or not. Secondly, we hope that choosing these very different diseases may provide some preliminary evidence as to whether and for which types of diseases stigma should be a concern, as often assumed by ethics committees (de Vries et al., 2012 & WHO, 2002) when reviewing proposals for genomics studies. It is important to note however, that RHD is strongly poverty-related (in fact, it is often described as a “disease of poverty”) and so could carry negative associations and some stigma.

6.6.4. Focusing on the Xhosa-speaking patient population

Due to the fact that the research design is comparative between patients from both the RHD Gen and SAX studies, working with the same population (Xhosa people) proved to be more practical in facilitating the research. The SAX study focuses exclusively on the Xhosa population. Therefore, for the purpose of this study, only people of Xhosa origin were enrolled.

6.6.5. Study sites

Participants in the study were recruited from various sites. RHD participants were recruited from a public hospital located in the southern suburbs of Cape Town, in the Western Cape, while SCZ participants were recruited from two public psychiatric hospitals (one in the southern suburbs and another in the Cape Flats region in the Western Cape). Additionally, some SCZ participants were recruited at a public hospital (within a psychiatric ward) located in a low-income community in East London, in the Eastern Cape. All these sites are in South Africa.

6.6.6. Recruitment process

Xhosa-speaking RHD patients who were enrolled in the RHD Gen study, were re-contacted telephonically and invited to participate in the current study. Those who agreed were invited to one of the 7 FGD sessions. Following a similar process, I also re-contacted SCZ patients who had participated in the SAX study and invited them to participate in the current study. All participants in both studies had signed consent documents which stipulated the possibility of being re-contacted. For the purpose of involvement in this study, participants also signed a consent form which was translated into isiXhosa (see Appendix E). The criterion for inclusion in this study was any male or female of Xhosa origin, who had been enrolled in the RHD Gen or the SAX studies.

6.7. Procedure

This study was conducted in three phases:

Phase 1: Obtain permission and ethical clearance

Phase 2: Translation and adaptation of the ISMI scale

Phase 3: Focus Group Discussions

6.7.1. Phase 1: Obtain permission and ethical clearance

The present study falls under a larger study in the Department of Medicine at the University of Cape Town (FHS HREC 204/2015 Stigma in African Genomics Research on Schizophrenia and Rheumatic Heart Disease, which is a sub-study linked to RHD Gen study: 016/2013 and the SAX study: 049/2013), and ethical clearance for the study had been granted before completion of data collection (see Appendix A). Through conducting this study, I committed to upholding all the conditions stipulated in the approval documents from the Human Research Ethics Committee, Faculty of Health Sciences at UCT.

6.7.2. Phase 2: Translation of the ISMI scale

The standardised ISMI scale used in the study was translated into isiXhosa using a five-stage translation design, which drew from methods recommended by Brislin (1970; 1986), and the WHO (Sartorius & Janca, 1996), and had proved effective in previous South African translation studies adapting psychiatric measures into Xhosa (e.g: Campbell & Young, 2016 and Steele & Edwards, 2008). Firstly, the measure was forward-translated independently by four isiXhosa-speaking healthcare professionals. Secondly, these translation reviewers met as a committee to discuss the resultant translations; particularly focussing on differences between the four translations and to select preferred translation choices for each questionnaire item. The resultant isiXhosa-translated scale (further referred to as ISMI/ISRHD-X) was quantitatively piloted by trained psychiatric nurses (under the SAX study) in a sample of 60 Xhosa participants with SCZ, while I piloted the ISRHD-X with a sample of 50 Xhosa-speaking RHD participants in the Western Cape. Thirdly, I qualitatively piloted the ISMI-X and ISRHD-X

scales in a smaller sub-sample of 5 Xhosa-speaking SCZ and 5 Xhosa-speaking RHD participants by using cognitive interviewing. Fourthly, these newly developed isiXhosa tools were back-translated into English by an independent Xhosa-speaking psychiatric nurse. Lastly, the translation group collaborated to review the back-translation and the piloting results to resolve any discrepancies pertaining to the scale. There is some debate in the literature about the advantages and disadvantages of utilising healthcare professionals in the translation process. This critique is presented Chapter 9, section 9.2. As the researcher, I led every step of this process. A greater elaboration of the translation of the tools is described in Chapter 9 of this thesis.

6.7.3. Phase 3: Focus group discussions

I organised and facilitated 13 FGDs (6 SCZ and 7 RHD) with a total of 82 research participants consisting of 36 people with SCZ and 46 with RHD. The FGDs drew on vignettes to explore the potential relation between different disease causal models with a focus on genetic explanations and the resultant stigma they received. Causal explanations included genetic, partially genetic and non-genetic (environmental) attribution of disease. Each FGD was opened with a welcome address followed by a discussion of the consenting process, and collection of demographic information.



Figure 2: FGD participants completing consent, demographics and ISMI/ISRHD-X scales

Socio-demographic particulars of the participants, including age, sex and education were also collected at the beginning of the interview to gain a better understanding of the backgrounds of participants (see Appendix F). Following this, video-vignettes (see descriptions on Appendix H) were shown to participants and during this session I facilitated the discussion based on the topic guides for the study.



Figure 3: Participants watching vignette

During the group sessions, participants were presented with a video of one of three vignettes. Each vignette comprised a different disease causal explanation: genetic, mixed-genetic and non-genetic/ environmental, for patient X (who was named Andile), who had the same disease as the individuals being interviewed. Each vignette had a voiceover presenting the storyline, along with questions at the end of each stage which were posed to the group for discussion.

The discussions which followed were centred on beliefs and experiences of Andile, considering the disease causation that was presented in the vignette that the group had watched. For the SCZ group I conducted two FGDs per disease category (i.e. two genetic, two environmental and two non-genetic). For the RHD group I conducted three FGDs with the genetic attribution vignette, and two for the environmental and the non-genetic explanations.

The groups concluded with a thorough debriefing session where participants were informed

that the vignettes were staged and that the characters in these stories did not have the disease, but were in fact acting a story to facilitate engagement in the group. Many participants expressed that they thought the storyline was real and some had wanted to befriend the character and exposed sympathy to his situation. Following explanation, they understood the value for the vignette in the FGDs. Participants were also provided with the opportunity to express any feelings or contribute to the discussion after they had learnt of the nature of the vignettes and completing the session. Figure 4 below indicates a schematic presentation of the FGD process.

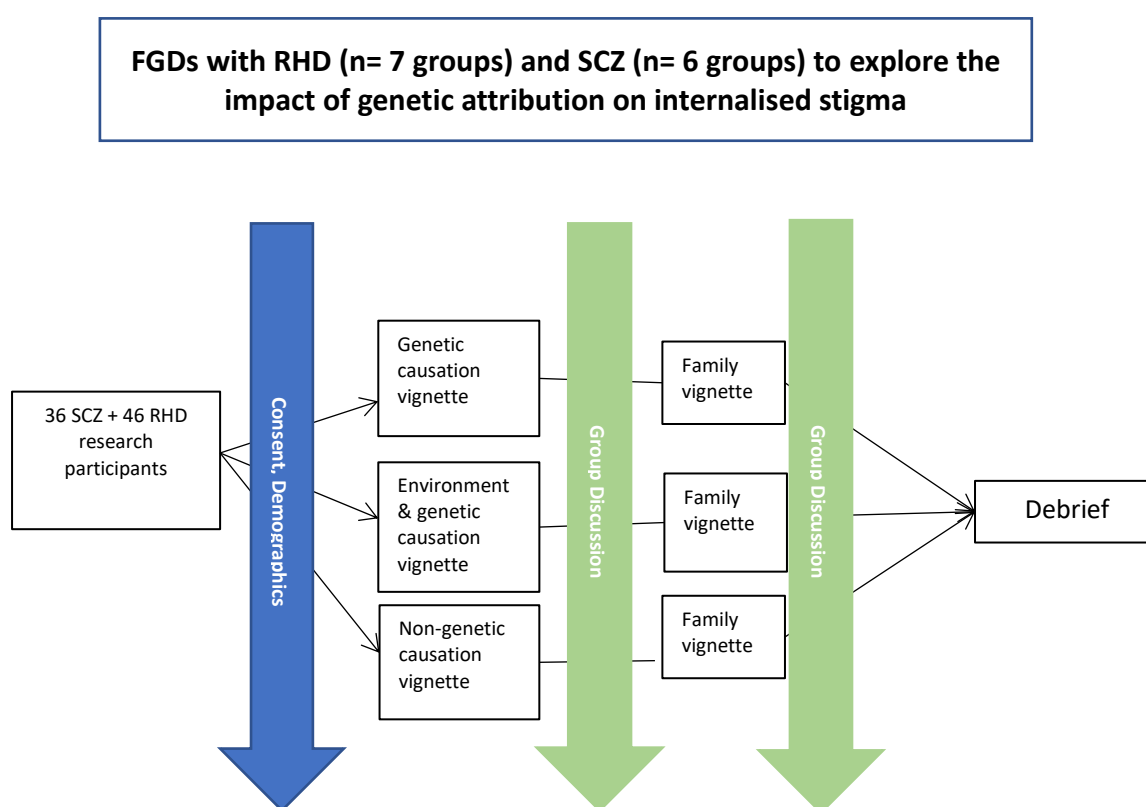


Figure 4: Schematic representation of focus group discussions

Topic guides for the vignettes are presented in Appendix H. Each FGD started with questions relating to the theme, “*What do people know about genetics?*” in an effort to explore participants’ associations with or understanding of genes, genetics and disease causation and

associations. This was followed by a discussion of the disease relevant to the group of people (RHD or SCZ) and examined topics like disease causation, consequences of the condition, as well as the impact of the disease on the person and their social lives (Lloyd, Jacob, Patel, St Louis & Bhugra, 1998). During this section of the FGD, I also explored beliefs in the likelihood that their condition could be remedied through treatment. Next, associative stigma was explored through eliciting participants' feelings about being friends with Andile or having him marry the participants sister. This component of the FGD topic guide explored questions such as, "*Would you be happy for Andile to marry your sibling*", "*Would you be likely to be friends with Andile*", and so forth. Overall, I explored the consequences of the different disease explanations on the stigma experienced by participants.

Ten participants were invited to each FGD resulting in group sizes ranging from 6 to 10 participants, depending on the number of attendees. Participants from the same disease group were randomly allocated to one of the three vignettes (see Appendix H for topic guides and vignettes). Discussions were closely guided to ensure relevance to the applicable vignette topic per group. As the researcher, I also explored respondents' understanding of genetics and remained conscious of the fact that participants may be somewhat challenged in terms of differentiation along the lines of 'DNA' or related to 'inheritance' and genetics, for instance. Thus, discussions were mediated based on my understanding of the concepts of genomics, stigma, as well as the Xhosa language and culture, in order to keep the structure of the discussions both meaningful and purposeful. This yielded some challenges in the discussion, for instance not having direct linguistic translations for terms meant having to make conceptual explanations in isiXhosa that were likely open to a range of different interpretations.

6.8. Development of the vignettes

The short stories were developed by drawing from vignettes used in previous studies by the Department of Psychiatry at UCT (Pain, 2012) and by Dr Jo Phelan at Columbia University (Phelan, 2005) and consultation with the team of investigators on the FHS HREC 204/2015 *Stigma in African genomics of Schizophrenia and Rheumatic Heart Disease* project at UCT (PI: Jantina de Vries). Separate vignettes for RHD and SCZ patients were developed. I identified and recruited individuals for particular characters for the vignettes (i.e. Andile, his mother, doctor, aunt, uncle, friends, neighbours) and locations (i.e. informal house structure, RDP house, clinic, doctor's room and community) for the filming of the vignettes. Scenes from the different locations mentioned above were filmed by a professional videographer with myself alongside him in order to ensure that the videos were in line with the storylines produced. Following filming, the vignettes were presented in the form of short videos. In total, the videographer produced two vignettes, each with three different explanations of disease causation, from genetic (e.g. "Andile is informed by his/her doctor that his/her condition is related to genetic") through mixed-genetic to non-genetic.

6.9. Demographics of Study Sample

The FGD sample consisted of a total of 82 participants (36 SCZ and 46 RHD). The SCZ sample consisted of 34 males and 2 females, while the RHD sample consisted of 7 males and 39 females. Notably, the SCZ sample had a younger age range from 20 to 48 years, with an average age of 33.91 years, while the RHD sample had an older age range from 19 to 76 years, with an older average age of 43.04 years (see Table 2). These differences in samples are illustrative of the same sex and age differences identified in the larger SAX and RHD Gen studies. One reason for this may be the recruitment strategies employed in these larger studies. For instance, a study investigating capacity to consent to research through a Xhosa language version of the

University of California, San Diego Brief Assessment of Capacity to Consent Questionnaire (UBACC) among SCZ patients ($n= 528$) recruited for the SAX study, 89% were males and only 10% females (Campbell et al., 2017). The authors suggested that these sex-related differences may reflect a higher prevalence of males with schizophrenia in state psychiatric facilities where these patients were recruited. Similarly, as Zuhlke (2015) describes, there is a higher rate of older females who attend primary care clinics for RHD. In a smaller Msc study by Faure (2018) who recruited mixed-ancestry RHD patients ($n= 52$) enrolled in the RHD Gen study to conduct FGDs which aimed to explore genetic attribution and stigma found that 70% of the enrolled participants were female.

Table 2: Socio-demographics of participants enrolled in the study

	RHD (n=46)	SCZ (n=36)
Age		
Range	23-75 years	20-53 years
Mean	43.04 years	33.91 years
Sex		
Male	7 (15.21%)	34 (94.44%)
Female	39 (84.78 %)	2 (5.56%)
Highest education level		
>Grade 7	7 (15%)	6 (16.67%)
<Grade 7	37 (80.43%)	30 (83.33%)
Unknown	2 (4.35%)	0 (0%)
Employment		
Unemployed	42 (91.30%)	32 (88.89%)
Employed	3 (6.52%)	3 (8.33)
Unknown	1 (2.17%)	1
Government Grant		
Yes	27 (58.70%)	22 (61.11%)
No	18 (39.13%)	14 (38.89%)
Unknown	1 (2.17%)	0 (0%)

6.10. Data Analysis

6.10.1. Qualitative Analysis: Transcribing and coding of FGD data

FGDs were tape-recorded then transcribed and translated verbatim and texts were stored in a password protected computer. Participants' names do not appear in the transcripts. A second year Master's student in the Xhosa Language Department at the University of the Western Cape was recruited as a research assistant to help with the translation and transcription of the data. During the FGDs, in addition to myself, at least one other individual (who was the co-facilitator for the session) was present to take notes about speaker sequence, body language and other aspects of the interactions which we then discussed together at the end of each FGD.

Overall, I transcribed 4 RHD and 4 SCZ group discussion transcripts, while the transcriber transcribed the remaining 5 recordings. Transcriptions done by the transcriber were checked by myself to ensure quality of the transcripts. Transcripts of FGDs were translated to English for analysis by myself and the recruited student. Both were used concurrently in the data analysis.

English versions of the transcripts were imported into NVivo 11 which is a computer program for managing text data (NVivo qualitative data analysis software, 2015). FGDs were analysed using thematic analysis, which is a standard approach for conducting a qualitative analysis of text data (Braun & Clarke, 2006; Morgan, 2002). Notes taken by myself and the co-facilitator, including the sequence of responses during the FGDs, were used to allocate passages to participants, in so far as possible, to be used in the analysis.

Data were analysed in multiple rounds of coding which lead to the identification of general

themes in the data. The process began with a hierarchical coding scheme which was developed by myself and my supervisors. First, I and my primary supervisor coded three transcripts each (independently). Then we met to discuss the themes which emerged and agreed on an initial coding scheme. This coding scheme was applied to a subset of transcripts. Coded text was then analysed to develop a hierarchical coding scheme. Thematic domains were identified through a process of intense reviewing of transcript data with specific codes developed afterwards for conceptual categories. Various discussions were held between myself and my primary supervisor to resolve discrepancies, along with regular scheduled supervision meetings with both of my supervisors and collaborators on the larger project of which this study falls under (FHS HREC 204/2015 *Stigma in African Genomics Research on Schizophrenia and Rheumatic Heart Disease*). Lastly, comments by the international researchers based at institutions in the United States of America involved in the larger study, such as Prof Paul. S. Appelbaum from Colombia University and Prof Patricia Marshall from Case Western University, assisted me to build a robust data analysis strategy with repetitive reviews of the coding process. Through these meetings and based on their views, along with mine and my supervisors it was decided to analyse the FGD data as one big dataset (as opposed to comparisons between the different scenarios; genetic, environmental and genetic and non-genetic) as there were very minimal differences in the nature of the dialogues in the groups.

6.10.2 Analysis of data from the translation of the internalised stigma scales

Qualitative and quantitative insights from the translations of the scales were gained from examining the data generated during the translation process. I sought to further understand how the construct of stigma was supported in the Xhosa language and the relevance of individual internalised stigma scale items for Xhosa people with SCZ and RHD, illustrated through their

psychometric properties. Demographic data were recorded in an Excel worksheet, cleaned, saved and then analysed.

6.11. Role of the researcher

Reflexivity on methodology: The mixed-methods approach required considerable expertise from myself as the researcher to be versed in both quantitative and qualitative research methods. Therefore, I had to equip myself with the necessary skills to facilitate the process of data collection, analysis and reporting as defined by a mixed-methods approach. This was achieved through familiarising myself with literature on mixed-methods research (Bryman, 2012; Creswell & Plano Clark, 2011; Johnson, Onwuegbuzie & Turner, 2007), as well as having frequent discussions with my supervisors. Furthermore, to enhance my research capacity during the degree, I attended a Doctoral level Mixed-Methodology Course (held during the International Summer School at the University of Oslo, in Norway) which focussed on training PhD candidates on mixed-methods approaches in social research. In addition, considering that my background was in qualitative research, and I was therefore more versed in that approach than in a quantitative approach, I audited a Masters level semester course focussing on analysis of quantitative data in social science research at UCT. Lastly, I sought multiple opportunities to present my research at different meetings and conferences involving South African, African and international audiences - where I would get critical feedback which I incorporated into the work. These training opportunities allowed me to hone and craft these skills and conceptually think about employing a mixed-methods approach in a single research study, which ultimately made the data collection, data analysis, as well as documenting this thesis a practical and meaningful experience.

Researcher's background: As the researcher, I hope that sharing my background will assist in illuminating the reasons for my observations and interpretations of this research. As Bryman (2012) suggests that qualitative research is often relatable to our contextual factors and as a result, the context and our relation to the context often inform the uniqueness of how we see the world. I am a 26 year old mother-tongue isiXhosa-speaking female, born in the rural village of eNqele, near the town of Alice in the Eastern Cape Province, South Africa. Despite living in the Western Cape Province for the past 20 years, my family and I continue to go 'home' to eNqele, about 934 kilometres (roughly 580 miles) from where we currently live, at least twice a year, sometimes more. Many of the times in which we go to the village, we attend or perform cultural ceremonies that form a significant part of our cultural values. Being raised, and attending schooling in a modernised (and primarily Westernised) setting in the Western Cape and being able to go 'home' to very rural surroundings in a context where life is largely guided by an African cultural worldview has been deeply meaningful to me. It is this background and reality which has allowed me the opportunity to gain a deeper understanding of both African and Western worldviews. Moreover, it is what has allowed me to make sense, as far as possible, to the realities of the participants in my study. As for my academic background, I completed an undergraduate in psychology from the University of the Western Cape, and then an honours and Master's degree in psychology at Stellenbosch University.

In my first year of the Master's degree I applied and was appointed in a research assistantship position in the larger study which my PhD project falls under in the Department of Medicine at UCT. I took up the position part-time during my second year of my Master's degree at Stellenbosch University. After completing my Master's degree, my current supervisors suggested I pursue a PhD degree at UCT and in 2016 I enrolled for this PhD.

6.12. RHD Data collection

RHD data collection took place from September to November 2016. During this time, 46 people with RHD were recruited to participate in the FGDs. Inviting these individuals to attend FGDs for this purpose posed various challenges as many of them were elderly women who faced physical mobility issues which impacted on travelling (see demographics of respondents on page 59). Financial constraints of participants were also considered, hence the decision to provide reimbursements for travelling to data collection sites. All scheduled FGDs had between 6 and 10 participants who attended while one of the FGDs only had 2 respondents of an initial 10 invitees. This low response rate could possibly be attributed to the adverse weather conditions on that specific day, considering that most of the participants relied on public transport. This session was cancelled and the participants reimbursed for their travel costs and invited to join another scheduled group discussion. Overall, the process continued without any other difficulties and during the FGDs, participants were easy to engage with.

6.13. SCZ Data collection

SCZ group sessions occurred from February until May 2017. These FGDs proved to be more challenging to organise, not in the least because this patient group is more vulnerable. Specific aspects of this vulnerability are discussed in the subsequent paragraph to this section. This caused practical challenges, for example in relation to their ability to travel independently to the FGD venues. Coordinating these FGDs involved having various meetings with psychiatric nurses, as well as the project coordinator of the SAX study to resolve certain logistical issues (i.e. location, suitability of participants to respective group sessions and how to inform potential participants about scheduled sessions). This was particularly difficult for a number of reasons, some of which are discussed below.

Firstly, patients recruited in the SAX study were individuals who had at some point been admitted to a psychiatric hospital. Many of these participants reported negative experiences of being admitted to psychiatric hospitals as some of them were admitted by force and not voluntarily. This created a deep sense of fear and resentment for these facilities which consequently influenced their decision to attend a FGD held at the same location. In some cases, the people with a SCZ diagnosis's parents or family members were strong motivators for their children to attend the sessions, however it was the individual with the condition who refused to attend. In these cases, potential participants were informed that their participation was voluntary and that they were under no obligation to participate. On the other hand, since the participants were outpatients and some of them had not been in a space with other individuals who had a SCZ diagnosis for some time, they were excited to attend the FGDs. This was mainly because it provided them with an opportunity to engage with other people who were living with the same condition.

As detailed in the demographics of the participants on page 78, the population available included mostly men with an average age of 34 years. Being a younger female, facilitating these FGDs was more challenging, as issues of gender power did come into play. For instance, in the first FGD, male participants made derogatory comments during the group session. That experience however helped me to reflect on my position, and thus develop and employ a stricter approach (which included emphasising rules relating to respect of fellow individuals) during the FGDs.

All FGD participants had previously enrolled in a genomics study (RHD Gen/ SAX) from which their contact details were obtained. However, the large amount of inconsistent contact details provided by individuals during their involvement in the SAX study posed another

challenge for recruiting these participants for the present study. Due to the fact that the contact details database for participants in the SAX study dated back to 2013, many of these individuals' contact numbers had changed, or were incorrect or incomplete. These challenges made it difficult to invite potential participants to be involved in this study.

6.14. FGD Data collection – General observations

Many of the participants enrolled were born in the Eastern Cape and had moved to the Western Cape in search of better work or living conditions. Some of the participants also relocated in search of better medical treatment for their illnesses, in the reportedly better facilities available in the Western Cape. Being born and bred in a similar context to them, I had an understanding of participants' backgrounds and to this effect, for the most part during the FGDs I experienced a sense of trust from participants that they felt comfortable sharing their experiences and perceptions with me, and the group at large. The FGDs were predominantly lively engagements.

Due to the selection of exclusively Xhosa-speaking people, efforts were made to ensure that all material, including consent documents, the video vignettes and the guiding questions for the FGDs were translated into isiXhosa. This promoted comprehension and allowed participants to understand and engage more fully with the material. Throughout the study, participants were assured that all discussions would be facilitated in their mother-tongue. It was noted that participants appeared comfortable during these group discussions because they could converse and express themselves in their home-language – an experience that is not common in other similar research (i.e. Solomon et al., 2012) or in many clinical interactions as they are often not conducted in the patient's mother-tongue.

Essentially, the interviews afforded me the opportunity to identify and grasp the perspectives of people diagnosed with the two diseases. However, during the FGDs, participants would sometimes choose not to elaborate their thoughts in an in-depth fashion which brought me to the conclusion that this was based on the assumption that I would understand their perceptions based on our potentially shared and somewhat similar backgrounds. This was especially depicted in statements such as “*you know*”, “*in our culture*”, “*for us*” and many similar expressions frequently mentioned in these discussions. In addition, participants often made facial and hand gestures, hereby suggesting that I would be able to interpret such non-verbal actions. In these instances, participants were encouraged to explain themselves in a more effective manner and by also emphasising my role as a researcher to fully comprehend and make sense of their views to ensure an accurate interpretation of the data.

6.15. Ethical considerations

Ethics approval for the study was sought from UCT’s Faculty of Health Sciences Human Research Ethics Committee prior to commencement of the study (see Appendix A). Research took place in accordance with South Africa’s Department of Health Ethics in Health Research Guidelines (2015), Declaration of Helsinki (Update 2013) and Good Clinical Practice (GCP) guidelines. I attended a GCP courses for during the period of completing the research. In addition, I considered the Code of Ethics of the American Sociological Association (issued in 1999). With regards to the FGDs, potential participants were contacted telephonically with a comprehensive explanation of the research project. Interested parties were invited to a group discussion at a hospital which they were familiar with due to their current outpatient status and them receiving treatment from these hospitals. Each participant was provided with an information sheet and after reading this, was asked to voluntarily sign an informed consent form before proceeding with the session (See Appendix D & E). Due to

low-literacy levels among some the participants, one-on-one support was provided to explain aspects of the study that were not clear, to answer questions and to assist during the signing of consent forms. Considerable debriefing was done after the FGD, in order to emphasise that these were hypothetical scenarios and make sure participants were eventually stable. During the consent process, it was also explained that confidentiality could not be guaranteed during and after the group discussion, and that individuals were not obligated to share any information which they felt uncomfortable to discuss. However, it was emphasised, and participants were assured that within the research documentation, confidentiality would be maintained. Participants were free to leave questions unanswered, or to stop and exit the session at any time, although none did. All interview transcripts were anonymised and all possible identifiers (such as name of the employer or hospital attending) were substituted with generic language. All transcripts were kept on password protected computers and were only shared on a need-to-see basis between myself, the assistant transcriber, my supervisors and the international advisory team.

Lastly, all FGDs were conducted by myself in isiXhosa, unless the participants themselves preferred to use English which none did. Consent materials were translated into isiXhosa to ensure that all individuals understood the material and what they were consenting to. Each participant received R100 (\$7) as reimbursement for transportation costs as well as refreshments and snacks during the FGDs.

6.16. Chapter summary

This chapter provided an outline of the research problem, the focus and aims of the study as well as the research questions. It also introduced the mixed-methods approach informing the study, as well as the, sampling strategies, data collection and data analysis methods used. By

reflecting on my subjective position as a researcher, I discussed my role as a researcher, along with data collection processes involving both patient groups. The chapter concluded with an overview of ethical considerations employed in this study. The next chapter presents the disease causal explanations identified by patients in this study.

CHAPTER 7: DISEASE CAUSAL ATTRIBUTIONS

7.1. Introduction

In this chapter I begin by presenting the sample characteristics and relevant descriptive statistics. These results are important for interpretation of the qualitative findings related to the study's research questions. Next I present findings relevant to the first question of this study, which is "*What causal models are employed by Xhosa people with schizophrenia and people with rheumatic heart disease to explain their illness, and to what extent do genetic explanations play a role in these causal models?*". I end the chapter with a summary of the aforementioned findings.

7.2. Demographic details of FGD participants

When conducting research, it is common for researchers to investigate certain characteristics of the sample in the study as these characteristics can often assist the researcher to gain a more nuanced understanding of the research findings. In this study the demographic details of the respondents relative to age, sex, highest level of education, employment status and government social grant receiver status were investigated. These results are provided in Table's 4 to 7.

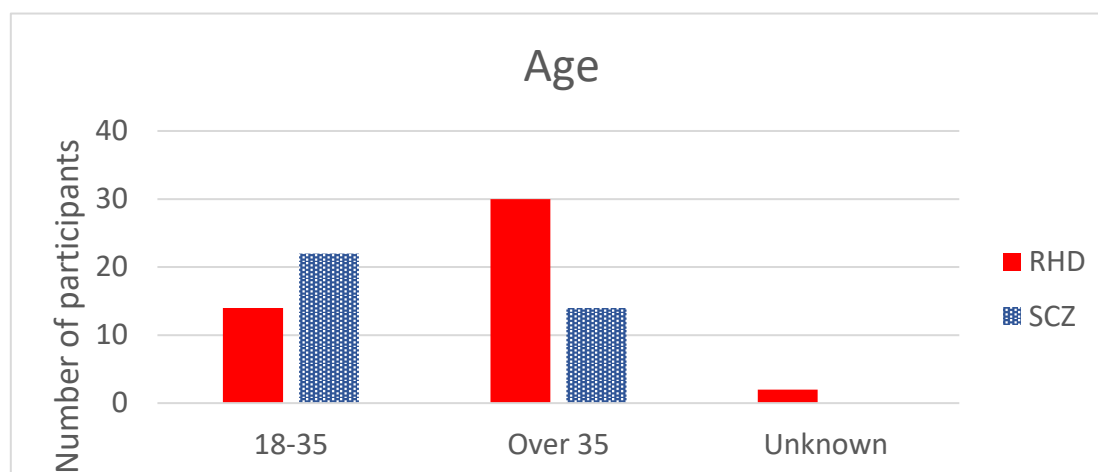
Table 4: *Distribution of participants' age categories*

	Frequency (%)	
	RHD (n=46)	SCZ (n= 36)

Age (years)		
18-35	14 (30.43%)	22 (61.11%)
Over 35	30 (65.22%)	14 (38.89%)
Unknown	2 (4.35%)	0 (0%)

A Chi-square test was performed to determine whether there was a significant age difference between the RHD and the SCZ groups. There were no significant differences with regard to age between the two groups: $\chi^2(4, n= 82) = 45, p = .081$. While the age range was between 18 to over 35 years, the RHD sample predominantly comprised of over 35-year-old patients (mean age being: 43.05 years) while the SCZ sample predominantly comprised of 25-35-year-old patients (mean age being: 33.92 years).

Graph 1: Age of participants



In terms of the sex variable in this study, it is notable that the RHD sample consisted mainly of females, while the SCZ sample comprised of mostly males. This was not too surprising as discussed in chapter 6 on page 78, this same trend is evident in the RHD Gen study (PI: Prof. Bonagni M. Mayosi) as well as the SAX study (PI: Prof. Dan Stein). A Chi-square test was

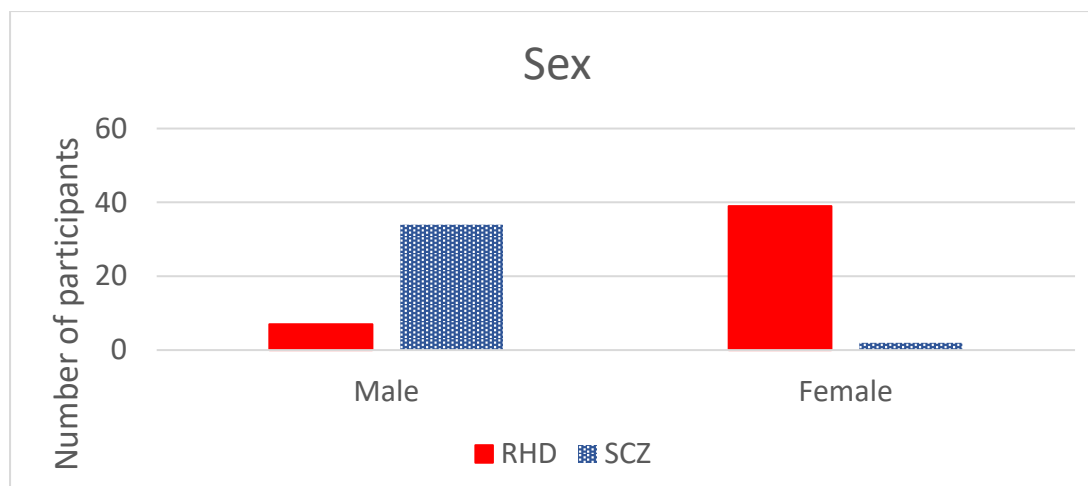
performed to determine whether there was a significant difference between the RHD group and the SCZ group with regard to sex. As anticipated the Chi-square test revealed that there is a significant difference with regard to sex between the two groups: $\chi^2(1, n = 82) = 50.71, p = 0.01$.

Table 5: *Distribution of participants' sex*

		Frequency (%)	
		RHD (n= 46)	SCZ (n=36)
Sex	Male	7 (15.21%)	34 (94.44%)
	Female	39 (84.78 %)	2 (5.56%)

The distribution of participants' sex is visually presented in the graph below and shows the extreme disproportion enrollment of men and women in these two groups. The resultant findings would need to be considered in relation to these differences in sex and age of participants.

Graph 2: Sex of participants



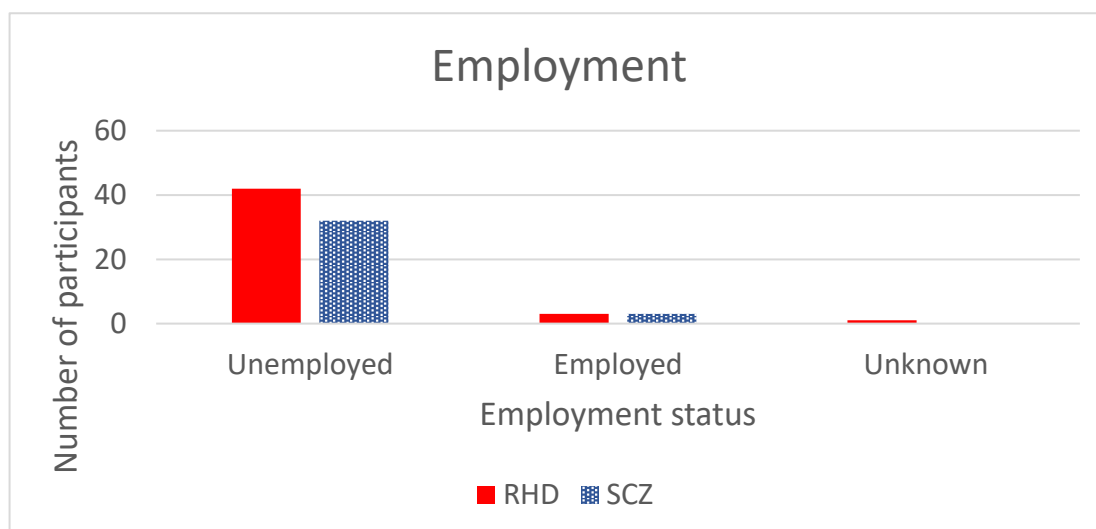
In addition to age and sex, the employment status of participants in this study was also investigated as a means to understand the participants' standard of living. Below table 6 presents the employment statuses of participants enrolled in this study.

Table 6: *Employment status of participants*

	Frequency	
Employment status	RHD (n=46)	SCZ (n= 36)
Unemployed	42 (91.30%)	32 (88.89%)
Employed	3 (6.52%)	3 (8.33)
Unknown	1 (2.17%)	1

From the table above, it is evident that for the RHD sample 42 out of 46 patients (91.30% of the sample) reported being unemployed. While for the SCZ sample 32 out of 36 patients (88.89%) were unemployed participants. The Chi-square test revealed that there is no significant difference with employment status between the two groups: $\chi^2(1, n = 80) = 0.103$, $p = 0.75$. A visual representation of the employment rates is displayed in Graph 9 below.

Graph 3: Employment status of participants



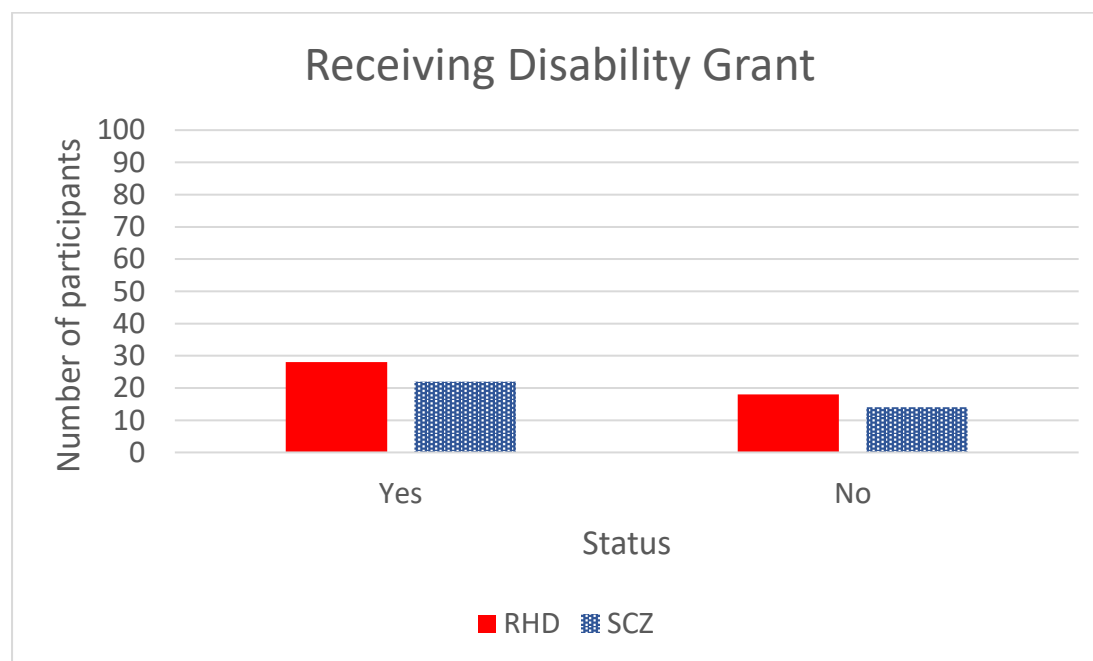
The high rate of unemployment observed across the two disease groups raises the question of how these patients financially provide for themselves and ensure that they can sustain themselves and their families. In the South African context, individuals who are unemployed and have a disability (a factor which disables them from getting ordinary employment easily) may apply to receive a government social support grant (of roughly 121 USD/ R1490) on a monthly basis. Below, Table 7 represents the number of people in this study who receive the social grant because of their unemployment and disability status across the two disease groups.

Table 7: *The number of participants who receive social grants*

	Frequency	
	RHD (n=46)	SCZ (n= 36)
Government Grant		
Yes	27 (58.70%)	22 (61.11%)
No	18 (39.13%)	14 (38.89%)
Unknown	1 (2.17%)	0 (0%)

Table 7 shows that 27 out of the 46 RHD patients (58.70%) and 22 out of the 32 SCZ patients (61.11%) receive government social grants, while just under 40% for each group does not receive social grant. The Chi-square test revealed that there is no significant difference in the receiving of a government grant between the two groups: $\chi^2(1, n = 81) = 0.0103, p = 0.92$. The high unemployment rate as well as the receiving or not receiving of social grants from the government and its implications for these patients is further explored in the reporting of the qualitative findings.

Graph 4: Distribution of participants' receiving social grants from the government



Participants' were also requested to report their highest level of education. This variable provided an opportunity to gain a sense of the education level of participants in this study.

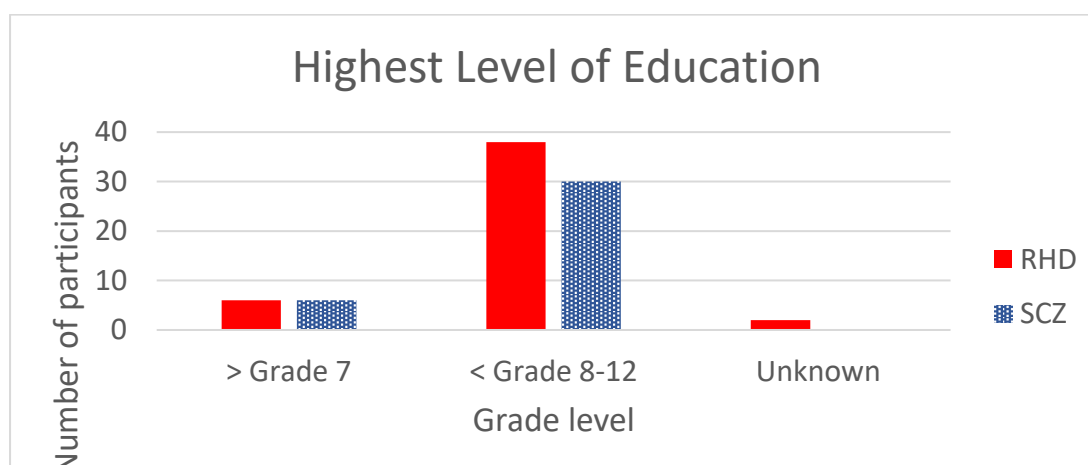
Table 8 displays the participants' highest level of education.

Table 8: *The highest level of education of participants*

Highest level of education	Frequency (%)	
	RHD (n=46)	SCZ (n= 36)
>Grade 7	7 (15.22%)	6 (16.67%)
<Grade 8 and above	37 (80.43%)	30 (83.33%)
Unknown	2 (4 .35%)	0 (0%)

Above 50% of the patients in both groups had either a Grade 11 or Grade 12 (the final year of secondary school in South Africa) or above. Evidence from the Chi square test suggests that there is no significant difference in education levels between the two groups. The chi-square statistic is 0.0083. The *p*-value is 0.93. The above 50% proportion of the sample having some secondary schooling suggests that the sample had a reasonable level of literacy to conceptualise and engage with the material used in this study. The levels of education of the participants are presented in Graph 5. below.

Graph 5: Participants' highest level of education



7.3. Disease causal attributions

Next, this chapter provides the qualitative data related to the causal models held by participants in this study. The findings are discussed guided by specific themes. These themes were identified in the thematic analysis process proposed by Braun and Clark (2006). Focus-group interview transcripts of the 13 FGDs which were conducted in this study, collectively contribute to the pool of data used to identify thematic patterns that surfaced in the study. As described in Chapter 6, during the FGDs participants watched a short clip of a vignette about a character named ‘Andile’ who is living in a South African township and has been diagnosed with either RHD or SCZ. The vignettes provided participants with a causal explanation for the disease (which was either genetic, environmental, or a combination of genetic and environmental causation). The participants were then asked to respond to a series of questions relating to their experiences and opinions of disease-stigma. Participants replied to the questions in relation to themselves and in relation to the character ‘Andile’. Therefore, the results below refer to personal and external perceptions of disease-stigma raised in the FGDs in relation to the two diseases.

The role of genetics and its influence on disease stigma is increasingly discussed in the context of ELSI research (Appelbaum, 2017; Kong et al., 2017). The concern is that placing an emphasis on genetic explanations to disease may influence the stigma associated with it in potentially harmful ways. Consequently, understanding beliefs of disease causation is of relevance and importance when investigating the stigma within different disease groups. As described in Chapter 6, this study aimed to explore the role of genetic attribution on disease-stigma in relation to internalised stigma experienced by schizophrenia and rheumatic heart disease Xhosa outpatients. In this chapter I describe the qualitative findings which emerged

relating to the causal attributions reported by participants, with a particular focus on their articulation of genetic causes to disease.

The causal attributions people give to disease are often shaped by their symptoms and their experience of living with that disease. Having a family history with someone who had the same disease may for example predispose people to associate their disease with a genetic cause. Conversely not having or knowing a person who has had the disease in the family or immediate social circle (and not having any genetic tests conducted) may lead to people attributing a disease to environmental, psychological, personal choices or cultural factors.

The following section presents data related to question 1 of the research, which is; *“What causal models are employed by Xhosa people with schizophrenia and people with rheumatic heart disease to explain their illness, and to what extent do genetic explanations play a role in these causal models?”*

Table 9: Disease causal attribution themes

MAIN THEMES	SUBTHEMES
1. Genetic causal explanation	
	a) Knowledge about genetics
2. Alternative causal explanations	
2.1 Psychosocial explanations	a) Environmental causes
	b) Psychological causes
	c) Personal lifestyle choices
2.2 Cultural explanations	

	a) Bewitchment/ Supernatural causes
--	-------------------------------------

7.3.1. Genetic attribution

Genetic explanations may influence understandings of human behaviour and the stigma associated with their behaviours (Phelan, 2005). The two diseases investigated in this study have complex explanations in terms of relating the disease to heredity in general and a potential genetic causation specifically. For instance, there is conflicting evidence in the health literature about the extent to which SCZ could be considered a genetic disease (Schizophrenia Working Group of the Psychiatric Genomics Consortium, 2014). In addition, while 40% of RHD can be explained by genetic predisposition (Engel et al., 2011), a stronger causality has been found for infection with Strep A and environmental conditions. The data in this study revealed that some participants are aware of a potential genetic attribution of their disease, while others may not have been. Notably, participants often spoke about genetics and heredity in similar ways and used these terms interchangeably (and this will be evident in the verbatim quotes which follow).

7.3.1. Knowledge about genetics

A critical component of this study was gaining an understanding of what participants know about genetics and heredity, as well as how they relate genetics to their disease. The question in the FGD guide which began to explore what participants understand about genetics is; 1. *What do you know about genetics?* This section presents the findings related to answers participants provided under the theme *Knowledge about genetics*. It is important to note that all our participants had previously participated in genomics research projects before, which may be why some of them are familiar with genetic terminology such as genomics, DNA and

heredity which are also terms used in the consent processes and community engagement activities they may have completed.

SCHIZOPHRENIA

In response to the first question participants in the SCZ sample displayed an understanding of genetics and genetic attribution to disease. When asked to explain genetics, many participants referred to heredity and in particular the inheritance of biological features and genes:

“I think that... I think that genetics has to do with genes. So let’s say for example your father... Say you inherited a gene from your father, then you have that gene. Later you realise that that gene is related to the disease your father has. Then you end up having the same disease. So that is inheritance.” (P.7: FGD 2)

“Genetics, what I know about genetics is like... if there is someone, like your father maybe, there are these things called chromosome networks, where if your father gets mentally disturbed you also end up falling in the same path. You would be aware that its genetics which caused that. That’s how I know it.” (P.1: FGD 2)

The above explanations are a representation of how some participants in the SCZ FGDs understood genetics. It is notable that these two examples were shared by participants who had a tertiary education. Not all participants demonstrated the same depth of understanding. In describing genetics, other participants highlighted a range of traits that can be inherited. Some participants related genetics to the idea of passing down of a physical trait (like looks for example):

“It’s like looking like your father or your mother... Like the things you have on your body, they may look like theirs.” (P.6: FGD 3)

“Yes, I was going to say perhaps the way you resemble a particular person. When you look like him or her, you have inherited those looks from your relative” (P.2: FGD 5)

Others spoke about passing down behavioural attributes:

“Hm. Okay, the genetics is like, say a child inherits something for example from the father. I am not sure if its genes or what. But then it is about a child inheriting attributes from their father. For example behavioural patterns. Say for example a child is disobedient and they do not listen to you at all, then people are able to say that ‘he inherited this behaviour from so and so’... I am talking about behavioural patterns, either of the father or of the mother.” (P. 6: FGD 2)

Another participant referred to it in terms of inheriting a habit from a family member.

“It’s like doing things that your parent used to do, like maybe you grow up to look like your parent a lot. And the things you do, people say you inherited those things from him” (P.5 FGD 3)

In addition to the physical and behavioural traits and habits which were understood by participants to be passed down in families, participants were also able to explain that a disease may be passed down in the family. This was explained in particular through relating genetics to the chances that Andile may pass that disease on to his children:

“If for example he has five children. Then two of the children may have the disease, because it can be understood that the one or two children who have it, got it through inheritance from Andile. So of the five children, two could have the disease and the rest may not.” (P.1: FGD 6)

“When it is genetic it means that he can still have a child or maybe a grandchild who may have the disease.” (P.10: FGD 4)

“So if a person is genetically related to someone at home. Like if maybe someone in the person’s family has been sick before, then they too end up being sick because of having the same genes.” (P.6: FGD 6)

Within the data, there was a great deal of association between genetics and relatives or family members. Exactly how traits are passed down amongst the relatives however was not clearly articulated in the FGDs but most participants were certain that they are passed down “somehow” in the family. Participants shared an understanding that a particular disease may be passed down in the family, and explained that a disease can skip a generation and be passed down to or express itself amongst grandchildren and not necessarily their parents. Moreover, some participants explained that other influences may trigger the disease onset, even if they have a genetic predisposition. For instance,

“Uh, something that could also put his children at risk of getting the disease is their own decisions. For example if a child uses drugs too much, then it will be more likely for the condition to emerge if it is genetic. Or for example if he abuses alcohol, it could also emerge. You see. Or if he is really hurt. For example I have a niece whose mother has schizophrenia. I also am a schizophrenia. But for me, schizophrenia emerged because I was using drugs. Well I was using weed [cannabis] for a long time, then I stopped, and then the schizophrenia began. I thought, and the doctors thought it was withdrawal symptoms, but then it was schizophrenia. So I always advise my niece that if she has anything that is hurting her feelings, for example if she is having problems in a romantic relationship, she should speak to someone about that. I tell her that because

she is likely to get ill, because this thing is genetic. You see for me, maybe I would not be like this. Maybe I wouldn't have been like this had I not used drugs. So as for Andile's child, he/she could have the illness, even though the symptoms may not emerge. It depends on the decisions he/she makes and things he/she abuses". (P.10: FGD 4).

There are a few things worth noting about the participant's quote above (P.10) firstly, he describes that he believes the disease is genetic. He has it, his niece has it and his mother's niece has it. Secondly, he also describes that although it may be genetic, it requires a trigger for onset. His trigger was cannabis, while he thought his nieces trigger may be "thinking too much" or stress. Thirdly, he suggests that Andile's child may have the disease gene passed down to him, but it may not express itself unless he or she engages in behaviours that may trigger it.

The view that SCZ requires a trigger was also shared by other participants, suggesting that Andile's children would be unlikely to develop this condition if they "treat themselves well" and avoid abusing substances which would put them in a position of being vulnerable to developing the disease. This alludes to the fact that in addition to the genetic causation explanation, personal lifestyle choices and decisions on behaviour are seen as having important implications to the development of the disease.

RHEUMATIC HEART DISEASE

While the SCZ participants began by discussing genetics in general and later related it to their disease, the RHD participants immediately described genetics in relation to their disease. For instance, when asked to share their understanding of genetics one participant described it as follows:

“I was told by the doctor that sometimes, you may have an illness because you have inherited it from someone in your bloodline. Someone in your family perhaps.” (P.1: FGD 2)

“When there is a history in your family, perhaps there is a person who suffered from heart disease, for example your grandfather, it may be said that you inherited it from him.” (P.2: FGD 6)

“I think heredity... I think it is something that is in the family. Let us say if my grandmother had a heart disease, her children and grandchildren can also have the heart disease.” (P.6: FGD 7)

Many participants noted that genetics may have to do with something being passed down through relatives or in the family, for instance from parents or grandparents to children. While some participants described that disease can also be passed down from uncles and aunts in the family.

“Me, it is said that there is my aunt [her mother’s sister] who had it. But I do not know how it connected with me.” (P.3: FGD 7)

Similar to the SCZ sample, these participants were also aware that it may be passed down to some offspring, while other children may not have the disease. An example of this was given by one participant who had a father with ‘RHD’. When asked whether any of her siblings have been diagnosed with the same disease, she responded by saying none of them had the disease (out of a total of six children born from her parents) (P.3: FGD 4). It is important to note here that the RHD participants did tend to conflate general heart disease and RHD. This may not be

altogether surprising considering that the term RHD does not exist in isiXhosa, therefore generally people with RHD refer to themselves as having a ‘heart disease’ (*isifo sentliziyo*) in the Xhosa language.

In light of that knowledge, another participant, described that she had a brother who died of RHD. Among that participant’s siblings, there were two children born from her parents and both of them had heart disease. The above examples point to the observation that some children may have the disease passed down from someone in the family, while others may not. This observation is supported by a comment by a participant in another FGD who voiced that she believes that not all children of someone with RHD would necessarily get the disease. She said:

“...but not all of them. Maybe there will be one who inherits the disease.” (P.7: FGD 2)

This understanding was commonly shared, see:

“It would depend on the genes. If your genes are different from your mother’s but are similar to your father’s, you might have it, if your father had it. If you have identical genes with your father who has the same condition, then you will have it. It depends on whose genes of your parents is stronger.” (P.6: FGD 1)

Although many RHD patients did recognise some contribution of genetics to their illness, many others had not thought about their disease in relation to genetics. However, many participants stated that they recalled having been asked by doctors before whether they knew anyone in their family who has had RHD before, and many described being the first person that they know of in their family who has the disease. See,

“I will talk about my own experience, I’m the only one who has this heart disease in my family I haven’t heard of anyone who had it before me, and so I wouldn’t say it’s inherited.” (P.3: FGD 2)

Five out of six participants in the first RHD FGD echoed the same sentiments as participant 3 above, all stating that they are the first people (they know of) to have a heart disease in their family and therefore they do not think that RHD has a genetic origin. In the other RHD FGD’s there was always at least one or more participants who held the same perception. Most of these participants identified other diseases however which they felt had a genetic component, like cancer, asthma and hypertension. Some participants indicated that they had been informed that the disease was potentially genetic by health professionals (i.e. doctors). The information they took away from those discussions however seemed inconsistent and left some of them confused about the nature of the genetic explanation. See,

“I was told by the doctor that my heart condition is genetic. He asked who has a heart condition in your family, and I told him that I don’t know anyone. Then he said, it is most likely genetic. But to my surprise, since he said it is genetic, there is no one in my family who has ever been ill with a heart condition. However, in my in-laws, my mother in-law has a heart condition. So I was confused about that, because even my daughters say that I have inherited the disease from her, but I am not sure how I could have inherited it from my in-law family.” (P.10: FGD 2)

“He [the doctor] asked me yes, whether there is someone who has had the condition in my family. I said that when I grew up and started understanding things, there was no one I knew of.” (P.5: FGD 2)

Some participants seemed to not have thought of the disease potentially being genetic until their encounter with this explanation in the FGD they participated in, even though they had previously participated in (and consented to) a genomics study. For example:

“For me I do not have any knowledge about genetics and heart disease. I was never informed about genetics or inheritance. I just heard about it now, but I did not inherit this disease from anyone. But maybe my child will inherit it though as the time goes on but for now she does not have it.” (P. 4: FGD 4)

When directly asked whether participants believed that they inherited the disease after they were diagnosed, many revealed that they did not consider that causal explanation until they reached adulthood. One participant said:

“No. It is only now that I am old when I realized that I inherited heart disease from my mother....Otherwise back then, nobody said anything about inheritance.” (P.1: FGD 4)

One observation from the FGDs is that some participants appeared to not take the genetic explanation seriously, which affected the way in which they responded to the proceeding questions. This may have been due to the fact that they had not really thought about the implications of their disease having a possible genetic cause. Moreover, some did not recall hearing this explanation before attending the FGD. Hence, their responses were based on the explanatory models which they held and strongly believed in as the cause of their illness. One participant however, generalised the perspectives of black Africans and said:

“Sometimes, for us black people, he [Andile] could think that... Like we take things for granted. He could think that this is not something serious, it's 'just' an inherited disease. Like we don't take genetics as a serious thing. If you inherited

something, you just think ‘oh well, this is how we are at home’ and take it lightly.”

(P.9: RHD FGD 3)

It is the above mentioned general view of ‘taking things lightly’ that is evident in some responses provided by participants in the FGDs. For instance a participant said:

“For example my daughter also has the disease, but she says she will not take treatment. She says, ‘I will take it the way that you did mom, only when I have a child as well’.” (P.7: FGD 3)

The decision made by the child in this regard and the parent who is allowing it suggests that they may not see the illness as a serious concern which requires immediate attention. While one participant attributed the disease to a biological cause relating to one’s own blood, she said:

“I think heart disease is a virus that is in the blood.” (P. 2: FGD 1)

7.4. Alternative causal explanations

The perceptions an individual has about a disease and its attribution is important as it influences on how these individuals understand disease and the stigma they experience related to the disease. Due to participants’ past involvement in genomics research many had some understanding of how genetics may play a role in the development of a disease. Some held this explanation alongside alternative causal models. The questions asked in the FGDs were specific in asking about the role of genetic knowledge on experiences of stigma (i.e. “whether knowing a disease is genetic may affect decisions on getting married/having children/getting a job etc.”). However, the data suggests many of the respondents described other non-genetic explanatory causal models which they believed may have played a more important role in

causing their disease. These alternative explanations included psychosocial and cultural explanations which will be discussed in the sections below.

7.4.1. Psychosocial explanations

Psychosocial explanations about disease causation can be understood as pertaining to psychological and social factors which influence an individual's mind, behaviour or experiences. The social and psychological factors influencing the health of an individual may be interrelated. For instance, living in poverty or not having being able to obtain sufficient means to survive, could create frustration and a sense of powerlessness. In this study, participants highlighted that a disease like SCZ or RHD is often attributed to psychosocial experiences (i.e. being influenced by their environment, psychological or their social relations and described these factors could have an impact on their physical and mental health). For instance, being in environments where it is not uncommon for people to witness situations such as shootings, stabbings, physical assault and gendered violence in households and the community may affect one's psyche and play a role in disease causation.

7.4.1.1. Environmental explanations

Under the theme of psychosocial explanations, the environment was seen as a salient contributing factor to the onset of the two diseases. The perceptions on how the environment can play a role in causing disease are discussed below.

SCHIZOPHRENIA

Amongst the SCZ sample, the environment within which one grows up was reported as having a considerable influence on the onset of the disease. To start off, participants noted that the house that Andile lives in could compromise his health. In the vignette, Andile is shown to live

in a RDP house in a township. A RDP house is a one-bedroom house (about 36 square meters in total) with a kitchen, small lounge and a bathroom. These houses are very small in size, do not have enough space, particularly for the large families who usually live in them, and often have poor ventilation. RDP houses are often situated in low resource areas requiring people to travel long distances to hospitals and clinics. Most participants in this study (from both the SCZ and the RHD groups) come from townships or low-income communities, some of them the very same township as the character, Andile. In these areas many of them live in these RDP houses which have been provided by the government since 1994 to demonstrably poor people. These houses are a means to replace the even poorer conditions many South Africans live in informal settlements with shacks. Although the aim of receiving these houses from government is to better their living conditions, these participants are suggesting that when one is ill with a disease, it is also unhealthy for them to be staying in such a small space with many other people. These problematic environmental challenges can even impact on help-seeking behaviours and medication compliance. For instance:

“Another thing that I think may affect him, is the situation in which he lives under. His environment maybe, since they say that he lives in an RDP house. Which means that he may not have access to the medication which could be most effective for his illness. Then it could be more difficult for him to get better. But if he was in, in, in a developed place, he would be able to have access to facilities which can help him.” (P.3: FGD 2)

The fact that the reason most people reside in those homes is because they are poor and can not afford to buy a house for themselves is another cause for concern, which is why participants motivated that it is important to try and find a way to move from this kind of housing structure.

“Andile’s life could be affected in the sense that he may not have the ability to assist his mother, since they stay in an RDP house. He may not be able to assist her with

getting a house. In order for his mother to have a better house, other than the RDP house that they live in, because it makes them live a poorer life.” (P.9: FGD 2)

For these participants both the structures for housing (RDP homes) and the township environment, associated with poverty, high rates of unemployment, high incidents of violence and drug abuse (Bähre, 2007; Ngqela & Lewis, 2012) were highlighted as not being conducive environments for an individual living with SCZ because they may have a negative influence on their physical and psychological well-being. This observation is highlighted by Mossakowski, (2008) who postulates that long-term exposure to poverty and unemployment significantly predicts the abuse of alcohol and other substances, especially between ages 27-35 years.

RHEUMATIC HEART DISEASE

The RHD participants also highlighted that living in a small RDP house may affect Andile’s health. Based on that knowledge participants in the study suggested that Andile would need a “proper place” (it is assumed that they meant a bigger home) to live in. One participant said:

“An RDP house has got a very small space and there is a lot of people. Everybody is breathing under one roof which can cause problems. TB is also easily spread because others are not healthy. It was bound to happen to him as he is living under unhealthy conditions... The government also needs to intervene and give him a proper home so his health can improve.” (P.6: RHD FGD 1)

Notably, living in poor, ill-ventilated housing is identified as a strong environmental factor causing the onset of RHD (Barth, 2013). Another participant related this view to her experience:

“For me at home, my mother received a small RDP house. I was sick with rheumatic fever and my brother had leukaemia. So my mother went to the hospital and reported that she has been given a small house while she has two sick children. She was given a letter to take to the committee and counsellors. From there on we received a bigger house with space. We now have a bigger and spacious house which we grew up in.”

(P.2: FGD 1)

While the problem about the physical environment was discussed by participants, another participant also related the cause of their disease to the nature of the environment:

“I grew with my grandmother smoking a cigarette called ‘Mrhameti’. When she was smoking the smoke would affect me badly to the point where I thought it would kill me because I did not feel alright when she smoked and I was around. So that resulted in me having difficulties in breathing. But she was my grandmother, so I had no choice.”

(P.3 FGD 1)

Some participants described their disease was caused by a germ or virus which is passed on through the environment they live in. One participant, in the 7th RHD FGD said she had received this explanation from her doctor. She explained that a germ creates an infection which then later develops into RHD. This explanation is supported by two other participants in another FGD who shared:

“I also think like ‘P.1’, maybe you are in a village, and you drinking water from the streams you don’t even know where it comes from. So there might be a germ or virus in that water that is how I think it can cause the disease. Maybe the water from the river would cause you to cough, have short breath, loss of appetite, it might be that the germ formed all these things after that it becomes a heart disease.” (P.4: FGD 2)

It is commonly known in the health literature that RHD is a disease of poverty. It is rare in developed wealthier countries and has a higher incidence rate in contexts with more poverty (Engel et al., 2011; Zuhlke, 2015). Most of our research participants in this study are unemployed (see Table 2 in Chapter 6), and these RHD participants clearly linked the consequences of poverty to disease causation – in terms of their living conditions, but also in terms of how those realities have an impact on the stress they have and how that related to their illness.

“Poverty is one of the difficult things that we go through and it can make you sick with stress. I am sure Andile is also thinking about how he and his family can get out of this poverty.” (P.4: FGD 4).

7.4.1.2. Psychological explanations

Under the psychosocial explanation, the psychological implications of past and present experiences of trauma, stress and emotional abuse also surfaced in the groups. There were many participants who reported that these experiences influenced their lives significantly and many of them felt that they may have caused the onset of their disease.

SCHIZOPHRENIA

Some participants in the SCZ FGDs suggested that experiencing a violent environment may trigger the onset of the disease. See for example,

“It is not being happy because you live with being abused by people in your community, people in your home and just people around you”. (P.4: FGD 3)

“What do I think causes it? I think it may be caused by being beaten up.” (P. 10: FGD

1)

While another participant discussed the influence of negative perceptions held by people in their community, about mental illness and how that may affect them psychologically:

“And it’s true my sister yey, when you are a mentally ill person living in the township, people often undermine you when it comes to a lot of things.” (P. 1: FGD 6)

This undermining could be the result of a loss of social status in the community, which in turn results in some participants feeling inferior, and reporting a loss in their self-confidence. Living in the township and not having a job that provides a sense of income can also cause stress which may result in the onset of disease.

“Not working means you can’t afford everything you need and want. When you are poor, you live in difficult circumstances”. (P.4: FGD 3)

In the literature review section of this thesis we discussed the quality of life in townships and went into detail about the challenges of living in a low-income community (see Chapter 2, section 2.7.3.) with high levels of unemployment, poverty violence and crime. It is no surprise that living in a low-income community can impact on one’s psychological health.

This ties in with the earlier suggestion made by many of the participants that once diagnosed with the disease, Andile should try to move away from his environment. This move may allow him to enhance his resilience which they feel is needed in order for him to function to the best of his ability.

In addition to the normalisation of violence, reported by many participants as a common occurrence in their community, the fear of being violently attacked was reported as a common

trigger of psychological distress amongst participants. Some participants feel that this constant sense of fear may also be the cause of their disease.

“P.4: Being scared sometimes. Being scared can also disrupt ones thinking.

I: Okay, being scared of what maybe?

P.4: Being scared by things, for example the killing of people.

I: Okay, so these would be things you would see where maybe?

P.4: These are things you would see in the township.” (P.4: FGD 6)

These concerns are unsurprising in the sense that in South Africa people are being killed in townships [informal shebeen’s] and other areas of townships or low-income communities in general almost on a daily basis. It is a common occurrence and for a mentally ill person who may struggle to control or defend themselves, it could be a cause for a deep sense of fear. This fear was mentioned by some participants as playing a role in developing the condition.

RHEUMATIC HEART DISEASE

For the RHD participants, psychosocial stress was described as having a prominent psychological implication on participants’ life experience. This feeling was echoed by many participants in this disease group and most of them felt strongly about the relation between stress, trauma and past negative experiences and the impact these may have on their psyche and heart. Many participants ascribed the cause of their disease to emotional stress, some of which was experienced during their childhoods and some during adulthood. Furthermore, many of the RHD patients described that the way in which you are treated at home, and the circumstance you live under whilst growing up may also have an influence on your health, which is similar to perspectives described by some of the SCZ participants. For example one participant in the RHD FGD said that:

“...to think too much, and being abused at home, it kills the heart...” (P.4: FGD 1)

“So I thought that it might be caused by the stress that I used to have at an early age, and I did not speak about my stressful things. I kept all of them into myself... Therefore, I think what causes heart disease is stress and to take things too much into your heart.” (P.3: FGD 7)

In relation to the stress, similar to the SCZ participants, some RHD participants also expressed experiencing abuse in their lives, and they attributed the cause of the disease to the stress of living through experiences of abuse.

“Children at school used to abuse me because when they see me they think I would faint or do something weird so that they would laugh at me, these are some of the things that affected Andile’s life.” (P.2: FGD 1)

“I think what causes heart disease is when maybe something happened, and you just ignore it, maybe someone hurt you or did something hurtful you will obviously think about that and then the minute you process it in your mind, your heart beats faster and starts pumping in a strange way. I think things like that affect the heart, because the heart pumps the blood. Even when you are overthinking maybe you are angry and you experience that the blood is not flowing well, the heart is beating faster and its paining before they do the operation at the hospital because you are angry.” (P.7: FGD 1)

While another participant who shared with the group her experience of abuse as an adult said:

“For me my husband mistreated me, he used to hit me always and he would not give me his salary at all claiming that he is the one who works for that money so he can

spend in whatever way... I have been abused emotionally, and for me the heart disease was caused by this abuse, because I did not have this disease when I was growing up and in my family, we have no history of the heart disease but abuse from my husband caused this illness.” (P.1: FGD 2)

While abuse and stress were described as having psychological implications which in some way may have contributed to individuals getting the disease, there were some contrasting views. Some participants stated that they got diagnosed with RHD when they were children, and they therefore do not believe that the cause of the disease for childhood onset would be stress. For instance,

“So my mother had this idea that a heart problem is only for older people, because they think a lot. Then, when I arrived at Red Cross Hospital, I realised that there are many children with heart diseases. That’s when I was told that this disease is not just for older people, because they have stress.” (P.1: FGD 1)

In support a few other individuals who were diagnosed with RHD at a young age did not believe that they developed the disease because of stress, but rather felt it was other causes which may have contributed to them getting the disease, for example the environment they lived in or the choices they made growing up.

7.4.1.3. Personal lifestyle choices

Personal lifestyle choices were also an important causal explanation which participants gave to their disease. Both groups of participants emphasised the importance of smoking, substance abuse, unhealthy foods and physical inactivity in disease causation with some voicing that they

believe that their inability to avoid engaging in those behaviours may have caused their disease. The different perspectives shared by the participants in the two groups are presented below.

SCHIZOPHRENIA

Many of the SCZ participants reported that lifestyle choices and an individual's behaviour may have contributed to them developing SCZ. A majority of participants believed SCZ was due to them having abused substances at some point in their lives. Examples of statements shared when participants were asked what they thought caused SCZ included:

“It is smoking too much drugs. It disturbs your thinking, then you end up robbing [stealing from] people, and you end up being beaten by people in your community because you are robbing them. Because your mind is not functioning as per usual, it is functioning in another way.” (P.9: FGD 1)

While another participant supported the above view and said:

“By using drugs maybe and also by using alcohol maybe where you find that you perhaps smoke and do everything and your brain does not come back to its proper state. And you end up losing your mind.” (P.5: FGD 5)

When asked about whether the participants thought Andile's child may have the disease, some participants suggested it would depend on the personal lifestyle choices that the child makes. These participants asserted that children needed to be aware that along with their agency in making these decisions came the knowledge that these may have health implications.

The critical role of substance abuse in causing the onset of SCZ was only affirmed by the fact that some participants made the assumption that Andile uses drugs, which is interesting as this

is not mentioned or suggested in the vignette they watched. However, considering that substance misuse is highly common in South Africa, especially amongst the youth – individuals between the ages of 16 and 34 years – it is understandable that these participants considered it to have an influence on the onset of the disease. The average age of these participants was 33 years old, falling well within the age group with the highest risk of drug use. Many of these participants reported misuse of substances in the past, and the association they make between substance abuse and the onset of SCZ may be in relation to their own experiences.

RHEUMATIC HEART DISEASE

Personal lifestyle choices were discussed differently by the RHD patients. Whilst there was some mention that Andile should not take drugs or abuse alcohol, this group did not place the same amount of emphasis on this as the SCZ sample. One participant said:

“Andile needs to change his ways. If for example he was drinking alcohol and smoking, and using other drugs, he needs to decide to change his old and wrong ways for the better.” (P.1: FGD 4).

Again, similar to the SCZ participants, some respondents also made mention that he needs to stay away from people and situations (for example parties or shebeens) which would influence him to consume alcohol.

This is also reflected in RHD FGD 6 where a participant said that Andile should be careful of the friends he chooses and monitor his alcohol intake. She said:

“Alcohol and the friends. In terms of friends, he should choose the friends he mingles with, because if you will be getting drunk while you are sick it is not right... he should

try to change now... Even the kind of food he eats. He would have to stop eating amagwinya [Vetkoek / fat-cakes]... ” (P.2: FGD 6)

The above comment shifts from highlighting the need to reduce the consumption of alcohol to highlighting the need to reduce the intake of unhealthy food, which was a prominent topic discussed in the RHD FGDs. In fact, the kind of diet participants are or were on before the onset of the disease was suggested to have significant implications on their heart condition. For instance,

“It because of the things that we eat daily, fatty foods, cooking oil consumption and so forth, they are the cause of heart disease because it’s not heredity.” (P.3: FGD 1)

“I think overthinking and consuming too much salt are the things that caused heart disease in my life.” (P.3: FGD 1)

The above extracts (about the food diet) relate to a different way in which personal lifestyle choices were discussed by group members. For example, as seen above, when it came to food, RHD participants were adamant that it is important that someone with RHD does not eat oily or salty foods, or too many green vegetables (which have a negative relation to Vitamin K in the blood system). An example of an extract which describes the participants’ awareness of avoiding certain foods and substances is displayed below.

“I avoid a lot of things, like cough syrup, raw food, and alcohol. I can’t have them, I must eat proper food and I must follow the right diet.” (P.3: FGD 4)

For this group, the consumption of healthy food was a focus under this theme, and it was linked to both contributing to the cause of the disease as well as to the management of the condition

after diagnosis. In addition to maintaining a good diet, many participants emphasised the importance of exercise as it is known to also contribute to an individual living a healthy lifestyle. These findings again ought to be understood against the background of the participants' environments and financial situations.

7.4.2 Cultural explanations

7.4.2.1. Bewitchment/Supernatural causation

In African contexts most people are more prone to understanding the world and living their lives through traditional cultural belief systems. As it has been discussed in the literature (Mkhize, 2003; Swartz, 1998), mentally ill individuals from African settings often attribute part of the cause of their illness to cultural beliefs (for example bewitchment i.e.: being cursed or poisoned through supernatural ways). The results below illustrate how these two disease groups view the role of witchcraft and or supernatural causes like evil spirits in the onset of disease.

SCHIZOPHRENIA

Among the SCZ participants for instance, one participant describes how he thought his illness emerged due to a supernatural cause (bewitchment) before he gained better knowledge on what caused his disease. He said:

“I used to think it was witchcraft, but then when I heard more about it I realised that it’s a blockage in the veins in your head.” (P.7: FGD 2)

Even though the above participant seemed to have changed or included an additional perspective to their own explanatory model, other participants stayed firm in their belief that their illness was caused by supernatural causes.

“What I think is that it is caused by witchcraft. Because I have experience with those things when it comes to me and things that have happened to me. So I think that maybe it does happen that, there is Satanism, or witchcraft which is involved. No matter what may be the main cause of it but I do think that those things do play a role in triggering it.” (P.5: FGD 2)

While another participant in the same FGD as the one above said:

“...I relate this to what [she] said, that it is related to witchcraft. So the person who did that to Andile is like someone who practices witchcraft.” (P.1: FGD 2)

While two other participants acknowledge that some people who develop SCZ may feel this way because of their cultural belief system. See,

“Other people start blaming neighbours of witchcraft, and they would start saying that as a family they need to move out of the neighbourhood because they are being targeted for bewitchment.” (P.3: FGD 2)

“It may also be caused by the thing of believing in things to do with witchcraft. Maybe you could be bewitched perhaps, then you notice that you are not the same as you used to be.” (P.6: FGD 4)

When asked to articulate how bewitchment occurs, some participants explained that they thought of bewitchment in the form of being poisoned, which can happen through eating food with poison served by someone who has the intention to bewitch them.

“Yes, poison food... Some people can give you food which is poisoned for you to be mentally ill. Then once you are ill. Once you start being mentally disturbed, then those people will start speaking to you on the side [which is when you hear voices]. That’s when they will say [to themselves or others], ‘hey, I have poisoned so and so’s child and I want them to go around picking up papers or eating from the bins.’ Ya.” (P.1: FGD 6).

These extracts are in accordance with the literature which documents that within Xhosa communities, individuals indicate that psychotic symptoms related to mental conditions like SCZ are attributed to witchcraft and spirit possession (Mbanga et al., 2002; Swartz, 1998). This was eloquently discussed by Campbell et al. (2017) who investigated Xhosa patients with SCZ’s understandings of delusions. Echoing these previous studies, many of the participants in the present study reported their beliefs in a supernatural cause which may have triggered the onset of the disease. In African cultures, it is believed that this causal explanation is often viewed as prevalent alongside the other causal views explained by participants. Moreover, individuals often attribute this explanation as identifying the ‘root cause’ of an illness, while western medicine manages the symptoms of psychosis. Hence, these participants suggested that there could be a combination of causes and disease causation may not be limited to genetic, psychosocial or cultural causes exclusively.

RHEUMATIC HEART DISEASE

It was intriguing but rather unexpected to note that in the first RHD FGD, participants suggested that the disease causation can be linked to supernatural reasons. One participant said:

“My mother, when I told her about it she thought and believed that it was evil spirits that caused it. I told her that it is a common sickness, there is a lot of people who are affected by it. She was hurting so it was not easy for her to accept it.” (P.4: FGD 1)

Two participants in the sixth RHD FGD also suggested that the cause of the disease was related to supernatural powers such as evil spirits.

“I am saying it is evil spirits.” (P.2: FGD 6)

“Me, it is said that there is my aunt who had it. I do not know how it connected with me. I would say it is heredity, but no, I also say it is evil spirits. [Laughter]. So I also think maybe it is that is what caused the illness.” (P.3: FGD 6)

Although P.3 above included the possibility of a genetic contribution to her illness, she also added to her explanatory model her belief in a supernatural cause. In the 7th RHD FGD participants also echoed the views expressed above by stating that RHD may be caused or at least enhanced by supernatural causes.

“And that is true, evil things will get to you through something that you have. If people want to bewitch you they will use this heart disease, or use the illness that you suffer from.” (P.4: FGD 7)

“...I mean I do agree that sometimes it would be evil spirits and it would enter through what you suffer from. If it is said that you suffer from heart disease, the evil spirit would use that heart disease. You see, it is things like that.” (P.1: FGD 7)

This suggests that cultural explanations of illness may also play critical a role in understanding RHD disease attribution.

7.5. Chapter summary

The above findings lead to what has been alluded to and sometimes stated by many of the participants in the study, that the disease causation can be linked to multiple causes all interacting to cause the disease. Many participants noted that even if genetic predisposition may be present, there would need to be another factor that would trigger the onset of the disease. Some participants referred to that factor as being the environment they are in or have been in, while others related it to psychological experiences they have encountered and some related it to the cultural beliefs that they hold. These participants therefore often attributed the disease they live with to multiple causes concurrently (including genetics).

Chapter 6 presented evidence of the causal explanations held by the SCZ and RHD participants in this study. The chapter began by defining disease causal explanations. Secondly, it presented qualitative data of participants' attributions of disease in relation to genetics, psychosocial and cultural explanations. The chapter demonstrated that for Xhosa people with SCZ and those with RHD, genomics as a causal explanation for disease, is considered in conjunction with other causal models. In the next chapter I discuss the findings of the study in relation to the stigma experiences revealed in the FGDs across both disease groups.

CHAPTER 8: EXPERIENCES OF STIGMA

8.1. Introduction

This chapter details the findings of the experiences of stigma reported by participants in this study. The following section draws on participant experiences of their illness specifically in relation to stigma as well as how they cope with their reality of having their disease. The responses were provided following exploring participants causation attributions. While it is acknowledged that it is impossible to gain an exact account of these participants realities, the discussion below is based on their own accounts. This chapter is divided into the categories presented in Table 10 below. For consistency, for each category I present evidence for the SCZ sample, followed by evidence from the RHD sample. Where relevant, within this chapter I have used quotes to communicate the voices of the participants in this study.

Table 10: Categories and themes

MAIN THEMES	SUBCATEGORIES
1. Knowledge about disease	
2. Evidence of existing stigma	a) Family, friends and community
	b) Marriage
	c) Having children
	d) Ability to earn an income/work
3. Coping strategies to overcome stigma	a) Social support
	b) Acceptance, openness and transparency

	c) Sense of purpose
	d) Health knowledge

8.2. Knowledge about the disease

Peoples' knowledge about disease is undoubtedly influenced by their perceptions, belief systems, disease-causal explanatory models and their worldviews which have been discussed in the previous chapter (Swartz, 1998). Below is a presentation of the shared views of Xhosa people, living with SCZ and RHD, about what they know or understand about their disease.

SCHIZOPHRENIA

For the SCZ patients, when asked the question: '*What do you know about schizophrenia?*' they often answered with examples of the symptoms that they remember experiencing when they became ill. In particular, people in these FGDs commonly described the illness in terms of positive (psychotic) symptoms. These included descriptions of experiences of hallucination, delusions, disorganised speech and behaviour to name a few. Describing their illness through symptoms is not necessarily the same as using the disease label – and describing an illness in this manner could be considered as distancing oneself from the illness label and its connotations. This is not unexpected, as in the Xhosa language, there is no term for schizophrenia, or even differentiations between different mental disorders. Individuals diagnosed with a mental disorder are often grouped by members in the cultural group in one term which is "ukuphazamiseka enqondweni" meaning in English, "a disturbance in the brain". This understanding has an implication on how the scientific label "schizophrenia" is received, acknowledged and internalised as referred to in the Modified Labelling Theory (Link et al., 1989). For example, one participant said: "*It is hearing voices.*" (P.6: FGD 1). Hearing voices is a common symptom which was highlighted by these participants. For instance:

“In my knowledge, the illness known as schizophrenic is a disease which attacks a person. For example I am sitting at home, and I hear something [a voice] which says go outside and run in the road. Run on the white line on the road. It’s like there is God. Or like there is a big god that is telling you to go outside and expose yourself to something.” (P.1: FGD 2)

This is an example of one of the few participants who actually mentioned the label “schizophrenic” in their dialogue. Many participants indicated that they understood SCZ to relate with disturbances in the mind, although they did not specify what happens in the brain. They also theorized that there may be a particular trigger (which many respondents propose to be bewitchment, the environment, stress or substance use) which may cause the disturbance in the natural state of the mind.

Another participant in FGD 4 highlighted the symptom of hallucination. He said,

“Having schizophrenia means seeing things that other people do not see, or hearing things that other people cannot hear.” (P.6: FGD 4)

In addition to hearing voices, disturbances in the mind and hallucinations, many participants associated ‘being sick’ with the time when they are ‘dirty’ and did not have motivation or energy to wash or clean up after themselves. They explained this as the time when they struggle (because of lack of interest) to do everything they were used to doing in their daily routines. There are many similar examples of how the participants in this study (who are patients themselves) described a person living with SCZ as being ‘dirty’. For example in the fifth SCZ FGD participant 3 said: *“When the illness starts, it makes him dirty, and he becomes darker.”* And again in the sixth FGD a participant said:

“One person may be very sick, and you notice that they even go around picking up papers. Like dirty things. And they even eat from the bins.” (P.10: FGD 6)

The association of psychiatric illness with being ‘dirty’ in relation to personal hygiene, eating from bins and other dirty behaviours has been well documented in the literature. For example Phelan and Link (2004) as well as Mbanga et al. (2002) write about the public’s tendency to ascribe the negative characteristic of being ‘dirty’ to mentally ill people. When relating this observation to the aetiology of the disease, this could be understood as the disorganised behaviour typical of a psychotic episode. That patients themselves also articulated these views in our FGD could be considered evidence of internalisation of these stereotypes.

With dirtiness described in this study as an indication of a symptom related to SCZ, it is not unexpected that participants perceive an important step towards recovery to be getting ‘cleaned-up’. The participants describe a range of strategies for ensuring people living with SCZ (for example Andile) become cleaned up. Starting with friendly conversations suggesting that he get cleaned up, to resorting to violence -which as discussed in the literature reviews, is a common act in South African low-income communities - to force him to clean-up, all in the name of friendship and care. But what counts as friendship in this group is contested. For instance, some participants emphasised that friends should be the ones who take the role of pushing Andile to take action.

“... When you are Andile’s friend you should be the person whom he is scared of. So that when he refuses to wash himself at home, his family can go and fetch you. When you arrive you should be able to threaten him and say ‘look boss, I will kick you, I am not going to beg you, I will stab you, you must wash now’, and he should wash.” (P.9: FGD 6)

This quote is an example of the normalisation of violence within the township communities that these participants come from (Bähre, 2007; Ngqela & Lweis, 2012). Moreover, it suggests that the participants are used to violence as a form of communication and a behaviour correcting strategy. This is evident in that participants even anticipate that their family members would call on someone to enforce violence in the name of care. This violence was also reported by participants to be a solution for when they do not want to seek treatment for their disease. This may further suggest the internalisation of stigma, that people with SCZ perceive themselves to be so helpless and stuck that this behaviour is acceptable and perceived as helping. Importantly, not all participants felt that using violence was acceptable and some expressed a desire to have conversations that encourage Andile to take better care of himself.

Although most participants knew the name of their disease, and were able to describe the symptoms they experienced when they became ill, many did not necessarily identify with the chronicity of the illness and therefore did not consider themselves to currently be ill. Even though they were open to describing their diagnosis, there was clear hesitance in labelling themselves as having schizophrenia and in thinking of themselves as ill. Participants also went to some effort to point out that they were not as 'sick' or as 'bad' as the character in the vignette. This is interesting because the video character was only very mildly depicted as hearing voices and experiencing hallucinations and otherwise clean and healthy.

From the data, four important observations can be made in relation to their knowledge about the disease: 1) Participants associated SCZ with positive symptoms such as hearing voices, hallucinations, delusions and disorganised behaviour (i.e. 'dirtiness'); 2) Participants described SCZ as an illness which has an influence on your mind, making a person living with it experience things which others around them do not experience, 3) Most participants in this

study often distanced themselves from the label of schizophrenia and its chronicity, and rather referred to “a time when they were ill” or had certain experiences – often referring to the symptoms they experienced and 4) Participants understand SCZ to be triggered by an individual’s personal lifestyle choices (i.e. abusing substances such as drugs for instance).

RHEUMATIC HEART DISEASE

In the RHD FGDs, individuals vividly recounted experiences of how they remember the symptoms starting and their journey to diagnosis. When asked ‘*What do you know about RHD?*’, participants discussed two primary aspects, namely the symptoms they experienced during the onset of their disease and the management of their symptoms (which for many included having a valve replacement operation). Despite the high prevalence of the disease in township communities in South Africa (Engel et al., 2011), many participants stated that before going to medical practitioners for a check-up of their symptoms, they did not have much knowledge of RHD. For instance,

“I didn’t know about RHD, it was my first experience hearing about it when I went to the private doctor.” (P.6: FGD 1)

One of the challenges to gaining information about the disease which participants reported was delayed diagnosis. Many individuals recalled having to go to local clinics multiple times, without receiving a correct diagnosis. Some, like P.6 above, resorted to going to a ‘private doctor’, which unlike the local clinic - which provides free health services - requires monetary payment for consultation, to get the necessary tests done resulting in the diagnosis (see the resource challenges in the public health care system in South Africa described in Chapter 2 of this thesis).

FGD participants described their illness in terms of symptoms like: a sore throat, previous diagnosis of rheumatic fever, swollen legs, shortness of breath and tiredness. For instance:

“Me my first time to have RHD, I started by having shortness of breath, I’d be unable to breathe and when I was unable to breathe I’d not be able to walk a long distance, then I went to the clinic and when I got to the clinic, I asked the doctor for an X-ray. The doctor put me on the X-ray machine and he found that there is something in my heart similar to a clot.” (P.5: FGD 1).

While another participant said:

“When you are someone with a heart disease, you start off by having a tight chest. And with your tight chest, it’s not like someone who has a chest problem. It feels like there is something coming up your chest. You keep on getting swollen, and getting swollen... You get tired easily. (P.4: FGD 3)

Many people in these group discussions echoed these symptoms, while some participants shared that their RHD started with a sore throat or what they now know was rheumatic fever. This is evident in the response of P. 2 (FGD 1) who explained that she recalled a period when she had rheumatic fever as child.

“As a young child other children used to avoid playing with me because I had a heart attack. I used to tell them that I have not had a heart attack, I had rheumatic fever. Then they would ask me what rheumatic fever is...” (P.2: FGD 1)

While P.2 above knew that she once had rheumatic fever, P.6 below was also aware of this previous diagnosis as the doctor had informed her mother, however she reported that her mother did not follow-suit with ensuring that she gets treatment.

“I was supposed to go to the clinic for injections for rheumatic fever every month, but that never happened. So my heart valves ended up leaking.” (P.6: FGD 1)

Some participants did not recall having been diagnosed with rheumatic fever at a young age, but many of them did recall having a sore throat at some point in their lives as children and then they recalled no longer feeling the pain after a few days.

A participant (P.4: FGD 6) shared how in her village when she had a sore throat it was believed to be mumps (which they called “*qilkwana*”). In order to cure the mumps (*qilikwana*) one had to sing a short song called “*qilkwana*”. After singing that song it was believed that the sore throat would go away. Therefore, that is what she did when she had a sore throat and it went away after a few days without being medically treated. This belief may be in relation to the evidence (Engel et al., 2011; Zuhlke et al., 2015) suggesting that after a few days of having an untreated sore throat the pain does indeed go away. A period later one develops rheumatic heart disease.

From the discussions in the RHD FGDs, four important observations can be made: 1) Participants appeared to have minimal information about RHD prior to their diagnosis; 2) Participants associated RHD with having a sore throat or a rheumatic fever diagnosis when they were children; 3) Participants describe RHD in relation to the symptoms they experienced before diagnosis (such as shortness of breath, tiredness and swollen legs); and 4) Some participants highlighted a cultural understanding of the precursor to the disease (RF) which they articulated as being mumps (*qilkwana*).

The descriptions of illness amongst the two disease groups varied. While the SCZ group highlighted the disease's relevance to disturbances in the mind (hearing voices and hallucinations) and dirty behaviour, the RHD group discussed their illness in relation to physical changes or pain which they experienced in their bodies (which is to be expected considering the psychological vs physical nature of the two diseases).

8.3. Experiences of stigma

Below is a presentation of the examples of accounts of stigma which the participants in this study experienced in their; *1) Family and Community, 2) Marriage, 3) Having Children, and 4) Ability to earn an income/ work life.*

8.3.1. Family and community

Diagnosis of an illness has the potential to change the way in which family and community members view a person living with a disease. Participants from both groups in this study expressed that they have experienced and anticipate experiencing more stigma, discrimination and abuse from people in their immediate environment because of their disease.

SCHIZOPHRENIA

Participants in the SCZ sample in particular expressed that they have experienced many instances of stigma and abuse by family and community members. They shared that following diagnosis, many people around them started looking down on them, treating them as 'useless people' who cannot contribute to decisions made in the family and in the community. This resulted in a strain on the relationships participants have with people around them.

At a community level, participants expressed that people tend to tease and bully someone who has SCZ, hence they anticipate that the patient in the vignette (Andile) will receive this kind of treatment from their community. Many participants expressed feeling that someone who has SCZ is often perceived as an inferior individual who is not liked by people in the community. In particular, the respondents felt that many people have prejudiced views when it comes to engaging with someone who has SCZ. For example, P.9 in FGD 1 said: *“Others may say that they like him and act like they like him [Andile], however that may not be true... I think people may crucify him for his disease.”*

Other participants expressed that the vignette character may experience discrimination. Participant 7 said: *“People may start abusing him, like friends, family or elders for instance.”* (P.7: FGD 1).

In relation to family, participant 7 (FGD 1) provided another view relating to the hope that family members ought to be the ones who empathise with someone who is diagnosed with SCZ.

“I think that the family may change, in the sense that they would try and become closer to him and kinder to him as well. I think also the fact that he did not do it to himself, for example through the use of drugs. His family may then support him.”

This latter view was highlighted by most of the SCZ participants, as they voiced that their families ought to be the people who support them and treat them with empathy. In addition, respondents revealed that an individual with SCZ should in fact aim to limit their engagement with individuals outside of the family as that may open them up to situations where they may be stigmatised or abused. Notably however, as mentioned earlier however, sometimes the

family members themselves also exert violence towards the person suffering from SCZ, possibly because they don't know how else to treat them when they behave strangely.

The reaction of the family and the community to an individual who is diagnosed with SCZ was largely tied to their belief of the cause of the disease. Participants expressed that if an individual inherited the disease from a family member or it is something which is passed down in the family, then the individual would likely be less stigmatised. Whereas, if the individual participated in a behaviour (such as smoking drugs or abusing alcohol) which the family and community believed may have caused the onset of the disease then participants suggested that the person living with the illness would be more stigmatised, as people may in some way blame them for bringing the disease on themselves.

Overall however, although it was reported by many in the groups that some form of stigma would be prevalent in their families, it was acknowledged that family support is an important protective factor for both the SCZ and RHD participants in this study. Hence, this theme is further elaborated on in the *Coping Mechanisms* section of this chapter.

RHEUMATIC HEART DISEASE

Similar to the SCZ group, some participants in the RHD FGD's felt that Andile may be looked down on by individuals in the community. For instance,

“Yes, it can happen that people look down on him since he is sick. Some people can even go to an extent of keeping his plate and spoons separately from theirs as they think his condition might be contagious. Like I said people are different. Some people may even call him names.” (P.1: FGD 4)

Concurring Chang et al. (2018) a few participants described the burden of collecting treatment each month and having to take pills everyday as an act which gave some people in the community the misconception that they are taking Antiretrovirals for HIV (which is highly stigmatised) rather than RHD. The stigma of having HIV is extremely strong in these participants' communities, therefore some explained that they carry their clinic cards with them and if someone suspects them to have HIV, they take it out and show them their diagnosis of RHD which is written clearly on their clinic card.

Similar to the SCZ participants' views, many RHD participants felt that the family should be protecting the person living with the disease from stigmatising encounters, again emphasising the importance of family as a protective factor towards stigma in this cultural group. For example, one participant said:

"If the family does not give Andile love, care and support then the outsiders will also treat him that way." (P.6: FGD 1)

Participants in this group also expressed that Andile may be perceived as an inferior individual in the community. For example, P.1 in FGD said, "...they can make him feel so small."

On the other hand, many participants described that family members may also treat Andile differently not because they want to offend him intentionally but because they perceive him as vulnerable and want to protect him. This could be evident in them treating Andile as a fragile person, and taking active steps to try and minimize any possible emotional or physical harm he may encounter, for instance by avoiding telling him bad news, *"for example there is bad news about death in the family, then the family may not want to tell him"* said P.9 in FGD 3. He proceeded to say:

“Yes, or if it comes to making decisions. Some people in his family may feel that they need to make decisions for him just because he has a heart condition and they think he cannot be told anything. Which will then make it his responsibility to always tell them that, ‘listen, even if there is bad news, don’t hide it from me because I have RHD, treat me as you do other people’. So Andile’s life might be affected by other people treating him differently because of his condition.” (P.9 FGD 3)

Some people expressed that Andile may be treated more positively because he has the disease and because people feel pity for him. This was expressed in the comment below.

“People will always feel pity of him, even when there is some work activities in progress [in the community], people will always be sympathetic towards him and ask him to sit down instead of taking part in the activities. Even, at work, if he was working, when workers are being reprimanded because of some delays in production he was going to be told not to worry and not to be alarmed because he is exempted from the scolding. So he will be discriminated in some way.” (P.4: FGD 6)

This was supported by some participants who also expressed having similar experiences where they have been told (either by people in their family, community or in the work environment) to sit down and rest because they are excused from working due to their disease. Participants described that this was not something they appreciated, as they wanted to be treated as equal human beings to other people and not be given better or different treatment due to having RHD. Another participant shared how it affected her spiritual life

“For example, in things that are connected with church. During the fasting times, it would not be accepted that I also fast. I would be reminded that I am taking a treatment and therefore I cannot fast. And I will be telling myself that I feel powerful and I would

be able to fast until I complete the period. But I will not be able to take part in the fasting activity because I will be prevented to do so due to the treatment I am taking”.

(P.3: FGD 6)

While in relation to Xhosa cultural activities, one male participant shared that people may not take Andile seriously:

“For example, in the villages [in the Eastern Cape Province] in preparation of burial service, it is young men who perform the responsibility of digging the grave-hole. So when it comes to him, people will say ‘oh that one, he is useless’, you see those negative comments. He cannot even make a suggestion and say, ‘Let us go and dig’, no, because people know that Andile is someone who cannot dig and cannot even carry a shovel, because he might just fall with it on his hands.” (P.5: FGD 6)

Described in this way, the inability to physically assist with activities which are deemed important and valuable based on cultural values held in the community may be a cause of stigma for at least some people with RHD. This is true particularly for those who reside in more traditional communities, like for instance villages in the Eastern Cape. And even though some people may be residing in the urban areas of the Western Cape, many RHD participants described going to the rural areas of the Eastern Cape at least once a year (usually in the December holidays, over the Christmas break) and sometimes more (like for instance in March/April which are the Easter holidays and the June or September school holidays or for funerals). During those periods they would be exposed to spaces where they can potentially be stigmatised for not being able to part-take in culturally valued activities.

Women in particular carry a heavier burden, as in the Xhosa culture they are expected to do a lot of the house work (including cooking, cleaning, washing etc.), all of which requires physical energy and strength. Another cultural expectation for women in the rural Xhosa communities is that they go to the river to collect water (usually in 25 litre buckets which they carry on their heads to and from the river) for the entire family to use each morning. When you are unable to do so, you are sometimes labelled as 'lazy' by people in your family and/ or community. Women in the group discussions made reference to the work needed to be done by a woman and some of them expressed how they struggle to fulfil those duties and often have to rest before completing them. Although acknowledging that some people may judge them for their inability to assist in this labour, some participants stated that their families understood their situation and would not ridicule them if they cannot complete these tasks. One participant said that when people know that you have a disease, and they know the cause of that disease, then they are more likely to be understanding and may not label you as being lazy.

Another reason mentioned (particularly by men) for being stigmatised by members of the family and the community is the inability to contribute financially towards things that require financing in the family and community. Notably Andile is unemployed and so are many of the participants in this study. Participants expressed that his [Andile's] views and opinions may not be considered equally because he cannot contribute to the family physically and financially. This relates to the cultural viewpoint that if an individual (usually a male in the Xhosa culture) does not contribute financially in the household, he loses the right to voice an opinion about important decisions made in the family and in the community. This suggests that at least sometimes, the cause of participants' exclusion is not primarily their diagnosis but may rather be related to whether or not that individual can fulfil social expectations and contribute to the

family and community. Thus, the persons' sense of respect and social status in society is often based on their ability to contribute financially.

8.3.2. Marriage

For many participants in the study, being diagnosed with their disease had considerable social implications, most notably with regard to marriage and having children. These two domains are discussed separately in this chapter as even though there may be some overlaps, some participants are married, while some are single but still had strong views on having children. I start with the domain of marriage. Of those who are married, many of them met their spouses before their diagnosis. Regardless of their marital status, respondents had contrasting views on whether or not they thought a person with RHD or SCZ could find a spouse who would want to marry them. The views on marriage expressed by participants in both disease groups are presented below.

SCHIZOPHRENIA

Two main views were dominant among the SCZ participants. Firstly many participants felt that it was not appropriate for a person with a mental illness to get married for different reasons. One of the reasons is that it would be difficult for the person to find a partner who would be attracted to them in the first place, primarily because of the perceived 'dirtiness' of a person with SCZ - described earlier in this chapter. Another reason given is that Andile's partner would experience a loss of social status by marrying someone with SCZ. They anticipated that a spouse of someone with SCZ would also be teased and bullied in their community. Therefore, some respondents felt that it is better for a person with SCZ not to get married or preferably to get married to someone who also had SCZ and will understand what it means to live with the illness. One comment which emphasises this view is presented below:

“He [Andile] cannot get married when he suffers from schizophrenia. His wife could be laughed at or she may speak badly, even to other women about him. He cannot fit into marriage when he has a mental disorder. Even me I cannot fit into marriage because I have a mental disorder. I would be laughed at and even my wife would be laughed at. How could she marry a person with a mental disorder?!” (P.4: FGD 3)

A few participants, however, felt that if the partner loves someone with SCZ and they are aware of it and understand the nature of the condition, then they may perhaps be able to support and live in a marriage with that person. These participants felt that a relationship would have a chance to grow into a marriage.

In addition, on attractiveness, some participants expressed that a woman may not want to get married to someone who does not have a job because they would not be able to support them financially. For these participants it seemed that the ability to provide for one’s partner and family plays a critical role in gaining a partner who is willing to be in a relationship with that person, which again may have to do with the social status that person will have in the family and in the community.

With regards to decisions about marriage, some participants felt that external individuals or sources should get involved when a person with SCZ wanted to get married, especially if they wanted to marry a person who does not have SCZ. One participant in addition said that the government should be involved in making the decision.

“The government prefers a person with a normal mental state to get married, not that when you are not well you are not normal but you are still under other people’s care

and why would you now want to get into marriage, while you are not well.” (P.5: FGD 3).

He proceeded to say that the government might not be happy with allowing a person with a mental illness such as SCZ to get married. Two participants in this FGD felt this way. This thought is in line with historical restrictive marriage policies for people with SCZ in the US for instance (Phelan, 2002). Other participants in the same group however disagreed with such views. One person who was of the opinion that the government should not have the capacity to decide whom an individual should ‘love’ and whom they should marry:

“As for myself, I do not see it that way. The government cannot decide for you who to get married to, it is up to you. You decide on that with your partner that you are getting married to... Now there at ‘what-what’ [meaning at the court] they ask you, ‘do you know this person?’ And if you say you do, they ask ‘so you are going to marry him as he is?’ and if you agree, it is okay, it is your right. So they will make you sign those documents, the both of you and you would have agreed as well. So it is not a forced agreement, you agree on your own.” (P.3: FGD 3)

As mentioned earlier, a few participants felt that a person with SCZ can get married to someone who also has SCZ. This seemed to cause less concern than someone who has SCZ marrying someone who does not have the disease. This difference in perspectives was based on the notion that a mentally ill person is more likely to meet another mentally ill person (who understands their situation) at a facility for mentally ill people.

Many participants either laughed or shared that they would disapprove of Andile marrying their sibling.

“I would not agree for my sister to get married to someone who suffers from mental disorder. That would even make other people to laugh at my sister. People like her friends for example.” [Laughter]. (P.4: FGD 3)

Again, the fear of loss of social status was highlighted by participants, hence the comment above relates to the fear of being ‘laughed at’, ‘teased’ or ‘bullied’ when associated (or in a relationship) with someone who has SCZ, and this was a common underlying fear which emerged in many of the SCZ focus groups. While in contrast, some participants felt that the decision depended on how Andile (or a person living with the disease) would treat the sister. If he treats her well and they are happy, then they would not have a problem with it or interfere in the relationship. If however he doesn’t, then they feel they would step in and advise the sister not to marry Andile. One participant related this decision to the chances of having children with the disease.

“I also would not agree at all...since he is ill and my sister is well and you find out that even if he would have a family, he might have children that do not have good health, just like him.” (P.2: FGD 3)

In summary, the evidence above suggests that the views of participants on marriage were strongly related to firstly, thoughts that a mentally ill person would not find someone who is interested in marrying them, secondly, the fear of loss of social status (i.e. being teased, bullied or looked down on) and thirdly, the possibility of having children with the same disease.

RHEUMATIC HEART DISEASE

In the RHD group, males and females presented very different views when it came to their opinions on marriage. Men were concerned with their ability to provide financially for a family. Women were concerned about the risk that pregnancy would impose for their lives. In relation

to the concern raised by men, a stark statement made by one of the participants in the RHD FGD 6 is:

“Who is going to get married to an unemployed man? A man whom when you need sanitary towels he will go and ask from his mother...” (P.1: FGD 6)

Another male participant (P.3) said: *“Andile is in trouble, because when you are a man you need to have a wife. How are you going to be able to practice lobola?”*. Lobola is bride price traditionally paid with cattle in African families, but in the 21st century it is paid with a high monetary value to the bride’s family. The above examples relate to the gender role expectation in African families, where a man is expected to take care of his family, both physically and financially, which was a prevalent theme in both disease group discussions. Instead for women, conversations around marriage linked closely to views on having children. Many women verbalised intense emotions when speaking about their fear of not being able to have children in a marriage. This fear was triggered by the fact that they reported doctors discouraging them from having children as they state that this would compromise both their health as well as the child’s health (i.e. it would be too risky to carry a pregnancy). See:

“Otherwise on his side he can continue dating because he is a man. For us women it can be difficult to date and to get married. We are always reluctant to get married. When you are married you are expected to bear children. While doctors say that it is difficult for us to carry children because of the disease. So you always ask yourself what is the point of getting married if you cannot have children.” (P.3: FGD 5)

In the Xhosa culture, as in many African cultures, women are strongly expected to get pregnant and give birth to a child, hence, many women felt that their potential inability to reproduce could pose a threat to their current or potential future relationships. The fact that one is

diagnosed which may compromise that ability (physically or psychologically) is a challenge which many of the participants have had to negotiate. Not having children has implications for the social status of the couple in their community. In addition to this expectation from society, many women expressed their desire to give love to a child of their own, while also acknowledging that children would be helpful when they needed to send someone to the store close by to purchase small items, like bread for instance. Males did not strongly share this concern as participants observed that male RHD patients can physically continue to reproduce and therefore that is not a reason for them not to get married. This is echoed by one of the participants who said: *“The man can get married. It’s a woman who may have a problem.”* (P.10: FGD 3)

One participant tearfully shared that when she was diagnosed with the disease, she made the decision not to have children. She told her then boyfriend that she does not plan to have children and that if he wants to have children he should leave her and look for someone else. The partner decided to stick with her and they got married and never had children. She acknowledged that it is possible to get married if your spouse understands your situation. Although acknowledging that people may stigmatise her and her husband, she reported that she does not take note of that as it is her health they are most concerned about. Contrastingly, P.1 in FGD 2 explained that her male partner abused and later left her, because she could not have children. By contrast, many of the older women who participated in the FGDs shared that they did manage to have children, and they did not see this as a barrier to getting married.

8.3.3. Having children

There are different views expressed by individuals in the two disease groups, however as discussed in the previous section there is an emphasis on how this ability to have children

affects decisions on aspiring to get married and it may have social implications for a married couple. One implication may be that the status of those two individuals may be tainted or compromised in society. An emphasis on concerns around having children with the disease were also raised by the participants in these groups, which informs the question of genetic attribution and possible stigma in a biological way. With that consideration, the domain of decisions of having children is discussed separately. This is done with the acknowledgement that there may be some repetition between the ensuing paragraphs and the immediately preceding ones.

SCHIZOPHRENIA

Participant responses on the possibility of a patient who has SCZ having children varied. SCZ participants differed in opinions in terms of whether or not (if an individual were to have children) his or her children would inherit the disease. One participant said:

“...they may be like him, like it could get passed down to his children.” (P.4: FGD 6)

While in contrast another participant spoke of the benefit of having children, as he said:

“I say that he could get children, and his children would know that their father has this condition. They would understand the illness and when they are older they could look after him. That’s what I think.” (P.10: FGD 6)

Putting these responses in context however, it is important to remember that most of the participants in the SCZ focus group discussions were male (only 3 females in a total of 36 participants). Therefore, their responses were indicative of a male perspective. For instance,

“I also agree that he could have children, because his sperms still works. As long as his sperm still works, he can have children.” (P.3: FGD)

The above comment about physical ability to reproduce is a similar argument brought forward in the RHD FGDs. When the participants were asked whether knowing the cause of the disease would affect his desire to have children, one participant said:

“Uhm, wanting children is another thing... For example let’s say his children, they could help him after a certain number of years, when he cannot do anything for himself. They could be there for him.” (P.7: FGD 6)

Again this participant reiterates a view which was expressed above, that having children may have some benefit for the patient as children have the potential to take care of the person living with a mental illness in the future.

When asked whether participants think that Andile’s children would have the same disease, again the responses varied. Some participants felt that some of his children may have it, while others said none of his children would have it, but instead it may appear in his grandchildren.

For instance:

“Maybe one of his children may have the disease. If let’s say he has five children, or four children. Maybe one of them could have the disease and inherit it from his father.” (P.10: FGD 6)

Other participants felt that Andile should not even consider having children as his children would be vulnerable to inheriting the disease and it would be irresponsible of him to take that risk.

RHEUMATIC HEART DISEASE

The conversation around bearing children amongst RHD participants (contrary to the SCZ participants, considering the fact that most of the participants in this disease group were females) with RHD was very different. Some participants felt that they are no different to other people, or expressed that they already have children who don't have the disease. However, there is a larger group of women who as mentioned before indicated that they have been discouraged by doctors to have children, as the pregnancy may be too risky for them because of their RHD. While for males (including Andile) it may be different. For instance, one participant shared:

“No. he can have children if he wants to. Take for instance my father when he was affected by the heart disease, he only had two children. He made five more children after his operation. Now he has seven children. So it does not affect his decision to have children.” (P.4: FGD 1)

While another participant (P. 5) supported this view and stated that Andile can have as many children as he wants as long as he can 'produce'. This is similar to the response from one of the participants in the SCZ FGD. That if he can biologically produce children, then there is no reason that a male cannot have children. The concept of masculinity varies in different cultures. For Xhosa people, being a man is characterised by a high level of respect from people in the Xhosa community. A man has a right to marry, inherit land and take responsibility for his family (Vincent, 2008). This participant therefore alludes to this understanding when he explains:

“As a man you would want to know about those things because we are producers. It might affect our manhood if our options are not explained to us.” (P.6: FGD 1)

While many women had different perspectives when it came to women and having children. Some comments are shared below.

“...When I got the heart disease I only had my first born who is now going to university. So what happened was that doctors told me that you can never be able to have children. So I got married and I told my doctors that I am now married. They told me that it’s dangerous to have children in my condition, I might end up dying. Every time you talk about having children they will tell you that it is not right to bear a child in your condition. So I used my gut instinct and just got pregnant.” (P.3: FGD 1)

Participant 3 above mentioned that she had two healthy children following her diagnosis. There was quite a range of views on this issue. Whilst some felt that they would “risk it” and have children despite the advice of doctors who have told them not to. Others stated that they listened to the doctors and either never had any or would not have more children.

8.3.4. Ability to earn an income/work

People diagnosed with the two diseases which we investigated are not always able to find or return to work, even after their symptoms have stabilized. In this instance, in South Africa these individuals are able to apply for a social grant which is a monthly stipend provided by the government to assist with day-to-day needs. This grant is not much – about the equivalent of R1490.00 (USD 121) – but means that individuals can at least contribute to their living costs. Many of the participants in this study were unemployed and in receipt of such a social grant. Whilst these grants are considered helpful in many cases, participants also described feeling negative about the fact that they cannot work for themselves and have to rely on a “handout” from the government or money they receive from family members. The views shared by the participants in the two disease groups are described below.

SCHIZOPHRENIA

The importance of being able to earn an income has already been touched on in some of the themes above. In this section I pay particular attention to how participants feel about (not) having a job and how it affects their overall standard of living. Participants described many reasons that would make it difficult for Andile to find or keep a job. These were to do with symptoms of the condition, side-effects of treatment, or even fears about being judged. See,

“When Andile first got sick at the age of 26, it would be even difficult for him to have courage to look for a job. Firstly, when Andile is filling in an employment form there will be a part that says health status. Andile would be scared to write that he has schizophrenia because no employer would want to employ a person with schizophrenia... his CV would be thrown away because they see that he is mentally disturbed”. (P.1: FGD 2)

Side-effects which included dizziness and tiredness were also observed by the researcher during the focus groups themselves. Two individuals (in two of SCZ FGDs) complained of these side-effects and requested to leave the group discussion in order to take a nap (as their concentration was compromised by the medication they had taken). It is likely that the limited concentration span of some participants with schizophrenia could affect individuals' ability to keep a full-time job. Another participant's view which supported the point that the side-effects of treatment may be a discouraging factor for Andile to find or keep employment is shared below:

“P.9: It could affect him even if he is employed in the sense that the treatment we're taking might not help him perform his duties properly, it might affect him physically and do things to his body.

I: Things like what?

P.9: Things like feeling dizzy...” (P.9: FGD 2)

Some participants however felt that Andile or a person with SCZ could possibly hold a job which requires more manual labour, like cutting grass (i.e. being a gardener) or cutting hair (being a barber). Some aspects which participants felt would be affected when he (Andile) works is his ability to think logically about situations he may encounter. Some participants expressed that the employer may be concerned about whether or not Andile would be able to think logically to solve issues related to his work. Participants also mentioned that Andile may be sensitive at work. He may take experiences personally or take offense when provided with criticism. One other reason is that Andile may not be able to keep a job because he may engage in strange behaviours while at work. These behaviours may compromise his and other’s safety. Others also felt that he may have negative habits like for instance being late for work often, which may also be because of the low motivation they may be feeling. Another factor identified is a question about how the condition may have affected Andile’s ability to obtain professional qualifications. Considering all of these factors, one participant simply concluded: *“His life would be largely affected because he would never be able to work again.”* (P.2: FGD 4)

One participant related his experience where he transitioned from working (before his diagnosis) to not working (after his diagnosis). He described that when he told his employer that he has schizophrenia, he was dismissed from employment. He shared that it was difficult to move from a position of being able to take care of himself financially, to a position of not being able to do so and depending on others.

Some participants acknowledged that they decided to resign from their jobs, because they could feel a change in their ability to think and reason in the workspace. As summarized in Table 2

in Chapter 6, 88.89% of the SCZ participants in this study were unemployed, which seems to validate the suspicion that Andile may not work again. In the vignette, Andile is described as struggling to find employment and living on the social grant he receives. Commenting on those aspects, some participants suggested that it could push Andile into a state of “learned helplessness”, where he expects other people to give him a hand-out, instead of learning or thinking of ways in which he can get money and support himself.

“Andile is someone who gets a government grant. So it is clear that since Andile is getting the government grant, he has not yet had the mind-set that he should go out and work. So in life it will be difficult for him to be able to do things for himself. He will think that he always needs to have someone looking after him. At all times.” (P.7: FGD 6)

One participant (P.10: FGD 6) related this to himself, and shared that although he receives a government grant, he still goes out to the farms in the Western Cape to seek short-term employment to get money to support himself. This is supported by P. 1 (in FGD 2) who stated that the government social grant is not enough to live the life he desires.

RHEUMATIC HEART DISEASE

Similarly, the thought that Andile should not be dependent only on the social grant received from the government is echoed by participants in the RHD sample. One participant proposed that it is not necessary to be employed by an employer. Rather, Andile ought to think creatively about how he can become an entrepreneur and make an income through having his own business. One example given is starting a barbershop, where he could cut people’s hair as a means to have an income. This kind of work would be flexible enough for him to rest if he feels tired, or take a day off if needed without having to explain to an employer. Although this

kind of work was also brought-up in the SCZ FGDs (e.g. being a barber) the idea of becoming an entrepreneur and having one's own business was not mentioned there.

Many participants felt that employers may not be comfortable to hire someone who has RHD because they may feel that the individual would have limitations which would compromise their productivity at work. One participant for example shared that her boss noticed that her feet were swollen when she was at work one day, after which he then asked her to go home and rest. She now fears that if he notices her feet swollen again, the boss will say she should stop the job because her feet regularly swell which affects her ability to walk. Or if a person living with RHD has painful hands they may not be able to do the job they are employed to do. This would affect the company's productivity and the person may be dismissed.

Another participant shared that employers may not want the responsibility of having to take their employees to the doctor if they become ill while they are at work. So allowing someone who has RHD to work for them may be "too much trouble". This may be emphasised by the general high levels of unemployment in South Africa, meaning that employers can easily find other healthy individuals to occupy vacancies. In reflecting on these kinds of challenges, one participant indicated that it may be better for Andile to not work.

For many of the participants in this study, when they conversed about employment, they related it to manual work. Most people who live in the low-income communities (townships or rural villages) have low levels of education and are not professionally trained. Given this reality, participants often end up in jobs which require strenuous labour (e.g. construction work for men and domestic work for women like being a cleaner). These jobs are usually available in the suburban areas and considering the public transport challenges in South Africa (see Chapter

2, on the public transport system challenges in South Africa), individuals usually have to travel long periods (i.e. one to two hours one way) to get to and back from work. This may be why many of these participants expressed that getting a job may be too difficult for Andile, given the fact that he resides in a township (Langa) and given his lack of qualifications. This is why some RHD participants advised that he raises his ambitions and tries to find and access opportunities to further his education, which may assist him in terms of getting a better job in the future. This was emphasised by a participant who said:

“What I can suggest for him is to get himself educated, as that way life would be much easier. He could get an office job. When he gets an office job, he will just sit in his office and not work hard physically. Otherwise, his life will be difficult in terms of getting a job. I wish he could get a grant [a government social grant] or something from the government and continue pursuing his education...” (P.3: FGD 4)

Another participant agreed with the statement above and said that Andile should get educated and obtain a qualification in order for him to get a good job. She explains that if he is not educated, he is more likely to get a job which requires physical strength, like being a brick layer for example, which would be a problem because his body is not fit for that. This may result in him remaining unemployed (much like the over 90% of participants in this study who are unemployed, see Table 2, in Chapter 6). In relation to this example, P.4. (FGD 4) shared her experience of when she had a job at a grocery store. She explained that she worked nightshift and she struggled because the manager did not understand why she was slow or could not do the work properly. In response, she decided to resign from her job because she could not physically keep up working in that environment. She concluded by saying: *“I could not change my situation. A sick person like Andile cannot work in such a working environment.”* (P.4: FGD 4)

Within the RHD group, many participants felt that it was important for Andile to try and get means to further his education as they emphasised that getting a qualification would allow him to get a job that did not require a lot of physical strength.

8.4. Coping Strategies

Coping strategies could mitigate experiences of stigma. Effective strategies could also have a positive influence on the life of the patient. Participants in this study described a range of strategies that helped them cope with their condition, including: social support; acceptance, openness and transparency; having a sense of purpose; and health knowledge. These strategies are discussed below.

8.4.1. Social support

SCHIZOPHRENIA

Social support can be described as the support of family, friends and others around the individual. For the SCZ participants, friends were viewed as less important figures in their lives. Although opinions about having friends varied, most people felt that friends would abuse or manipulate a person with SCZ, therefore they were to be protected from such persons. For instance,

“People may start using him, like friends... They may see him as dumb and useless. And some of his old friends may not understand him anymore.” (P.7: FGD 1)

Many other participants had similar views about having friends as a mentally ill person. For example,

“So I think that Andile yey, Andile yey, he may be fine if he lives under his mother’s guidance [family support]. Ja, and he should forget about friends. Because friends yey,

they may always be disturbing him or calling him by names he may not like... Ja. Or let's say that Andile wants to do something, and then his friends prevent him from doing the thing he wants to do because they undermine him simply because he is mentally ill. And it's true my sister yey, when you are a mentally ill person living in the township, they like to undermine you when it comes to a lot of things. (P.1: FGD 6)

This was evident in a comment made by one of the participants where they expressed feelings of undermining Andile because of his disease, even though they have the same diagnosis.

"I could be friends with him, but I couldn't for instance, uhm be in contact with him every day. I could end up getting hurt as his friend. I can sit with him, but not every time. And the thing is I am young, and he is also young. But to me if I experience certain things I can handle them well, however for him because he has a disability, he will struggle to handle those things. Also he can't be free out there, yet I can go out and do things that young people do. He is basically like an old person, he cannot do the things young people like to do. So in that way, I cannot be his friend. (P.7: FGD 1)

This can be considered as a form of discrimination expressed by someone who also has a mental illness and is likely to have been exposed to such stigma, similar to the stigma power concept described by Phelan and Link (2015). On the other side, there were also a few participants who felt that friends may also provide support and encouragement to a mentally ill person. See,

"It is important to have friends because it is where you will seek assistance sometimes you see... there are some friends who will offer you help." (P.4: FGD 5)

Both these opinions feed into the ways in which different people cope and think about the disease. These participants seem to consider family as the most important source of support

for a person living with SCZ. Participants expressed that they would expect family members to play a huge role in supporting them in all avenues of their lives, from financial support, encouragement to take treatment, and to protect them from insults of people in the community. For instance one participant in the FGDs said:

“I think that the family may change, in the sense that they would try and become closer to him and kinder to him as well. I think also the fact that he did not do it to himself, for example through the use of drugs. His family may then support him.” (P.7: FGD 1)

This participant touches on an underlying theme in the discussions: the causation of the disease and how that influences a person’s experience of stigma. This is further elaborated in the next chapter. However, for the purposes of this section the above participant says that his [Andile’s] family would support him if he did not do it (the disease) to himself. Some participants mentioned that they think abusing substances (which can be considered as an individual’s choice to do so) can be one of the causes of the onset of the disease. Thus, if an individual did not participate in this behaviour, or they did however they learn that the disease is linked to genetic causes, this removes some of the blame from the individual and in that instance the family is more likely to be supportive.

Two other participants alluded to the fact that some of the blame may be shifted from him to the family because of the genetic relation. They commented that this may change the way in which the family relates to a person with SCZ (i.e. they could be more sympathetic and ‘kinder’) simply because they believe the cause of the disease is not attributed to his behaviour.

“It may change it, because it is maybe something that is passed down in the family.”
(P.10: FGD 1)

“It may change because it is known that someone in the family has had the disease before. And knowing that he knows that he is not the first one to get it.” (P.8: FGD 1)

These quotes may contribute to alleviating the blame posed towards the patient with the disease, however it may shift the blame to other family members.

Contrastingly, P.3 in FGD 2 disagreed and said: *“I would say that knowing the cause of your disease is not helped by blaming others in your family.”* Instead this participant went on to express the value of accepting one’s disease. This acceptance is further elaborated on in the next theme.

RHEUMATIC HEART DISEASE

Contrary to the SCZ group, RHD participants placed great value on having friends as a source of support. Most of these participants felt that friends would not look down on a person with RHD, instead if they are well informed about the condition, they may be equipped to provide support. One participant described,

“As far as my understanding goes, my friends never looked down on me. Some of them have passed on now, but they used to treat me normally. If one has true friends, then they will not look down on you. They will always be the ones to comfort him [Andile] and uplift him. If they care about him they will treat him normally. They will give him the support he needs so that he does not feel isolated. ... Friends must always show love and support towards you. You must be free and happy when you are around them.”

(P.6: FGD 1)

Many other participants echoed the same feeling about having friends for support. Participants especially said that it would be important for someone with RHD to have friends with the same illness, as they would then have the space to share their experiences of living with the disease. They would also have an opportunity to share their different coping strategies for living with the disease.

Although a majority of people felt that it would be helpful to have friends, there were a few participants who expressed that friends may look down on a person diagnosed with RHD.

“They can look down on Andile when he tells them about his condition. Especially if they are not fully informed about the disease and how it came about...” (P.3: FGD 1)

Hence, similar to the SCZ participants, these respondents also highlighted the importance of family support. In fact participants stressed that when one is diagnosed with RHD it is expected and common that their family change the way in which they relate to that person by showing a greater sense of support and encouragement. *“Yes... They also need to support him more.”* (P.3: FGD 4)

In agreement with the above, one participant shared how her family shows their support for her.

“Support is really needed from the family when you have a heart disease. Sometimes you feel tired and do not feel like doing anything. Especially for me after the operation, I often feel tired. When I feel tired I just do not want to do anything. My mother just says I must go and rest if I do not feel like doing anything.” (P.4: FGD 1)

“...getting care from other people like your family can help put him at ease with his disease. Feeling cared for, will make him feel better... Even his extended family can get involved, like for example by taking Andile out for dinner some nights at their homes. This will help him feel loved and cared for and at a later stage he will make the decision to live a full life. He must be around positive people.” (P.1: FGD 4)

8.4.2. Acceptance, openness and transparency

SCHIZOPHRENIA

Across the SCZ FGDs the acceptance of the illness was brought up frequently by participants. For instance one participant shared that he had trouble accepting his disease.

“Another problem we face is that most people who have schizophrenia face a challenge of not being able to accept their condition for the first few years. For example I also had difficulty accepting it myself... What I’m trying to say is you find it hard to accept it.” (P.3: FGD 2)

While another participant said:

“...he needs to accept his condition. He needs to acknowledge that he is not well. He has schizophrenia.” (P.6: FGD 4)

“I think that Andile would be fine. What I can suggest for him is that he must talk about his condition from the word go...” (P.5: FGD 5)

Despite it being challenging for some people, many participants suggested that if one fully accepts their illness they are able to be open and share it with other people which results in

people being more understanding. Acceptance and openness were important subthemes as they were often related to participants receiving support from different sources. However, secrecy about their disease was seen as a contributing factor to fuelling the assumptions people in their community made about their disease. Although there were a few participants who felt that it was not necessary to tell people about their diagnosis, a large majority of the group felt that it is important to be open and transparent about their illness. For instance, in response to a participant's comment about not telling people about their illness, one participant said:

“You see, this illness, you do not have to hide it. There are lots of illnesses out there, and illnesses are not meant to be secrets. No matter what kind of illness you might happen to have, an illness is not something that is meant to be hidden.” (P.6: FGD 5)

Furthermore, some participants expressed that if you are open and transparent about your disease, it allows people an opportunity to understand your illness which could mean that they become more supportive.

“So for example they would have a better idea of whether they need to encourage him [Andile] to collect his medication at the clinic if he cannot do that, for example. Also if he has a job, they can be supportive and come up with ideas on how he can manage his condition. That could change the way they relate to him in a positive way you see. Especially if they know that it is not by choice that he has the mental illness. If they do research about it and find out the causes of the illness, that it is caused by circumstances you grew up under and so forth. For example if you have stopped taking the drugs, you are just like other normal people. If they look at you as a normal person, then at least that reduces the stigma. I mean, you could also reduce the stigma by telling yourself ‘ag I am going to live with this illness’.” (P.1: FGD 4)

Like many other participants, P. 1 above suggests that acceptance is an important step in dealing with one's illness. This is contrary to another coping mechanism which participants also mentioned, which involves isolating oneself from people and their natural environment. This is expressed in the dialogue below.

"P.3. Oh! Andile stays in Langa?"

I. Yes.

P.3. Does he not have any other place which he can relocate to maybe, so he can be able to fix himself for a while? Like maybe in the Eastern Cape or to his family relatives?"

I. So do you think... let us talk about that, so do you think other people do what you are saying, they leave their homes and maybe relocate to the Eastern Cape for instance?"

P. 3. Yes, maybe he can heal in the Eastern Cape, maybe this place where he is, it is not good for him. Another place could be better for him, he could come back well and having gained a little bit of weight." (FGD 5)

This was supported by a personal experience of another participant who said that he had taken some time and temporarily moved to the Eastern Cape (which is a less urbanised province in South Africa where the majority of Xhosa people in the country are originally from, see Chapter 2, page 45 for more details on the origins of Xhosa people) during the course of his illness. He explains that being in a rural, calmer environment (as opposed to life in the urban areas) helped him get better. SCZ participants who were interviewed in the Eastern Cape also suggested that even if you are in the Eastern Cape, moving to a very rural village or another village than the one a person is originally from (i.e. different environment) may help a person with SCZ. See,

"Another thing I think that can change his [Andile's] life is a change of environment. Moving from where he is to a new environment with new people and starting a new life.

If he can get a quiet place which will allow him time to deal with his sickness, that would be good. Moving from one place to another has helped me a lot. Not that there was a problem where I lived before, just that the change of environment helped me a lot and that could help him too.” (P.5: FGD 2)

“I fully support what P.5 is saying, that change of environment makes the sickness better. For example moving from the township to the villages.” (P.3: FGD 2)

To the contrary, some people felt that changing environment symbolised “running away” from reality, and they felt that leaving their natural environments and going to another space would not help them. For example,

“The thing is, you cannot run away. One cannot run away from his or her life. You must accept what you are facing at a particular time... Running away will not help you. This place that you are running away to is the same as the one you are running from. There will be no difference.” (P.10: FGD 5)

In relation to acceptance, participants often mentioned that a source which may help them accept their condition is their religious beliefs, mentioning their faith in God or Allah. There were countless examples where participants expressed that a mentally ill person should go to church, and that they should put their faith in God.

“That all depends on God, the creator...It is the Creator who knows, you will never know.” (P.1: FGD 3)

When referring to Andile, one participant said:

“They don’t know that God still loves Andile, and can support Andile to at least improve in the things he does in life.” (P.1: FGD 6)

Although it was not mentioned in the video clip which participants assumed Andile was a Christian. Some said that he should go to church as that will help him. This suggests the importance placed on religion amongst these participants. The importance of going to church and keeping faith was discussed in four out of the six SCZ focus groups.

“For example, me I am a church going person, so if I am attending church during the day, that keeps me busy. So Andile should also try something that will keep his mind busy.” (P.5: FGD 5)

Many other participants across the SCZ FGDs insisted that Andile (or a person living with SCZ) should go to the church. Going to one of these places was viewed as having the potential to assist an individual to accept and cope with the disease. The value of accepting and believing in God’s will was viewed as very important amongst participants with SCZ. It also allowed participants to have hope for a better future. There were many examples of participants expressing the value of religion and how praying and having faith can assist one in accepting their illness.

RHEUMATIC HEART DISEASE

A majority of the RHD participants also emphasised the importance of accepting one’s illness. These participants made particular reference to the fact that acceptance is the best strategy to ensure that one lives a peaceful life with minimal stress and sleepless nights.

“You must accept whatever negative thing that you are experiencing. That is why you do not sleep. That is what happens to me, when I am experiencing a negative thing, it

will not affect me immediately but it will bother me at night. It stays on my mind and that is why I cannot sleep. I will just sleep five minutes then I am awake.” (P.6: FGD 1)

“You need to accept the situation that God has put you in.” (P.3: FGD 3)

Similar to the SCZ participants, religious beliefs were an important source of support for these participants. Like above, there were many inferences where participants mentioned putting their faith in God or Allah and that God or Allah would not forsake them. When referring to Andile, one participant said, *“He must pray to God”* (P.3: FGD 4), while another participant said: *“...it would depend on God.”* (P.1: FGD 5).

Some participants in this group also felt it is important to be transparent about the illness. For example,

“I think Andile is just like other people. The fact that he has RHD does not change him, or anything about him. It’s all about the way he shares that information with people and that will depend on how he accepts his condition first.” (P.1: FGD 3)

Similar to the SCZ participants, these participants felt that the way in which the individual views themselves is the way in which other people will see and treat them. Hence it is important to behave the way you would like others to treat you. For example, if he does not think less of himself, then others would not treat him as inferior to them. Similarly, if one allows people in their family to constantly treat them as though they are ill, weak and unable to participate in family decisions, then that is how people will come to see them. It is up to them to inform their family members that they want to be involved in decision making and they want to be informed about things that are happening in the family.

“...because he has a heart disease they may feel that he should not be told any bad news. Or if it comes to making decisions. Some people in his family may feel that they need to make decisions for him just because he has a heart condition and they think he cannot be told anything. Which will then make it his responsibility to always tell them that, ‘listen, even if there is bad news, don’t hide it from me because I have RHD, treat me as you do other people’. So Andile’s life might be affected by other people treating him differently because of his condition... Yes, and because other people do not understand him.” (P.9: FGD 3)

8.4.3. Sense of purpose

SCHIZOPHRENIA

Another strategy for coping with the condition, which was suggested by participants in the groups, is through developing a sense of purpose and having the will-power to proceed with life. For instance, many participants emphasised the fact that as a mentally ill person, it is important to keep busy and to do things which will involve getting out of the house and engaging with other people. For example,

“P.5: It would be good that he even attends one of these educational institutions that are meant for people with mental disorders.

I: You would send him to the educational institutions?

P.5: Yes, for people with mental disorders, they would be there together and meet-up with him and they would study with him.” (P.5: FGD 3)

Participants 1 and 2 in FGD 3 mentioned that another way to keep busy is to join an exercise group in the community (a group playing soccer for example), again alluding to the importance of meeting and surrounding oneself with other people. Additionally, participant 3 in FGD 3

suggested that Andile invests time in playing video games to keep him busy throughout the day. In particular, the participant called it a way to ‘kill time’ (P.3: FGD 3).

Some participants had faith in Andile’s life and reiterated that one should not ‘give-up’ on their lives no matter what their condition. For example, one participant said:

“I think, well, like I had said before, I think that even if Andile is sick, he should not give-up on himself. He should try and find jobs if possible, so that he can sustain himself.” (P.5: FGD 6)

So, having will-power and the confidence to go out and engage with other people was highlighted as an important coping strategy. That being said, the many examples mentioned earlier in the chapter about people looking down on a person with a mental disorder, or seeing them as inferior may make this process that much more difficult. For example, one patient said:

“Your confidence goes down when you know that you are ill. Even if you learn to cope, but your confidence is no longer on the level it was on before you were diagnosed with this disease.” (P.10: FGD 4)

But whilst other respondents acknowledged that the level of confidence one has in themselves does decrease, they still reiterated that it is important to look beyond that and try to find a sense of will-power in order to continue living in a reasonable manner.

RHEUMATIC HEART DISEASE

RHD participants also felt that Andile has the potential of gaining a sense of purpose and living a fulfilled life. Something touched on but not fully elaborated in the SCZ FGDs was the hope that Andile has to create a better future for himself, through for instance getting a job that will

allow him to better his living conditions. One way of doing that mentioned by the RHD participants is through Andile taking action and becoming serious about furthering his studies, as a way to ensure a better future for himself and his mother. They expressed that he has the potential to obtain a degree and practice in a profession of his choice. For instance,

“He can also further his studies and be what he wants to be. I have a doctor I met in the Eastern Cape who also has a heart disease but he is a doctor today.” (P.2: FGD 1)

In agreement another participant in the FGD said:

“Andile can continue to pursue his dreams. He would also need good support from his parents and everyone around him. His life does not have to stop because he has a heart condition.” (P.5: FGD 1)

The perception that someone with RHD can continue to pursue their dreams was highly supported by respondents in these FGDs. Many people felt that this diagnosis should not be a cause to give up on pursuing one’s dreams. However, they acknowledged that living in a poverty stricken environment can be a barrier towards achieving those dreams.

8.4.4. Health knowledge

SCHIZOPHRENIA

As discussed above, being open about the illness and in the process educating other people was emphasised as an important strategy to cope with the disease. One participant explicitly said,

“...since our friends in the townships are not educated about this sickness, it would be nice if the nurses would take time out and educate the community and talk about the sickness and how these people should be treated... So it would be nice if nurses would go and educate the community on how to treat mentally ill people.” (P.1: FGD 2)

Participants provided numerous examples about how people in their community do not understand mentally ill people. For instance,

“...Some of his old friends may not understand him anymore.” (P.7: FGD 1)

“People don’t understand you.” (P.1: FGD 2)

While another participant said,

“No, maybe if they thought that he is a drug addict but they find out that it is caused by heredity, they will treat him differently, because they now understand that it is not drugs that caused his illness” (P.3: FGD 5)

These extracts demonstrate how participants expressed the lack of understanding about mental illness amongst people in their community. The participants in this study themselves had to travel vast distances to access services, like for example the psychiatric hospitals they attend to access treatment and psychiatric consultations. As reported by them, this kind of service is not available in their community, hence their community members are not exposed to knowledge of mental health. In addition, the psychiatric nurses and doctors in the hospitals they attend are often not Xhosa-speaking (but rather English speaking) and therefore the participants expressed that they do not usually have an opportunity to engage with people and gain knowledge about their disease in their mother-tongue. These elements presented as barriers towards creating a space for mental health knowledge in the township or rural communities that these participants are from.

RHEUMATIC HEART DISEASE

Similar to the SCZ participants, RHD participants also highlighted the importance of informing other people about their illness as a means of educating them about the condition. Many of the participants felt that people in their communities are ill-informed about the nature of their condition and therefore it is their responsibility to inform them in order to avoid misunderstandings and people making judgements. For instance,

“They can look down on Andile when he tells them about his problem. Especially if they are not fully informed about the disease and how it came about. They would not take it seriously. So he is the only one who can explain it better to them so they can understand him.” (P.3: FGD 1)

While another participant said,

“You must always explain to people. When I am sitting with friends usually they say I am sitting with a watch. I always tell them that there’s no watch. I explain to them that it is a heart valve that have inserted in me because mine has stopped working. I always make them understand.” (P.6: FGD 1)

In relation to educating people about the illness they are living with, many participants shared similar sentiments as the ones expressed by people in the SCZ FGDs. The above mentioned coping strategies were highlighted as important to enhance resilience for living with their disease, and participants expressed that they played a helpful role in how they manage the disease and the stigma which is a result of their disease.

8.5. Chapter summary

This chapter has presented the findings which emerged in the focus group discussions with people living with SCZ and people living with RHD. The chapter has highlighted the recurring

themes which relate to the knowledge participants have about their disease, their opinions on existing stigma experiences related to the two diseases as well as the coping mechanisms they employ to deal with the disease they are living with. From these findings it is clear that these participants have experienced stigma in different ways. As anticipated and supported by the literature the SCZ group reported greater experiences of stigma. While it was not known whether the RHD group would report any stigma experiences, our results show that this group does report experiencing some milder forms of stigma because of their disease. The chapter detailed features of stigma relating to: a) *family, friends and community*; b) *marriage*; c) *having children*; d) *ability to earn an income/work*. Furthermore, it discussed the coping strategies employed by people with RHD and SCZ to overcome stigma, including: a) *social support*; b) *acceptance, openness and transparency*; c) *sense of purpose* and; d) *health knowledge*. In the next results chapter we provide another exploration of internalised stigma experiences guided by insights from translating the internalised stigma scale into isiXhosa.

CHAPTER 9: INTERNALISED STIGMA SCALE

9.1. Introduction

During the 19th and 20th century, ideas and conceptualisations about disease were consolidated in North American and European contexts (Mkhize, 2003). These developments led to a creation of an international system of diagnosis. Importantly, those involved in developing such classifications believed that they could be applied cross-culturally (Mkhize, 2003), without thoroughly considering the differences in the ways in which diseases manifest across cultures (Draguns & Tanaka-Matsumi, 2001).

From as early as 1904, the field of cultural comparison in the context of psychiatry was initiated by Emile Kraepelin, in an attempt to investigate the dementia praecox (the original term for schizophrenia) in Java, which later progressed to comparisons among Native Americans, African Americans and Latin Americans (Heaton, 2013; Jikek, 1995). In the 1960's and 70's the International Pilot Study of Schizophrenia (IPSS) was formulated (Satorius, Shapiro & Jabalensky, 1974), which involved testing whether effective criteria for schizophrenia cross-culturally could be determined by investigating the disease across nine different catchment areas globally (including Ibadan, Nigeria for the African context), these investigations all utilised a research instrument, which was developed following a Euro-American context. While there have been progressive results of these investigations the question still arises whether it is possible that a disease (whilst presenting with similar symptoms across different contexts) is understood in the same way by people of different contexts (Heaton, 2013). Heaton (2013) discusses the developments of transcultural psychiatry and the 'new cross-cultural psychiatry' during 1980s. He highlights the implications of considering a universal human psyche as a point of departure for mental health theorists. Since then, the field has largely evolved and

progressed in North American and European contexts. Scholars such as Patel and Prince (2010) report that there are core common symptoms of mental health globally. In the same breath, it is equally important to consider that presentations of mental illness differ in different contexts (Desjarlais, Eisenberg, Good, Kleinman, 1995; Swartz, 2014). While there is some literature on mental ill health in African contexts (Adewuya & Makanjuola, 2005; Adewuya & Oguntade, 2007; Patel, 1995; Seedat et al., 2002), most of the currently available psychiatric (and health) measures used in research were originally developed for North American and European contexts, in which a dominant biomedical explanatory model for illness is generally applied (Mkhize, 2003). Kohrt et al (2014) raised important questions about the appropriateness of the use of biomedically oriented measures of disease cross-culturally. This is an important question, however it is equally important to consider that some constructs may be universally relevant, others may be unique to the cultural or disease groups. Applying a measure like the Internalised Stigma of Mental illness scale can highlight the similarities and differences.

In 1977, Kleinman critiqued the simple translation and application of such instruments developed in European contexts to non-European cultural groups. In 2014 however, Yang and colleagues conducted a systematic review investigating the advances in cross-cultural measurement of culture-specific stigma. These authors found that 77% out of the 196 articles included in their study utilised adapted stigma-measures which were originally developed in Western-European contexts (Yang et al., 2014). Being one of the first scholars to contribute to highlighting the significance of cross-cultural psychiatry, Kleinman (1977) emphasised the need to give greater attention to the nuances of culture in this process. Hence, he contributed to the introduction of the 'new cross-cultural psychiatry'. 'New cross-cultural psychiatry is

centred on the belief that it is problematic to solely import psychiatric instruments (largely developed in Western countries) without considering cultural differences of the intended context. This supports Draguns and Tanaka-Matsumi's (2001) conclusion that culture and psychopathology ought to be studied in consideration of the individual's personal experiences of the disease. Following a large body of literature conducted under cross-cultural psychiatry there was an initiation of the Global Mental Health (GMH) Movement (Patel & Prince, 2010). The GMH movement has a specific goal of improving the lives of all individuals with mental ill health (Patel & Prince, 2010). Kirmayer and Swartz (2013) describe that there are many reasons why cultural factors should be a central concern to global mental health. For researchers in particular, these scholars articulate that culture is critical for clarifying the role which social and cultural factors have in illness and treatment. For clinicians they highlight that it is important for interpreting symptoms and informing appropriate interventions (Kirmayer & Swartz, 2013).

The WHO has provided evidence on lack of treatment for most people with diseases in low and middle income countries (WHO, 2011). Exploring the inequality in representation of different population groups in health research is of importance to all health researchers, practitioners and the broader society. Given that language barriers are considered as one reason for a lack of involvement of specific population groups in health research, the option of translating measures is often utilised by researchers (Yang et al., 2014). Simple translation of instruments however can produce misleading results (Kaiser, Kohrt, Keys, Khoury & Brewster, 2013). The GMH movement has taken great strides in developing new methodologies for adapting tools to be appropriate for use in local settings (Braathen, Vergunst, Mji, Mannan & Swartz, 2013).

The WHO has encouraged the development of global psychiatric measures, as well as guidelines for their adaptation and translation across different contexts (Sartorius & Janca, 1996). However, translating health measures well is a laborious task which, when done thoroughly, utilises considerable resources and time (Steele & Edwards, 2008) leading some critics to question whether it is worth the effort. For instance, Keiser et al. (2013) translated the Beck Depression Inventory and the Beck Anxiety Inventory – for use among Kreyól-speaking individuals in Haiti and in the end found some items in the scales were non-equivalent due to a lack of specificity, interpersonal interpretation or conceptual non-equivalent. As evident from the literature (Smit et al., 2006; Yang et al., 2014), translating a measure investigating a construct developed in one context (i.e. a European context) to a distinctly different context (i.e. an African context) is very challenging and may not produce as accurate description of concepts relevant to the target population's realities (Keiser et al., 2013). Hence, scholars from the Global Mental Health movement propose a local, emic approach to develop measures which are locally relevant and largely guided by qualitative methods.

We sought in this study to find a way of quantifying the internalised stigma experiences of Xhosa people with SCZ and RHD. One approach would be to draw from a global mental health perspective guided by qualitative methods to develop a local internalised stigma measure specific to our target populations. The advantages of this include having a culturally relevant scale which is locally valid and comprehensible, however disadvantages include extensive time, effort and costs involved in developing a new measure. Furthermore, another disadvantage is that the resultant measure would not be comparable with data from other settings. A second approach was a more traditional translation design that sought to adapt an already well-researched and established internalised stigma scale. The advantages of this approach included less need for extensive resources, the possibility of comparisons with other

international samples within the same disease groups (for example the extensive research conducted globally on internalised stigma experienced by patients with schizophrenia), however disadvantages included the possibility of missing local conceptualisations of stigma and internalised stigma experiences for the two disease groups. Moreover, another important disadvantage may be the challenge of adapting a scale for mental health for use among people with a physical disease (i.e. rheumatic heart disease) as it would likely exclude internalised stigma experiences unique to those patients. Considering our budget, the fact that this quantitative data would be adding to additional qualitative data generated from FGDs on internalised stigma experiences, and engagement with the original ISMI scale developer who explained that the scale had been translated and adapted for use among many psychological and physical diseases / conditions we decided on the more traditional translation approach.

There are at least two additional reasons why we embarked on the translation process of the ISMI scale. First, the absence of a psychological resources measuring internalised stigma for African language speaking South Africans meant that contributions to the development of meaningful internalised stigma measures would be a valuable contribution to the field. Second, the acknowledgement that many Xhosa-speakers have limited knowledge of the English language (Steele and Edwards, 2008), which is the source language of the ISMI tool, and simply applying this tool in English to our participant population groups would not necessarily give us real insight into their unique understanding of internalised stigma. This study's translation design and findings therefore provide valuable insights for future researchers conducting genomics and stigma research, and particularly those adapting standardised tools developed in western contexts for use among African population groups.

We opted for a comprehensive translation design that generated data about how the construct of internalised stigma was supported in the Xhosa language in terms of psychometric properties, and the relevance of internalised stigma items with each of our Xhosa patient disease groups. This information provided a foundation for future development of internalised stigma scales for Xhosa people with SCZ and specifically RHD.

A number of challenges occurred during the translation process which suggested that the scores of the scales had some limitations. These limitations led to an inability to compare internalised stigma scores across the RHD and SCZ samples. Recognising these limitations we chose not to use the scale in collecting data during the focus group discussions. Instead in this chapter we discuss the translation process, piloting of the translated tools and the frequency of endorsements of items to understand the relevance of these stigma experiences in each of these disease groups.

Importantly, in this chapter we focus on sharing the insights gained through this process in relation to how the concept of stigma is understood in the Xhosa language. This is important particularly in the context of this study which is centred on the concerns raised regarding the increase in genomics research with African population groups. As mentioned before these population groups have not frequently been included in genomics research. Even where they have, the research is often conducted by English speaking researchers, either by collecting data in English or through the use of an interpreter (Solomon et al., 2008), however, Drennan and Swartz (1996; 2002) identify some of the challenges of using interpreters in research. The translation design process followed in this study, which was led by the researcher who is first-language isiXhosa speaker may provide valuable insights for future researchers developing or translating standardised instruments for use among South African population groups.

9.2. Approaches to understanding culture and health

Measuring disorders with standardised tools across different contexts is controversial (Smit et al., 2006). There are different perspectives (Relativist vs Universalist) in global debates in consideration of language, culture and translation of health measures (de Jong & Ommeren, 2002; Smit et al., 2006; Swartz, 1998; Swartz, 2012). The universalist/empiricist approach maintains that language refers to things and serves the purpose of articulating a 'reality out there'. Thus different languages have different sets of labels for realities which are common across the world (Smit et al., 2006; Swartz, 1998). This approach is centred in biomedical science and focusses on labelling of symptoms or experiences. The approach brings forth multiple discrepancies between universal science and experiences of individuals in local communities (de Jong & Ommeren, 2002). Translation of instruments according to this approach is often increasingly difficult as it is about finding applicable labels in two languages which are referring to the same thing, despite coming from completely different historical, social and cultural contexts (de Jong & Ommeren, 2002; Swartz, 1998). Researchers such as Brislin (1980) and Hambleton, Merenda and Spielberger (2004) have commented on the frustration of attempting to translate instruments from one language to another. As Steele and Edwards (2008) maintain, unfortunately translation of tools is not just about finding equivalent words in a dictionary, since words often gain meaning from their context and cultural background of the language.

The relativist perspective puts an emphasis on culture and language, by recognising that they are so intertwined that it is difficult to differentiate between the two. Language plays an integral role in the construction of meaning (Swartz, 1998). This position maintains that social construction plays a critical role in terminology used by individuals to describe disorders. Language plays an integral role in the construction of their meaning making (Swartz, 1998).

Therefore, thoughts, feelings and emotions are governed by the words we use and the vocabulary and sentence structure available in our language (Swartz, 1998). This alludes to the perception that we evaluate 'reality' through the words we use. Thus people living with a disease, from a particular cultural group somewhat create their own language for talking about and understanding their illness, hence it is important for researchers and clinicians to comprehend and acknowledge their perspectives. This approach argues that translating tools across different languages is a complex process and not solely about finding appropriate words to use in the target language. Both perspectives have their implications and there have been many debates regarding which is most useful (Swartz, 2012). One of the main reasons the universalist approach is still often applied (Yang et al., 2014) is that it can access large samples of people and results can be compared with other contexts, yet studies employing a relativist perspective generally enrol smaller samples and generally can not be compared across contexts.

The hermeneutic/ constructionist approach maintains that translation is a complicated process as it does not only involve changing labels for things in the world, but also considers the role language plays in influencing emotions (Swartz, 1998). For instance, while the English language is comprised of a large variety of emotive descriptions, there is evidence that the Xhosa language has far less emotive terminology, but rather tends to draw on a broader range of somatic descriptions of illness (Campbell & Young, 2016; Steele & Edwards, 2008; Swartz, 1998). This has an influence on the linguistic translation process and the way in which individual questionnaire items are then understood across language versions of a psychometric tool. Which is why many scholars (Adewuya et al., 2011; de Jong & Ommeren 2002, Lock, 1987, Kleinman, 1997, Swartz & Drennan, 2000) emphasise that translated instruments do not necessarily measure one reality, but rather a cultural understanding of illness (typically biomedical) that is context specific. With this in mind we understood that translating the

Internalised Stigma of Mental Illness Scale into Xhosa would provide insights into how the construct of internalised stigma, as conceptualised in the ISMI, was supported in the Xhosa language. This was demonstrated through the psychometric properties of the resultant internalised stigma scales, and the relevance of the ISMI questionnaire items for Xhosa people with SCZ and RHD as evident from their endorsements of these items.

9.3. Internalised stigma and disease

As discussed in greater depth in chapter 4 of this thesis, Corrigan (1998) defines internalised or self-stigma as involving an individual devaluing themselves, experiencing marginalisation, living in secrecy, shame and intentional social withdrawal. Some of the effects of internalised stigma include hopelessness, low self-esteem, disrupted social adaptation, and often results in reduced adherence to medication (Link & Phelan, 2001; Livingston & Boyd, 2010). Considering that internalised stigma impacts on how patients live with their illness and their attitudes towards help-seeking and adherence to medication (which has implications for their recovery), this study sought to understand how causal explanations, specifically interested in how a genetic explanation to disease may relate to internalised stigma of SCZ and RHD.

To date few studies have provided empirical data on the internalised stigma experiences in African populations. Those who have include: Assefa, Shibre, Asher, & Fekadu, (2012) in an Ethiopian population of outpatients with SCZ; Adewuya et al. (2011) in outpatients with mental illness in Nigeria and; Botha et al. (2006) in schizophrenia patients in South Africa. These authors all report degrees of internalised stigma in their participant groups. As a result, a quantitative indication of internalised stigma experiences in the Xhosa people with the two diseases enrolled in this study, is helpful for informing the second research question of this

study (*What are the internalised stigma experiences of Xhosa people with schizophrenia and rheumatic heart disease?*).

Given that there is strong evidence that internalised stigma is associated with a range of negative outcomes (Corrigan, 1998; Livingston & Boyd, 2010), the lack of conceptual clarity on how different cultural groups understand the concept of internalised stigma is concerning. In the South African context, in particular, there is currently no standardised tool developed to measure internalised/self-stigma for non-English speaking population groups. Botha et al. (2006) utilised an English version of the ISMI tool across three home language groups, namely: English (n= 17), Afrikaans (n= 77) and isiXhosa (n= 6). The authors did not disclose whether and how they translated this scale. Interestingly, 34 participants in their study (more than 50% of the sample) reported to not have completed primary school. In the UK, Corker, Brown and Henderson (2015) conducted a study using the original ISMI scale and an adapted version of the ISMI for rheumatoid arthritis (RA) (in which case the only adaptation they made to the scale for use with a RA group was to change the term mental illness to rheumatoid arthritis - they called it the ISMI-Rheumatoid Arthritis scale) to compare levels of internalised stigma in patients with a mental illness and physical disease (RA). Overall the authors found that the patients with a mental illness had higher levels of internalised stigma (2.5 vs. 2.2, $p < .01$) (Corker et al., 2015). In India, Stevelink, van Brakel and Augustine (2011) adapted the ISMI scale for use among people with HIV and people with Leprosy (an infectious curable physical disease). These authors created two versions of the tool and again made only one adaptation to the scale for use with the HIV and Leprosy groups: replacing the term mental illness with HIV and Leprosy. The mean scores on the ISMI for the two disease groups was 2.3 for people with HIV and 2.2 for people with Leprosy ($p = 0.056$) which is above the midpoint of 2 set by the scale developer (Ritcher et al., 2003; Stevelink et al., 2011). In relation to RHD, Chang et al.

(2018), who used a set questionnaire they developed to investigate the impact of stigma among Ugandan women with RHD, found that RHD related stigma was comparative to HIV stigma in their context. These authors however did not disclose where and how they acquired the questionnaire they used in their study. Additionally, they did not disclose the translation process they followed as their questionnaire was also translated into Luganda (a local language in Kampala, Uganda) (Chang et al., 2018).

What seems apparent from these studies above is that the extremely influential role of internalise stigma scale preparation, translation and adaptation for use across languages and disease groups is not well recognised, nor does it seem to feature in the interpretation of results quantifying internalised stigma experiences. Currently, there is no known standardised Xhosa scale measuring internalised stigma. UK researchers Brohan et al (2013) who developed the Discrimination and Stigma scale for mental illness, have recommended additional work to be done to develop relevant stigma measures. Additionally, both in the African context and globally, there is no known standardised scale measuring stigma among patients who have heart disease.

Scholars such as Campbell & Young (2016), Drennan, Levett and Swartz (1991), Steele and Edwards (2008), Smit, van der Berg, Bekker, Seedat and Stein (2006) identify the lack of psychiatric instruments available for use by people who speak African languages such as isiXhosa as a concerning matter in the South African context. This is especially concerning, when considering that the Xhosa people account for the second largest population group in the country, 16%, while isiZulu (which is similar to isiXhosa) accounts for 22% of the population. These two languages are followed by 13.5% of the population who are first language Afrikaans speakers and 9.6% who are first language English speakers

(<https://www.brandsouthafrica.com/people-culture/culture/languages-of-south-africa>).

Considering these percentages, it is disturbing to note that most standardised health tools available in South Africa are in English and Afrikaans, which means that available tools are not adequate for use by large parts of the South African population which serves as a barrier for a large proportion of the South African population from utilising health tools in their mother tongue. It is important that we address this gap, but do so in a manner that recognises the limitations of a translation approach, and interpret findings from scales produced through translation designs within the context of these limitations.

9.3.1. The Measure: Internalised Stigma of Mental illness scale

A number of measures have been developed to assess stigma experiences of people living with a mental illness. A literature review conducted by Wu et al. (2012) found that two of the most widely used stigma scales are: the Internalised Stigma of Mental Illness (ISMI) scale (Ritsher (Boyd), Otilingam, & Grajales, 2003) and the Self-Stigma of Mental Illness Scale (SSMI) scale (Corrigan et al., 2006). The ISMI scale was selected for this study because it potentially could provide a quantitative measure of internalised stigma experiences for our two disease groups, drawing on Corrigan and Watson's (2002) theoretical framework of stigma which was discussed in Chapter 4 of this thesis. The scale has demonstrated consistently high psychometric properties across contexts in the USA, Europe and the UK, and different languages (Wu et al, 2012) which suggests good transportability to a South African setting. We sought permission from the scale developer (Jennifer Boyd) to translate and use the ISMI scale in this study.

The large spread of use of the ISMI scale in the literature is demonstrated by the number of different languages, cultures, conditions and situations it has been adapted for use in, globally.

There are more than 55 versions of the scale in languages such as: Arabic, Armenian, Bengali, Bulgarian, Chinese (Mainland, Taiwan, Hong Kong), Croatian, Dutch, English (USA, South Africa), Estonian, Farsi, Finnish, French, German, Greek, Hebrew, Hindi, Japanese, Khmer, Korean, Lithuanian, Lugandan, Maltese, Polish, Portuguese (Portugal, Brazil), Romanian, Russian, Samoan, Slovenian, Spanish (Spain), Swahili, Swedish, Tongan, Turkish, Urdu, and Yoruba (Boyd, et al., 2014). This evidence suggests that the tool appropriately captures the broad concept of internalised stigma in mental illness across such different contexts. That the scale has been adapted for use in diseases which are not mental illnesses (i.e. Leprosy and Rheumatoid Arthritis) (Corker et al., 2015; Rensen, Bandyopadhyay, Gopal & Van Brakel, 2011) also supported the potential use of the scale to measure internalised stigma experiences in our RHD sample. However as mentioned earlier, these studies did not adequately account for the limited adaptation of the tool for use in these other medical illnesses and internalised stigma experiences unique to our RHD group will likely be overlooked by the ISMI. Boyd et al. (2014) also emphasises that further work is necessary to establish the extent to which culture influences the experiences of internalised stigma. Within this study, this aspect is also considered with sensitivity to the particular cultural background of the Xhosa culture.

In the studies which this instrument has been used in, the ISMI scale demonstrates high internal consistency across all subscales with cronbach's α ranging from 0.74 to 0.92 (Ritsher (Boyd) et al. 2003; Boyd, Adler, Otilingam, & Peters, 2014; Ersoy & Varan, 2007; Kira, Lewandowski, Templin, Mohanesh & Abdulkhalek, 2011), except the Stigma Resistance subscale (which as Lysaker et al. 2007 describes, measures a different construct). As a result, Boyd et al. (2014) notes that most of the studies which used the ISMI, opted not to include the Stigma Resistance subscale in their analysis, as this subscale resulted in lower reliability scores.

Fewer studies report validity, nonetheless, the most common type of validity reported is convergent and divergent validity, where the ISMI compared favourably with other instruments measuring similar constructs, such as the Devaluation-Discrimination Scale and Self-esteem scale (Ritcher et al., 2003). These authors also report that with identical methodology, the ISMI indicated low correlations with scales measuring different constructs such as the Personal Empowerment scale which demonstrated a good indication of divergent validity (Ritcher et al., 2003). Overall, the psychometric properties of the translations, as reported by Boyd et al, (2014) suggest that the tool transports well into different languages, cultures, conditions and situations in European and North American contexts.

The transportability of the tool in different languages has demonstrated good psychometrics in various European studies, for instance, in Ocisková, et al. (2014) the Czech translated version of the ISMI for use in people with mental illness demonstrated good reliability in the form of high internal consistency ($\alpha = 0.91$) and convergent validity with the Beck Depression Inventory-II (BDI-II) (Ocisková, et al., 2014). Increasingly, it has also been adapted for use in low and middle income countries, for instance a version adapted and translated into Yoruba by a Yoruba-speaking psychiatrist and a Yoruba linguist was used with Yoruba-speaking people in Nigeria to measure internalised stigma of outpatients with mental illness. The Yoruba version of the ISMI demonstrated high internal consistency ($\alpha = > 0.84$) and test re-test reliability, a measure of stability over time ($r_{kk} = 0.86$).

In the South African context, the ISMI English language version has been used in a preliminary study investigating internalised stigma reported by people living with schizophrenia (Botha et al., 2006). Within their study, Botha et al (2006) describe that the original English tool is a validated measure. However, as observed before, these authors did not discuss whether and

how they translated the tool (given that their participants' home languages were English, Afrikaans and isiXhosa). Following modifying the ISMI to include 6 items measuring abuse as a form of self-stigma, an important finding by Botha et al. (2006) which is further explored in this study, is that experiences of abuse were highly reported by the Xhosa people in their study. Based on their recommendation, in this study we included 6 items in the ISMI scale which tap into experiences of abuse in this population group. The psychometric properties of these items are assessed independently of the items included in the original ISMI scale. The items are:

- Item 30: *“People call me names because I have ...”*;
- Item 31: *“People have been physically abusive towards me because I have ...”*;
- Item 32: *“People have been verbally abusive towards me because I have ...”*;
- Item 33: *“I find it difficult to attend clinic appointments because people will know that I have...”*;
- Item 34: *“I think the media has a negative influence on the way people perceive ...”*
- Item 35: *“I find it difficult to take my tablets every day because they remind me that I have...”*.

As highlighted in this chapter, most psychiatric tools are developed for use with individuals of European descent. This is critical to emphasise, as these individuals come from a different cultural context and often have a different socioeconomic status which has an influence on their ability to access education and health information. Moreover, they often have a different cultural worldview, which influences their perspectives on illness experiences (Mkhize, 2003). It therefore becomes necessary for researchers in contexts such as Africa, to sensitively translate and adapt these tools for use among local population groups (Drennan, et al., 1991; Steele & Edwards, 2008; Swartz, 1998). One of the well acknowledged challenges of the

translation of tools developed in the Western contexts for local population groups, is the different conceptualisations of illness explanations expressed by individuals in non-European contexts (Swartz, 1998). Moreover, Lund and Swartz (1998) discuss the absence of a 'psychological' language within the Xhosa language. These authors emphasise the complexities of discussing psychological concepts in an African language. As an attempt to confront this challenge, this study used a 5-stage translation design, drawn from methods and suggestions from the literature on the translation of instruments (Campbell & Young, 2016). The resultant Xhosa language version of the Internalised Stigma of Mental Illness (ISMI-X)/and Internalised Stigma of RHD (ISRHD-X) scales were used to better understand how the concept of internalised stigma was supported in the Xhosa language (through psychometrics of the scales) and the relevance of these individual internalised stigma scales items within each disease group using frequencies of item endorsements. Below I describe the translation and validation process used to inform the second research question of the study (*What are the internalised stigma experiences of Xhosa people with schizophrenia and rheumatic heart disease?*).

9.3.2. Structure scoring and psychometric properties of the ISMI scale

The original ISMI scale is a 29 item tool comprised of 5 subscales namely, 1. Alienation (6 items), 2. Stereotype Endorsement (7 items), 3. Discrimination Experience (5 items), 4. Social Withdrawal (6 items) and 5. Stigma Resistance (5 items). The first four subscales measure internalised stigma experiences, while the fifth subscale measures stigma resistance (or resiliency towards stigma). Based on suggestions from Botha et al., (2006) about the prevalence and potential impact of abuse on internalised stigma in South African Xhosa people, in this study we have included a sixth subscale measuring experiences of abuse (6 items).

According to Ritsher et al. (2003), the alienation subscale measures an individual's experience of feeling less than an ordinary member of society or being excluded from society due to their condition. The stereotype endorsement subscale investigates the extent to which the patient agrees with widely accepted stereotypes about people with an illness. The discrimination experience subscale measures the individual's perception of the way other people treat him or her assuming they know about his or her condition. The social withdrawal subscale is concerned with the extent to which individuals avoid contact with others based on the perception that they do not want to burden them with their health issues or based on the fear of rejection if people learn that they have a specific disease. Lastly, the stigma resistance subscale determines the extent to which an individual is able to be resilient towards internalised stigma (Ritsher et al., 2003). The included abuse subscale measures the individual's experience of physical and verbal abuse in relation to having a disease label.

Total scores and subscale mean scores are calculated for each participant. Each item is scored on a Likert scale ranging from 1 =strongly disagree, 2= disagree, 3= agree to 4 = strongly agree. A total mean item score is obtained by dividing the total score by the number of completed responses (excluding the Stigma Resistance items as suggested by Lysaker et al. 2007 and in this study excluding the six items in the added Abuse subscale), usually 24 (if all items on the scale are completed). The first four subscales are scored in accordance with the Likert scale values, but the fifth subscale (Stigma Resistance) is reverse scored and analysed independently of the total scale. A mean score for each subscale is obtained by calculating the total for the subscale and dividing it by the number of completed items in the subscale.

9.4. Translation Method

As described previously, translation of instruments from Western to non-Western languages has been reported as a challenging process (Bravo, Canino, & Rubio-Stipec, 1991; de Jong & Ommeren, 2002; Steele & Edwards, 2008). It is difficult to assess to what extent the psychological terminology often used in health instruments can be translated with confidence across different cultures (Van de Vijver & Leung, 1997). Hence, scholars such as de Jong and Ommeren (2002) propose the use of qualitative methods (including focus group discussions and individual interviews) as a primary approach to investigating the illness experiences of a population before developing a scale which is informed by these experiences. In agreement, Kleinman (1977) denotes the importance of investigating how individuals in local cultures experience health problems.

While acknowledging this perspective as particularly important, developing an instrument emanating from qualitative research is a lengthier and more extensive process, requiring more resources and capacity. One challenge to following this approach is that it often makes it difficult to compare the results of the newly developed scale with those employed cross-culturally (Van de Vijver & Leung, 1997). Hence, many researchers prefer translating instruments which have shown evidence of good psychometric properties and transportability across cultures and contexts, for the intended target group (Yang et al., 2014). Although the process of scale translation itself is difficult, using a combination of previously suggested methods is an important step to attempt to provide the best possible version of the scale (de Jong & Ommeren, 2002; Van de Vijver & Leung, 1997). Hence, this study attempted to use a combination of methods from various authors (i.e. Brislin, 1970; Campbell & Young, 2016; Evans et al. 2002; Satorius & Janca, 1996; Swartz, 1998; Steele & Edwards, 2008) to develop a Xhosa version of the internalised stigma scale for use among people with RHD and SCZ.

Steele & Edwards (2008) propose that the translation process requires a rigorous design in order to adapt scales in a culturally relevant and comprehensible form while staying true to the meaning of the original items. In this study the translation and adaptation of the ISMI scale followed a five-stage mixed-methods design to attempt to develop as thorough a Xhosa translation as possible. The stages included i) Forward-translation; ii) Committee Approach iii) Back-translation iv) Quantitative pilot and v) Qualitative Pilot.

Prior to beginning the translation process, we composed a team of bilingual translators who were suitable to assist in the translation process (Brislin, 1970). Below, I discuss how we went about identifying suitable individuals for this task, before proceeding to discuss the various stages in greater detail.

9.4.1. The selection of the translation team

The WHO Guidelines suggest that it is important to ensure that the translation of a standardised tool considers linguistic, psychological, and cultural differences in the intended populations by choosing experts with relevant skills (Satorius & Janca, 1996). We looked at the suitability of translators beyond their knowledge of the two languages involved in the test adaptation. Following Steele and Edwards (2008), we considered it important that translators were first-language isiXhosa-speakers, having knowledge of the culture, adequate knowledge of the English language and were directly involved in health research conducted with people who have one of the two conditions (SCZ and RHD).

This study selected translators based on the following criteria:

- i) Have knowledge of the two languages involved as they are home-language isiXhosa speakers and

- ii) Have completed health courses in the source language which is English,
- iii) Have knowledge of the Xhosa culture,
- iv) Have experience in doing health research with one of the two patient groups.

In accordance with these inclusion criteria, four bilingual translators were invited to be involved in the translation process. The translators included two male isiXhosa speaking psychiatric nurses working with SCZ patients in the Department of Psychiatry at UCT, as well as one female and one male healthcare worker who work with RHD patients in the Department of Medicine at UCT. An external female isiXhosa speaking retired psychiatric nurse and research coordinator from the Department of Psychiatry at Stellenbosch University was invited to assist in facilitating the translation process. The reason for inviting an external individual is that, as Steele and Edwards (2008) maintain, in group meetings, it is possible for dominant individuals to strongly influence the discussion, in the process leaving more reserved individuals' opinions unacknowledged. The external individual was senior (in age and professional status) to the other group members and had much experience in translating scales therefore was very familiar with the translation process and could manage dominant personalities with confidence, while encouraging more submissive group members to make valuable contributions.

This resulted in a team of three males and two females (excluding the researcher). All of these individuals, as well as myself the researcher, are first-language isiXhosa speakers and three had acquired tertiary education training at English language institutions. All individuals involved had experience in administering health measures with patients from one of the disease groups, in both English and isiXhosa. This team allowed for an exchange in views about the

scale items, based on the individual expertise of members of the team, in training, education and their cultural background (Brislin, 1970).

9.4.2. Translation design

i) Step 1: Forward-translation

Forward-translation is defined as translating an instrument from the original language, also referred to as the source language, to the target language (Brislin, 1970; Wild et al., 2005). As done in previous studies (Corker et al., 2015; Rensen et al., 2011) prior to forward-translation, the term mental illness was replaced with heart disease in the English version of the scale adapted for use among people with RHD and was provided to the two of the translators who would forward-translate the version into Xhosa. The ISMI scale was forward-translated, from English to isiXhosa, independently by four members of our translation team (2 for the SCZ and 2 for RHD). Each translator was given a month to complete the translations and then send the Xhosa translation of the scale back to the researcher. Once I had received all four forward-translation versions of the scales, I tabulated the individual scale item translations for each comparison. This step is important as it allowed for similar forward translations to be compiled for discussion in the committee meeting (Campbell & Young, 2016; Wild et al., 2005).

ii) Step 2: Committee approach

The committee approach included all the translators involved in the translation design, myself and my supervisors coming together for two meetings. The committee met twice during the translation process. In the first meeting (which took place on a Saturday from 8:30am to 3:00pm) the four forward-Xhosa translations of the internalised stigma scale were presented in a table format for discussion and comparison. Translators were requested to select and decide upon the most appropriate Xhosa translation for each item, suitable for use by isiXhosa-

speaking participants across different areas of the country, including urban and rural contexts. The translators selected one Xhosa translation for each item, changing only the disease name for the two disease groups. Towards the end of the first meeting the team had developed two versions of the tool. One targeted individuals with mental illness where the term “mental illness” was translated into two terms used interchangeably in the items on the scale, in consideration of linguistic and grammatical syntax. These Xhosa words are: “*uphazamiseka engqondweni*” and “*isigulo sengqondo*”. For the scale which targeted individuals with rheumatic heart disease the term “mental illness” was replaced by heart disease which was translated to the Xhosa term “*isifo sentliziyo*”. Due to the absence of the term “Rheumatic” in isiXhosa, the word was dropped and substituted by “heart disease”, this was deemed fitting, given that the original tool also uses the broad term mental illness and not a specific mental condition. This process resulted in a preliminary Xhosa version of the internalised stigma scale for both the RHD and SCZ population groups. This version was electronically reviewed and commented on by all members a week after the translation team met. It was important to facilitate this step in the translation design as the risk of not implementing this step may result in an instrument which contains too much of one person’s style of writing and conceptualisations (Drennan, et al, 1991; Rabie, & Naidoo, 2018; Wild et al., 2005).

iii) Step 3: Back-translation

Back-translation involves the translation of the new language version tool back into the source language (Brislin, 1970; Brislin, 1986; Steele & Edwards, 2008; Wild et al., 2005). This is usually carried out by an individual who is a first-language speaker of the target language and fluent speaker of the original instrument language and had not seen the original tool (Campbell & Young, 2016). In this study an independent psychiatric nurse involved in the SAX study (who had not seen the original English ISMI scale), blindly back-translated the isiXhosa

versions of the tools to the English language. The psychiatric nurse was given two weeks to translate the two scales from isiXhosa back to English.

There is some debate in the literature about the advantages and disadvantages of using healthcare professionals as back translators in a translation team. On the one hand the advantage of using a psychiatric nurse in the back-translation is that the individual may be familiar with the dialect used by patients given their experience in administering various psychological instruments in English and isiXhosa to isiXhosa-speaking patients in different South African psychiatric hospitals. However, there are also limitations such as that the healthcare professionals may back-translate scales into clinical terminology which is different from patient understanding as they may not be able to separate their conceptual knowledge of the constructs measured in the scale from the back-translation they produce. Ultimately we decided that the advantages of using healthcare staff - familiar with the source language and the target language, familiar with these two patient groups and how they describe their condition and having knowledge of the common questions they may ask about their illnesses and typical challenges they faced in their treatment and recovery - out-weighted the disadvantages inherent in their familiarity with the constructs measured. To compensate for the limitations in using a psychiatric nurse for back-translation, we included a cognitive interviewing component in our translation design to explore how Xhosa-speaking patients from the two disease-groups ($n= 10$) were understanding each item on the internalised stigma scale. Based on recommendations from these steps we adapted the scales to ensure conceptual clarity and ease of meaning for the target population.

Upon back-translating the tool to English the nurse returned the back-translations to me and I combined the original version of the scale (in the source language, English), the Xhosa versions

of the scale (as developed by the translation team in the first committee meeting) and the back-translation version of the scale in a summary table for discussion and comparison by the translation team during a second translation team meeting, as suggested by Campbell & Young (2016). This summary assists in highlighting any discrepancies which were evident, and helps facilitate discussion around more appropriate translation choices. The back-translation process raised some important discrepancies which were debated and explored in the second committee meeting which consisted of all the translators, myself and my supervisor. The second translation meeting took place eight months after the first meeting. It also took place on a Saturday from 8:30am to 3:00pm. A sample of the discrepancies identified during the back-translation are presented in Table 11 below.

Table 11: *Examples of the review of the back-translation of the ISMI/ISRHD-X*

	Original items	ISMI-X / ISRHD-X items	Back-translated items
1	I feel out of place in the world because I have a mental illness	<i>Ndiziva ndingamkelekanga emhlabeni kuba ndiphazamisekile engqonweni</i>	Due to my mental instability, I don't feel welcome in the world.
	I feel out of place in the world because I have a heart disease	<i>Ndiziva ndingenandawo ehlabathini kuba ndinesifo sentliziyo</i>	I feel like I don't have a place on earth due to my heart disease
5	I am embarrassed or ashamed that I have a mental illness	<i>Ndiziva ndinodano okanye ndinentloni kuba ndiphazamisekile engqondweni</i>	I feel embarrassed or ashamed because I suffer from mental illness.
	I am embarrassed or ashamed that I have a heart disease	<i>Ndiziva ndinodano okanye ndinentloni kuba ndinesifo sentliziyo</i>	I feel embarrassed or ashamed because I suffer from heart disease.
16	I am disappointed in myself for having a mental illness	<i>Ndiziva ndinodano ngesiqu sam kuba ndiphazamisekile engqondweni</i>	I feel ashamed of myself as a person due to having a mental illness.
	I am disappointed in myself for having a heart disease	<i>Ndiziva ndinodano ngesiqu sam kuba ndinesifo sentliziyo</i>	I feel ashamed of myself as a person due to having a heart disease.

29	Stereotypes about the mentally ill apply to me	<i>Iingcamango ngabantu abagula ngengqondo ziquka nam</i>	I am included in the opinions society has on people with a mental illness
	Stereotypes about people with heart disease apply to me	<i>Iingcamango ngabantu abanesifo sentliziyo ziquka nam</i>	I am included in the opinions society has on people with heart disease

The back-translation step revealed some difficulty in finding linguistically and conceptually equivalent terms across the two languages for some concepts related to internalised stigma experiences used in the scale items (see complete document with back-translations on Appendix H). For example, as evident in the table above, items 5 “embarrassed” translated to “ndinodano” and in item 16 “disappointed” also translated to ndinodano”. These are good examples of the English language having a greater selection of emotive terminology (i.e. embarrassed and disappointed mean different emotional states, but in the Xhosa language they are labelled as one term). Items 1 and 29 are good examples for presenting the difficulty in achieving conceptual equivalence between the English and Xhosa language. In item 29 “stereotypes” have been lightened in Xhosa to “opinions / iingcamango”, but in English the term “stereotypes” holds more negative consequence and association than “opinion”. This choice of language does change the intensity of the sentence and associated meaning. As a result, it may change the way individuals endorse these items across the two languages. Similarly, item 1 “I feel out of place” is a common idiom in the English language relating to feelings of “not belonging”, which is not common idiom in the Xhosa language and as presented in the back-translation, could be interpreted in a slightly different manner by participants who complete the scale. Within this same example, the reference to mental illness in the original English statement and the interpretation of the back-translator to “mental instability/ *ndiphazamisekile engqondweni*” changes the degree of intensity in the question, arguably with the second seeming more severe. This however can also be viewed as an example

of a literal rather than a broad translation of the words from the perspective of the back-translator.

Key proposed changes to the translation included paying attention to the items highlighted in the back-translation, i.e. item 1: “I feel out of place in the world because I have a mental illness / *Ndiziva ndingamkelekanga **emhlabeni** kuba ndiphazamiseke ngokwasengqondweni*” changed to “*Ndiziva ndingamkelekanga **ehlabathini** kuba ndiphazamiseke ngokwasengqondweni*”. The word for “world” was changed because **emhlabeni** can have two meanings, “world” and “soil”, while **ehlabathini** is only used when referring to the “world”.

Item 17: “Having a mental illness has spoiled my life” was initially translated to “*Ubomi bam bonakele ngenxa yesigulo sokuphazamiseka engqondweni*” which translates to “My life has been ruined because of having a mental illness”. In the second meeting, the degree and sentence order of this item was changed to “*Ukuba nesigulo sengqondo kubuphazamisile ubomi bam*” which states, “Having a mental illness has disturbed my life”. This is an example of difficulty finding an equivalent word for “spoiled” in the Xhosa language, because “ruined” could be considered as having a more intense meaning, yet the alternative “disturbed” seems subtler.

Item 5: “I am embarrassed or ashamed that I have a mental illness” / “*Ndiziva **ndinodano** okanye ndinentloni kuba ndiphazamisekile engqondweni*” which was changed to “*Ndiziva **ndiphoxekile** okanye ndinentloni kuba ndiphazamisekile ngokwasengqondweni*”. The word embarrassed was now changed to **ndiphoxekile** meaning “ashamed” as opposed to “**ndinodano**” which means disappointed, as it has a slightly different meaning from embarrassed. This is also an example where the sentence was reordered in consideration of syntax, i.e. the Xhosa statement can be back translated to “I am ashamed or embarrassed that I have a mental illness”.

Item 29: “Stereotypes about the mentally ill apply to me / *“Iingcamango ngabantu abagula ngengqondo ziquka nam”*” which was back-translated as “Opinions about the mentally ill apply to me” was then changed to *“Iingcamango ezingezizo zabantu malunga nesigulo sengqondo nam ziyandichaphazela”* which translates to “Negative opinions about mental illness apply to me”.

Following the forward-translation, quantitative and qualitative piloting and the back-translation of the ISMI/ISRHD-X scales, the committee met again eight months later to discuss the results and discrepancies which emerged during the first four steps of the design. The second committee meeting also aimed to establish semantic, idiomatic and conceptual equivalence. Semantic equivalence relates to whether, after translation, the meaning of the item has remained the same (de Jong & van Ommerman, 2002). This was aimed for through the changes made to the items (i.e. items 1, 5,16 & 29). Idiomatic equivalence refers to ensuring that idioms or words ordered in a particular way, of which the meaning is reliant on knowledge of the culture (Steele & Edwards, 2008), are translated as far as possible to mean the same or similar thing in the target language. For instance, item 1 of the ISMI includes the idiom, *“I feel out of place in the world, because I have a mental illness / heart disease”*. This idiom refers to feeling like ‘one does not belong’ in the world and not necessarily what these words may seem to mean when focussing on the literal sense (i.e. literally feeling out of place). This example was translated to *“Ndiziva ndingena ndawo emhlabathini, kuba ndiphazamisekile engqondweni/ ndine sifo sentliziyo”*. Which was back translated to “I feel like I don’t have a place in the earth because of my mental illness / heart disease”. Conceptual equivalence relates to a construct having the same meaning across language or cultural groups (Harchi, Choi, Abbot, Catalano & Bliesner, 2006). Within the committee meeting, translators

were requested to decide on translations of items in the scale, word for word, however, as found in Steele & Edwards (2008), they often opted to translate items based on the broad meaning of the statement. This may be a threat for linguistic and grammatical-syntactical equivalence however, it increases the conceptual equivalence. For example, item 23's sentence structure changed subtly from "I can't contribute anything to society because I have a mental illness / heart disease" to "*Andikwazi kuba negalelo ekuhlaleni nakweyiphi na into kuba ndiphazamisekile engqondweni / ndinesifo sentliziyo*" which is "I can't contribute, in anything in the community, because I have a mental illness / heart disease". As done in previous studies by Drennan (1998) and Steele's (1996) translation as cited in Steele and Edwards (2008), at this stage translation of some of the items changed and other options for translating statements and sentence structure were proposed. These changes were made in the attempt to provide as close a conceptual translation to the English version as possible. During the meeting the senior group member read both translated versions (for SCZ and RHD) of each item, following which the group discussed and agreed on the selected translations.

These challenges in obtaining linguistic and conceptual equivalence are well documented in the South African literature (i.e. Campbell & Young, 2016; Swartz & Drennan, 2000; Steele, 2003; Steele & Edwards, 2008). These authors caution that in some instances these challenges hinder the production of a high-quality tool that holds the same meaning or measures the same construct across the two languages. It is therefore likely that the final translation produced in this study will only provide a general or broad impression of some of the internalised stigma experiences of Xhosa people with SCZ and those with RHD, and that more culturally specific experiences, uniquely supported by the Xhosa language and culture, as well as the specific disease group, will remain unaccounted for unless qualitatively explored. It is also unlikely that we will be able to replicate the same psychometric structure as the original tool, hence there

may be some limitations regarding the transportability of some subscales and items. This is further investigated by examining the psychometric properties of the Xhosa tools (i.e. through measuring the reliability and validity of the translated tools).

iv) Step 4.1: Mixed methods piloting

○ *Quantitative pilot*

The ISMI/ISRHD-X scales resulting from the first committee meeting were then quantitatively piloted which allowed us to assess the psychometric properties. This pilot involved administering the tool in a subsample of patients with SCZ (n= 60) or with RHD (n= 50) in order to establish preliminary psychometric properties of the translated Xhosa versions. I recruited the RHD patients (who were already enrolled in the larger RHDGen study) when they attended a check-up at a hospital in the Western Cape Province, South Africa. I first explained the present study to potential participants, then if they volunteered to participate, I proceeded to explain the informed consent documents (specific for this process, see Appendix E). Following completion of the informed consent form, participants completed a demographic form which requested their age, highest level of education, area where they reside, date of disease diagnosis, and a question which asked whether they have had a heart operation and if so when it was conducted (see Appendix F). Next, the participants went through the scale and completed the items, while checking whether they believe the isiXhosa translations of each item are an equivalent of the English language item on the scale (both the English and Xhosa language versions were on the scale, with one below the other). As far as possible, patients also reviewed the scale for spelling and grammatical errors in the Xhosa versions.

For the SCZ subsample (n=60), participants completed the ISMI-X as part of a battery of psychological measures that were administered during their participation in the SAX study,

following completing of an informed consent process, as well as the Structured Diagnostic Interview for DSM-IV Axis I Disorders (SCID) (First, Spitzer, Gibbon & Williams, 2012). Importantly, these patients also completed the Xhosa version of the Discriminations and Stigma Scale (DISC) scale as part of this battery. The DISC is an internationally established measure of discrimination and stigma experiences of people with SCZ and the English version of the tool has been used as a measure of convergent validity with the ISMI in a preliminary study by Brohan et al. (2013). Patient recruitment, consent, the SCID interview and subsequent psychometric battery were completed by trained psychiatric nurses at psychiatric hospitals in both the Western and Eastern Cape provinces South Africa. A total of 60 SCZ patients were enrolled. An important difference to note here is that the RHD participants only completed the ISRHD-X scale, while the SCZ participants completed the ISMI-X scale after a lengthy psychiatric interview and additional psychometric measures, with many reporting fatigue when they got to completing the last scale which was the ISMI-X scale.

- *Qualitative pilot*

The qualitative pilot of the tool was carried out through cognitive interviews (Miller, 2003). Cognitive interviewing was originally developed for survey research but has subsequently been adapted for use in psychometric tool development (Miller, 2003). Within this study, cognitive interviewing was conducted with a small sample of patients (five in each disease group) to ensure conceptual equivalence of item wordings in the Xhosa versions of the scales. During these cognitive interviews RHD and SCZ participants were asked to complete the scale independently, while also verbally answering two questions to the researcher, namely;

1. *What did the question make you think of?*
2. *Why did you respond in that way?*

These cognitive interviews were audio recorded and transcribed. The themes which emerged from their responses to these questions were tabulated and prepared for comparison as they were analysed thematically. The patient responses and interpretations of the Xhosa version of the scale were then further used to provide evidence for the usability of the Xhosa scale.

iv) Step 4.2: **Mixed methods piloting results**

○ *Quantitative pilot results*

For the quantitative pilot, the completed scales from both samples were used to investigate psychometric properties of reliability and validity in the ISMI/ISRHD-X scales. In addition, the Xhosa version of the DISC was completed by a small sample of the SCZ respondents ($n=32$) and was used as a measure of convergent validity.

Socio-demographic characteristics of participants

Prior to presenting the psychometric properties, the socio-demographics of the pilot sample participants is presented to highlight important differences between groups that may account for differences in results of the scale development. The demographics of participants in the piloting of the ISMI/ISRHD-X scales are presented in table 10 below. This table reveals that the RHD sample ($n=50$) is over represented with female participants ($n=41$, 82%) while the SCZ sample ($n=60$) is over represented with male participants ($n=57$, 95%). In addition, a younger age range is observed (mean age: 30.30 years, the age ranging between 20-53 years) in the SCZ sample as opposed to a 42.26 years mean age (ranging between 23-75 years) in the RHD sample.

Table 12: *Demographics of RHD and SCZ samples*

	RHD (n=50)	SCZ (n=60)
Age		
Range	23-75 years	20-53 years
Mean	42.26 years	30.30 years
Sex		
Male	9 (18%)	57 (95%)
Female	41 (82%)	3 (5%)
Highest education level		
<ul style="list-style-type: none"> • Completed tertiary studies 	1(2%)	4 (6.67%)
<ul style="list-style-type: none"> • Some secondary school 	40 (80%)	45 (75%)
<ul style="list-style-type: none"> • Some primary school 	8 (16%)	10 (16.67%)
<ul style="list-style-type: none"> • No school 	1 (2%)	0 (0%)

All the participants who completed the ISMI/ISRHD-X are first language isiXhosa speakers and the education level between the two samples is relatively similar, with 75% or more participants in each sample with at least some secondary schooling. The assumption may be that people with schizophrenia would have lower levels of education because of the cognitive impairments associated with the illness. Yet RHD is closely associated with poverty which may explain reduced education levels in this sample.

9.5. Psychometric properties

As opposed to simply using instruments developed abroad in the South African context, Foxcroft (1997) highlights the importance of investigating psychometric properties and providing evidence of the standard requirements for reliability and validity of a tool before

using it in a different cultural group. This study aims to adhere to that call by presenting the psychometric properties of the ISMI/ISRHD-X scale.

This is also in line with Wild et al. (2005), who maintain that the best way to ensure usefulness of a scale in a local context is to assess the validity and conceptual equivalence of the newly translated tool through psychometric validation. Quality assurance of measures is however heavily dependent on the methodology used (Sartorius & Janca, 1996). In this study we investigate the psychometric properties of the ISMI/ISRHD-X scales using measures of utility, reliability and validity across the RHD and SCZ samples. Following capturing the data on the Excel computer programme, utility of the scale was considered in relation to the number of completed scales in each group. To determine the reliability and validity of the tool we used the computer programme SPSS.25 (IBM SPSS, 2017). Reliability indicators included internal consistency of the total scale and subscales, which was measured using Cronbach's alpha (α) (Cronbach, 1951). Validity was established for the ISMI-X subscales using evidence of construct and convergent validity with the Xhosa version of the DISC using Spearman's rho.

a) Utility

Utility relates to the quality of data as assessed by the completion rates of data and the score distributions (Lamping et al., 2002). In order to assess whether the ISMI/ISRHD-X is acceptable to the Xhosa patients with SCZ and RHD, we examined the completion rates (number of scales completed per group), while also investigating the number of scales with missing items. Within the RHD sample a total of 50 questionnaires were administered of which 47 (94%) were completed in full, while 2 (4%) had one omitted item, 0 (0%) had two items omitted, and 1 (2%) had three or more omitted items. Within the SCZ sample a total of 60

questionnaires were administered. Of these questionnaires 47 (78.33%) were completed in full, 9 (15%) had one item omitted, 0 (0%) had two items omitted, while 4 (4.66%) had 3 or more items omitted. These figures demonstrate that the completion rates are high across the two disease groups, suggesting good readability and ease of use of the ISMI/ISRHD-X measure in both samples. These results are summarised in Table 13. below.

Table 13: *Utility of RHD and SCZ ISMI/ISRHD-X scales*

ISMI-X Pilot	Utility (scale items completed)
Samples:	
SCZ sample	
n=60	47 (78.33% completed all items) 9 (15% omitted 1 item) 4 (6.66% omitted 2 or more items)
RHD sample	
n=50	47 (94% completed all items) 2 (4% omitted 1 item) 1 (2% omitted 2 or more items)

In the RHD sample, these omitted items included items 2 (1 omission), 3 (1), 7 (1), 18 (1), 24 (1) and 29 (1). While in the SCZ sample the items omitted included items 1 (2 omissions), 2, (1), 4 (1), 9 (1), 15 (1), 18 (1), 19 (1) and 26 (3). There were more items omitted in the SCZ sample in comparison with the RHD sample, yet neither group demonstrated a single item omitted more than 3 times, suggesting further evidence for the utility of these items.

There was a marked difference in completion rates between the RHD and SCZ group. This difference is likely the result of differences in how the instrument was administered in each disease group. Participants in the RHD group completed only the ISRHD-X, while for the SCZ group, participants completed the ISMI-X scale after completing the SCID and a series of other measures (which usually took about 2 hours to complete). As mentioned before, it is likely the lower completion rates were indicative of fatigue within the SCZ group.

Within the SCZ and RHD samples, the questionnaires with 2 or more items omitted were considered unusable and removed from further analyses, leaving a total sample size of 56 for the SCZ sample and 49 for the RHD sample. The reliability results presented below are based on the 56 valid SCZ questionnaires as well as the 49 RHD questionnaires.

b) Reliability

Reliability assesses whether a measure consistently reflects the construct that it is measuring (Field, 2013). Reliability of the ISMI/ISRHD-X scales was investigated using internal consistency applying Cronbach's α which is the most commonly used measure of reliability (Cronbach, 1951). Kline (1999) maintains that a level of 0.7 is a desirable representation of reliability, while other authors suggest that values as low as 0.5 are acceptable in the early stages of research (Nunnally, 1978). Empirical research has reported a high degree of internal consistency for the ISMI scale original English version, used in other studies with outpatients, with internal consistency scores ranging from 0.80 to 0.92 for the overall scale (Assefa et al., 2012; Boyd et al., 2013). In studies where the stigma resistance subscale was not included in the total scores, similarly internal consistency ranged from 0.81 to 0.92 (Boyd et al., 2013). Table 12. below reflects the Cronbach's α values of the total ISMI/ISRHD-X scales and

subscales thereof across the SCZ and the RHD samples in the present study, along with the original scores obtained in the original English version study (Ritsher et al., 2003).

Table 14: *Internal consistency coefficients reported for the ISMI-X scales*

Internal consistency	Original English version (Ritcher (Boyd) et al., 2003)	ISMI-X SCZ		ISRHD-X RHD	
		Cronbach's α	CI: 95%	Cronbach's α	CI: 95%
Total ISMI scale (24 items)	0.91	0.90	(0.76-0.910)	0.89	(0.759-0.856)
Alienation (6 items)	0.79	0.73	(0.596 - 0.827)	0.64	(0.455-0.775)
Stereotype endorsement (7 items)	0.72	0.82	(0.737-0.884)	0.70	(0.554-0.813)
Discrimination experience (5 items)	0.75	0.78	(0.669-0.859)	0.70	(0.540-0.813)
Social withdrawal (6 items)	0.80	0.86	(0.788-0.907)	0.80	(0.704-0.878)
Stigma resistance (5 items)	0.58	0.57	(0.362-0.732)	0.76	(0.637-0.856)
Abuse (6 items)	-	0.78	(0.675-0.860)	0.86	(0.788-0.913)

Internal consistency for the total scale was high in both the SCZ and RHD ($\alpha = 0.90$ and 0.89), and commensurate with the internal consistency of the original ISMI English language version ($\alpha = 0.91$). In addition, acceptable internal consistency is demonstrated across all of the subscales ranging from 0.57 to 0.86 in the SCZ sample and 0.64 to 0.80 in the RHD sample. The Abuse subscale also demonstrated adequate internal consistency at 0.78 for SCZ sample and 0.86 for the RHD sample.

c) Validity

Terre Blanche and Durrheim (1999, p. 83) as cited in Bhana (2006), attest that validity relates to an examination of whether the instrument provides a good degree of fit between the conceptual and operational definitions of the construct, as well as whether the measure is usable for the intended purpose. There are various types of validity, for the purpose of this study we investigate construct and content validity within both disease groups as well as convergent and divergent validity within the SCZ group.

- **Construct Validity**

Construct validity examines the extent to which an instrument behaves in a theoretically sound manner. It is measured by investigating the correlations between subscales within a scale that are expected to measure the same construct. Keszei et al. (2010) maintains that internalised stigma is a construct which cannot easily be measured through physical attributes. Numerous tools have been developed, primarily in North American and European contexts, consisting of experiential attributes to measure this theoretical construct. In psychological and social sciences these abstract experiential variables are called hypothetical constructs. The original English ISMI scale developed by Jennifer Ritcher [Boyd] and colleagues (2003) has five

subscales (i.e. Alienation, Stereotype Endorsement, Discrimination Experience, Social Withdrawal and Stigma Resistance) which are developed based on evidence from a substantive literature review (largely based on research conducted in the USA, UK and European contexts) that reports that these are important associated components of the construct, internalised stigma. In the South African context, Abuse was also viewed as a construct related to internalised stigma (Botha et al., 2006). In this study we included an additional subscale of abuse as an indicative measure of internalised stigma experienced by Xhosa people with the study diseases (Botha et al., 2006). To measure whether the aforementioned subscales are in fact related to the internalised stigma construct among this African population group, a correlation of the subscales and the total tests was considered. The correlation between the scales assesses the degree to which they measure related aspects of the construct. We hypothesised that all the subscales (with the exception of the Stigma Resistance subscale – which measures a different construct) would show significant positive correlations with the total ISMI-X score, in the moderate range ($r= 0.30 - 0.50$), in accordance with criteria suggested by Brohan et al., (2013).

Table 15: Within-scale correlations RHD sample (n= 49)

	Total ISRHD- X	A	SE	DE	SW	SR	AB
Total ISRHD- X	1.000	$r= 0.748^{**}$ p= 0.000	$r= 0.882^{**}$ p= 0.000	$r= 0.784^{**}$ p= 0.000	$r= 0.841^{**}$ p= 0.000	$r= 0.057$ p= 0.696	$r= 0.653^{**}$ p= 0.000
A		1.000	$r= 0.662^{**}$ p= 0.000	$r= 0.478^{**}$ p= 0.001	$r= 0.390^{**}$ p= 0.006	$r= 0.160$ p= 0.271	$r= 0.304^{*}$ p= 0.034

SE			1.000	$r= 0.544^{**}$ $p= 0.000$	$r= 0.676^{**}$ $p= 0.000$	$r= 0.161$ $p= 0.270$	$r= 0.561^{**}$ $p= 0.000$
DE				1.000 .	$r= 0.566^{**}$ $p= 0.000$	$r= -0.029$ $p= 0.844$	$r= 0.539^{**}$ $p= 0.000$
SW					1.000 .	$r= -0.068$ $p= 0.643$	$r= 0.674^{**}$ $p= 0.000$
SR						1.000 .	$r= 0.111$ $p= 0.446$
AB							1.000

Table 13. Correlation with subscales in ISMI-X for the schizophrenia sample. (A= Alienation, SE= Stereotype Endorsement, DE= Discrimination Experience, SW= Social Withdrawal, SR= Stigma Resistance, AB= Abuse).
 $p < 0.05^*$; $p < 0.01^{**}$

For the ISRHD-X scale, indeed strong positive correlations were found between the ISRHD-X total and subscale scores ($n= 49$). In correlation with the total, all of the subscales (excluding the stigma resistance subscale) demonstrated at least moderate positive correlations (0.3) and most subscales displayed a strong correlation. Within-scale analysis presents moderate to strong correlations, with the exception of the Stigma Resistance subscale (which is measuring a different construct). For the SCZ sample, the within-scale correlation results are presented in Tables 16 below.

Table 16: Within-scale correlations SCZ sample ($n= 56$)

	Total	A	SE	DE	SW	SR	AB
ISMIS							

Total	1.000	$r= 0.777^{**}$ $p= 0.000$	$r= 0.792^{**}$ $p= 0.000$	$r= 0.706^{**}$ $p= 0.000$	$r= 0.850^{**}$ $p= 0.000$	$r= 0.415^{**}$ $p= 0.000$	$r= 0.637^{**}$ $p= 0.000$
ISMI-X	.						
A		1.000	$r= 0.493^{**}$ $p= 0.000$	$r= 0.460^{**}$ $p= 0.000$	$r= 0.509^{**}$ $p= 0.000$	$r= 0.307^*$ $p= 0.021$	$r= 0.479^{**}$ $p= 0.000$
SE			1.000	$r= 0.311^*$ $p= 0.019$	$r= 0.598^{**}$ $p= 0.000$	$r= 0.506$ $p= 0.270$	$r= 0.495^{**}$ $p= 0.000$
DE				1.000	$r= 0.530^{**}$ $p= 0.000$	$r= 0.183$ $p= 0.177$	$r= 0.367^{**}$ $p= 0.005$
SW					1.000	$r= 0.288^*$ $p= 0.031$	$r= 0.630^{**}$ $p= 0.000$
SR						1.000	$r= 0.175$ $p= 0.197$
AB							1.000

Table 8. Correlation with subscales in ISMI-X for the schizophrenia sample. (A= Alienation, SE= Stereotype Endorsement, DE= Discrimination Experience, SW= Social Withdrawal, SR= Stigma Resistance, AB= Abuse).
 $p < 0.05^*$; $p < 0.01^{**}$

For the ISMI-X scale, strong positive correlations were found between the ISMI-X total and subscale scores ($n= 56$). In correlation with the total, all of the subscales (including the stigma resistance subscale) meet the threshold (0.3) and most subscales displayed a strong correlation. Within-scale analysis presents mostly moderate correlations. It's interesting to note that the Stigma Resistance subscale shows moderate correlations with the overall scale as well as with the Alienation and Social Withdrawal subscales within the SCZ sample. In support of the qualitative data in chapter 8 under the section coping strategies, and the literature (Du Plessis et al., 2004; Sorsdahl et al., 2012) one explanation for these correlations may be the SCZ description of alienation and social withdrawal as a coping strategy to mitigate perceived

stigma and discrimination from the general public. Therefore, alienation and social withdrawal may be strategies for managing stigma and increasing stigma resiliency for this sample.

- **Convergent and Divergent Validity**

As described by Diamantopoulos and Schlegelmilch (1997) convergent validity was considered in relation to the extent to which the ISMI-X was positively related to other measures which investigate the same concept. Preliminary literature suggests that stigma and discrimination are related constructs, for instance, Thornicroft et al., (2007) explain that stigma is a mark or sign of disgrace which usually brings forth negative attitudes. For a person with a mental illness, this stigma can also contribute to discrimination for example when applying for a new job or maintaining a current job. This study utilised a comparison scale which measures discrimination (the Discrimination and Stigma scale) that has recently been translated for isiXhosa-speaking patients with a mental illness. Previous research in the UK has utilised the ISMI and the DISC English versions (i.e. Brohan et al. 2013) and indicated adequate correlations between the two scales. Evidence of convergent and divergent validity of the ISMI/ISRHD-X scales was examined in comparison with the DISC Xhosa version scales completed by the subsample ($n= 32$) of the SCZ participants in this study. Prior to presenting the scores, I present the demographics of the smaller sample of SCZ participants who completed both the ISMI-X and the Xhosa version of the DISC in totality ($n= 32$).

Table 17: *Demographics of SCZ sample that completed ISMI and DISC scales*

$n= 32$		
Sex	Male	32 (100%)
	Female	0 (0%)

Age	Average	30 years
	Range	21 – 50 years
Highest level of education		
	Some primary schooling	4 (12.5%)
	Some secondary schooling	26 (81.25%)
	Tertiary qualification	2 (6.25)

As noted in the table above, a total of 32 participants completed all items on the ISM-X and the DISC. All of these participants are male with a mean age of 30 years. Of these respondents 2 (6.25 %) have tertiary qualifications while 26 (81.25%) have some secondary schooling and 4 (12.5%) have some primary schooling.

Only participants who completed both the Xhosa versions of the ISMI and the DISC scales and had less than 3 items omitted in each scale were included in the analysis of convergent and divergent analysis ($n= 32$). Subscale scores of the ISMI-X and DISC were compared using Spearman's rho (Field, 2013) which is used for ordered or categorical data such as the data elicited from Likert scales utilised in the ISMI and DISC Xhosa version response scales. Results are presented in Table 12 to follow.

We also investigated divergent validity following Diamantopoulos and Schlegelmilch's (1997, p. 34) definition of divergent validity, which refers to measuring the extent to which an instrument is not related to scales/subscales of different concepts which have no expected theoretical relationship. We aimed to achieve this by investigating the relationship between the

ISMI-X Stigma Resistance and DISC Treated Unfairly subscale, as these two scales are expected to measure different theoretical constructs (Brohan et al., 2013).

The convergent and divergent validity of the ISMI-X was investigated as per the hypotheses below. Only the DISC Treated Unfairly subscale was used for comparison based on Brohan et al. (2013) recommendation that this is the most relevant subscale which in their study proved to meet the psychometric requirements. A significant moderate to strong correlation (0.3 or greater) was considered as the criterion. Based on the establishment of a relationship between stigma and discriminatory behaviour, we hypothesized that we would see the following relationships in our sample.

1. the ISMI-X Total will have a positive significant relationship with the DISC Treated Unfairly subscale
2. The ISMI-X Discrimination Experience will have a positive significant relationship with the DISC Treated Unfairly subscale
3. ISMI-X Stigma Resistance subscale will have no association with the DISC Treated Unfairly

Table 18: Results for correlations with the ISMI-X and DISC (n= 32)

	DISC Treated Unfairly
ISMI-X total (excluding SR)	$r = 0.097, p = 0.60$
- Alienation	$r = 0.229, p = 0.104$
- Stereotype Endorsement	$r = -0.083, p = 0.325$
- Discrimination Experience	$r = 0.337^*, p = 0.030$
- Social Withdrawal	$r = 0.082, p = 0.328$
- Stigma resistance	$r = 0.127, p = 0.244$

* $p < 0.05$ ** $p < 0.01$

The ISMI-X total score (excluding the Stigma Resistance subscale) showed no association with the DISC Treated Unfairly subscale ($r= 0.097$, $p= 0.60$) within the SCZ group. The Alienation, Stereotype Endorsement, Social Withdrawal, Stigma Resistance all showed no association with the DISC Treated Unfairly. Only the ISMI Discrimination Experience subscale and the DISC Treated Unfairly subscale demonstrated a moderate positive correlation and thus met the threshold ($r= 0.337^*$, $p= 0.030$).

These results could be for a number of reasons: firstly, these results could suggest problems with the Xhosa translation of some of the ISMI and DISC items. Secondly, it could be related to the assumption that internalised stigma and discrimination are highly correlated in this population group. This assumption is not supported by these results in this study, as the Discrimination Experience subscale only showed a moderate positive correlation. This is supported by Brohan et al. (2013) who describe that while discrimination and stigma may be related, there is evidence to suggest that the relationship is not strong and that there may be some variation between the two terms (Dembling, et al. 1999). In this context, considering that for many generations, history attests that Xhosa people have been subjected to discrimination in many aspects of their lives (Xhosa & Zwane, 1995; Salo, 2003), based in many instances on race, discrimination may not necessarily be specifically associated with increased experiences of internalised stigma in Xhosa people with SCZ. Because the ISMI-X scale did not meet the threshold for convergent validity with the DISC Treated Unfairly subscale as found in Brohan et al. (2013), it can be argued that the ISMI/ISRHD-X scale warrants further investigation of the tool prior to recommending it for use in future studies. For the purposes of this study however, we did not have a large enough sample to perform factor analysis, therefore this is a recognised limitation of this scale.

As a measure of divergent validity, as hypothesised, the ISMI-X Stigma Resistance subscale did not show a significant association with the DISC Treated Unfairly subscale ($r= 0.127$, $p= 0.488$). This result is commensurate with the work of Ritche et al. (2003), Lysaker et al. 2007 as well as Sibitz, Unger, Woppaman, Zidek, & Amering (2009) who explain that the Stigma Resistance subscale measures a different construct.

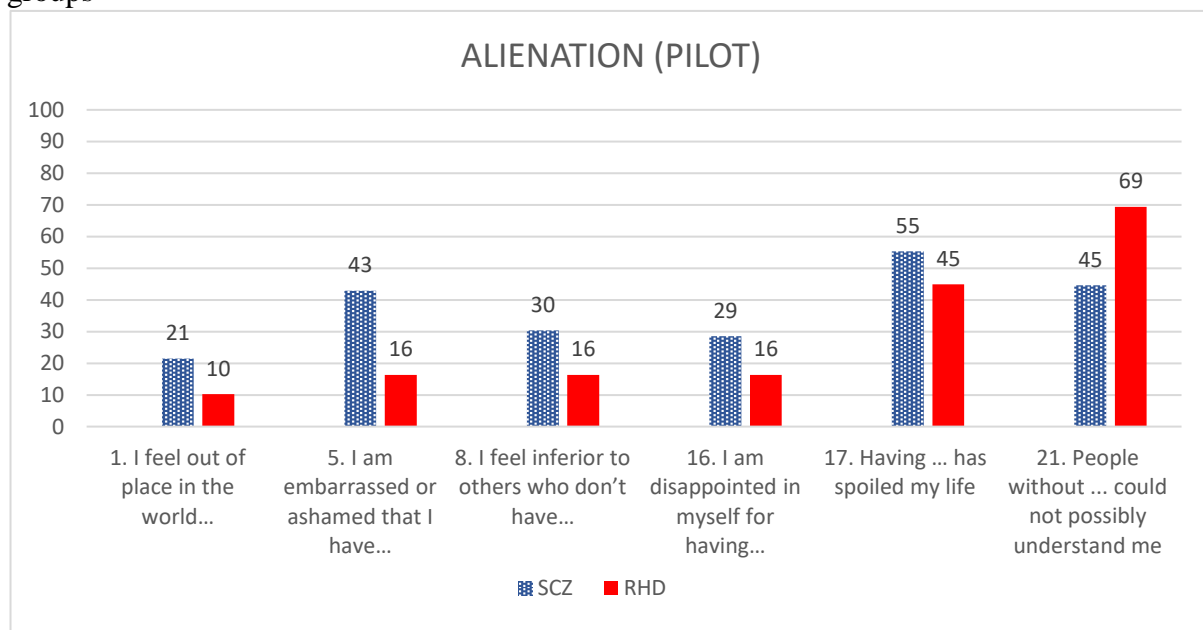
- **Content Validity**

Content validity refers to the relevance of each item for the particular cultural and disease group (Smit et al., 2006). One method is to examine items which are most frequently and highly endorsed by participants for each disease group across each subscale. This is an attempt to detect items which are relevant and meaningful in relation to the life experiences of the participants (Flaherty et al., 1988). In each of the subscales therefore, all of the “agree” and “strongly agree” items are tallied up and presented in the form of graphs below.

Within the Alienation domain, over 40% of participants within the SCZ sample endorsed items 5, 17 and 21 which refer to internalised stigma experiences of shame or embarrassment about their illness, feeling as though the illness had ruined their lives and that others without the illness could not understand them. These items appeared to be the most relevant and meaningful internalised stigma descriptions for the SCZ group within the Alienation domain. In comparison 30% or less endorsed items 1, 8 and 16 relating to feeling out of place in the world, inferior and disappointed in themselves because of their illness. These lower, less frequent endorsements suggest these were not as meaningful or relevant internalised stigma experiences with the SCZ group.

Within the RHD group only two items (17 and 21) received high and frequent endorsements while the remaining 4 were endorsed by less than 20% of the RHD group. These results suggest that most of the internalised stigma items in the alienation domain were not particularly relevant to the RHD group with the exception of items relating to experiences of the illness ruining their lives and that others without the illness couldn't understand them.

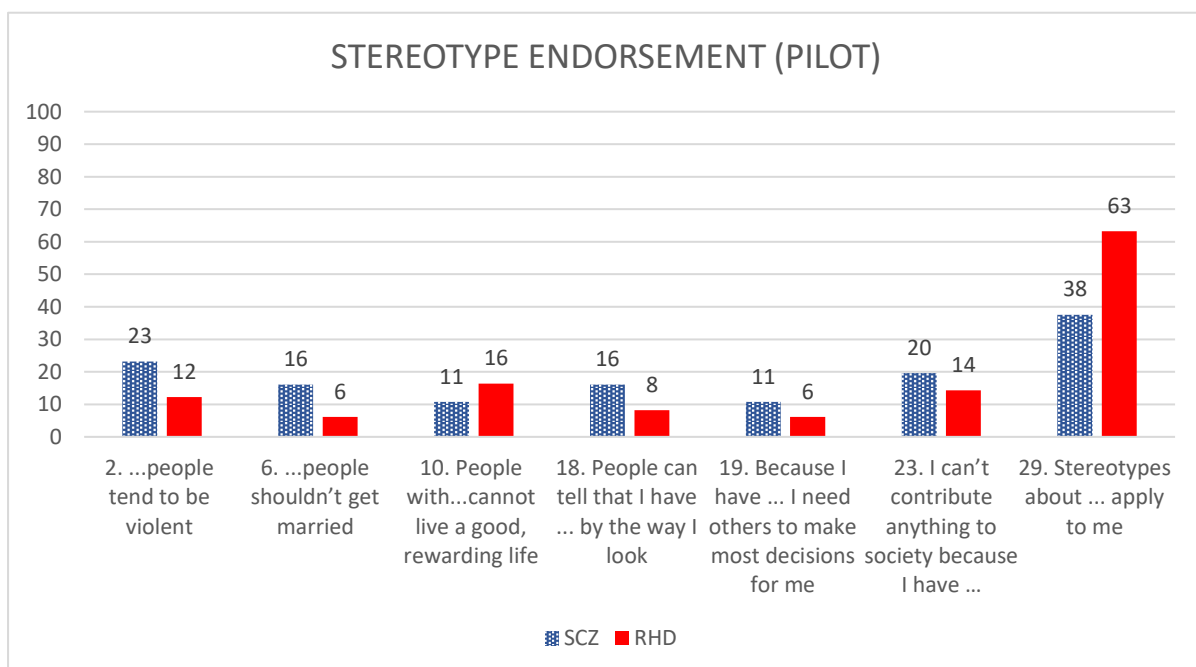
Graph 6: Comparison of endorsements of the Alienation subscale within the RHD and SCZ groups



The Stereotype Endorsement domain was poorly endorsed across both the SCZ and RHD with the exception of item 29. This is an interesting finding in that item 29 refers to stereotypes about the illness relating to the participant. While both RHD and SCZ participants seemed to endorse this experience in theory, when practical examples of stereotypes were presented in items 2,6,10,18,19 and 23, participants did not frequently endorse these experiences. One reason for this may be how the broad concept of stereotypes was translated into Xhosa. The word 'stereotypes' does not exist in the Xhosa language, but the translation team in this study decided to keep this item and thus translated the word 'stereotypes' to "*iingcamango*", which

can be directly translated to “opinions” in the English language. In the English language there is a difference between stereotypes and opinions, with the aforementioned holding a greater degree of negativity. This may have contributed to how participants endorsed items with this term. The difficulty in using the term was also discussed by Adewuya et al.’s (2011) as they reported that Yoruba-speaking patients with mental illness did not understand this word.

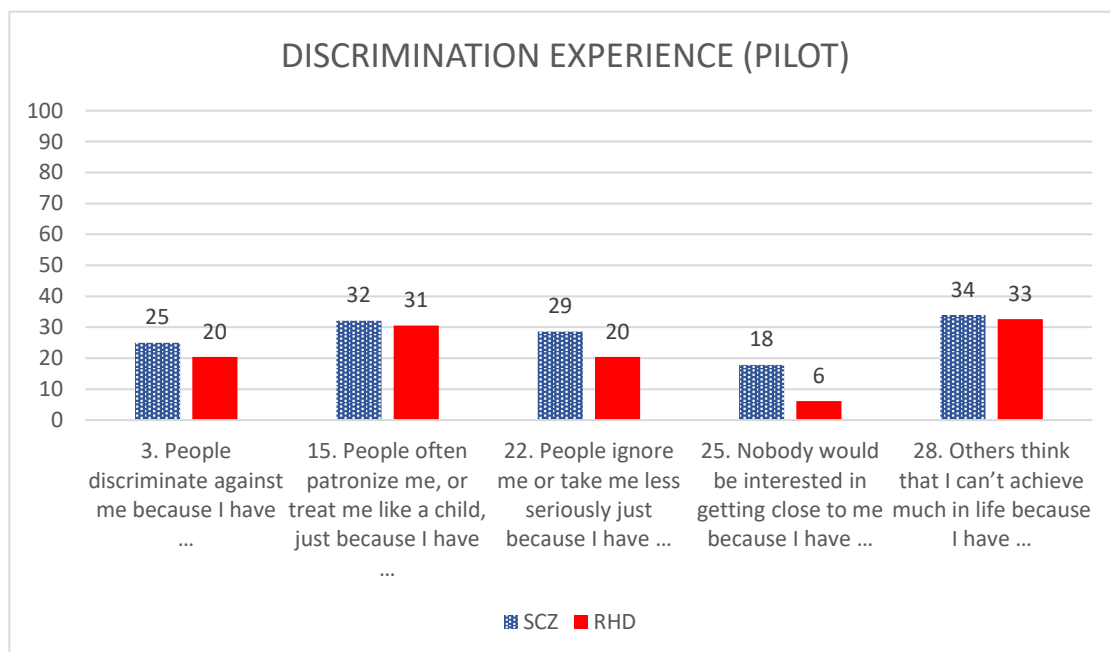
Graph 7: Comparison of endorsements of the Stereotype subscale within the RHD and SCZ groups



Generally, the Discrimination Experience subscale presented low endorsements. The items which are most endorsed (but by less than 40% of participants) are items 28 and 15. These items specifically relate to other people thinking the person with an illness can not achieve to the same potential as other people and therefore demonstrating that believe that by treating the patient like a child. The rest of the items, 3, 22 and 25 were poorly endorsed with less than 30% in both samples endorsing each of the items. These items relate to acts of people discriminating against them, ignoring them or not wanting to be close to them because they have their SCZ or

RHD. This may be further evidence for the normalised discrimination which Xhosa people have generally experienced in history, therefore suggesting that these disease label may not largely increase those discrimination experiences. It is possible that these items may not be relevant descriptions of internalised stigma accounts in this population.

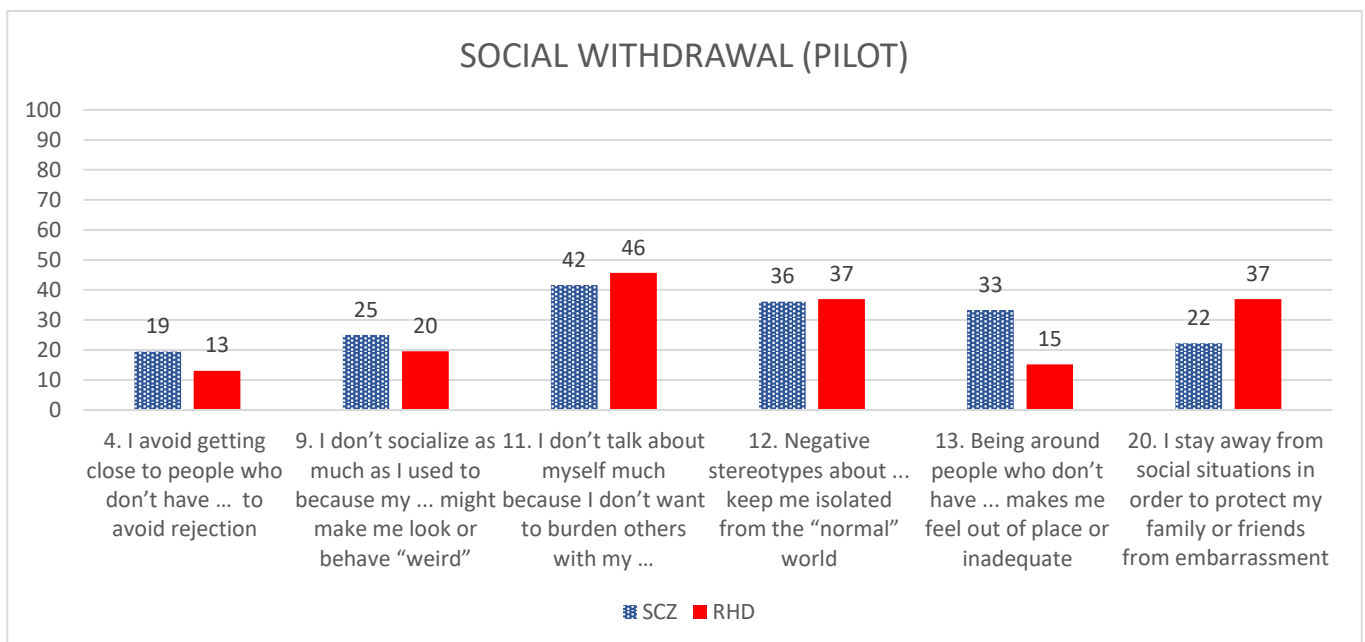
Graph 8: Comparison of endorsements of the Discrimination Experience subscale within the RHD and SCZ groups



For the social withdrawal subscale, the items which was endorsed above 40% for both the SCZ and RHD samples is item 11. This item relate to patients isolating or restricting themselves from talking about themselves to others in the fear of burdening others with experiences of their illness. The second most endorsed item is item 12, which relates to the influence of stereotypes held by others keeping patients from social engagements. This item however also uses the term stereotypes which may not be accurately understood in the Xhosa language, hence it was translated to the term ‘opinions’. This suggests that for these Xhosa individuals these

items are the most relevant descriptions of internalised stigma in this domain. The least cited items in this subscale are items 4, 9 and 20. These items are related to the fear of unpredictable behaviour causing embarrassment for the patient or the patient’s family. It is understandable that these items were minimally endorsed by RHD patients who may not have a marked change in behaviour because of their disease. Notably, more than a third of the RHD participants did endorse item 20, which may relate to an issue of answering half the question, as discussed in the qualitative pilot results below.

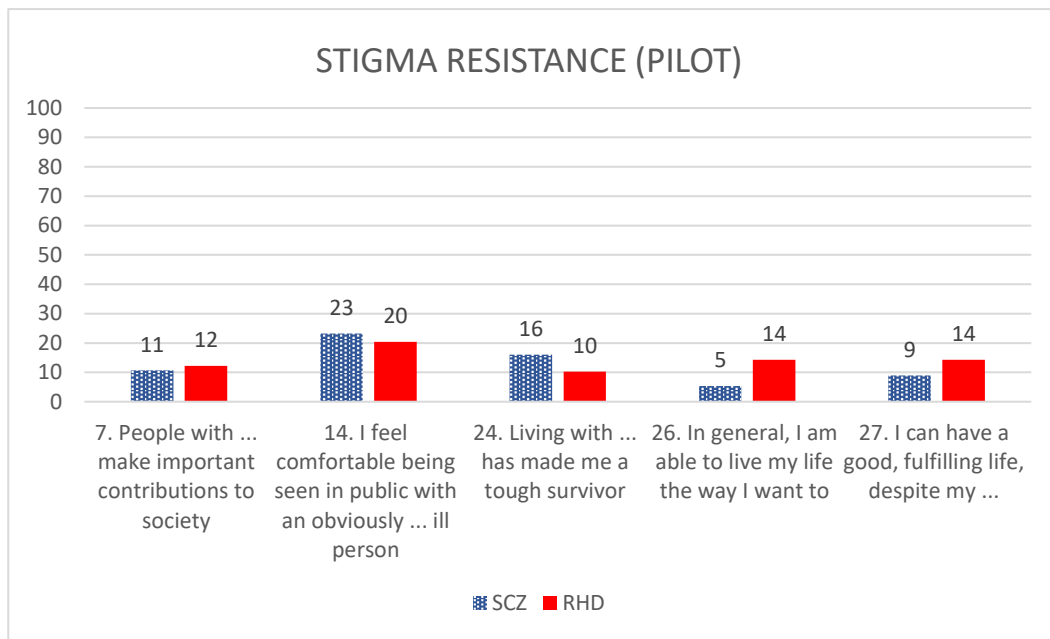
Graph 9: Comparison of endorsements of the Social Withdrawal subscale within the RHD and SCZ groups



In the stigma resistance subscale, all items across both samples demonstrated poor endorsements. This may relate to limited accounts of experiences of discrimination (as evident in the discrimination domain endorsements) or stigma. It may also relate to the internalisation of stigma experiences to the point that participants do not consider themselves as resilient

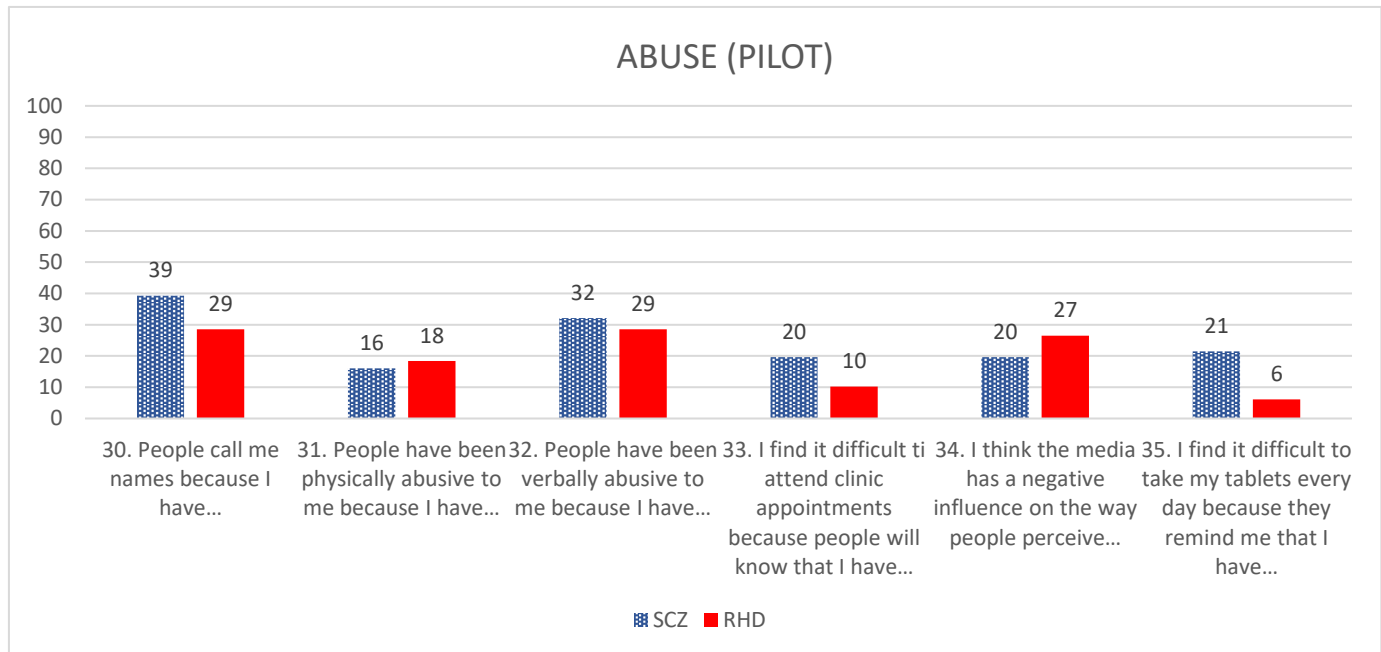
towards them. The low endorsements may also be related to the translated versions of the items. For instance, with item 7, there was much confusion regarding two commonly used terms in English, which are ‘contributions’ and ‘society’. Coming from a background of having minimal financial resources (i.e. most participants in this study being unemployed) and having a condition which compromises physical ability, participants were unsure of what kind of contribution this item could be referring to. Whether it was financial or one which requires physical strength, they often felt like they were not in a position to do so. The term society was also challenging to translate, even for the translation team, hence it was translated to the term ‘community’ which means something slightly different in English. Item 24 also contains an English idiom “being a tough survivor”. Translating that idiom to mean the same thing in isiXhosa was also difficult. These examples highlight the challenges in finding linguistically equivalent language across English and isiXhosa. Overall, across both samples the items on this domain (which as discussed earlier measures a different construct) were generally less than all the other subscales measuring internalised stigma, which could be because of the translation issues or because of items not resonating with the participants. See the stigma resistance subscale endorsements in graph 10 below.

Graph 10: Comparison of endorsements of the Stigma resistance subscale within the RHD and SCZ groups



All items in the Abuse subscale demonstrated poor endorsements below 40%. The items most endorsed in the SCZ sample is item 30 and 32. These items specifically relate to being verbally abused by others because of having SCZ. Interestingly, although poorly supported, the RHD sample also endorsed these items most within this subscale. Generally however, the items in this subscale did not show evidence that these items are particularly relevant descriptions of experiences of internalised stigma in these two disease groups. More specifically items 31, 33, 34 and 35 which relate to being physically abused, difficulty attending clinic appointments and taking treatment as they may reveal to others that these patients have the specific disease that they have and the influence of the media's broadcasting of the illness were not perceived as relevant items regarding these patients internalised stigma accounts.

Graph 11: Comparison of endorsements of the Abuse subscale within the RHD and SCZ groups



Summary

In sum, the examination of utility of the internalised stigma Xhosa language version in the SCZ and RHD disease groups demonstrates high completion rates of the scale: 47 (94%) fully completed scales in the RHD sample and 47 (78.33%) in the SCZ sample. While reduced completion rates in the SCZ sample was likely due to performance fatigue, overall these results indicate good readability and ease of use of the ISMI/ISRHD-X tools in both samples. Reliability, in the form of cronbach's α was acceptable to high for both scales across the total scales and subscales. In terms of construct validity, the instrument demonstrated good correlations across the subscales. All of the subscales, with the exception of the stigma resistance subscale, showed moderate to strong positive correlations (Brohan et al. 2013). Evidence of content validity was the most problematic with very few internalised stigma items being frequently and highly endorsed for both the SCZ group in the ISMI-X and the RHD group in the ISRHD-X. These findings suggest that many of the internalised stigma items used

in these scales are not as relevant and meaningful in the Xhosa language samples, and the disease groups we translated the scales for use in. This is a marked limitation of the Xhosa language versions of these scales. Within the ISMI-X scale convergent validity with the DISC Treated Unfairly subscale was not significant for the ISMI total scale which may suggest translation issues in either or both the ISMI-X and the DISC Xhosa version or a less marked association between discrimination and internalised stigma in this sample due to a history of systematic discrimination based on race and not mental illness. Notably, the Discrimination Experience subscale of the ISMI did show a moderate positive significant correlation with the DISC Treated Unfairly subscale ($r= 0.337^*$, $p= 0.030$). The divergent validity assessment was met as the Stigma Resistance subscale indicated no relationship with the DISC Treated Unfairly subscale.

Table 19: *Summary of the psychometric properties of the ISMI/ISRHD-X scales*

Psychometric Properties	Constitute Parts	Criterion	Was criterion met?								
Utility	Completion rate of the scales	Following the Maximum Endorsed Frequencies criterion (Brohan et al., 2013), with a criterion of $\geq 80\%$ completed responses.	RHD: Yes (94%) SCZ: No (78.33%)								
Reliability	Internal Consistency	$\alpha > 0.6$	<table style="width: 100%; border: none;"> <tr> <td style="width: 30%;"></td> <td style="width: 15%; text-align: center;">RHD</td> <td style="width: 15%; text-align: center;">SCZ</td> <td style="width: 30%;"></td> </tr> <tr> <td>Total Scale</td> <td style="text-align: center;">Yes</td> <td style="text-align: center;">Yes</td> <td></td> </tr> </table>		RHD	SCZ		Total Scale	Yes	Yes	
	RHD	SCZ									
Total Scale	Yes	Yes									

			<i>Subscales</i> Alienation Yes Yes Discrimination Experience Yes Yes Stereotype Endorsement Yes Yes Social Withdrawal Yes Yes Stigma Resistance Yes Yes Abuse Yes Yes
Validity	Construct validity	r.>.30 (Brohan et al., 2013)	RHD SCZ Total Scale Yes Yes <i>Subscales</i> Alienation Yes Yes Stereotype Endorsement Yes Yes Discrimination Experience Yes Yes Social Withdrawal Yes Yes Stigma Resistance No No Abuse Yes Yes
	Content validity	>40% endorsed – considered meaningful items <40% endorsed suggest possibly problematic, not meaningful internalised experiences in this group	RHD SCZ >40% >40% Alienation items 17, 21 5, 17, 21 Stereotype Endorsement 29 29 Discrimination Experience NA NA Social Withdrawal 11 11 Stigma Resistance NA NA Abuse NA NA
	Convergent Validity	ISMI total (excluding SR) will have a	No ($r= 0.097$, $p= 0.60$)

		<p>significant association with the DISC Treated Unfairly subscale</p> <p>The ISMI Discrimination Experience subscale will have a significant association with the DISC Treated Unfairly subscale</p>	<p>Yes ($r= 0.337^*$, $p= 0.030$)</p>
	<p>Divergent Validity</p>	<p>ISMI subscale Stigma Resistance will have no significant association with the DISC Treated Unfairly</p>	<p>Yes ($r= 0.127$, $p= 0.488$)</p>

Qualitative pilot results from the cognitive interviews

Items that challenged both SCZ and RHD participants

Feedback from the cognitive interviews ($n= 5$ SCZ and $n= 5$ RHD) indicated that a number of items on the scale were difficult for patients to understand. For both the SCZ and the RHD subsamples the following items were identified as particularly confusing:

- Item 29 “Stereotypes about the mentally ill apply to me / “Stereotypes about people with heart disease apply to me” which in Xhosa was translated to “*Iingcamango ngabantu abagula ngenqondo ziquka nam*” and “*Iingcamango zabantu malunga nesifo sentliziyo nam ziyandichapazela*”,
- Item 23 “I can’t contribute anything to society because I have a mental illness/ I can’t contribute anything to society because I have a heart disease” which was translated to “*Andikwazi ukuba negalelo ekuhlaleni nakweyiphi na into kuba ndiphazamisekile engqondweni*” and “*Andikwazi kuba nagalelo ekuhlaleni nakweyiphi na into kuba ndinesifo sentliziyo*”
- Item 24 “Living with mental illness has made me a tough survivor/ “Living with heart disease has made me a tough survivor” translated to, “*Ukuphila ndinophazamiseko engqondweni kundenze ndaphumelela kwimeko ezinzima*” and “*Ukuphila nesifo sentliziyo kundenze ndaphumelela kwimeko ezinzima*” were identified as particularly confusing.

One possible reason for these items being challenging relates to the recognised limited amount of descriptive words in the Xhosa language (Campbell & Young, 2016; Steele & Edwards, 2008). In relation to that, participants reported challenges in understanding the term ‘stereotypes’ used in the scale, (i.e. items 29 “Stereotypes about mentally ill people/ people with heart disease apply to me” “*Iingcamango ngabantu abagula ngenqondo/ abane sifo sentliziyo ziquka nam*”). The word ‘stereotypes’ does not exist in the Xhosa language, but the translation team in this study decided to keep this item and thus translated the word

‘stereotypes’ to “*iingcamango*”, which can be directly translated to “opinions” in the English language. In the English language there is a difference between stereotypes and opinions, with the aforementioned holding a greater degree of negativity, meaning there may be a difference in how people endorse those questions. This challenge also arose for item 12 of this scale, which also uses the same term ‘stereotypes’.

Another example is item 23 “I can’t contribute anything to society because I have a mental illness / heart disease” “*Andikwazi kuba negalelo ekuhlaleni nakweyiphi na into kuba ndiphazamisekile engqondweni / ndinesifo sentliziyo*”. Through the cognitive interviews, two words in this item proved difficult for the patients ($n= 3$ SCZ and $n= 5$ RHD) to grasp. The first word was ‘contribution’. Some participants thought it related to financial donations or physical labour such as participating in building community facilities, both of which many felt they were not in a position to assist with. These acts are viewed as valuable and important social engagements in the Xhosa culture. Others attributed it to sharing knowledge about their disease with people in their community. The other difficult word in this item was ‘society’, which, for the lack of finding another word, was translated to ‘community’ which is also holds a slightly different meaning. These examples highlight the challenges in finding linguistically equivalent language across English and isiXhosa. The same challenge arose for item 7 of this scale, which also used this term ‘society’.

Item 24 reads, “Living with a mental illness/ heart disease has made me a tough survivor” / “*Ukuphila ndinophazamiseko engqondweni/ isifo sentliziyo kundenze ndaphumelela kwimeko ezinzima*”, directly translating to “Living with a mental illness/ heart disease has made me overcome difficult situations”. During the cognitive interviews, patients from both disease groups ($n= 5$ SCZ and $n=4$ RHD) reported difficulty in understanding the euphemism “tough

survivor” and this item generated much debate amongst the reviewers of the translation. Following consulting the English to isiXhosa Oxford Dictionary, the translation team reached the consensus that the phrase does not exist in the Xhosa language and it is therefore best to remain with “Living with a mental illness/ heart disease has made me overcome difficult situations”. This is an example of how an English idiom, is difficult to translate to carry the same meaning in an African language.

Items that challenged the SCZ participants specifically

Items that were highlighted as particularly difficult for SCZ participants included items 9 and 4. Item 9 reads: “I don’t socialise as much as I used to because my mental illness might make me look or behave weird / *Andisakonwabeli kakhulu ukuhlala nabanye abantu njengoko ndandiqhele ukwenza kuba isigulo sam sengqondo sindenza ndibonakale kwaye ndenze izinto ezingaqhelekanga*”. Again this item may be difficult to engage with as the SCZ repeatedly reported their tendency to practice self-isolation and withdrawal from social spaces, as echoed by SCZ participants in Zerwech (2000).

Item 4, I avoid getting close to people who don’t have a mental illness to avoid rejection / “*Ndiyazikhwebula ukuba kufutshane kubantu abangaphazamisekanga engqondweni ukuze ndingaziva ndingamkelekanga*”. For both items 9 and 4, the SCZ patients reported difficulty in answering these items based on their explanations that they relate to the first part of the question ‘avoid getting close to people’, in a general sense and not necessarily solely avoid people who are not mentally ill. Hence, throughout the study many voiced their beliefs in social withdrawal and self-isolation as a protective measure or coping strategy from experiencing stigma. This may be why there is evidence of the Alienation and Social Withdrawal subscales

significantly relating to the total internalised stigma scale for the SCZ sample. This is also described in the coping strategies section (in Chapter 8) by the SCZ patients enrolled in the study.

In summary some of the challenges that were highlighted through this qualitative pilot were that, first, these Xhosa patients struggled to understand items with idioms common in the English language, but foreign to their home language. Second, for the translators it became evident that English colloquial expressions were very difficult to translate into conceptually equivalent Xhosa terms – which is similar to what other scholars found (Campbell & Young, 2016; Steele & Edwards, 2008; Swartz & Drennan, 2000). Third, an African language like isiXhosa does not have many labels for specific terms. This challenge was echoed by Adewuya et al. (2011) who used the ISMI to investigate self-stigma among Yoruba psychiatric outpatients in Nigeria. For example, as mentioned earlier, participants in Adewuya et al.'s (2011) study also described that they did not know what a stereotype is. In their research, they opted to remove items referring to stereotypes in the scale.

Overall the translation design employed in this study provided very helpful insights into how challenging it was to begin engaging with the construct of internalised stigma in the Xhosa language, let alone in two very different disease groups. The resultant Xhosa translation of the ISMI for use with Xhosa people with SCZ and RHD demonstrated mixed psychometric properties, despite an extremely thorough translation design and the very best efforts by the research team. We had hoped to use the ISMI-X and ISRHD-X scales to quantify and possibly compare internalised stigma experiences across these two disease groups, but our psychometric results raise questions about the reliability and validity of scores obtained on these translated scales. As a result, we chose not to use the scales with our FGD participants.

Discussion of the process

The translation and adaptation of ISMI/ISRHD-X scales were completed within a period of nine months. This is a time and cost intensive exercise considering that the final Xhosa translation still demonstrated problematic items. In addition, it is likely that new factors associated with internalised stigma experiences, unique to the Xhosa language and how it supports experiences of stigma, as well as the unique illness experiences of the two disease groups (SCZ and RHD) may need to be integrated into these internalised stigma Xhosa language version scales in the future to ensure a more comprehensive appraisal of internalised stigma. This same finding has been noted in the literature (Campbell & Young, 2016; Steele & Edwards, 2008, Swartz, 1998). One additional limitation of this tool is that, as was done in previous translation studies, this tool was not tested with the test-retest method (Brohan et al., 2013) nor did we have a large enough sample to perform factor analysis. Piloting in a larger sample would allow for further investigation of the psychometric structure of the tool (Brohan et al., 2010a, 2010b, 2011, 2013). Hence, future studies should continue to expand on associated factors that may be meaningful to the construct of internalised stigma in Xhosa populations with SCZ and RHD, and continue to evaluate the reliability and validity of the current ISMI/ISRHD items and subscales prior to using it in their studies.

Translations of the ISMI into other European languages like Croatian (Margetić, Jakovljević, Ivanec, Margetić & Tošić, 2010), Spanish (Múnoz, Sanz, Pérez-Santos & Quiroga, 2011) and German (Sibitz, Amering, Unger, Seyringer, Bachmann & Shrank, 2011) have shown small psychometric differences with the original English ISMI version, suggesting good transportability of the measure across these different European contexts. In the African context, another translation of the ISMI scale was conducted in Ethiopia (Assefa, et al., 2012). For the Ethiopian context the Amharic version, which is the most widely spoken language in Ethiopia,

also showed good internal consistency and was thus utilised as a tool to measure internalized stigma of SCZ patients in their context.

However, this was the first translation and adaptation completed for a South African language (isiXhosa). The translation of the ISMI scale from its source language (English) into isiXhosa proved to be more challenging. Even with the extensive time and resources utilised for this process, language and cultural differences proved very difficult to overcome in some items. If resources allow it may be a better use of time in future to develop scales measuring important constructs in the particular context from preliminary qualitative research, as they may be more relevant to the context (King et al., 2007).

Limitations of the translation process

Translations of scales developed in one context for use in another context have a number of limitations. This study's translation process is no exception. Like most standardised scales (Yang et al., 2014) the ISMI scale was originally developed in a western context to measure mental illness stigma (Ritcher et al., 2003). Although there are 55 known adapted and translated versions of the ISMI scale, a number of adapted scales for different conditions (i.e. for conditions such as; Substance Abuse (Boyd et al., 2014), Eating Disorders (Griffiths, Costa, Boyd, Murray, Mitchison & Mond, 2016), Epilepsy (Boyd et al., 2014), HIV and Leprosy (Stevellink, van Brakel & Augustine, 2011) and Inflammatory Bowel Disease (IBD) (Taft, Ballou & Keefer, 2012) much like in this study, have followed the guidance of the scale developer and only replaced the term "mental illness" in the scale with the disease or condition they are aiming to investigate (Boyd, 2014).

Some scholars however, followed the same guidance and did not change the item wording but instead included other items they believed were relevant to the disease under investigation. For example, the Internalised Stigma of Depression version includes one other item which reads, “People often make fun of me because I have depression” (Boyd et al., 2014). In this study, we included six other items measuring abuse, which were cited as particularly relevant for investigating internalised stigma among South African Xhosa people (Botha et al., 2006).

Other researchers did not change the majority of item wording in the scale but did change or omit one or more items which they believed were not relevant to the condition (either in the initial translation/ adaptation phase or later in their revised or brief versions) (Boyd et al., 2014). An example of the latter is the Inflammatory Bowel Disease version (Taft, Ballou & Keefer (2012), which changed “People with mental disease tend to be violent” to “People with IBD tend to be *dirty*” and the ISMI: Leprosy Version which completely omitted this item.

Our experience from changing the disease name highlighted important limitations to consider when following that process for the Xhosa language and for the two disease groups. We therefore suggest that a more rigorous adaptation of the ISMI, applying qualitative methods, as suggested by King et al., 2007, in identifying the internalised stigma experiences unique to these two disease groups – particularly the RHD group, would have been a more effective approach.

Development of the RHD version of the ISMI presented in this work, drawing from the psychometrics and qualitative feedback of internalised stigma experiences within the FGDs may be an interesting direction for future research. The translation process, small pilot study and the ISMI/ISRHD-X study results reveal which individual internalised stigma items are

largely supported by our samples of Xhosa people with SCZ and RHD, but many would require modifications or deletions. Results from the FGDs, presented in Chapter 8 of this thesis, highlight valuable internalised stigma experiences for each disease group that are not currently included in the ISMI. In particular, the physical manifestation of RHD (i.e. fatigue, decreased productivity, difficulty breathing, ability to perform manual labour, reproductive challenges - for women - and feelings of 'inferiority' due to the label of having the disease and social exclusion from activities) identified in this study should be considered.

Notably, there would be challenges to conducting substantial changes to a standardised instrument. Firstly, for RHD patients for instance, it would require an extensive amount of time, funding and resources to identify RHD patients' experiences of stigma and then develop these into individual scale items that could be piloted in the development of a future scale. Second, the results of the newly developed instrument would not be comparable with findings in other studies in the literature. However, the data emanating from a newly developed scale starting with a qualitative component to identify themes and constructs held by the population and then including those into a scale, would yield highly relevant, context specific data that would make a valuable contribution to understanding internalised stigma experiences in different disease groups, in different languages. While this was beyond the scope of this thesis due to a lack of time and funding, we do hope that the data collected in this study provides an insightful starting point that would guide future researchers pursuing that specific endeavour.

With these limitations in mind we decided not to use the ISMI-X and ISRHD-X with our FGD participants. Instead we drew from the psychometric results to inform our second research question: (*What are the internalised stigma experiences of Xhosa people with schizophrenia*

and rheumatic heart disease?) and these insights are considered in the discussion chapter (Chapter 10) of this thesis.

9.6. Summary of the main findings of the study

Chapter 7 of this study revealed the causal attribution models held by Xhosa people with SCZ and those with RHD. The attribution models which were identified in this study include genetic, environmental, psychological, personal choices and cultural explanations. While some individuals identified one of these explanations, many held a combination of two or more of these models concurrently, suggesting the relevance of a multifactorial model for these disease groups.

Chapter 8 of this study revealed that the main stigma experiences reported by Xhosa people with SCZ are; a) experiencing bullying, b) experiencing violence or abuse, c) non-approval of marriage for a person with SCZ due to an anticipation of associative / courtesy stigma for spouse or children, d) fear of children having the disease, e) discrimination in obtaining and maintaining employment due to having the disease label. The main stigma experiences reported for people with RHD are; a) people tend to look down on them, b) reported experiences of social exclusion because of the disease label, c) experiences of negative labels assigned to patients (i.e. being 'lazy', d) employment limitations, e) limited chances of getting married were related to women with RHD, mainly due to reproductive risks associated with RHD and for men due to foreseen lack of employment/financial struggle and f) some related the frequent collection and taking of medication to people with RHD being mistaken by individuals' in the community for an indication of having HIV/Aids. Internal acceptance of these stigma experiences may lead to increased internalised stigma among Xhosa people with an SCZ or RHD disease label.

Chapter 9 investigated the psychometric properties of the translated ISMI/ISRHD-X scale. Although the scale has been widely used across different contexts with different diseases, this study found minimal evidence that the constructs of the scale are well supported – as they are portrayed in the scale items – for the Xhosa language. The construct which appeared to be the most relevant for our participants was the alienation subscale, which had three items that were endorsed by more than 40% of the samples. This supports Sorsdahl, et al. (2012) finding who used the ISMI English version scale among mental health advocacy group members in South Africa, and found the alienation subscale to be endorsed the most. The items most endorsed in the alienation subscale for the Xhosa samples in this study are;

- Item 17: “having ... has spoiled my life”
- Item 21: “people without ... could not possibly understand me...”
- Item 29: “stereotypes about ... apply to me”

The other item which was endorsed by more than 40% of participants from both the SCZ and RHD sample is under the social withdrawal subscale, this item is;

- Item 11: “I don’t talk about myself much because I don’t want to burden others with my ...”

An additional item endorsed by more than 40% of participants in the SCZ sample is item 5 which is (“I am embarrassed or ashamed that I have ...”). Overall a large number of items in the scale across both samples revealed poor endorsement rates in the pilot, which suggests that these particular items may not be relevant descriptions of internalised stigma experiences for Xhosa people who have SCZ or RHD. This is also a conclusion highlighted by Sorsdahl et al. (2012) who found that with the exception of the alienation subscale, individuals in their study reported low internalised stigma. The lack of evidence – based on the pilot process in this study – to support their relevance resulted in us making the decision not to use the scale

during the FGDs. Internalised stigma items specific to the disease and cultural groups would need to be investigated in future studies.

9.7. Chapter summary

First, the chapter discussed approaches to understanding culture and translation. Next I discussed the translation process employed in this study in order to translate and adapt the measure (Internalised Stigma of Mental Illness Scale) for use by Xhosa-speaking patients with SCZ and those with RHD. Then the chapter sought to present the psychometric properties (which included the utility, reliability and validity) of the newly developed ISMI/ISRHD-X scales. The limitations of the translation process are also discussed. Lastly, it ended with a summary of the main study findings identified in chapters 7, 8 and 9. Next, chapter 10 presents discussion based on the study findings.

CHAPTER 10: DISCUSSION, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

10.1. Introduction

This study used a mixed methods approach to explore how the causal attributions, particularly focussing on a genetic attributions held by Xhosa people with schizophrenia or rheumatic heart disease may relate to internalised stigma. The project was framed in the context of ethical concerns around how genomic research – which would likely lead to greater attribution of illness to genetics – could increase stigma associated with disease. This concern is often raised by researchers and ethics committees regardless of the condition that is being investigated. We sought to explore this concern through patients who participated in two ongoing genomics research projects at the University of Cape Town, one on rheumatic heart disease – not a traditionally stigmatised disease – and one on schizophrenia, for which there is considerable stigma.

I explored participants' views on causal explanations to disease by showing them video-based vignettes emphasising either (1) a genetic cause, (2) a gene-environment cause or (3) an environmental cause. I explored participants' stigma experiences in the FGDs through a series of semi-structured questions. In the previous three chapters, I described our study results. In this chapter, I present my interpretation and discussion of these study findings.

This study sought to add to the limited literature on genomics research and its possible impact on stigma experienced by African patients with a psychological or a physical disease. The Attribution Theory, Modified Labelling Theory and Stigma Framework are used to guide the discussion which follows. The Attribution Theory specifically focusses on perceptions of causation rather than the actual cause or the accuracy of these causal beliefs. This theory can also inform behavioural responses or actions of individuals making inferences about a condition or disease (Weiner, 1998). The theory can also be used to understand whether or not an attribution could lead to psychosocial consequences, i.e. stigmatised perceptions and discriminatory behaviours. The Modified Labelling Theory was used in this study to better explore whether the disease labels under investigation could lead to expectations of devaluation and thus internalised stigma experienced by the patients. Corrigan and Watson's (2002) Stigma Framework was used to position the discussion based on the constructs of stigma covered in their theory.

10.2. Causal models of Xhosa people with SCZ and RHD

Question 1: What causal models are employed by Xhosa people with schizophrenia and people with rheumatic heart disease to explain their illness, and to what extent do genetic explanations play a role in these causal models?

To answer the first research question of this study, we asked patients what they attribute to be the cause of their disease, what they know about genetics and how they think genetics may have played a role in their disease onset. As described in Chapter 5, the Attribution Theory suggests that disease attributions are based on locus of control (internal vs external), controllability (controllable vs uncontrollable) and stability (stable vs unstable).

10.2.1 Genetic Attribution

The first major finding of this study is that most participants with SCZ and RHD were able to define genetics, and some were able to link genetics to disease causation. Largely, participants articulated that a disease related to genetics can be passed down through inheritance, and that it is possible that it may skip a generation - suggesting they may be recessive (Condit, 2010; Henderson & Maguire, 2000). How the inheritance process occurs was not clear to them. With regard to inheritance, participants largely associated “genetics” with family members and discussed genetic attribution mostly in relation to a genetic predisposition. Some thought that inheritance of genetics could occur during the period when a woman is pregnant, while others said it may occur through the birth process. In both instances, participants referenced an exchange or mixing of blood between the mother and child at some point during pregnancy. Importantly, participants expressed an understanding that a predisposition for a disease may be passed down through either the paternal or maternal bloodline.

Despite their general knowledge of genetics, the research participants did not frequently support solely a genetic causal explanation for their disease. Even though some participants were able to recall family members who had a heart disease or mental illness (without being certain of the exact diagnosis) or related that they had seen symptoms of the disease in their children, most participants were not convinced that genetics played a strong role (as suggested in the genetic determinism concern) in causing their disease. This finding suggests that these participants are not likely prone to deterministic and fatalistic thinking as cautioned by some researchers (i.e. Dar-Nimrod & Heine, 2011). The individuals who did consider a genetic explanation often did so in combination with other factors which may have “triggered” the disease.

For instance, many of the SCZ participants highlighted that if an individual has a ‘gene’ associated with the onset of SCZ, the development of the disease still required a particular trigger. Such triggers described by participants included stress (which they often called “over-thinking” – as also defined in Lund & Swartz, 1998; Ngobe, 2015; Swartz, 1998), severe poverty, substance abuse or bewitchment. Similarly, the RHD participants placed much emphasis on the influence of emotional trauma, pain and anger (what they referred to as their “broken-heart”) as triggers for the onset of their disease. Such a perception was also described by Zuhlke, Perkins and Cembali (2018) and is understandable because the heart is often associated with being the centre of a person's thoughts and emotions. Overall, solely biogenetic attributions were minimally supported by the SCZ and RHD participants in this study. This finding is largely in line with other research on South African people's conceptualisation of disease (Faure, 2018; Mbanga et al., 2002; Naanyu, 2009; Ngobe, 2015). Possible reasons for this finding are explored in section 10.3. of this chapter. The other causal explanations which were supported by individuals in this study are discussed below.

10.2.2. Psychosocial Explanations

10.2.2. a) Environmental Explanations

A large number of RHD participants related the cause of their disease to either a gene-environment explanatory model or solely an environmental model. This finding is supported in the RHD literature (Watkins et al., 2016) where high prevalence rates of RHD are often found in poverty-stricken environments, such as Africa, Asia, and parts-of Australia. In particular, in South Africa, the highest prevalence of RHD is among people living in low-income communities. For instance, Engel et al. (2011) found a high prevalence of RHD in

Langa and Bonteheuwel townships. Notably, Langa is the community from which the fictional character in the vignettes (Andile) and many of the patients recruited in this study originated.

In my study, RHD participants largely related the cause of their disease to environmental factors, or at least to an interaction of such factors with others - including genetics. This finding resonates with those from a study in the US, where Bates and colleagues used FGDs to explore people's beliefs around the causation of heart disease. Participants in this study described that even if there were a "gene for heart disease", both environmental and genetic factors would likely play a role in the onset of heart disease. Similar to this study, Bates and colleagues concluded that participants did not report a genetically deterministic view on disease causation.

Another explanation described by RHD participants in this study included past personal lifestyle experiences, such as, unhealthy eating habits, food insecurity and no access to gyms (due to financial limitations) as well as abusing substances such as drugs and alcohol. Because heart conditions are popularly attributed to a poor lifestyle (where heart disease can be prevented by eating healthily and exercising), it is unsurprising that these participants cited poor past lifestyle decisions as a contributing cause of their disease.

For the SCZ participants who come from a similar environment (i.e. low income communities), past personal lifestyle experiences were also highlighted as a contributory cause for their disease. The use of cannabis and other drugs was cited commonly as a past behaviour choice by many participants, whether during social engagements with friends or alone. One participant, for example, reported having used cannabis for 11 years prior to being diagnosed with SCZ. The influence of cannabis on the development of SCZ has been thoroughly investigated. Studies have found that individuals who use cannabis from an early age have a

higher chance of experiencing psychosis during their lifetime (Henquet, Murray, Linszen and van Os, 2005; Jones et al., 2018). This suggests that the attribution presented by participants in this study is plausible as a causal explanation. But, although evidence suggests that cannabis use is a risk for psychotic disorder onset as also acknowledged by some participants in this study, this is often only the case when combined with another factor such as genetic susceptibility (Henquet et al., 2005). In this study, participants echoed such a nuanced understanding and considered substance abuse as a trigger existing alongside other factors including a genetic predisposition.

It was surprising to witness participants cite drug use as a factor influencing SCZ causation, since none of the vignettes used in the FGDs in the present study referred to this explanation. The assumption is therefore that it relates closely to personal experiences in the participants' environment. The RHD participants who come from the same communities also highlighted the need to make an effort to avoid spaces where drugs are easily available. For them, it was regarded as a good practice to stay away from these spaces as it would otherwise adversely affect the management of their disease. This of course is well known regarding substance use in South African townships (Parry, 2005).

9.2.2. b) *Psychological Explanations*

Psychological explanations were also highlighted by participants in the study, relating them to stress and trauma. Stressful life events such as childhood trauma which included different forms of physical, sexual and emotional abuse and the loss of a parent or sibling at a young age, hold significant health implications. In South Africa, black people are disproportionately more exposed to stressful life events and psychological stresses due to higher rates of low socioeconomic status. In the low-income communities my participants come from, one

particular phenomenon is crime and violence (Ngqela & Lewis, 2012). RHD and SCZ participants in my study reported that high rates of crime and violence translated into a background fear of experiencing violence because of their disease. The knowledge of not being in a safe environment may affect mental wellness (Ngqela & Lewis, 2012).

The hypothesis that stress affects the onset of SCZ is explained in the Traumatic Neurodevelopmental (TN) model of schizophrenia, discussed by Read, Moskowitz and Collony (2001). The TN Model documents similarities between the effects of traumatic occurrences on the development of the brain, as well as the biological abnormalities found in people with SCZ (Read et al., 2001). Read and colleagues argue that for some adults diagnosed with SCZ, traumatic life events or significant losses and deprivation may not only "trigger" SCZ but may also mould the neurodevelopmental abnormalities which underlie the heightened sensitivity to stresses which are often found in adults who are diagnosed with SCZ, if they occur early enough in the individual's life and/or are sufficiently severe.

Applying the TN model, Read, Morrison and Ross (2005) describe that it is critical for researchers and clinicians to explore experiences of early traumatic events and stresses among patients with psychotic symptoms. For instance, many of the participants in this study highlighted experiences of child physical and emotional abuse, which is consistent with the literature on child abuse and psychosis in general as well as within SCZ (Read et al. (2005). These earlier traumatic experiences were echoed in this study.

With the RHD sample we found that participants also expressed experiences which impacted them emotionally (such as emotional abuse and in some instances physical abuse)

which they also described as “triggering” their disease onset. In particular, for the RHD group, stress in relation to poverty and to childhood trauma were highlighted as a strong causal explanation for the onset of the disease. Similarly, for the SCZ group, stress enacted through “thinking too much” because of the circumstances they lived under was attributed to causing the disease.

Although there is no known literature to support this causal effect in relation to RHD, there is general evidence that suggests that psychological stressors can "trigger" heart disease. Dimsdale (2016) and Skeptoe and Kivimaki (2013) for instance emphasise that there is evidence for the deleterious effects of stress on the heart. These authors further elaborate that vulnerability and resilience factors play a role in enhancing or reducing those effects.

10.2.3. Cultural Explanations

Cultural causes were cited by many participants in this study. Many of the SCZ participants supported cultural causes – which they described as bewitchment – for their disease. Given that over 90% of the SCZ participants are Xhosa males who have a low-level of education, this finding supports Naanyu (2009) who found that black South African males who have a low-level of education are more likely to endorse non-biogenetic explanations for mental illness. Currently it has been 25 years after the country became a democracy, yet black South Africans continue to be deprived of adequate educational facilities, which means that it is likely that they may not be as exposed to modern scientific knowledge about biological disease causation as they are to cultural explanations which may be held by members in their community.

Understanding the cultural explanations held by different African cultures is a critical step

in understanding how the cultures develop their disease causal models. Attention to cultural understandings of physical and mental health has gained traction as an important element in mainstream medical literature (Stewart, 2003). Previous studies conducted in Ghana (Kyei, Dueck, Indart, & Nyarko, 2012), Ethiopia (Assefa et al., 2012), Kenya (Mamah, et al., 2012; Muga, & Jenkins, 2008) and South Africa (Mbanga et al., 2002; Swartz, 1998) report that a large number of African patients refer to cultural belief systems when considering disease causation. This finding is evident in my data for both RHD and SCZ participants. Many participants across both groups (although more so in the SCZ sample than the RHD sample) related the “root cause” of their disease to cultural explanations. In contrast to the US culture, which Sabatello (2018) describes as highly individualistic, the cultural explanatory model often held by Xhosa people considers multiple supernatural factors external to the individual having a collective role in causing a disease (Mkhize, 2003; Naanyu, 2009; Nwoye, 2015).

Although, I did not intend to explore these cultural beliefs on disease causation, in the course of my FGDs it became evident that many participants cited witchcraft, evil spirits and sorcery as reasons for the onset of the two diseases. Congruent with previous research (Campbell et al., 2017), bewitchment was reported as a common causal explanation in the SCZ sample, but surprisingly also featured as a causal explanation for RHD. Participants describe bewitchment in one of three ways: Firstly, participants explained that it was possible for an individual who desires to bewitch another to consult with a witch doctor (traditional doctor) in order to obtain *muti* (traditional herbal medicine) which would allow them to poison the individual they wished to bewitch. Secondly, participants described the act of magically sending evil spirits (*umoya omdaka*) to the individual they wanted to bewitch. Finally, participants described that bewitchment could occur through a dream

(ukuthakatha ngephupho).

These definitions were consistent with those provided by traditional healers (Bantjes et al., 2017; Mzimkulu & Simbayi, 2006). A primary reason for people to use witchcraft to bewitch another was reported by participants in this study to be jealousy. The desired outcome is to negatively affect a person's wealth, mental health, or physical health. These participants' accounts of the cultural explanations of illness feed into a bewitchment framework (Campbell et al, 2017) which has been supported in research relating to mental illness in other African populations, such as the Sotho people with SCZ (Mosotho, Louw, & Calk, 2011) and depression (Mosotho, Louw, Calitz, & Esterhuysen, 2008) in South Africa and in the surrounding African countries such as Namibia (Maslowski, Rensburg & Mthoko, 1998).

The evidence from this study suggests that this causal explanation is important to consider in genomics research conducted in African population groups, primarily because it plays a critical role in their health models. Particularly, for Xhosa people with SCZ and those with RHD, this explanation is identified as critical in relation to understanding conceptualisations around disease causal explanations.

Naanyu (2009) denotes that African cultural groups may be drawing their causal attribution models based on beliefs passed down through generations; such in this study the example of a disease being associated with a genetic cause prevalent in a particular family that was suggested by some participants to having results of the entire clan group being associated with that disease. Africans may also have different cultural beliefs which may uniquely inform their perceptions on genetics having an influence in causing a disease (O'Neill, McBride, Alford and Kaphingst, 2010). Genetic and cultural attribution are

sometimes thought of as independent, however it is possible that these two causal models may interact and when conducting genomics research on African populations it may important to consider both.

This study found that Xhosa people with SCZ and RHD attribute a multitude of casual explanations to their disease onset. How they decide on their held causal attributions is complex, and as found in Bates (2005), the transmission model of genetics information, in a linear and causal sense, does not hold up well with this population group. Scholars such as Dar-Nimrod & Heine (2011) have suggested concerns around deterministic thinking, i.e. fears of individuals being exposed to information about a genetic cause to disease resulting in the belief that a disease is caused solely by their genes, therefore creating beliefs that it is fixed and unchangeable. This is also referred to as genetic fatalism (Bates, 2005). Evidence from this study is in contrast to that belief, as we found that individuals were open to considering a genetic cause for their disease – if aware of one – but they integrate that knowledge with their already held causal beliefs. The causal explanations these participants held, often concurrently, included both the biomedical model of illness, as well as alternative causal illness models. The alternative causal explanations included psychosocial causes (such as environmental, lifestyle choices, and psychological) and cultural explanatory causes. Even though there is no easy way to separate the causal explanations, in this study there was a definite emphasis on non-biogenetic causes.

10.3. Genetic causation vs other Causal Models

There are at least three possible reasons why participants in this study predominantly highlighted environmental and cultural explanatory causes for illness, rather than biogenetic

explanations. Firstly, it is important to consider the participants' sociodemographic backgrounds. The socio-demographic factors of participants in the study (see Table 2, Chapter 6 page 78) indicate that the level of education of these participants is low, (roughly 50% of the RHD sample have a Grade 11-12 level of education and 33% of SCZ participants have Grade 11-12), which is a low level of education when compared with, for instance, participants in genomics studies in North America (i.e. Sabatello et al., 2015). In the Sabatello et al. study (2015) which investigated the effects of genetic attribution on stigma related to epilepsy in a US sample, more participants had college degrees (52%). From other research (Naanyu, 2009) conducted in South Africa, we know that black South Africans with low-levels of education endorsed non-biogenetic causes for mental illness, which may be because of the lack of exposure to biological explanations through education curriculum. Given that exposure to scientific biomedical information is a known contributing factor to influencing causal beliefs (Condit, 2010) the lack thereof can explain the limited emphasis placed by these participants on that disease causal model. Other studies on physical diseases (Bham & Ross, 2005 & Hundt et al., 2004) also found that black South Africans articulated environmental and cultural explanations for disease onset. Thus, individuals who have a higher level of education, may be more prone to accepting a genetic explanation to disease in comparison to those who may not as they may have been exposed to modern medical thinking. This would be consistent with Phelan et al. (2006) who propose that individuals who have had exposure to medical thinking are more likely to endorse genetic attributions to illness and seek biomedical treatment.

Secondly, participants who identified other causes instead of a genetic explanation may have done so due to the complex nature of the science and of the genetic contribution in these two diseases. For instance, Muhammad (2018), who investigated the genetics of RHD through the

use of twin-studies, reveals that there is a shared genetic susceptibility in identical twins. In addition, Engel, Stander, Adeyemo and Mayosi (2011), as well as Muhammad (2018) report that there is an increased concordance in developing Rheumatic Fever (RF) in monozygotic twins in comparison to dizygotic twins. Overall, regarding RHD, quantitatively, the heritability in twin studies has been estimated at 60%, with up to six-fold risk in monozygotic twins compared with dizygotic twins (Engel et al., 2011). Finally, Engel and colleagues (2011) document that familial and twin studies provide evidence of genetic susceptibility in RHD. However, the pattern of inheritance in RHD does not follow the simple mendelian single-gene inheritance, and in fact, is difficult to comprehend. Which is in support of Masiye (2015) who found that within the RHDGen study, there was difficulty in understanding scientific terms such as genomics, genetics and genes.

Although data from those studies supplies critical evidence of possible heritability and genetic susceptibility of RF and RHD, precisely how this information can be thoroughly translated and understood by patients especially those with low-levels of formal education is not clear. Findings from Faure (2018) for instance indicate that RHD patients mostly do not consider their disease cause in relation to genetics, but rather to multiple factors including environmental and personal choices. Richards and Ponder (1998) note that, even in Western contexts, among lay people where there is an assumed higher awareness of genetics, the relationship between concepts such as “genes” or “DNA”, and inheritance of disease, are not clearly understood as they are too complex. This suggests that the challenges faced by health practitioners and researchers in explaining these terms, and the challenges faced by patients with low levels of education to fully understanding genetic explanations, may account for why Xhosa RHD participants were not certain of the role of genetics in the onset of their disease. This may also

be a reason why they attributed their condition to alternative causes which they find easier to access, understand and make sense of.

Similar findings in the SCZ patients sampled for this study provides further support for this possible explanation. Research suggests that SCZ is highly heritable. In 2014, a systematic review was published by the Schizophrenia Working Group of the Psychiatric Genomics Consortium (PGC) on the biological insights of SCZ, relating to genetic *loci* (Schizophrenia Working Group of the Psychiatric Genomics Consortium, 2014). In their study, they provided findings for 128 independent associations covering 108 conservatively-defined *loci* that reach genome-wide significance. Although they provide novel findings (i.e. 83 conservatively-defined *loci* that reach genome-wide significance, but which had not been reported) these associations do not necessarily imply genetic causality. How heritability translates into inherited genetic variants in the aetiology of schizophrenia is complex in itself (see, for example the Sullivan, Kendler and Neale, 2003). A lack of clarity in the scientific community makes the translation of these findings into accessible and meaningful explanations for SCZ patients, especially those with low levels of education, extremely challenging. Add to this an additional layer of language translation of these explanations into Xhosa, where the language simply does not have the linguistically equivalent vocabulary to support them, means researchers find themselves with considerable challenges in ensuring that genetic explanations are accessible, understandable and meaningful for these patients.

Finally, the most obvious explanation for their condition for almost all of the participants in this study is the experience of poverty. Many diseases prevalent in South African low income communities are intimately related to the experiences of deprivation which can be understood based on the history of apartheid and segregation in South Africa (Swartz, 1998). Even though

it is 25 years following the end of the apartheid era, the consequences of it are still largely felt in township and rural communities. Black South Africans have mostly been disadvantaged and largely at the receiving end of marginalisation and discrimination. One past relevant example is the Group Areas Act in 1950, where black South Africans were moved from fertile to infertile land based on their racial profiles (Mesthrie, 1993). Xhosa people were moved to the Eastern Cape Province of South Africa. Most of them did and continue to reside in rural, underdeveloped areas in the Eastern Cape (Mesthrie, 1993). Some moved to more urbanized provinces, such as the Western Cape, where they mostly reside in townships. This is important to note, since Goffman (1963) documented that gaining an understanding of stigma requires an acknowledgement of the stigmatised group's social structure. Culture, history, and present sociodemographic characteristics matter when one considers stigma. In this light, below I discuss the findings relevant to the second question of this study, which explores whether and how these Xhosa patients experience internalised stigma.

10.4. Internalised stigma experiences of Xhosa people with SCZ and RHD

Question 2: What are the internalised stigma experiences of Xhosa people with schizophrenia and those with rheumatic heart disease?

This study found that Xhosa people with SCZ do experience internalised stigma. This finding echoes the findings of Botha et al. (2006) who investigated internalised stigma experiences of South African patients from diverse language backgrounds (including first language isiXhosa-speakers) through the use of the Internalised Stigma of Mental Illness Xhosa scale. The uniqueness of this study lies in that it uses a mixed-methods approach, and draws on rich qualitative data shared by Xhosa patients living with SCZ or RHD. Patient perspectives,

particularly patients with a mental illness, have not largely been included in research studies in South Africa. Following the constructs discussed in Corrigan and Watson (2004) as well as Thornicroft et al's (2007) (see chapter 4 of this thesis) descriptions of their framework of stigma, this study found that the participants in this study conceptualised their internalised stigma experiences in relation to: stereotypes (negative connotations); prejudice (ignorance or misinformation); and discrimination. While not using these direct terms, SCZ patients in this study described a range of these experiences in various domains of their lives. The Modified Labelling Theory by Struening et al. (1989) was also considered in order to understand how the label of the disease may produce different outcomes from participants, i.e. the theory proposes that some individuals will either be secretive about their disease, try to educate others or withdraw from social contacts due to the fear of rejection. Importantly, this study also provides evidence that the RHD patients in this study do report internalised stigma experiences which will be discussed below under the different disease labels.

SCHIZOPHRENIA

Stereotypes

This study found that the stereotypes related to SCZ in this population group were that people with SCZ are perceived as 'dirty', 'ugly', 'unpredictable' and 'violent'. These are commonly cited stereotypes about people with SCZ in preliminary research from the perspective of the general public (Angermeyer & Matschinger, 2004), family members (González-Torres, Oraa, Arístegui, Fernandez-Rivás & Guimon, 2006) and health care professionals (Schulze & Angermeyer, 2003). Given that these are perspectives often held by members of the general public, caregivers and even health professionals (Harangozo et al., 2014; Ross & Goldner, 2009; Schulze & Angermeyer, 2003), it interesting to see them echoed in this study by the patients themselves about other patients with the disease. This suggests that these participants

have internalised or are in agreement with the generally held stereotypes and views often associated with a person with a SCZ label. This is also evident in that the item which was most endorsed by SCZ patients in the ISMI-X pilot sample in the stereotype subscale which reads “stereotypes about ... apply to me” (n= 38%). Participants also associated a person with SCZ as unable to communicate appropriately, hence some felt that having this disease meant they would not be able to attract and communicate with a potential spouse. Difficulty attracting a partner therefore led to feelings of limited chances of having children of their own. A decision to not have children was associated with; the fear of passing on the disease to offspring; the fear of not being able to take care of their children (physically and financially) because of their disease; and the fear of their partner and children experiencing stigma and discrimination because of their parent’s disease – what can be called “anticipated stigma and discrimination”. Based on the commonly held stereotypes about SCZ, many of these patients articulated an expected outcome of rejection. Based on the ISMI-X pilot data how these participants cope with this expectation is by practicing alienation and social withdrawal.

Prejudice

Participants described several ways in which the stereotypes about people with schizophrenia were internalised, and this affected their self-esteem. The feelings of “learned helplessness” and inferiority were articulated to affect their self-esteem. While the feelings of disgust and shame expressed by some patients about engaging with a person with SCZ suggest that these patients would even detach themselves from themselves if they could. This is depicted in one participant’s statement saying “who would want to be around someone who has schizophrenia”. This may be why many of them distanced themselves from the label of SCZ, and rather reflected on “when they were ill”, as though SCZ is not a chronic life-long disease. This is potentially the best way they can limit the feelings of not wanting to live with

themselves having that label. Again this finding is reflected in the ISMI-X pilot data results where 55% of SCZ participants endorsed the item “Having ... has spoiled my life”, and 45% endorsed the item “People without ... could not possibly understand me”. These are suggestive of the internalisation of society’s views on individuals with a disease label of SCZ.

Discrimination

Most of the stigma and discrimination mentioned was as a result of prejudice and stereotypes about people with SCZ, such as that they are ‘disabled’, unworthy of receiving the same human rights (i.e. marriage and having children) as “normal” people and that they are incompetent (for instance, in terms of employment). In the social context, the SCZ group highlighted three recurring stigma experiences regarding family, friends and community. Firstly, at the family level, most participants emphasised that they were subjected to discrimination (i.e. not being treated like their siblings or being treated as inferior, some even highlighting being introduced by family members to third parties as ‘the child with the mental problem’). This discrimination was thought to affect how external people (including those from their community) treated them which in turn affected how they felt about themselves. This is reflected in Link et al.’s (1989) description of the Modified Labelling Theory which describes that individuals internalise the social conceptions enacted by the people in their social networks in relation to their mental illness and this affects how they view themselves. This is evident in the ISMI-X pilot sample scale items endorsed most in the discrimination experience subscale, as 34% endorsed the item “Others think I can’t achieve much in life because I have ...” and 32% of participants agreed that “People often patronise me, or treat me like a child because I have ...”.

SCZ participants also shared experiences of lost friendships and/or decisions to socially withdraw from friends since receiving the SCZ diagnosis, often because of the negative

attitudes (prejudice) and stereotypical beliefs held by friends and people in their community about mental illness (Hugo, Boschhoff, Traut, Zungu-Dirwayi & Stein). Hence, some participants explained that they maintained social distance as a result of experiencing verbal and physical abuse. Being in a community where violent behaviour is normalised and frequently reported as a behaviour-correcting “solution” by many of the participants in this study and others (Botha et al., 2006), the fear of violence as a reaction to stigma is a valid and understandable threat for people living in township communities in South Africa (Ngqela & Lewis, 2012). For these patients, the fear of stigma itself could be so highly internalised that it leads to isolation as a protective behaviour in what Phelan (2005) terms as “anticipatory stigma” or anticipatory discrimination.

While these experiences seemed to trouble the participants, they portrayed an understanding that the behaviour they received from others would be fuelled by family and community members’ ignorance and misinformation about mental illness. As a means to rectify such ignorance, some participants suggested that nurses and doctors should engage with communities and share knowledge about mental illness, to inform general public and their families and communities.

In relation to finding and maintaining employment, as found in the UK by Dinos et al. (2004), disclosing a diagnosis of a mental illness to employers carries many disadvantages. Firstly, some participants reported being dismissed from their jobs or being undermined by employers – as if they were incompetent (Angermeyer & Matschinger, 2004). Secondly, they expressed being made to feel like an outcast by other employees (othering). For participants in these two disease groups, this resulted in a decision to refrain from applying or continuing with employment once diagnosed. While this created a sense of dependency – as the participants no

longer had a salary of their own – the discrimination and the ‘anticipated discrimination’ these patients believe they would receive in the employment environment proved too great for them to willingly engage in it.

Others reported fear of disclosing their mental health condition on their résumé as that may influence employers to have negative views about employing them which further prohibited them from obtaining employment. With these examples the outcome enacted by the patients would often be secrecy. These findings would be important to consider in developing the work on an internalised stigma measure for Xhosa people with SCZ.

RHEUMATIC HEART DISEASE

Stereotypes

The most commonly cited stereotypes about living with RHD reported in this study were that a woman with RHD cannot have children, and that if one has RHD they cannot maintain employment. The reproductive consequences were also described in Chang et al. (2018) and the limited employment prospects belief was described by participants in Faure (2018). Another stereotype which has been associated with RHD is the misconception that the individuals have HIV/Aids, which I found in this study but is echoed by Chang et al. (2018).

Prejudice

Negative attitudes related to the first stereotype were articulated by participants in this study. The reported negative attitudes were from members of the community, the family, medical practitioners, as well as from the individuals with RHD themselves. The community members may believe that a woman with RHD may not bear her own children, making her “less of a woman”. While it is true that pregnancy is a potentially lethal health challenge for females with

RHD because of additional pressure on the heart caused by greater blood volumes, there are measures which can be put in place to assist a woman with RHD to have a child of her own. Due to the real risks of pregnancy however, generally female RHD patients reported frequently being advised by medical professionals to not attempt pregnancy – especially in communities where there are minimal health resources to monitor their pregnancies (Chang et al., 2018). Most of the women with RHD in this study shared that they had been told by their doctor that their heart is not strong enough to support a pregnancy. These participants echo those from Chang et al. (2018) who reported that 100 percent of the Ugandan women with RHD in their study ($n= 50$) reported receiving the same information from medical practitioners. Internalising this real possibility – of not having children of one's own – was deeply traumatic for many patients in this study, with some of them weeping in the focus groups. Chang et al. (2018) agreed that “society looks down on a woman who cannot have children due to a heart condition” and from the patients in this study's reactions, this affects their sense of self. Additionally, RHD patients had negative preconceived attitudes and hopes regarding finding and maintaining employment. This was due to the physical limitations they have because of the disease (i.e. inability to carry heavy things or walk long distances). Due to their low-levels of education, the realistic possibility of finding employment often meant getting jobs which require manual labour (e.g. construction). There was a shared belief however that their physical limitations compromised their possibilities for obtaining such employment. For the Xhosa men who are often culturally expected to be breadwinners, this proved to be a difficult reality to bear. Financial reliance on others could result in males experiencing name-calling and negative attitudes from those in their family and community. This however was not the same for women. Furthermore, there seemed to be a public stigma experienced by some RHD patients due to the misconception that they have HIV/Aids based on their frequent collection of medication from the local clinics.

This resulted in some degree of distress for the patients and a desire to “prove” to people that they did not have HIV.

Discrimination

Many women in this study, voiced experiencing undesirable social moments including stigmatisation and emotional abuse by their partners and/or their partner’s family or the community because of their difficulty to fall pregnant and carry a child to full term. These incidents placed particular strain on marriages and relationships, especially because in African cultures there is the perception that a good marriage is one in which children are born (Cates et al., 1985). Marriage aside, single women also expressed a deep longing to have children of their own, some saying, “even if it is just to send them to the store to purchase small things like bread or milk”. Value was placed on having someone there who would be able to do those small tasks and be of company to the parent when needed.

Overall, the internalisation of the psychosocial consequences of not being able to bear children have been studied broadly, and the incidents of anxiety, concern, depression and marital problems have been reported by scholars such as Berg and Wilson (1990), Downey and McKinney (1992) and Chang et al. (2018). Contrastingly, there were some women with RHD who had had healthy children of their own despite the advice from their doctors, which resulted in other women being very hopeful to also carry their own children one day. This however, was not the general view on this topic. Generally, it was a major concern which made decisions regarding marriage and child-bearing a deeply difficult topic to resolve for these participants. The difficulty finding employment resulted in some experiences of discrimination within the family and employment sector. The unfair treatment by people in these domains may be internalised by these participants. Some reported some discrimination in social gatherings,

where people related the patient taking treatment for RHD to taking ARV's. Internalisation of these acts of discrimination could result in negative outcomes for the patient.

Very few of these descriptions are internalised stigma experiences currently captured by the ISMI and would be extremely relevant in future developments of a Xhosa language version of a RHD internalised stigma scale. Based on insights from the ISMI/ISRHD-X pilot data, the internalised stigma experiences which were commonly shared by participants in the two (RHD and SCZ) samples, albeit to somewhat different degrees, were that: 1. "Having ... has spoiled my life" and 2. "People without ... could not possibly understand me" ; 3. "Stereotypes about ... apply to me" and 4. "A person with their disease would struggle to get employment".

The differences, identified through the qualitative findings, between the two samples is that many of the SCZ patients felt that it would be difficult for someone with the disease to find a partner for marriage due to the consequences of social distancing. The SCZ sample often felt that people would not want to associate with someone who has SCZ. Reasons given were that the person would decrease their 'social status', would be embarrassed by them because they would not be able to act in a socially appropriate manner. By contrast, the RHD patients thought that it is certainly possible to find a spouse when one has been diagnosed with the disease, on condition that it is someone who makes an effort to learn about the disease and thus support the partner with the disease. Many of these participants felt that they would gladly support another person with RHD, share experiences and encourage them to live a healthy lifestyle while maintaining their disease. With this group there were minimal accounts of social distancing reported due to the disease label. These important differences highlight why it would be important in future studies to carefully adapt internalised stigma scales to reflect stigma experiences unique to the disease group under investigation.

10.5. How genetic attribution may relate to stigma

Question 3: How do the genetic disease causal explanations of Xhosa people with schizophrenia or rheumatic heart disease relate to their internalised stigma experiences, if at all?

The third question guiding this study was how genetic explanations of disease could relate to internalised stigma experiences. This question specifically takes issue with the often-repeated but ill-founded assumption in ethics literature on genomics research that it can lead to or increase stigma associated with diseases. This study found that stigmatisation related to genetics is complex and difficult to pinpoint, especially in the unique historical, environmental and cultural dynamics in South Africa. While many of the participants reported various forms of internalised stigma, these stigma experiences seemed to converge in a complex manner with the historical, cultural and environmental realities of their lives. Against a heterogeneous and dynamic set of disease causal beliefs and stigma experiences that intersect with the realities of South Africa's unequal society, genetic explanations of illness seem exceedingly unlikely to substantively influence internalised stigma experiences across the two disease groups.

In accordance with the Attribution Theory, a genetic attribution may be considered internal, stable and uncontrollable. Furthermore, findings of this study suggest that blame, rejection and anger from external parties are not likely to be attributed to the patient when the disease is believed to have a genetic factor. Therefore, internal attributions present as more tolerated by the patients. This informs the argument by Phelan (2005; 2006) that details that disease-related stigma and associated characteristics like blame, rejection and anger are greater if

the person suffering from the condition carries greater personal responsibility (Phelan, 2005; Phelan, 2006). Additionally, there is some evidence from this study which echoes Shostak et al. (2009) in suggesting that in instances of reduced personal blame and internalised stigma, stigma may be extended to family members where a disease is attributed to a genetic factor. Diallo et al. (2015) discusses this kind of genetic stigma as stigma by association – associative / courtesy stigma.

The lesser the external stigma towards the individual, the more tolerance the individual may receive from others which may result in less internalised stigma. The SCZ patients reported less tolerance and an anticipation of social distance from the vignette character and any individual who has SCZ. This was articulated mostly by individuals with SCZ, where they did not want to become friends or have the character marry into their family. In contrast, the RHD patients reported more empathy, support and tolerance for the vignette character and towards an individual with RHD – regardless of the cause. The RHD respondents had a completely opposite view, as they were willing to welcome and support another person with RHD.

In keeping with the Modified Labelling Theory, one way of to better understand the possible relation between genetic attribution and internalised stigma, is through observing the responses of participants based on the disease label. Specifically, the responses in relation to the questions which asked participants if they anticipated changes in social distance and treatment of the fictional character following a diagnosis with SCZ or RHD and being told that it is caused by genetics. The kinds of responses of individuals who have internalised stigma are expected to present are secrecy and withdrawal (as suggested by Struening et al. 1989). The kinds of responses expected from individuals who demonstrate limited internalisation of stigma related to promoting health education about the disease and no social distance to the character. The

participants with SCZ in my study often offered responses of withdrawal and secrecy, which as defined in the MLT points to increased internalised stigma. Some of the participants acknowledged that education – about the disease and possible causes – to the general public may be one way to minimise external stigma and influence public perceptions in relation to common stereotypes, prejudice and discrimination which may influence their self-perception. Most of the participants with the RHD label rejected the response of secrecy and withdrawal. These participants affirmed the need for transparency and openness as a means of providing greater awareness and education about RHD in their communities. This outcome is in contrast to the MLT model's proposed theory that individuals who internalise stigma would have an outcome of secrecy. This difference however, could be because this disease is not generally known as a stigmatised condition in communities. Therefore, patients with the disease may not be as prone to concealing their diagnosis. This however, does not necessarily mean that they have not internalised the stigma that they described. The suggested increased health education about their disease in their communities could be considered as a coping strategy to confront the reported prejudice, discrimination and stigma they receive due to having the disease.

In relation to passing on genetic traits to children, SCZ participants who presented more descriptions related to internalised stigma, discussed that they would attribute blame towards themselves if they were to have offspring with the same disease because they fear that their children would be subjected to stigma in the same ways which they have been. This can be understood in relation to *step 1* of the Modified Labelling Theory which affirms that individuals with internalised stigma internalise feelings of devaluation based on or in the fear of discrimination. Some of the RHD participants who reported having children with symptoms of RHD, did not seem to attribute the same feeling of self-blame and devaluation onto themselves.

This suggests that in this example RHD patients may not have internalised the stigma of passing on a potentially genetically related disease to their offspring.

The three ways in which genetic stigmatisation is understood in the literature is through, 1. stigmatisation through anticipation, 2. stigmatisation through rejection and 3. stigmatisation by affiliation. The latter eloquently summarises the example of SCZ patients having a fear of having children or getting married, in the anticipation that these individuals may experience stigmatisation and rejection from society due to their affiliation with the patient (DiMillo et al., 2015). This understanding of genetic stigmatisation was not shared by patients who have RHD in this study. The different behavioural responses mentioned above across individuals with the two different disease labels may provide insights on the importance of considering differences in diseases when suggesting claims about the possibility of intensifying stigma in genomics research. Additionally, when using internalised stigma scales, it is important to consider the nuanced differences of stigma shared by people with a physical or psychological disease.

Based on the Attribution Theory, in reference to the finding of other causal explanations being prominent among Xhosa people with SCZ and RHD, contrastingly non-biogenetic causes (i.e. personal lifestyle choices) may be considered external, unstable but controllable by the individual, therefore more blame and stigma may be attributed to the individual. For instance, the examples provided in this study where some RHD participants attribute the cause of the disease to personal lifestyle choices they had made (i.e. unhealthy eating habits and a lack of exercise) may be seen as being in the individual's control. A non-biogenetic explanation shared by SCZ participants is that they attributed the cause of their disease to substance abuse (i.e. using cannabis for an extended period of time). These decisions may also be viewed as within the individual's control, unstable (as they are open to changing based on the individual) and

based on the external environment an individual is in and therefore may be more stigmatising than a genetic causal model. This however would need to be further explored in future research.

Additionally, the environmental and psychological causes may also be perceived as external, unstable and uncontrollable. For example, participants who expressed being abused as children may not have had control over that situation, therefore even though they may have experienced external stigma, they may be living with less internalised stigma through the presence of low levels of self-blame or blame towards the individual. Rather, blame may be attributed to the immediate family members or those who afflicted the toxic environment the individual grew up in and may have perpetuated the psychological and physical abuse they experienced.

The cultural explanation may be perceived as external, unstable and uncontrollable, also yielding less internalised stigma for the individual. The traditional beliefs of illness causation held by these participants related to bewitchment, which was reported to be a result of jealousy by the person bewitching them (Campbell et al., 2015). A genetic explanation may be held in conjunction with cultural beliefs. An example described by a participant (P.5 SCZ FGD 2) articulates that knowing that the disease is genetic may create anticipated stigma for not only the individual, but also those in their respective clan group – given the knowledge that genetic diseases run in families (this is with the understanding that individuals may share a clan name and not be biologically related or they may come from different families). In this example, individuals from those families may be rejected by others in the community based on the suspicion that there is “something in their blood” which people need to be safe guarded against. This may relate to the “quarantine mentality” described by Markel et al. (1992), which was described earlier in the thesis as a potential reason for stigma in relation to genetics because of

society trying to keep the general population “pure” from mixing with people falling in a stigmatised group.

The lack of emphasis on a genetic attribution evident in this study could be due to the fact that a genetic explanation of disease causation’s influence on stigma may have been over-estimated (Racine et al., 2010; Appelbaum, 2017). This study therefore, in accordance with other studies (Lebowitz, Pyun, & Ahn, 2014; Lebowitz & Ahn, 2014) found difficulty in separating the genetic and nongenetic causes of disease and their possible influence on stigma.

The main finding of the study is that Xhosa people with SCZ and RHD presented a multitude of factors that may have influenced their disease onset independently or concurrently. In agreement with Spiro (1991), who reports that a person can simultaneously be described as having SCZ (a label coined following biomedicine as a discipline), be bewitched according to African cultural models and be possessed by evil spirits according to religious structures (i.e. the church for Christians). This example is fitting for many patients in this study, as most, if not all, of them are aware of the biomedical term for their diagnosis but still hold other explanations for their illness simultaneously (i.e. “being bewitched”). Even though they have been exposed to genetic explanations – through the genomics studies they have been involved in – this exposure may not have been sufficient to completely shift their perceptions to those feared through deterministic thinking. As Weiner (1986) documented, it is possible to hold more than one causal belief for developing a disease and the factors which make an individual susceptible to developing a disease may vary across different individuals. It is also certainly possible that causal beliefs vary even within a single individual at different times.

10.6. Conclusion

This thesis explored the causal models held by Xhosa people with SCZ and RHD. Through employing mixed-methods, the study focussed on gaining an understanding of the possible relation between genetic attribution and internalised stigma in these disease groups. Through a qualitative approach, the study used focus group discussions (FGDs) to explore first, the causal models held by Xhosa people with RHD and SCZ. Their responses were sought through presenting the participants with vignettes which focussed on a genetic, a combination of genetic and non-genetic, as well as non-genetic explanations and then noting their shared perceptions of their beliefs about these causes. These findings suggest that the SCZ and RHD participants attributed their disease causation to a multitude of explanations – some which were not presented in the vignettes, such as cultural causes – with minor reference to genetics. Other causal explanations, including psychosocial and cultural explanations, were more important explanatory models for these population groups. The second question of the study aimed to gain an understanding of the internalised stigma experiences of Xhosa patients with SCZ and RHD. In addition to probing responses to stigma encounters in the FGDs, the study also sought to quantify internalised stigma experiences within the two disease groups using a Xhosa translation of the Internalised Stigma of Mental illness scale (ISMI) (Ritcher et al., 2003). The study applied a five-stage translation design in order to adapt and translate the measure. Psychometric investigations demonstrated important limitations with the resultant translations which illustrated the challenges of exploring the construct of internalised stigma in African languages like Xhosa, and the uniqueness of internalised stigma experiences within different disease groups like SCZ and RHD.

To answer the third research question as to whether and how a genetic attribution may relate to internalised stigma, despite the emphasis placed on a genetic causal attribution during focus group discussions, the lack of emphasis by participants on attribution when discussing stigma

experiences suggests genetic attribution may not have a strong influence on internalised stigma for these population groups. Findings from this research are valuable in that they reveal that it is critical for both researchers and clinicians to understand the explanatory models of disease held by patients as having a plausible influence on their beliefs on treatments that are acceptable to them. Additionally, an awareness of the different explanatory models also creates an opportunity for researchers or clinicians to negotiate the biomedical explanation for the specific disease, while simultaneously creating a common ground between the patient and researcher. As was found in previous studies (Naanyu, 2009) participants in this study did not emphasise solely a biomedical explanation (i.e. genetic attribution) to their disease onset. From this investigation, three things are apparent. Firstly, even though genetics are mentioned as a possible causal explanation, there is no evidence in this study to suggest that a greater emphasis on genetics in disease causation – which could be an outcome of genomics research – would likely play any role in increasing or decreasing stigma in this population group. This is a crucially important finding, not only because the concern that genomics could increase stigma is routinely made in discussions about the ethics of such research, but also because this was the first study purposively designed to explore this hypothesis on the African continent. Secondly, even though there were reported accounts of stigmatisation, these perceptions were reported as stigma relating to the disease label itself, rather than the belief of a genetic causation. This suggests that social realities, shared patterns of belief and attribution of disease to causal explanations play a collective role in people's experiences of stigma.

Moreover, it is critical to keep in mind that biomedicine is recognised as a cultural product developed in a Eurocentric context. For this reason, the use of the biomedical approach in relation to health in a non-Western context needs to be approached with sensitivity and a cross-cultural difference awareness. Specifically, research has shown that work focusing on Africans

in particular, requires cognisance of African cultural beliefs. Thus, African cultural approaches have been described and discussed in this thesis and it is necessary to consider the differences between the explanatory models held by African people in the larger discussion of genetic attribution to disease. Culture and context play intrinsic roles in how people understand disease and therefore, cannot be disregarded when conducting genomics research.

Furthermore, in the African context, historical discourses such as colonisation led to ideas and decisions made in the Western world being imposed on Africa. Based on experiences such as those and their influence on people's perceptions, it is therefore necessary for biomedical and genomics researchers to consider both the political and historical underpinnings of the health system available for different individuals in African countries. For instance, exceedingly high levels of poverty in many African countries have resulted in substandard health care which could subsequently persuade individuals to enrol in genomics research (for monetary and special health care benefits). However, the question remains whether these individuals believe in the biomedical explanatory causal model. Building on other evidence in the literature, this study reveals that Xhosa people with SCZ and those with RHD, maintain complex explanatory models for their disease. In this regard, genetics prove to be one of multiple explanations that they hold.

The distinct decision to place less emphasis on genetics as a concern for stigma amongst the population groups suggests that this causal explanation (in isolation) is not as pertinent for the Xhosa people in this study as is speculated in other populations. Moreover given the mixed evidence found in studies with other populations, it appears that the relation between genetic attribution and stigma may not be consistent across different population groups. In this study, a strictly biogenetic view of SCZ and RHD is not commonly supported by the Xhosa people

with SCZ and RHD in this study, therefore the concerns often raised in relation to this view are not evident to hold true for these participants. In fact, the aforementioned alternative causal explanatory models, including psychosocial and cultural views are more commonly held by individuals in these disease groups and therefore, need to be considered in African genomics research. This is important because these causal explanatory models were often held concurrently. Essentially, participants drew from a combination of genetic, psychosocial and cultural causal explanations. Hence, these models may potentially hold their own implications about the experiences of stigma for people with these diseases.

10.7. Strengths and Limitations

A major limitation of this study is that it is a cross-sectional study which does not use a pre and post intervention design, meaning it can not report on causality. The accounts of participants which are presented in this study are also not enough to make a conclusion on genetic attribution and stigma. Instead, these accounts provide us with a deeper understanding as to why, for these patients, genetic attribution may not directly influence their stigma. Although this thesis presents the views expressed by participants, it is acknowledged that due to its small sample, the views expressed do not capture the entire scope of patients' beliefs of genetics (alongside other disease models) and the possible implications for stigma. Other limitations and strengths of the study are presented below.

10.7.1. Bilingual researcher

Being a bilingual, mother-tongue isiXhosa researcher with a master's level English language educational background, it was easy to build rapport, to engage and to understand participants enrolled in this study. Although the research was conducted in the participants' home language, some of the concepts explored (such as genetics) proved to be challenging to explain or engage

in discussions. Previous studies have documented challenges relating to the complexity of biomedical terminology (Tindana, Bull, Amenga-Etego & de Vries, 2012; Marshall et al., 2014 & Marsh, Kamuya, Mlama, Williams & Molyneux, 2010). This is also emphasised in South African mental health literature (Campbell et al., 2015; Drennan et al. 1991; Steele & Edwards, 2008; Swartz, 1998). Even though the study was conducted in isiXhosa, some of the participants would use English words for key terms like genetics or DNA during discussions, with occasional inconsistencies in how certain English words were interpreted in relation to their actual definition. An important challenge that this study grappled with was finding linguistically and conceptually equivalent terminology, particularly for the internalised stigma scale selected for use in this study. A real asset of this study is that it was conducted by a researcher fluent both in English and Xhosa, and with a conceptual understanding of the scientific nature underpinning the concepts under investigation.

In terms of language, within the translation process of the ISMI tool, the translation of FGD vignettes (from English to isiXhosa) and the translation of the FGDs conducted in isiXhosa to English for analysis, it was found that there is often no single correct translation for every word (Muller, 1994). An example of this can be seen with the ISMI scale, where words were proposed by the translation team, debated and utilised, with some patients unable to grasp these concepts and the resultant low endorsements of items in the scales. This in itself suggests that amidst significant efforts to ensure the most accurate translations, there is a possibility of mistranslation in the final version of the tool, which is one of the reasons we decided not to use these tools in the FGDs. Fundamentally, the difficulties of finding appropriate terminology in the Xhosa language is well documented in the literature (see Drennan et al., 1991; Muller, 1994; Steele & Edwards, 2008; Steele, 1997; Swartz, 1998). Thus, the study acknowledges this

limitation of the newly translated isiXhosa tools, in terms of capturing the equivalent constructs as the original tool.

10.7.2. Culture

Despite the commonly known power-dynamics of the research process in this study, mutual and shared cultural backgrounds between the researcher and participants allowed for easy synchronisation and building of rapport. In this regard, adhering to cultural norms created a foundation of trust based on the assumption that most Xhosa people are deeply rooted in a cultural knowledge system. In this instance, gestures such as greetings, introductions and through patients sharing their clan names with which I was familiar, made it easier to create a sense of comfort and to establish rapport before and during the sometimes deeply personal dialogues shared during the research process. In essence, this study also reiterates the importance of having a researcher who understands not only the language, but also the culture of the target population.

10.7.3. Sample

A notable limitation of the study was the highly limited and greatly skewed sample population. For instance, the SCZ sample largely comprised of young males (94.44%, with an average age of 33years). Although this is representative of the sex difference in the larger SAX study, the resultant data may not adequately represent the views of older Xhosa people, as well as Xhosa women with SCZ. Similarly, the RHD sample (in accordance with the larger RHDGen study) consisted of mostly older females (84.78% with an average age of 43 years) and therefore, these views might not necessarily represent those of younger people and Xhosa males with RHD. The sex differences are a major limitation of this research and as a result any comparisons between the two samples should be made with caution.

10.7.4. Recruitment

For both population groups, although I gained access to an extensive existing database with contact details of RHD and SCZ patients who had previously consented to being contacted for future studies, I still encountered significant challenges to accessing potential study participants. Multiple efforts were made to contact the participants enrolled in the study. Despite these efforts, the study still concluded with a smaller sample than I had aimed for.

However, the fact that this specific study falls under two then ongoing genomics studies with available databases also contributed to its strength. In this regard, having access and being able to contact patients who had been previously enrolled in these genomic studies made it easier to expand on the foundation they had previously received, and in some instances the psychoeducation on genomics they had received. Consequently, this created a sense of openness from the participants to enrol in this study, simultaneously creating ease of discussion and reference.

10.7.5. Focus groups

Low levels of literacy amongst participants accounted for the fact that most of these individuals needed assistance from the researcher or the co-facilitator of the FGDs to complete the consent and demographic information forms. This resulted in a prolonged document completion time-frame during the sessions. Additional assistance from the researcher was required based on literacy challenges faced by participants despite the fact that these documents were translated into isiXhosa for convenience. Consequently, this resulted in very long FGDs which may have led to participants being fatigued towards the end, thus influencing their responses. Fatigue may specifically have affected SCZ participants, who often had a shorter concentration span. This limitation may have affected the richness of the data yielded in the FGDs.

A mélange of factors such as differences in background, geographic location, households, as well as different coping mechanisms to living with their disease, posed various challenges on facilitating and managing the FGDs. Occasionally, participants were unaware of the behavioral skills required when participating in a group discussion (for example, participants did not understand why it was necessary to wait for their speaking turn instead of interrupting the other person). This often made hearing their responses and understanding the sequence of discussion in the group a somewhat difficult task (e.g. for the researcher when listening to the voice recordings and during transcription). Also, the tendency of some participants to interrupt and speak over others, sometimes discouraged others to respond to questions, thus resulting in numerous questions being answered either in agreement with the dominant speakers in the group, or individuals opted not to respond to the questions already extensively answered by others. Which may be a limitation to the voices and views expressed in the FGDs.

Even though identifying, recruiting and involving Xhosa people living with SCZ in group discussions was not an easy process, essentially the uniqueness of this research resides in its ability to document patients communicating their experiences in their own voice and presenting them with the opportunity to be heard. Notably, most of the research interrogating the relation between stigma and genetic attribution in a mental illness has focused on the views of the general public or people caring for people living with the mental illness; this study is an exception to that trend. Participants in this study had also completed the UBACC scale (through the larger SAX study) investigating ability to consent to research, which meant that their responses were based on a basic understanding of genomics research and the research process. Additionally, many of the participants reported the research experience to be enriching as it was the first time some of them were presented with a space to meet, share and engage with

other individuals from similar backgrounds living with the same disease. They articulated that this fostered a feeling of “I am not alone in this”.

10.7.6. Internalised stigma scale

This study provided important evidence about the limited transportability of the ISMI to a South African SCZ and RHD Xhosa language speaking group. Despite a comprehensive translation design, psychometric properties showed very real limitations with the resultant tools. Further adaptations and psychometric testing is necessary to strengthen the usefulness of the scale for the two disease groups. More specifically, in future work, qualitative data on aspects relevant to RHD stigma would need to be included in an internalised stigma scale for people with RHD. We had hoped to use the ISMI and ISRHD-X scale data to determine if there is statistically significant differences in the two disease groups – however because of the limitations of the tools – this was not possible. Importantly, our qualitative data suggests that many of the important internalised stigma experiences unique to these two disease groups were not captured by the ISMI. Even though there are some overlaps with certain experiences of stigma across the two disease groups, there are also stark differences. These are identifiable in the rates of item endorsements presented in chapter 9 of this thesis. The endorsement rates provide valuable insights going forward in terms of which items should be considered and which should possibly not be considered when developing an internalised stigma scale for these disease groups. Important adaptation involving a thorough qualitative process, needs to be done when preparing these types of scales for use in African languages and different disease groups.

10.8. Recommendations

The findings lend themselves to several recommendations. The findings of this study add to

African genomics literature and provide empirical evidence about what people of an African population group understand about genetics. Given the increase in genomics studies being conducted in the continent, and the challenges of engaging with African populations about genomics research (Tindana et al., 2012; Marsh et al., 2010; Marshall et al., 2014 & Masiye, 2015) knowledge of what African people know and believe about genetics and disease is valuable for researchers designing genomic studies for African population groups. A second recommendation is that clinicians, genomic researchers, scientists and professionals working with or treating patients with RHD and those with SCZ, should be aware of the diverse and complex causal models that patients hold about their disease. This is important because it affects how, when and why they choose to take and adhere to Western medicine provided in local health facilities. In this case, decisions around treatment are important because they affect the recovery process of the patient, their lives in general and it also has implications for their families, communities and societies at large. Considering the South African context, and more so, other countries in Africa that are grossly under-resourced (e.g. availability of medication and poor infrastructure) and the limited capacity of health staff (i.e. doctors, nurses, psychiatrists and psychologists) in these facilities, it is important to ensure that when the opportunity arises, patients are engaged with in a sensitive manner. Furthermore, dialogues around diagnosis, cause of disease, prognosis and recovery should be considerate of patients' cultural beliefs. This can be achieved by proposing and enrolling health staff in training programs which foster education in different cultural belief systems and how they understand and relate to the biomedical approach to disease (e.g. short courses, workshops, seminars, or conferences). Moreover, there is a clear need to think deeply about how to create improved accessibility for individuals who speak African languages to participate fully in health research.

Thirdly, this research has clearly indicated that ethics discussions that revolve around the risk of stigma arising as a consequence of genomics research, need to be more nuanced and take into consideration the complexity of this possible relation. Where stigma is raised as a concern in genomics research, this risk is often presented in linear terms: if you speak about diseases in terms of genetic attribution, then this increases the stigma associated with those conditions. This research – which presents the first purposively conducted study exploring this relation on the African continent – does not provide evidence of this linear relation. Going forward, where claims of stigma are made in the context of genomics, scholars need to be more specific about the circumstances in which this risk could be likely to affect African people.

Fourthly, considering the translation and adaptation of the Internalised stigma scale process employed in this study, there are important insights to be considered in future research. The most obvious being that it seems more valuable to develop measures guided by qualitative data regarding real and relevant experiences within local communities. The richness of the data revealed in this study is evidence that there is much to be gained by conducting small-scale studies with individuals living with the particular disease of interest. And considering the push for biomedicine to use dominant biomedical instruments which have proven to be useful in Eurocentric contexts, these measures need to be applied sensitively in African contexts - with researchers having some knowledge of the context and cultural background of African populations. Insights gained from this study's attempt to translate a measure developed in a Eurocentric context and to apply the measure to local populations has highlighted that there are real limitations which come with this process. In future, it is therefore important for researchers to weigh up the extensive costs of this traditional translation process and the limitations which the resultant scales may have and make a decision based on that whether it is a worthy process to follow.

Fifth and lastly, in relation to theory, it is critical for researchers to develop theories which consider the African paradigm and cultural belief models. This means that cultural components such as beliefs around bewitchment and supernatural causes and idioms commonly used in the target language should be considered in attribution theories employed in future studies among African population groups. In essence, knowledge, awareness and consideration of these elements needs to be reflected in debates around the ethical aspects of African genomics research.

In conclusion, empirical studies investigating the possible relation between genetic attribution on disease stigma are only beginning to be extended to the African context. To the best of our knowledge, there are very few published studies focusing on exploring stigma in relation to genomics in Africa. This study has therefore made a valuable contribution to the literature which explores this question among people in the African continent. The notion that genetic attribution could cause or increase stigma is simplistic and needs to be understood in the context of the nuanced and complex disease models used by African participants. As found in this study, these attribution models may be influenced by culture, personal and family history, social and economic reasons. The referred to attribution models may in turn also have implications on experiences of internalised stigma and these complexities ought to be considered.

REFERENCES

- Abayomi, O. Amato, D. Bailey, C. Bitanhirwe, B. et al. (2014) The 4th Schizophrenia International Research Society Conference, 5 –9 April 2014, *Florence, Italy: A summary of topics and trends*. 159, 2–3, e1-e22
<https://doi.org/10.1016/j.schres.2014.08.032>
- Adewuya, A. O., & Makanjuola, R. O. A. (2005). Social distance towards people with mental illness amongst Nigerian university students. *Social Psychiatry and Psychiatric Epidemiology*, 40(11), 865-868. doi: 10.1007/s00127-005-0965-3
- Adewuya, A. O. , Owoeye, A. O., Erinfolami, A. O., & Ola, B. A. (2010). Correlates of self-stigma among outpatients with mental illness in Lagos Nigeria. *International Journal of Social Psychiatry*. 57(4): 418–427 doi: 10.1177/0020764010363522
- Adewuya, A. O., & Oguntade, A. A. (2007). Doctors' attitude towards people with mental illness in Western Nigeria. *Social psychiatry and psychiatric epidemiology*, 42(11), 931-936. doi: 10.1007/s00127-007-0246-4
- Alonso, J., Buron, A., Rojas-Farreras, S., De Graaf, R., Haro, J. M., De Girolamo, G., ... & ESEMeD/MHEDEA 2000 Investigators. (2009). Perceived stigma among individuals with common mental disorders. *Journal of affective disorders*, 118(1-3), 180-186. doi: <https://doi.org/10.1016/j.jad.2009.02.006>
- Anderlik, M. R., & Rothstein, M. A. (2001). Privacy and confidentiality of genetic information: *What rules for the new science? Annual Review of Genomics and Human Genetics*, 2, 401–433.
- Angermeyer MC, Holzinger A, Carta MG, Schomerus G: Biogenetic explanations and public acceptance of mental illness: *systematic review of population studies*. *Br J Psychiatry* 2011, 199(5):367-372.

- Appelbaum, P. S. (2017) . Who's Afraid of Psychiatric Genomics?, *The American Journal of Bioethics*, 17:4, 15-17, doi: 10.1080/15265161.2017.1284937
- Assefa, D., Shibre, T., Asher, L., & Fekadu, A. (2012). Internalised stigma among patients with schizophrenia in Ethiopia. *a cross-sectional facility-based study. BMC Psychiatry* 2012, 12 :239
- Atkins, M.P. (2016). A Mixed Methods Approach to Challenging Stigma at a Faculty of Education. PhD Thesis. University of Western Ontario. <https://ir.lib.uwo.ca/etd/4051>
- Baffoe, M. (2013). Stigma, discrimination & marginalization: Gateways to oppression of persons with disabilities in Ghana, West Africa. *Journal of Educational and Social Research*, 3(1), 187-198. doi: 10.5901/jesr.2013.v3n1p187
- Bähre, E. (2007). *Money and Violence: financial self-help groups in a South African township* (Vol. 8). Brill.
- Bangura, A. K. (2012). From Diop to Asante. Conceptualizing and contextualizing the Afrocentric paradigm. *The Journal of Pan African Studies*, 5, 103–125.
- Bantjes, J., Swartz, L., & Cembi, S. (2017). “Our lifestyle is a mix-match” . Traditional healers talk about suicide and suicide prevention in South Africa. *Transcultural Psychiatry*. 55(1) 73–93 doi: 10.1177/1363461517722065
- Barth, D. (2013). *The effect of distance to health facility on the maintenance of INR therapeutic ranges in rheumatic heart disease patients from Cape Town*, Thesis submitted for the degree of MPH at the University of Cape Town.
- Bates, B.R., Lynch, J.A., Bevan J.L., & Condit, C. (2005). Warranted concerns, warranted outlooks. *A focus group study of public understandings of genetic research / Social Science & Medicine* 60, 331–344

- Beckwith, J. (1991). Foreword: the human genome initiative: genetics' lightning rod. *American Journal of Law & Medicine.*, 17, 1.
- Bham, Z. & Ross, E. (2005) Traditional and Western medicine: cultural beliefs and practices of South African Indian Muslims with regard to stroke. *Ethnicity and Disease* 15, 548–554.
- Bhana, A. (1999). Participatory action research: A practical guide for realistic radicals. *Research in practice: Applied methods for the social sciences*, 227-238.
- Botha, U. A., Koen, L., & Niehaus, D. J. (2006). Perceptions of a South African schizophrenia population with regards to community attitudes towards their illness. *Social Psychiatry and Psychiatric Epidemiology*, 41(8), 619-623.
- Bottorff, J. L., Ratner, P. A., Balneaves, L. G., Richardson, C. G., McCullum, M., Hack, T., ... & Buxton, J. (2002). Women's interest in genetic testing for breast cancer risk: the influence of sociodemographics and knowledge. *Cancer Epidemiology and Prevention Biomarkers*, 11(1), 89-95. Retrieved from <http://cebp.aacrjournals.org/content/cebp/11/1/89.full.pdf>
- Boyd, J. E., Adler, E. P., Otilingam, P. G., & Peters, T. (2014). Internalised Stigma of Mental Illness (ISMI) scale: a multinational review. *Comprehensive Psychiatry*, 55(1), 221-231.
- Boyd, J. E., Katz, E. P., Link, B. G., & Phelan, J. C. (2010). The relationship of multiple aspects of stigma and personal contact with someone hospitalized for mental illness, in a nationally representative sample. *Social psychiatry and psychiatric epidemiology*, 45(11), 1063-1070. doi: <https://doi.org/10.1007/s00127-009-0147-9>
- Boyd, J. E., Otilingam, P. G., & DeForge, B. R. (2014). Brief version of the Internalised Stigma of Mental Illness (ISMI) scale: Psychometric properties and relationship to depression, self-esteem, recovery orientation, empowerment, and perceived devaluation and discrimination. *Psychiatric Rehabilitation Journal*, 37(1), 17.

- Braathen, S. H., Vergunst, R., Mji, G., Mannan, H., & Swartz, L. (2013). Understanding the local context for the application of global mental health: A rural South African experience. *International Health*, 5(1), 38-42. doi: 10.1093/inthealth/ihs016
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Bravo, M., Canino, G. J., Rubio-Stipec, M., & Woodbury-Fariña, M. (1991). A cross-cultural adaptation of a psychiatric epidemiologic instrument: The diagnostic interview schedule's adaptation in Puerto Rico. *Culture, medicine and Psychiatry*, 15(1), 1-18.
- Breheny, M. (2007). Genetic attribution for schizophrenia, depression, and skin cancer: Impact on social distance. *New Zealand Journal of Psychology*, 36(3), 154.
- Brislin, R. W. (1986). Research instruments. *Field methods in cross-cultural research*, 8, 137-164.
- Brislin, R.W. (1970). Back-translation for cross-cultural research. *Journal of Cross-Cultural Psychology*, 1, 3, 185-216.
- Brohan, E., Clement, S., Rose, D., Sartorius, N., Slade, M., & Thornicroft, G. (2013). Development and psychometric evaluation of the Discrimination and Stigma Scale (DISC). *Psychiatry Research*, 208(1), 33-40.
- Brohan, E., Slade, M., Clement, S., & Thornicroft, G. (2010). Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *BMC health services research*, 10(1), 80.
- Bryman, A. (2012). Sampling in qualitative research. In A. Bryman (Ed.), *Social research methods* (4th ed., pp. 415-429). Cape Town, South Africa: Oxford University Press.
- Buhrmann, M. V. (1977). Western psychiatry and the Xhosa patient. *South African Medical Journal*, 51(14), 464-466.

- Bührmann, M. V. (1984). *Living in two worlds: Communication between a white healer and her black counterparts*. Human & Rousseau.
- Byrne, P. (2000). Stigma of mental illness and ways of diminishing it. *Advances in Psychiatric treatment*, 6(1), 65-72. Retrieved from: <http://beyachad.tripod.com/updates/doc-rtf/stigma1.pdf>
- Campbell, M. M., & Young, C. (2016). A Xhosa language translation of the CORE-OM using South African university student samples. *Transcultural psychiatry*, 53(5), 654-673.
- Campbell, M. M., Sibeko, G., Mall, S., Baldinger, A., Nagdee, M., Susser, E., & Stein, D. J. (2017). The content of delusions in a sample of South African Xhosa people with schizophrenia. *BMC psychiatry*, 17(1), 41.
- Campbell, M. M., Susser, E., de Vries, J., Baldinger, A., Sibeko, G., Mndini, M. M., ... & Stein, D. J. (2015). Exploring researchers' experiences of working with a researcher-driven, population-specific community advisory board in a South African schizophrenia genomics study. *BMC medical ethics*, 16(1), 45.
- Carapetis, J. R., & Zühlke, L. J. (2011). Global research priorities in rheumatic fever and rheumatic heart disease. *Annals of pediatric cardiology*, 4(1), 4.
- Carapetis, J. R., McDonald, M., & Wilson, N. J. (2005). Acute rheumatic fever. *The Lancet*, 366(9480), 155-168.
- Carver, R. B., Castéra, J., Gericke, N., Evangelista, N. A. M., & El-Hani, C. N. (2017). Young adults' belief in genetic determinism, and knowledge and attitudes towards modern genetics and genomics: the PUGGS questionnaire. *PloS one*, 12(1), e0169808.

- Cathoor, K., Hutsebaut, J., Schrijvers, D., De Hert, M., Peuskens, J., & Sabbe, B. (2014). Preliminary study of associative stigma among trainee psychiatrists in Flanders, Belgium. *World journal of psychiatry*, 4(3), 62. doi: [10.5498/wjp.v4.i3.62](https://doi.org/10.5498/wjp.v4.i3.62)
- Catz, D. S., Green, N. S., Tobin, J. N., Lloyd-Puryear, M. A., Kyler, P., Umemoto, A., ... & Wolman, F. (2005). Attitudes about genetics in underserved, culturally diverse populations. *Public Health Genomics*, 8(3), 161-172. doi:10.1159/000086759
- Chang, A. Y., Nabbaale, J., Nalubwama, H., Okello, E., Ssinabulya, I., Longenecker, C. T., & Webel, A. R. (2018). Motivations of women in Uganda living with rheumatic heart disease: A mixed methods study of experiences in stigma, childbearing, anticoagulation, and contraception. *PloS one*, 13(3), e0194030.
- Cohn, E. G., Henderson, G. E., & Appelbaum, P. S. (2016). Distributive justice, diversity, and inclusion in precision medicine: what will success look like?. *Genetics in medicine*, 19(2), 157.
- Collins, K. M., Onwuegbuzie, A. J., & Johnson, R. B. (2012). Securing a place at the table: A review and extension of legitimization criteria for the conduct of mixed research. *American Behavioral Scientist*, 56(6), 849-865.
- Condit, C. M. (1999). "How the Public Understands Genetics: Non-deterministic and Non-discriminatory Interpretations of the 'Blueprint' Metaphor," *Public Understanding of Science* 8: 169-180.
- Condit, C.M. (2018). "The Person on the Street Will Utilize Information about Their Genes in Line with Their Existing Beliefs and Preferences Rather Than Being Substantially Swayed in New Negative Directions". Paper presented at the Looking for the Psychosocial Impacts of Genomic Information Conference. Columbia University. New York City

- Condit, C. M., Gronnvoll, M., Landau, J., Shen, L., Wright, L., & Harris, T. M. (2009). Believing in both genetic determinism and behavioral action: a materialist framework and implications. *Public Understanding of Science, 18*(6), 730-746. doi: 10.1177/09636625080940
- Condit, C. M., Parrott, R. L., & O'Grady, B. (2000). Principles and practices of communication processes for genetics in public health. *Genetics and public health in the 21st century: Using genetic information to improve health and prevent disease, 549-568.*
- Connell, A., Koen, L., Niehaus, D., Cloete, K. J., Jordaan, E., & Botha, U. (2015). Religious Delusions in a Xhosa Schizophrenia Population. *Journal of religion and health, 54*(5), 1555-1562.
- Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: historical roots of current public health challenges. *The Lancet, 374*(9692), 817-834. doi: 10.1016/S0140-6736(09)60951-X
- Corker, E., Brown, J., & Henderson, C. (2016). How does self stigma differ across people with psychiatric diagnoses and rheumatoid arthritis, and how does it impact on self-esteem and empowerment?. *Psychology, health & medicine, 21*(8), 993-1005. doi: <https://doi.org/10.1080/13548506.2016.1139139>
- Corrigan, P. W. (1998). The impact of stigma on severe mental illness. *Cognitive and behavioral practice, 5*(2), 201-222.
- Corrigan, P. W., Markowitz, F. E., & Watson, A. C. (2004). Structural levels of mental illness stigma and discrimination. *Schizophrenia bulletin, 30*(3), 481-491.
- Corrigan, P. W., & Rao, D. (2012). On the self-stigma of mental illness: Stages, disclosure, and strategies for change. *Canadian Journal of Psychiatry, 57*(8), 464-469.

- Corrigan, P. W., Rowan, D., Green, A., Lundin, R., River, P., Uphoff-Wasowski, K., . . . Kubiak, M. (2002). Challenging two mental illness stigmas: Personal responsibility and dangerousness. *Schizophrenia Bulletin*, 28(2), 293-309.
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9(1), 35-53.
- Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World psychiatry*, 1(1), 16.
- Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*, 25(9), 875-884.
- Crabb, J., Stewart, R. C., Kokota, D., Masson, N., Chabunya, S., & Krishnadas, R. (2012). Attitudes towards mental illness in Malawi: a cross-sectional survey. *BMC Public Health*, 12(1), 541.
- Creswell, J. W., & Clark, V. L. (2011). *Designing and Conducting Mixed Methods Research*. Thousand Oaks, California: SAGE Publications.
- Creswell, J. W., & Clark, V. L. P. (2017). *Designing and conducting mixed methods research*. SAGE Publications.
- Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *psychometrika*, 16(3), 297-334.
- Crossman, P. (2004). Perceptions of “Africanisation” or “endogenisation” at African universities: issues and recommendations. *African universities in the twenty-first century*, 2, 319-340.
- Daar AS, Singer PA, Persad DL, et al. Grand challenges in chronic non-communicable diseases. *Nature* 2007; **450**: 494–96.

- Dar-Nimrod, I., & Heine, S. J. (2011). Genetic essentialism: on the deceptive determinism of DNA. *Psychological bulletin*, 137(5), 800.
- Davison, C., Smith, G. D., & Frankel, S. (1991). Lay epidemiology and the prevention paradox: the implications of coronary candidacy for health education. *Sociology of Health & Illness*, 13(1), 1-19. doi: <https://doi.org/10.1111/j.1467-9566.1991.tb00085.x>
- De Jong, J. T., & Van Ommeren, M. (2002). Toward a culture-informed epidemiology: Combining qualitative and quantitative research in transcultural contexts. *Transcultural Psychiatry*, 39(4), 422-433.
- Dembling, B. P., Chen, D. T., & Vachon, L. (1999). Life expectancy and causes of death in a population treated for serious mental illness. *Psychiatric Services*, 50(8), 1036-1042. doi: <https://doi.org/10.1176/ps.50.8.1036>
- Desjarlais, R., Eisenberg, L., Good, B., & Kleinman, A. (1995). *World mental health: Problems and priorities in low-income countries*. New York, NY, US: Oxford University Press.
- de Vries, J., & Pepper, M. (2012). Genomic sovereignty and the African promise: mining the African genome for the benefit of Africa. *Journal of Medical Ethics*, medethics-2011.
- de Vries, J., Bull, S. J., Doumbo, O., Ibrahim, M., Mercereau-Puijalon, O., Kwiatkowski, D., & Parker, M. (2011). Ethical issues in human genomics research in developing countries. *BMC medical ethics*, 12(1), 5.
- de Vries, J., Jallow, M., Williams, T. N., Kwiatkowski, D., Parker, M., & Fitzpatrick, R. (2012). Investigating the potential for ethnic group harm in collaborative genomics research in Africa: Is ethnic stigmatisation likely?. *Social science & medicine*, 75(8), 1400-1407.

- de Vries, J., Stein, D. J., Kamuya, D., & Singh, I. (2017). Psychiatric genomics: Ethical implications for public health in lower-and middle-income countries. *The American Journal of Bioethics*, 17(4), 17-19.
- Department of Health. (2015). *Ethics in health research: Principles, processes and structures* (2nd ed.). Retrieved from:
http://www0.sun.ac.za/research/assets/files/Integrity_and_Ethics/DoH%202015%20Ethics%20in%20Health%20Research%20-%20Principles,%20Processes%20and%20Structures%202nd%20Ed.pdf
- Diallo, R. N., Gadj, M., Hennig, B. J., Guèye, M. V., Gaye, A., Diop, J. P. D., ... & Faye, O. (2017). Strengthening human genetics research in Africa: report of the 9th meeting of the African Society of Human Genetics in Dakar in May 2016. *Global health, epidemiology and genomics*, 2.
- Dietrich, S., Matschinger, H., & Angermeyer, M. C. (2006). The relationship between biogenetic causal explanations and social distance toward people with mental disorders: Results from a population survey in Germany. *International Journal of Social Psychiatry*, 52(2), 166-174.
- Dinos, S., Stevens, S., Serfaty, M., Weich, S., & King, M. (2004). Stigma: the feelings and experiences of 46 people with mental illness: qualitative study. *The British Journal of Psychiatry*, 184(2), 176-181.
- Dos Santos, M. M., Kruger, P., Mellors, S. E., Wolvaardt, G., & Van Der Ryst, E. (2014). An exploratory survey measuring stigma and discrimination experienced by people living with HIV/AIDS in South Africa: the People Living with HIV Stigma Index. *BMC Public Health*, 14(1), 80.
- Dovidio, J. F. (2001). On the nature of contemporary prejudice: The third wave. *Journal of Social Issues*, 57(4), 829-849.

- Dovidio, J. F., Major, B., & Crocker, J. (2000). *The social psychology of stigma*. New York, NY: The Guilford Press.
- Drennan, G., Levett, A., & Swartz, L. (1991). Hidden dimensions of power and resistance in the translation process: A South African study. *Culture, Medicine and Psychiatry, 15*(3), 361-381.
- Duster, T. (2004). *Backdoor to eugenics*. Routledge.
- Economou, M., Richardson, C., Gramandani, C., Stalikas, A., & Stefanis, C. (2009). Knowledge about schizophrenia and attitudes towards people with schizophrenia in Greece. *International Journal of Social Psychiatry, 55*(4), 361-371. doi: 10.1177/0020764008093957
- Emsley R. A., Niehaus, D. J., Mbang, N. I., et al. (2001). The factor structure for positive and negative symptoms in South African Xhosa patients with schizophrenia. *Schizophrenia Research, 47*, 149–157
- Engel, M. E., Stander, R., Vogel, J., Adeyemo, A. A., & Mayosi, B. M. (2011). Genetic susceptibility to acute rheumatic fever: a systematic review and meta-analysis of twin studies. *PLoS One, 6*(9), e25326.
- Ersoy, M. A., & Varan, A. (2007). Reliability and Validity of the Turkish Version of the Internalised Stigma of Mental Illness Scale.
- Evans, C., Connell, J., Barkham, M., Margison, F., McGrath, G., Mellor-Clark, J., & Audin, K. (2002). Towards a standardised brief outcome measure: Psychometric properties and utility of the CORE-OM. *The British Journal of Psychiatry, 180*(1), 51-60.
- Farrelly, S., Clement, S., Gabbidon, J., Jeffery, D., Dockery, L., Lassman, F., ... & Thornicroft, G. (2014). Anticipated and experienced discrimination amongst people with schizophrenia, bipolar disorder and major depressive disorder: a cross sectional

study. *BMC psychiatry*, 14(1), 157. <http://www.biomedcentral.com/1471-244X/14/157>

Faure, M. C. (2018). *Stigma and African genomics research: An exploration of stigma associated with the genetic attribution of rheumatic heart disease* (Masters dissertation, University of Cape Town).

Folb, N., Lund, C., Fairall, L. R., Timmerman, V., Levitt, N. S., Steyn, K., & Bachmann, M. O. (2015). Socioeconomic predictors and consequences of depression among primary care attenders with non-communicable diseases in the Western Cape, South Africa: cohort study within a randomised trial. *BMC public health*, 15(1), 1194.

Fiske, S. T., & Taylor, S. E. (1991). Attribution theory. *Social cognition*, 22-41.

Flowers, E., Froelicher, E. S., & Aouizerat, B. E. (2012). Gene-environment interactions in cardiovascular disease. *European Journal of Cardiovascular Nursing*, 11(4), 472-478.

French, K. A., & Poppas, A. (2018). Rheumatic Heart Disease in Pregnancy: Global Challenges and Clear Opportunities. doi:
<https://doi.org/10.1161/CIRCULATIONAHA.118.033465>

Garrison, N. A., Brothers, K. B., Goldenberg, A. J., & Lynch, J. A. (2019). Genomic Contextualism: Shifting the Rhetoric of Genetic Exceptionalism. *The American Journal of Bioethics*, 19(1), 51-63. Retrieved from
<https://doi.org/10.1080/15265161.2018.1544304>

Gaskell, G., Bauer, M. W., Durant, J., & Allum, N. C. (1999). Worlds apart? The reception of genetically modified foods in Europe and the US. *Science*, 285(5426), 384-387.

Gericke, J. E. (1995). Major depressive disorder: an epidemiological study in the Rocklands community.

- Gericke, N., Carver, R., Castéra, J., Evangelista, N. A. M., Marre, C. C., & El-Hani, C. N. (2017). Exploring relationships among belief in genetic determinism, genetics knowledge, and social factors. *Science & Education*, 26(10), 1223-1259. doi: <https://doi.org/10.1007/s11191-017-9950-y>
- Ghaemi, S. N. (2009). *A clinician's guide to statistics and epidemiology in mental health: Measuring truth and uncertainty*. Cambridge University Press.
- Girma, E., & Tesfaye, M. (2011). Patterns of treatment seeking behavior for mental illnesses in Southwest Ethiopia: a hospital based study. *BMC psychiatry*, 11(1), 138.
- Gobo, G. (2008). Re-conceptualizing generalization: Old issues in a new frame. *The SAGE handbook of social research methods*, 193-213.
- Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24(6), 734-749. doi: <https://doi.org/10.1111/1467-9566.00316>
- Griffiths, S., Costa, D. S., Boyd, J. E., Murray, S. B., Mitchison, D., & Mond, J. M. (2016). Facilitating research on eating disorders stigma: validation of the internalised stigma of mental illness scale for use in people with eating disorders. *Advances in Eating Disorders*, 4(3), 293-308.
- H3Africa Consortium. 2014. Research capacity. Enabling the genomic revolution in Africa. *Science*, 344, 1346-8.
- Hatch, S. L., Gazard, B., Williams, D. R., Frissa, S., Goodwin, L., Hotopf, M., & SELCoH Study Team. (2016). Discrimination and common mental disorder among migrant and ethnic groups: findings from a South East London Community sample. *Social psychiatry and psychiatric epidemiology*, 51(5), 689-701. doi: 10.1007/s00127-016-1191-x

Harvey, J. H., & Weary, G. (1984). Current issues in attribution theory and research. *Annual review of psychology*, 35(1), 427-459.

Heatherton, T. F. (Ed.). (2003). *The social psychology of stigma*. Guilford Press.

Heaton, M. M. (2013). *Black skin, white coats: Nigerian psychiatrists*, Hughes, R., & Hughes, R., & Huby, M. (2002). The application of vignettes in social and nursing research. *Journal of advanced nursing*, 37(4), 382-386.

Hellman, D. (2003). What makes genetic discrimination exceptional?. In *Genetics and Gene Therapy* (pp. 169-208). Routledge.

Henderson, B. J., & Maguire, B. T. (2000). Three lay mental models of disease inheritance. *Social Science & Medicine*, 50(2), 293-301.

Hickson, J., & White, E. (1989). Career maturity development in black South African adolescents: Implications for vocational counselling. *South African Journal of Education*, 9(1), 77-81.

Hirst, M. (2005). Dreams and medicines: The perspective of Xhosa diviners and novices in the Eastern Cape, South Africa. *Indo-Pacific Journal of Phenomenology*, 5(2). doi: 10.1080/20797222.2005.11433901

Howes, O. D., & Murray, R. M. (2014). Schizophrenia: an integrated sociodevelopmental-cognitive model. *The Lancet*, 383(9929), 1677-1687. doi: [https://doi.org/10.1016/S0140-6736\(13\)62036-X](https://doi.org/10.1016/S0140-6736(13)62036-X)

Hugo, C. J., Boshoff, D. E., Traut, A., Zungu-Dirwayi, N., & Stein, D. J. (2003). Community attitudes toward and knowledge of mental illness in South Africa. *Social psychiatry and psychiatric epidemiology*, 38(12), 715-719.

IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.

- Hundt, G. L., Stuttaford, M. & Ngoma, B. (The SASPI team) (2004) The social diagnostics of stroke-like symptoms: healers, doctors and prophets in Agincourt, Limpopo province, South Africa. *Journal of Biosocial Science* 36, 433–443.
- Hunt, X., Swartz, L., Carew, M. T., Braathen, S. H., Chiwaula, M., & Rohleder, P. (2018). Dating persons with physical disabilities: The perceptions of South Africans without disabilities. *Culture, health & sexuality*, 20(2), 141-155. doi: 10.1080/13691058.2017.1334964.
- Igberase, O. O., Morakinyo, O., Lawani, A. O., James, B. O., & Omoaregba, J. O. (2012). Burden of care among relatives of patients with schizophrenia in midwestern Nigeria. *International Journal of social psychiatry*, 58(2), 131-137.
- Irlam, J., Mayosi, B. M., Engel, M., & Gaziano, T. A. (2013). Primary prevention of acute rheumatic fever and rheumatic heart disease with penicillin in South African children with pharyngitis: a cost-effectiveness analysis. *Circulation: Cardiovascular Quality and Outcomes*, 6(3), 343-351.
- Jilek, W. G. (1995). Emil Kraepelin and comparative sociocultural psychiatry. *European Archives of Psychiatry and Clinical Neuroscience*, 245(4-5), 231-238.
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of mixed methods research*, 1(2), 112-133.
- Kerr, A., Cunningham-Burley, S., & Amos, A. (1998). Drawing the line: an analysis of lay people's discussions about the new genetics. *Public Understanding of Science*, 7(2), 113-133.
- Keszei, A. P., Novak, M., & Streiner, D. L. (2010). Introduction to health measurement scales. *Journal of psychosomatic research*, 68(4), 319-323.
- Khosa, D., & Zwane, W. (1995). Final report of the children and violence intervention project: Centre for the Study of Violence and Reconciliation. *South Africa*.

- Khoury, M. J., Gwinn, M., Burke, W., Bowen, S., & Zimmern, R. (2007). Will genomics widen or help heal the schism between medicine and public health?. *American journal of preventive medicine*, 33(4), 310-317. doi:10.1016/j.amepre.2007.05.010
- King, M., Dinos, S., Shaw, J., Watson, R., Stevens, S., Pasetti, F., ... & Serfaty, M. (2007). The Stigma Scale: development of a standardised measure of the stigma of mental illness. *The British Journal of Psychiatry*, 190(3), 248-254.
- Kinney, A. Y., DeVellis, B. M., Skrzynia, C., & Millikan, R. (2001). Genetic testing for colorectal carcinoma susceptibility: focus group responses of individuals with colorectal carcinoma and first-degree relatives. *Cancer*, 91(1), 57-65. doi:
- Kira, I. A., Lewandowski, L., Ashby, J. S., Templin, T., Ramaswamy, V., & Mohanesh, J. (2014). The traumatogenic dynamics of internalised stigma of mental illness among Arab American, Muslim, and refugee clients. *Journal of the American Psychiatric Nurses Association*, 20(4), 250-266.
- Kirmayer, L.J. & Swartz, L. (2013). Culture and global mental health. *Global mental health: Principles and practice*, 41-62
- Kleinman, A. M. (1977). Depression, somatization and the "new cross-cultural psychiatry". *Social Science & Medicine (1967)*, 11(1), 3-9.
- Kohrt, B., Hadley, C., & Hruschka, D. (2009). Culture and epidemiology special issue: Towards an integrated study of culture and population health.
- Kong, C., Dunn, M., & Parker, M. (2017). Psychiatric genomics and mental health treatment: Setting the ethical agenda. *The American Journal of Bioethics*, 17(4), 3-12.
- Kvaale, E. P., Gottdiener, W. H., & Haslam, N. (2013). Biogenetic explanations and stigma: A meta-analytic review of associations among laypeople. *Social science & medicine*, 96, 95-103.

- Kvaale, E. P., Haslam, N., & Gottdiener, W. H. (2013). The 'side effects' of medicalization: A meta-analytic review of how biogenetic explanations affect stigma. *Clinical psychology review, 33*(6), 782-794.
- Kyei, J. J., Dueck, A., Indart, M. J., & Nyarko, N. Y. (2014). Supernatural belief systems, mental health and perceptions of mental disorders in Ghana. *International Journal of Culture and Mental Health, 7*(2), 137-151.
- Laegsgaard, M. M., Stamp, A. S., Hall, E. O. C., & Mors, O. (2010). The perceived and predicted implications of psychiatric genetic knowledge among persons with multiple cases of depression in the family. *Acta Psychiatrica Scandinavica, 122*(6), 470-480.
- Landrine, H., & Klonoff, E. A. (1992). Culture and health-related schemas: A review and proposal for interdisciplinary integration. *Health Psychology, 11*(4), 267.
- Landrine, H., & Klonoff, E. A. (1994). Cultural diversity in causal attributions for illness: The role of the supernatural. *Journal of behavioral medicine, 17*(2), 181-193.
- Lebowitz, M. S., & Ahn, W. K. (2012). Combining biomedical accounts of mental disorders with treatability information to reduce mental illness stigma. *Psychiatric Services, 63*(5), 496-499.
- Lebowitz, M. S., Ahn, W. K., & Nolen-Hoeksema, S. (2013). Fixable or fate? Perceptions of the biology of depression. *Journal of consulting and clinical psychology, 81*(3), 518.
- Lebowitz, M. S., Pyun, J. J., & Ahn, W. K. (2014). Biological explanations of generalized anxiety disorder: Effects on beliefs about prognosis and responsibility. *Psychiatric Services, 65*(4), 498-503.
- Levin, M. E. (2011). Effects on quality of care and health care worker satisfaction of language training for health care workers in South Africa. *African Journal of Health Professions Education, 3*(1), 11-14.

- Levin, S., & Van Laar, C. (Eds.). (2006). *Stigma and group inequality: Social psychological perspectives*. Psychology Press.
- Liamputtong, P. (2011). *Focus Group Methodology: Principles and Practice*. London: SAGE Publications.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual review of Sociology*, 27(1), 363-385.
- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American sociological review*, 400-423.
- Lloyd, K. R., Jacob, K. S., Patel, V., Louis, L. S., Bhugra, D., & Mann, A. H. (1998). The development of the Short Explanatory Model Interview (SEMI) and its use among primary-care attenders with common mental disorders. *Psychological medicine*, 28(5), 1231-1237.
- Li, J., Li, J., Thornicroft, G., & Huang, Y. (2014). Levels of stigma among community mental health staff in Guangzhou, China. *BMC psychiatry*, 14(1), 231. doi: <https://doi.org/10.1186/s12888-014-0231-x>
- Lock, M. (1987). DSM-III as a culture-bound construct: Commentary on culture-bound syndromes and international disease classifications. *Culture, Medicine and Psychiatry*, 11(1), 35-42.
- Lucas, K. (2011). Making the connections between transport disadvantage and the social exclusion of low income populations in the Tshwane Region of South Africa. *Journal of Transport Geography*, 19(6), 1320-1334.
- Luhmann, T. M.. (2000) *Of two minds: The growing disorder in American psychiatry*. New York, NY: Alfred A. Knopf.

- Lukachko, A., Hatzenbuehler, M. L., & Keyes, K. M. (2014). Structural racism and myocardial infarction in the United States. *Social Science & Medicine*, *103*, 42-50.
- Lund, C., & Flisher, A. J. (2009). A model for community mental health services in South Africa. *Tropical Medicine & International Health*, *14*(9), 1040-1047.
- Lund, C., & Swartz, L. (1998). Xhosa-speaking schizophrenic patients' experience of their condition: psychosis and amafufunyana. *South African Journal of Psychology*, *28*(2), 62-70.
- Lund, C., Breen, A., Flisher, A. J., Kakuma, R., Corrigall, J., Joska, J. A., ... & Patel, V. (2010). Poverty and common mental disorders in low and middle income countries: a systematic review. *Social science & medicine*, *71*(3), 517-528.
- Lund, C., Brooke-Sumner, C., Baingana, F., Baron, E. C., Breuer, E., Chandra, P., ... & Medina-Mora, M. E. (2018). Social determinants of mental disorders and the Sustainable Development Goals: a systematic review of reviews. *The Lancet Psychiatry*, *5*(4), 357-369.
- Lynch, J., Bevan, J., Achter, P., Harris, T., & Condit, C. M. (2008). A preliminary study of how multiple exposures to messages about genetics impact on lay attitudes towards racial and genetic discrimination. *New Genetics and Society*, *27*(1), 43-56.
- Lysaker, P. H., Roe, D., & Yanos, P. T. (2006). Toward understanding the insight paradox: internalised stigma moderates the association between insight and social functioning, hope, and self-esteem among people with schizophrenia spectrum disorders. *Schizophrenia bulletin*, *33*(1), 192-199.
- MacDougall, C., & Fudge, E. (2001). Planning and recruiting the sample for focus groups and in-depth interviews. *Qualitative health research*, *11*(1), 117-126.

- Mamah, D., Mbwayo, A., Mutiso, V., Barch, D. M., Constantino, J. N., Nsofor, T., ... & Ndetei, D. M. (2012). A survey of psychosis risk symptoms in Kenya. *Comprehensive psychiatry*, *53*(5), 516-524.
- Margetić, B. A., Jakovljević, M., Ivanec, D., Margetić, B., & Tošić, G. (2010). Relations of internalised stigma with temperament and character in patients with schizophrenia. *Comprehensive Psychiatry*, *51*(6), 603-606.
- Marsh, V. M., Kamuya, D. M., & Molyneux, S. S. (2011). 'All her children are born that way': gendered experiences of stigma in families affected by sickle cell disorder in rural Kenya. *Ethnicity & health*, *16*(4-5), 343-359.
- Marsh, V., Kombe, F., Fitzpatrick, R., Williams, T. N., Parker, M., & Molyneux, S. (2013). Consulting communities on feedback of genetic findings in international health research: sharing sickle cell disease and carrier information in coastal Kenya. *BMC medical ethics*, *14*(1), 41.
- Marshall, P. A., Adebamowo, C. A., Adeyemo, A. A., Ogundiran, T. O., Strenski, T., Zhou, J., & Rotimi, C. N. (2014). Voluntary participation and comprehension of informed consent in a genetic epidemiological study of breast cancer in Nigeria. *BMC medical ethics*, *15*(1), 38.
- Masiye, F. (2015). *Ethical challenges in obtaining informed consent for the genomics of rheumatic heart disease: a qualitative study*. (Master's Thesis, University of Cape Town, South Africa).
- Mason, M. (2010, August). Sample size and saturation in PhD studies using qualitative interviews. In *Forum qualitative Sozialforschung/Forum: qualitative social research*, *11*(3)
- Matoane, M. (2012). Locating context in counselling: The development of indigenous psychology in South Africa. *Psychotherapy and Politics International*, *10*(2), 105-115.

- Mayosi, B. M., & Benatar, S. R. (2014). Health and health care in South Africa—20 years after Mandela. *New England Journal of Medicine*, *371*(14), 1344-1353.
- Mayosi, B. M., Flisher, A. J., Lalloo, U. G., Sitas, F., Tollman, S. M., & Bradshaw, D. (2009). The burden of non-communicable diseases in South Africa. *The lancet*, *374*(9693), 934-947. doi:10.1016/S0140-
- Mayosi, B. M., Lawn, J. E., Van Niekerk, A., Bradshaw, D., Karim, S. S. A., Coovadia, H. M., & Lancet South Africa team. (2012). Health in South Africa: changes and challenges since 2009. *The Lancet*, *380*(9858), 2029-2043.
- Mazama, A. (2001). The Afrocentric paradigm: Contours and definitions. *Journal of Black Studies*, *31*(4), 387-405.
- Mbanga, N. I., Niehaus, D. J. H., Mzamo, N. C., Wessels, C. J., Allen, A., Emsley, R. A., & Stein, D. J. (2002). Attitudes towards and beliefs about schizophrenia in Xhosa families with affected probands.
- McCabe, R., & Priebe, S. (2004). Explanatory models of illness in schizophrenia: comparison of four ethnic groups. *The British Journal of Psychiatry*, *185*(1), 25-30.
- McGregor, J. (2010). Racial, ethnic, and tribal classifications in biomedical research with biological and group harm. *The American Journal of Bioethics*, *10*(9), 23-24.
- Mehta, S., & Farina, A. (1997). Is being “sick” really better? Effect of the disease view of mental disorder on stigma. *Journal of Social and Clinical psychology*, *16*(4), 405-419.
- Meiser, B., Mitchell, P. B., McGirr, H., Van Herten, M., & Schofield, P. R. (2005). Implications of genetic risk information in families with a high density of bipolar disorder: an exploratory study. *Social science & medicine*, *60*(1), 109-118.

- Mental Health Commission of Canada, 2009. *Toward recovery and well-being: A framework for mental health strategy for Canada*. National Library of Canada: Canada
- Miller, K. (2003). Conducting cognitive interviews to understand question-response limitations. *American Journal of Health Behavior*, 27(1), 264-272.
- Mirza, I., Hassan, R., Chaudhary, H., & Jenkins, R. (2006). Short Report Eliciting explanatory models of common mental disorders using the Short Explanatory Model Interview (SEMI) Urdu adaptation-a pilot study. *JPMA. The Journal of the Pakistan Medical Association*, 56, 461.
- Mkize, D. L. (2003). Towards an Afrocentric approach to psychiatry. *South African Journal of Psychiatry*, 9(1), 3-6.
- Morgan, D. L. (2002). Focus group interviewing. *Handbook of interview research: Context and method*, 141-159.
- Mosotho, L., Louw, D. A., Jacobus, F., & Calitz, W. (2011). The manifestation of anxiety among Sesotho speakers. *South African Journal of Psychology*, 41(4), 437-450.
- Mosotho, N. L., Louw, D. A., Calitz, F. J., & Esterhuyse, K. G. (2008). Depression among Sesotho speakers in Mangaung, South Africa. *African journal of psychiatry*, 11(1), 35-43.
- Mossakowski, K. N. (2008). Is the duration of poverty and unemployment a risk factor for heavy drinking?. *Social science & medicine*, 67(6), 947-955.
doi:10.1016/j.socscimed.2008.05.019
- Mshana, G., Hampshire, K., Panter-Brick, C., & Walker, R. (2008). Urban–rural contrasts in explanatory models and treatment-seeking behaviours for stroke in Tanzania. *Journal of biosocial science*, 40(1), 35-52. doi:10.1017/S0021932007002295

- Muga, F. A., & Jenkins, R. (2008). Public perceptions, explanatory models and service utilisation regarding mental illness and mental health care in Kenya. *Social psychiatry and psychiatric epidemiology*, 43(6), 469-476, doi 10.1007/s00127-008-0334-0
- Muhammad, B. (2018). *Genetics of Rheumatic Heart Disease in Africa*. (Doctoral dissertation, University of Cape Town, South Africa)
- Muñoz, M., Sanz, M., Pérez-Santos, E., & de los Ángeles Quiroga, M. (2011). Proposal of a socio-cognitive-behavioral structural equation model of internalised stigma in people with severe and persistent mental illness. *Psychiatry Research*, 186(2-3), 402-408.
- Munung, N. S. (2015). *African researchers' perceptions and expectations of the benefits of genomics research in Africa: a qualitative study* (Master's Thesis, University of Cape Town, South Africa).
- Mzimkulu, K. G., & Simbayi, L. C. (2006). Perspectives and practices of Xhosa-speaking African traditional healers when managing psychosis. *International Journal of Disability, Development and Education*, 53(4), 417-431.
- Naanyu, V. (2009). *Social Context and Mental Illness Stigma in South Africa*. (Doctoral dissertation, Moi University School of Medicine, Kenya).
- Ngqela, N., & Lewis, A. (2012). Exploring adolescent learners' experiences of school violence in a township high school. *Child Abuse Research in South Africa*, 13(1), 87-97.
- Niehaus, D. J. H., Oosthuizen, P., Lochner, C., Emsley, R. A., Jordaan, E., Mbanga, N. I., ... & Stein, D. J. (2004). A culture-bound syndrome 'amafufunyana' and a culture-specific event 'ukuthwasa': differentiated by a family history of schizophrenia and other psychiatric disorders. *Psychopathology*, 37(2), 59-63.
- Nteta, T. P., Mokgatle-Nthabu, M., & Oguntibeju, O. O. (2010). Utilization of the primary health care services in the Tshwane Region of Gauteng Province, South Africa. *PLoS one*, 5(11), e13909.

- Nuffield Council on Bioethics. (1993). *Genetic screening: ethical issues*. London: Nuffield Council on Bioethics.
- Nwoye, A. (2015). African psychology and the Africentric paradigm to clinical diagnosis and treatment. *South African Journal of Psychology*, *45*(3), 305-317.
- Ocisková, M., Praško, J., Kamarádová, D., Látalová, K., Kurfürst, P., Dostálová, L., & Ticháčková, A. (2014). Self-stigma in psychiatric patients—standardization of the ISMI scale. *Neuroendocrinology Letters*, *35*(7), 624–632
- O'Neill, S. C., McBride, C. M., Alford, S. H., & Kaphingst, K. A. (2010). Preferences for genetic and behavioral health information: the impact of risk factors and disease attributions. *Annals of Behavioral Medicine*, *40*(2), 127-137. ISSN: 0172-780X; ISSN-L: 0172-780X
- Onwuegbuzie, A. J., & Collins, K. M. (2007). A typology of mixed methods sampling designs in social science research. *The qualitative report*, *12*(2), 281-316.
- Parker, M., Bull, S. J., de Vries, J., Agbenyega, T., Doumbo, O. K., & Kwiatkowski, D. P. (2009). Ethical data release in genome-wide association studies in developing countries. *PLoS medicine*, *6*(11), e1000143.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social science & medicine*, *57*(1), 13-24.
- Parry, C. D. (2005). South Africa: alcohol today. *Addiction*, *100*(4), 426-429.
- Parrott, R. L., Silk, K. J., & Condit, C. (2003). Diversity in lay perceptions of the sources of human traits: genes, environments, and personal behaviors. *Social Science & Medicine*, *56*(5), 1099-1109. [https://doi.org/10.1016/S0277-9536\(02\)00106-5](https://doi.org/10.1016/S0277-9536(02)00106-5)

- Parott, R., K. Silk, J. Weiner, C. Condit, T. Harris, and J. Bernhardt. 2004. Deriving lay models of uncertainty about genes' role in illness causation to guide communication about human genetics. *Journal of Communication* 54: 105-22.
- Patel, V. (1995). Explanatory models of mental illness in sub-Saharan Africa. *Social Science & Medicine*, 40(9), 1291-1298. doi: [https://doi.org/10.1016/0277-9536\(94\)00231-H](https://doi.org/10.1016/0277-9536(94)00231-H)
- Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative social work*, 1(3), 261-283.
- Pescosolido BA. 2013. The public stigma of mental illness: What do we think; what do we know; what can we prove? *J. Health Soc. Behav.* 54:1–21
- Pescosolido, B. A., & Martin, J. K. (2015). The stigma complex. *Annual review of sociology*, 41, 87-116. doi: 10.1146/annurev-soc-071312-145702
- Pescosolido, B. A., Martin, J. K., Long, J. S., Medina, T. R., Phelan, J. C., & Link, B. G. (2010). "A Disease Like Any Other"? A Decade of Change in Public Reactions to Schizophrenia, Depression, and Alcohol Dependence. *American Journal of Psychiatry*, 167(11), 1321-1330.
- Petersen, I., Fairall, L., Bhana, A., Kathree, T., Selohilwe, O., Brooke-Sumner, C., ... & Patel, V. (2016). Integrating mental health into chronic care in South Africa: the development of a district mental healthcare plan. *The British journal of psychiatry*, 208(s56), s29-s39. doi: 10.1192/bjp.bp.114.153726
- Phelan J, Link B. (2012). Genetics, addiction and stigma. In *Genetic Research on Addiction: Ethics, the Law, and Public Health*. Edited by Chapman AR. Cambridge: Cambridge University Press. 174-194
- Phelan, J. C. (2002). Genetic bases of mental illness—a cure for stigma?. *TRENDS in Neurosciences*, 25(8), 430-431.

- Phelan, J. C. (2005). Geneticization of deviant behavior and consequences for stigma: The case of mental illness. *Journal of Health and Social Behavior*, 46(4), 307-322.
- Phelan, J. C., & Link, B. G. (2004). Fear of people with mental illnesses: The role of personal and impersonal contact and exposure to threat or harm. *Journal of Health and Social Behavior*, 45(1), 68-80.
- Phelan, J. C., Cruz-Rojas, R., & Reiff, M. (2002). Genes and stigma: The connection between perceived genetic etiology and attitudes and beliefs about mental illness. *Psychiatric Rehabilitation Skills*, 6(2), 159-185.
- Phelan, J. C., Link, B. G., & Dovidio, J. F. (2008). Stigma and prejudice: one animal or two?. *Social science & medicine*, 67(3), 358-367.
- Phelan, J. C., Lucas, J. W., Ridgeway, C. L., & Taylor, C. J. (2014). Stigma, status, and population health. *Social science & medicine*, 103, 15-23.
- Phelan, J. C., Yang, L. H., & Cruz-Rojas, R. (2006). Effects of attributing serious mental illnesses to genetic causes on orientations to treatment. *Psychiatric Services*, 57(3), 382-387
- Popejoy, A. B., & Fullerton, S. M. (2016). Genomics is failing on diversity. *Nature News*, 538(7624), 161–164. doi:10.1038/538161a.
- Potgieter, C., Pillay, R., & Rama, S. (2006). *Women, Development & Transport in Rural Eastern Cape, South Africa*. HSRC Press.
- Quinn, D. M., Williams, M. K., & Weisz, B. M. (2015). From discrimination to internalised mental illness stigma: The mediating roles of anticipated discrimination and anticipated stigma. *Psychiatric rehabilitation journal*, 38(2), 103.
doi: [10.1037/prj0000136](https://doi.org/10.1037/prj0000136)

- Rabie, S., & Naidoo, A. V. (2018). Validating the adaptation of the first career measure in isiXhosa: the South African Career Interest Inventory–isiXhosa version. *South African Journal of Psychology*, 0081246318772419.
- Radua, J., Ramella-Cravaro, V., Ioannidis, J. P. A., Reichenberg, A., Phiphophatsanee, N., Amir, T., Yenn Thoo, H., Oliver, D., Davies, C., Morgan, C., McGuire, P., Murray, R. M. & Fusar-Poli, P. (2018) What causes psychosis? An umbrella review of risk and protective factors. *World Psychiatry* 17:49– 66
- Ramsey, E. M., Achter, P. J., & Condit, C. M. (2001). Genetics, race, and crime: An audience study exploring The Bell Curve and book reviews. *Critical Studies in Media Communication*, 18(1), 1-22.
- Read, J., Fosse, R., Moskowitz, A., & Perry, B. (2014). The traumagenic neurodevelopmental model of psychosis revisited. *Neuropsychiatry*, 4(1), 65.
- Read, J., van Os, J., Morrison, A. P., & Ross, C. A. (2005). Childhood trauma, psychosis and schizophrenia: a literature review with theoretical and clinical implications. *Acta Psychiatrica Scandinavica*, 112(5), 330-350.
- Rensen, C., Bandyopadhyay, S., Gopal, P. K., & Van Brakel, W. H. (2011). Measuring leprosy-related stigma—a pilot study to validate a toolkit of instruments. *Disability and Rehabilitation*, 33(9), 711-719.
doi: <https://doi.org/10.3109/09638288.2010.506942>
- Reydon, T. A., Kampourakis, K., & Patrinos, G. P. (2012). Genetics, genomics and society: the responsibilities of scientists for science communication and education. *Personalized Medicine*, 9(6), 633-643. doi: 10.2217/pme.12.69. DOI: 10.2217/pme.12.69
- Ritsher, J. B., Otilingam, P. G., & Grajales, M. (2003). Internalised stigma of mental illness: psychometric properties of a new measure. *Psychiatry research*, 121(1), 31-49. doi: 10.1016/j.psychres.2003.08.008.

- Robertson, K. A., & Mayosi, B. M. (2008). Rheumatic heart disease: social and economic dimensions. *SAMJ: South African Medical Journal*, 98(10), 780-781.
- Robertson, K. A., Volmink, J. A., & Mayosi, B. M. (2006). Towards a uniform plan for the control of rheumatic fever and rheumatic heart disease in Africa-the Awareness Surveillance Advocacy Prevention (ASAP) Programme. *South African Medical Journal*, 96(3), 241-245.
- Rose, D., Willis, R., Brohan, E., Sartorius, N., Villares, C., Wahlbeck, K., & Thornicroft, G. I. N. D. I. G. O. (2011). Reported stigma and discrimination by people with a diagnosis of schizophrenia. *Epidemiology and Psychiatric Sciences*, 20(2), 193-204.
- Rüsch, N., & Corrigan, P. W. (2002). Motivational interviewing to improve insight and treatment adherence in schizophrenia. *Psychiatric Rehabilitation Journal*, 26(1), 23-32. [dx.doi.org/10.2975/26.2002.23.32](https://doi.org/10.2975/26.2002.23.32)
- Rüsch, N., Todd, A. R., Bodenhausen, G. V., & Corrigan, P. W. (2010). Biogenetic models of psychopathology, implicit guilt, and mental illness stigma. *Psychiatry research*, 179(3), 328-332.
- Sabatello, M. (2018). A Genomically Informed Education System? Challenges for Behavioral Genetics. *The Journal of Law, Medicine & Ethics*, 46(1), 130-144. doi: 10.1177/1073110518766027.
- Sabatello, M., & Appelbaum, P. S. (2016). Raising genomic citizens: Adolescents and the return of secondary genomic findings. *The Journal of Law, Medicine & Ethics*, 44(2), 292-308. doi:10.1177/1073110516654123
- Sabatello, M., & Juengst, E. 2018. *On the Original and Enduring Concerns about Genetic Essentialism, Fatalism, and Stigmatization*. Paper presented at the Looking for the Psychosocial Impacts of Genomic Information Conference. Columbia University. New York City

- Sabatello, M., Phelan, J. C., Hesdorffer, D. C., Shostak, S., Goldsmith, J., Sorge, S. T., ... & Ottman, R. (2015). Genetic causal attribution of epilepsy and its implications for felt stigma. *Epilepsia*, *56*(10), 1542-1550. doi: 10.1111/epi.13113.
- Salo, E. (2003). Negotiating gender and personhood in the new South Africa: Adolescent women and gangsters in Manenberg township on the Cape Flats. *European journal of cultural studies*, *6*(3), 345-365. Retrieved from: <http://ecs.sagepub.com/content/6/3/345.full.pdf+html>
- Sankar, P., Cho, M. K., Wolpe, P. R., & Schairer, C. (2006). What is in a cause? Exploring the relationship between genetic cause and felt stigma. *Genetics in Medicine*, *8*(1), 33-42.
- Saravanan, B., Jacob, K. S., Johnson, S., Prince, M., Bhugra, D., & David, A. S. (2007). Belief models in first episode schizophrenia in South India. *Social psychiatry and psychiatric epidemiology*, *42*(6), 446-451. doi: 10.1007/s00127-007-0186-z
- Sartorius, N., & Janca, A. (1996). Psychiatric assessment instruments developed by the World Health Organization. *Social psychiatry and psychiatric epidemiology*, *31*(2), 55-69.
- Savulescu, J., & Kerin, J. (1999). The “geneticisation” of disease stigma. *The Lancet*, *354*, SIV16.
- Schizophrenia Working Group of the Psychiatric Genomics Consortium. 2014. Biological insights from 108 schizophrenia-associated genetic loci. *Nature*, *511* (7510), 421–27.
- Seedat, S., Stein, D. J., Berk, M., & Wilson, Z. (2002). Barriers to treatment among members of a mental health advocacy group in South Africa. *Social Psychiatry and Psychiatric Epidemiology*, *37*(10), 483-487. doi: 10.1007/s00127-002-0577-0
- Seedat, S., Williams, D. R., Herman, A. A., Moomal, H., Williams, S. L., Jackson, P. B., ... & Stein, D. J. (2009). Mental health service use among South Africans for mood, anxiety and substance use disorders. *South African Medical Journal*, *99*(5). 346-352.

- Senior, V., Marteau, T. M., & Weinman, J. (2000). Impact of genetic testing on causal models of heart disease and arthritis: an analogue study. *Psychology & Health, 14*(6), 1077-1088. doi: <https://doi.org/10.1080/08870440008407368>
- Shibre, T., Negash, A., Kullgren, G., Kebede, D., Alem, A., Fekadu, A., ... & Jacobsson, L. (2001). Perception of stigma among family members of individuals with schizophrenia and major affective disorders in rural Ethiopia. *Social Psychiatry and Psychiatric Epidemiology, 36*(6), 299-303.
- Shostak, S., Freese, J., Link, B. G., & Phelan, J. C. (2009). The politics of the gene: Social status and beliefs about genetics for individual outcomes. *Social Psychology Quarterly, 72*(1), 77-93.
- Sibitz, I., Unger, A., Woppmann, A., Zidek, T., & Amering, M. (2009). Stigma resistance in patients with schizophrenia. *Schizophrenia bulletin, 37*(2), 316-323, doi:10.1093/schbul/sbp048
- Sifunda, S., Reddy, P. S., Braithwaite, R. B., Stephens, T., Bhengu, S., AC Ruiters, R., & Van Den Borne, B. H. (2007). The relationship between alcohol and drug use and sexual behaviour amongst prison inmates in developing countries: The case of South Africa. *International Journal of Prisoner Health, 3*(1), 3-15.
- Simbayi, L. C., Kalichman, S., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Internalised stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social science & medicine, 64*(9), 1823-1831.
- Smit, J., Van den Berg, C. E., Bekker, L. G., Seedat, S., & Stein, D. J. (2006). Translation and cross-cultural adaptation of a mental health battery in an African setting. *African Health Sciences, 6*(4). 215-222.

- Solomon, G., Greenberg, J., Futter, M., Vivian, L., & Penn, C. (2012). Understanding of genetic inheritance among Xhosa-speaking caretakers of children with hemophilia. *Journal of genetic counseling*, 21(5), 726-740. 1-15.
- Sorsdahl, K. R., & Stein, D. J. (2010). Knowledge of and stigma associated with mental disorders in a South African community sample. *The Journal of nervous and mental disease*, 198(10), 742-747.
- Sorsdahl, K. R., Flisher, A. J., Wilson, Z., & Stein, D. J. (2010). Explanatory models of mental disorders and treatment practices among traditional healers in Mpumalanga, South Africa. *African Journal of Psychiatry*, 13(4) 284-290.
- Sorsdahl, K. R., Kakuma, R., Wilson, Z., & Stein, D. J. (2012). The internalised stigma experienced by members of a mental health advocacy group in South Africa. *International Journal of Social Psychiatry*, 58(1), 55-61. doi: 10.1177/0020764010387058
- Sorsdahl, K. R., Mall, S., Stein, D. J., & Joska, J. A. (2010). Perspectives towards mental illness in people living with HIV/AIDS in South Africa. *Aids Care*, 22(11), 1418-1427.
- Sorsdahl, K., Stein, D. J., Grimsrud, A., Seedat, S., Flisher, A. J., Williams, D. R., & Myer, L. (2009). Traditional healers in the treatment of common mental disorders in South Africa. *The Journal of nervous and mental disease*, 197(6), 434-441.
- Spiro, M. (1991). *Illness models of relatives of African psychiatric patients: Implications for a family-based service* (Doctoral dissertation, University of Cape Town).
- StatsSA (Statistics South Africa), (2013), *Quarterly Labour Force Survey, Quarter 4*, Statistical release: P0211. Statistics South Africa, Pretoria, South Africa. Retrieved from https://www.researchgate.net/profile/Inge_Wessels2/publication/257777286_Rising_t

o_the_challenge_Towards_effective_parenting_programmes/links/545511960cf2cf51647dd14a.pdf#page=92

- StatsSA (Statistics South Africa), (2018), *Quarterly Labour Force Survey, Quarter 2*, Statistical release: P0211. Statistics South Africa, Pretoria, South Africa. Retrieved from <http://www.statssa.gov.za/publications/P0211/P02112ndQuarter2018.pdf>
- Steele, G. I., & Edwards, D. J. (2008). Development and Validation of the Xhosa Translations of the Beck Inventories: 1. Challenges of the translation process. *Journal of Psychology in Africa, 18*(2), 207-215.
- Steele, G. I., & Edwards, D. J. (2008). Development and validation of the Xhosa translations of the Beck Inventories: 2. Item analysis, internal consistency and factor analysis. *Journal of Psychology in Africa, 18*(2), 217-226.
- Stein, J. (2003). HIV/AIDS stigma: The latest dirty secret. *African Journal of AIDS Research, 2*(2), 95-101.
- Steptoe, A., & Kivimäki, M. (2013). Stress and cardiovascular disease: an update on current knowledge. *Annual review of public health, 34*, 337-354.
- Stevenson, S. A. M., Van Brakel, W. H., & Augustine, V. (2011). Stigma and social participation in Southern India: Differences and commonalities among persons affected by leprosy and persons living with HIV/AIDS. *Psychology, Health & Medicine, 16*(6), 695-707.
- Sullivan, P. F., Kendler, K. S., & Neale, M. C. (2003). Schizophrenia as a complex trait: evidence from a meta-analysis of twin studies. *Archives of general psychiatry, 60*(12), 1187-1192. doi:10.1001/archpsyc.60.12.1187
- Sumathipala, A., Siribaddana, S., Hewege, S., Sumathipala, K., Prince, M., & Mann, A. (2008). Understanding the explanatory model of the patient on their medically unexplained symptoms and its implication on treatment development research: a Sri Lanka Study. *BMC psychiatry, 8*(1), 54.

- Swartz, L. (1998). *Culture and mental health-A Southern African view*. Cape Town: Oxford University Press
- Swartz, L. (2012). An unruly coming of age: The benefits of discomfort for global mental health. *Transcultural Psychiatry*, *49*(3-4), 531-538 doi: 10.1177/1363461512454810
- Swartz, L., & Drennan, G. (2000). Beyond words: Notes on the 'irrelevance' of language to mental health services in South Africa. *Transcultural Psychiatry*, *37*(2), 185-201.
- Swartz, L., Kilian, S., Twesigye, J., Attah, D., & Chiliza, B. (2014). Language, culture, and task shifting—an emerging challenge for global mental health. *Global health action*, *7*(1), 23433. doi: 10.3402/gha.v7.23433.
- Taft, T. H., Ballou, S., & Keefer, L. (2013). A preliminary evaluation of internalized stigma and stigma resistance in inflammatory bowel disease. *Journal of Health Psychology*, *18*(4), 451-460.
- Tekola, F., Bull, S. J., Farsides, B., Newport, M. J., Adeyemo, A., Rotimi, C. N., & Davey, G. (2009). Tailoring consent to context: designing an appropriate consent process for a biomedical study in a low income setting. *PLoS neglected tropical diseases*, *3*(7), e482.
- Tekola, F., Bull, S., Farsides, B., Newport, M. J., Adeyemo, A., Rotimi, C. N., & Davey, G. (2009). Impact of social stigma on the process of obtaining informed consent for genetic research on podoconiosis: a qualitative study. *BMC medical ethics*, *10*(1), 13.
- Theron, L. C. (2007). Uphenyongokwazi kwentsha yasemalokishini ukumelana nesimo esinzima: A South African study of resilience among township youth. *Child and adolescent psychiatric clinics of North America*, *16*(2), 357-375. doi:10.1016/j.chc.2006.12.005

- Thornicroft, G., Brohan, E., Rose, D., Sartorius, N., Leese, M., & INDIGO Study Group. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *The Lancet*, 373(9661), 408-415. doi: 10.1016/S0140-6736(08)61817-6
- Thornicroft, G., Rose, D., Kassam, A., & Sartorius, N. (2007). Stigma: ignorance, prejudice or discrimination?. *The British Journal of Psychiatry*, 190(3), 192-193.
- Thornicroft, G., Brohan, E., Kassam, A., & Lewis-Holmes, E. (2008). Reducing stigma and discrimination: Candidate interventions. *International journal of mental health systems*, 2(1), 3. Retrieved from: <https://doi.org/10.1186/1752-4458-2-3>
- Thachuk, A. K. (2011). Stigma and the politics of biomedical models of mental illness. *International Journal of Feminist Approaches to Bioethics*, 4(1), 140-163.
- Tindana, P., Bull, S., Amenga-Etego, L., de Vries, J., Aborigo, R., Koram, K., ... & Parker, M. (2012). Seeking consent to genetic and genomic research in a rural Ghanaian setting: a qualitative study of the MalariaGEN experience. *BMC medical ethics*, 13(1), 15.
- Truter, I. (2007). African traditional healers: Cultural and religious beliefs intertwined in a holistic way. *South African Pharmaceutical Journal*, 74(8), 56-60.
- Tygart, C. E. (2000). Genetic causation attribution and public support of gay rights. *International Journal of Public Opinion Research*, 12(3), 259-275. Retrieved from <https://doi.org/10.1093/ijpor/12.3.259>
- Van de Vijver, F. J., Leung, K., & Leung, K. (1997). *Methods and data analysis for cross-cultural research*. California: Sage Publications.
- Van Os, J., Rutten, B. P., & Poulton, R. (2008). Gene-environment interactions in schizophrenia: review of epidemiological findings and future

directions. *Schizophrenia bulletin*, 34(6), 1066-1082. doi:
<https://doi.org/10.1093/schbul/sbn117>

- Van Schalkwyk, G., De Vries, J., & Moodley, K. (2012). " It's for a good cause, isn't it?"- Exploring views of South African TB research participants on sample storage and re-use. *BMC Medical Ethics*, 13(1), 19.
- Vaughn, L. M., Jacquez, F., & Bakar, R. C. (2009). Cultural health attributions, beliefs, and practices: Effects on healthcare and medical education. *The Open Medical Education Journal*, 2(1).
- Vergunst, R., Swartz, L. Mji, G., MacLachlan, M., & Mannan. H. (2015). “You must carry your wheelchair” – Barriers to accessing health care in a South African rural area. *Global Health Action*, 8.
- Vergunst, R., Swartz, L., Mji, G., MacLachlan, M., & Mannan, H. (2015). ‘You must carry your wheelchair’–barriers to accessing healthcare in a South African rural area. *Global health action*, 8(1), 29003.
- Vincent, L. (2008). ‘Boys will be boys’: traditional Xhosa male circumcision, HIV and sexual socialisation in contemporary South Africa. *Culture, Health & Sexuality*, 10(5), 431-446.
- Vukojević, B. (2016). Creswell JW: Research design: Qualitative, quantitative, and mixed methods approaches, London: Sage publications, 2009. *Politeia*, 6(12), 191-194.
- Wanjiru, M. J. 2016. *Attributions of mental illness among young people seeking psychiatric treatment in Kenya at a national hospital in Nairobi*. (Doctoral dissertation, University of Nairobi. Kenya)
- Watkins, D., Zuhlke, L., Engel, M., Daniels, R., Francis, V., Shaboodien, G., ... & Ali, S. (2016). Seven key actions to eradicate rheumatic heart disease in Africa: the Addis

Ababa communique. *Cardiovascular journal of Africa*, 27(3), 184. doi: 10.5830/CVJA-2015-090.

Weiner, B. (1986). *An attributional theory of motivation and emotion*. New York, NY: Springer-Verlag

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.

Williams, D. R., Herman, A., Stein, D. J., Heeringa, S. G., Jackson, P. B., Moomal, H., & Kessler, R. C. (2008). Twelve-month mental disorders in South Africa: prevalence, service use and demographic correlates in the population-based South African Stress and Health Study. *Psychological medicine*, 38(2), 211-220.

World Bank (2000). *World development report, 1999/2000: Entering the 21st century*. Washington DC: World Bank. Retrieved from <https://openknowledge.worldbank.org/handle/10986/5982>

Yakubu, A., Tindana, P., Matimba, A., Littler, K., Munung, N. S., Madden, E., ... & De Vries, J. (2018). Model framework for governance of genomic research and biobanking in Africa—a content description. *AAS open research*, 1. doi: [10.12688/aasopenres.12844.1](https://doi.org/10.12688/aasopenres.12844.1)

Yang, L. H., Kleinman, A., Link, B. G., Phelan, J. C., Lee, S., & Good, B. (2007). Culture and stigma: Adding moral experience to stigma theory. *Social science & medicine*, 64(7), 1524-1535.

Zühlke, L. J. (2015). *Outcomes of asymptomatic and symptomatic rheumatic heart disease* (Doctoral dissertation, University of Cape Town).

Zühlke, L., Perkins, S., & Cembi, S. (2018). Rheumatic heart disease patient event: Cape Town hosts 4th Annual Listen to My Heart Rheumatic Heart Disease for patients at the South African Heart Association meeting in 2017. doi:10.1093/eurheartj/ehy19

Zühlke, L. J., & Steer, A. C. (2013). Estimates of the global burden of rheumatic heart disease. *Global heart*, 8(3), 189-195. doi: <https://doi.org/10.1016/j.gheart.2013.08.008>

Appendix A: HREC Ethics Letter



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338
Email: lamess.emedi@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

09 December 2016

HREC REF: 204/2015

Dr J De Vries
Medicine
J52-16
UCT Centre for Clinical Research

Dear Dr De Vries

PROJECT TITLE: STIGMA IN AFRICAN GENOMICS RESEARCH ON SCHIZOPHRENIA AND RHEUMATIC HEART DISEASE

Thank you for submitting your Amendment dated 25 October 2016 to the Faculty of Health Sciences Human Research Ethics Committee for Full Committee Review.

Date of Full HREC Meeting: 25 November 2016

Decision: The amendment was approved at the full HREC meeting held on 25th November 2016.

Voting for approval was as follows: Present: 15 members; Approved: 13 members; not approved: 0; Abstentions: 2 members.

The Committee also voted regarding whether future amendments and annual approvals could be expedited.

Permission to expedite further amendments and annual approvals was granted at the Full Committee meeting held on 25th November 2016.

Voting for permission to expedite was as follows: Present: 15 members; Approved: 13 members; not approved: 0; Abstentions: 2 members.

The HREC acknowledges that MSc student Marlyn Faure and PhD student Olivia Matshabane will also be involved in this study as included in the submitted amendment to the HREC.

Please quote the HREC REF in all your correspondence.

Yours sincerely

signature removed to avoid exposure online

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

HREC REF 204/2015

Appendix B: Permission to translate Internalised Stigma of Mental illness Scale

From: Jennifer Boyd <jennifer.boyd@ucsf.edu>
Date: Tuesday 19 April 2016 12:33 AM
To: Microsoft Office User <mm.campbell@uct.ac.za>
Subject: RE: Translation of the ISMIS into Xhosa

Hi Megan,

Thank you for your inquiry.

Yes, you have my permission to make both versions, as long as you provide me with a copy of your final versions so that I may share them with others who may wish to use them in the future. I have attached most of the currently available versions in case they are of use to you – some of them are for conditions outside of mental illness. This will help to prevent multiple versions in the same language. Also I call it the ISMI scale, not ISMIS scale. Others have called it the ISMIS but then the last S would be for scale.

Please contact me again should you have further questions.

Best regards,

Jennifer

Appendix C: Information sheet for focus group discussions with RHD/SCZ patients

'SAX/RHD' to be replaced by the specific disease name relevant to the group of participants in each FGD.

Title of the Study: Stigma in African genomics research on Schizophrenia and Rheumatic Heart Disease

Introduction and summary

We are researchers from the University of Cape Town and would like to speak with you about rheumatic heart disease/schizophrenia and how it affects your life. We are mostly interested in knowing whether having this disease causes you to feel like there is a stigma on you – that is, whether it makes other people look at you in a negative way. We would also like to talk with you about genetic research: what you understand about it, and if it could change stigma relating to your disease. We are asking you to take part in a group discussion on these topics. The other people in the group are patients with the same disease as you have. We will also ask you to answer some questions on paper. All the discussions will take place in Xhosa. We will take about two hours for the discussion.

Intshayelelo nesishwankathelo

Singabaphandi abaphuma kwiYDyunivesiti yase Kapa yaye sinqwenela ukuthetha nani malunga nesifo sentliziyo esondeleyo nesifo sokuphazamiseka kwengqondo needlela ezibuchaphazela ngayo ubomi benu. Sinomdla wokwazi ukuba ingaba xa unezizifo uziva unechaphaza elibi na okanye kwenza uluntu lukujonge ngokungamnkelekiyo. Sifuna kwakhona ukuthetha nani ngophando lofuzo, ukuba nazi ntonina ngalo yaye lungakutshintsha na ukujongwa komntu kakubi xa enesifo esithile. Sicela ukuba nithabathe kwingxoxo apho kuqwalaselwa ezi zihloko zibandakanywe ngasentla. Abanye abantu kulamaqela banazo nabo ezi zigulo njengani. Siyakunicela kwakho ukuba niphendule imibuzo ebhaliweyo. Zonke ezi ngxoxo zizakwenziwa ngesiXhosa yaye kuyakusithabatha ubuncinane iiyure ezimbini.

Objective

We hope to use the findings of this study to understand better if genetic research could influence the stigma relating to rheumatic heart disease schizophrenia. With stigma we mean whether your disease makes people look at you or treat you in a negative way. With genetic research, we talk about the kind of research that looks at the genetic material. Genetic material is like the building blocks of your body, and it is what makes people in families look like each other. Sometimes, genetic material is involved in the development of diseases. We want to discuss with you whether you think you would see your disease differently if you knew the cause was genetic.

Injongo

Sinethamba lokusebenzisa ziphumo zolu phando ukuqwalasela ukuba iziphumo zophando ngokuzalana azingebi nampembelelo na kwichabhaza elibekwa kwabo banophazamiseko lwengqondo. Ngechaphaza sithetha ukuba isigulo sakho asingebi senza abantu bakujonge ngeliso lokukweya kusini na. Ngophando lokuzalana sithetha sithetha ngesakhiwo sozalwano esithi senze umzimba lo wakho ufane nabakuni. Ngamanye amaxesha olufuzo luthilubene nxaxheba ekwenzekeni kwezifo emizimbeni yethu. Sifuna ukuqonda ukuba xa unokuyazi ukuba isigulo sakho senziwe lufuzo, ungasithatha ngendlela eyahlulaleyo kusinina.

The Researchers

This project is led by Drs. Jantina de Vries and Megan Campbell at the University of Cape Town (UCT). They work with other researchers at UCT and in the United States.

Abaphandi

Olu phando lukhokelwe ngoogqirha uJantina de Vries no Megan Campbell beYunivesiti yaseKapa. Basebenza nabanye abaphandi kwiYunivesiti yaseKapa kwakunye nabase USA.

Participants

We will conduct this study with patients who have either schizophrenia or rheumatic heart disease (RHD). We hope to speak with 70 patients with RHD and 70 with schizophrenia. We contacted you because you also participated in the RHDGen/Schizophrenia genomics project. We would also like to interview 30 family members of patients who participated in the group discussions.

Abathathi nxaxheba:

Olu phando sizakulenza kubantu abanesifo esondeleyo sentliziyo kwanabo abanophazamiseko lwengqondo. Sinethemba lokuthetha nabantu abakumyinge wamashumi asixhenxe kwisigulo ngasinye. Sinichonge nina kuba benithabathe inxaxheba kuphando lwethu olungaphambili. Sizakucela kwakhona ukuba nodliwano ndlebe namalungu entsapho ezigulane ezithabatha inxaxheba kwezingxoxo abangamashumi amathathu.

Methods

If you agree to participate, you will be part of a group discussion with other patients that have the same disease as you do. The group will be small, about 6-10 people. The group discussion will consist of four components: *Ukuba uyavuma uthabatha inxaxheba koluphando, sizakuthetha nawe kwakunye nabanye abantu abaso esisifo sakho (6-10 yabantu) kwinxoxo ngaxeshanye. Ezinxoxo zizakohlulwa kube kane:*

1. We will first ask you to answer some questions on paper. This will include questions about your disease experiences and whether you feel any stigma or discrimination because of your disease.
Sizakubuza imibuzo esephepheni. Le mibuzo izakuthetha ngesifo sakho kunye namava akho okuphila nesisifo, kwaye izakubuza ngesenyeliso othe wasifumana ngenxa yokuphila nesisifo.
2. We will then have a short group discussion about rheumatic heart disease/ schizophrenia and what you know about genetics.
Sizakuthetha nabanye abantu abanaso esisifo unaso (RHD/SCZ) malunga no fuzo.
3. We will then tell you a story about a patient with your disease, and what the doctor tells him about how he got it.
Sizakukubalisela ibali lomntu onesisifo nawe unaso, kwaye ugqhira uzakumchazela lomntu ngezizatho zesifo sakhe.
4. We will then conclude with a last group discussion where we talk about that story, and whether the story would change any of the stigma you may experience with your disease.
Sizakugqibezela ngokuthetha malunga nebali eliyelavezwa koluphando, kwaye sibuze imibuzo yokuba isenyeliso singatshintsha njani xa abantu besiva amava womntu onesisifo.

Risks and benefits

There are some risks relating to taking part in this study. Most of all, you could find it upsetting to talk about your disease and any stigma you feel. We will talk with you about how you feel after the group discussion, to make sure you are not upset. If you would like to talk to us after you've left, then you can call us on 021 650 5716 and we will make sure to put you in touch with people who can help. One of the members of our research team is a

counselling psychologist. She will be able to counsel you about any negative aspects relating to your study participation. She can also direct you to people who can help longer-term. The benefit of this study is that it will help us understand whether genetic research can decrease stigma for rheumatic heart disease/schizophrenia. With the findings, we will be able to do better genetic research in the future. It may also be a benefit for you to be in a group of people who have the same disease as you do, to talk about how the disease makes you feel.

Imingcipheko nobungozi

Ikhona imingcipheko ethi inxulumane nokuthabatha inxaxheba kwesi sifundo. Abanye benu bangazifumana bekhathazekile ngokuthetha ngesifo sakho kwakunye nechaphaza othi uzive unalo. Kodwa ke siyakuthi sincokole malunga nendlela eniziva ngayo emva kwengxoxo mpikiswano ukuqinisekisa ukuba anikhathazekanga. Kwaye ukuba unqwenela ukuthetha nathi emva kokuba nimkile ningasitsalela umnxeba kule nombolo: 021 6505716 kwaye siyakuthi siqinisekise ukuba sinidibanisa nabantu abayakuthi banincede. Esi sifundo siyakuthi sisincede ukuba sazi ukuba ingaba izifundo ngofuzo zingalicutha na ichaphaza okanye ibala ngesifo sentliziyo esondeleyo okanye isifo sengqondo. Ngeziphumo ke siyakukwazi ukuba sense izifundo ezingcono zofuzo kwilixa elizayo. Kwaye zinganalo negalelo xa umntu ekwiqumru lengxoxo mpikiswano nabantu abanesifo esifanayo nesakho xa nithetha ngendlela isifo esinenza nizive ngayo.

Privacy

We will record and write down the group discussion. At the start of the interview, we would like to get some information about you – including your name – but we will not share your name with anybody. When we write the discussion down it will not have your name on it. We will share the writings between all the researchers on the project. When we report on our research, we may use some of the sentences that you said. If we use one of your sentences, it will appear together with a brief description of you (for instance, ‘RHD/Schizophrenia patient’), and a code for the discussion (for instance, Focus Group 06). However, it is important to remember that the discussion will take place in a group. We will ask everybody in the group to keep the discussion confidential, but it is possible that somebody could talk to others about it. If you want, you can use another name for yourself during the discussion, so that nobody in the group will know your real name. It is up to you if you want to do that.

Imfihlo

Sizoshicilela, sibhale phantsi ingxoxo zeqela. Ekuqaleni kovavanyo, sizakucela ukufumana iincukacha ngawe, kunye negama lakho – kodwa igama lakho alizukwaziswa kumntu wonke. Igama lakho alizubonakaliswa kwingxixoxo esiyibhalileyo. Ingxelo ebhaliweyo izakwaziswa kubo bonke abaphandi bophulo. Xa sisenza inkcazelo ngophando, sisenokuzisebenzisa ezinye izivakalisi ozithethileyo. Apho sisebenzise esinye isivakalisi sakho, sizakubonakala kunye nengcaciso emfutshane yakho (umzekelo, `RHD/Schizophrenia) kunye ne nombolo yengxoxo (umzekelo iqela elikethekileyo 06). Yonke ingcombolo nenkcukacha efumaneka koluphando nemalunganawe iyakuba yimfihlo, kodwa kungenzeka ukuba omnye umntu oyewathatha inxaxheba koluphando athethe nabanye malungo noluphando. Ukuba uyathanda ungasebenzisa elinye igama xa uthatha inxaxheba koluphando. Oko Kkkuwe.

Withdrawal

You do not have to answer all the questions during the group discussion. For instance, if we ask a question and it makes you feel uncomfortable, you can just tell us. Also, you can decide to leave the discussion at any time.

Ukurhoxa

Awunyanzelekanga uphendule yonke imibuzo ngexesha lengxoxo yeqela. Umzekelo, uba sibuzo umbuzo ube ukwenza uzive ungakhululekanga, angasixeleva. Kwakhona, ungasithatha isigqibo uyishiye ingxoxo nangaliphi na ixesha.

Compensation

We would like to thank you for the time that you took to be part of our study. We will pay for the cost of your transport (R50) and give you a small voucher (R75) for your mobile phone.

Imbuyekezo

Sizakucela ukukubulela ngexesha olichithileyo waba nathi kwimfundo yethu. Sizakukhulawula ngendleko ozihlawulileyo kwezothutho (R100)

Contact Information

If you have any questions or comments about this project, or if you want to speak more about the project, you can contact Olivia Matshabane on 084 293 6376. If you prefer, you can also send an email: olivia.matshabane@uct.ac.za

Inkcukacha zonxibelelwano

Ukuba ngaba unemibuzo okanye ufuna ukuphawula ngoluphulo, okanye ukongeza malunga noluphulo, ungasitsalela ucingo kulomxeba 021 650 5716 (utsalele uJantina de Vries). Ungaphinde utsalele umxeba uOlivia Matshabane ku 084 293 6376 okanye ungasithumelelela i-email: olivia.matshabane@uct.ac.za.

Appendix D: Consent Form

Title of the Study: Stigma in African genomics research on Schizophrenia and Rheumatic Heart Disease

Informed Consent

Key points to remember of this study:

Imba ebalulekileyo ukuba uyikhumbule:

- We are doing a project to explore whether genetic knowledge would change the stigma relating to schizophrenia (SCZ) and rheumatic heart disease (RHD)
Senza Uphando lokuqondisisa ukuba ingaba ulwazi lwezinto zemfuzo lungazitshintsha njani na isenyeliso esinxulumene nokuphazamiseka engqondweni kunye nesifo esondelelo sentliziyo.
- We will speak to RHD and SCZ patients about their experiences of stigma.
Sizakuthetha nabantu abaphila nesigulo sokuphazamiseka engqondweni kunye nabantu abaphila nesifo sentliziyo malunga na mava abo esinyeliso esinyeliso esinxulumene nokuphazamiseka engqondweni.
- You don't have to give us your real name if you would prefer for us not to know it.
Awunyanzelekanga ukuba usinike igama lakho ukuba awunqweneli silazi.
- We would like to record the conversation. This is for us to keep good track of what was discussed. We will not tell anyone your name or let it be known it was you who participated.
Singathanda ukuyishicilela incoko yethu. Lonto iyakukusinceda ukuqinisekisa ukuba konke okuthethiweyo kuselugcinweni. Siyagqinisekisa ukuba asiyikwazisa mntu ngegama lakho okanye ukuba ubukhe wathabatha inxaxheba koluphando.

Please remember that your participation is voluntary, and there are no consequences if you do not want to participate. You can withdraw in the future if you want. Please contact Dr Jantina de Vries or Olivia Matshabane if you no longer want to participate, or if you would like to discuss any of the issues that came up when we spoke with you.

Sicela ukhumbule ukuba inxaxheba yakho yintando yakho, kwaye akukho sinyanzeliso ukuba awunamqweni wokuthabatha nxaxheba. Ungayeka na nini na xa uthanda. Sicela unxibelelane no Gqirha uJantina de Vries okanye uOlivia Matshabane, ukuba awusenamda wokubayinxalenye yoluphando, okanye ukuba ufuna ukuncokola nangantoni na esithe sathetha ngayo koluphando.

Consent Statement:

- I agree to participate in the Stigma in Genomics research project;
Ndiyavuma ukuthabatha inxaxheba kuphando lwezenyeliso zemfuzo.
- I understand that my participation is voluntary and that I can withdraw at any moment;
Ndiyayiqonda into yokuba inxaxheba yam kwesisifundo ayisosinyanzelo kwaye ndivumelekile ukuyeka xa ndithe ndathanda njalo.
- I understand that I am participating in research, and that I will not benefit from this; except by receiving compensation for my travelling to the amount of R100.
Ndiyayiqonda into yokuba ngokuthabatha inxaxheba koluphando akukho nzuzo endiya kuyifumana ngaphandle kwe mali engage R100 yokukhwela.
- I have been given the opportunity to ask questions and these have been answered.
Ndinikiwe ithuba lokubuza imibuzo, kwaye yaphenduleka.

Participant name or pseudonym/Igama lomthathi nxaxheba _____

Participant Signature/ Umtyikityo _____

Date/ Umhla _____

Name of person taking consent/ Igama lomntu othabatha isivumelwano _____

Signature/ Utyikityo _____

Date/ Umhla _____

Appendix E: Demographic Data Collection Sheet for FGDs

This section to be completed by Research Staff prior to distributing this form to participants

FGD Number:

Disease group (SCZ or RHD):

Participant name or pseudonym/ Igama okanye igama lamaxoki:

Age/ Iminyaka] Under 18
] 18-25 years
] 25-35 years
] Over 35 years

Sex/ Isini] Male
] Female

Highest level of education/ Ibanga lemfundo eliphezulu] No formal education
] Grades 1-7
] Grades 8-10
] Grades 11-12
] More than Grade 12

Employment/ Ukuphangela] Unemployed
] Employed fulltime
] Employed part-time

Average income/ Umvuzo] Less than R500 per week
] R500-R1000 per week
] R1000-R2000 per week
] More than R2000 per week

Government disability grant/ Uyasifumana isibonelelo sika rhulumente] Yes
] No

How old were you when your condition was first diagnosed?

Wawuna ngaphi nokufumanisa kwakho ukuba unesisifo?

Under 18

└ 18-25 years

└ 25-35 years

└ Over 35 years

Appendix F: FGD Process

Step	Activity	Approximate time (min)
1	People enter the room and sit down	
2	Thank people for being there. Explain the study, ask if everything is clear and if everyone is happy.	10 min
3	Explain need for written informed consent and distribute signature pages; get informed consent	15 min
4	Administer the short questionnaire with demographic data	5-10 min
5	<i>Explain (repeat) what will happen next with regards to the video which will be watched and the discussion to follow in between</i>	5 min
6	Short debrief – is everybody ok?	5 min
7	Start the FGD and its duration	60 min
8	At the end, ask if there are any questions. Contain and debrief the group.	30 min
9	Thanks and small reimbursement for travel money	5 min

Appendix G: FGD topic guide and vignette RHD patients

What we want to get from the FGDs is a sense of whether genetic attribution would impact on stigma associated with the two diseases.

Questions/purpose of FGDs:

- Explore existing stigma relating to RHD and SAX
- Explore knowledge about genetics and genomics

NOTES: The scenarios in these topic guides were translated to isiXhosa and then developed into short videos by a professional film maker. These videos were screened during the FGDs.

Start FGD

Scope general understanding of genetics

- You have all been involved in a genetics/genomics research project – can you tell us a little bit about what genetics/genomics is? Do you remember what the nurse told you?
- First explore whether interviewees have any conception of genetics.
- Then explain what this is, mentioning family inheritance, family members sharing physical and disease traits. Useful phrases are ‘things that run in the family’, ‘things that are in the blood’, and also explanations about how particular features (e.g. shape of the face or the body) are often shared between family members – e.g. you can look like your mum or your dad. Also, diseases move in families in that same way.

Vignette (turned into short video, with questions appearing on the screen)

Story stage 1

Andile is 26 years old and lives with his mother in an RDP house in Langa. He is unemployed and gets a government disability grant each month to support them. Andile has rheumatic heart disease or what is also called valve disease, and first became ill four years ago. He then became very tired and was often short of breath. He also went to the hospital many times for simple things that other people would not get very ill of, like flu. His mother found this very strange and worrying. She took him to the hospital where the doctor told them that Andile had rheumatic heart disease and began treating him.

- What do you know about rheumatic heart disease?
- What do you think causes it?
- How will having rheumatic heart disease affect Andile’s life?
- How do you think other people will respond to Andile when they know he has rheumatic heart disease?
 - o Is it likely that Andile will be looked down on by others?

Story stage 2 (all stages turned into very short videos, with questions appearing on the screen)

(i) *Genetic*: Andile wanted to know what had caused his rheumatic heart disease. The doctor explained that although this disease is triggered by an infection, how likely a person is to develop it runs in the family/ is hereditary/in the genes, which means that it was passed down from his parents and previous generations in the family. He asked if Andile remembered anyone else in the family who had similar problems. Andile remembered having an uncle who also had heart problems.

- So the doctor tells Andile that his rheumatic heart disease is caused by something passed down in his family. How will this affect Andile's life? [After open-ended responses, follow up with specific probes below, if not already mentioned; to explore further ask "How?"]
 - a. Will it change how his family relates to him?
 - b. Will it change how his friends relate to him?
 - c. Will it affect the chances that a boss would give him a job?
 - d. Will it affect the chances that he'll get married?
 - e. Will it affect his decisions about having children?
 - f. Will it change the chances that he will want treatment?
 - g. How else might it change his life?

(ii) *Mixed environmental/genetic*: Andile wanted to know what had caused his rheumatic heart disease. The doctor explained that although this disease is triggered by an infection, how likely a person is to develop it partly runs in the family/ is hereditary/in the genes, and partly depends on the circumstances the person lives in. The doctor asked where Andile grew up. Andile tells him that for most of his life, she lived in a shack they shared with his aunt. The doctor asked if Andile could remember whether he had ever had a really sore throat, followed by pain in his body. He remembered that he was very ill when he was about six, and then again in his early twenties. The doctor tells Andile that his disease is caused by a combination of things in his blood (his genes), the sore throat and where he grew up.

- So the doctor tells Andile that his rheumatic heart disease is partly caused by something passed down in his family and partly by the circumstances in which he grew up. How will this affect Andile's life? [After open-ended responses, follow up with specific probes below, if not already mentioned; to explore further ask "How?"]
 - a. Will it change how his family relates to him?
 - b. Will it change how his friends relate to him?
 - c. Will it affect the chances that a boss would give him a job?
 - d. Will it affect the chances that he'll get married?
 - e. Will it affect his decisions about having children?
 - f. Will it change the chances that he will want treatment?
 - g. How else might it change his life?

(iii) *Environmental*: Andile wanted to know what had caused the rheumatic heart disease. The doctor explained that although this disease is triggered by an infection, how likely a person is to develop it partly depends on the circumstances the person lives in. For example, people who live in crowded,

poorly ventilated houses are more likely to get RHD. He asked if Andile could remember whether he had ever had a really sore throat, followed by pain in his body. He remembered that he was very ill when he was about six, and then again in his early twenties.

- So the doctor tells Andile that his rheumatic heart disease is caused by the circumstances in which he grew up. How will this affect Andile's life? [After open-ended responses, follow up with specific probes below, if not already mentioned; to explore further ask "How?"]
 - a. Will it change how his family relates to him?
 - b. Will it change how his friends relate to him?
 - c. Will it affect the chances that a boss would give him a job?
 - d. Will it affect the chances that he'll get married?
 - e. Will it affect his decisions about having children?
 - f. Will it change the chances that he will want treatment?
 - g. How else might it change his life?

Story stage 3 (turned into short video with questions appearing on the screen)

Andile's mother is friendly with your parents and you all happen to meet up one day. Andile's mother wants to introduce you to her son and hopes that the two of you would become friends.

- How would you feel about becoming friends with Andile?
- How would you feel about introducing Andile to other people in your family?
- How would you feel if Andile wanted to date or marry your sister?
- Do you think Andile's children would also develop this disease? All of them, or just some of them?

Appendix H: FGD topic guide and vignette SCZ patients

What we want to get from the FGDs is a sense of whether genetic attribution would impact on stigma associated with the two diseases.

Questions/purpose of FGDs:

- Explore existing stigma relating to RHD and SAX
- Explore knowledge about genetics and genomics

NOTES: Topic guides and vignettes were discussed with SCZ study recruiters to get their input on typical patient presentation. The scenarios in these topic guides were translated into isiXhosa and developed into short videos by a professional film maker. These videos were screened during the FGDs.

Start FGD

Scope general understanding of genetics

- You have all been involved in a genetics/genomics research project – can you tell us a little bit about what genetics/genomics is? What do you remember about what the nurse told you?
- First explore whether interviewees have any conception of genetics.
- Then explain what this is, mentioning family inheritance, family members sharing physical and disease traits. Useful phrases are ‘things that run in the family’, things that are in the blood’, and also explanations about how particular features (e.g. shape of the face or the body) are often shared between family members – e.g. you can look like your mum or your dad. Also, diseases move in families in that same way.

Vignette

Story stage 1 **(turned into short video with questions appearing on the screen)**

Andile is 26 years old and lives with his mother in an RDP house in Langa. He is unemployed and gets a government disability grant each month to support them. Andile has schizophrenia and first became ill four years ago. He started hearing strange voices that scared him and started believing that it was too dangerous to leave his house. His mother found his behaviour very strange and worrying. She took him to the hospital where the doctor told them that Andile had schizophrenia and began treating him.

- What do you know about schizophrenia?
- What do you think causes it?
- How will having schizophrenia affect Andile’s life?
- How do you think other people will respond to Andile when they know he has schizophrenia?
 - o Is it likely that Andile will be looked down on by others?

Story stage 2 **(all story stages turned into short video with questions appearing on the screen)**

(i) *Genetic*: Andile wanted to know what had caused his schizophrenia. The doctor explained that schizophrenia runs in the family/ is hereditary/ in the genes, which means that it was passed down from his parents and previous generations in the family. He asked if Andile remembered anyone else in the family who had similar problems. Andile remembered an uncle who other family members said behaved in strange ways and reported hearing scary voices.

- So the doctor tells Andile that his schizophrenia is caused by something passed down in his family. How will this affect Andile's life? [After open-ended responses, follow up with specific probes below, if not already mentioned; to explore further ask "How?"]
 - a. Will it change how his family relates to him?
 - b. Will it change how his friends relate to him?
 - c. Will it affect the chances that a boss would give him a job?
 - d. Will it affect the chances that he'll get married?
 - e. Will it affect his decisions about having children?
 - f. Will it change the chances that he will want treatment?
 - g. How else might it change his life?

(ii) *Mixed environmental/genetic*: Andile wanted to know what had caused his schizophrenia. The doctor explained that schizophrenia is partly hereditary/ in the genes, which means that it was passed down from his parents and previous generations in the family. But carrying the genes alone was not enough: it probably was also caused by the circumstances that Andile had been exposed to in his life. The doctor asked if Andile could remember anyone else in the family who had similar symptoms. Andile remembered an uncle who other family members said behaved in strange ways and reported hearing scary voices. The doctor also asked if he could remember anything very challenging, difficult or traumatic that happened in his life. Andile said that his father died when he was a baby, and that his mother had been unable to find fulltime employment. They often had little money and not enough food or a warm place to stay. Andile and his mother were alone without family to depend on. Andile was teased, bullied and beaten by older children in the community, and spent a lot of time alone. The doctor tells Andile that his disease is caused by a combination of things in his blood (his genes) and his experiences growing up.

- So the doctor tells Andile that his schizophrenia is partly caused by something passed down in his family and partly by the circumstances in which he grew up. How will this affect Andile's life? [After open-ended responses, follow up with specific probes below, if not already mentioned; to explore further ask "How?"]
 - a. Will it change how his family relates to him?
 - b. Will it change how his friends relate to him?
 - c. Will it affect the chances that a boss would give him a job?
 - d. Will it affect the chances that he'll get married?
 - e. Will it affect his decisions about having children?
 - f. Will it change the chances that he will want treatment?
 - g. How else might it change his life?

(iii) *Environmental*: Andile wanted to know what had caused his schizophrenia. The doctor explained that schizophrenia was caused by the circumstances that Andile had been exposed to in his life. He asked if Andile could remember anything very challenging, difficult or traumatic that he had experienced. Andile said his father had died when he was a baby, and that his mother had been unable to find fulltime employment. They often had little money and not enough food or a warm place to stay. Andile and his mother were alone without family to depend on. Andile was teased, bullied and beaten by older children

in the community, and spent a lot of time alone.

- So the doctor tells Andile that his schizophrenia is caused by the circumstances in which he grew up. How will this affect Andile's life? [After open-ended responses, follow up with specific probes below, if not already mentioned; to explore further ask "How?"]
 - a. Will it change how his family relates to him?
 - b. Will it change how his friends relate to him?
 - c. Will it affect the chances that a boss would give him a job?
 - d. Will it affect the chances that he'll get married?
 - e. Will it affect his decisions about having children?
 - f. Will it change the chances that he will want treatment?
 - g. How else might it change his life?

Story stage 3 (turned into short video with questions appearing on the screen) Andile's mother is friendly with your parents and you all happen to meet up one day. Andile's mother wants to introduce you to her son and hopes that the two of you would become friends.

- How would you feel about becoming friends with Andile?
- How would you feel about introducing Andile to other people in your family?
- How would you feel if Andile wanted to date or marry your sister?
- Do you think Andile's children would also develop this disease? All of them, or just some of them.

Appendix I

Internalised Stigma of Mental Illness Xhosa Version (ISMI-X)					
Sex: Isini		M / F			
Age: Iminyaka yakho					
Highest level of education: Ibanga lemfundo eliphezulu					
Where do you live? Uhlala phi		URBAN / PERI-URBAN / RURAL			
		1	2	3	4
		Strongly disagree/ <i>Andivumi kakhulu</i>	Disagree/ <i>Andivumi</i>	Agree/ <i>Ndiyavuma</i>	Strongly agree/ <i>Ndiyavuma kakhulu</i>
Alienation					
1	I feel out of place in the world because I have a mental illness <i>Ndiziva ndingamkelekanga ehlabathini kuba ndiphazamiseke ngokwasengqondweni</i>				
5	I am embarrassed or ashamed that I have a mental illness <i>Ndiziva ndiphoxekile okanye ndinentloni kuba ndiphazamiseke ngokwasengqondweni</i>				
8	I feel inferior to others who don't have a mental illness <i>Ndiziva ndizeya kubantu abangaphazamisekanga engqondweni</i>				
16	I am disappointed in myself for having a mental illness <i>Ndiziva ndinodano ngesiqu sam kuba ndiphazamiseke ngokwasengqondweni</i>				

17	Having a mental illness has spoiled my life <i>Ukuba nesigulo sengqondo kubuphazamisile ubomi bam</i>				
21	People without mental illness could not possibly understand me <i>Abantu abangaphazamisekanga engqondweni ngekhe bayiqonde imeko yam</i>				
Stereotype Endorsement					
2	Mentally ill people tend to be violent <i>Abantu abaphazamisekileyo engqondweni bakholisa ukuba ndlongo-ndlongo</i>				
6	Mentally ill people shouldn't get married <i>Abantu abaphazamisekileyo engqondweni abafanelanga ukutshata</i>				
10	People with a mental illness cannot live a good, rewarding life <i>Abantu abaphazamisekileyo engqondweni abanakho ukuphila ubomi obulungileyo nobunembuyekezo</i>				
18	People can tell that I have a mental illness by the way I look <i>Abantu bangatsho ukuba ndiphazamisekile engqondweni ngendlela endibonakala ngayo lwezigqibo</i>				
19	Because I have a mental illness, I need others to make most decisions for me <i>Kuba ndiphazamisekile engqondweni ndifuna abanye abantu bandithathele uninzi</i>				

23	I can't contribute anything to society because I have a mental illness <i>Andikwazi kuba nagalelo ekuhlaleni nakweyiphi na into kuba ndiphazamisekile engqondweni</i>				
29	Stereotypes about the mentally ill apply to me <i>lingcamango ezingezizo zabantu malunga nesigulo sengqondo nam ziyandichaphazela</i>				
Discrimination Experience					
3	People discriminate against me because I have a mental illness <i>Abantu bayandicalu-calula kuba ndiphazamisekile engqondweni</i>				
15	People often patronize me, or treat me like a child, just because I have a mental illness <i>Abantu bakholisa ukundiphatha okomntwana kuba ndiphazamisekile engqondweni</i>				
22	People ignore me or take me less seriously just because I have a mental illness <i>Abantu baye bangandihoyi okanye bangandithatheli ngqalelo kuba ndiphazamisekile engqondweni</i>				
25	Nobody would be interested in getting close to me because I have a mental illness <i>Akukho mntu uyakuba nomdla wokusondela kum kuba ndiphazamisekile engqondweni</i>				

28	<p>Others think that I can't achieve much in life because I have a mental illness</p> <p><i>Abanye abantu bacinga ukuba andinakuze ndiphumelele kangako ebomini kuba ndiphazamisekile engqondweni</i></p>				
Social Withdrawal					
4	<p>I avoid getting close to people who don't have a mental illness to avoid rejection</p> <p><i>Ndiyazikhwebula ukuba kufutshane kubantu abangaphazamisekanga engqondweni ukuze ndingaziva ndingamkelekanga</i></p>				
9	<p>I don't socialize as much as I used to because my mental illness might make me look or behave weird</p> <p><i>Andisakonwabeli kakhulu ukuhlala nabanye abantu njengoko ndandiqhele ukwenza kuba isigulo sam sengqondo sindenza ndibonakale kwaye ndenze izinto ezingaqhelekanga</i></p>				
11	<p>I don't talk about myself much because I don't want to burden others with my mental illness</p> <p><i>Andithethi kakhulu ngam kuba andifuni ukwenzela abanye abantu uxanduva ngesigulo sam sokuphazamiseka engqondweni</i></p>				
12	<p>Negative stereotypes about mental illness keep me isolated from the 'normal' World</p> <p><i>Ingamango ezimbi ezithethwa ngophazamiseko lwengqondo zindenza ndiziguzule kwizinto eziqhubekayo ehlabathini 'eliqhelekileyo'</i></p>				

13	Being around people who don't have a mental illness makes me feel out of place or inadequate <i>Ukuba phakathi kwabantu abangaphazamisekanga engqondweni kundenza ndizive ingathi ndilahlekile okanye ndimncinci</i>				
20	I stay away from social situations in order to protect my family or friends from embarrassment <i>Ndihlalela kude le kwindawo zolonwabo ukuze ndikhusele usapho lwam kunye nabahlobo bam kuhlazo</i>				
Stigma Resistance					
7	People with mental illness make important contributions to society <i>Abantu abaphazamisekileyo engqondweni banegalelo elibalulekileyo ekuhlaleni</i>				
14	I feel comfortable being seen in public with an obviously mentally ill person <i>Ndiziva ndikhululekile esidlangalaleni nomntu ocacileyo ukuba uphazamisekile engqondweni</i>				
24	Living with mental illness has made me a tough survivor <i>Ukuphila ndinophazamiseko lwengqondo kundenze ndaphumelela kwimeko ezinzima</i>				
26	In general, I am able to live life the way I want to <i>Ngokuqhelekileyo, ndiyakwazi ukuphila ubomi ngendlela endifuna ngayo</i>				
27	I can have a good, fulfilling life, despite my mental illness <i>Ndingaba nobomi obuhle obanelisayo nangona ndiphazamisekile engqondweni</i>				

Experiences of Abuse

30	<p>People call me names because I have a mental illness <i>Abantu bandibiza ngamagama kuba ndiphazamisekile engqondweni</i></p>				
31	<p>People have been physically abusive towards me because I have a mental illness <i>Abantu bebendihlukumeza ngokwasemzimbeni kuba ndiphazamisekile engqondweni</i></p>				
32	<p>People have been verbally abusive towards me because I have a mental illness <i>Abantu bebethetha rhabaxa ngakum, kuba ndiphazamisekile ngokwase engqondweni</i></p>				
33	<p>I find it difficult to attend clinic appointments because people will know that I have a mental illness <i>Ndifumana kunzima ukuya ekliniki nje ngoko kumisiwe kuba abantu bazakwazi ukuba mna ndiphazamisekile engqondweni</i></p>				
34	<p>I think the media has a negative influence on the way people perceive mental illness <i>Ndicinga ukuba izinto ezisasaza iindaba zinempembelelo engeyiyo kwindlela abantu abajonga ngayo abantu abaphazamisekileyo engqondweni</i></p>				
35	<p>I find it difficult to take my tablets every day because they remind me that I have a mental illness <i>Ndifumanisa kunzima ukusela ipilisi zam yonke imihla kuba zindikhumbuza ukuba ndiphazamisekile engqondweni</i></p>				

Internalised Stigma of Rheumatic Heart Disease Xhosa Version (ISRHD-X)					
Sex: <i>Isini</i>		M / F			
Age: <i>Iminyaka yakho</i>					
Highest level of education: <i>Ibanga lemfundo eliphezulu</i>					
Where do you live? <i>Uhlala phi</i>		URBAN / PERI-URBAN / RURAL			
Have you had an operation performed? <i>Wakhe watyandwa na ngaphambili?</i>		Y / N			
If yes, date of operation: <i>Ukuba kunjalo, umhla:</i>					
		1	2	3	4
		Strongly disagree/ <i>Andivumi kakhulu</i>	Disagree/ <i>Andivumi</i>	Agree/ <i>Ndiyavuma</i>	Strongly agree/ <i>Ndiyavuma kakhulu</i>
<i>Alienation</i>					
1	I feel out of place in the world because I have a heart disease <i>Ndiziva ndingamkelekanga ehlabathini kuba ndinesifo sentliziyo</i>				
5	I am embarrassed or ashamed that I have a heart disease <i>Ndiziva ndinodano okanye ndinentloni kuba ndinesifo sentliziyo</i>				
8	I feel inferior to others who don't have a heart disease <i>Ndiziva ndizeya kubantu abangenasifo sentliziyo</i>				
16	I am disappointed in myself for having a heart disease <i>Ndiziva ndinodano ngesiqu sam kuba ndinesifo sentliziyo</i>				
17	Having a heart disease has spoiled my life <i>Ubomi bam bonakele ngenxa yesifo sentliziyo</i>				
21	People without heart disease could not possibly understand me <i>Abantu abangenasifo sentliziyo ngekhe bayiqonde imeko yam</i>				
<i>Stereotype Endorsement</i>					
2	People with heart disease tend to be violent <i>Abantu abanesifo sentliziyo bakholisa ukuba ndlongo-ndlongo</i>				

6	<p>People with heart disease shouldn't get married</p> <p><i>Abantu abanesifo sentliziyo abafanelanga ukutshata</i></p>				
18	<p>People with heart disease cannot live a good, rewarding life</p> <p><i>Abantu abanesifo sentliziyo abanakho ukuphila ubomi obulungileyo nobunembuyekezo</i></p>				
19	<p>Because I have a heart disease, I need others to make most decisions for me</p> <p><i>Kuba ndinesifo sentliziyo ndifuna abanye abantu bandithathele uninzi lwezigqibo</i></p>				
23	<p>I can't contribute anything to society because I have a heart disease</p> <p><i>Andikwazi kuba nagalelo ekuhlaleni nakweyiphi na into kuba ndinesifo sentliziyo</i></p>				
29	<p>Stereotypes about people with heart disease apply to me</p> <p><i>lingcamango ezingezizo zabantu malunga nesifo sentliziyo nam ziyandichapazela</i></p>				
Discrimination Experience					
3	<p>People discriminate against me because I have a heart disease</p> <p><i>Abantu bayandicalu-calula kuba ndinesifo sentliziyo</i></p>				
15	<p>People often patronize me, or treat me like a child, just because I have a heart disease</p> <p><i>Abantu bakholisa ukundiphatha okomntwana kuba ndinesifo sentliziyo</i></p>				
22	<p>People ignore me or take me less seriously just because I have a heart disease</p> <p><i>Abantu baye bangandhoyi okanyebangandithatheli ngqalelo kuba ndinesifo sentliziyo</i></p>				

25	Nobody would be interested in getting close to me because I have a heart disease <i>Akukho mntu uyakuba nomdla wokusondela kum kuba ndinesifo sentliziyo</i>				
28	Others think that I can't achieve much in life because I have a heart disease <i>Abanye abantu bacinga ukuba andinakuze ndiphumelele kangako ebomini kuba ndinesifo sentliziyo</i>				

Social Withdrawal

4	I avoid getting close to people who don't have a heart disease to avoid rejection <i>Ndiyazikhwebula ukuba kufutshane kubantu abangenasifo sentliziyo ukuze ndingaziva ndingamkelekanga</i>				
9	I don't socialize as much as I used to because my heart disease might make me look or behave weird <i>Andisakonwabeli kakhulu ukuhlala nabanye abantu njengoko ndandiqhele ukwenza kuba isifo sam sentliziyo sindenza ndibonakale kwaye ndenze izinto ezingaqhelekanga</i>				
11	I don't talk about myself much because I don't want to burden others with my heart disease <i>Andithethi kakhulu ngam kuba andifuni ukwenzela abanye abantu uxanduva ngesifo sam sentliziyo</i>				
12	Negative stereotypes about heart disease keep me isolated from the 'normal' World <i>Ingamango ezimbi ezithethwa ngesifo sentliziyo zindenza ndiziguzule kwizinto eziqhubekayo ehlabathini 'eliqhelekileyo'</i>				
13	Being around people who don't have a heart disease makes me feel out of place or inadequate <i>Ukuba phakathi kwabantu abangenasifo sentliziyo kundenza ndizive ingathi ndilahlekile okanye ndimncinci</i>				

20	I stay away from social situations in order to protect my family or friends from embarrassment <i>Ndihlalela kude le kwindawo zolonwabo ukuze ndikhusele usapho lwam kunye nabahlobo bam kuhlazo</i>				
Stigma Resistance					
7	People with heart disease make important contributions to society <i>Abantu abanesifo sentliziyo banegalelo elibalulekileyo ekuhlaleni</i>				
14	I feel comfortable being seen in public with a person who obviously has heart disease <i>Ndiziva ndikhululekile ukubonwa esidlangalaleni nomntu ocacileyo ukuba unesifo sentliziyo</i>				
24	Living with heart disease has made me a tough survivor <i>Ukuphila nesifo sentliziyo kundenze ndaphumelela kwimeko ezinzima</i>				
26	In general, I am able to live life the way I want to <i>Ngokuqhelekileyo, ndiyakwazi ukuphila ubomi ngendlela endifuna ngayo</i>				
27	I can have a good, fulfilling life, despite my heart disease <i>Ndingaba nobomi obuhle obanelisayo nangona ndinesifo sentliziyo</i>				

Experiences of Abuse					
30	People call me names because I have a heart disease <i>Abantu bandibiza ngamagama kuba ndinesifo sentliziyo</i>				
31	People have been physically abusive towards me because I have a heart disease <i>Abantu bebendihlukumeza ngokwasemzimbeni kuba ndinesifo sentliziyo</i>				

32	<p>People have been verbally abusive towards me because I have a heart disease</p> <p><i>Abantu bebethetha rhabaxa ngakum, kuba ndinesifo sentliziyo</i></p>				
33	<p>I find it difficult to attend clinic appointments because people will know that I have a heart disease</p> <p><i>Ndifumanisa kunzima ukuya ekliniki nje ngoko kumisiwe kuba abantu bazakwazi ukuba ndinesifo sentliziyo</i></p>				
34	<p>I think the media has a negative influence on the way people perceive heart disease</p> <p><i>Ndicinga ukuba izinto ezisasaza iindaba zinempembelelo engeyiyo kwindlela abantu abajonga ngayo abantu abanesifo sentliziyo</i></p>				
35	<p>I find it difficult to take my tablets every day because they remind me that I have a heart disease</p> <p><i>Ndifumanisa kunzima ukusela ipilisi zam yonke imihla kuba zindikumbuza ukuba ndinesifo sentliziyo</i></p>				

Appendix J: Back-translation

	Original English	Xhosa	Back-translation English
	<p><i>Strongly disagree</i></p> <p><i>Disagree</i></p> <p><i>Neither agree or disagree</i></p> <p><i>Agree</i></p> <p><i>Strongly agree</i></p>	<p><i>Andivumi kakhulu</i></p> <p><i>Andivumi</i></p> <p><i>Ndivuma ndingavumi</i></p> <p><i>Ndiyavuma</i></p> <p><i>Ndiyavuma kakhulu</i></p>	<p>Highly Disagree</p> <p>Disagree</p> <p>Partially Agree</p> <p>Agree</p> <p>Highly Agree</p>
	<p>I feel out of place in the world because I have a mental illness</p> <p><i>I feel out of place in the world because I have a heart disease</i></p>	<p><i>Ndiziva ndingamkelekanga emhlabeni kuba ndiphazamisekile engqonweni</i></p> <p><i>Ndiziva ndingenandawo ehlabathini kuba ndinesifo sentliziyo</i></p>	<p>Due to my mental instability, I don't feel welcome in the world.</p> <p>I feel like I don't have a place on earth due to my heart disease</p>
	<p>Having a mental illness has spoiled my life</p> <p><i>Having a heart disease has spoiled my life</i></p>	<p><i>Ukuba nesigulo sengqondo kubuphazamisile ubomi bam</i></p> <p><i>Ubomi bam bonakele ngenxa yesifo sentliziyo</i></p>	<p>Having a mental illness has disrupted my life</p> <p>My life has been ruined by having a heart disease</p>
	<p>People without mental illness could not possibly understand me</p> <p><i>People without heart disease could not possibly understand me</i></p>	<p><i>Abantu abangaphazamisekanga engqondweni ngekhe bayiqonde imeko yam</i></p> <p><i>Abantu abangenasifo sentliziyo ngekhe bayiqonde imeko yam</i></p>	<p>People who do not suffer from a mental illness will never understand my situation</p> <p>People who do not suffer from heart problems</p>
	<p>I am embarrassed or ashamed that I have a mental illness</p> <p><i>I am embarrassed or ashamed that I have a heart disease</i></p>	<p><i>Ndiziva ndinodano okanye ndinentloni kuba ndiphazamisekile engqondweni</i></p> <p><i>Ndiziva ndinodano okanye ndinentloni kuba ndinesifo sentliziyo</i></p>	<p>I feel embarrassed or ashamed because I suffer from mental illness</p> <p>I feel embarrassed or ashamed because I suffer from heart disease</p>

<p>I am disappointed in myself for having a mental illness</p> <p><i>I am disappointed in myself for having a heart disease</i></p>	<p><i>Ndiziva ndinodano ngesiqu sam kuba ndiphazamisekile engqondweni</i></p> <p><i>Ndiziva ndinodano ngesiqu sam kuba ndinesifo sentliziyo</i></p>	<p>I feel ashamed of myself as a person due to having a mental illness.</p> <p>I feel ashamed of myself as a person due to having a heart disease</p>
<p>I feel inferior to others who don't have a mental illness</p> <p><i>I feel inferior to others who don't have a heart disease</i></p>	<p><i>Ndiziva ndizeya kubantu abangaphazamisekanga engqondweni</i></p> <p><i>Ndiziva ndizeya kubantu abangenasifo sentliziyo</i></p>	<p>I feel inferior to people who are not mentally ill</p> <p>I feel inferior to people who don't suffer from heart diseases</p>
<p>Stereotypes about the mentally ill apply to me</p> <p><i>Stereotypes about people with heart disease apply to me</i></p>	<p><i>lingcamango ngabantu abagula ngengqondo ziquka nam</i></p> <p><i>lingcamango ngabantu abanesifo sentliziyo ziquka nam</i></p>	<p>I am included in the opinions society has on people with a mental illness</p> <p>I am included in the opinions society has on people with heart disease</p>
<p>People can tell that I have a mental illness by the way I look</p> <p><i>People can tell that I have a heart disease by the way I look</i></p>	<p><i>Abantu bangatsho ukuba ndiphazamisekile engqondweni ngendlela endibonakala ngayo</i></p> <p><i>Abantu bangatsho ukuba ndinesifo sentliziyo ngendlela endibonakala ngayo</i></p>	<p>Its evident that I have a mental illness just by looking at me</p> <p>Its evident that I have a heart disease just by looking at me</p>
<p>Mentally ill people tend to be violent</p> <p><i>People with heart disease tend to be violent</i></p>	<p><i>Abantu abaphazamisekileyo engqondweni bakholisa ukuba ndlongo-ndlongo</i></p> <p><i>Abantu abanesifo sentliziyo bakholisa ukuba ndlongo-ndlongo</i></p>	<p>People with a mental illness tend to be violent</p> <p>People with heart disease tend to be violent</p>
<p>Because I have a mental illness, I need others to</p>	<p><i>Kuba ndiphazamisekile engqondweni ndifuna</i></p>	<p>I prefer people to make decisions on my</p>

	<p>make most decisions for me</p> <p><i>Because I have a heart disease, I need others to make most decisions for me</i></p>	<p><i>abanye abantu bandithathele uninzi lwezigqibo</i></p> <p><i>Kuba ndinesifo sentliziyo ndifuna abanye abantu bandithathele uninzi lwezigqibo</i></p>	<p>behalf because I am mentally ill</p> <p>I prefer people to make decisions on my behalf because I have a heart disease</p>
	<p>People with a mental illness cannot live a good, rewarding life</p> <p><i>People with heart disease cannot live a good, rewarding life</i></p>	<p><i>Abantu abaphazamisekileyo engqondweni abanakho ukuphila ubomi obulungileyo nobunembuyekiso</i></p> <p><i>Abantu abanesifo sentliziyo abanakho ukuphila ubomi obulungileyo nobunembuyekiso</i></p>	<p>People with mental illness cannot live a good and peaceful life</p> <p>People with heart disease cannot live a good and peaceful life</p>
	<p>Mentally ill people shouldn't get married</p> <p><i>People with heart disease shouldn't get married</i></p>	<p><i>Abantu abaphazamisekileyo engqondweni abafanelanga ukutshata</i></p> <p><i>Abantu abanesifo sentliziyo abafanelanga ukutshata</i></p>	<p>People who are mentally ill arent suited for marriage</p> <p>People with heart disease arent suited for marriage.</p>
	<p>I can't contribute anything to society because I have a mental illness</p> <p><i>I can't contribute anything to society because I have a heart disease</i></p>	<p><i>Andikwazi kuba negalelo ekuhlaleni nakweyiphi na into kuba ndiphazamisekile engqondweni</i></p> <p><i>Andikwazi kuba nagalelo ekuhlaleni nakweyiphi na into kuba ndinesifo sentliziyo</i></p>	<p>I cannot have any sort of contribution in society because I have mental illness</p> <p>I cannot have any sort of contribution in society because I have heart disease</p>

<p>People discriminate against me because I have a mental illness</p> <p><i>People discriminate against me because I have a heart disease</i></p>	<p><i>Abantu bayandicalu-calula kuba ndiphazamisekile engqondweni</i></p> <p><i>Abantu bayandicalu-calula kuba ndinesifo sentliziyo</i></p>	<p>People discriminate against me because I am mentally ill</p> <p>People discriminate against me because I have a heart disease</p>
<p>Others think that I can't achieve much in life because I have a mental illness</p> <p><i>Others think that I can't achieve much in life because I have a heart disease</i></p>	<p><i>Abanye abantu bacinga ukuba andinakuze ndiphumelele kangako ebomini kuba ndiphazamisekile engqondweni</i></p> <p><i>Abanye abantu bacinga ukuba andinakuze ndiphumelele kangako ebomini kuba ndinesifo sentliziyo</i></p>	<p>Some people think that I will never succeed in life because I am mentally ill</p> <p>Some people think that I will never succeed because I have a heart disease</p>
<p>People ignore me or take me less seriously just because I have a mental illness</p> <p><i>People ignore me or take me less seriously just because I have a heart disease</i></p>	<p><i>Abantu baye bangandinaki okanye bangandithatheli ngqalelo kuba ndiphazamisekile engqondweni</i></p> <p><i>Abantu baye bangandinaki okanye bangandithatheli ngqalelo kuba ndinesifo sentliziyo</i></p>	<p>People never take me seriously because of my mental illness</p> <p>People never take me seriously because I have a heart disease</p>
<p>People often patronize me, or treat me like a child, just because I have a mental illness</p> <p><i>People often patronize me, or treat me like a child, just because I have a heart disease</i></p>	<p><i>Kumaxesha amaninzi abantu bandiphatha okomntwana kuba ndiphazamisekile engqondweni</i></p> <p><i>Kumaxesha amaninzi abantu bandiphatha okomntwana kuba ndinesifo sentliziyo</i></p>	<p>Most of the time people treat me like a child because I have a mental illness.</p> <p>Most of the time people treat me like a child because I have heart disease</p>
<p>Nobody would be interested in getting close</p>	<p><i>Akukho mntu uyakuba nomdla wokusondela kum kuba</i></p>	<p>Nobody would want to be near me</p>

<p>to me because I have a mental illness</p> <p><i>Nobody would be interested in getting close to me because I have a heart disease</i></p>	<p><i>ndiphazamisekile engqondweni</i></p> <p><i>Akukho mntu uyakuba nomdla wokusondela kum kuba ndinesifo sentliziyo</i></p>	<p>because I have a mental illness</p> <p>Nobody would want to be near me because I have a heart disease</p>
<p>I don't talk about myself much because I don't want to burden others with my mental illness</p> <p><i>I don't talk about myself much because I don't want to burden others with my heart disease</i></p>	<p><i>Andithethi kakhulu ngam kwabanye abantu kuba andifuni ukubanika uxanduva ngesigulo sam sokuphazamiseka engqondweni</i></p> <p><i>Andithethi kakhulu ngam kwabanye abantu kuba andifuni ukubanika uxanduva ngesifo sam sentliziyo</i></p>	<p>I rarely talk about myself with other people because I don't want to burden them with my mental illness</p> <p>I rarely talk about myself with other people because I don't want to burden them with my heart disease.</p>
<p>I don't socialize as much as I used to because my mental illness might make me look or behave weird</p> <p><i>I don't socialize as much as I used to because my heart disease might make me look or behave weird</i></p>	<p><i>Andisakonwabeli kakhulu ukuhlala nabanye abantu njengoko ndandiqhele ukwenza kuba isigulo sam sengqondo sindenza ndibonakale kwaye ndenze izinto ezingaqhelekanga</i></p> <p><i>Andisakonwabeli kakhulu ukuhlala nabanye abantu njengoko ndandiqhele ukwenza kuba isifo sam sentliziyo sindenza ndibonakale kwaye ndenze izinto ezingaqhelekanga</i></p>	<p>I no longer enjoy being around people as I used to because my mental illness makes me do things I'm not used to</p> <p>I no longer enjoy being around people as I used to because my heart disease makes me do things that I'm not used to.</p>

<p>Negative stereotypes about mental illness keep me isolated from the 'normal' World</p> <p><i>Negative stereotypes about heart disease keep me isolated from the 'normal' World</i></p>	<p><i>Ingamango ezimbi ezithethwa ngophazamiseko lwengqondo zindenza ndiziguzule kwizinto eziqhubekayo ehlabathini 'eliqhelekileyo'</i></p> <p><i>Ingamango ezimbi ezithethwa ngesifo sentliziyo zindenza ndiziguzule kwizinto eziqhubekayo ehlabathini 'eliqhelekileyo'</i></p>	<p>Negative opinions on mental illness make me distance myself from things that happen in the "normal" world</p> <p>Negative opinions on heart disease make me distance myself from things that happen in the "normal" world.</p>
<p>I stay away from social situations in order to protect my family or friends from embarrassment</p> <p><i>I stay away from social situations in order to protect my family or friends from embarrassment</i></p>	<p><i>Ndihlalela kude le kwindawo zolonwabo ukuze ndikhusele usapho lwam kunye nabahlobo bam kwihlazo</i></p> <p><i>Ndihlalela kude le kwindawo zolonwabo ukuze ndikhusele usapho lwam kunye nabahlobo bam kwihlazo</i></p>	<p>I stay far away from places of leisure to protect myself and my family from embarrassment</p> <p>I stay far away from places of leisure to protect myself and my family from embarrassment.</p>
<p>Being around people who don't have a mental illness makes me feel out of place or inadequate</p> <p><i>Being around people who don't have a heart disease makes me feel out of place or inadequate</i></p>	<p><i>Ukuba phakathi kwabantu abangaphazamisekanga engqondweni kundenza ndizive ingathi ndilahlekile okanye ndimncinci</i></p> <p><i>Ukuba phakathi kwabantu abangenasifo sentliziyo kundenza ndizive ingathi ndilahlekile okanye ndimncinci</i></p>	<p>Being among people who are not mentally ill makes me feel lost and inferior</p> <p>Being among people who don't have heart disease makes me feel lost and inferior.</p>
<p>I avoid getting close to people who don't have a</p>	<p><i>Ndiyazikhwebula ukuba kufutshane kubantu abangaphazamisekanga</i></p>	<p>I distance myself from being close to people who don't suffer from</p>

<p>mental illness to avoid rejection</p> <p><i>I avoid getting close to people who don't have a heart disease to avoid rejection</i></p>	<p><i>engqondweni ukuze ndingaziva ndingamkelekanga</i></p> <p><i>Ndiyazikhwebula ukuba kufutshane kubantu abangenasifo sentliziyo ukuze ndingaziva ndingamkelekanga</i></p>	<p>mental illness so that I don't feel unwelcome</p> <p>I distance myself from being close to people who don't suffer from heart disease so that I don't feel unwelcome</p>
<p>I feel comfortable being seen in public with an obviously mentally ill person</p> <p>I feel comfortable being seen in public with a person who obviously has heart disease</p>	<p><i>Ndiziva ndikhululekile esidlangalaleni nomntu ocacileyo ukuba uphazamisekile engqondweni</i></p> <p><i>Ndiziva ndikhululekile esidlangalaleni nomntu ocacileyo ukuba unesifo sentliziyo</i></p>	<p>I feel at ease in the presence of a mentally ill person</p> <p>I feel at ease in the presence of a person who has heart disease.</p>
<p>In general, I am able to live life the way I want to</p> <p><i>In general, I am able to live life the way I want to</i></p>	<p><i>Ngokuqhelekileyo, ndiyakwazi ukuphila ubomi ngendlela endifuna ngayo</i></p> <p><i>Ngokuqhelekileyo ,ndiyakwazi ukuphila ubomi ngendlela endifuna ngayo</i></p>	<p>Normally, I am able to live my life the way I want to</p> <p>Normally, I am able to live my life the way I want to.</p>
<p>I can have a good, fulfilling life, despite my mental illness</p> <p><i>I can have a good, fulfilling life, despite my heart disease</i></p>	<p><i>Ndingaba nobomi obuhle obanelisayo nangona ndiphazamisekile engqondweni</i></p> <p><i>Ndingaba nobomi obuhle obanelisayo nangona ndinesifo sentliziyo</i></p>	<p>I can have a good and fulfilling life regardless of my mental illness</p> <p>I can have a good and fulfilling life regardless of my heart disease</p>

<p>People with mental illness make important contributions to society</p>	<p><i>Abantu abaphazamisekileyo engqondweni banegalelo elibalulekileyo ekuhlaleni</i></p>	<p>People with a mental illness play an important role in the community</p>
<p>People with heart disease make important contributions to society</p>	<p><i>Abantu abanesifo sentliziyo banegalelo elibalulekileyo ekuhlaleni</i></p>	<p>People with heart disease play an important role in the community</p>
<p>Living with mental illness has made me a tough survivor</p>	<p><i>Ukuphila ndinophazamiseko engqondweni kundenze ndaphumelela kwimeko ezinzima</i></p>	<p>Living with a mental disorder has seen me get out of difficult situations</p>
<p>Living with heart disease has made me a tough survivor</p>	<p><i>Ukuphila nesifo sentliziyo kundenze ndaphumelela kwimeko ezinzima</i></p>	<p>Living with a heart disease has seen me get out of difficult situations</p>
<p>People call me names because I have a mental illness</p> <p><i>People call me names because I have a heart disease</i></p>	<p><i>Abantu bandibiza ngamagama kuba ndiphazamisekile engqondweni</i></p> <p><i>Abantu bandibiza ngamagama kuba ndinesifo sentliziyo</i></p>	<p>People call me names because I am mentally ill</p> <p>People call me names because I have heart disease</p>
<p>People have been physically abusive towards me because I have a mental illness</p> <p><i>People have been physically abusive towards me because I have a heart disease</i></p>	<p><i>Abantu bebendihlukumeza ngokwasemzimbeni kuba ndiphazamisekile engqondweni</i></p> <p><i>Abantu bebendihlukumeza ngokwasemzimbeni kuba ndinesifo sentliziyo</i></p>	<p>People physically abused me because of my mental illness</p> <p>People physically abused me because I have a heart disease</p>
<p>People have been verbally abusive towards me because I have a mental illness</p> <p><i>People have been verbally abusive towards me</i></p>	<p><i>Abantu bebendithuka kuba ndiphazamisekile ngokwase ngqondweni</i></p> <p><i>Abantu bebendithuka kuba ndinesifo sentliziyo</i></p>	<p>People swore at me because of my mental illness</p> <p>People swore at me because I have a heart disease</p>

<p><i>because I have a heart disease</i></p>		
<p>I find it difficult to attend clinic appointments because people will know that I have a mental illness</p> <p><i>I find it difficult to attend clinic appointments because people will know that I have a heart disease</i></p>	<p><i>Ndifumanisa kunzima ukuya ekliniki nje ngoko kumisiwe kuba abantu bazakwazi ukuba mna ndiphazamisekile engqondweni</i></p> <p><i>Ndifumanisa kunzima ukuya ekliniki nje ngoko kumisiwe kuba abantu bazakwazi ukuba ndinesifo sentliziyo</i></p>	<p>I find it difficult to go to the clinic as required because people will know I have a mental disorder</p> <p>I find it difficult to go to the clinic as required because people will know I have a heart disease</p>
<p>I think the media has a negative influence on the way people perceive mental illness</p> <p><i>I think the media has a negative influence on the way people perceive heart disease</i></p>	<p><i>Ndicinga ukuba abasasazi bendaba banempembelelo enegxeke ngendlela abantu abajonga ngayo abantu abaphazamisekile engqondweni</i></p> <p><i>Ndicinga ukuba abasasazi bendaba banempembelelo enegxeke ngendlela abantu abajonga ngayo abantu abanesifo sentliziyo</i></p>	<p>I think that news reportes have a negative influence on how people percieve mentally ill patients</p> <p>I think that news reporters have a negative influence on how people perceive heart disease patients</p>
<p>I find it difficult to take my tablets every day because they remind me that I have a mental illness</p> <p>I find it difficult to take my tablets every day because they remind me that I have a heart disease</p>	<p><i>Ndifumanisa kunzima ukusela ipilisi zam yonke imihla kuba zindikhumbuza ukuba mna ndiphazamisekile engqondweni</i></p> <p><i>Ndifumanisa kunzima ukusela ipilisi zam yonke imihla kuba zindikhumbuza ukuba mna ndinesifo sentliziyo</i></p>	<p>I find it hard to take my medication daily because it reminds me of my mental illness</p> <p>I find it hard to take my medication daily because it reminds me of my heart disease.</p>