

The lived experiences of HIV/AIDS related stigma reduction programmes on young females in rural Hlabisa District

by

Melissa van Rooyen

submitted in accordance with the requirements for the degree of

MASTER OF ARTS

in the subject

PSYCHOLOGY

at the

University of South Africa

Supervisor: Dr Sibusiso Mhlongo

February 2015

DEDICATION

This work is dedicated to the participants in this study. You have been brave in sharing your stories with me, and have inspired a new passion for this topic in me. I truly thank you and hope you find peace.

DECLARATION

I, Melissa van Rooyen, declare that: 'The lived experiences of HIV/AIDS related stigma reduction programmes on young females in rural Hlabisa District' is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I have not previously submitted this work, or part of it, for examination at UNISA for another qualification or at any other higher education institution.

ACKNOWLEDGEMENTS

- I would like to thank my supervisor, Dr Sibusiso Mhlongo. This has been a long road, which I could not have walked without you. None of your effort has gone unnoticed or unappreciated. I am truly grateful for your assistance and patience during this time.
- I would like to thank the Africa Centre, especially Lungi, without whom this research would not have been possible. Your cooperation is greatly appreciated.
- I would also like to thank Ida Scheepers, a constant in my academic life. From 2008 you have kindly taught me, supported me, and most importantly, became a very special friend to me.
- Lastly, I would like to thank my husband. You have sacrificed the most to make this opportunity possible for me. Thank you for never allowing me to give up, and never allowing me to stop believing in working hard for a better future. Thank you for your invaluable support in helping me to juggle a demanding job, life and this research endeavour.

ABSTRACT

The phenomenon of stigmatisation in the transmission of HIV/AIDS was highlighted in this study, and considered from a social constructionist perspective. The lived experiences of 20 participants were explored in the context of a stigma reduction programme. Perceived meanings attached to stigma, and its influence on participant behaviour was revealed through narratives. The influence of the programme on participant meaning making and perceptions was also revealed, and found that the meaning of stigma remained unchanged, and therefore stigma was not reduced. Not discounting the therapeutic platform of the programme in enabling co-construction of new perspectives which enabled coping mechanisms for participants in dealing with their circumstances. It is recommended that studies such as this be used to assist future stigma reduction programmes to identify their roles in meaning making regarding stigma, with the premise in mind that if meaning shifts, experiences will shift.

Key words: HIV/AIDS, HIV/AIDS-related stigma, stigma reduction programmes, social constructionism, narratives, lived experiences, HIV/AIDS transmission, HIV/AIDS preventative behaviours, enacted stigma, perceived stigma, young females

Table of contents

No.		Page no.
	Dedication	i
	Declaration	ii
	Acknowledgements	iii
	Abstract	iv
	Table of contents	v
	List of tables	x
Chapter 1	Introduction	1
1.1	Introduction	1
1.2	Brief overview of the study	1
1.3	Theoretical framework	5
1.4	Research problem and research questions	7
1.5	Aims and objectives	8
1.6	Conclusion of chapter one	8
Chapter 2	Literature review	9
2.1	Introduction	9
2.2	Origin of stigma	9
2.2.1	Origin of stigma as a moral violation	10
2.2.2	Origin of stigma as a socially constructed phenomenon	12
2.3	Definition of HIV/AIDS-related stigma	14
2.4	Forms of stigma	15
2.5	Impact of HIV/AIDS-related stigma on HIV/AIDS prevention	17
2.6	HIV/AIDS-related stigma and infection rates	19
2.6.1	Reported infection rate statistics	19
2.6.2	Reported lowered infection rate statistics	19
2.6.3	Inconsistency in HIV/AIDS prevalence and reported mortality rate	20
2.6.4	Population group seemingly vulnerable to HIV/AIDS	22
2.7	Stigma reduction programmes	23
2.7.1	Current initiatives and programmes	24
2.7.1.1	The United Kingdom's Department for International Development	24
2.7.1.2	Horizons Programme	25
2.7.1.3	Treatment Action Campaign	26
2.7.1.4	Ethiopian Federal Ministry of Health	27
2.7.2	Outcomes of stigma reduction programmes	28

2.8	Current stigma reduction efforts implemented at the Africa Centre for Health and Population Studies	29
2.9	Recommendations and suggestions for stigma reduction programmes	32
2.10	Conclusion	36
Chapter 3	Methodology	37
3.1	Introduction	37
3.2	Philosophical and epistemological underpinning of the study	37
3.3	Research design	40
3.4	Sampling	41
3.4.1	Sampling method	41
3.4.2	Sampling procedure	42
3.5	Data collection instrument and procedure	43
3.6	Data analysis	45
3.7	Study trustworthiness	47
3.8	Ethical considerations	48
3.9	Conclusion	50
Chapter 4	Findings	51
4.1	Introduction	51
4.2	Participant background	51
4.3	Findings	54
4.4	Focus Group findings	55
4.4.1	Focus Group finding: Desire to preserve social identity	55
4.4.1.1	Overview	55
4.4.1.2	Participant narratives	57
4.4.1.3	Summary	60
4.4.2	Focus Group finding: Facing struggles in coming to terms with the implications of living with HIV/AIDS	60
4.4.2.1	Overview	60
4.4.2.2	Participant narratives	62
4.4.2.3	Summary	65
4.4.3	Focus Group finding: Restored sense of community	66
4.4.3.1	Overview	66
4.4.3.2	Participant narratives	67
4.4.3.2.1	Narratives of the sub theme support	67
4.4.3.2.2	Narratives of the sub theme acceptance	70
4.4.3.2.3	Narratives of the sub theme solidarity	71
4.4.3.3	Summary	72
4.4.4	Focus Group finding: Social influence on programme	73
4.4.4.1	Overview	73
4.4.4.2	Participant narratives	73

4.4.4.3	Summary	75
4.5	Individual Interview findings	76
4.5.1	Individual Interview finding: Gender inequality as source of stigma and HIV/AIDS infection	77
4.5.1.1	Overview	77
4.5.1.2	Participant narratives	77
4.5.1.3	Summary	82
4.5.2	Individual Interview finding: Self in relation to HIV/AIDS and stigma	83
4.5.2.1	Overview	83
4.5.2.2	Participant Narratives	84
4.5.2.2.1	Narratives of the sub theme self as victim	84
4.5.2.2.2	Narratives of the sub theme self as good	87
4.5.2.2.3	Narratives of the sub theme self-acceptance	89
4.5.2.3	Summary	90
4.5.3	Individual Interview finding: Prioritising living with HIV/AIDS and stigma	91
4.5.3.1	Overview	91
4.5.3.2	Participant narratives	92
4.5.3.3	Summary	96
4.5.4	Individual Interview finding: Empowerment	96
4.5.4.1	Overview	96
4.5.4.2	Participant narratives	97
4.5.4.2.1	Narratives of the sub theme knowledge of hope for the future	97
4.5.4.2.2	Narratives of the sub theme knowledge of HIV status	99
4.5.4.2.3	Narratives of the sub theme knowledge of HIV/AIDS	101
4.5.4.3	Summary	102
4.6	Conclusion	103
Chapter 5	Discussion of findings	104
5.1	Introduction	104
5.2	Interpretation of findings	105
5.3	Focus Group theme: Desire to preserve social identity	105
5.3.1	Interpretation from a social constructionist perspective	105
5.3.2	Interpretation in the context of the research question	107
5.3.3	Interpretation in the context of literature	107
5.3.4	Implication of the interpretation	109
5.4	Focus Group theme: Facing struggles in coming to terms with the implications of living with HIV/AIDS	110
5.4.1	Interpretation from a social constructionist perspective	110
5.4.2	Interpretation in terms of the research question	111
5.4.3	Interpretation in the context of literature	111
5.4.4	Implication of the interpretation	112

5.5	Focus Group theme: Restored sense of community	113
5.5.1	Interpretation from a social constructionist perspective	113
5.5.2	Interpretation in the context of the research question	114
5.5.3	Interpretation in the context of literature	114
5.5.4	Implication of the interpretation	116
5.6	Focus Group theme: Social influence on programme	117
5.6.1	Interpretation from a social constructionist perspective	117
5.6.2	Interpretation in the context of the research question	117
5.6.3	Interpretation in the context of literature	118
5.6.4	Implication of the interpretation	118
5.7	Individual Interview theme: Gender inequality as source of stigma and HIV/AIDS	119
5.7.1	Interpretation from a social constructionist perspective	119
5.7.2	Interpretation in the context of the research question	121
5.7.3	Interpretation in the context of literature	122
5.7.4	Implication of the interpretation	124
5.8	Individual Interview theme: Self in relation to HIV/AIDS and stigma	124
5.8.1	Interpretation from a social constructionist perspective	125
5.8.2	Interpretation in the context of the research question	126
5.8.3	Interpretation in the context of literature	127
5.8.4	Implication of the interpretation	128
5.9	Individual Interview theme: Prioritising living HIV/AIDS and stigma	128
5.9.1	Interpretation from a social constructionist perspective	129
5.9.2	Interpretation in the context of the research question	132
5.9.3	Interpretation in the context of literature	133
5.9.4	Implication of the interpretation	134
5.10	Individual Interview theme: Empowerment	135
5.10.1	Interpretation from a social constructionist perspective	135
5.10.2	Interpretation in terms of the research question	136
5.10.3	Interpretation in the context of literature	136
5.10.4	Implication of the interpretation	137
5.11	Limitations	139
5.12	Overlapping themes	140
5.13	Recommendations	142
5.14	Conclusion	142
6	References	148
 Appendices		
Appendix A	Informed consent form: Focus group participants	158
Appendix B	Informed consent form: Individual interviews	159

List of Tables

Table 1	Example of focus group chart	44
Table 2	Focus Group themes	55
Table 3	Individual Interview themes	76

CHAPTER ONE: INTRODUCTION

1.1 Introduction

The role of HIV/AIDS-related stigma in the transmission of HIV/AIDS is highlighted in this study, and considered from a social constructionist perspective. The response to stigma, in the form of stigma reduction programmes, provides a context for exploring the lived experiences of participants in such programmes. Social constructionism offers a framework with which to explore the socially constructed nature of HIV/AIDS-related stigma, the lived experience of participating in such a programme, and the influence of such a programme on participant meaning making. Chapter one presents a brief overview of the study, and due to the central social constructionist orientation in this study, an overview of the theoretical framework is presented here; thereafter the aims and objectives of the study are stated.

1.2 Brief overview of the study

This study explored the lived experiences of females aged between 18 and 24, participating in an HIV/AIDS-related stigma reduction programme in Hlabisa in rural KwaZulu-Natal, South Africa. This stigma reduction programme was implemented and managed by the Africa Centre for Health and Population Studies, in Hlabisa. The Africa Centre is a joint initiative of the South African Medical Research Council and the University of KwaZulu-Natal, also receiving funding from the Wellcome Trust in the United Kingdom. The Africa Centre conducts demographic surveys and HIV/AIDS research in this rural area of the Hlabisa District.

The stigma reduction programme consists of home based private testing for HIV status, and offers education around HIV/AIDS and stigma, counselling and ongoing support groups.

Potential female participants were identified on the basis of having participated in the stigma reduction programme. An invitation was extended for 20 potential participants to participate in this study. The study consisted of a focus group discussion made up of 20 participants, who met for one focus group discussion session. Ten of these participants also agreed to participate in a single in-depth interview.

The main data consisted of narratives collected through the focus group discussion, and the narratives from the individual in-depth interviews, conducted separately. Narratives revealed participants' socially constructed meanings around HIV/AIDS-related stigma, their experience of the programme and the programme's influence on their personal meaning making. Narratives also revealed that HIV/AIDS-related stigma was not reduced in their community, despite efforts to achieve this.

HIV/AIDS-related stigma has been revealed to be a socially constructed phenomenon (Major & O'Brien, 2005; Meyer, 2010), therefore indicating stigma to be lodged in our language and social interactions (Becvar & Becvar, 2005). HIV/AIDS-related stigma has also been identified as a major contributing factor in the ongoing transmission of HIV/AIDS (Mawar, Sahay, Pandit, & Mahajan, 2005). Therefore, the role of HIV/AIDS-related stigma in the ongoing transmission of HIV/AIDS is also a social constructionist matter, as stigma is a social construction.

Due to the contributing role of stigma in the transmission of HIV/AIDS, much attention has been directed at efforts to reduce such stigma, through stigma reduction programmes. Unfortunately, most of these programmes are not yielding the desired outcomes of significantly reducing stigma (Lekganyane, 2010; Mahajan, Sayles, Patel, Remien, Ortiz, Szekeres, & Coates, 2008). From a social constructionist lens, the lack of desired outcomes indicates an unchanging meaning in the language and social interactions in which stigma is lodged (Becvar

& Becvar, 2005). In recognition of the socially constructed nature of stigma, stigma reduction programmes should ideally influence or shift the socially constructed meanings around stigma, in order to yield more satisfying outcomes. Therefore, the narratives of the lived experiences of those participating in such programmes are key in perceiving whether participants' socially constructed meanings around stigma have been shifted or not.

Three important aspects of stigma have been identified, namely the socially constructed nature of stigma, the role of stigma in the transmission of HIV/AIDS, and the lack of desired outcomes of stigma reduction programmes in reducing stigma. This suggests the need to explore the lived experiences of participants in HIV/AIDS-related stigma reduction programmes. In exploring the lived experiences of participants, their narratives revealed that the programme failed to shift their socially constructed realities regarding the meaning of stigma, which consequently remained unchanged.

Participant narratives revealed previously unknown life worlds regarding the meaning of participating in the programme, and the nesting of participants' lives in the larger discourse of society, which enforced stigma. Terre Blanche, Durrheim and Painter (2006) state that narratives allow for insight into how subjective and intersubjective understandings and experiences are derived from these larger social narratives. Considering this, the larger social discourses in which participants find themselves largely influence their perceptions and experiences. This was confirmed through themes identified from participant narratives. These themes indicated the larger social discourses which participants lived by, and which influenced their range of behaviours.

According to social constructionism we structure our lives according to meaning making through language. Costall (1980) expressed the implication of this notion by echoing Wittgenstein's perception that limitations in his language places limitations on his world,

suggesting the limitations and possibilities of our meaning making through language. Therefore, the narratives we live by place parameters on our life worlds; our life worlds are directly proportional to our narratives. This notion was also reflected in the findings of this study, as participants' meanings and experiences were limited to the larger social meaning in which they found themselves. Participant narratives also offered insight, rather than causal factors, into the lack of desired outcomes of stigma reduction programmes, in revealing that larger discourses and meanings attached to stigma remained unchanged throughout the programme.

This focus of the study was supported within an intentional drift between its social constructionist underpinning and theoretical literature to add demonstrative substance to the study. Herewith, a theoretical picture of stigma is presented, as well as a social constructionist challenge to this picture. Additionally, participant narratives were used to probe the influence of the programme on social constructs underpinning stigma. The importance of the social construction of stigma became evident, and its relevance to the HIV/AIDS arena was confirmed.

In exploring the lived experiences of participants, participant narratives were revealed as limited and monotonous, and indicative of limited range of behaviours. The suggested social constructionist motif is therefore, that the persistence of HIV/AIDS-related stigma is a problem of limited narratives, agreeing with Costall's (1980) echo of Wittgenstein's notion of limited behaviours corresponding with limited language. Becvar and Becvar (2005:91) supported this by stating that a "change in language equals a change in experience; for reality can only be experienced, and this reality is inseparable from the pre-packaged thoughts of the society". If this premise is accepted, then a shift in the social constructions of participants may equal a shift in their experiences regarding stigma.

1.3 Theoretical framework

Social constructionism considers the way in which our world is constructed. Social constructionism posits that language is the means by which we construct our world through social interaction (Becvar & Becvar, 2005). This interaction allows for certain ideas, beliefs or meanings to be constructed collectively, or what Bateson referred to as an ecology of ideas (Bateson, 1972). These, in turn, become the framework according to which we structure our lives and experiences, or our framework for meaning making. This illustrates how our lives are influenced by, and nested in, the larger discourses of society in which we have had a part in constructing, enforcing and maintaining, through participating and behaving according to dominant discourses. The dominant discourse also refers to cultural, political, and the historical context within which we find ourselves. For example, the gender discourse into which we are socialised tells us that females should be sensitive, soft and caring, and that males should be aggressive, assertive and strong (Mynhardt, 2006). We adjust ourselves to adhere to this discourse, and we conform our behaviours within the parameters of what the discourse allows, therefore maintaining and contributing to the discourse. This resonates with Foucault's (1972) notion of the powerful implications of such dominant discourses in influencing our meanings, constructions and behaviours, or collectively, our reality.

In his discussion on Socratic thinking, de Botton (2000) highlights the influence of the dominant discourse, or rather the dangers of an unquestioned dominant discourse, in referring to the work of Socrates. He reports that, according to Socrates, problems arise when this dominant discourse is left unquestioned in terms of its construction, and its influence on meaning making. He further illustrates the weightiness of Socrates' beliefs, as he was sentenced to death because he questioned and examined this ecology of ideas, and encouraged those around him to do the same (2000). Considering Socrates' willing surrender to death, rather than

renouncing his ideas, the importance he placed on questioning this state of reality is highlighted. Adding to this, King (2004, p.132) highlights our role in this meaning making by expressing the notion of Nietzsche: “Whatever has value in our world now does not have value in itself, according to its nature – nature is always value-less, but has been given value at some time, and it was we who gave and bestowed it”. Thus, HIV/AIDS-related stigma has become meaningful, because we assigned certain meanings to it, and are now living by them. This further implies that such meanings are not absolute, and are subject not only to social construction, but also to reconstruction.

In keeping with the social constructionist grounding of this study, the lived experiences of participants were explored and participants’ narratives interpreted. This study looks through a social constructionist lens. Therefore, according to Becvar and Becvar (2005), one cannot fully and objectively know the reality of the participants; but only know one’s interpretations of the meaning of participants’ narratives, whilst keeping in mind one’s own role in participating in that meaning making. They also state that one cannot know the truth about people or other phenomena in any objective way, but only one’s constructions of them, which one must then attempt to accurately represent.

Language is the form of meaning making in this study, and therefore, a social constructionist stance is required in exploring lived experiences. The manner in which participants’ use language and tell their stories leads to an understanding of the meaning attached to their experiences of the stigma reduction programme, as well as their nesting in the larger social discourses that play a role in maintaining stigma.

This study did not attempt to reach causal conclusions attributed to the lack of success of these programmes, but rather considered the narratives of the lived experiences of participants in these programmes. This allowed for meaningful insight into the lived experiences of those

participating in a stigma reduction programme, all the while remaining congruent with the social constructionist underpinning of the study by staying alert to the possible shifting of social constructions relating to stigma. The narratives around the lived experiences of participants confirmed the socially constructed nature of stigma, as well as the role of participant narratives in meaning making around stigma. A resounding confirmation of the breeding ground of stigma in our language and social interactions was revealed, as the stigma reduction programme did little to shift the meaning of stigma, or its lodgement in language and social interaction

1.4 Research problem and research questions

This study is an exploration into the lived experiences of females aged between 18 and 24 in the HIV/AIDS-related stigma reduction programme running at the Africa Centre in rural Hlabisa. Relatively few interventions to reduce HIV/AIDS-related stigma have been rigorously explored, documented, and published in developing countries (Brown, Trujillo, & Macintyre, 2001), especially lived experiences of such programmes. Such research on the experiences of participating in these programmes is arguably needed if future research is to benefit. Exploring the lived experiences of such a programme may also reveal more about such programmes than quantitative evaluation of programme success rate. This study focused on the lived experiences of an HIV/AIDS-related stigma reduction programme, rather than an evaluation of such a programme. Exploring lived experiences provides this field with much needed insight into how participants experience such programmes. The research problem guiding this study is: What are the lived experiences of participants who participate in a HIV/AIDS-related stigma reduction programme? Flowing naturally from this problem, the following questions arise:

- How do participants experience the HIV/AIDS-related stigma reduction programme?

- How does participation in such a programme influence participants' experience and perception of stigma?
- How does participation in such a programme influence participants' perception of HIV/AIDS and living with HIV/AIDS?
- Did participation in this programme have a meaningful impact on the lives of participants?
- Has participants' meaning of stigma shifted or been influenced?
- Has participants' socially constructed meanings of HIV/AIDS been shifted or influenced?

1.5 Aims and objectives

The goal of this study was to find out what the experiences are of females participating in a stigma reduction programme. In order to find out what participant experience are, verbal interviews and focus group was required to gather narratives around their experiences. Focus group and interviews were used to answer the research questions, which gave an impression of participant experiences.

1.6 Conclusion of chapter one

This study explored the lived experiences of participants in an HIV/AIDS-related stigma reduction programme, and was firmly nested within a social constructionist perspective, emphasising participant narratives. A theoretical background is presented in chapter two in the form of a literature review, and the methodology of the study is presented in chapter three. The findings are presented in chapter four, with a concluding discussion in chapter five.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

In chapter two the origin of stigma, the definition and different forms of stigma is described, confirming stigma's socially constructed nature. This leads to a discussion of stigma's role in the transmission of HIV/AIDS and a brief discussion of the status of HIV/AIDS in South Africa. HIV/AIDS-related stigma reduction programmes are discussed, as well as the efficacy thereof, highlighting the need for exploration into participant experiences of these programmes. Lastly, recommendations for stigma reduction programmes from literature is discussed. This highlights what is perceived to be effective in achieving the desired outcomes of reduced stigma, if implemented in programmes.

2.2 Origin of stigma

The following description of the origin of stigma highlights two important aspects of interest. The first is stigma as an indicator of a moral violation (Goffman, 1963), and the second is the social constructionist nature of stigma (Meyer, 2010). Both descriptions are closely related, and overlap in places, but are presented respectively for the sake of clarity.

Throughout the descriptions which follow, the social formation and maintenance of stigma becomes apparent. Along with it, possibly the revelation that our own life worlds have unwittingly been intertwined into this construction, as Foucault (1972) recognised the powerful implication of these social constructions in our meaning making. Both descriptions relate the concept of stigma as being long standing, and thus becoming monotonous in our social constructions (Becvar & Becvar, 2005), and the concept of stigma attached to a negative meaning.

2.2.1 Origin of stigma as a moral violation

Stigma originated as a Greek word in the sixteenth century (Goldin, 1994). Stigma referred to a marking or tattoo which was cut or burned into the skins of criminals, slaves, or traitors, as an identification of individuals who disqualify from full social acceptance (Goffman, 1963). Interestingly, the ancient Greek word for prick, referring to the mark which was pricked into the skin, was the word “stig” (Stuart, 2005). This was where the word stigma was derived from. Thus, the actual stigma markings were used to identify and judge people who did not comply with social norms or standards of the time, especially referring to their moral status. This compliance is dependent on the values of the contextual society, as Crocker, Major and Steele (1998) explain that stigma is some attribute that conveys a devalued social identity within a particular societal context.

More recently the focus has shifted from the actual marking of stigma to the person bearing the mark of the stigma (Goldin, 1994). The implication of this is that even if the so called marking disappears, the person is still identified as one attached to stigma. The origin of stigma, therefore, is birthed in the social perception of a violation of moral standards, and also functions as a sign that judgement must follow (Goffman, 1963). This highlights the first important point regarding the origin of stigma, in that it implies a moral violation.

The discrediting attribute or marking of stigma, as referred to by Goffman (1963), is thus not the origin or onset of stigma. The origin or onset of stigma takes place when the decision that a violation has occurred, is made. The decision that a violation has occurred is collectively preconceived in our minds in the form of moral standards and social expectations (Goffman, 1963). Here is a point of overlap with the socially constructed origin of stigma. Thus, the social setting in which we find ourselves, may largely determine the reaction to violations of contextual expectations, norms and standards. Stigma therefore remains subjective.

Moral or social standards may differ from one country to another, from one society to another and from one community to another. Consequently, violations of standards may differ in these different contexts, which means that stigma may differ in these different contexts, accordingly. The violation of moral standards that caused the stigma one hundred years ago, may not receive the same reaction if a similar violation occurred today. For example, 60 years ago homosexuality or public display of one's homosexual inclination may have been unacceptable, because homosexual behaviour was socially or morally unacceptable (Loftin, 2007). Today, the social situation is different in societies in which homosexuals are encouraged to express their sexuality publically, and to freely practice their sexual orientation. This is apparent in movements such as "Gay Pride" and the legalisation of gay marriages in some countries. In these societies, social and moral standards have shifted to a meaning in which homosexuality is not a stigma any longer. It is therefore undeserving of judgement, as no perceived violation of standards occurred. Conversely, there are countries such as Uganda in which homosexuality remains an illegal practice.

Observing HIV/AIDS specifically, it is apparent why HIV/AIDS is a stigma, considering its association with existing socially unacceptable behaviours. Literature shows that HIV/AIDS-related stigma often stems from pre-existing stigmas relating to sex and intravenous drug use (UNAIDS, 2007). HIV/AIDS is stereotypically associated with socially unacceptable behaviours, such as promiscuity and drug abuse, because these are regarded as the two primary modes of infection (Campbell, Foulis, Maimane, & Sibiyi, 2005). Moreover, HIV/AIDS is also associated with homosexual practices and sex workers (Mawar et al., 2005).

Due to mode of transmission, observers may automatically conclude that a person living with HIV/AIDS has engaged in one of these perceived unacceptable behaviours in contracting the

virus. This indicates a moral judgement about the perceived circumstances of HIV/AIDS infection (Herek, Capitano, & Widaman, 2003).

Stigma therefore arises when the perception occurs that a set of standards or expectations have been violated (Brown et al., 2001). Stigma takes place within social interactions when an individual's social identity no longer meets the requirements set by society. Individuals living with HIV/AIDS demonstrate awareness of this moral judgement exercised upon them, in portraying themselves innocently and blaming their infection on the infidelity of their promiscuous partners (Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012).

This association between engaging in unacceptable behaviours and infection is also reflected in public HIV/AIDS education campaigns, in which personal responsibility is emphasised (Sumari-de Boer et al., 2012). Therefore, infection may be regarded as a self-induced result of immoral or irresponsible behaviour, as perceived HIV/AIDS lifestyles are typically characterised by sexual overindulgence and carelessness, instead of self-control and risk management (Sumari-de Boer et al., 2012). Consequently, stigma is possibly reinforced through such campaigns, as they infer socially unacceptable behaviours contributing to infection.

An important consideration is that not all occurrences of stigma involve a moral violation or a perception of a moral violation, but stigma may still occur in terms of judgement. For instance, the elderly did not violate a moral standard in terms of aging, but may still be stigmatised. For the purpose of this study the focus was specifically on stigma related to HIV/AIDS.

2.2.2 Origin of stigma as a socially constructed phenomenon

A more focused consideration of the origin of stigma reveals that it collectively originates in the social meaning making process of societies, which are then communicated through

language (Jordaan & Jordaan, 1998). Major and O'Brien (2005) and Meyer (2010) agree and state that stigma is socially constructed. HIV/AIDS-related stigma is therefore not a tangible entity, but socially constructed by societies, who have attached certain meanings to HIV/AIDS. These meanings are constructed and communicated through language, and entrenched through behaviours such as stigmatising. Similarly, Anderson and Goolishian (1992) refer to problems as socially constructed realities, which are maintained by behaviour and organised in language. This notion is reflected in the construction and maintenance of stigma.

This is the second important point regarding the origin of stigma, namely the social constructionist origin thereof. From a social constructionist epistemology we can say that stigma does not exist objectively on its own, but rather through our conversational construction thereof. A worthwhile consideration is the above statement by Goldin (1994) that stigma originated as a word for a marking (stig), rather than a tangible element that was empirically discovered or created. This is in keeping with the social constructionist nature of stigma, which emphasises its origin in the collective meaning making of society, in whatever forms meaning is made.

In summary, stigma originates in the collective perceptions and language of individuals, in which we intersubjectively create and attach a meaning of stigma when a violation occurs in our particular context of moral standards. Implied in this conception is the possibility that ascribed meaning is fluid – both subjectively and intersubjectively.

Participants' meanings of lived experiences provide imperative cues to bridge the gap between what stigma means now and what it could mean in future. For example, a new narrative may lead to more satisfying experiences which exclude the current meaning of stigma. As witnessed in the homosexual status of today, it is possible to shift social perspectives and meanings. The

initial thread throughout this study is that of intersubjective meaning shifting as a confident future possibility for society to perceive and live with new meaning.

2.3 Definition of HIV/AIDS-related stigma

Prior to the exploration of personal lived experiences of participants, it was necessary to consider the definition of stigma. This allows insight into the so called dominant discourse of stigma (Hill & Kurtz, 2008) and secures a theoretical grounding. What follows is a description of the various definitions of stigma to create an impression of the meanings attached to the social construction of stigma.

HIV/AIDS-related stigma refers to stigma that is relevant to people associated with HIV/AIDS specifically. Different literature sources offer varying definitions of HIV/AIDS-related stigma, but a dominant definition describes stigma as a discrediting attribute of those who possess an undesirable difference, such as HIV/AIDS (UNAIDS, 2007).

To gain more insight into the definition of stigma it is helpful to consider how other literature sources define stigma, and to also bear in mind that differences in defining the concept may be attributed to its origin in the social realm (Meyer, 2010). According to UNAIDS (2007) HIV/AIDS-related stigma is the process or action of the devaluation of people living with HIV/AIDS, or people associated with HIV/AIDS, whereas Brown et al. (2001) refer to stigma as a common reaction to disease. Literature reports stigma to be both an action and a reaction. It is a reaction to a disease as posited by Brown et al. (2001), and the reaction manifests in the form of judgement or devaluation as reported by UNAIDS (2007).

Any mention of stigma is incomplete without considering Goffman's writings, and it is worthwhile touching upon them again here. Goffman (1963) referred to stigma as the process of global devaluation, to which UNAIDS (2007) agreed, of individuals who possess a deviant

attribute or characteristic. In terms of HIV/AIDS, Goffman's framework would posit the following: HIV/AIDS acts as the marker that an individual is morally polluted, and should then be treated as such. The negative treatment of the individual, based on their real or perceived HIV status, takes the form of enacted or perceived stigma (which will be discussed next). Later definitions of stigma added to Goffman's ideas, and revealed the strong emphasis on its social constructionist nature.

Bear in mind that stigma is not the only reaction to disease, but for the purposes of this study, stigma remains the focus. Stutterheim, Pryor, Bos, Hoogendijk, Muris and Schaalma (2009) combine the view of stigma as a social construction and devaluation, by stating that stigma is a social phenomenon in which a person is considered to be tainted or flawed, and then treated accordingly. A combination of these definitions helps to encompass the concept of what HIV/AIDS-related stigma includes, whereas on their own the definitions seem incomplete.

It has been shown that there is no single definition of stigma that encompasses all of its facets completely and fully, in all situations and contexts. Holding an open-ended definition is helpful when dealing with anything that is socially constructed, as it is bound to shift over time and place, and to reflect changes in society. For the purpose of this study all of the above definitions are relevant and concludes that HIV/AIDS-related stigma is a consistently negative socially constructed phenomenon in which individuals associated with HIV/AIDS are treated in a negative way, due to their real or perceived HIV status.

2.4 Forms of stigma

The two forms of stigma are briefly presented here to illustrate the expression of stigma. Literature has revealed two forms of stigma which include anticipated (or perceived) stigma and enacted stigma (Sumari-de Boer et al., 2012).

Anticipated or perceived stigma refers to the internalised stigma of the individual with HIV/AIDS. This takes the form of fear, shame and guilt experienced by the individual about their illness (Ivanova, Hart, Wagner, Aljasseem, & Loutfy, 2012). Anticipated or perceived stigma is associated with high levels of anxiety and depression in individuals, especially women, living with HIV/AIDS (Ivanova et al., 2012). This anxiety and depression are attributed to the real or perceived fear of societal attitudes, and potential discrimination because of their status (Brown et al., 2001).

Enacted stigma refers to externally expressed stigma in the form of a variety of negative actions including devaluing, rejection, abandonment, violence and ostracism toward the individual either having, or perceived as having HIV/AIDS, from another individual (Campbell et al., 2005; Cluver, Gardner, & Operario, 2008; Stutterheim et al., 2009). High levels of enacted stigma are reported in affected communities in South Africa, ranging from subtle rejection to physical violence (Cluver et al., 2008). An infamous occurrence of enacted stigma occurred in 1998 in a Durban township, when Gugu Dlamini, an HIV/AIDS activist, was killed by members of her own community after she disclosed her HIV/AIDS status (Brown et al., 2001). She has since come to epitomise enacted stigma in its worst form (Jewkes, 2006).

Enacted stigma also takes on the following forms in family settings: being advised to conceal one's status, being avoided or treated with exaggerated kindness; and in health care settings: awkward social interaction, leading to psychological distress for the sufferer (Stutterheim et al., 2009). Extreme cases have been reported in which parents refer to their children as evil, because the children have contracted HIV/AIDS (Campbell et al., 2005). It has also been reported that families hide HIV positive family members to avoid shame, because of the association between HIV/AIDS and sex, and the link between sexual promiscuity and sin (Campbell et al., 2005). This confirms the origin as a moral violation. These individuals were

held responsible for their status due to their perceived choice to engage in risky behaviour, which is a violation of the social standards in which they find themselves (Mawar et al., 2005).

Enacted stigma is particularly strong in situations in which it is believed that an individual's behaviour has contributed to infection, and is exacerbated by the perception of incurability (Ogden & Nyblade, 2005). Enacted stigma lingers even after the death of the individual with HIV/AIDS in cases in which the actual cause of death may never be revealed in order to spare the family shame (Statistics South Africa, 2010).

The next section illustrates how anticipated and enacted stigma impact on prevention strategies, and thus directly contributing to the transmission of HIV/AIDS.

2.5 Impact of HIV/AIDS-related stigma on HIV/AIDS prevention

In this section the negative impact of HIV/AIDS-related stigma on the ongoing transmission of HIV/AIDS is briefly discussed, especially in terms of hampering prevention efforts. Literature refers to HIV/AIDS-related stigma as a social response actively contributing to the spread of HIV/AIDS (Mawar et al., 2005). Meyer (2010) supports this by reporting stigma as the central contributor to the HIV/AIDS epidemic, as do Bekele and Ali (2008) who reported that HIV/AIDS-related stigma has fuelled the transmission of HIV/AIDS.

HIV/AIDS-related stigma actively impacts on the transmission of the virus through discouraging individuals from engaging in a range of behaviours which aid prevention of infection and transmission of HIV/AIDS (Campbell et al., 2005; Mawar et al., 2005). These behaviours include testing for status, disclosure of status to sexual partners, and condom use (Brown et al., 2001). Individuals are discouraged from engaging in these behaviours due to fear of HIV/AIDS-related stigma (Blake, Jones, Taylor, Reid, & Kosowski, 2008; Herek et al., 2003), which manifests in the form of isolation, rejection, violence, condemnation and loss of

partner or economic support from partner (Blake et al., 2008). Behaviours aiding in the prevention of transmission are therefore avoided to avoid stigma.

HIV/AIDS-related stigma also mitigates against the taking of Antiretroviral (ARV) drugs (UNAIDS, 2007), and from seeking medical care once diagnosed (Campbell et al., 2005). This aspect is related to treatment of HIV/AIDS, and not prevention of transmission. For the purpose of this study it is noted that HIV/AIDS-related stigma impacts on treatment of HIV/AIDS, but the focus of this study remains on prevention of transmission.

To maintain an inclusive perspective, it must be acknowledged that HIV/AIDS-related stigma is not solely responsible for the spread of HIV/AIDS. The widespread prevalence of HIV/AIDS is reported to also be attributed to poverty, illiteracy, the apartheid system, occupational health risks, migrant labour, overcrowded and unhygienic accommodation and political aspects (Magwaza, 2009), as well as poor health care systems and limited resources for prevention and care (Heeren, Jemmot, Ngwane, Mandeya, & Tyler, 2013). While the aforementioned factors are acknowledged, this study focused on the role of stigmatisation as a driver of HIV/AIDS.

This overview of literature reveals the perpetuating impact of HIV/AIDS-related stigma (enacted and anticipated) on the transmission of HIV/AIDS. A closer look at the status of HIV/AIDS in South Africa reflects the consequences of the failure to curb the spread of HIV/AIDS, and the importance of focusing on this area. Therefore, the focus of the study remains HIV/AIDS-related stigma, but an illustration of its consequences justifies the relevance of this topic.

2.6 HIV/AIDS-related stigma and infection rates

2.6.1 Reported infection rate statistics

HIV/AIDS is a virus that interferes with the human immune system causing the infected individual to be more susceptible to opportunistic infections, and death, if left untreated. According to UNAIDS (2012) 34 million people were living with HIV/AIDS globally in 2011, with 5.6 million of that figure attributed to South Africa. In 2008 a reported 5.7 million were living with HIV/AIDS in South Africa (Heeren et al., 2013), with 5.4 million people living with HIV/AIDS in South Africa in 2006 (Dorrington, Johnson, Bradshaw, & Daniel, 2006). According to these sources it appears as though the number has remained at an average of 5.56 million from 2006 to 2011.

Due to the high infection rates, South Africa is referred to as the HIV/AIDS capital of the world (Magwaza, 2009). Moreover, these infection rates may be under-reported, as many South Africans may never access official health care, or know their status, or may pass away without the correct cause of death being recorded (Birnbaum, Murray, & Lozano, 2011). Thus, the overriding message of these figures remains one of epidemic proportions.

2.6.2 Reported lowered infection rate statistics

The probable impact of HIV/AIDS-related stigma is also reflected when considering reported lowered infection rates. UNAIDS (2012) report that there were 700 000 fewer new infections across the world in 2011 than in 2001. According to UNAIDS (2012) the landscape of HIV/AIDS has improved, particularly in sub-Saharan Africa. They also report that in South Africa specifically, the new infection rate has been reduced by 41%. In observing data of the lower infection rate, one must consider what it may be conveying. The lower infection rate may be indicative of prevention programmes achieving success in reducing infection rates

(UNAIDS, 2012), but considering the role of HIV/AIDS-related stigma in the transmission of HIV/AIDS, this interpretation may be simplistic. For example, fear of HIV/AIDS-related stigma may have escalated to the point where individuals are not getting tested at all, or fewer individuals are getting tested, and thus the updated infection rate appears lowered. This fear was also reflected in Steinberg's (2011) book "Three Letter Plague", the journey of a young man who had every opportunity and reason to test for his HIV status, but refused to do so due to stigma.

Considering the infection percentages, as well as the reports of lowered infection rates, the reality remains that people are living with the effects of HIV/AIDS. South Africa's population has grown from 5 million in 1902 to more than 43 million in 1999 and it is expected to grow between to 46 and 62 million by 2021, depending on the impact of HIV/AIDS, and fertility rates (van Aardt 2001-2002). Taking into consideration the projected population size reported by Aardt, any percentage affected in a population of this magnitude is significant.

2.6.3 Inconsistency in HIV/AIDS prevalence and reported mortality rate

When considering the infection rate of HIV/AIDS and the death rate attributed to HIV/AIDS, there appears an inconsistency in this data. According to the Statistical release P0309.3 from Statistics South Africa (2010), only 18 325 of the total 543 856 deaths in South Africa in 2010 were caused by HIV/AIDS. This accounts for 3.4% of that year's deaths.

The highest cause of death, at 43.3%, was classified as other natural causes, and the second highest was Tuberculosis at 11.6%. There is therefore the possibility that the reported 3.4% is not an accurate reflection of HIV/AIDS driven mortality. This may be because many people may die without an official or accurate cause of death being established (Statistics South Africa, 2010). In 2010 31% of causes of deaths were recorded according to the opinion of the medical practitioner, 15% according to the opinion of the medical practitioner on duty and 13% were

through interviews with family members (who may not always reveal the true cause of death in fear of being stigmatised) (Statistics South Africa, 2010). Only 8.7% of causes of deaths were recorded according to autopsies, and 3.4% according to post mortem examinations. Therefore, not all deaths are officially examined, and 59% of causes of deaths are based on combined opinions and interviews, which may be inaccurate.

In South Africa, deaths that are caused by HIV/AIDS are often misclassified by 14 other conditions, according to Birnbaum et al. (2011). Their research found that more than 90% of HIV/AIDS deaths were misattributed to other causes during 1996 to 2006, and that death certificate audits revealed a 45% error of all recorded deaths. According to the guidelines given in the International Classification of diseases and Related Health Problems, the cause of death should be recorded as HIV/AIDS even if the individual dies from a co-morbid condition caused by HIV infection (World Health Organisation, 2010). This suggests that if the individual died of Tuberculosis and was HIV positive, the medical practitioner filling out the cause of death is likely to record Tuberculosis as the cause of death, where it should be recorded as HIV/AIDS.

There is therefore an inconsistency between the percentage of the population infected with HIV/AIDS and the percentage of the population succumbing to an HIV/AIDS death. Could this inconsistency be attributed to the efficacy of ARV treatment, or are causes of death incorrectly recorded? The fact that deaths are inaccurately recorded involves fear of stigma for the family left behind. For example, a family member giving information about the deceased may omit the HIV status of the deceased to spare themselves stigma and shame. This may create a falsely optimistic view of HIV/AIDS infection and mortality rates. This may contribute to complacency in the fight against HIV/AIDS, because the true reality of the devastation is masked behind the consequences of HIV/AIDS-related stigma.

2.6.4 *Population group seemingly vulnerable to HIV/AIDS*

A closer consideration of the pattern of infection rate of HIV/AIDS will assist in highlighting seemingly vulnerable population groups, and serves as an indicator of the progression of HIV/AIDS (Dorrington et al., 2006). The vulnerable group identified through literature also guided the selection of the population group to participate in this study, namely young females.

Statistics South Africa (2013) indicated a steady increase in HIV/AIDS prevalence from 2002 to 2013, climbing from 15.9% in 2002 to 17.4% in 2013, specifically for women aged 15-49. Shisana, Rehle, Simbayi, Zuma, Jooste, Pillay-van-Wyk, Mbelle, Van Zyl, Parker, Zungu, Pezi, and the SABSSM Implementation team (2009) agreed with this in reporting more than 15% of the population aged 15-49 living with HIV/AIDS, of which women make up the predominant percentage. This is also supported by Dorrington et al. (2006) who reported that the highest prevalence of infection was among women aged 15-49, which makes up 21.2% of that population group in 2006. Therefore, women in the 15-49 year old age bracket have been identified as a vulnerable group with regards to HIV/AIDS infection, over a long period of time.

It is noteworthy to consider why mostly women contribute to a higher infection rate, or more accurately: why it appears as though more women are infected than men. At first glance the explanation for more women being infected than men may arouse pre-conceived ideas of female promiscuity, but closer consideration reveals different potential explanations. More women are diagnosed with HIV/AIDS, because more women are being tested for HIV/AIDS (Venkatesh, Madiba, de Bruyn, Lurie, Coates, & Gray, 2011; Visser, 2012). Women are tested when they become pregnant, whereas this is not the case with men. Pregnant women are tested for HIV/AIDS due to health policies focused on preventing mother-to-child transmission. It is

therefore more accurate to report that more women are being tested for HIV/AIDS, and found to be positive, than men.

The possibility of men and women having an equal share in infection rate, and not a disproportionate infection rate as currently reflected, may have two possible implications. The first being that the perception of a disproportionate percentage of women infected is eliminated, which may also reduce stigmatisation of women (Visser, 2012). The negative implication, however, may be that previous reports of infection rates have been underrated, and that they may in fact have been higher than previously indicated.

Literature has therefore reported that the perceived population group most at risk of contracting HIV/AIDS, and the population group with the seemingly highest infection rate, remains the female population group between 15-49 years of age (Dorrington et al., 2006; Statistics South Africa 2010 and Visser, 2012). Consequently, this population group has been stigmatised to a larger degree, and labelled as the main carriers of the virus (Visser, 2012).

2.7 Stigma reduction programmes

Stigma reduction programmes attempt to reduce HIV/AIDS-related stigma through various methods and tools. As with any programme it may or may not be successful in certain or all contexts. This section briefly describes various programmes implemented, followed by a brief description of the programme running at the Africa Centre, and recommendations and suggestions from literature for stigma reduction programmes. This provides an overview of the current status of programmes running, their success in achieving outcomes or lack thereof, and what information reports yield regarding the programmes.

2.7.1 *Current initiatives and programmes*

2.7.1.1 The United Kingdom's Department for International Development

The Department for International Development (DFID) in the United Kingdom has responded to HIV/AIDS in an effort to reduce HIV/AIDS-related stigma through supporting, in the region of, one hundred programmes in addressing HIV/AIDS-related stigma (Carr & Nyblade, 2007). This is done through raising awareness of stigma through public education, empowering excluded groups to advocate for their rights, for improved services to them and mobilising role models and leaders to foster openness and respect (Carr & Nyblade, 2007). This includes raising awareness of what stigma is and the benefits of reducing it, addressing fears and misconception about HIV/AIDS transmission and providing skills to challenge stigma and change behaviour.

They also promote a participatory approach (in which people reflect on their own attitudes and actions through interactive workshops, role playing and discussions), the empowerment approach (where persons affected by HIV/AIDS stigma are empowered to become agents of change, and peer-to-peer support groups are formed to address perceived stigma within themselves) and promoting enabling environments through policies and laws (Carr & Nyblade, 2007).

They also provide Anti Stigma toolkits which can be adapted to fit specific interventions or programmes. The toolkit has 11 modules and over 135 participatory exercises targeting the truth about HIV/AIDS, reducing stigma, people living with HIV/AIDS friendly achievement checklist, and a “called to care” section specifically for faith based programmes (Carr & Nyblade, 2007).

The Department for International Development (DFID) in the United Kingdom therefore includes resources involving information, advocacy and behaviour modification. Some of these do not enable social constructions to be shifted as it implies an expert imposing something on the participant. However, they do promote participatory approaches with workshops, for example. Discussions and role playing in these workshops is where social constructions have a possibility of being formed or shifted, as discussions and sharing narratives are conducive to this taking place.

2.7.1.2 Horizons Programme

A specific case study of one of the programmes the Department for International Development (DFID) in the United Kingdom support, is “Involving Young People in the Care and Support of People living with HIV and AIDS” in Zambia. This programme was implemented by the Horizons Programme, in which youth were trained to be adjunct family caregivers. This not only bridged the gap in carer service delivery but also reportedly reduced stigma in the communities in which the youth worked.

To determine efficacy of the programme, researchers selected 30 anti-AIDS clubs from two communities in Luapula Province to receive the following: 1) HIV prevention training, 2) club management, and 3) care and support training. An additional 30 anti-AIDS clubs from two communities in the Northern Province only received: 1) HIV prevention training and 2) club management, but not care and support training.

Club members were interviewed before and after the training took place, as were community members. These interviews revealed that club members from the Luapula Province, who received care and support training in addition to HIV prevention training and club management, were more likely to have provided care and support to people living with HIV/AIDS in the

household, than those from the Northern Province, who did not receive care and support training. This was indicative of lowered stigma in the Luapula Province.

Luapula members reported up to two visits per week to families affected by HIV/AIDS, and people they cared for reported satisfaction with these services. They also reported more accepting attitudes regarding HIV/AIDS (Carr & Nyblade, 2007). The data gathered relied on the feedback of club members and community members of these specific provinces, thus being qualitative in nature. It may be that this programme yielded success in reducing stigma as participants interacted with HIV/AIDS sufferers. This enabled social constructions to be shifted, instead of receiving information about HIV/AIDS-related stigma exclusively.

2.7.1.3 Treatment Action Campaign

The Treatment Action Campaign in South Africa is also supported by the Department for International Development (DFID) in the United Kingdom (Carr & Nyblade, 2007). One of their better known stigma reduction efforts made use of a T-shirt with “I’m positive” printed on the front. The late Nelson Mandela wore this T-shirt on various occasions, in an attempt to de-stigmatise HIV/AIDS. Its intention was to send a bold message about openness and honesty in addressing stigma related to HIV/AIDS.

This programme has also encouraged and created a model for HIV-positive leadership, with one of the programme founders openly living with HIV/AIDS. The programme challenges ignorance and myths surrounding HIV/AIDS through awareness and educational activities. The reported results of their efforts include, amongst others, 1) increasing understanding of HIV/AIDS and its treatment among the public and health care providers, 2) de-stigmatising HIV/AIDS to a degree by the late Nelson Mandela wearing their shirt and disclosing his son’s death of HIV/AIDS (Carr & Nyblade, 2007).

The desired outcome of “increasing understanding of HIV/AIDS and treatment” is challenging to measure, as an informational programme may be provided, but the uptake or positive response thereof is not guaranteed. Also, the claim of de-stigmatising HIV/AIDS through the late Nelson Mandela wearing their shirt would also be challenging to measure, as stigma attitudes are challenging to measure. It is conceivable that, with an icon wearing an “I’m positive” shirt, that the icon’s fans and followers were influenced by the message. But bearing in mind the socially constructed nature of HIV/AIDS-related stigma (Meyer, 2010), the success estimate may be falsely optimistic.

The Treatment Action Campaign (Carr & Nyblade, 2007) is therefore information and awareness orientated, and geared toward instilling unashamed ownership of one’s status. The T-shirt initiative may send the message that some people are not afraid to disclose their status, but this in itself may not challenge the socially constructed meanings of stigma. Stigma is a social construction and therefore addressing it with information and behaviour modification may be less effective, unless information allows for new meaning making regarding stigma.

2.7.1.4 Ethiopian Federal Ministry of Health

Stigma reduction and awareness efforts designed by the Ethiopian Federal Ministry of Health included the Information, Education and Communication (IEC) strategy (Bekele & Ali, 2008). Bekele and Ali (2008) stated that IEC interventions, such as interpersonal communication, pamphlets and educational videos, have been developed to improve awareness of HIV/AIDS and reduce HIV/AIDS-related stigma and discrimination in Ethiopia. The IEC strategy appeared effective when implemented among teenagers in Ethiopia and showed a reduction in stigmatizing and discriminatory attitudes in school teenagers when implemented in India (Bekele & Ali, 2008).

This intervention employed four different methods: interpersonal communication, pamphlets, educational videos and a combination of the three methods, which may have increased the success rate, instead of employing one method or intervention exclusively. Other sources support this view by stating that education about HIV/AIDS transmission alone is not sufficient to reduce or eliminate stigma (Jewkes, 2006). They maintain that stigma reduction work should challenge individual attitudes and beliefs and address the social processes which maintain stigma.

2.7.2 Outcomes of stigma reduction programmes

HIV/AIDS knowledge, attitudes, and behaviour modification campaigns represent a widely implemented intervention strategy in resource limited countries (Mahajan et al., 2008). Some of these campaigns are broadcast on radio or television to target large audiences, or are distributed through media, such as posters and pamphlets for smaller audiences. Mahajan et al. (2008) believe these could potentially reduce stigma. According to these authors, a broadcast intervention in Botswana aimed at HIV/AIDS-related stigma, demonstrated that mass media interventions can be effective in reducing stigma. In this intervention, a soap opera, *The Bold and the Beautiful*, included a 2-year story line aimed at HIV/AIDS awareness and education. Viewers of this soap opera showed lower levels of HIV/AIDS-related stigma, compared to non-viewers. Results were measured by a validated-item stigma scale (Mahajan et al., 2008).

It was noted that many of these studies had weak designs and it is evident that there are mixed outcomes. This may be because stigma takes on different forms in different settings, and each programme must be tailor made for the context in which it will be implemented and for the relevant participants, for it to be effective. These results also did not take into account the personal experience of the target population. Programmes are also challenging to assess for efficacy because measuring attitudes poses a challenge in some contexts, or researchers are

without the right scales of measures (Mahajan et al., 2008). Additionally, because the study was quantitative it is not clear if lowered HIV/AIDS-related stigma was solely due to viewing the programme, or if other factors were involved. Qualitative inquiries may achieve better success in determining this, as narratives potentially provide more insight than quantitative data.

Sengupta, Banks, Jonas, Miles and Smith (2011) reviewed literature to determine the effectiveness of some HIV/AIDS-related stigma reduction interventions. Of their 19 studies, only 14 demonstrated effectiveness in reducing stigma. Only 2 of these 14 were considered good studies based on their quality and the statistical analysis used to demonstrate effectiveness. This illustrates that there may be programmes and interventions implemented which are not yielding the desired outcomes.

The social constructionist nature of stigma proves challenging to reduce or manipulate in the form of programmes, especially those based on information and behaviour modification. The participatory approach of some programmes is more in keeping with social constructionism, but the exploration of personal experiences of participants still remains absent.

2.8 Current stigma reduction efforts implemented at the Africa Centre for Health and Population Studies

The Africa Centre is situated in Somkele in the Hlabisa District, which is a rural population in KwaZulu-Natal. This section describes efforts to reduce HIV/AIDS-related stigma implemented at the Africa Centre, in the form of a stigma reduction programme. The Africa Centre focuses on population studies, empirical HIV/AIDS research, testing and treatment. Due to the Africa Centre's focus on empirical HIV/AIDS research, data acquired through testing for HIV/AIDS is a necessity. An obstacle was identified in the community's reluctance to test

for HIV/AIDS. To circumvent this obstacle an HIV/AIDS-related stigma reduction initiative was implemented in order to encourage people to test.

Background information to this programme was provided by an Africa Centre employee closely involved in this programme. Initial contact was made with the Africa Centre through an existing contact at the Africa Centre, an operations manager, who referred the researcher to the coordinator of the HIV/AIDS counselling and testing department. The coordinator of the HIV/AIDS counselling and testing department oversees counselling and testing and is directly involved with the programme.

Statistics South Africa (2011) indicate that 53.8% of the Hlabisa District population is aged between 15-64 years of age, with an unemployment rate of 52.6% for 2011. Female headed households are indicated to be at 58.9% for 2011. Small scale farming is common, as the Hlabisa District is set in the hills of KwaZulu-Natal. Formal buildings are limited to primary health care clinics, a hospital, government schools, churches, the Africa Centre, informal shops, and the nearby Somkele Mine.

The Africa Centre is involved at 21 Department of Health clinics, in which they conduct their research. Here, they also partner with the Department of Health in running the Hlabisa HIV treatment and care programme. Due to low numbers in testing for HIV/AIDS at the clinics, the Africa Centre started a home based testing initiative in 2009, which they refer to as a stigma reduction programme. Because the home based testing is private, stigma is circumvented. Through this initiative the Africa Centre goes into the community's homes and offers in-home testing and counselling.

This initiative has been successful, according the Africa Centre's coordinator of counselling and testing, who reported that data reflected in-home testing for men at 39%, compared to clinic

testing for men at 20%. These results are obtained in partnership with the Department of Health, as records of testing and results are recorded by the Africa Centre health workers (nurses, doctors, data capturers) in conjunction with Department of Health employees who also conduct testing and data capturing.

In addition to home based testing, the Africa Centre's stigma reduction efforts include road shows with the aim of educating communities around HIV and AIDS, aiming to impact on stigma specifically. In these road shows, people are encouraged to disclose their status publicly in order to help others who are fearful to test for their status, according to the coordinator of counselling and testing. The Africa Centre also offers an environment for support groups to form in which individuals gather to discuss their issues relating to HIV/AIDS.

What the Africa Centre refers to as their stigma reduction programme, therefore consists of home based testing and road shows in the form of mobile units, both facilitated by Africa Centre staff. The mobile units advertise in advance that the Africa Centre is visiting a school, or sports event or some gathering. Once in the community, they hold workshops, discussions, announcements and offer counselling to the present audience. They provide information about HIV/AIDS and stigma over a loud speaker and also offer workshops for smaller groups to learn more about HIV/AIDS and stigma. They offer on the spot private testing, and have tents with counsellors who counsel individuals, and discuss treatment options with individuals or small groups. From here relevant individuals are referred to clinics, with a referral number so that the Africa Centre is able to follow up whether individuals did indeed seek medical care. This programme, which started in June 2009 thus combines information about HIV/AIDS and stigma, testing, counselling and support group discussions, with the aim of reducing stigma.

According to the counselling and testing coordinator, Africa Centre data reflects that the Africa Centre tested over 75 000 people in the area. Of these people over 50 000 HIV/AIDS positive

testees have gone for their CD4 test in order to know their clinical status, at the end of 2011. They also currently have over 18 000 people on antiretroviral treatment, according to the counselling and testing coordinator. Again, these results have been obtained through Africa Centre staff, through capturing the count of testee's via data capturers from information supplied by clinic staff. This programme therefore appears to be effective for 34% of this population of 220 000 in engaging these individuals in preventative behaviours.

It is not apparent how the programme has been personally experienced by females aged between 18 and 24, the target population of this study (or by any population group for that matter). The Africa Centre display a count of 75 000 tested in their programmes at the end of 2011, but personal experiences are excluded from this information. Such information is vital, as it may become apparent that a certain group in the population is not responding to the programme, and if not, the programme may need to be adjusted, or separate programmes implemented to target this population. Especially if it is a high risk population such as females aged between 18 and 24. It is also not apparent if being a participant in the programme has influenced participant meaning making related to stigma, or the social discourses maintaining it.

2.9 Recommendations and suggestions for stigma reduction programmes

Andrew Steer, the director of the Policy and Research Division of the Department of International Development (United Kingdom) states that taking action against HIV/AIDS-related stigma is essential to halt and begin to reverse the transmission of HIV and AIDS (Carr & Nyblade, 2007). "Taking action" has taken the form of stigma reduction efforts through programmes and initiatives worldwide. These programmes differ from each other, according to the expertise and opinion of programme developers. Research has assisted in determining what content should be included in programmes in order to be effective and yield the desired

outcomes. The content of programmes is largely based on addressing the causes of HIV/AIDS-related stigma.

Lack of awareness of HIV/AIDS-related stigma and its effects, fear of contracting HIV/AIDS through everyday contact, and linking people with HIV/AIDS to immoral behaviour have been identified as the causes of HIV/AIDS-related stigma (Kalichman, Simbayi, Jooste, Toefy, Cain, Cherry, & Kagee, 2005). Causes of enacted stigma specifically include fear of HIV/AIDS itself, the fear of being infected, and the fear of death caused by HIV/AIDS (Brown et al., 2001). Therefore, on the surface level it appears as though lack of information regarding HIV/AIDS and how it is transmitted plays a large role, as well as fear of the virus and fear of interaction with people living with HIV/AIDS.

Literature posits that reducing stigma requires intervention and education programmes which impart information about HIV/AIDS first of all (Mawar et al., 2005), although Jewkes (2006) argued that educational interventions alone have little effect on stigma. These programmes also need to address issues of treatment and prevention to establish social norms based on acceptance and respect for HIV/AIDS infected individuals. Attitudinal change through greater knowledge and political will, for example, through human rights, is considered as the most significant approach to challenge existing stigma (Mawar et al., 2005).

Kalichman et al. (2005) identified the importance of empowering people living with HIV/AIDS to know and assert their rights, enlisting public figures to advocate against stigma (as with the Treatment Action Campaign), and promoting laws to protect the rights of people living with HIV/AIDS, as strategies to combat stigma. Stigma may also be reduced through a variety of intervention strategies including information, counselling, coping skills acquisition, and contact with people living with HIV/AIDS (Brown et al., 2001). Therefore, knowledge about HIV/AIDS alone is not sufficient to reduce stigma, but rather a combination of knowledge and

contact or interaction with people living with HIV/AIDS (Chao, Gow, Akintola & Pauly, 2010).

Jewkes (2006) maintained that shifting discourse around stigma and HIV/AIDS is a more suitable approach, but that it has been notably absent from recommendations on how to reduce stigma. UNAIDS (2007) agree with an information and experience approach and add that the most promising approaches to stigma reduction are a combination of the following: empowerment of people living with HIV/AIDS, updated education about HIV/AIDS (education must be aimed at individuals affected by the virus, as well as those who are not, as this will eliminate misconceptions), and activities involving direct or indirect interaction between people living with HIV/AIDS and key audiences. They also report that the participatory approach, which involves activities that encourage dialogue, interaction and critical thinking, is at the core of several promising stigma reduction programmes, which involve interactive workshops with diverse audiences (diverse audiences meaning individuals affected by HIV/AIDS as well as those not affected by HIV/AIDS). Role plays, discussions and reflection exercises in these programmes foster greater understanding of false assumptions underlying the stigma, the harm stigma cause and the need to change attitudes and behaviours (UNAIDS, 2007). This approach appears to be more in keeping with shifting socially constructed meanings of stigma.

In contrast to openness and honesty regarding divulging status, Mawar et al. (2005) state that eliminating HIV/AIDS-related stigma would require long-term participation in the following areas:

- An individual's HIV status must remain confidential, and unauthorised disclosure of this information should be condemned (although other researchers disagree, and advocate the normalisation of testing and public disclosure of status)

- Discrimination on the basis of HIV status should be prohibited
- Public education efforts must directly confront HIV/AIDS-related stigma and these efforts must enable norms that increase acceptance, respect and compassion for the infected

These recommendations appear viable, but to increase acceptance, respect and compassion as indicated above may prove challenging, as stigma is a social phenomenon, not a tangible entity which can be manipulated. To increase acceptance, respect and compassion (Mawar et al., 2005), may prove to be an unrealistic ideal, as social beliefs are difficult to alter, and even if they are altered, it may prove a challenge to measure this change. An added challenge is that varying beliefs and practices operate in different contexts, which imply ever changing influential factors that must be taken into account, in each and every context.

Partnering in the following areas may help reduce HIV/AIDS-stigma according to UNAIDS (2007):

- Build an understanding of and commitment to stigma reduction by using existing tools for measuring stigma
- Know the prevalence of stigma and its impact as a response to HIV/AIDS
- Promote and facilitate programme evaluation and operational research
- Evaluate outcomes of programmes

The last point highlights the need for extensive research on the influence of stigma reduction programmes on relevant participants. This can be known through exploring the lived experiences of participants of such programmes. Collecting data about stigma poses a challenge in terms of measuring attitudes, which also contributes to limited research (Mahajan et al., 2008). Therefore exploring lived experiences may prove more effective in bridging this gap in available data.

It is evident that there are many recommendations as to what stigma reduction programmes should look like, but not much research data to illustrate what is effective and what is ineffective, and in which contexts. UNAIDS (2007) listed research on stigma reduction programmes as an important principle in combating HIV/AIDS-related stigma. For this reason it is important to explore the personal experiences of programme participants.

2.10 Conclusion

HIV/AIDS-related stigma governs the stigmatised through fear, and discourages individuals from engaging in behaviours that prevent further transmission. Quantitative research uses statistics to provide a picture of what HIV/AIDS and stigma reduction programmes look like, but personal experiences and social constructions are excluded. Because HIV/AIDS, HIV/AIDS-related stigma and the participation in HIV/AIDS-related stigma reduction programmes are personal experiences, the research must reflect this: personal experiences. Exploring personal experiences of participants reveal narratives about themselves and the programmes they have attended, that may not be otherwise known, even with quantitative evaluation of the programme.

CHAPTER 3: METHODOLOGY

3.1 Introduction

In this chapter the philosophical underpinning of this study is described, the research approach and the rationale thereof, as well as the research design and methods. Ethical considerations are also included in this chapter. The qualitative approach of this study allows for exploring personal experiences of participants, while a social constructionist epistemology underpins the study.

3.2 Philosophical and epistemological underpinning of the study

Applebaum (2011) highlighted the manner in which Giorgi consistently commenced his psychological presentations by highlighting the presentation's underlying philosophical principles. This was done to prompt within his students a consideration that any approach to psychology is undeniably founded upon underlying epistemological assumptions. According to Applebaum (2011) Giorgi posited that one must be sufficiently acquainted with philosophy in order to engage in the epistemological assumptions underlying one's study. That is to say, we must consider how we came to think the way we do, or believe what we believe (Applebaum, 2011), as it allows us to consider our tradition of thought (Brufee, 1986). The origin of epistemology has to do with our desires and efforts to make our world more understandable (Jordaan & Jordaan, 1998) and its concern with how we know what we know (Keeney, 1979). We want to understand our world, so we explore it from different frameworks of knowing.

Social constructionism finds itself within a Post Modern epistemology, an alternative way of observing how we come to know what we know (Keeney, 1979), than the traditional Modernist epistemology. King (2004) traces the modernist epistemology as far back as 570 BCE when

Pythagoras claimed that the world can be explained through numbers; Pythagoras in turn influenced Aristotle, who claimed that experience, rather, is the source of knowledge (empiricism). Empiricism became the disposition of the times as many of the great intellects passed this epistemology down to influential individuals, such as Alexander the Great (King, 2004). According to King (2004) Locke was especially influential with his “Essay concerning Human Understanding” in which he stated that knowledge is purely empirical. Not satisfied with Pythagoras’ ideas, Socrates set a scepticism in motion with his dictum of his certainty that he knows nothing (King, 2004). This scepticism contributed to the revelation that it is us who give meaning to our world, according to Nietzsche in the late 1800’s (King, 2004). Although not directly influenced by Nietzsche, Popper added that the meaning of our world and our knowledge is created in our minds and dependent on our contexts. According to King (2004) this eventually led to the conclusion that language plays a significant part in this creation, as posited by Derrida. Bateson later suggested the shared or interrelated nature of this construction of realities, our stories, pointing to an ecology of ideas shared amongst one another (Becvar & Becvar, 2005).

Basic assumptions of the Modernist epistemology holds that reality or truth is objective and that only one universal truth exists; that causality is linear; and that things can only be known through empiricism, as posited by Aristotle and Locke (King, 2004). The positivist and quantitative approach places itself squarely within this way of thinking. This scientific principle of an objective truth or reality which can only be known through empiricism also received severe criticism from the 1960’s onwards from scientists and biologists such as Bateson, Maturana and Varela regarding what we deem as reality. They favoured the post-modernist paradigm, which opened a gateway to the notion that truth and reality are relative.

Social constructionism deems what we consider reality, to be socially constructed, instead of universal and fixed (Berger & Luckmann, 1966). This implies that our individual construction of this reality may not be identical to the next person's, because it is not fixed. Looking through a social constructionist lens takes into account the interaction between individuals, groups and societies in their social contexts, through language. For example, we socially construct a meaning around stigma through language (Jordaan & Jordaan, 1998). The accent is on dialogue or language or narratives as the basis of social co-creation of the meanings we ascribe to our world (Jordaan & Jordaan, 1998).

From a social constructionist epistemology it can be said that HIV/AIDS-related stigma does not exist objectively on its own, but rather through the conversational co-construction thereof. Hoffman (1985, p. 384) supports this view, stating that our ideas about the world are "shared ideas, consensually arrived at and mediated through givens like culture and language". Similarly, Gergen (1985) states that social constructionism focuses on the process of describing and explaining this socially constructed world, and therefore he also, like Hoffman, emphasises that language plays a large part. Both views are reconciled by the assumption that we create or give meaning to our world by talking about it to one another. We can thus say that our language reveals our beliefs about certain things, which is why looking at narratives in this study was important. In summary, our reality is constructed as a function of the belief systems according to which we operate, and we create these belief systems by languaging about it when we interact with one another (Becvar & Becvar, 2005). The meaning making process is thus emphasised.

A social constructionist epistemology is consistent with the research question, the literature review, the aims and objectives of this study as well as a natural extension of the researcher's ecosystemic orientation regarding social sciences. This orientation rests in the belief that

participants are experts in their own realities (Anderson & Goolishian, 1992), which are intersubjectively and socially constructed. All that can be known about participant realities is that which participants communicate, and the researcher's interpretation of what is communicated. Because this study focused on personal experiences, this disqualifies it from a positivist approach, as the focus is not empirical data or causal factors relating to stigma, but constructions of meaning making as encountered in the personal experiences of participants. Because individual experiences cannot be measured or quantified, a qualitative approach is necessary to achieve the aim of the study. Qualitative research suggests that the focus of the study dictates the design of the study (Becvar & Becvar, 2005).

3.3 Research design

The aim of exploring the lived experiences of participants with the objective of gathering and exploring the narrative data from semi structured individual in-depth interviews of 10 participants, and a semi structured focus group discussion of 20 participants, was realised through a qualitative approach in an exploratory case study. The research method was guided by the approach of this study, which is grounded in the social constructionist epistemology.

A qualitative approach was best suited, as the focus excluded quantitative data and numbers (Kheswa & Duncan, 2011). An exploratory enquiry guided the study, with the focus on the narratives of participants, which revealed the meanings attached to their experiences (Berglund, 2007). Looking at meaning through narratives reveals how participants' subjective understandings and experiences are derived from the larger social narratives (Terre Blanche et al., 2006). According to Genosko (1996) Guattari refers to this influence of the larger social narrative as mass conditioning. Exploring narratives of participant experiences in a focus group as well as individual in-depth interviews allowed for individual meanings to surface as well as interactive meanings within the group. It also revealed how the programme has influenced their

meaning making and perceptions, as well as their nesting in their contextual mass conditioning (Genosko, 1996).

The focus group discussion consisting of 20 participants was semi structured to allow for natural flow of discussion. Focus group discussion was employed to explore subjective as well intersubjective meanings through narratives related to participating in a stigma reduction programme. Focus group discussion allowed for narratives from multiple participants simultaneously, and also created an environment conducive to discussion, as participants were able to feel comfortable due to the number in the focus group, which comprised of 20 participants (Kweshu & Duncan, 2011). Semi structured individual in-depth interviews, consisting of 10 participants, was also employed to explore personal narratives of participants. The focus group discussion revealed the general meaning or consensus held by this group collectively regarding their experiences of the programme, whereas individual in-depth interviews revealed more personal and subjective meanings. Within the narratives themes were identified which revealed participant meaning as well as the larger social discourse governing participants' meaning making.

3.4 Sampling

3.4.1 Sampling method

Purposive sampling was employed in the form of convenient sampling strategy (Terre Blanche et al., 2006) to select 20 participants for the semi structured focus group discussion, 10 of which agreed to participate in an additional semi structured individual in-depth interview. Participant selection was made up of females aged between 18 and 24 who have participated in the Africa Centre stigma reduction programme.

3.4.2 *Sampling procedure*

Focus group participants and individual interview participants were selected on the grounds of the following criteria:

Inclusion criteria

- Participants were females
- Participants were aged between 18 and 24
- Participants participated in the Africa Centre stigma reduction programme in the recent past (6 months)

The criteria are justified as it appears as though an estimated 8.7% national prevalence of HIV/AIDS infection is found in young people aged 15-24 in South Africa (Heeren et al., 2013). It appears that woman worldwide aged 15-24 years of age are 1.6 times more likely to contract HIV/AIDS than men (Ivanova et al., 2012), which was also reflected in Shisana et al. (2009), who reported that 15% of the population aged between 15-49 were living with HIV/AIDS, with women occupying a predominant percentage of this infection.

The participant selection process was done through a notice at the Africa Centre which announced the study and which invited willing participants that met the abovementioned criteria to contact the Africa Centre's coordinator of counselling and testing for further details. The notice was ineffective in successfully attracting potential participants. Thereafter, the counselling and testing coordinator identified participants that met the required criteria and invited each participant to voluntarily participate in the study, after which participants were informed of the date and time that the research would take place, as well as the venue.

3.5 Data collection instrument and procedure

The philosophical underpinning and qualitative approach of the study guided the data collection procedure (Griffith, Griffith, & Slovik, 1990) and allowed for a wider range of observation than quantitative data. The method of data collection for individual interviews, included verbal semi structured in-depth interviews and written notes, as well as partially recorded discussions (four individual interviews were permitted to be recorded). Some individual interview participants were not comfortable with their interviews being recorded, and opted for note taking exclusively. Four participants did allow for interviews to be recorded as well as note taking. Not all the participants in the focus group agreed to recording taking place, and therefore detailed notes were taken during the discussion instead of a recording, as well as verbatim quotes being written down immediately during the discussion. Data consists of participant narratives of experiences of the stigma reduction programme, as well as the narratives guided by the natural flow of open discussion. Semi structured discussion during the focus group allowed for free expression from participants, as did the semi structured individual in-depth interviews.

During the initial meeting with participants, the aim and structure of the study was explained. The focus group took place on the first day, and its duration was 105 minutes. Thereafter, individual interviews took place for the following five days (made up of ten participants), each interview varying from 45 minutes to 60 minutes. Participants' level of understanding and ability to communicate in English was sufficient, as the discussion and interviews took place in English. Some translations of contextual words in Zulu were translated by the counselling and testing coordinator.

The focus group discussion and individual interviews commenced at a manageable pace, as English was the participants' second language and, therefore, took time to explain exactly what

they meant. The slower pace allowed for careful note taking, and also the researcher checking that she understood what was being said, taking the language barrier into consideration.

The focus group was especially challenging to manage, due to its size. Before commencement of the focus group, the researcher had an informal introduction to the setting, with the aim of familiarising herself with the participants and their seating arrangements. The researcher prepared an A2 size chart for each question beforehand to simplify note taking during the focus group discussion, as well as blank charts for unexpected questions or topics:

Table 1: Example of focus group chart

Have any of you experienced stigma? How has the programme influenced your perspectives on stigma and your experiences of stigma?	
Participant	Notes
Focus Group Participant 1	
Focus Group Participant 2	
Focus Group Participant 3	
Focus Group Participant 4	
Focus Group Participant 5	
Focus Group Participant 6	
Focus Group Participant 7	
Focus Group Participant 8	
Focus Group Participant 9	
Focus Group Participant 10	
Focus Group Participant 11	
Focus Group Participant 12	
Focus Group Participant 13	
Focus Group Participant 14	
Focus Group Participant 15	
Focus Group Participant 16	
Focus Group Participant 17	
Focus Group Participant 18	
Focus Group Participant 19	
Focus Group Participant 20	

Individually numbered labels from 1-20 were fastened to the chair legs, in plain view of the researcher. When a focus group participant spoke, the researcher could then efficiently identify which participant was speaking. The researcher would then go to the specific participant's number column on the chart and record the note. The disadvantage of a group this size was that between two and four participants remained mostly silent throughout most of the discussion, and therefore their input was minimised.

3.6 Data analysis

Narrative analysis was employed to identify themes (thematic coding) that emerged from participants' narratives. Themes revealed meaning through narratives, in keeping with social constructionism. Narrative analysis was employed in an attempt to also understand participant narratives as shared in the research setting (Terre Blanche et al., 2006). Narratives refer to participants' verbal accounts of personal experiences of the stigma reduction programme, which developed over the course of semi structured individual in-depth interviews and/or semi structured focus group discussion (Riessman, 2005). Narratives are viewed as the social product that is produced by participants in their social, cultural and historical context (Corey, 2009), and therefore revealed a great deal regarding their experiences and their perceptions.

The data to be analysed consisted of four transcribed interviews and detailed notes of 10 in depth interviews, and notes of the focus group discussion of 20 participants. This was done as authentically as possible, taking participant context, larger social discourse and co-creation of meaning into consideration. Narratives is the natural way to enquire of personal experience as Sandelowski (1991) posits that we understand and shape our lives through narratives. Narratives provide a platform for participants to make sense of their experience, and help them make sense of their world (Riessman, 2005), and to convey this sense to the researcher. Using narrative analysis confirms and reinforces the importance of language in constructing reality.

It is also important to note that narrative analysis is not used to extrapolate facts about the world, or to determine truth, but rather to gain better understanding (Richmond, 2002).

The narrative analysis attempts to condense the rich narratives into themes which are then interpreted as understood by the researcher. Themes are valuable in presenting the understanding of human experience as it is lived in its context (Terre Blanche et al., 2006). Participant experiences are not disconnected or isolated, but connected to one another, and therefore themes are present in their narrative recollection of their experiences (Grobler, Schenck, & du Toit, 2003). Themes reveal the shared experiences participants have in common (Grobler et al., 2003), and how participants relate in repetitive patterns to their worlds in different situations and different times (Terre Blanche et al., 2006).

Terre Blanche et al. (2006) indicate three approaches to data in order to identify themes. The approach to the data is significant as it enables the researcher to engage in participant narratives to identify themes: First of all immersion in the data is essential to familiarise oneself with the data (Terre Blanche et al., 2006). Immersion enables the researcher to familiarise herself with the data, and becoming acquainted with the details of the data. Secondly, unpacking the data involves laying out the meanings of the words in the data. Here, thematic similarities and connections are identified (Terre Blanche et al., 2006). Lastly, associating the data with the context in which it was created enables the researcher to grasp the fullness of the meaning of the data (Terre Blanche et al., 2006).

Ten individual interviews and 20 participants in the focus group allowed for repeated patterns to be of significance (Richmond, 2002) as repeated patterns formed themes which interlinked between participants. This showed individual and grouped meanings attached to the experience of the programme.

After the recorded in-depth individual interviews were transcribed, thematic coding took place (only the four interviews which received permission for recording, other interviews consisted of notes). Narratives were read through to become familiar with the data (immersion). Thereafter, each narrative was read through repeatedly until themes were identified (unpacking). The context of the research setting and within which the narratives took place was also considered in the thematic coding process (associating). The themes were written down under “Interview Participant 1”. This was done with all ten individual in-depth interviews. The result was Interview Participant 1 – 10 with summarised themes, and verbatim sentence examples to illustrate themes where applicable. Thereafter, the ten individual collections of themes were compared to identify common themes. The same steps were followed for the focus group, for the data which compiled of notes taken during the discussion, which also included verbatim quotes. Verbatim quotes which captured a striking revelation or concept, or a repetitive theme was written down to present and authenticate the findings.

3.7 Study trustworthiness

In terms of qualitative research, it is more suitable to refer to credibility rather than validity in this study (Terre Blanche et al., 2006). As social constructionism underpins this study, it relies on the researcher’s interpretation of the participants’ narrative to gain understanding, and not on objective measures. Therefore, what is understood and reported by the researcher is the researcher’s interpretation of participant narratives as communicated by the participant. The researcher cannot fully exclude her ideas, influences and assumptions in interpreting data, and this makes the researcher a participant in meaning making and not an objective observer. To compensate for this, the act of interpretation must be accompanied by constant consideration and reflection. This action was practiced throughout the study. To compensate for possible misinterpretation of the narratives, a research assistant also coded themes as an additional

safeguard against bias or misunderstanding. The assistant also served to identify overpowering subjectivity in the analysis as two interpretations are more credible than one.

Reliability also posed a challenge, as participants' narratives are not constant entities, but ever changing, through interaction and meaning making (Becvar & Becvar, 2005). This study aimed at dependability rather than reliability through thick, rich, and detailed descriptions of narratives and interpretations of narratives (Terre Blanche et al., 2006). These narratives were considered and treated as authentic and real experiences as shared by these participants.

Rogers' person-centred approach to interviewing and discussion was employed to aid participants in feeling free to express themselves (Grobler et al., 2003). The presence of the familiar counselling and testing coordinator assisted in participants feeling comfortable and trusting to share real and authentic narratives. Bracketing was used in interpretation of data to increase accuracy. Bracketing implies engaging in the data, of which the second form was useful in terms of revisiting data to reflect on the evolving comprehension of the data and interpretation thereof (Fischer, 2009).

3.8 Ethical considerations

The protection of participant well-being is essential in terms of ethical requirements. Prior to commencement of the research, the aim and purpose and procedures of the study were explained to participants. Participants were made aware that they did not have to reveal any information they did not wish to. Participants were asked to sign a consent form after explaining it to them. Voluntary participation was also explained, and freedom to exit the study at any stage thereof, was guaranteed to participants. Discussions were confidential and anonymous.

The following ethical implications were considered and compensated for:

- **Invasion of privacy:** the researcher ensured participants that they may refuse to answer any question they wish, with no explanation or consequence. Participants were also made aware that they may refuse the audio recordings of the individual in depth interviews if they chose to do so, as with the focus group.
- **Identity:** Participants' identities were protected during individual interviews and the focus group discussion, and participants were also free to join the group under an alias name. Alias names such as "Focus Group Participant 1" were used automatically in interpreting data to protect identity of participants
- **Fear of exposure:** the study was conducted in a neutral environment at the Africa Centre. The study was also closed to new participants who wished to join later or during the discussion, and also closed to any and all outside individuals
- **Comfort level of participants:** participants were informed that they may leave at any stage of the study if they experienced discomfort or confusion
- **Emotional wellbeing:** the Africa Centre counselling and testing coordinator accompanied the entire study, and was available to meet counselling needs during and/or after the study
- **Trust:** the topics of the discussions were private and sensitive and therefore trust was essential in order for open discussion. The counselling and testing coordinator facilitated a trusting relationship between the participants and the researcher, due to her familiarity to participants
- **Autonomy:** Participants are autonomous in the sense that they make decisions regarding themselves. Participant autonomy was respected as participants were free to decide to participate in the study or not, free to decide what information they divulge, and free to make their own decisions during the research, without coercion or influence.

- **Benevolence:** To help participants leave better off than when they arrived, the counselling and testing coordinator offered counselling in the form of de-briefing after the study
- **Informed consent:** the nature, procedure and purpose of the study was explained to all participants, together with the principle of informed consent
- **Appreciation:** the researcher compensated for all travelling costs, in order to prevent participants feeling used. Participants were also reassured that their narratives count and that it was important to the researcher to comprehend what they were experiencing based on genuine care and concern

3.9 Conclusion

Auerswald (1985) posited that we use a set of immanent rules to think by when we define reality, and therefore our epistemology. Hoffman (1985) shared a similar notion regarding the rules we use to make sense of our world. The perspective, or set of rules, for this study enabled the researcher to explore how participants made sense of their world, particularly their experience of participating in a stigma reduction programme. The larger social discourse governing meaning in the lives of participants were revealed, as well as the influence the programme had on shifting these. Social constructionism permitted the researcher to simultaneously explore the lived experiences of participants relating to the programme, and influences on participants' set of rules (Auerswald, 1985) used in making sense of their world. The next chapter presents the researcher's findings of exploring the lived experiences of participants.

CHAPTER 4: FINDINGS

4.1 Introduction

Chapter four presents the findings of exploring personal experiences of participants. The focus group findings are presented separately from the in-depth individual interviews, as different themes emerged from the focus group and the individual in-depth interviews. The findings are presented in the forms of themes which emerged in participant narratives, as interpreted by the researcher. Narratives are participants' accounts of their experiences and constructions of reality, and are therefore, individually true for them (Hoffman, 1985). The themes extracted from the narratives and presented here, portray the researchers understanding of what was being said, in an attempt to present this meaning in the understandable form of themes.

The general finding was that most themes between participants overlapped, which will be discussed in chapter five, as well as themes between the focus group and the individual interviews. The main difference between the individual interviews and the focus group was the tone of their story telling. The focus group atmosphere in conveying their experiences was light hearted and relaxed during the discussion. Conversely, the individual interviews atmosphere was more serious and heavy. The socially constructed realities in which participants lived became apparent, as most participants' experiences were consistent with this larger social discourse.

4.2 Participant background

Background information to participants is presented here to create a more rounded context in which to receive the findings of the narratives. Background information was provided directly by participants throughout the course of the focus group and individual interviews. As participants told of their experiences, background information surfaced. Consulting literature

regarding this population group confirmed what participants revealed regarding their background, as literature reports resonated with the reports of participants.

The majority of participants lived in poor economic conditions with their families (parents, grandparents, siblings). Most of the participants were currently involved in unstable relationships, and most of them indicated that they were unhappy because of their partner's constant infidelity. One participant indicated that she will not get involved with men until she is married (alluding to sexual consummation of marriage). Participants indicated their desire for employment, most hoping for work as a domestic worker, as poverty was rampant in their community.

Participants were from the Hlabisa District, and received education in this community through formal government schooling. Their narratives were indicative of a patriarchal structure within the community and in their homes. They used words like "*tradition*" and "*culture*" to indicate and justify practices such as polygamy and the exclusive traditionally feminine clothing they wear, in the form of dresses. All participants were proficient in English, but some were not fluent, and therefore some narratives took place at a slower pace. Participants were familiar with the Africa Centre because the Africa Centre is physically situated within their community, and many of the community members are employed there. Familiarity with the Africa Centre is also due to the programme, as the programme has been an ongoing initiative. There were indications of friendships between some of the participants, who seemed to have met through the programme. All the participants were unmarried, and had never been married before, and indicated this to be due to the cultural practice of lobola. Participants explained that the practice of lobola, which involved the payment in the form of money or livestock, to their guardian (normally the parents, or if these are absent, the grandparents) in exchange for their hand in marriage. Participants indicated lobola to be costly, and the men's reluctance to pay this large

sum of money in order to get married. Men were reluctant, according to participants, because poverty was widespread and paying lobola would place large financial burdens on these men, and therefore men opted not to enter into marriage.

Statistics South Africa (2004) indicated that KwaZulu-Natal has the largest population per province in South Africa, at 9.4 million people, with 84.9% of this being black African, followed by 8.5% Indian/Asian, 5.1% white and 1.5% coloured. KwaZulu-Natal had an unemployment rate of 28.7% in September 2004, according Statistics South Africa (2004). Females aged 15 to 34 headed most of the households in KwaZulu-Natal at 42.9% (Bradshaw et al., 2003). Baumann (2006) reported that the Zulus in KwaZulu-Natal are some of the poorest people in sub-Saharan Africa, and that 86% of the population is illiterate. The setting in which participants found themselves was characterised by poverty, HIV/AIDS and general despair surrounding their circumstances.

A typical experience of the programme for participants followed the following sequence: participants experienced initial contact with the programme through the home based testing offered by the Africa Centre. After the home based testing the Africa Centre counselled participants, and participants were urged to join the support group made available through the programme. This support group consists of HIV/AIDS positive individuals who get together to discuss their problems and issues around HIV/AIDS, and in doing so offer support to one another. The Africa Centre also encouraged participants to attend workshops offered through the programme. These programmes offer practical information around HIV/AIDS. Most participants in the focus group and individual interviews have encountered the home based testing, and all of the participants attended the workshops and joined the support groups. The support groups are attended on an ongoing basis for ongoing support. This support group was

revealed to be something of a lifeline to participants in their experience of living with HIV/AIDS and coping with stigma.

4.3 Findings

The findings are presented under main theme headings, with sub themes under the relevant headings. The themes present the focus group and the individual interviews respectively, under the relevant theme headings.

Themes identified in the focus group included:

- Desire to preserve social identity
- Facing struggles in coming to terms with the implications of living with HIV/AIDS
- Restored sense of community
- Social influences on programme

Themes identified in the individual in depth interviews:

- Gender inequality as source of stigma and HIV/AIDS infection
- Self in relation to HIV/AIDS and stigma
- Prioritising living with HIV/AIDS
- Empowerment

The findings are presented respectively under themed headings. The findings include an overview of that which was revealed through participant narratives of their experiences. Thereafter examples of participant narratives are presented to substantiate the finding and the theme. Each theme concludes with a summary to outline the main ideas of the theme. The interpretation of the findings are discussed in chapter five.

4.4 Focus Group findings

Table 2: Focus Group themes

Theme	Participants articulating meaning unit
Desire to preserve social identity	2, 4, 5, 7, 8, 10, 12, 13, 16, 18, 19 11/20 participants articulated around this theme
Facing struggles in coming to terms with the implications of living with HIV/AIDS	2, 3, 5, 6, 7, 10, 13, 18, 19, 20 10/20 participants articulated around this theme
Restored sense of community	1, 3, 5, 6, 7, 8, 9, 10, 12, 13, 14, 18, 19, 20 14/20 participants articulated around this theme
Social influence on programme	2, 3, 4, 6, 7, 8, 10, 14, 16, 18, 19 11/20 participants articulated around this theme

4.4.1 Focus Group finding: *Desire to preserve social identity*

4.4.1.1 Overview

During the focus group discussion participants were asked by the researcher what their experiences were regarding HIV/AIDS-related stigma. Thereafter, participants were asked to consider possible influences that the programme had on them personally regarding experiences related to stigma. Participants used the word stigma to refer to enacted stigma, and the researcher applied this understanding during the discussion.

The discussion revealed that participants had experienced enacted stigma due to the disclosure of their status, in that when their status became known, stigma was the usual reaction from the

person they disclosed to. Participants also witnessed fellow community members being stigmatised when that person was identified as being associated with HIV/AIDS, especially females. Participants therefore linked stigma directly to public knowledge of one's status. Consequently, disclosure of their HIV status was avoided due to this experience, and this natural deduction.

Participants believed that when they kept their status private, that they themselves could not be linked to HIV/AIDS, thus avoiding stigmatisation. Their social identity disconnected from HIV/AIDS would consequently remain intact. The urgent sense of the importance of not being stigmatised was expressed throughout the discussion. Avoiding stigma appeared to be significant because of the unwanted negative experience of being stigmatised. Stigma attached to HIV/AIDS also damages the social identity of participants, which is essential to much desired social acceptance.

The experience of participating in the programme has enabled participants to achieve their goal of avoiding stigma through the privacy of testing through the programme's home based testing initiative. This initiative aims to reduce the stigma barrier to testing, so that individuals are able to know their status, which may potentially enable them to receive medical treatment and may also enable them to take preventative measures in the form of condom use.

Participants therefore articulated that the programme enabled them to test in private, thereby avoiding stigma attached to testing. This aspect of the programme's assistance in testing in private has inadvertently confirmed participants' deduction that keeping one's status undisclosed helps to avoid enacted stigma, and has thus reinforced this behaviour of non-disclosure. Participants indicated that they felt that stigma was "*lowered*" through the home based testing, when stigma was essentially circumvented through the home based testing.

4.4.1.2 Participant narratives

Throughout the focus group discussion, responses to the question were laced with experiences of enacted stigma, specifically linked to disclosure of HIV status. Eleven focus groups participants participated in the discussion contributing to this theme. Participants shared experiences, specifically in their community setting, which they perceived to be experiences of enacted stigma. Participants shared how they were treated with enacted stigma by friends, partners, and even family members, due to perceived HIV status. Participants expressed personal experiences with tones of contempt and hurt at their experiences. Participants shared experiences of being called derogatory names, being rejected and even abandoned, all the while witnessing the demise of their social identity coupled with their diminishing social good standing and acceptance.

Participants revealed that the programme enabled them to keep their testing private, and consequently they were able to keep their status private if they chose to. Therefore, the programme has assisted participants in avoiding stigma related to testing, by creating an environment which assured privacy in testing. This has helped them to be in control of who they disclose to, which has helped them manage stigma so to speak, and experience reduced instances of stigma. For other participants, problematic circumstances arose when, at the prompting of their programme counsellors, participants disclosed their status to family members and/or partners and/or close friends. After disclosure they experienced enacted stigma, and therefore have opted for future non-disclosure of their status, to avoid experiences of enacted stigma.

Within the focus group, participants agreed with one another that the home based testing of the programme reduced stigma in their community, because nobody is aware that testing for HIV/AIDS has taken place. Focus Group Participant 5 explained that she feels this has “lowered” stigma in her community, because people are able to test in the privacy of their home and that this privacy is conducive to creating an environment in which people to feel safe to test, as “nobody sees the testing”. She explained that if nobody is aware that testing has taken place, stigma will not be experienced. According to her this has reduced stigma. She added that this has caused more people to get tested than before. She explained that, in her opinion it is important to reduce stigma, as stigma places negativity on the person receiving it, and this experience is unpleasant.

Likewise, Focus Group Participant 7 recalled how she too felt “safe” to test with the programme’s home based testing, as she felt assured of privacy. Thereafter, she decided to confide in her family and share her status with them, to which they reacted with shock and disbelief. She added that things have not been the same since, as she believes they perceive her to be different from them. She explained that this has been very difficult for her, as she relies and depends on them.

Focus Group Participant 8 also added that the home based testing helped her to protect the privacy of her status, and that this is very important in order to keep functioning in their close knit community. For this reason she believes the home based testing initiative has had a positive impact on her and her community.

An important talking point in the focus group was the experience of stigma, as participants expressed great contempt for enacted stigma, and therefore avoiding it was extremely important to them. Focus Group participants 4, 8 and 10 shared that they had intentions to test in the past, as they suspected possible infection, but they were too afraid of experiencing stigma often

coupled with testing in public health care facilities. Therefore, they did not test. The home based testing changed this for them and they have tested since.

Focus Group Participant 2 articulated quite passionately about enacted stigma as she expressed that experiencing stigma is so unpleasant that she believes anyone would want to avoid it. She expressed that the derogatory names that people call those with HIV/AIDS, the rejection from one's peers and the gossip was especially unpleasant. She reasoned that to protect herself against the negative experiences of enacted stigma, it is wise to keep her status private. There was general agreement around this point. Although the programme's counsellors encouraged participants to disclose their status, participants said their experiences discourage them from doing so. Counsellors encourage participants to disclose as part of instilling preventative behaviours, rather than exposing them to enacted stigma, according to the counselling and testing coordinator. Focus Group Participant 7 expressed that she does not agree with the counsellors in the programme regarding disclosing their status, as only "*bad things follow*" when adhering to this advice. She expressed that she walks around with constant fear of people finding out that she is living with HIV/AIDS. Although she has told her family, she has deemed it wise to not disclose to anyone other than her immediate family.

Likewise, Focus Group Participant 4 expressed disagreement with the programme encouraging disclosure of status, and expressed her belief that even counsellors would keep their status secret, and believes that they do this already. She believes that there is too much risk in disclosing one's status in terms of outside reactions, loss of friends and gossip. Focus Group Participants 12, 16, 18 and 19 also expressed that they disagree with the programme counsellor's promptings to disclose their status, as they perceived that this will only make an already bad situation worse. Focus Group Participants 12 and 18 did agree, however, that it is important to tell one's family so that they can offer support and help, but disclosing to anyone

else was not something they would consider. Focus Group Participant 13 revealed that she did listen to her counsellor regarding disclosure, but that she was “*punished*” for this decision when people she disclosed to referred to her as “*OMO*”. She added that she will not make the mistake of disclosing again. She revealed that she disclosed to her close friends from school first, and this information was not kept confidential, and now she fears that more and more people will find out. She explained that this betrayal from her friends in revealing her secret has discouraged her from disclosing to anyone else.

4.4.1.3 Summary

The overall feel of this particular theme was propelled by brief, but heated recollections of experiences of enacted stigma, whilst at the same time justifying actions of non-disclosure. The importance of protecting themselves from enacted stigma was felt throughout the discussion, as participants experienced social rejection when associated with HIV/AIDS. Maintaining a social identity dissociated from HIV/AIDS was imperative for good standing and acceptance. This had substantial value for participants as social beings. The meaning of the programme’s home based testing was especially significant to participants, as it offered a means to keep a desirable social identity intact, through avoiding an association to HIV/AIDS that is often coupled with testing for HIV/AIDS. This demonstrated and confirmed the perceived beneficial effect of confidentiality regarding HIV/AIDS status for participants.

4.4.2 *Focus Group finding: Facing struggles in coming to terms with the implications of living with HIV/AIDS*

4.4.2.1 Overview

Within the focus group setting participants were asked what stigma factors played an influential role in their experience of living with HIV/AIDS, and how the programme influenced these

factors. Ten focus group participants indicated that stigma factors impact on important aspects in living with HIV/AIDS. Participants shared that stigma plays a role in their sexual activities, in that they are nervous of insisting on condom use, and that stigma plays a role in their social standing in their community (as overlapping with the above theme of desire to preserve social identity). But the most significant experiences shared were the influence of stigma on adherence to antiretroviral treatment. Participants indicated that this impacts on their everyday living with HIV/AIDS.

Participant narratives revealed that the fear of stigma has induced a reluctance in taking ARV treatment. Participants indicated that they are aware of the importance of taking ARV drugs as treatment for HIV/AIDS, and that taking ARV treatment is an important part of living with HIV/AIDS, but that stigma impacts on this awareness. They indicated that this is knowledge that they can understand, but stigma discourages them from applying this knowledge and acting on it.

The reluctance to take ARV treatment is mainly attributed to the side effects of ARV treatment. There are side effects such as diarrhoea, nausea, vomiting, and skin ailments, but the main side effect that is of concern to participants is lipodystrophy. This involves unwanted fat distribution in the body, leaving legs and buttocks with little fat, leading to a male-like physique. The side effects of ARV treatment have personal and cultural implications for participants, which influence their decision making regarding taking ARV treatment. The personal implication is that the visible side effects of taking ARV therapy reveals that one is taking ARV treatment, and this is associated with a positive HIV status (this is related to fear of one's status becoming known). The cultural implication is that the side effects of the ARV treatment include undesirable masculine features in the female body due to fat loss and fat distribution. This is incompatible with cultural expectations of the desirable feminine physique, and also hampers

the ability to attract a husband, as the cultural prescription of a desirable woman is not muscular.

Participants were in agreement that they feared this side effect as it may rob them of their femininity, but ultimately realised that they could not risk dying to avoid a possible side effect. Participants shared how the programme has helped them to realise that their lives are more important than ARV treatment side effects, and have therefore made the decision to comply with the treatment.

The support group assisted greatly in shifting perspectives regarding treatment compliance, as participants witnessed other members of the programme support group living on ARV treatment and still retaining an acceptable feminine physique. According to these participants, this put them at ease and encouraged them to start on ARV treatment. Therefore, the support group influenced participants to take ARV treatment because participants witnessed others doing the same, and this created a break in the barrier. The programme therefore assisted participants in coming to terms with the implications of living with HIV/AIDS in terms of adhering to ARV treatment, despite possible stigma.

4.4.2.2 Participant narratives

Focus Group Participant 20 expressed how the effects and fear of stigma affect them in many areas of their lives. For her specifically, the fear of being stigmatised urges her to go to great lengths to keep the fact that she is living with HIV/AIDS private. She recalls how she felt trapped in the difficult decision of taking ARV treatment. She expressed anxiety related to taking ARV treatment, because she feared the visibility of the side effects in her body. She explained her struggling with this decision, but that her counsellor at the programme finally persuaded her, pointing out two choices: either risk stigma associated with ARV treatment or

death. The counsellor added that if she does not take the treatment she will begin to waste away, which will reveal her HIV status regardless, so she may as well take the treatment. She revealed that coming face to face with these two choices was an awakening experience for her.

Similarly, Focus Group Participant 3 shared her belief that ARV treatment reveals one's status. She substantiated this by adding that she is able to identify fellow community members, mainly females, who are on ARV treatment, by their physical appearance. She revealed that this also influenced her decision to start on ARV treatment, due to the fear of exhibiting side effects in her body. She realised that she must shift her focus past this and focus on her health, and this means complying with ARV treatment. She revealed that it has been easier than she expected, as her family help her to adhere to treatment requirements and regimes. In agreement with the discussion, Focus Group Participants 2 and 10 also briefly added that stigma was a factor in not taking ARV treatment for them as well, and that they live with the fear of being stigmatised, daily.

Focus Group Participant 6 revealed that taking ARV treatment is more challenging for women than men. She explained that she fears that as soon as she starts on the ARV treatment she will lose her feminine features and appear "*too strong*". She explained that a nurse told her that the male features that she was enquiring about are due to the side effects of the ARV treatment in that it gives the body a muscular physique, especially the legs. Her fears revealed general cultural expectations of what women in her community are expected look like, and the importance of conforming to this expectation to attract a boyfriend/ husband. She revealed that a "*real*" woman looks well rounded and certainly not muscular or possessing any male features. She explained how this clashed with what she wants to like.

Focus Group Participant 5 agreed with this, and explained that women on ARV treatment who have these "*strong legs*" receive looks of rejection from the community. She continued that it

is always important to conform to expectations, especially to make one's partner "*happy*". She revealed that physical appearance is important in her community, she believes it can "*get you places*" and it can also "*get you the good husband*". Compromising this with ARV treatment perplexed her constantly.

Focus Group Participant 13 also nodded in agreement with the importance and desire to conform to social expectations, as this ensures acceptance within their cultural system. Likewise, she revealed this expectation to be associated with their physical appearances, and taking ARV treatment may change their appearances. She expressed her fears that this is a tremendous risk to take, but a risk that must be taken.

Focus Group Participant 2 explained that she also feared the possibility of looking manly, but she has realised that this is a chance she must take if she wants to survive. She indicated that the programme brought her to the realisation that she must decide between dying from HIV/AIDS and living on ARV treatment with its consequences. She also realised that the "*manly*" side effects are not guaranteed, and that the chance is worth taking.

Focus Group Participants 5 and 18 expressed similar sentiments on the importance of taking ARV therapy over the concern for their appearances. Focus Group Participant 18 expressed: "*How can your looks help you when you are dead from HIV?*" Focus Group Participant 19 agreed with this and revealed her awareness that her health was more important than her looks, but when faced with stigma her reasoning became blurred. Most participants seemed to agree with this realisation.

When questioned about how participants came to the decision to comply with ARV treatment despite their fears, participants revealed that the programme has influenced them through the

support group, and through reminding them that ARV treatment is important if they want to live a functional life.

Focus Group Participant 7 recalled specifically how her counsellor reminded her repeatedly that death is imminent if she chooses to reject ARV treatment, and how she did not heed this warning initially. She later realised that she is more fearful of dying than she is of taking ARV treatment, and has since been on treatment. She added that she witnessed many people in the programme's support group who are taking ARV treatment and who have still retained their original feminine physique, and this set her at ease. She added that she also cannot ignore those who are suffering the unwanted side effects. She expressed sympathy toward these women and revealed that she hopes that she does not suffer a similar fate.

Without the much needed medical intervention in the form of ARV treatment, participants stand little chance in the fight against HIV/AIDS, and being reminded of this on a constant basis through the programme counsellors has helped some participants to overcome their fears, and comply with the therapy. In short, participants' perspectives were influenced to value their lives over their physical appearances. The programme support group succeeded in escalating the importance of the ARV treatment over fear of stigma, which has proved to be effective according to participant narratives.

4.4.2.3 Summary

Within this theme participants revealed the far reaching impact of fear of stigma. Participants integrated this fear into their daily experience of living with HIV/AIDS, by revealing how this fear of stigma impacted their decision to take ARV treatment, potentially threatening their lives. The programme helped participants to accept the possibility of stigma, whilst emphasising the need to comply with ARV treatment. Coming to terms with the need for ARV

treatment against the possibility of their status becoming known is an ongoing challenge for participants, and also a source of anxiety. Participants demonstrated resilience in adapting their understanding of what is important to support a healthy future for themselves, largely due to the influence of participating in the programme.

4.4.3 Focus Group finding: Restored sense of community

4.4.3.1 Overview

Participants were asked to share how the experience of the programme influenced their daily lives. Participants began to share narratives of a restored sense of community in their daily lives. They shared that the programme restored this, after stigma had robbed them of it. Narratives revealed a sense of community between participants themselves, and between participants and the programme, with a positive familiar relationship between the parties. Within the theme of community lie three sub headings that knit together to form the umbrella theme of community. The sub headings include support, acceptance and solidarity, each overlapping the other.

Participants indicated that the programme has provided them with much needed support in the form of the support group within the programme. It is here where they also experienced acceptance in spite of their status, and were able to form a sense of solidarity with the members of the support group.

Other experiences such as caring programme workers, and fear of coming to the Africa Centre for counselling or support groups, were isolated, with the community theme being a constant. Participants believe that their lives are more satisfying due to this restored sense of community. This theme is therefore a theme of recreating and discovering again what was believed to be lost, and the human trajectory toward togetherness, which appears lost through stigma and

division. Here the obstacle (stigma) to experiencing a sense of community is bypassed by creating a new sense of community in which solidarity, support and acceptance is built around their common identity as HIV/AIDS sufferers.

4.4.3.2 Participant narratives

4.4.3.2.1 Narratives of the sub theme support

Within the stigma reduction programme there are workshops, support groups and counselling, which is freely available to participants. A sense of the support group being therapeutic was revealed through narratives. The commonality in positive HIV statuses between members of the programme support group, revived a sense of community between participants, where they previously experienced isolation and division. Participants therefore felt that their status and community members' reaction, in the form of stigma, isolated them from the community. Because the support group was comprised of mainly HIV positive members, stigma reactions were absent. Therefore, their HIV status did not create division amongst them as with the community. Within the support group members hold discussions around HIV/AIDS, their status and their experiences in general, which has evolved into an ongoing support system for its members. Participants indicated that this platform for discussion has helped them face and cope with many problems related to HIV/AIDS and stigma.

Focus Group Participant 3 revealed that it was easier to openly talk about HIV/AIDS in the programme support group. She expressed that talking about her problem of HIV/AIDS to other people in a group has helped her to cope with HIV/AIDS in her own life. She recalled that prior to joining the support group, she had concerns about being HIV positive and death associated with HIV/AIDS. She revealed the therapeutic effect of talking, and how this act soothed her

fears. She added that she is not ignorant in that she still faces struggles, but feels she is better able to cope with these struggles with the help of the support group.

Focus Group Participant 5 joined in and agreed that she had serious concerns about her condition. She feared that she would die before long, and revealed that she contemplated suicide. She expressed that if she was going to “*die anyway*”, she may be able to spare herself the shame of an HIV/AIDS death if she commits suicide. Both participants recalled how frightening it was because they felt alone and isolated, and were afraid to open up to anyone for help.

There was a general agreement that HIV/AIDS made them feel isolated from their family and friends, and also how they contemplated suicide as an option. Participants revealed an inability to cope with their situation due to the isolation, and perceived suicide as a solution. Focus Group Participant 20 revealed that this is a common reaction to finding out one’s status due to accompanied shock and fear. Focus Group Participants 6 added that she is also aware that suicide is a common reaction to finding out one’s status, and according to her, especially young people feel their only option is suicide. She perceived this mainly to be due to the sense of total loss and disconnectedness from much needed support systems. She also perceived that participating in the programme’s support group will help such individuals to realise that there is a better way to cope with HIV/AIDS, as it did for her.

Focus Group Participant 9 added that things changed for her when she joined the programme’s support group as she realised that she was not alone, or the only one going through this experience: “*I see that I’m not alone in this struggle*”; she explained how this helped her to feel like she was no longer isolated. She added that it has helped her to not think about suicide anymore, she explained that she went from being anxious about her status and contemplating suicide, to talking openly about it within the support group. Consequently she feels encouraged

about her future. Likewise, Focus Group Participants 5 and 7 added that they also experienced this sequence of emotions, in that they went from feeling fear and isolation to feeling supported.

When asked how being in the support group influenced their experience regarding their feelings of being isolated from their community and contemplating suicide, participants pointed to the value of the support group. They expressed that it has helped them cope with living with HIV/AIDS through discussions, which offered support and understanding. Focus Group Participant 8 explained that outside of the context of the programme her community do not talk about HIV/AIDS. She described this silence to be problematic, as she perceived talking to be beneficial in surviving negative experiences, and to finding solutions to problems. Therefore, not having anyone to talk to was unsettling for her, which led to feelings of disconnectedness and isolation. She revealed that even though everybody knows HIV/AIDS is there, it is still a taboo topic which is not to be discussed.

Focus Group Participant 9 and 18 added that they had questions about HIV/AIDS, but the silence around HIV/AIDS prevented them from getting answers. They both indicated fear of what was happening to them concerning their status, mainly because they did not understand it. Focus Group Participant 12 added that when she joined the support group, she had less fears because she *“could see”* that she wasn't alone. Focus Group Participant 3 revealed a personal experience to illustrate that the experience of the support in this programme was a positive experience and that it changed her life: *“My life at home turned bad after I started to get sick. My family treated me bad, and I feel like they were strangers to me. I had nobody to help me or to talk”*. She went on to explain how having people to talk to helped her feel connected again, and feel like she is supported and has people to count on: *“this thing has helped me, you can see that I can smile now”*.

4.4.3.2.2 Narratives of the sub theme acceptance

Participant narratives indicated an absence of enacted stigma within their experiences of the programme itself, in dealings with programme staff members and other programme participants. However, enacted stigma was still present in their interactions with their community and families, according to their narratives. The absence of enacted stigma inside the programme was welcomed as acceptance, and created narratives with safe haven undertones.

Participants shared experiences of stigma from their community members, which was perceived as personal rejection. Participants especially mentioned names that were imposed upon them in their narratives of their community's rejection of them. They expressed heated contempt for two of the frequently used names, "*OMO*" and "*three legged pot*". Some of the participants had experienced either of these names being forced upon them by people aware of their HIV status, or people using three fingers when referring to participants in general conversation.

Focus Group Participant 10 specifically recalled being referred to by the name "*OMO*". She explained that this is because "*OMO*", the washing powder, has three letters and therefore refers to HIV, which also has three letters. She revealed that people do not like saying the word HIV, and therefore create and use synonyms for it.

Other participants in the group began to speak loudly and demonstrated that people with HIV/AIDS are identified in their community by pointing three fingers at them. Participants demonstrated this sign holding the index, middle and ring finger together. The contempt for this labelling was obvious within the discussion, as voices were raised and participants began

speaking simultaneously with clear emotion in reaction to this personal rejection, perceived as an attack.

Focus Group Participant 13 experienced rejection from her family when she informed them of her HIV status. She revealed that her family was reluctant to use the same utensils as she does, and that because of this she believes they regard her as a “*bad person*”. She expressed how pleasant it was when she was treated with acceptance within the programme dealings, especially within the support group.

The contrast of rejection outside the programme, and acceptance inside was also reiterated by Focus Group Participant 1 as she added to Focus Group Participant 13’s experience of rejection from her family. She recalled that since she revealed her status, her home environment has been tense. She believes that consequently she has lost the acceptance of her family. She expressed that she regards the members of the support group as her friends, because they accept her. She expressed hope that in time her family will also accept her in this way.

4.4.3.2.3 Narratives of the sub theme solidarity

Participants expressed a familiar and a togetherness bond with each other. When speaking within the focus group, narratives largely contained “*we*” rather than “*I*”. When referring to “*we*” hands would touch their chests and eyes would glide over the group, demonstrating the relationship and understanding between them. Participants expressed that discussions with each other in the programme helped them to accept their status, and they feel like they have a social connectedness again. They expressed that they have regained the social part of their lives again.

Focus Group Participant 7 expressed that talking about their similar struggles around living with HIV/AIDS and dealing with stigma has helped them to unite with each other, whereas she

believes silence (as in the community) separates them by means of stigma. Focus Group Participants 8 and 18 added that the fellowship between them is due to their common HIV status; an element causing discord in other contexts.

Focus Group Participant 14 also identified that she had friendships inside the programme support group that were absent outside of the programme. She stressed the relief of having friends again, as she placed great value on her friendships. She expressed the notion of not being able to live without friends. Focus Group Participant 16 indicated that the support group has been the source of new friends for many of them, with Focus Group Participant 19 adding that this is because they are all “*the same*” within the group, with no HIV status or stigma dividing them from one another. The support group within the programme has therefore opened up a gateway to new unions and fellowship, which participants perceived to be a source of strength.

4.4.3.3 Summary

The theme of restored community highlighted the need of participants to remain socially connected and accepted. Stigma separated participants from their community, which was indicated through a strong sense of “*us*” and “*them*” narratives within focus group discussion, consequently instilling the sense of solidarity between participants within the focus group. The programme’s support group has therefore restored something that participants thought to be lost, and at the same time assisted participants in positively coping with their circumstances surrounding a positive status.

4.4.4 *Focus Group finding: Social influence on programme*

4.4.4.1 Overview

During the focus group participants expressed the potential of the programme to benefit others, as it had benefitted them. However, participants indicated tradition as governing an unwillingness within their community to participate in the programme.

Participant narratives were indicative of a strong sense of tradition, and the importance placed on this way of being. Participants revealed traditional dress code as playing an influential role, and impeding upon the support or participation of the programme. Traditional dress code for women in this community is limited to skirts and dresses, specifically excluding leggings or pants. Conversely, programme staff uniforms include leggings or pants, and therefore violate this dress code. Participants indicate this to be a barrier in reaching, especially the traditional and older members of their community.

Participants did not provide explanations for these parameters placed on women's dress code, but rather attributed it to a sign of respect. Their deep consideration when questioned about this, indicated an unquestioned acceptance of this tradition. Participants were able to identify this tradition as an influential factor, but did not assign a positive or negative value to it for them personally. This was helpful feedback, as it identified a possible barrier to receptivity in the target population.

4.4.4.2 Participant narratives

Participants were asked around their experiences of the stigma reduction programme, specifically if it was perceived to be impacting their community. Participants shared that there are members being impacted through the programme's testing, counselling, support group and

information around HIV/AIDS. Eleven participants shared that although community members are being impacted, there are some that are not being reached by the programme. They revealed that the more traditional members of their community do not “*believe*” in the programme, mainly due to its manner of presentation.

Further probing revealed that not observing traditional dress code, as with the Africa Centre staff, was interpreted as disrespect to men and to the older community members. This perceived disrespect overshadows the programme with lack of trust and lack of credibility. Focus Group Participant 14 explained that her own family is reluctant to participate in the programme. She explained that an environment in which females dress in leggings or pants is perceived as disrespectful to many community members, and will therefore be unpleasant for them to be present in such an environment. When asked why this is so, she shrugged her shoulders and replied that it has always “*been their way*”.

Focus Group Participant 2 shared a similar sentiment in that she has confidence in this programme and the good it is able to do through information. She expressed an awareness that it does not penetrate into her community due to the way the programme “*comes to you*”, referring to the programme staff violating traditional dress code. She said for women in this culture to show respect to males, which was very important, they had to wear dresses or skirts. This adherence to dress code was therefore a sign of respect, according to her.

Focus Group Participant 4 added that this causes the more traditional members of their community to assume the entire programme is bad and disrespectful because of this one element. She perceives this to be a loss, and preventing her community from “*moving forward*”.

It became clear that this was an important theme in participants' community, and indicative of the importance of conformity if one is to be accepted. Conformity was also important to participants personally, as Focus Group Participants 8, 10, 16 and 18 added that they place great importance on conforming and showing respect, and therefore they themselves do not wear unacceptable clothing for women. They went as far as admitting that they do not, nor have they ever, owned a pair of leggings or pants. They also did not consider this to be a restriction or a "*bad thing*", it was just accepted as "*decent*" behaviour.

Therefore, although conforming was important to participants, they were able to move past this barrier in order to benefit from the programme. Focus Group Participants 3, 6, 7 and 19 admitted that this barrier made it more difficult for them to attend the programme, not because they experience the programme as being disrespectful, but because they feared that their participation in this programme will in itself be interpreted as an act of disrespect by their families. They reasoned that for them to participate in the programme is the same as them agreeing with the dress code of programme workers, and therefore agreeing with females "*disrespecting*" their people. But they admitted that because quite a few people participate in this programme it made them feel safe to also participate. They also admitted that they had little choice but to participate, as there were no other options left for them in terms of getting help regarding HIV/AIDS.

4.4.4.3 Summary

Traditional ways of being within this community are important, and adherence to these ways played a large role in the receptiveness of the programme in reaching all of the community members. Participants realised that little that was offered by this programme to the more tradition-bound members of the community would be easily accepted. They admitted that only

when people become desperate in their struggle with HIV/AIDS will the programme be their last resort.

4.5 Individual Interview findings

Table 3: Individual Interview themes

Theme	Participants articulating meaning unit
Gender inequality as source of stigma and HIV/AIDS infection	<p>2, 3, 5, 6, 7, 9, 10</p> <p>7/10 participants articulated around this theme</p>
Self in relation to HIV/AIDS and stigma	<p>1, 2, 3, 4, 5, 6, 7, 9, 10</p> <p>9/10 participants articulated around this theme</p>
Prioritising living with HIV/AIDS and stigma	<p>1, 2, 3, 4, 5, 9, 10</p> <p>7/10 participants articulated around this theme</p>
Empowerment	<p>1, 2, 3, 4, 5, 6, 7, 8, 9</p> <p>9/10 participants articulated around this theme</p>

4.5.1 Individual Interview finding: Gender inequality as source of stigma and HIV/AIDS infection

4.5.1.1 Overview

Within the individual interviews participants were asked individually about the experience of being a female living with HIV/AIDS, participating in a stigma reduction programme. Participants' narratives were indicative of the larger social discourse of gender's influence in this rural setting.

This setting comprised of traditional Zulu homesteads, and traditional Zulu patriarchal hierarchy systems of male leaders, in the form of Kings, Chiefs and Indunas. Narratives indicated this discourse as influencing their behaviours, contributing to their infection and playing a role in stigma, as they perceive stigma to be more focussed on women than on men. Participants therefore attributed these experiences to being female in this patriarchal setting of deeply rooted unequal social standing, compared to their male counterparts. Participants agreed that the programme has helped them on many levels, but can do nothing for their social standing in the community as subservient females.

4.5.1.2 Participant narratives

In their narratives, seven participants referred to their unequal social standing as females within their community, and the enormous role this plays in terms of living with HIV/AIDS and facing stigma. Participants specifically referred to the impact of this on their personal romantic relationships. Seven participants expressed this inequality in their relationships with their partners, in which they are treated unfairly, have little say in the relationship dynamics and their forced need for a partner for economic support.

All seven of the participants contributing to this theme attributed their infection to their adulterous partners, as polygamy is a common male practice in this context. They revealed that

room for negotiation within the sexual context of their relationships would allow for protection against infection. When asked how this could be achieved, participants alluded to condom use, because their partners are “*sleeping around*” and thereby transmitting HIV/AIDS. But, currently their position in their relationships does not allow the negotiation of condom use. Negotiation around polygamy versus monogamy appears limited as well.

Interview Participant 2 revealed that being a woman in this community, especially one living with HIV/AIDS, is a disadvantage. She reported that this disadvantage has contributed to her role as scapegoat for people’s “*sins*”. She added that when things go wrong in her own family, for example when her brother got dismissed from his work due to intoxication on duty, her grandmother blamed her. Her grandmother believes that she has brought a curse on the family with her HIV status and perceived sexual transgressions. She made reference to similar examples in which she is blamed for general misfortune and even spiritual “*bad luck*”. Her use of the word “*blame*” was indicative of her belief that she was not the real cause of these problems. Further discussion also revealed that she perceives her femaleness to be a disadvantage in her personal romantic relationships. Here, she reiterated the vulnerability of being female, in that her partner occasionally assaults her when he is angry or intoxicated, because “*he can*”.

Interview Participant 3 articulated a similar perception of women in relationships. She expressed that being female means being at risk, especially in sexual relationships. She shared that being female implies an unspoken expectation of sexual favours or sexual engagements. She understood it as a role to be fulfilled: “*When your man wants things...you know those things... you have to give it, how can you say no? The thing is you can’t say no. Many times I want to just say no to him, maybe I’m angry at him, but he always gets his way*”. When asked to elaborate on what this means she continued: “*If you don’t want to have, you know, sex with*

him he can get angry, sometimes it can get bad, maybe he can hit you. This thing is for the women to give men what they want, you know with sex. I think it's always for the woman to please that man, so he can be pleased if he gets what he wants". This notion of the male partner's sexual desires being fulfilled at will by the female with little choice, or at least knowledge of a choice or negotiation, appeared to be an unspoken agreement amongst couples as Interview Participant 3 continued: *"But it's not bad all the time, this is how things go with us."* She articulated a similar notion relating to their forced sexual performance in their relationship settings: *"...you must just do it, just perform. He can get disappointed if you say no, and he can go somewhere else for the same things".*

This absence of freedom to choose to engage or not to engage in sexual activities with their partners was where participants felt they were at their most vulnerable to infection. According to participants, in the midst of their surrender to their *"feelings"* or urges, and the desires of their partners, they were aware of the risk they were taking in engaging with a partner who they either knew, or strongly suspected, of being unfaithful. The researcher enquired about condom use initiated by participants, to which participants explained that negotiating for condom use is unlikely to be accepted coming from a female. Negotiation for condom use, according to participants, was therefore not permitted within these sometimes forced sexual activities, as recalled by Interview Participant 7: *"No, men don't like condoms, I want him to use it, but he can't enjoy it, so he tells me if he's not enjoying it here with me, how can he stay with me? This hurts me because I know he has already been with other women so I'm in this danger for HIV... and I'm thinking it's better to give him his way, you know, I can lose him to some other woman".* It appeared important not to lose a partner to another woman, and Interview Participant 7 therefore justified her acceptance of her partner's infidelity and forced sexual activities by this factor. She revealed that she feared losing him, and therefore she did what was necessary to keep him.

Interview Participant 9 revealed that life as a woman is challenging in her community due to the manner in which she is treated by men. She revealed that she contemplated if men even really like women, because to her, it appears as though men just want to use women, and then “go be” with their male friends. She shared that she perceived this to be unfair because men “get away” with a lot more than women do, and that women get blamed more than men. She explained that most men “get away” with infidelity because it is common practice, but if a woman is caught cheating she is severely punished. She believes that these double standards are responsible for her HIV/AIDS status: *“To be women...this thing is not easy. Even now with HIV it makes it difficult because it causes me to struggle...My life is difficult in this place. The men, it’s easy for them, they don’t need us, but they want us for one thing. That is how I have HIV...I can see that for men it is easy, they just carry on. But it is not easy to be a woman”*. She further indicated that she feels it is unfair that men get away with this, and do not seem to suffer the same consequences as women: *“I know I got this HIV because he is not faithful. But I can see that I am the one suffering, and not him! He is not having this trouble, he is not treated badly, he is just carrying on. Eh! That is wrong...you know, even his mother, she says to him I am the bad one, but I can see she knows about all his women. So I’m asking myself, why I am I the bad one? Is it not your son who is bad?”*

It appears that her boyfriend is not displaying signs or symptoms of HIV/AIDS, and therefore the participant believes he has escaped HIV/AIDS somehow, maybe simply because he is male. She indicated that she has broken off their relationship after she got infected, but has gone back to him again, and then broken off the relationship again and so forth. She indicated that her partner’s mother interferes with their relationship, and she suspects that his mother may know of her status, and is trying to keep her son from being in a relationship with her. She felt resentment toward her partner’s mother, because she believed that his mother is aware of her son’s infidelity and “sleeping around” but is still blaming her for all the trouble in her son’s

life. The researcher understood the situation to be that her partner has not been for testing, but that he suspects her to be infected, as his mother does. Despite this, their unstable relationship remain ongoing. This unstable relationship indicates that the programme has not had an influence on this participant's choice of involvement in the setting that the participant perceives to have infected her. The source of this decision remains the larger social discourse around gender inequality, as the same dynamics are still at play, manifesting in repeated patterns of self-destructive behaviour.

Likewise, Interview Participant 10 recalled an experience of inequality within the relationship dynamic. She reported a vulnerability to being taken advantage of, due to the economic position men are in, compared to women. She perceived men to be better off economically, and to use this advantage to manipulate women, and women reluctantly comply: *"When you are hungry or have nothing it doesn't matter what you allow. The men know this and use me. Men have everything, women have nothing"*. The researcher enquired if she correctly understood what was being said, by asking if poverty plays a role in contributing to this inequality dynamic. The participant explained that although it is common for women to be subservient to men, it seems exacerbated when poverty is involved. She perceives this to position men in even greater power roles, and to exert this over women: *"Being so poor can make you do things, you are just surviving, so you don't always think right. Sometimes there are lots of days with no food in the house...it's desperate. The men, they use this, they can make you promises to give you money or things for sleeping with him, but after he is finished he forgets his promises. That is how you can feel used, and then you can still be hungry"*.

She indicated her belief that nothing can change her social standing, but that employment would contribute to alleviating sexual exchanges for economic rewards. Therefore as long as

there is poverty women will keep getting infected by their partners, and as long as the inequality amongst men and women remain infection will continue likewise.

Interview Participant 5 also expressed her experience of being an HIV/AIDS positive female as unfair and unequal to that of men, especially in her community. She perceives the circumstances of women to be far worse than that of men, in that more women suffer from HIV/AIDS, more women suffer from poverty and more women are stigmatised than men. She ended by stating that she believes that there is very little hope to alleviate this inequality with *“nobody to help me”*.

Although the programme created a platform for women to share their struggles within the support group, it did not alleviate their unequal status within their community setting, and the larger social discourse around this remained unchanged. Interview Participant 6 expressed that the support group discussions have been a form of a coping mechanism, but that talking has not changed her situation.

4.5.1.3 Summary

The experience of being a female living with HIV/AIDS in this rural setting was a disheartening story to hear, and sensations of hopelessness were overwhelming when these stories were shared. The larger governing authority of gender discourse appeared untouchable in this setting. Participants related their HIV infection and being stigmatised as being contingent upon their femaleness, and for this reason felt the programme had little to no power in improving their circumstances or experiences. Participants did however, identify the value of the programme support group in assisting them in coping with their experiences.

The gender issue was therefore related to the unequal status of women in their community structure, and the inequality in their romantic relationships, and what is expected of them as

women. Participants believed this to be directly related to their infection. These experiences are important as participants believed these experiences to be directly related to their status, and therefore has caused them to be participants in the programme. There was no mention made of the programme targeting the unfair and unequal treatment of women in sexual relationships, but then again, culturally speaking this does not seem to be in issue that needs to be addressed. The programme did not perturb or shift females standing in the romantic relationship setting, or empower them to negotiate for protection against infection.

4.5.2 Individual Interview finding: Self in relation to HIV/AIDS and stigma

4.5.2.1 Overview

Within the individual interviews participants were asked to share about themselves and how HIV/AIDS-related stigma has affected this story of self, as well as the influence of the programme on these. Participants proceeded to share stories of how they saw themselves through their own eyes, how stigma has shifted this perspective, and how participating in the programme has enabled them to see themselves, once again in a more satisfying light.

This theme related to identity is grounded in participant narratives gravitating toward identities and perspectives of self, and how the programme has influenced these. These narratives therefore revealed how participants regarded themselves in their own esteem, as well as how they believed others perceived them. Other's perception of them was directly related to stigma.

Participating in the programme opened up new gateways of viewing themselves, even if other's concepts of them remained unchanged. Participants shared how participating in the programme has helped them to form more positive images regarding their identity, especially an identity related to living with HIV/AIDS. Three major identity themes surfaced throughout the interviews: the self as victim, self as good, and self-acceptance.

Participants were able to use their experience of the programme and apply it to shift their self-perception to a more positive and satisfying perception. Narratives around themselves had to do with a shift from perceived stigma within themselves, toward a more satisfying self-identity. Although participants still feared enacted stigma and still experienced negative emotions linked to their HIV status, they were able to utilise the support group within the programme to shape non self-stigmatising concepts around their identities, which enabled them to live more satisfying lives.

It appears as though perceived stigma regarding self-concepts was reduced to a degree, although not eliminated, through the support group within the programme, but not enacted stigma, which still played a large part in their lives.

4.5.2.2 Participant Narratives

4.5.2.2.1 Narratives of the sub theme self as victim

Participant narratives around this theme specifically involved the influence of how others perceived them, or the identity related to stigma imposed on them. This was directly related to the perception of females living with HIV/AIDS as sexually promiscuous. This was a stigma identity automatically placed on females living with HIV/AIDS, according to participants.

Participants shared explanations to inform the researcher of what “*really goes on*”, and to illustrate how stigma functions to tarnish their reputations. Participants shared that their partners are not monogamous and this “*sleeping around*” is the breeding ground of their partners’ infection, which is then transmitted to them. According to participants, the erroneous belief that all females living with HIV/AIDS are promiscuous, and therefore, are deserving of their fate, is actually true of their partners. The focus here is therefore on how these circumstances have created a reality where participants become victims. Here, they find

themselves caught between a false perception of who people perceive them to be, and who they know themselves to be. Therefore, their concern was mainly the label forced on them, how this has influenced their self-concept, and how the programme has assisted them in centering themselves once again in a satisfying identity. Although this perception fuelling stigma is not corrected or eliminated in the community, participants were able to identify these as just that: perceptions, and adjust their ways of seeing themselves away from this.

Interview Participant 9 revealed that she has remained faithful in all her relationships, but she believes men are less likely to remain faithful or monogamous. She explained that her partner's inability to control his sexual urges has punished her with HIV/AIDS: *"I know him, when he sees a new girl he wants her, he doesn't think if she has been sleeping around, all he thinks about is sex"*. She feels that only women carry this label of promiscuous individuals deserving HIV/AIDS, but in fact men should carry this label because it describes them better. She added an awareness of many men who she perceives to be promiscuous, and that they have attached a sense of pride to this perceived promiscuity as an accomplishment of *"having many women"*.

Interview Participant 3 recalled that she felt victimised due to a promiscuity label put on her. She expressed hurt at this label, as she perceives herself to be conservative. She expressed the futility in attempting to change this perception or label now attached to her: *"Once people think something about you, that's for life, it's difficult to change it. Especially if they say, "that one, she sleeps around". People say that, especially us women, are responsible for HIV because of sex. It's easy for them to say that because they don't know what really happens. You can't even try to explain, they don't want to hear – they don't listen to me. Now I even give up to explain"*.

Interview Participant 2 believed that her partner's aunt has *"cursed"* her, and consequently she contracted HIV/AIDS, while her partner escaped this fate (he has not been tested and is not showing any symptoms of infection). She believes his aunt did this because she *"hates"* her,

as the aunt has accused her of being sexually immoral and angering the ancestors. She added that a common perception of women living with HIV/AIDS is that of being sexually immoral.

Interview Participant 5 expressed the fear that “*everyone*” believes that she is living a sexually immoral life, without “*evidence*”. She revealed that she feels wronged at being falsely accused of a matter this serious, and that people believe that she deserves HIV/AIDS. She also revealed that with many women the circumstances around transmission of HIV/AIDS involves forced sexual activities, or even rape coupled with violence and assault. She expressed: “*they don’t know my life*”. She expressed that if people really understood what was actually happening, maybe it would change things, but she admitted people just like to believe what they believe because it is easy. She expressed a sense of relief in sharing these narratives with the researcher, as she perceives this as a step in revealing what her real lived circumstances are, as opposed to her perceived circumstances.

Participants revealed that in most instances their HIV/AIDS infection was due to the unfaithfulness of their partners, also expressed by Interview Participant 7: “*My boyfriend has girlfriends, eh, everywhere! I know this. He comes back and he gives me HIV. What can I do? He is a man, if he wants to have lots of girls he won’t listen to me. I’m tired of him*”. This narrative alluded to an ongoing involvement with her partner. She revealed an awareness of his travels to various towns in search of employment, and engagements in different sexual relationships in these contexts. Whether she has disclosed to her partner was not revealed.

Interview Participant 9 revealed the absence of trust in her polygamous relationship: “*All these men do the same all the time! Even if I tested negative, I must test again to be sure, because you know these men are not faithful. You must keep testing, because one day he can bring home HIV*”. She elaborated that before she tested positive she used to test repeatedly because she did not trust her partner’s fidelity to her. She went on to explain that she suspected unfaithfulness,

and she knew it was a just a matter of time before she too was infected. She shrugged her shoulders and said she cannot insist on using condoms because she is the woman: “*What is left for me to do?*”

A sense of being wronged covered these narratives. Participants voiced repeated concern of the widely believed misconception within their community that HIV/AIDS equals sexual promiscuity. Coming to terms with their status and being confronted with the misconception of promiscuity threw participants into turmoil regarding their identities. But participating in the support group of the programme has reassured and confirmed within participants, that the misconceptions are just that.

Most participants were ill-treated in the form of enacted stigma because of the perception of promiscuity. The programme does not address this incorrect belief that leads to enacted stigma within the community, and therefore does not alleviate the burden of participants carrying this label. But through the support group participants were able to stay grounded in their belief that they are not promiscuous, and this has helped them to avoid the initial self-blame that usually attends the discovery of HIV positive status.

4.5.2.2.2 Narratives of the sub theme self as good

Closely linked to the self as victim narrative was the participants’ subtle attempt to convince the researcher that they are in fact good and moral people, who have to deal with a circumstance that should not have happened to them, an undeserving fate, according to their perceptions. Participants shared a resilience related to rising above a condemning self-concept due to their status.

The support groups in the programme contributed to this resilience and appeared to have been a lifeline for most participants in maintaining their self-identities as the people they had always

believed themselves to be, after momentarily being distracted by an identity of a promiscuous “*OMO*”.

Although community members’ perceptions related to HIV positive females still remained unchanged, participants were able to return to their core beliefs around the goodness within them. Within the support group, participants have grounded themselves again in who they were before they discovered infection: Interview Participant 4 revealed that she was reminded through the programme that she is still a good person, especially through the support group. She explained at first that testing positive was confusing for her in terms of how she viewed herself. She explained that this confusion was due to how she had always felt about herself, and the picture stigma paints of a female living with HIV/AIDS. She said that reconciling these two identities was a source of anxiety for her, because the stigma identity was overwhelming and widely believed. She admitted that she experienced a sense of loss of herself during this period: “*this thing about what people say about HIV confuses you, you can even forget about that person you are inside*”. When asked how the support group managed to help her, she pointed to the therapeutic effects of communicating with other participants who were struggling with the same issues. Standing in agreement that the labels put on them are false, has reminded her that those stigma identities were false, and that they do not change who she is.

Similarly, Interview Participant 6 revealed that the programme has helped her not to surrender to a destructive identity around HIV/AIDS: “*Why must HIV change who I am. Here I can see again who I am.*” Participant 7 indicated that she remembers the person she used to be: “*Before HIV I remember I was even happy even if I have many problems. My life is difficult, then HIV came, and that made me a different person.*” She explained that she felt different about herself and this affected her behaviour. She revealed that she had negative feelings toward herself, and

had difficulty in dealing with HIV/AIDS on a daily basis due to mixed emotions: *“People told me why I am acting different...they ask me why I don’t want to do the same things as before, why am I not doing things with my friends... I’m thinking I feel different, I didn’t want to do anything or see anyone...I felt sad”*. She added that she now feels more positive, she feels like the sadness has left her, especially because she was able to talk about her problem of HIV/AIDS, in the support group. She added that in this setting she realised that other people living with HIV/AIDS are not what she thought, and she can see that they are functioning and even happy. At first she thought that this could never happen for her, but as time progressed she too adjusted her emotions and self-concept to a more satisfying one: *“You know, I can see these people with my eyes, I think, they have this thing (HIV), how can they talk openly and smile? But later this thing happened for me too, and now I feel even like I feel before this thing happened”*.

4.5.2.2.3 Narratives of the sub theme self-acceptance

Interview Participants shared that participating in the programme has contributed to their self-acceptance, in terms of living with HIV/AIDS. Some participants revealed that they experienced fear about what HIV/AIDS will mean for them, but they experienced a positive shift within the programme’s support group about what it means to be HIV/AIDS positive.

Participants were unsure about how living with HIV/AIDS will affect their health, bodies, relationships and placing possible parameters on behaviours such as, sexual activities and child bearing. They were apprehensive about how living with HIV/AIDS would make them stand out from the rest of the community, and what this would mean in terms of social interactions and accepting themselves.

Interview Participant 9 explained that she feels that HIV/AIDS is becoming more common now, due to an increasing number in infections in her community. She believes that more people are dealing with the same problem (HIV/AIDS) and that this helps people to think about HIV/AIDS as a more common or general illness, like high blood pressure, for example. She feels that this will help people living with HIV/AIDS to feel integrated once again: *“Many people now have HIV, and it is almost like a common disease. So it means that I can be normal and I am still the same person. People must see that I am still a person, even with HIV, I am still someone”*.

Interview Participant 3 expressed a sense of acceptance of past events and an intention of moving forward through self-acceptance: *“I can’t always stay angry at myself. This misfortune has happened, but I can still live my life”*. Interview Participants 1 and 10 admitted that it is difficult to get past HIV/AIDS, because it stays with you forever. But accepting it is better than not accepting it. They expressed that this makes day to day life more bearable. The overall outcome of their experience of self-acceptance was related to dealing with perceived stigma to a degree within the support group in the programme, although not eliminated.

4.5.2.3 Summary

Five Interview Participants mainly centred their self-concept around themselves as victims in circumstances that have contributed to their infection. Their main concern was outsiders’ misconception of them as promiscuous or loose females responsible for HIV/AIDS. It was important to them for people not to have a false perception of them, especially a taboo one assigned by stigma. The placing of blame on a party other than themselves contributed to a helplessness fused into their circumstances, yet a simultaneous resilience in staying true to their self-perceptions in terms of avoiding self-blame for the infidelity of their partners.

Interview Participants 4, 6 and 8's focus was mainly pointed at themselves as good, as opposed to bad. Interview Participants 1, 3, 9 and 10 have moved to a place of self-acceptance, and a surrender to their circumstances, but not a surrender to an identity that is incongruent with their perceptions, but rather an acceptance of an identity which they are able to live with. The identity theme within the individual interviews indicated a mindful shift from an HIV/AIDS identity, to an individual living with a disease identity. The support group discussions in the programme played a particularly large role in this shift, creating a platform to construct more satisfying self-concepts.

Although participants did not indicate that the support group discussions has reduced enacted stigma within the community, it is obvious that it has reduced perceived stigma within themselves regarding their identities. These narratives illustrated the power of creating new narratives, as in the support group discussions, to allow for new, more satisfying experiences.

4.5.3 Individual Interview finding: Prioritising living with HIV/AIDS and stigma

4.5.3.1 Overview

During the individual interviews participants were asked how living with HIV/AIDS fits into their daily lives, and how coping with HIV/AIDS stigma fits into their daily lives. They were also asked to consider how participating in this programme may have influenced these circumstances, or their perceptions of these circumstances. What followed were narratives that were unexpected and surprising regarding the priority of HIV/AIDS in participants' lives.

It was revealed that although HIV/AIDS is considered a problem to participants, it was not a primary problem in their lives, as is expected of a life changing disease such as HIV/AIDS. Participants revealed that for them, and for most of their community, HIV/AIDS is "*just another problem*" on top of already existing difficulties. When questioned about what takes

precedence over HIV/AIDS in their lives, participants revealed that sometimes stigma is regarded as a bigger problem than HIV/AIDS, but poverty outweighs all of these. According to participants poverty has been ravaging this community longer than they can remember, and HIV/AIDS simply added to daily struggles.

The counselling and testing coordinator later revealed the following: *“In this community poverty overshadows everything. The people don’t have food to eat, and employment is a hopeful, but unrealistic wish. HIV is simply not always a priority”*. Participants therefore regarded living with HIV/AIDS as a lesser problem to attend to in their daily lives. Participants contextualised coping with HIV/AIDS and enacted stigma in their daily lives, as a lesser problem than that of living with poverty. The significance of this may not be obvious, but participants revealed that poverty is creating an additional barrier to testing and seeking medical care, as well as creating a platform for vulnerability to infection.

Daily life is already a struggle for survival for community members, and so testing for HIV/AIDS just adds another dimension to their struggles, and is therefore avoided by most, especially the poorest of the poor. In their estimation it is better to remain ignorant to their status, as life is already difficult. According to participants most believe HIV/AIDS to be a death sentence regardless, therefore, testing to seek medical care is not even a consideration, as it is believed to be futile. Participants therefore feel that poverty is a major contributing factor to their people succumbing to HIV/AIDS.

4.5.3.2 Participant narratives

Poverty was an issue for participants specifically because unemployment is so widespread in this rural setting. The Africa Centre provides employment, although not enough to alleviate poverty in this setting. The next place for employment opportunity is the town of Mtubatuba,

which is situated 15km from their community. The problem they also face is not limited to scarce employment opportunities, but also getting to the employment opportunities in Mtubatuba. They explained that they need transport to get to Mtubatuba, which costs money, which they don't have to begin with. In short, they explained that to them, they were in an impossible situation. Therefore, the lack of employment has led to widespread poverty in their personal lives, according to participants.

Interview Participant 10 described her circumstances as dire: *"In my life I already have many problems, being poor makes everything bad. At my house I have many people to take care of, but I can't get a job. How can I even look for a job? One of my brothers, he is the security guard, he brings money home for us, but even his money is not enough. I can't think what I would do without my brother"*. She also added that living with HIV/AIDS makes her situation worse, as she is afraid that she may not be strong enough to work if the opportunity arises.

Interview Participant 3 expressed that poverty also influences her community's attitude toward HIV/AIDS: *"Some people think about HIV, and then they think about how poor they are. They say being poor is more to worry about than some HIV"*. She went on to explain that this lowers the priority placed on testing for status. She believes this the reason why people do not give attention to the Africa Centre's programme: *"All they can think about is being poor. Things around you don't matter. It's like you can only think about this thing all the time"*. She revealed that she experiences anxiety about living with HIV/AIDS, especially about people finding out, but then her concerns over poverty overshadow her concern over her status. She reported that she is constantly aware of poverty, as she is faced with the continuous uncertainty of where her next meal might come from. The constant worry has made a home in her life, as she added this worry never leaves her: *"...sometimes I don't have the strength to think about HIV, because all my strength goes to being poor. But I know that I must remember that I am living with HIV,*

because otherwise I will forget to take my ARV... but this worry makes you forget about other things like that”.

Interview Participant 5 recalls constant distress about her financial situation, and its negative effects on her sleeping habits. She reported lying awake regularly, worrying about how to provide for her younger siblings. She attributes the cause to her problems to poverty, and therefore believes that much needed finances will solve many of her problems. She added that sometimes there is little time to consider HIV/AIDS, or to think about how to live with it.

Interview Participant 4 explained in more detail how HIV/AIDS testing and poverty are related. She explained that poverty causes people to question the importance of testing, as it does nothing to solve their problems. She added that survival is challenging as it is, without adding a positive HIV status into the equation.

Interview Participant 1 revealed that she is aware of people who have tested positive, but that they are too poor to afford transport to collect their ARV treatment. She feels that this is truly a bad situation, because of their awareness of their need for ARV treatment, and their inability to access it. She suggested that the programme can help by taking the treatment to HIV/AIDS sufferers. She believes this to be the reason for delayed testing, as *“testing can wait”*, but poverty cannot wait as it is experienced daily. She also commented on poverty being the main cause of the spread of the virus, due to testing being a low priority.

Interview Participant 2 revealed a desperate dynamic between HIV/AIDS and poverty, in which poverty is driving individuals to purposefully make themselves vulnerable to HIV/AIDS infection. Once tested and found to be positive it is believed there is a possibility of receiving a government disability grant for their HIV/AIDS status. She perceives this as an impossible situation in which hope for employment has dwindled to the point where HIV/AIDS is used as

a means of income to support their hungry and struggling families. She believes that these individuals regard poverty as a worse fate than HIV/AIDS, and therefore make themselves vulnerable to HIV/AIDS in an attempt to alleviate poverty. She also added she personally knows someone who has done this. She wasn't sure if the grant has paid out as of yet, as she revealed her scepticism of the grant.

Interview Participant 9 shared similar experiences of poverty taking precedence over HIV/AIDS, but it was her hopelessness which summed up life in her unforgiving circumstances: *“People don't know my life, it's hard. Every day I ask what will happen today? I hope for a job, but you know there is nothing. Poverty kills us, people think HIV kills us, but poverty kills more. We can hope for a better future, but it doesn't come”*.

When questioned about how participants decided that HIV/AIDS was important enough to get tested for, participants revealed that many of them had suspected they may be infected. The home based testing protected them from enacted stigma, and they therefore felt that it was best to test. Since then, the counselling received from the programme has helped them to see that HIV/AIDS is as important to manage and consider as poverty. From here, the importance of managing HIV/AIDS effectively through counselling and ARV treatment was instilled in participants and adhered to - according to Interview Participant 10: *“We can see that HIV is important. We realised in this programme that it is our responsibility to do this thing so that we can live”*. She added to this that she feared having to cope with HIV/AIDS and poverty, but that the programme helped them to see that they are in fact living with HIV/AIDS, and poverty should not prevent them from managing HIV/AIDS.

4.5.3.3 Summary

Participants' experiences of living with HIV/AIDS and dealing with enacted stigma were overshadowed by poverty. Coping with poverty reduced their willingness to test for HIV/AIDS, as poverty is the overriding reality in their daily experience. Thus, HIV/AIDS does not qualify as an immediate problem to be addressed, and discovery of one's status may simply add another problem to an already overwhelming life situation. In this sense, poverty was perceived as a driver of transmission. Participants revealed, however, that the programme has helped them to see, that even with poverty, they can still manage their HIV/AIDS status, that poverty does not have to prevent them from surviving HIV/AIDS or shape their response to HIV/AIDS.

4.5.4 *Individual Interview finding: Empowerment*

4.5.4.1 Overview

In enquiring about the influence of the programme on participants' perceptions of HIV/AIDS and stigma, participants revealed positive influences regarding this experience. The majority of the participants indicated a sense of empowerment through participating in the programme, which helped them to view HIV/AIDS in a more constructive light. This sense of empowerment was attributed to knowledge gained through the programme. This was a positive aspect for participants, as narratives related to the empowerment theme used positive words to describe these experiences.

Participants also believed that the knowledge from the programme is able to reduce stigma related to HIV/AIDS, but that this knowledge is not reaching the community. Therefore in their own experience, the knowledge that empowered them has influenced their perspective on

HIV/AIDS and stigma, but it has not successfully penetrated the community in order to reduce enacted stigma.

4.5.4.2 Participant narratives

Participants were asked if their experience of the programme had influenced their perception of HIV/AIDS and stigma, and if so, what did this mean for them. Participants revealed that the programme has influenced how they perceive HIV/AIDS, and this meant that they felt more empowered regarding their status and that it has helped them to manage living with HIV/AIDS in a more effective manner. Narratives that indicated a sense of empowerment in participants were identified under three sub themes: knowledge of hope for the future, knowledge of HIV/AIDS, knowledge of HIV status. Participants also revealed that this information has shifted their perspectives of stigma as well, in that they realise that people stigmatise for the wrong reasons, because of erroneous beliefs.

4.5.4.2.1 Narratives of the sub theme knowledge of hope for the future

Participant narratives revealed a sense of empowerment within themselves, as they indicated that participating in the programme has helped them to realise that HIV/AIDS is not an automatic death sentence. Interview Participant 5 indicated that the programme has benefitted her, as it has helped her view HIV/AIDS and the implications of living with it, differently. When asked to elaborate she expressed that before she participated in this programme, she was unsure regarding the implications of HIV/AIDS on her health. This left her unsure about her future. She became faced with her own mortality, quality of life and the fear of HIV/AIDS symptoms. She described this as a frightening time for her. The programme provided relief in the form of information that ARV treatment is available and effective, and that people live successfully on this treatment. She added that this information has encouraged her to start on

ARV treatment. She also witnessed how people around her, specifically people in the programme support group, are also functioning successfully on ARV treatment.

Interview Participant 9 shared a similar sentiment in that she previously feared HIV/AIDS, due to witnessing many people dying from HIV/AIDS in her community: *“Everybody is scared of this thing...all the time we can see some people dying from this, this makes you to fear for your life”*. She assumed that death was the natural course when one becomes infected. But she has realised, through the programme counselling, that HIV/AIDS is not an automatic death sentence, and that even with HIV/AIDS she can still have a future: *“Even now I can see I didn’t die, I even feel good in my body...I don’t feel like someone who must die”*.

Similar to Interview Participant 9, Interview Participant 6 revealed that HIV/AIDS is feared due to the deaths attributed to HIV/AIDS in their community, even though this cause is often denied. She continued to explain that she witnesses people becoming emaciated and coughing excessively, and shortly after the person dies. She has identified this as the *“path”* of HIV/AIDS. She added that she believed her fate would follow the same *“path”* as those she has witnessed dying, but she feels very fortunate that she has found out about ARV treatment, because this has given her a *“second chance in life”*.

Interview Participant 4 also admitted that she feared an HIV/AIDS death. She reported feeling trapped, but experienced a degree of freedom through knowledge of the efficacy of ARV treatment. She revealed that she had been praying for a way out. She contemplated different ways to make this happen, such as suicide or running away from home. She expressed that she was very relieved when her counsellor told her that ARV treatment is available to manage HIV/AIDS, and that she perceived this to be the chance she has been praying for.

Interview Participant 2 expressed hope in a “good” future because she no longer has certain death looming over her. She attributed her positive outlook to the programme, which “saved” her.

4.5.4.2.2 Narratives of the sub theme knowledge of HIV status

Interview Participant 9 revealed that the programme has encouraged her to test, as she suspected that she might have HIV/AIDS. She reported delaying getting tested, due to fear of being found out. Conversely, she reported feeling “safe” with the home based testing: *“At that time I’m thinking I must test, because I need to know about this thing...but you are scared when you think people gonna find out. I didn’t want people to know”*.

Interview Participants 2 and 3 both shared experiences of anxiety regarding testing in public health care settings, because they weren’t sure who to trust. Both reported believing that somehow their testing would become known, and they would be exposed. Interview Participant 3 shared that the home based testing made her feel comfortable, and that she had “nothing to lose” by taking the test.

Interview Participant 4 likewise revealed that knowledge about her status is attributed to the home based testing. She added that, although the result was not what she hoped, she feels better for testing: *“knowing my status was a good thing. I know now”*. She recalled that “always wondering” whether she had or didn’t have HIV/AIDS was worse than knowing that she has HIV/AIDS. She revealed that the anxiety of not knowing made her weak in terms of taking action.

Similarly, Interview Participant 8 stated that it is important to be aware of one’s status, and that the programme is a means of achieving this in a “risk free” manner. It became evident that

participants felt that it was important to know their status, and attached an empowerment undertone to knowing their status, even if the HIV status turns out to be HIV positive.

Interview Participant 6 added that, for her, it was important to test, because knowing her status enabled her to “*have control*” over HIV/AIDS. She feels that not knowing her status means that HIV/AIDS has control over her. Therefore, this knowledge of status shifted “*power*” according to her. She added that being ignorant regarding her status gives opportunity to HIV/AIDS to “*catch you out*”, implying something unexpected and uncontrollable.

Interview Participant 1 pointed out the more specific value of knowing her status by stating if she hadn’t tested, she would not have been receiving ARV treatment and she would continue to get weak and eventually succumb to death. According to her knowing her status helped her to fight against HIV/AIDS. Interview Participant 7 revealed that she feels psychologically empowered through knowing her status, as this enabled her to also fight against HIV/AIDS. She added that it is impossible to fight against HIV/AIDS if you are not aware of its presence in your body. She reasoned that it was her body, and she was responsible for knowing what was going on with it. She explained that she does not want to walk around with HIV/AIDS unawares, as with some people she is aware of.

Therefore most participants’ narratives indicated a positive experience in gaining knowledge of their status, even though most participants’ narrative of their experiences seemed to indicate their status was positive. They felt that they at least had options now, even with an HIV/AIDS positive status. They felt empowered to fight the disease through knowledge, counselling and ARV treatment.

4.5.4.2.3 Narratives of the sub theme knowledge of HIV/AIDS

Participants indicated positive experiences of programme workshops, support groups and counselling in which they gained knowledge of HIV/AIDS, previously absent. Gaining this knowledge empowered them, as HIV/AIDS was no longer an unknown element to face, but rather a comprehensible, manageable and tolerable disease.

Interview Participant 9 also indicated a shift in power, as did Individual Participant 6, from HIV/AIDS to herself because of valuable information she received through the programme. She explained that this information helped her to understand HIV/AIDS better, and for her, understanding it better helped her to make better decisions for herself. She indicated a sense of relief from the confusion she experienced previously, as she explained she knows “*what to do*” now. She indicated that the information gained through the programme has alleviated the darkness and uncertainty around HIV/AIDS, as the information has exposed what the virus is, and how she can manage it: “*If you can know about HIV it is very good, because then it can help you to know what to do. If I didn’t know these things, I can make bad choices, some choices like saying no to ARV, then I can die... When this thing comes, it is confusing, you don’t know what it is that is happening now...All this information can help you to know what is happening.*”

Interview Participant 7 added that although the information is overwhelming initially, this awareness added something positive to her life. She referred to knowledge as an empowerment tool for herself and for others. She shared that she hopes to protect her younger sister from HIV/AIDS through sharing this knowledge with her, and so impact her sister the way the programme has impacted her. She feels hopeful that this knowledge will “*save*” her sister.

Participants also highlighted that they feel lack of information causes the spread of HIV/AIDS and stigma. Interview Participant 8 noted that she personally believes HIV/AIDS is on the rise due to lack of information around HIV/AIDS. When asked how she came to this conclusion, she revealed that this ignorance has contributed to her infection, amongst other factors, and can therefore also contribute to the infection of others.

Interview Participant 1 also linked vulnerability to infection to information about (sexual) behaviour. She admitted that she had been behaving recklessly in the past, despite being warned against such conduct. A shift took place at the realisation that her counsellor's persistence in warning against her actions and the danger she placed herself in, was for her benefit. She indicated a fresh start, in heeding the information shared with her.

It may seem unusual that participants only learned about the disease after contracting it, but it became apparent that little information was previously available to them in an accessible form. Verbal communication regarding information around HIV/AIDS was received well, but other modes were not referred to.

4.5.4.3 Summary

The empowerment theme is supported by experiences of gaining knowledge around HIV/AIDS, HIV/AIDS status and hope for the future. Participants valued the information provided through the programme, and believe this information has the potential to reduce enacted stigma through awareness.

Within themselves, this knowledge has shifted participants understanding of HIV/AIDS and has provided them with tools to manage their illness, whereas previously HIV/AIDS was perceived as a death sentence. This deeper understanding regarding HIV/AIDS was also identified by participants as something that may potentially reduce stigma within the

community. Therefore the programme has successfully shifted previously unhelpful meanings attached to HIV/AIDS, to more helpful and satisfying meanings for participants through communication of information. In terms of reducing stigma directly, the programme has proved less effective, according to participant experiences.

4.6 Conclusion

Chapter four presented the findings of the focus group and the individual in depth interviews of participant narratives. The narratives were grouped into themes to illustrate participant experiences and how these were lodged within their larger socially constructed realities. Themes expressed patterns in experiences amongst participants which were governed by the larger socially constructed reality, within which they found themselves. The focus of the narratives was not concentrated on whether the programme was a good or bad experience, but rather concentrated around their meanings and the narrative world they found themselves living in. Therefore it focussed on their social constructions and how participating in the programme has influenced these. Even though the overall experience of the programme was positive, there were many negative themes binding the narratives concerning their lives and their experiences as human beings. The programme's support group offered a platform in which coping mechanisms were constructed, which enabled participants to deal with their experiences.

CHAPTER 5: DISCUSSION OF FINDINGS

5.1 Introduction

The social constructionist underpinning of this study reaches its expressive climax in chapter five. Here, the phenomenological realities of participants as expressed in their narratives, are especially emphasised (Becvar & Becvar, 2005), and interpreted according to a social constructionist perspective, as understood by the researcher.

Participant narratives allowed for limited, but accessible insight into the experience of participating in a stigma reduction programme. Focusing on the experiences of participants through narratives and the meanings attached to these experiences invited the researcher to linger with this phenomenon (Finlay, 2011), in order to effect authenticity in interpretation. Herewith, this research offers a humble aspiration for this programme: if we change our social constructions, or narratives, our experiences will change. This endeavour moves away from understanding behaviour (in order to manipulate it), to understanding stories (in order to co-create new stories for more satisfying experiences).

Each theme presented in the previous chapter is interpreted here, and discussed in the following format:

- from a social constructionist perspective
- in the context of the research question
- in the context of literature
- implication of the interpretation

Chapter five also discusses the limitations of the study and the significance of the overlapping themes, before offering recommendations and a conclusion.

5.2 Interpretation of findings

The discussion that follows reflect the researcher's interpretations of the narratives shared by participants. This interpretation represents the researcher's appreciation of the everyday human experience of participants, and an interpretation of the meanings participants attach to their human experience (Finlay, 2011). This is not an attempt to explain participant behaviour (Finlay, 2011) but to explore the experience of being human, especially in the setting of being a participant in a stigma reduction programme.

In representing the meanings of participants, it is imperative to be conscious of one's own role in the research setting. The social constructionist epistemology implies that the encounter between participants and the researcher is a construction or meaning making process in itself, both influencing the meaning making of the other (Henning, 2002). Jung's (1933, p. 49) expression of this notion of mutual influence was translated as such: "the meeting of two personalities is like the contact of two chemical substances: if there is any reaction, both are transformed". The constant consideration of this served the act of interpretation well.

5.3 Focus Group theme: Desire to preserve social identity

Participants' narratives around this theme highlighted the presence of enacted stigma in their lives, the desire to keep their HIV/AIDS status private and the perception of the programme achieving a reduction in enacted stigma within the community, when rather it was circumvented.

5.3.1 Interpretation from a social constructionist perspective

Participants strongly desired to maintain social good standing within their community and social networks, which was coupled with a dissociation from HIV/AIDS. To achieve this goal

their positive HIV status had to remain private. The value of social acceptance was strongly evident, as was its role as a driver of behaviour. What is deemed as socially acceptable or unacceptable is created and maintained through social conditioning, and governs behaviour, as was evident in the non-disclosing practices of participants. This illustrated the powerful implication of social expectations and desires to conform, created and maintained through language and social interactions (Becvar & Becvar, 2005). According to participants, exposure to enacted stigma is mitigated by private testing and non-disclosure, suggesting the persistence of stigma as a driver of behaviour, and a reality lodged in language and social interaction (Becvar & Becvar, 2005). Participant narratives confirmed the powerful impact of the stigma discourse, as it influenced decision making related to their behaviours. This was evident in behaviours in which participants opted for non-disclosure of status in order to protect themselves from stigma. Participants are in essence giving in to the pressure of stigma in order to maintain their social identity, thereby maintaining its power to shape behaviour.

According to participants the quantity of enacted stigma can be manipulated through removing knowledge of testing and association with HIV/AIDS, and therefore the experience of stigma is perceived as contingent upon another's awareness of their status. Participant narratives therefore revealed that participants perceived a reduction in stigma in their community, although personal experiences of enacted stigma were still present. This was indicative that the meaning of stigma remained unchanged, but still experienced in varying degrees due to private testing and non-disclosing behaviours. Participant narratives revealed patterns in experiences related to monotonous meaning of stigma as constructed in language and maintained through social interactions, which governed participant behaviours and shaped their experiences. As social constructions do.

The socially constructed nature of stigma was therefore confirmed through participant narratives. Stigma was revealed to have maintained its socially constructed meaning as posited by Goffman, through social interactions expressed in participant experiences. This discourse has shaped participant beliefs around HIV/AIDS, and given rise to a range of specific stigma-avoidance behaviours. Thus, stigma not only maintains barriers between those who have HIV/AIDS and those who do not, but also undermines the behaviours that may reduce transmission.

5.3.2 Interpretation in the context of the research question

The research problem focused specifically on participant experiences of participating in a stigma reduction programme. Participating in this programme enabled participants to avoid stigma in terms of testing privately and taking control over disclosure of status. The provision of this option has confirmed participant beliefs that status should be kept private, as it avoids enacted stigma. Therefore, the larger social meaning of stigma in which participants already live, was maintained within the context of this programme. The influence on participant experience was therefore avoidance of enacted stigma, with stigma still attached to its original meaning. The direct influence on the meaning making of participants was therefore a confirmation that avoiding stigma is to be strived for at all, and any costs.

5.3.3 Interpretation in the context of literature

The importance participants placed on keeping their testing for their HIV status private due to fear of stigma, resonated with literature findings in which Ndinda, Chimbwete, McGrath and Pool (2007) reported that stigma influenced the decision of participants in KwaZulu-Natal to disclose.

In this theme, participants disagreed with the programme urging them to disclose their status, and revealed that only “*bad things*” will come of disclosing, as some of them have already experienced. Similar findings were reported by Mogotlane, Hazell and Mthembu (2007) in KwaZulu-Natal in which women did not disclose their status to community members. Similarly, Blake et al. (2008); Jasseron, Mandelbrot, Dollfus, Trocmé, Tubiana, Tegla, Faye, Rouzioux, Blanche and Warszawski (2013); Stadler, Delany and Mntambo (2008) and Zuch and Lurie (2011) reported findings of experiences of rejection, labelling and name calling linked to divulging status, which resonated with the findings of this study. Participants shared experiences of loss of friendships, estrangement from family members, rejection by partner and name calling such as “*OMO*” or “*three legged pot*”. The name calling specifically referred to names with three letters which was used as a code for HIV, which also has three letters. This was also reported by Stadler et al. (2008) who reported that in Soweto HIV/AIDS is referred to as “*Z3*”, a BMW motor vehicle which also has three letters.

The home based testing offered by the programme encouraged testing, because testing in public health care facilities was feared. Participants revealed that testing stations are monitored by community members, who have concluded that testing that does not take up much time is usually a negative test result. But if the individual remains in the testing station for an extended period of time, this is usually an indication of a positive test result. Positive test results are followed by counselling and discussion of treatment plans, and therefore take longer than negative test results. Jewkes (2006) reported that testing is avoided to avoid stigma, as with this theme. Likewise, Kalichman, Simbayi, Kaufman, Cain, Cherry, Jooste and Mathiti (2005) reported results in Cape Town where health workers revealed that HIV/AIDS-related stigma was the most important reason why testing for their HIV status was avoided. Therefore, similar experiences of enacted stigma were found in literature, with similar patterns of non-disclosure

or reluctance to test in public health care facilities. Similar findings in literature indicate that the meaning of stigma related to HIV/AIDS is consistent throughout in South Africa.

5.3.4 Implication of the interpretation

The desired outcome of the stigma reduction programme is to reduce stigma. Considering this aim from a social constructionist perspective, implies that the socially constructed meaning attached to stigma must be shifted, for a shift in the manifestation of stigma to take place. For stigma to look different it must mean something different. In the case of participant narratives it appears as though the programme did not influence participants' perception and meaning of stigma, but rather confirmed the existing negative meaning thereof. Patterns such as non-disclosing behaviours were indicative of perceptions that an HIV positive status is something to be hidden, due to its negative meaning, which invokes stigma. Goldin (1994) suggested approaching stigma from a phenomenological perspective, emphasising communication or discourse around stigma. This programme attempted to counteract stigma, instead of shifting its meaning. Counteracting stigma implies that it still has the same meaning, and therefore being HIV positive still has the same meaning.

A serious implication is that participants' behaviours are guided by the very meaning of stigma. This implies that participants subscribe to the meaning of stigma; that it is "*bad*" to be HIV positive. According to Becvar and Becvar (2005), subscribing to this meaning equals participating in this meaning, as participant behaviour contributes to, reinforces and maintains the meaning of stigma. Narratives about non-disclosure and private testing revealed a limited range of behaviour bound by stigma discourse, as of yet there has not been a new narrative or meaning around stigma.

5.4 Focus Group theme: Facing struggles in coming to terms with the implications of living with HIV/AIDS

Focus Group participants' narratives around stigma factors influencing their experience of living with HIV/AIDS, revealed a fear of taking ARV treatment. Participants indicated that the programme emphasised the importance of taking ARV treatments, which they eventually heeded to.

5.4.1 Interpretation from a social constructionist perspective

Behaviour patterns around fear of taking ARV treatment revealed the larger social discourse which participants lived by. This governing discourse of stigma impacted upon participants' ARV treatment behaviours through discouraging ARV treatment, due its negative connotation and association with HIV/AIDS.

The second discourse revealed through participant narratives, was that of cultural expectations regarding gender. Specifically, participants revealed that as women they are expected to conform to certain physical appearances as set out by their society and to be physically desirable to the opposite sex. This revealed that participants perceived males in their culture to select wives based on specified physical appearances. Failure to conform disqualifies them from social acceptance as well as the possibility of marriage.

These social expectations are linked to the social discourse of gender within this patriarchal community, left unexamined, as participants do not question why or where these expectations originate from. According to participants, the side effects of taking ARV treatment is incompatible with cultural expectations set out for women, and therefore acts as a barrier to social acceptance and finding a husband.

5.4.2 Interpretation in the context of the research question

Participating in the programme enabled a wider range of possibilities regarding ARV treatment. Participants' perception of taking ARV treatment was influenced by interactions with other participants of the programme who were already living on ARV treatment, and still retained their female form. This allowed participants to expand on their range of behaviours, which was governed by the larger social discourse of stigma and also of gender. The governing properties of larger social discourse were confirmed in participant narratives, whilst at the same time revealing what it meant for them to be human in this social discourse. Their narratives revealed that they are young females living with HIV/AIDS in a community in which they strive to comply with demands set out through larger social discourses. This conformity ushers them into an outer reality characterised by powerlessness and a desperate trajectory to survival, as dictated by a discourse of stigma and gender inequality.

5.4.3 Interpretation in the context of literature

The findings of participants' struggle with living on ARV treatment was consistent with literature findings. Ivanova et al. (2012) reported negative feelings in the form of anxiety linked to taking ARV treatment, but were not able to establish the reason for this link. This theme offered possible insight into the link between negative feelings and taking ARV treatment.

Kalichman et al. (2005) and Sumari-de Boer (2012) also confirmed stigma as a barrier to adherence to ARV treatment in their study, as well as fear of side effects of ARV treatment, as with this theme. The support group and counsellors helped participants realise the necessity of taking ARV treatment. This was confirmed by Mynhardt (2006) who reported how context, such as the support group, has the ability to influence attitudes, as with the attitudes in this study regarding ARV treatment. This kind of contact helped participants to experience that

individuals are successfully functioning while taking ARV treatment. This was the strongest influence in shifting their perspective.

Conversely, Zuch and Lurie (2011) argued that ARV treatment will reduce stigma because it is able to prolong life, and therefore removes the fear of HIV/AIDS as a certain death sentence. Participants' experience indicated that this is not the case in their community, as the side effects of masculinity has a double burden: that of revealing that one has HIV/AIDS and that of failing to meet social expectations linked to the physical appearance of a woman, and therefore not fulfilling their gender role. Therefore, although ARV treatment positively affected participants, it remained attached to a negative meaning in the greater community of this setting.

5.4.4 Implication of the interpretation

Participants' temporary reluctance to take ARV treatment revealed a desperate and life threatening attempt to remain connected to the HIV negative category (Goldin, 1994), as opposed to the HIV positive category. Belonging to this category was understandably important to participants, due to exemption from enacted stigma. Belonging to this category incognito was achievable, as long as there were no visible signs, such as physical side effects of ARV treatment. The implication of this is that the governing stigma discourse is advocating participants into making a life threatening choice of possible non-compliance to ARV treatment, rather than suffering stigma and social rejection.

The programme offered an alternative meaning for participants to live by, and was successfully adopted by most participants. The meaningful shift took place within the programme's support group, in which participants witnessed other participants complying with ARV treatment and still appearing "*normal*". This was the visual proof that shifted participants' perspective and encouraged them to make the decision to take ARV treatment.

The programme has therefore effectively shifted meaning, which helped participants to shift their behaviour, as a new range of behaviours became available through new meaning. Therefore, although the programme did not reduce stigma, as its description suggests, it did accomplish a more beneficial outcome in that it shifted meaning and extended participants' behaviour range related to taking ARV treatment.

5.5 Focus Group theme: Restored sense of community

The socially devastating outcome of HIV/AIDS was the loss of participants' sense of community. The support group was a therapeutic experience in which participants experienced support, acceptance and solidarity. Their social needs were therefore met in the context of the programme.

5.5.1 Interpretation from a social constructionist perspective

Because a sense of community is socially constructed, participants were able to use language in the support group to construct new narratives related to community. Therefore, participants explored new possibilities regarding community within the support group in the form of discussion. Participants were able to engage in new narratives to restore an important aspect which was lost to them due to stigma. This was accomplished through creating a new meaning attached to community within the programme support group, a meaning which enabled participants to experience acceptance, support and solidarity.

Their previously lost sense of community was therefore successfully reconstructed in the context of the programme with fellow HIV positive participants. Therefore, engaging in the support group and co-constructing new meanings through narratives was participants' act of searching for a new ecology of ideas to live by (Bateson, 1972). Participants created norms of

meaning through which they could open up a new way of behaving in the context of living with HIV/AIDS.

There is much emphasis placed on the manner in which people talk about a problem in certain environments (Avis, Pauw, & van der Spuy, 1999). Participants spoke differently about their problems in the environment of the support group, and were able to behave and feel differently from what was possible in their communities. Avis et al. (1999) posit that the way in which a problem is talked about influences the problem and the experience of the problem. Therefore, the social interaction within this group has created new meaning in this group.

5.5.2 Interpretation in the context of the research question

Looking at participant meaning of a restored sense of community reveals that the programme has successfully enabled participants to create new meaning attached to community. This has therefore enabled them to experience a sense of community through feeling supported, accepted and solidarity with one another. The need to reconstruct a new sense of community was indicative of stigma not being successfully reduced in the surrounding community, as rejection, disconnectedness and isolation was still an experienced reality for participants in that setting, due to stigma. Participants were not successfully integrated back into their community, and thus sought a new one. This reveals that the context of meaning making within the community regarding social acceptance remained unchanged.

5.5.3 Interpretation in the context of literature

The support group within the programme facilitated open talk and communication between HIV positive members. The discussions, or meaning making, in the support groups was revealed to be the main factor in creating the positive experience of community amongst participants. This was also reiterated in the literature recommendations from chapter two, and

from this study it has proven to be a positive experience for participants, with positive implications on participant wellbeing. But this did not achieve the desired effect of reducing stigma; in fact, it appeared to strengthen the already existing barrier between HIV positive and the HIV negative people. This does not facilitate an opportunity for oneness.

The importance of experiencing this sense of community was also confirmed in literature. This sense of community is indicated to be important to the physical and psychological health of participants due to a link between social relatedness and mortality (Hubble, Duncan, & Miller, 2008). In a study by Theorell, Blomkvist, Jonsson, Schulman, Berntorp and Stigendal (1995), they refer specifically to findings that showed that men with HIV/AIDS with limited social support deteriorated far more rapidly compared to men with social support (Hubble et al., 2008).

Blake et al. (2008) found that women in their study also experienced social problems in the form of rejection, negative effects on relationships with loved ones and interaction with community. As a result, they experienced isolation, as in this theme. Zuch and Lurie (2011) also reported the social alienation and isolation attached to HIV/AIDS, and Ndinda et al. (2007) reported similar findings in rural KwaZulu-Natal. In the same study they also reported that a clinic provided a strong support system for participants, in which participants received HIV/AIDS education, emotional support, positive group identity, solidarity and open talk. Similar findings were found to be true of this study in participants' experience of the stigma reduction programme. Kurzban and Leary (2001) identified the importance of positive social contact for psychological and physiological health, suggesting that humans have a fundamental need to belong through social acceptance, or what they referred to as social preservation. This need was revealed through participants' co-creation of a new sense of community in order to fulfil this need.

5.5.4 Implication of the interpretation

The meanings behind the patterns of participant behaviour (Carroll, Adkins, Foth, Parker, & Jamali, 2008) revealed that participants were able to co-construct new narratives, but that these are not applicable in all contexts. The new meaning of acceptance, support and solidarity was limited to the experience of the support group, and has not been integrated into the outside community. Therefore, participants still did not experience a sense of community within their community, as meaning within the community remained unchanged. Therefore, the meaning constructed within the support group, is limited to the support group. This means that meaning and behaviour are context bound for participants. The division created by their status still remained, but participants were able to form a new group to have their social needs met.

Describing their experience of the programme as one of a sense of community indicates that participants have grouped themselves (HIV positive) together as a community. Narratives indicated references to us (HIV positive) and them (those that have not tested yet, or those that are negative). This meaning may prevent either group (us and them) from accepting one another as the dialogue alone has created an unseen wall or barrier. The sub theme of support was especially strong in the “us” and “them” placement.

Ironically, this new-found and therapeutic sense of commonality accentuates the perception of difference between support group members and their communities. Although participants demonstrated resilience in co-creating new meaning and living more satisfying lives, the new, richer meanings they subscribed to reinforced already existing division. Therefore, stigma maintained its meaning attached to division.

5.6 Focus Group theme: Social influence on programme

The perception that traditional ways of being are influencing effectiveness of the programme, reiterates the governing power of the larger social discourses. These are set out as social parameters which prescribe acceptable range of behaviours for society members. Participants live in a patriarchal community with traditional values and ways of being, which includes a specified dress code for females, as a demonstration of respect for the males and older figures within their community. This particular way of being, albeit neutral in terms of good or bad, is contributing to a large portion of the community remaining unresponsive to the programme, due to the perception of showing disrespect.

5.6.1 Interpretation from a social constructionist perspective

Social constructionism emphasises the social constructionist nature of the traditional ways of being, as set out in participant narratives. Participants appear bound by these ways of being in a sense that they are conforming to it. They have, however, not allowed these ways of being to keep them from attending the programme, as have other community members. Participants have therefore identified traditional ways of being as having value in being adhered to in the sense of social acceptance. But they have also identified the value of the programme in enabling them to cope with living with HIV/AIDS and dealing with stigma.

5.6.2 Interpretation in the context of the research question

It is evident from the reports of participants that traditional ways of being are discouraging a large portion of the community from participating in the programme. This reveals that the

Africa Centre may be unaware of this obstacle, and therefore unaware that it is preventing community members from receiving what the programme has to offer.

5.6.3 Interpretation in the context of literature

Owen (1995) confirmed the governing actions of cultural ways of being in defining what appropriate behaviour is, and what it is not, as was evident in this theme's findings of traditional influences in this community. Likewise, Campbell et al. (2005) reported similar governing actions at work in their study in which cultural contexts hindered the success of their peer programme, in that traditional leaders remained extremely conservative in their approaches and ways of being. They refer to Foucault's notion of power hierarchies, such as the patriarchal system of this community, and note how they are maintained through socialisation into behaviours that support this power hierarchy. This theme revealed similar notions at work.

5.6.4 Implication of the interpretation

The implication is that the patriarchal system is simultaneously maintained, together with the transmission of HIV/AIDS through stigma. This is done through the socialising behaviour of women wearing dresses as a form of respect and subservience to men, therefore reinforcing and maintaining the patriarchal system.

It also serves to covertly maintain the power system of stigma, due to the fact that efforts to reduce stigma in the form of the programme are hampered through lack of attendance due to the traditional dress code. Campbell et al. (2005) refer to stigma as a covert system of power, and it is powerfully maintaining the transmission of HIV/AIDS due to the fact that it is not being reduced. The programme may benefit from considering the traditional and cultural context in which it finds itself, in order to recognise aspects that are possibly contributing to ongoing stigma.

5.7 Individual Interview theme: Gender inequality as source of stigma and HIV/AIDS

When participants were asked to personally reflect on what it is like to be a female living with HIV/AIDS in their community, especially in the setting of the programme, deeply rooted patterns of inequality, specifically based on gender, were revealed. Participants shared how they felt used by men, that they had little say in sexual negotiations, and that certain things were expected of them in their relationships and in the community. Participants felt that they were not equal to men and unquestionably treated as such.

5.7.1 Interpretation from a social constructionist perspective

The context of this theme was within a patriarchal leadership system in participants' community, which lays strong emphasis on gender discourse to maintain its power (Campbell et al., 2005). Jordaan and Jordaan (1998) ascribe the meaning of gender roles to this patriarchal discourse, emphasising the disproportionate ownership of power by males, at the expense of females, as was illustrated in this theme.

Interpreting gender from a social constructionist perspective reveals that gender is a social construction. Avis et al. (1999) posit that gender roles are the result of social and cultural processes, linked to the dominant discourse operative in particular communities. They also argue that the structure of a society is usually organised according to a dominant discourse, such as gender.

Mynhardt (2006) reported that gender stereotypes cause us to see ourselves and others in a certain way (this point also becomes evident in the section on the identity theme). The different traits characterising genders serves as a dividing social category of male and female. It places the two sexes in boxes, which serves to control how sexes evolve into genders, and then behave

accordingly. This gender identity is developed from an early age, between the ages of four and seven (Mynhardt, 2006), and is thus deeply ingrained by the time we reach adult social identities and roles. Avis et al. (1999) agreed that gender discourses are instilled from a young age, and plays a determining role in our lives regarding how we behave and identify ourselves.

Papalia, Sterns, Feldman and Camp (2002) state that through socialisation, gender roles become embedded in an individual's identity, which then places a filter on their views of reality. For example, to participants in the programme, it is normal for men to have multiple sexual partners, consequently contributing to their infection.

Furthermore, Avis et al. (1999) report that the biological side of gender indicates the actual sex distinctions in people, and this in turn involves certain social and cultural values. They state that children learn what behaviours are associated with, and expected of different genders from a young age through observing, and a punishment/ reward system (1999). Avis et al. (1999) provide an historical example of gender roles from the 19th century, in which the functionality of a woman was limited to be purely reproductive in nature and that women should not be educated, or the correctness of a traditional patriarchal family. Possibly considered as sexist in modern day, these statements were nonetheless accepted and lived by. Participants' role in this theme as subservient and the giver of sexual pleasure may be interpreted as sexist in the feminist discourse, but within this context it remains accepted and lived by.

Kalichman et al. (2005) confirmed the social constructionist nature of gender by stating that gender is a system of social classification which in turn influences access to power, status and material resources, as also reflected in narratives of the experiences of participants in this study. They also added that all human societies allocated more power to men than to women, and therefore higher status (2005), agreeing with the findings of this theme.

5.7.2 Interpretation in the context of the research question

Participants expressed the larger gender discourse within which they lived. These narratives highlighted important aspects of what is expected of women and how this impacts on their daily lives. These narratives serve as a powerful indication of how the gender discourse influences behaviour, and the implication of leaving the meaning and origin of this discourse unquestioned.

In the context of the research question participants related their experience of being female and living with HIV/AIDS as a disadvantage, with the programme having a therapeutic effect, but unable to change their circumstances. Participants attributed the incidence of infection in women by their partners to the inequality in the romantic relationships setting. Consequently, a greater burden of stigma was placed on women, than on men.

The gender inequality between men and women is also reflected in the disproportionate infection rate of more women being infected (Dorrington et al., 2006). An unquestioned acceptance of this statistic reflects society's endorsement of the gender discourse. Considering the impact of enacted stigma on HIV/AIDS testing for both men and women, it would be an act of gender stereotyping to not consider the reason attributed to this disproportionate statistic, as already discussed.

Considering the impact of gender discourse on participants, it is important to consider the meaning of being a female participating in this programme. Being female impacts on how one experiences life, therefore the experiences reported by participants are unique to them as females in this setting. The gender term female, although indicating physical female sex characteristics, and what it means, has been socially constructed. Rorty (1979) suggests that

we did not cause or create all things, but that we do give meaning to them. For example, we did not cause or create gender, but we did assign certain meanings to it. Participants' narratives alluded to control exercised over them - socially, physically and sexually, due to the prescribed meaning of femaleness in this patriarchal community.

5.7.3 Interpretation in the context of literature

Narratives of participants regarding the implication of gender inequality, resonates with literature, and confirms that gender inequality not only has an effect on the identities, behaviour and relationships of women, but also directly influences their vulnerability to HIV/AIDS (Kalichman et al., 2005). According to Jordaan and Jordaan (1998), gender inequality includes discrimination against women, underemployment of women, violence against women and the violation of women's rights. They also report that the stereotyping of women creates expectations of what women should be like - for example, sensitive, emotional and gentle. Participants expressed this in that they were expected to look a certain way and behave in certain ways in their contexts, such as exclusively wearing dresses and being sexually submissive to men.

Kalichman et al. (2005) reported that culturally sanctioned gender roles nurture power imbalances which are linked to women's vulnerability to HIV/AIDS infection. This is due to the gender power imbalance, which places the woman in a subordinate role. This implies that women have little to no power to negotiate in sexual relationships, for example, condom use for protection against HIV/AIDS infection (Mogotlane et al., 2007; Stadler et al., 2008). Mogotlane et al. (2007) and Stadler et al. (2008) also reported that gender inequality places women in inferior roles in which they engage in transactional sex with men for economic gain in order to survive, which agrees with Kalichman et al.'s (2005) report of men having more power than women. Participants' narratives of this theme confirmed these findings.

In their study of gender attitudes, Kalichman et al. (2005) found that both men and women held beliefs about the traditional and submissive roles of women. Moreover, they found that women agreed and endorsed the stereotypical role of a woman, which resonated with this theme, in which participants did not question, but rather subscribed to this role. This emphasises the impact of not questioning societal discourses.

Mogotlane et al. (2007) reported that vulnerability to HIV/AIDS is high in cultures in which monogamous relationships are not obligatory, agreeing with this theme. The women in their study maintained that the transmission of HIV/AIDS was due to polygamy and their partners' refusal to wear condoms. They explained that in Zulu culture it is acceptable, and regarded as a status symbol, for men to have multiple sex partners. This reveals the deeply embedded and unquestioned inequality of women in these communities, around which their identities are shaped.

This implied two subtleties exposing the silent control of gender discourse: firstly, this implied that women had little to no negotiating power during sexual activities, and this allowed men to refuse condom use. Secondly, women wanted their partners to wear condoms because of their knowledge of their partners having more than one sex partner, and of the risk this posed. But rather than addressing the prevalence of polygamy within the relationship, this was not questioned, even though this, according to participants, was a contributing factor in infections within romantic relationships, as with this theme.

Poverty also placed participants in a position in which they felt pressurised to permit risky sexual activities, because of the economic support they stand to gain or lose. Participants explained that when one has nothing, there is nothing to lose, and therefore taking sexual risks seemed reasonable to them at the time. Stadler et al. (2008) confirmed this exchange of risky sex as a survival strategy, which in turn enforces the poverty theme. They reported cases of

females being purposefully infected by their partners, being in abusive relationships, and being the victim of sexual violence (Stadler et al., 2008). In their study, women remained reactive to these circumstances and despairingly accepted their fate, as with participants in this theme (Stadler et al., 2008).

5.7.4 Implication of the interpretation

An awareness that gender is socially constructed permits the consideration that gender is not a fixed truth, but a reality that can be challenged. Participants accepted gender as an immovable reality existing in their lives and linked to their physical gender. They identified the limitations this placed on them in terms of their behaviour and experiences, but this was not questioned by participants, rather dutifully accepted. Corey (2009) stated the importance of understanding and acknowledging oppression of women and the limitations imposed on them by their gender. It is not necessary to change the social gender role prescription per se (Corey, 2009), but to strive for a shift in oneself regarding the acknowledgement of the presence of this gender discourse, and the meaning given to it. The implication is that as long as gender inequality is unquestionably accepted, it has the potential to fuel both stigma and HIV/AIDS transmission.

5.8 Individual Interview theme: Self in relation to HIV/AIDS and stigma

Participants revealed how living with HIV/AIDS and stigma has influenced their self-perceptions. These narratives permitted a glimpse into the personal reflection on the self as exercised by participants. Articulating these to the researcher revealed that which influenced participants' building blocks to construct an identity related to HIV/AIDS and stigma. Narratives indicated periodic fluctuations in their personal self-perceptions yielding to the influence of HIV/AIDS, and especially stigma. These were largely based on the opinion or reaction of others, which was mainly grounded in stigma.

5.8.1 Interpretation from a social constructionist perspective

Participant narratives revealed that they are socially connected beings, and therefore stigma had a large influence on how they perceived themselves, as stigma influenced their social identities. Participant narratives illustrated the powerful ability of social factors such as discourse or meaning making, to influence or even shape their beliefs, and consequently, their experiences. Stigma influenced what participants believed about themselves, and this consequently influenced their behaviours.

This is important when considering the impact of participants' perceptions of themselves, irrespective of the validity of these perceptions. Individuals will behave according to what they believe, and therefore experience what they believe. Baron, Byrne and Branscombe (2006) refer to this phenomenon as a self-fulfilling prophecy. Participants may be comparing themselves to society in order to evaluate their self-perceptions as compatible or incompatible (Baron et al., 2006). Therefore, how others view them is not only significant, but this information may be used to gauge whether their self-perceptions are accurate or not, and may be used to adjust self-perceptions. The discourse of stigma becomes harmful, as it places females living with HIV/AIDS in a category, with an identity assigned to it.

A constructive shift took place within the participatory meaning making of the programme's support group, in that participants were able to create new meaning in this environment which was compatible with their self-perceptions prior to infection. Therefore, the authoring in the support group of a non-stigmatised identity affirmed participants' original views of themselves. The support group was pivotal as participants now associated with the group, and adopted the new identities formed by the group. Meyer, Moore and Viljoen (2003) posit that a person's identity reflects the need to determine one's place in society. This illustrates participants' preoccupation with how others view them, and the participants' desire to meet these standards.

The identity theme revealed and confirmed the larger dominant discourse of the community that participants found themselves in. Consideration of the dominant discourse revealed that participants have a limited range of behaviours within their horizon of behaviours to choose from, as behaviours are governed by meanings and perspectives. If perspectives are widened, then our range of behaviours widens likewise. Participants illustrated this in acting on newly constructed perspectives of self.

Being socialised into dominant discourses, like gender, puts patterns in place for interpreting experiences and meaning (Owen, 1995). Eatough, Smith, and Shaw (2008) agreed with this and posit that we make sense of ourselves through our interactions with our environment. The physical consequence of living with HIV/AIDS appeared to have less effect on self-perception than the stigma-driven social implications of the disease. Participant identities are socially constructed, as they deduce who they are from feedback they receive from others, and also what they have learnt about themselves through their experiences and through others (Johnson, 2006).

5.8.2 Interpretation in the context of the research question

Exploring the lived experiences of participants of this stigma reduction programme revealed their identities, which were shaped by their experiences and social factors. In the context of the research question they live according to their perception of their identities, and these place parameters on their range of behaviours.

Participants' identity narratives were directly related to their behaviours. Participant narratives revealed that participants view themselves in a certain way. These views are shaped by the larger dominant discourses in which they find themselves, such as gender and their culture. What does this have to do with their experiences regarding the HIV/AIDS programme? Just

this: it reveals that even if the programme was effective in reducing stigma, that HIV/AIDS transmission would still take place in their instances. Participants explained that their infections were caused by unfaithful partners who refused condom use, and that even in the absence of stigma, the cultural norms sanctioning polygamy would remain in place.

5.8.3 Interpretation in the context of literature

A study by Camp, Finlay and Lyons (2002) resonated with this theme's narratives of self. The findings of participants being aware of society's negative perceptions of women living with HIV/AIDS, and participants' rejection of this invalid perception, resonated with the findings of Camp et al. (2002), who reported similar findings.

Within the support group, being HIV positive meant accepting their status and implementing coping mechanisms. Support groups play an influential role in this identity of self-acceptance according to Johnson (2006), as he explains that relationships play a role in building a positive identity. His finding agreed with those of this theme.

Goffman (1963) stated that society teaches us to categorise its members by attributes that we apply as social identity. One's own social identity is therefore the consequence of the assessment of others. Participants act according to this socialisation by conforming to the social identity attributed to them. In society, the participants failed to meet social standards, but in the support group there were different standards, and therefore a different identity lived by in this setting. Romanyshyn (2008) posits that we know ourselves through the world, and that therefore the context in which we find ourselves plays a role in how we see ourselves. Participants used the context of the support group to co-create new perceptions of themselves through discussions, which confirmed Anderson and Goolishian's (1992) notion of the transformational power of narratives.

5.8.4 Implication of the interpretation

The dominant discourse which allocates power to one sex at the expense of the other (Kalichman et al., 2005), appears to be directly linked to the HIV/AIDS status of women, according to participants' narratives. Therefore, although aware of these contributing factors to their status and social standing, there was no avenue to explore that might offer them choice in the matter. This was perceived as a fixed reality. One which it seems most females adhere to in this community.

This reality, however, is not fixed, it is malleable, and it is malleable in the minds and meaning making of participants. Participants do not have to conform to identities which are not constructive to their wellbeing. Anderson (1992) posits that we define ourselves through language, as language influences our self-perceptions. Furthermore, language has the ability to shift who we are, as a shift in our language takes place; consequently, we use language to become who we desire to be (cited in Becvar & Becvar, 2005). This specific use of language in conversing with one another was evident in this theme, especially the context of the support group, to create more satisfying meanings relating to self.

5.9 Individual Interview theme: Prioritising living HIV/AIDS and stigma

The unexpected revelation that living with HIV/AIDS and stigma was a secondary to poverty, revealed much more than the dire financial situation of participants. Living with HIV/AIDS and stigma was not their primary experience in terms of day to day living. Although experienced daily, it was not the greatest influence and factor in their daily lives. The daily effects of living in poverty overshadowed all aspects of their lives, according to participants. They were able to manage and cope with HIV/AIDS and stigma to a degree, but they had no

means of managing and coping with poverty. Narratives were indicative of powerlessness, hopelessness and defeat.

5.9.1 Interpretation from a social constructionist perspective

Considering participants' emphasis on poverty from a social constructionist perspective, reveals that this is an influential discourse, as well as a material condition in which participants live (Yapa, 1996). Therefore, poverty is a socially constructed reality as well as a material condition labelled "poverty" in which participants find themselves. Moreover, poverty is how participants described the world which they experience and live in to the researcher.

What does poverty signify or mean in the lives of participants? According to participants, poverty signifies that they are poor, unemployed, that they lack sufficient income to supply their wants and needs. Factors (such as HIV/AIDS and stigma) therefore become secondary. These narratives were indicative of participants operating in a survival mode, so to speak (Carroll et al., 2008), as they considered most aspects secondary to poverty.

Poverty highlights the gap between what participants have and what participants lack (Yapa, 1996), which negatively affected the lives of participants. Yapa (1996) argues that what constitutes poverty is set out as a lack of basic needs, and contingent upon levels of income. The concept of poverty is therefore defined and categorised within the material condition of lack of what is specified as basic needs. The realisation of living in poverty therefore sets in, as soon as the condition of lack is identified. Yapa (1996) also reports that needs are constructed purposefully for capitalist gains, which leaves the poor dissatisfied with their material condition, and labelled as poverty stricken. Therefore, if we say that one is poor if one is not in possession of food, shelter and health care, then that material condition which characterises lack of food, shelter and health care receives a meaning and label of "poor".

He furthermore argues that this exact discourse is part of the problem of poverty. This notion raises questions such as: were people poor before they were told that they were poor? For example, did ancient Khoisan tribes live in poverty because they lacked a specified level of income, or what is today specified as basic needs? Or, more importantly, did they consider themselves as poor or living in poverty? Yapa (1996) posits that the meaning of poverty is negotiated, and therefore receives meaning when it is given meaning. Therefore, the meaning of an insufficient material condition is first created socially in language, then it becomes an insufficient material condition for whoever fits the category and accepts the negotiated meaning.

Conversely, Levering (1992) states that certain things still exist even if there is no word for it. For example, heat will still exist even if we did not have a word for it. In other words the material condition now called poverty existed before it received the label poverty, the problem is that a negative meaning has been attached to poverty, a meaning that it is a problem that must be solved. In short, in the words of participants *"it is bad to be poor"*.

What becomes apparent is that participants arranged their lives and meanings around a poverty narrative, consequently applying a negative meaning to their material condition. Although socially constructed, the meaning of poverty to participants has devastating effects on their human experience. To participants, poverty is a reality which they experience daily. Participants lived in a narrative of poverty which affected them negatively on a daily basis, and therefore it is significant and real to them regardless of the social constructionist nature thereof. Narratives were laced with lack, despair and a constant presence of inadequacy that has become a master narratives in their lives, as they confirmed that poverty overshadows everything in their lives. By everything, they meant everything from their relationships, health, and social interactions and their perceptions of themselves.

The poverty narrative was revealed to be a common theme in their community as well, and not limited to their own personal lives. This narrative of being poor, unemployed, and lacking sufficient income was a significant negative narrative for participants. As participants shared the devastating stories of their circumstances, the question remained: What narratives can be constructed to enable participants to live more satisfying lives? When enquired about what would alleviate poverty, their automatic response was - employment: *“If I can get a job I can be fine”*. This indicates a linear answer to a complex and socially constructed meaning.

Participants’ immersion in the poverty theme also highlighted the significance of absent themes or what is not being said (Richter & Muller, 2005): for example, being poor rules out being rich. Living in poverty rules out having enough to eat, adequate shelter, adequate health care and employment. Being poor rules out being healthy. Being poor rules out being accepted. Being poor rules out being content and satisfied. Being poor rules out living a successful life. The researcher contemplated the effects of this narrative when accepted as inevitable, as with this theme, concluding that such effects may be profoundly limiting.

Closely related to poverty and linked to the transmission of HIV/AIDS, was participants’ perception as to the cause of HIV/AIDS transmission. Participants perceived people in rural communities such as theirs, who are predominantly poor and lacking access to information about HIV/AIDS, as vulnerable to HIV/AIDS infection. When asked about the Africa Centre’s role in providing information to the community, participants indicated that many community members live in deeply rural locations and cannot afford transport to the centre to gain access to the information. Moreover, participants reported that members of their community are living in such poverty, that they view HIV/AIDS as a secondary problem. Consequently, people did not prioritise testing for their HIV status, because if tested positive, they would have yet another problem to deal with, in addition to their already pressing problem of poverty.

Participants revealed that poverty is such a vast and far reaching problem that it affects every aspect of their lives. This included not having enough food to eat or to feed their entire family, limited housing, and inadequate health care from government clinics and hospitals, lack of funds for transport, and limited schooling. The objective of this study was to explore the lived experiences of participants, and the meanings held by participants about those experiences (Finlay, 2011). It was therefore important to reflect on what poverty means to participants, and what it means to experience poverty. Participants point to poverty as the “*worst problem in my life*”. Poverty is viewed by participants as an objective problem which can be solved through employment opportunities. The implication of this is that there is only one solution in the minds of participants to poverty, and that is employment. This closes off exploring other avenues.

5.9.2 Interpretation in the context of the research question

The narratives around poverty confirmed its primary position in the lives of participants. The community narrative of poverty is the master narrative that influences all other narratives, as this is the main interpretation of their lives within the context of this environment. In terms of lived experiences, participants demonstrated a shift in the importance they placed on their health in terms of living with HIV/AIDS, as opposed to the sole primary importance previously placed on poverty. Participants indicated the value of the programme in highlighting, through counselling, that they can still focus on and manage living with HIV/AIDS, even while experiencing poverty. They became aware that poverty does not have to overshadow their concern for their health. The programme had little power to impact the larger poverty discourse and experience, but helped participants to not allow poverty to hamper their management of living with HIV/AIDS.

5.9.3 *Interpretation in the context of literature*

Participant narratives were consistent with literature findings around poverty, and the influence of the poverty narrative in the daily lives and experiences of participants. Viewing poverty from a social constructionist point of view revealed the socially constructed nature thereof, and participant narratives revealed the daily effects and consequences of this narrative construction which they live by. Of course, there are many ways to understand poverty, but for the purpose of this study the focus remains on social constructionism, to include our meaning making role in a phenomenon such as poverty. The narrative of poverty is nonetheless significant, as White (1993) explains that narratives shape our lives, and narratives which we live by have real, not imagined, effects.

Baumann (2006) reported that KwaZulu-Natal is one of the poorest regions in sub-Saharan Africa. This is consistent with participant reports and experiences of poverty, especially in rural areas. Dunkle, Jewkes, Brown, McIntyre, Gray and Harlow (2003) reported transactional sex as a direct consequence of poverty. Here, poverty stricken individuals exchange sexual favours for much needed commodities such as food or money, subsequently contributing to the transmission of HIV/AIDS. This was consistent with narrative reports of participants either engaging in similar behaviour, or having knowledge of others who do. This is often the case as the bread winner of the family succumbs to death from HIV/AIDS (Collins & Leibbrandt, 2007) and leaves the rest of the family desperate to survive.

Participants' narratives around poverty resonated with Goldin's (1994, p. 1363) report of the president of the Zaire Association for the Defence of Human Rights: "With an empty stomach, no job and often no place to sleep" little attention can be given to HIV/AIDS. Dionne, Gerland and Watkins (2013) agreed with this primary concern of poverty over HIV/AIDS in their study, in which they found that two thirds of participants in Malawi reported food security or money

to be their main concern, rather than health issues related to HIV/AIDS. They also found HIV/AIDS to be a low priority and concern, even amongst HIV/AIDS positive participants. They reported that a study in 2005 revealed economic survival to be a main topic of conversation rather than HIV/AIDS. Therefore, literature findings resonate with this theme in highlighting the impact of poverty on HIV/AIDS prevention and transmission.

5.9.4 Implication of the interpretation

This theme demonstrated that participant narratives are contingent upon the dominant discourse of poverty. Failure to recognise the effects of this discourse on participants' lives may lead to contributing to the discourse. Constant reflection was needed by the researcher on her own dominant discourse and how this influenced the interpretation of participants' narratives. The implication of this finding is the obvious need for reflection on how our narratives guide, influence and shape our lives. Socrates encouraged Athenians to question and challenge the social context of their taken for granted life worlds, expecting freedom to follow (de Botton, 2000). Questioning ours may have similar outcomes.

Participants shared what defined them through telling the stories of their lives. The meaning of poverty, to participants, remains strongly negative, as socially, it is associated with negative concepts such as lack, need, and low class. From their experiences it was revealed how the poverty discourse contributes to stigma as well as HIV/AIDS infection. This contributes to maintaining the status quo of the larger context and discourse in which participants make meaning.

The recognition that poverty plays a role in stigma and HIV/AIDS is imperative for effective HIV/AIDS-related stigma reduction programmes. Albeit that poverty may not be reduced through any such programmes, the awareness of its role is a step towards a choice in enforcing

or maintaining its meaning, as de Botton (2000) reminds us of Socrates notion of awareness of our larger social meaning making. Questioning the poverty discourse may not alleviate the condition of poverty, but may assist in highlighting its impact on our lives, HIV/AIDS and stigma.

5.10 Individual Interview theme: Empowerment

Participant narratives revealed how they moved from a perceived disempowered state, to a perceived empowered state regarding HIV/AIDS and stigma. Participants believed that the information impacted them in a significant manner and that they felt psychologically stronger than before. They therefore felt empowered through knowledge.

They perceived knowledge to expand their range of behaviours regarding HIV/AIDS, which has enabled them to live more satisfying lives. This was specifically related to knowledge that HIV/AIDS is not a death sentence if they adhere to ARV treatment, knowledge around HIV/AIDS, as this answers questions surrounding what is happening to their bodies, and knowledge of HIV status, as this enables a degree of control over HIV/AIDS through action.

5.10.1 Interpretation from a social constructionist perspective

Speaking from a social constructionist perspective it is perceived that it is not the actual knowledge that empowered participants, but how the knowledge was utilised, applied and the meanings participants attached to it. Participants demonstrated great resilience and desire to survive in attaching a constructive meaning to the information or knowledge given to them through the programme. This revealed that participants possessed this ability to gain mastery over their circumstance, or what they perceived as empowerment, even prior to the programme.

The knowledge or information served as a tool to be used by participants to construct positive meanings regarding their experiences around HIV/AIDS and stigma. This was supported by participants who attached value to the knowledge gained through the programme, mainly because of what the knowledge enabled them to do; in other words participants had the ability to effectively implement what they had learnt to benefit their circumstances. In implementing the knowledge it meant that knowing about HIV/AIDS, and their status, enabled participants to have more choices (Owen, 1995). Therefore, what they did with the knowledge impacted their lives.

5.10.2 Interpretation in the context of the research question

Participants' experience of empowerment in the context of the research question revealed that, although the programme did not reduce stigma in the manner it originally set out to, it did enable a shift in participants, despite this. The programme effectively influenced participants, through knowledge, for participants to shift their meanings and therefore shift their behaviour to more constructive behaviours such as perceived control over HIV/AIDS and a better understanding thereof.

5.10.3 Interpretation in the context of literature

Participants perceived the programme to be empowering, as they viewed the knowledge gained through the programme as a positive element which could save lives, reduce stigma and prevent further transmission of HIV/AIDS. Mkandawire, Tenkorang and Luginaah (2012) confirmed the link between lack of knowledge around HIV/AIDS and vulnerability to infection. Phaladze, Human, Dlamini, Hulela, Hadebe, Sukati, Makoe, Seboni, Moleko and Holzemer (2005) also reported that people were unaware that HIV/AIDS is not an automatic death sentence, and that one can live successfully and productively with HIV/AIDS on ARV treatment. This has the potential to influence the perception of HIV/AIDS as an automatic death sentence (Zuch &

Lurie 2011), and also prevent possible suicides linked to HIV/AIDS. Zuch and Lurie (2011) also confirmed the perception of HIV/AIDS as an automatic death sentence, and that information about ARV treatment helped people to realise that they had a future – a perception that was confirmed when HIV/AIDS sufferers witnessed others living on ARV treatment. They also reported that support groups help people to accept their status, following the normalising effect of realising how many people suffer from the disease, as with this empowerment theme.

According to participants the programme was the source of knowledge gained. Participants did not indicate other effective sources of information around HIV/AIDS. Participants also revealed that it is not socially acceptable to openly discuss HIV/AIDS, therefore the topic remains dark and uncertain. Stadler et al. (2008) confirmed that talking openly about HIV/AIDS is not common practice, and participants in this theme agreed that this silence contributes to the spread of HIV/AIDS. Stadler et al. (2008) also indicated empowerment through knowledge around HIV/AIDS, and the importance of knowing ones status. These findings, along with the findings of this theme, concludes the value of awareness and the power of knowledge in a format in which it can be applied.

5.10.4 Implication of the interpretation

Although empowerment through knowledge did not directly impact enacted stigma in participants' community, it did produce a more satisfying way of living for participants. Participants indicated a control over HIV/AIDS, and therefore, power. Considering their possession of power in the larger discourses of poverty and gender, the perception of power over HIV/AIDS was a positive element for them. Consequently, choices were available to them.

Macintyre, Rutenberg, Brown and Karim (2004) reported that knowledge by itself is not likely to alter the behaviour of the receiver, and the question was raised as to what happens between receiving knowledge and behaviour change. The answer it seems, is personal relevance, in this case the actual, possible or suspected HIV/AIDS status of the individual. To the participants, knowledge around HIV/AIDS has now become significant as it bears a direct relationship to them. Perhaps earlier on in their lives knowledge around HIV/AIDS would not have been significant, as it did not have any relation to them personally. As one participant recalled, her church tried to warn her that her behaviour was increasing her vulnerability to HIV/AIDS, but this did not impact her. Only when she learned of her status, did knowledge around HIV/AIDS have a bearing on her life.

A personal example from the researcher's life to illustrate the point is that she suffered the loss of a parent due to rabies. Prior to the death, information around rabies had very little impact on, or interest for the researcher, but after the encounter with rabies, information around rabies became valuable and had a direct impact on the behaviour of the researcher, and preventative measures were implemented. Information carries different meaning in our lives, depending on our experience of it, or our relationship to it.

Jordaan and Jordaan (1998) posit that we are in constant communicative contact with our world and we must be able to receive information about our environment; therefore, as soon as HIV/AIDS becomes part of our environment we are able to receive and integrate information about it. The problem with this sequence is that by the time participants learned about HIV/AIDS, it was too late.

The link participants made between information and empowerment also implies that they attribute empowerment within themselves to outside factors, such as the programme giving them information. For participants, the main experience was that they received information and

used it to make decisions in their own lives, to take control of HIV/AIDS, and to be better off for it. They had a say in what happens regarding this virus in their bodies, not the other way around. The implication for existing and future programmes is to package information to make it relevant, before it becomes relevant.

5.11 Limitations

This study is grounded in social constructionism, which may be perceived as a limitation. This implies that the data gathered may inadvertently be skewed or forced to fit the researcher's own understanding or meaning making (Owen, 1995). Therefore, the researcher's understanding or meaning making must be objective, or excluded to prevent it from influencing data. But excluding one's own understanding or meaning making would not be possible, and can therefore not be considered a practical suggestion in social constructionism. An acute self-awareness is therefore required with a constant contemplation of one's own participation in the meaning making of the research process.

The constant awareness of meaning making also allowed the application of the sincerest form of being in the moment during the focus group and interviews. Constant checking and re-checking to determine if what was heard was correctly understood, assisted in participant meaning being understood as best and as authentically as possible. Being in the present moment with participants as they offered their narratives invoked sensations within the researcher, as only allowing one's self to be in the moment can do.

Laverty (2003) refers to Husserl's phenomenology requiring being in the moment, or consciousness of what is heard, felt, experienced, and seen. Being in the moment allows for a true experience of the phenomena at hand, which in turn permits a more authentic understanding of that is being communicated. These sensations which the narratives invoked

on the researcher, were indicative of what participants were portraying in their narratives, and could therefore be used in attempting to understand what was being said. These interpretations were presented in this chapter as honestly as possible.

The grounding in social constructionism also served the opposite function, that is, non-limiting in its revelation of the larger discourses of participants, which confirmed their narratives in their true form. From a quantitative perspective, which emphasises generalisability and objectivity (Terre Blanche et al., 2006), social constructionism may be regarded as a liability. However, social constructionism allows more to be seen, heard and felt. Therefore, considered a strength when dealing with persons and their deeply personal and social worlds.

Due to their subjective and interpretive nature, the findings of this study may not be scientifically generalisable as quantitative data allow for, but they have revealed the life worlds of participants who are in the midst of living the very topic of this study. Therefore, these accounts are deemed relevant. The size of the focus group also conferred confidence that what was understood from one participant was confirmed and reiterated by another participant and so forth.

5.12 Overlapping themes

The overlapping themes served to create an overall picture of the social discourses, within which participants lived, each influencing the other, with patterns of behaviour demonstrating their governing authority in the lives of participants.

In the focus group, participants' desire to preserve social identities overlapped with facing struggles in coming to terms with the implications of living with HIV/AIDS. Both themes manifested in behaviour patterns aimed at concealing the reality of HIV/AIDS in the eyes of their community, through non-disclosure practices and reluctance to ARV treatment. This

highlighted the unchanged meaning of stigma and the impact of this discourse on participant behaviour, aimed at the same outcome of dissociation with HIV/AIDS.

Similarly, themes such as social parameters on programme and prioritising living with HIV/AIDS expressed the priority of the programme within this context as adhering to tradition and the problem of poverty over and above attendance to the programme. The priority placed on the programme, and consequently HIV/AIDS were highlighted in these two themes. These two themes centred on factors discouraging community members from benefitting from the programme. Both tradition and poverty were prioritised above HIV/AIDS, and therefore impacted on the health of this community.

Likewise, prioritising living with HIV/AIDS, gender inequality as source of stigma and HIV/AIDS infection, desire to preserve social identity and social parameters on programme expressed larger social discourse related to injustice or inequality. These discourses related to gender inequality, social or economic inequality (poverty) and tradition, directly impacting on the overall experience and enforcement of stigma. Campbell et al. (2005) posit that stigma supports systems of inequality, and in effect serves to maintain this power imbalance. Participants agreed that their experiences of gender and social inequality directly contributed to their HIV/AIDS infection, which is exacerbated by stigma. This suggests an unequal distribution of power in the context of participants' environment. Even the positive themes such as empowerment had power undertones in that power has been given by the programme to participants via knowledge.

The overlapping themes were therefore also an indication of power distribution as maintained by a dominant discourse, as manifested in certain areas such as gender, economics, knowledge and health. Participants' narratives were indicative of control exercised over them through these themes, in terms of parameters on behaviours, through limiting discourses. The

overlapping themes were a reflection of the intertwined social meaning making system, with its implications for the lives of participants, and participants' roles in maintaining and contributing to these.

5.13 Recommendations

The findings of this study highlighted the personal lived experiences of participants in the Africa Centre's stigma reduction programme, and therefore revealed how participants experienced this programme, and the influence of the programme on their lives. Discourses were highlighted through participant narratives, which influenced and reinforced stigma, as unquestioned and unchallenged. It may prove constructive if future studies explore the lived experiences of more stigma reduction programmes, as with this study, in order to better understand how participants experience such programmes, and what meanings they attach to such programmes. The influence of such programmes may then become apparent.

This may contribute to programmes acknowledging their role in meaning making, as well as a responsibility in co-creating new meaning relating to stigma together with participants, for more satisfying meanings. The programmes' role in meaning making of participants may therefore contribute to new meaning for participants which may consequently contribute to living more satisfying lives.

5.14 Conclusion

This study set out to explore the lived experiences of participants in an HIV/AIDS-related stigma reduction programme. What the study discovered was 20 unique and resilient participants who freely shared their lives with an unknown researcher. The narrative rendering of these women's lived experiences revealed what few other explorations can reveal: their meaning making, their social discourses, how their lives are shaped through discourses, their

experiences of phenomena, and what these experiences mean. This, in turn, revealed how larger social discourses imprisoned participants in experiences of social injustice, gender inequality, poverty and HIV/AIDS and stigma. Moreover, it revealed participants' natural trajectory toward resilience and survival, despite their circumstances.

Although narratives were disturbingly dark and sad - through themes such as the desire to maintain social identity, coming to terms with the implications of living with HIV/AIDS, gender inequality as a driver of HIV/AIDS infection and stigma, and prioritising living with HIV/AIDS, participants demonstrated a light within themselves through themes of restored sense of community, self in relation to HIV/AIDS and stigma, and empowerment.

In terms of the programme specifically, it was found that enacted stigma was not reduced, but rather circumvented, as narratives revealed the ongoing experience of enacted stigma, as well as the meaning of stigma remaining firm and unchanged. Narratives also revealed stigma's foundation in the bedrock of power relations enacted through patriarchy and economics. Narratives revealed how participants were able to use the programme to co-construct more satisfying narratives for themselves, despite the larger social discourses of poverty, gender and culture. The programme therefore had therapeutic potential in its capacity for narrative co-construction of new and wider perspectives.

The experiences of the programme revealed to participants, and the researcher, that although not significantly successful in reducing stigma as the programme set out to do, it has offered a platform to influence participants, and when participants transform, their experiences transform. The programme highlighted that which cannot be lost to participants, despite the losses suffered through HIV/AIDS and stigma. For example, participants perceived their sense of community to be lost to them through HIV/AIDS, but realised through this apparent loss, that their sense of community is indeed something they cannot lose, as they have the choice to

co-construct what and who they deem as community. A platform for co-creation which was enabled through the support group.

Anderson and Goolishian (1992) posit that, as humans, we generate meaning through language. This implies that the power to create meaning lies within us and our languaging. Meaning is not an out there object, but an intersubjective social construct, which is transformed through new narratives, which co-construct new meanings, which manifests in new behaviours. Participants were able to use the programme as a platform to exercise this ability. Therefore, although the programme did not shift the meaning of stigma in the community at large, it enabled participants to activate a shift within themselves which led to the adoption of richer perspectives and behaviours. The imperative remains to effect such transformation in the broader community and culture, in which stigma, gender inequality, and power relations remain in place, and undermine community wellbeing in the context of HIV/AIDS.

Participant narratives confirmed the powerful impact of the stigma discourse, as it influenced participants' decision making related to their behaviours. Participants were in essence conferring currency on a harmful discourse by allowing it to mould their behaviour. Subscribing to the meaning of stigma serves to reinforce and maintain its meaning. A division is built into in these discourses: poverty is a division between the rich and poor; gender is a division between male and female; HIV/AIDS-related stigma is a division between those perceived to be healthy and those perceived to be ill. Even in psychology division is created: the abnormal and the normal, each implying an unequal possession of power. When we socially divide ourselves we create marginalised and minority groups, and we make society weaker by creating division through social discourses as illustrated in participant experiences.

So what was the motivation behind this study? To illustrate the lodgement of stigma in our language as a monotonous discourse and meaning making, and the consequences of this. And

therefore, the need to concentrate on language and meaning making around stigma in participants. Literature reported that stigma is not fixed - it is malleable because it is socially constructed, but to understand this better we need to identify its lodgement in participant narratives. The key therefore, would not be to reduce stigma or to attempt behaviour modification of participants, but to create a context in which new perspectives may be introduced.

Challenging these set and monotonous meanings of stigma may prove valuable in introducing new perspectives, as Anderson and Goolishian (1992) highlighted the transformational power of narratives. This may be accomplished by negotiating meaning through narratives, stories and conversations, as the problem, so to speak, is lodged in language. If meaning is changed, behaviour is changed, and therefore experiences change. A sentence summarising the entire study would be a reiteration of Costall's (1980) reference to Wittgenstein's notion that limitations in our languaging are in equal proportion to the limitations in our experiences.

What is needed is a sensitivity to how we language intersubjectively, and the possible impact of words. What we speak has its origin in our minds, as King (2004) reminds us of Derrida's notion that words reflect the workings of the mind. The importance of being tentative about thoughts appears also in Proverbs 23:7 (New King James Version), in which it states that as we think in our hearts, so are we. When we interact, meaning is inadvertently created, but we do have the power to yield to this meaning, or shift it to create a more satisfying and constructive way of being.

How can data that attest to what people are going through be put to use? The usefulness lies in confidently illustrating the impact of an unquestioned social discourse, as posited by Foucault (1972). More specifically, earlier it was stated that HIV/AIDS-related stigma is a problem of monotonous and limited narratives. Narratives which are lodged in larger social discourses,

which ascribe and dictate meaning. This was illustrated through the narratives of the experiences of participants in the context of the stigma reduction programme, a programme which attempted change through behaviour modification. According to Owen (1995) the social constructionist approach should use qualitative methods to look at how meanings change. He suggests that when looking at problems, that the addressing of symptoms, or problem solving are not necessarily effective from the viewpoint of social constructionism. This point was confirmed by participant narratives, as stigma has not been reduced or removed within their context. Owen (1995) further posits that engaging in coping mechanisms, which enable acceptance and more satisfying experiences despite unchanged circumstances, is a measure of positive therapeutic experience. This was also confirmed by participant narratives as already discussed.

Now that attention is directed at this submission of the importance of meaning making, an urgent inquiry into meaning making around stigma and the role of larger social discourses should be evident. Here, de Botton's (2000) reference to Socrates' questioning of the larger social meaning making surfaces once again, and this study indicates the merit of identifying that a phenomenon such as stigma enters our collective minds and consequently we adhere to its meaning which is then expressed through our behaviour patterns (Leaf , 2013). Equally important is its lodgement in larger social discourses related to injustice and inequality.

To prevent this notion from morphing into an idealistic, unattainable statement, focus is directed back to the platform which the programme created. This platform was used by participants to create more satisfying and constructive ways of being in an unforgiving context. If more such platforms are used to challenge existing social injustices through expanding narratives that yield more satisfying social constructions and ways of being, we may be well on our way to meaning making that works for everyone, as every individual is responsible for

their own meaning making. Providing a context in programmes in which shifting perceptions can flourish, is key. Shifting perceptions offers an option in keeping with social constructionism. Hoffman (1985) reminds us that we do not live according to an objective out there reality, but according to our constructions of it. If it is our constructions of meaning, we can shift it. We change, therefore our experiential world changes.

6 References

- Anderson, H., & Goolishian, H. (1992). The client is the expert: a not-knowing approach to therapy. In S. McNamee, & K. J. Gergen, *Therapy as Social Construction* (pp. 25-39). London: Sage Publications Ltd.
- Anderson, T. (1992). Reflections on reflecting with families. In S. MacNamee, & K. J. Gergen, *Therapy as Social Construction* (pp.54-68). London: Sage Publications Ltd.
- Applebaum, M. H. (2011). Amedeo Giorgi and Psychology as a Human Science. *NeuroQuantology*, 9(3), 518-525.
- Auerswald, E. H. (1985). Thinking about Thinking in Family Therapy. *Family Process*, 24(1), 1-12.
- Avis, P., Pauw, A., & Van der Spuy, I. (1999). *Psychological Perspectives: An introductory workbook*. Cape Town: South African Pearson Education.
- Baron, R. A., Byrne, D., & Branscombe, N. R. (2006). *Social Psychology Eleventh Edition*. London: Allyn & Bacon/ Pearson.
- Bateson, G. (1972). *Steps to an ecology of mind*. Chicago: University of Chicago Press.
- Baumann, L. C. (2006). Behavioral Health for All. *Annals of Behavioral Medicine*, 32(3), 226.
- Becvar, D. S., & Becvar, R. J. (2005). *Family Therapy: A Systemic Integration (6th Edition)*. Boston: Allyn & Bacon.
- Bekele, A., & Ali, A. (2008). Effectiveness of IEC interventions in reducing HIV/AIDS-related stigma among high school adolescents in Hawassa, Southern Ethiopia. *Ethiopian Journal of Health Development*, 22(3), 232-242.
- Berger, P. L., & Luckmann, T. (1966). *The Social Construction of Reality*. New York: Penguin Books.

- Berglund, H. (2007). Researching entrepreneurship as lived experience. In H. Neergaard, & J. Ulhoi, *Handbook of Qualitative Research Methods in Entrepreneurship* (pp. 75-93). Cheltenham: Edward Elgar.
- Birnbaum, J. K., Murray, C. J., & Lozano, R. (2011). Exposing misclassified HIV/AIDS deaths in South Africa. *Bulletin of the World Health Organization*, 89, 278-285.
- Blake, B. J., Jones Taylor, G. A., Reid, P., & Kosowski, M. (2008). Experiences of women in obtaining human immunodeficiency virus testing and healthcare services. *Journal of the American Academy of Nurse Practitioners*, 20(1), 40-46.
- Brown, L., Trujillo, L., & Macintyre, K. (2003). Interventions to reduce HIV/AIDS stigma: what have learned? *AIDS Education and Prevention*, 15(1), 49-69.
- Bruffee, K. A. (1986). Social Construction, Language, and the Authority of Knowledge: A Bibliological Essay. *College English*, 48(8), 773-790.
- Camp, D. L., Finlay, W. M., & Lyons, E. (2002). Is low self-esteem an inevitable consequence of stigma? An example from women with chronic mental health problems. *Social Science Medicine* 55(5), 823-834.
- Campbell, C., Foulis, C. A., Maimane, S., & Sibiya, Z. (2005). "I have an evil child at my house": Stigma and HIV/AIDS Management in a South African Community. *American Journal of Public Health*, 95(5), 808-815.
- Carr, D., & Nyblade, L. (2007). *Taking action against HIV Stigma and discrimination*. London: Department for International Development.
- Carroll, J.-A., Adkins, B., Foth, M., Parker, E., & Jamali, S. (2008). My place through my eyes: A social constructionist approach to researching the relationships between socioeconomic living contexts and physical activity. *International Journal of Qualitative Studies on Health and Well-being*, 3(4), 204-218.
- Chao, L.-W., Gow, J., Akintola, G., & Pauly, M. (2010). HIV/AIDS Stigma attitudes among educators in KwaZulu-Natal, South Africa. *Journal of School Health*, 80(11), 561-569.

- Cluver, L. D., Gardner, F., & Operario, D. (2008). Effects of Stigma on the Mental Health of Adolescents Orphaned by AIDS. *Journal of Adolescent Health, 42*, 410-417.
- Collins, D. L., & Leibbrandt, M. (2007). The financial impact of HIV/AIDS on poor households in South Africa. *AIDS, 21*(7), 75-81.
- Corey, G. (2009). *Theory and Practice of Counselling and Psychotherapy (Eighth Edition)*. Belmont: Thompson Books/ Cole.
- Costall, A. (1980). The Limits of Language: Wittgenstein's later Philosophy and Skinner's Radical Behaviourism. *Behaviorism, 8*(2), 123-131.
- Crocker, J., Major, B., & Steele, C. (1998). Social Stigma. In D. Gilbert, & S. Fiske, *Handbook of Social Psychology* (pp. 504-511). McGraw Hill: Boston.
- de Botton, A. (2000). *The Consolations of Philosophy*. London: Penguin Books.
- Dionne, K. Y., Gerland, P., & Watkins, S. (2013). AIDS Exceptionalism: Another Constituency Heard From. *AIDS and Behavior, 17*(3), 825-831.
- Dorrington, R., Johnson, L. F., Bradshaw, D., & Daniel, T. (2006). *The Demographic Impact of HIV/AIDS in South Africa*. Cape Town: Centre for Actuarial Research.
- Dunkle, K., Jewkes, R., Brown, H., McIntyre, J., Gray, G., & Harlow, S. (2003). *Gender-based violence and HIV Infection among pregnant women in Soweto*. Tygerberg: AusAID.
- Eatough, V., Smith, J., & Shaw, R. (2008). Women, anger and aggression: An interpretative phenomenological analysis. *Journal of Interpersonal Violence, 23* (12), 1767-1799.
- Finlay, L. (2011). *Phenomenology for Therapists: Researching the Lived World*. Chichester: John Wiley & Sons.
- Fischer, C. T. (2009). Bracketing in qualitative research: Conceptual and practical matters. *Psychotherapy Research, 19*(4), 583-590.
- Foucault, M. (1972). *The Archaeology of Knowledge & The Discourse on Language*. New York: Pantheon Books.

- Genosko, G. (1996). *The Guattari Reader: Pierre-Félix Guattari*. Oxford: Blackwell Publishers Ltd.
- Gergen, K. J. (1985). The Social Constructionist Movement in Modern Psychology. *American Psychologist*, 40(3), 266-275.
- Goffman, E. (1963). *Stigma: Notes on the management of Spoiled Identity*. London: Penguin Books.
- Goldin, C. S. (1994). Stigmatization and Aids: Critical issues in public health. *Social Science and Medicine*, 39(9), 1359-1366.
- Griffith, J. L., Griffith, M. E., & Slovik, L. S. (1990). Mind-Body problems in Family Therapy: Contrasting First- and Second Order Cybernetic approaches. *Family Process*, 29(1), 13-28.
- Grobler, H., Schenck, R., & Du Toit, D. (2003). *Person-centred Communication: Theory and Practice*. New York: Oxford University Press.
- Heeren, G. A., Jemmott, J. B., Ngwane, Z., Mandeya, A., & Tyler, J. C. (2013). A Randomized controlled pilot study of HIV risk-reduction intervention for sub-Saharan African University Students. *AIDS and Behavior*, 17(3), 1105-1115.
- Henning, C. (2002). Confronting Data Analysis with Constructivist Philosophy. In K. Jajuga, A. Sokolowski, & A. Bock, *Studies in Classification, Data Analysis, and Knowledge Organization* (pp. 235-243). Berlin: Springer
- Herek, G. M., Capitanio, J. P., & Widaman, K. F. (2003). Stigma, Social Risk, and Health Policy: Public attitudes toward HIV surveillance policies and the Social Constructionism of illness. *Health Psychology*, 22(5), 533-540.
- Hill, D. M., & Kurtz, D. L. (2008). The effects of stigma on Aboriginal women living with HIV/AIDS. *Canadian Journal of Aboriginal Community-based HIV/AIDS Research*, 1(1), 5-14.
- Hoffman, L. (1985). Beyond power and control: Toward a second order family systems therapy. *Family Systems Medicine*, 3(4), 381-396.

- Hubble, M. A., Duncan, B. L., & Miller, S. D. (2008). *The Hearth and Soul of Change: What Works in Therapy*. Washington: American Psychological Association.
- Ivanova, E. L., Hart, T. A., Wagner, A. C., Aljasseem, K., & Loutfy, M. R. (2012). Correlates of Anxiety in Women Living with HIV of Reproductive Age. *AIDS and Behaviour*, *16*(8), 2181-2191.
- Jasseron, C., Mandelbrot, L., Dollfus, C., Trocmé, N., Tubiana, R., Tégas, J. P., . . . Warsawski, J. (2013). Non-Disclosure of a Pregnant Woman's HIV Status to her Partner is Associated with Non-Optimal Prevention of Mother-to-Child Transmission. *AIDS and Behavior*, *17*(2), 488-497.
- Jewkes, R. (2006). Beyond Stigma: Social Responses to HIV in South Africa. *The Lancet*, *368*(9534), 430-431.
- Johnson, D. W. (2006). *Reaching Out: Interpersonal Effectiveness and Self-actualization (Ninth Edition)*. Boston: Pearson Education.
- Jordaan, W., & Jordaan, J. (1998). *People in Context (Third Edition)*. Johannesburg: Heinemann Academic.
- Jung, C. (1933). *Modern Man in search of a Soul: Translated by W.S Dell and C.F Baynes*. London: Harvest/HBJ Book
- Kalichman, S. C., Simbayi, L., Jooste, S., Toefy, Y., Cain, D., Cherry, C., & Kagee, A. (2005). Development of a Brief Scale to Measure AIDS-Related Stigma in South Africa. *AIDS and Behavior*, *9*(2), 135-143.
- Kalichman, S. C., Simbayi, L., Kaufman, M., Cain, D., Cherry, C., Jooste, S., & Mathiti, V. (2005). Gender Attitudes, Sexual Violence, and HIV/AIDS Risks among Men and Women in Cape Town, South Africa. *The Journal of Sex Research*, *42*(4), 299-305.
- Keeney, B. P. (1979). Ecosystemic epistemology: An alternative paradigm for diagnosis. *Family Process*, *18*(2), 117-129.

- Kheswa, G., & Duncan, N. (2011). The stigmatisation of children affected by HIV and AIDS in a Gauteng township area. *South African Professional Society on the Abuse of Children, 12(1)*, 38-50.
- King, P. J. (2004). *One Hundred Philosophers*. Cape Town: Zebra Press.
- Kurzban, R., & Leary, M. R. (2001). Evolutionary Origins of Stigmatization: The functions of social exclusion. *Psychological Bulletin, 127(2)*, 187-208.
- Laverty, S. M. (2003). Hermeneutic Phenomenology and Phenomenology: A comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods, 2(3)*, 1-29.
- Leaf, C. (2013). *Switch on your brain*. Grand Rapids: Baker Books.
- Lekganyane, M. R. (2010). Anticipated and enacted stigma among female outpatients living with HIV: the case of Chris Hani Baragwanath Hospital, South Africa (Masters Thesis). Retrieved from Electronic Theses and Dissertations Unisa <http://hdl.handle.net/10500/3758>.
- Levering, B. (1992). The language of Disappointment: On the Language Analysis of Feeling Words. *Phenomenology and Pedagogy, 10*, 53-74.
- Loftin, G. M. (2007). Unacceptable Mannerisms: Gender Anxieties, Homosexual Activism, and Swish in the United States, 1945-1965. *Journal of Social History, 40(3)*, 577-596.
- Macintyre, K., Rutenberg, N., Brown, L., & Karim, A. (2004). Understanding Perception of HIV Risk among Adolescents in KwaZulu-Natal. *AIDS and Behavior, 8(3)*, 237-250.
- Magwaza, B. W. (2009). Knowledge of and exposure to the HIV/AIDS workplace programme and stigma and discrimination amongst employees of the South African Police Services (SAPS): a study at the Pretoria Head Office (Masters Thesis). Retrieved from: Unisa Theses and Dissertations (Sociology) <http://hdl.handle.net/10500/3765>.
- Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Ortiz, D., Szekeres, G., & Coates, T. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendation for the way forward. *AIDS, 22(2)*, 67-79.

- Major, B., & O' Brien, L. (2005). The Social Psychology of Stigma. *Annual Review of Psychology*, 56, 393-421.
- Mawar, N., Sahay, S., Pandit, A., & Mahajan, U. (2005). The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian Journal of Medical Research*, 122(6), 471-484.
- Meyer, M. E. (2010). *A sociological analysis of the nature, extent and comprehensiveness of stigma in people living with HIV/AIDS in areas of the Gauteng Region (Ekurhuleni, Sedibeng and West Rand)*. Unpublished Master's thesis .
- Meyer, W., Moore, C., & Viljoen, H. (2003). *Personology: From Individual to Ecosystem (Third Edition)*. Sandown: Heineman Publishers.
- Mkandawire, P., Tenkorang, E., & Luginaah, I. N. (2012). Orphan Status and Time to First Sex Among Adolescents in Northern Malawi. *AIDS and Behaviour*, 17(3), 939-950.
- Mogotlane, S., Hazell, E., & Mthembu, B. (2007). Women's cultural perspectives on reasons for HIV/AIDS prevalence in a rural area of the Kwa Zulu-Natal province of South Africa. *Africa Journal of Nursing and Midwifery*, 9(2), 35-43.
- Mynhardt, J. C. (2006). *South African Supplement (2nd Edition) to Social Psychology (Eleventh Edition)*. Cape Town: Lynn Koch.
- Ndinda, C., Chimbwete, C., McGrath, N., & Pool, R. (2007). Community attitudes towards individuals living with HIV in rural KwaZulu-Natal, South Africa. *AIDS Care*, 19(1), 92-101.
- Ogden, J., & Nyblade, L. (2005). *Common at Its Core: HIV-Related Stigma Across Contexts*. International Centre for Research on Women.
- Owen, I. R. (1995). Social Constructionism and the theory, practice and research of psychotherapy: A phenomenological psychology manifesto. *Boletin de Psicologia*, 46, 161-186.
- Papalia, D., Sterns, H., Feldman, R. D., & Camp, C. (2006). *Adult Development and Aging (3rd Edition)*. New York: McGraw-Hill.

- Phaladze, N. A., Human, S., Dlamini, S. B., Hulela, E. B., Hadebe, I. M., Sukati, N. A., . . . Holzemer, W. L. (2005). Quality of Life and the Concept of "Living Well" with HIV/AIDS in Sub-Saharan Africa. *Journal of Nursing Scholarship*, 37(2), 120-126.
- Richmond, H. J. (2002). Learners' Lives: A Narrative Analysis. *The Qualitative Report*, 7(3), Retrieved from <http://.nova.edu/sss/QR/QR7-3/richmon.html>.
- Richter, A., & Müller, J. (2005). The forgotten children of Africa: Voicing HIV and Aids orphans' stories of bereavement: a narrative approach. *HTS Theological studies*, 61(3), 999-1015.
- Riessman, C. K. (2005). Narrative Analysis. In N. Kelly, C. Horrocks, K. Milnes, B. Roberts, & D. Robinson, *Narrative, Memory, and Everyday Life* (pp. 1-7). Huddersfield: University of Huddersfield.
- Romanyshyn, R. D. (2008). Journeying with Van den Berg. *Janus Head*, 10(2), 397-414.
- Rorty, R. (1979). *Philosophy and the mirror of Nature*. Princeton: Princeton University Press.
- Sandelowski, M. (1991). Telling Stories: Narrative Approaches in Qualitative Research. *Journal of Nursing Scholarship*, 23(3), 161-166.
- Sengupta, S., Banks, B., Jonas, D., Miles, M. S., & Smith, G. C. (2011). HIV Interventions to reduce HIV/AIDS Stigma: A systematic review. *AIDS and Behavior*, 15(6), 1075-1087.
- Shisana, O., Rehle, T., Simbayi, I. C., Zuma, K., Jooste, S., Pillay-van-Wyk, V., . . . SAMSSM III Implementation team. (2009). *South African National HIV Prevalence, incidence, Behaviour and communication survey 2008: turning tide among teenagers?* Cape Town: HSRC.
- Stadler, J., Delany, S., & Mntambo, M. (2008). Women's perceptions and experiences of HIV prevention trials in Soweto, South Africa. *Social Science Medicine*, 66(1), 189-200.
- Statistics South Africa. (2004). *Statistics South Africa Provincial Profile 2004 KwaZulu-Natal*. Pretoria: Statistics South Africa.

- Statistics South Africa. (2010). *Statistical release P0309.3 Mortality and causes of death in South Africa, 2010: Findings from death notifications*. Pretoria: Statistics South Africa.
- Statistics South Africa (2011). *Statistics by Place: Hlabisa*. Pretoria: Statistics South Africa.
- Statistics South Africa. (2013). *Statistical release P0302 Mid-year population estimates*. Pretoria: Statistics South Africa.
- Steinberg, J. (2011). *Three letter plague: A young man's journey through a great epidemic*. Johannesburg: Random House.
- Stuart, H. (2005). Fighting stigma and discrimination is fighting for mental health. *Canadian Public Policy*, 31, 21-28.
- Stutterheim, S. E., Pryor, J. B., Bos, A. E., Hoogendijk, R., Muris, P., & Schaalma, H. P. (2009). HIV-related stigma and psychological distress: the harmful effects of specific stigma manifestations in various social settings. *AIDS*, 23(17), 2353-2357.
- Sumari-de Boer, I. M., Sprangers, M. A., Prins, J. M., & Nieuwkerk, P. T. (2012). HIV Stigma and Depressive Symptoms are related to adherence and Virological Response to Antiretroviral treatment among immigrant and indigenous HIV Infected patients. *AIDS and Behavior*, 16(6), 1681-1689.
- Terre Blanche, M., Durrheim, K., & Painter, D. (2006). *Research in Practice (2nd Edition)*. Cape Town: Juta Publishers.
- Theorell, T., Blomkvist, V., Jonsson, H., Schulman, S., Berntorp, E., & Stigendal, L. (1995). Social support and the development of immune function in human immunodeficiency virus infection. *Psychosomatic Medicine*, 57(1), 32-36.
- UNAIDS. (2007). *Reducing HIV stigma and Discrimination: a critical part of national AIDS programmes*. Geneva: Joint United Nations Programme on HIV/AIDS
- UNAIDS. (2012). *UNAIDS report on the global AIDS epidemic*. Geneva: Joint United Nations Programme on HIV/AIDS.
- van Aardt, C. (2001-2002). The impact of HIV/Aids on the South African labour market from a critical perspective. *SA Journal of demography*, 8(1), 47-61.

- Venkatesh, K., Madiba, P., De Bruyn, G., Lurie, M., Coates, T., & Gray, G. (2011). Who Gets Tested for HIV in a South African Urban Township? Implications for Test and Treat and Gender-Based Prevention Interventions. *Journal of Acquired Immune Deficiency Syndromes*, 56(2), 151-165.
- Visser, M. (2012). Women, HIV and Stigma. *Future Virology* 7(6), 529-532.
- White, M. (1993). Deconstruction and therapy. In S. Gilligan, & R. Price, *Therapeutic Conversations* (pp. 22-61). New York: Norton & Co.
- Yapa, L. (1996). What Causes Poverty? A Postmodern View. *Annals of the Association of American Geographers*, 86(4), 707-728.
- Zuch, M., & Lurie, M. (2011). "A Virus and Nothing Else": the Effect of ART on HIV-Related Stigma in Rural South Africa. *AIDS and Behavior*, 16(3), 564-570.

APPENDIX A

INFORMED CONSENT FORM

You will be asked to participate in a focus group of 20 participants, where we will have a discussion around your experiences of the stigma reduction programme. The discussion will be verbal, but the researcher will take written notes where audio recordings are not permissible. You are free to express your experiences, and you are also free to not answer some of the questions.

You may leave the focus group at any stage you wish.

You are also assured of complete protection of your identity, as all your details will remain confidential. The data gained from the focus group will not be linked or connected to your name; neither will your name be used at any stage during the study.

The data gathered during the group discussion will be used to gain an overall insight into your experiences, as a group and as individuals, of the stigma reduction programme. This data will be used in a research paper to highlight the experiences of females aged between 18 and 24 of the stigma reduction programme. There is very little research in this area and your stories will provide valuable insight into this area.

I HEREBY AGREE THAT I UNDERSTAND THE ABOVE, AND AGREE TO VOLUNTARILY PARTICIPATE IN THIS STUDY

PARTICIPANT NAME

CONTACT NUMBER

PARTICIPANT SIGNATURE

DATE:

APPENDIX B

INFORMED CONSENT FORM

You will be asked to participate in individual interviews, where the researcher will interview you on a personal basis. The focus of the interview will be on your experiences of the stigma reduction programme. The interview will be verbal, but the researcher will take written notes as well as record the interview with an audio recorder. You may specify if you do not want the interview to be recorded. You are free to express your experiences, and you are also free to not answer some of the questions.

You may leave the interview at any stage you wish.

You are also assured of complete protection of your identity, as all your details will remain confidential. The data gained from the interview will not be linked or connected to your name; neither will your name be used at any stage during the study.

The data gathered during the interview will be used to gain an overall insight into your experiences of the stigma reduction programme. This data will be used in a research paper to highlight the experiences of females aged between 18 and 24 of the stigma reduction programme. There is very little research in this area and your stories will provide valuable insight into this area.

I HEREBY AGREE THAT I UNDERSTAND THE ABOVE, AND AGREE TO VOLUNTARILY PARTICIPATE IN THIS STUDY

PARTICIPANT NAME

CONTACT NUMBER

PARTICIPANT SIGNATURE

DATE:

I HEREBY AGREE TO THE INTERVIEW BEING RECORDED WITH AN AUDIO RECORDER

PARTICIPANT SIGNATURE

APPENDIX C

ETHICAL CLEARANCE FORM FOR HIGHER DEGREE RESEARCH PROPOSALS

SECTION A CANDIDATURE DETAILS

- A1 Full name of candidate **Melissa van Rooyen**
- A2 Academic and professional qualifications **BEd, Honours in Psychology – cum laude**
- A3 Personal particulars
- 3.1 Student number: **3446-888-9**
- 3.2 Email address: **melissal@yebo.co.za**
- 3.3 Phone number: **082 752 7673 or 035 550 2006**
- 3.4 Supply your current address: **P.O. Box 16, Mtubatuba, 3935**

(required only if it differs from the address given when you registered at Unisa)

- A4.1 Promoter/supervisor
- 4.1.1 Name: **Dr Sibusiso Mhlongo**
- 4.1.2 Department: **Department of Psychology**
- 4.1.3 Contact number or email address: **mhlonsd@unisa.ac.za**

A4.2 Co-promoter/co-supervisor (if applicable)

- 4.2.1 Name: _____
- 4.2.2 Department: _____
- 4.2.3 Contact number or email address: _____

SECTION B DETAILS OF RESEARCH PROJECT

B1 Title of the thesis/dissertation

The lived experiences of HIV/Aids related stigma reduction programmes on young females in rural Hlabisa District

B2 Supply a short abstract of the proposal (maximum of 300 words)

HIV/Aids-related stigma has been identified as a major obstacle in preventing the spread of HIV/Aids, in South Africa and around the globe. The current status of HIV/Aids in South Africa is discussed as well as the different forms of stigma, and its role in hampering prevention efforts. Stigma has been identified as a social response to HIV/Aids and those affected by HIV/Aids. This social response (stigma) is feared, as its expression takes the form of abandonment, rejection, isolation and violence amongst other factors. For these reasons individuals avoid preventative behaviours such as getting tested, disclosing their status, and seeking medical care, to name but a few, as these activities may lead to individuals being stigmatised. This in turn results in the spread of HIV/Aids. Recognising the key role stigma plays in thwarting prevention efforts has led to action being taken in the form of stigma reduction programmes. The goals of these programmes are to reduce stigma, and subsequently encourage the practice of preventative behaviours, which result in curbing the spread of the virus. Many stigma reduction programmes have been created and implemented; some of these are discussed as well as recommendations from various sources regarding the suggested content of these programmes. Throughout the discussion it becomes clear that stigma reduction programmes remain an understudied area in terms of research done on the lived experiences of participants of the programmes. The research that has been done is discussed, and the need for a qualitative enquiry into the lived experiences of these programmes is highlighted. Participant experiences of stigma reduction programmes are the main focus of the proposed study.

B3 Specify the objectives of the research, as described in your full research proposal

The objective of the study is to explore in detail the experiences of participating in an Africa Centre stigma reduction programme, of females aged between 18 and 24 living in rural Hlabisa

B4 Describe the method by which you will conduct your research, including details on the research design and techniques of data analysis

An exploratory based case study of individuals through in depth interviews as well as a focus group will be employed for the proposed study.

This study will thus employ an exploratory enquiry, with a qualitative approach, into the experiences of an HIV/Aids related stigma reduction programme of females aged between 18 and 24. The proposed study is exploratory in nature with its focus on participant's narratives, thus qualitative measures are best suitable as one is not dealing with quantitative data or only numbers.

An exploratory based case study of individuals through in depth interviews as well as a focus group will be employed, as these provide for rich information about participants and their experience

Focus group is employed to gain subjective as well as intersubjective experiences of participants of the stigma reduction programme. Individual in depth interviews will also be employed in order to uncover individual meaning attached to their experiences.

The subjective narratives of participants will be explored, to determine their personal experiences of the stigma reduction programme implemented by the Africa Centre near Somkhele, Hlabisa District. In exploring the experiences of the stigma reduction programme of females aged between 18 and 24, language will be the main component that will be taken into consideration within the context of data collection.

The method of analysis employed will be qualitative narrative analysis by way of identifying themes (thematic coding) that emerge from participants' narratives. Themes, relationships and patterns will reveal meaning that participants give to their experiences. The narrative analysis will be employed for both the group discussion and the individual interviews.

B5 Describe the source of your research participants, and how you intend to find a sample (not required for purely theoretical studies)

Participants must be females aged between 18 and 24, who have participated in the Africa Centre's stigma reduction programme. A notice will be placed at the Africa Centre announcing the study, and willing and relevant individuals can report to the Counselling and Testing Lead to express their interest in participating. Twenty of these individuals will be selected to participate in the focus group, and ten of the focus group individuals will also be asked to participate in the individual interviews. The Counselling and Testing Lead will inform the individuals who have been selected of the date and time of the study. The Counselling and Testing lead's role is to merely be there for individuals who express interest out of their own free will, to coordinate with them the date and time of study.

B6 Describe whether your data collection techniques will fall in any of the categories below

B6.1	Personal, social or other information to be collected directly from research participants (e.g. questionnaire or interview)	Yes	No
B6.2	Participants are to undergo psychometric testing ^a	Yes	No
B6.3	Participants are to undergo a physical examination ^b	Yes	No
B6.4	Participant behaviour will be observed directly (live or by camera)	Yes	No
B6.5	Identifiable information will be collected about people from available records (e.g. medical records, staff records, student records, etc.)	Yes	No
B6.6	Other data collection method that may impact on anonymity or privacy of participants	Yes	No
B6.7	If question B6.6 was answered 'yes' please supply details:		

B7 If question 6.2 (relating to psychometric testing) was answered 'yes', please answer the questions below

B7.1	Is the assessment measure suitable in terms of its purpose and the individual(s) for whom it will be used?	Yes	No
B7.2	Will the participant(s) be informed with regards to the aim of the assessment and the use of the results?	Yes	No
B7.3	Have issues of feedback been clarified with the participant(s)?	Yes	No
B7.4	Have issues of confidentiality of the results been clarified with the participant(s)?	Yes	No
B7.5	Will the assessment measure be administered by an appropriately qualified person? (Applicable in case of restricted psychometric tests)	Yes	No
B7.6	Have you considered all copyright and related issues that are applicable to this instrument and made required arrangements with the test publisher/distributor? (Applicable in case of restricted standardized tests)	Yes	No
B7.7	If the answers to any of the questions B7.1 to B7.6 were 'no', please supply reasons:		

- B8 Give the age range of participants in this study ^c **18 – 24 years of age**
- B9 Describe procedures that will be used to obtain informed consent from research participants and other relevant affected persons (such as parents and guardians)

Before interviews and focus group is conducted:

- **the purpose of the study will be explained to participants verbally in their home language,**
- **the meaning of informed consent will be explained verbally in their home language**
- **Participants will then be asked to sign the informed consent form before interviews and/or focus group commences.**

- B10 If any risks are posed by the research project, describe these as well as steps that will be taken to limit the possibility of harm to research participants (any discomfort, pain/physical or psychological problems/side-effects, persecution, stigmatisation or negative labelling should be considered. Also see Appendix 5A for a list of possible risk factors)

- **Invasion of privacy of participants, to combat this, the researcher will make it clear that participants may refuse to answer any question they wish with no explanation**
- **Identity: Participant’s identity will be protected during interviews and focus group and they may join the group under a different name if they wish. Different names will be used in interpreting the narratives to protect true identity. The participants will be guaranteed of anonymity.**
- **Exposure: to combat this, the researcher will conduct the group discussion and interviews in a neutral environment, such as a community hall or the Africa Centre venue. The area where the group discussion will take place will also be private and the group closed to new or outside individuals.**
- **Participants may start to feel unsure or uncomfortable during the discussion and interviews, and thus will be informed upfront that they may leave when they wish to do so.**
- **Emotional well-being of the participants: the Africa Centre Counselling and Testing Lead will accompany the researcher. She will be available to meet counselling needs during or after the discussion, if needed.**
- **Benevolence: To ensure participants leave better than when they arrived, the Counselling and Testing Lead will offer counselling to participants after the discussion. If there are participants who did not undergo testing as a result of the programme, counselling will be offered to encourage them to do so. If participants did receive testing counselling will be offered for any concerning matters related to the discussion. Participants may want to find out what services are available to them in terms of treatment, rights, and grants.**
- **Participant vulnerability: it is unknown before the group discussion and individual interviews (and may remain unknown during the group discussion and interviews) whether participants have HIV/Aids or are vulnerable in this area, it will also remain their decision to disclose or not (although there will be NO requirement or request to do so during the research). Their possible vulnerability will remain protected during the research and if they decide to disclose, counselling will be offered after the discussion as well as medical and psychological options available to the participant.**

^c For participants 18 or older, the informed consent form should be submitted. For minors or in cases where diminished responsibility exists, a consent form to be signed by the parent or legal guardian must be submitted.

B11 Do the intended research participants fall under the category that can be described as “vulnerable participants”^d

Yes	No
-----	----

B12 If question 9 was marked ‘yes’, please provide details and steps that will be taken to protect these participants:

It is unknown before the group discussion and individual interviews (and may remain unknown during the group discussion and interviews) whether participants have HIV/Aids or are vulnerable in this area, it will also remain their decision to disclose or not (although there will be NO requirement or request to do so during the research). Their possible vulnerability will remain protected during the research and if they decide to disclose, counselling will be offered after the discussion as well as medical and psychological options available to the participant.

B13 Are participants likely to incur any costs by participating in this research?

Yes	No
Yes	No

B14 Will any kind of compensation or reward be presented to research participants?

B15 If Question 5 (above) was answered ‘Yes’, please supply details:

Participants will incur travelling costs from their homes to the Africa Centre to participate in the research. Monetary compensation will be given to each participant to cover the taxi fare or travelling costs for the research. The cost of the taxi from local surrounding areas are R20 one way, thus each participant will receive R40 to cover fare to and from the Africa Centre.

^d See the *Policy on Research Ethics of UNISA*, page 1 and especially page 15, paragraph 3.10

B16	Will any arrangements for indemnity be made?	Yes	<input checked="" type="checkbox"/>
-----	--	-----	-------------------------------------

B17 If Question 5 (above) was answered 'Yes', please supply details:

n/a	
-----	--

B18	Will any special arrangements be made for steps to be undertaken in case of adverse events or harm is experienced by the participants attributable to their participation in the study? (E.g. debriefing, counselling etc.)	<input checked="" type="checkbox"/>	No
-----	---	-------------------------------------	----

B19 If Question 5 (above) was answered 'Yes', please supply details:

<p>The Africa Centre Counselling and Testing Lead will be present throughout the study to provide counselling or psychological support in the case of any adverse event.</p>	
---	--

B20 If countries other than South Africa are involved in the research project, list the countries here, as well as the nature of the involvement of each:

n/a

B21 If institutions other than UNISA (e.g. clinics, hospitals or schools) are involved list the relevant institutions here and specify the nature of the involvement of each

The Africa Centre's stigma reduction programme is the focus of participants' experiences, but other than that the Africa Centre is not involved in the proposed study. The experiences of the programme is the focus, but there is no connection between the proposed research and the programme or the Africa Centre.

B22 If question 21 above is answered 'yes', will any of the institutions listed require ethical clearance from an appropriate ethics committee at UNISA before the research study can proceed?

Yes	No
-----	---------------