

**An exploration of stigmatisation relating to the terms used to  
refer to HIV and AIDS amongst women in a rural area in the  
Eastern Cape**

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## **Declaration**

I declare that this thesis is my own work. References, citations and borrowed ideas have been acknowledged. It is being submitted in partial fulfilment of the degree of Master of Social Science (Clinical Psychology) at the University of KwaZulu-Natal, Pietermaritzburg, South Africa. This work has not been submitted previously for any degree or examination at any other University.

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## **Abstract**

This thesis explores the terms used by women in a rural area of the Eastern Cape Province to reference HIV/AIDS. Exploring whether these terms are stigmatising and investigating and describing how they are stigmatising is at the heart of this study. Stigma is a barrier to HIV/AIDS related public health interventions. In order to understand HIV/AIDS stigma, this study considers the complex social and psychological processes that underpin the construction of HIV/AIDS stigma through an examination of the terms used to refer to HIV/AIDS. This project employs a qualitative research design and draws on an existing NRF Thuthuka project on sexual health, sexual risk behaviours and HIV. A purposive sampling technique was used to sample a total of 36 transcripts collected from interviews and focus groups. Thematic analysis was used to code and analyse the data. The findings of this study suggest that HIV/AIDS related fear propels an 'othering' response, a necessary psychological coping mechanism in the face of the overwhelming threat HIV/AIDS represents. This is fundamental to the generation and perpetuation of stigma. Cognisance of these processes is essential in rendering HIV/AIDS interventions increasingly effective.

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## Chapter 1: Introduction

South Africa has the largest population of people living with HIV/AIDS worldwide. In 2015 the total number of people living with HIV in this country was estimated at approximately 16.9 million (Statistics S.A., 2015). HIV/AIDS related stigma has been identified as a barrier to HIV/AIDS related public health interventions and implicated in the perpetuation of this disease (Maughan-Brown, 2006). According to Maughan-Brown (2006, p. 166), stigma is a complex social and psychological process that “plays to deep-rooted social fears and anxieties”. Stigma involves a process of devaluation of a person based on actual or suspected HIV infection and is associated with fear, shame, silence and discrimination (UNAIDS, 2008). Although stigma may not necessarily result in discrimination (Deacon, 2006), it is detrimental to the psychical and psychological health of people living with HIV/AIDS (PLWHA). Fear of stigma may adversely impact people’s willingness to engage in preventative healthcare behaviours, access or comply with treatment or disclose their status to others, including sexual partners (Skinner & Mfecane, 2004). In order to reduce the negative impact of stigma on society, it is essential to understand how stigma occurs and how it functions (Deacon, 2005). Therefore consideration of the social and psychological processes involved in the generation of HIV/AIDS stigma becomes necessary in order to develop effective responses to stigma (Maughan-Brown, 2006).

Since South African women and girls are specifically vulnerable to and at risk of HIV (Parker & Colvin, 2007 as cited in Van der Riet, 2009), this study has focused on describing and exploring references to HIV/AIDS among women in a rural area of the Eastern Cape Province. To this end a qualitative research design has been utilised. The terms used by participants to refer to HIV/AIDS have been considered in an attempt to understand their responses to HIV/AIDS and PLWHA. This study was aimed at exploring whether the terms used to reference HIV/AIDS are stigmatizing as well as describing how they are stigmatizing. This project forms part of a larger NRF study on sexual health, sexual risk behaviour and HIV/AIDS. The data collected from the original study have been sampled and analysed with the current research focus in mind.



The next chapter will include a review of the literature pertaining to stigma and HIV/AIDS. This section will focus on defining stigma and examining the social processes involved in stigma formation as well as considering the impact of HIV/AIDS related stigma. This provides a theoretical framework through which the data have been analysed. The methodology chapter will outline the research process as well as consider issues relating to the ethics and the credibility, dependability and transferability of this study. The subsequent chapter will present the analysis of the data. This will be followed by a discussion of the results in which the terms used to reference HIV/AIDS will be discussed in relation to stigma.

## Chapter 2: Review of the literature

In this chapter HIV/AIDS related stigma will be explored through consideration of the terms used to reference HIV/AIDS. Various definitions of stigma will then be outlined. This will be followed by an examination of different models of stigma generation. The social processes implicated in the construction of stigma will be explored. This includes reviewing the mechanisms by which HIV infection is identified in another. Issues associated with HIV/AIDS related fear, blame, gossip and silence will also be considered in light of stigma generation. The protective process of 'othering', in which an 'us' and 'them' is constructed as a means of distancing the self from the perceived danger HIV/AIDS represents, will be examined as a reaction to HIV/AIDS related fear. Finally the impact of HIV/AIDS related stigma will be outlined.

Sub-Saharan Africa has the largest HIV infection rate in the world. According to UNAIDS (2015) 25.8 million people were living with HIV in Sub-Saharan Africa in 2014. It was estimated that there were 1.4 million new HIV infections in sub-Saharan Africa in 2014 (UNAIDS, 2015). Of the total number of PLWHA in 2014, only 41% were found to be accessing antiretroviral treatment. The HIV/AIDS pandemic perpetuates despite intervention programmes in this region. The rate of new infections as well as the lack of utilisation of healthcare services in some contexts suggests that there may be a need to focus on other factors that may be influencing people's vulnerability to HIV and their reluctance to access treatment opportunities.

Since the onset of the HIV/AIDS epidemic in the 1980's, HIV has been highly stigmatised, despite campaigns to eliminate discrimination and educate the public regarding HIV and AIDS. According to Skinner and Mfecane (2004) stigma and discrimination play significant roles in not only the development of the epidemic but its maintenance. Deacon (2006, p. 418), asserts that stigma is a "major barrier to health care and quality of life in illness management". Understanding the social and psychological influences of stigma is vital for the development of effective responses to stigma (Maughan-Brown, 2006). The Prime Minister of Tanzania (as cited in Skinner & Mfecane, 2004, p. 158) stated that "if we are to address stigma, we must first understand it". Therefore research aimed at understanding the social processes underpinning stigma relating to HIV/AIDS is crucial to the improvement of effective HIV and AIDS intervention strategies (Deacon, 2006).

## 2.1 Defining stigma

Variability exists in the definition of the concept of stigma. According to Link and Phelan (2001) researchers have found a common theoretical perspective of stigma difficult to develop. This is evident in the variations in the definitions of stigma. Goffman (1963 as cited in Link & Phelan, 2001) defined stigma as an attribute that is significantly discrediting in which the individual is viewed by society as possessing an undesirable difference resulting in a spoiled identity for the stigmatised. Herek (2002) defines stigma as “an individual’s negative attitude towards a social group, which matches the negative evaluations of society towards the attributes held by that group” (as cited in Deacon, 2006, p. 420). Link and Phelan (2001, p. 367) argue that

stigmatisation is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories and the full execution of disapproval, rejection, exclusion and discrimination.

The term stigma may be applied when elements of “labelling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows them to unfold” (Link & Phelan, 2001, p. 367). Although these definitions commonly point to a process of devaluation, there remains no consensus regarding what fully comprises stigma (Deacon, 2006). Whether or not to include discrimination in a definition of stigma is at the heart of this debate. Discrimination is understood to be a form of “enacted stigma” whereby stigma is acted upon (Nyblade et al., 2005, p. 2).

Deacon (2006) argues that the negative effect of stigma is not contingent on the presence of discrimination. Rather discrimination is but one element of disadvantage that may occur as a result of health related stigma. Stigma “always results in blaming, shaming and status loss for the stigmatised person or group” (Deacon 2006, p. 424). It is for this reason Deacon (2006) proposes that it is unnecessary and unhelpful to define stigma as something that results in discrimination. According to Deacon (2006, p. 422) “defining stigma in terms of discrimination narrows our understanding of the range of effects stigma can have, and

presupposes an over-simplistic relationship between stigma and consequent or existing disadvantage”. Rather stigmatising beliefs and the effects of certain stigmatising beliefs need to be distinguished in order for the dialogue on stigma to move from a theoretical level to a more practical level (Deacon, 2006). This enables us to consider the negative consequences of stigma with greater clarity in order to gain an improved understanding of how health-related stigma leads to disadvantage apart from discrimination (Deacon, 2006).

### **2.1.1 Formulations of stigma**

For the purposes of this discussion, three formulations of stigma and its consequent disadvantage will be focused upon. Although these theories of stigma differ in aspects of their compilation relating to the process by which a person or group is devalued, they share a common conceptualisation of stigma as a social process. Stigma is understood to be embedded in social power relationships (Deacon, 2006). Parker and Aggleton (2003) support the view that stigma may be defined in terms of social processes linked to power relations. Maughan-Brown (2006) advocates that stigma is a complex social process that is dependent on specific cultural contexts. Neuberg, Smith and Asher (2000) assert that the specific behaviours or traits, containing stigma, are defined by the individual cultures or subcultures in which they occur. When combined with the “process of devaluation”, they engender stigma (UNAIDS, 2003 as cited in UNAIDS, 2008, p. 76). Link and Phelan (2001, p. 375) maintain that “stigma is entirely dependent on social, economic and political power”. In addition to sharing a social constructionist perspective on stigma formation, each of these models propose a process of identification and labelling as part of stigma formation. Identification relates to the attribution of an HIV positive status to an individual who is believed to be infected with HIV/AIDS. The individual is then labelled according to the socially constructed meanings specific to the context in which this process has occurred. This will be explored further below. At this point it is important to note that stigma is generated through socially shared meanings relating to the identification and labelling of out-groups (Maughan-Brown, 2006).

The first formulation of stigma to be focused on in this discussion is described by Link and Phelan (2001) who propose that a combination of interrelated components engender

stigma. These components include, firstly, human differences being distinguished and labelled by people according to social context and significance. This is followed by a process of stereotyping in which a labelled person is linked to undesirable traits or characteristics. Thirdly the idea of an 'other' is created, resulting in the separation of 'oneself' from the stigmatised group. This is accomplished through placing labelled persons in distinct categories in order to create some degree of separation of "us" from "them". This includes instances in which efforts to separate us from them are available in the nature of the labels conferred. The experience of discrimination and loss of status by labelled persons reflects the fourth component of stigma formulation. This loss of status occurs within the social milieu and is determined by the social constructs of the particular community (Goodall, 2008). The exercise of power comprises the final component which generates stigma. The assertion of power is realised through a separation of 'us' from 'them' which results in a devaluation of the stigmatised group. Stigma thus removes power from the stigmatised person resulting in a reduction of the self-worth and the social status of the stigmatised person or group (Link & Phelan, 2001).

Deacon's (2006) description of the formulation of stigma aims to facilitate an understanding of both the individual and social dimensions of stigma. According to Deacon (2005, p. 18) stigmatisation "helps to create a sense of control and immunity from danger at an individual and group level". Deacon (2006) defines stigma as a social process. Firstly, illness is constructed as preventable or controllable. Secondly behaviours which caused the illness are identified and cast as 'immoral'. Thirdly these behaviours are associated with 'carriers' of the illness in out-groups, drawing on existing social constructions of the 'other'. Certain people are thus blamed for their infection and finally status loss is projected onto the 'other', which may (or may not) result in disadvantage to them. Deacon (2005) suggests the allocation of negative meanings on to the other by the stigmatiser, is intrinsic to loss of status. It is for this reason that Deacon (2005) suggests that the concept of status loss is akin to the idea of social death. When considering Deacon's third point on existing social constructions of an 'other', Goodall (2008) points out that the specific context in which an 'other' is constructed is essential to understanding the meaning and function of the construction. Schwandt (1994 as cited in Goodall, 2008) supports this view and maintains that people are active agents in the process of comprehending and the construction of

shared meanings. Therefore the construction of an 'other', relating to HIV/AIDS stigma may be motivated by "different reasons in different social contexts" (Goodall, 2008, p. 4).

Maughan-Brown (2006) advocates that the construction of HIV/AIDS stigma is a dynamic and complex social process which includes firstly the identification, accurate or inaccurate, of someone who has HIV/AIDS. This person is then assigned negative values which results in devaluation or loss of reputation. Finally this person may experience discriminatory behaviour, which includes inaction towards them.

Maughan-Brown (2006) suggests that those expressions of negative judgements (symbolic stigma) and prejudice towards other groups are in fact significant predictors of negative behavioural intentions when considering HIV/AIDS stigma. The assignment of negative values to a person based on actual or suspected HIV infection is damaging even though it may not result in direct discrimination. According to Deacon (2006) the attribution of negative values may result in the individual internalising these negative attributes and self-stigmatising. This is an important aspect of HIV/AIDS related stigma and has bearing on individuals' willingness to engage in health care behaviours. This will be discussed in greater detail in subsequent sections.

## **2.2 Fear and HIV/AIDS related stigma**

The motivation behind stigmatisation of people with HIV/AIDS is often embedded in fear and a lack of knowledge regarding how HIV is transmitted (UNAIDS, 2008). Joffe (1999 as cited in Deacon, 2006) implicates fear as fundamental to engendering the psychological blaming and 'othering' response and thus stigma. This fear includes fear of experiencing physical symptoms, illness and death as well as fear of social isolation (Goodall, 2008). In this sense perceptions of personal risk (physical and psychological) and fear thereof becomes a driving force behind stigmatisation. Herek (2002) maintains that that AIDS related stigma is, in part, shaped by fear of HIV and proposes that the intensity of stigmatisation of people with HIV is related to the extent that it is believed an individual may be physically, socially or morally tainted through interaction with HIV positive people. According to Goodall (2008, p. 9), "fear and the generation of stigma may be viewed as

cyclical, in that fear of HIV/AIDS-related stigma, additively combines with fear of the disease generating further stigma and as a result, increasing associated fear”.

Stigma founded in the perception that interaction with PLWHA poses a direct threat to one’s physical well-being is referred to as instrumental stigma (Maughan-Brown, 2006). It is driven by self-preservation, a psychological need to protect one’s self in light of an infectious disease which is potentially terminal in nature. In the absence of a cure, fear of being infected increases the stigmatisation of people living with HIV (Petros, Airhihenbuwa, Simbayi, Ramlagan & Brown, 2006).

### **2.2.1 Fear of death and HIV/AIDS**

Fear relating to HIV/AIDS stigma includes a fear of death. Niehaus (2007) argues that stigma relating to HIV/AIDS is mainly generated as a result of the association between death and AIDS. Skinner and Mfecane (2004) suggest that a diagnosis of HIV is seen as equivalent to death. The view of AIDS and PLWHA as “waiting room for death”, the “dead before dying” and “corpses that live” supports this construct of HIV (Niehaus, 2007, p. 848). Furthermore Niehaus (2007, p. 856) suggests that “AIDS seems to be marked by a peculiar compression of time, and the symbolic load of labelling seems so overpowering that it immediately signifies death” so that “even the newly infected person is ‘tainted with death’”.

From an African perspective of death, the cause of death is fundamental to the esteem of the individual, their family and the collective identity of their community because physical death is believed to be a transition into a spiritual life (Nzioka, 2000). Therefore an individual’s spiritual life is directly influenced by the conditions of their death in the physical life (Nzioka, 2000). According to Nzioka (2000) HIV/AIDS has become a metaphor for physical and moral contamination because of it being a highly moralised disease associated with various forms of stigma due to its means of transmission. It is for this reason death resulting from HIV/AIDS is considered a ‘bad’ or ‘undignified’ death which is the responsibility of the individual and has bearing on the afterlife. Nzioka (2000) proposes that death as a result of HIV is perceived as a form of punishment for behaviour that contravenes social rules and that despite the circumstances that led to infection, moral judgment is

exacted through stereotypical beliefs. The significant association between AIDS and death engenders and sustains fear surrounding HIV/AIDS.

### **2.3 Identification and labelling through 'markers' of HIV/AIDS**

The above models of stigma formulation all reference a process of identification and labelling as part of stigma formation. Identification and labelling may include the (accurate or inaccurate) detection of signs, symptoms or characteristics of HIV, otherwise known as 'markers' in another individual. This person is then identified and labelled as HIV positive based on these markers which are associated with HIV infection. In addition to markers denoting the presence of HIV, Duffy (2005, as cited in Naidoo, Uys, Greef, Holzemer, Makoe, Dlamini, Phetlhu, Chirwa & Kohi, 2007) suggests that the physical signs, such as skin changes and weight loss that occur during the advanced stages of HIV infection are also considered indicators that this person has likely engaged in immoral behaviours. According to Crocker (1998, as cited in Dovidio, Major & Crocker 2000), a primary schema, through which everything about the person carrying the stigmatising mark may be understood, is afforded by physical markers.

In addition to physical markers, Link and Phelan (2001 as cited in Skinner & Mfecane, 2004, p. 162) maintain that "certain behaviours such as the use of condoms have become signifiers of the epidemic, leading to possible rejection of those who initiate their use". In this regard behaviours related to preventative healthcare or treatment may be used to denote the presence of HIV/AIDS and result in stigmatisation (Skinner & Mfecane, 2004). This may have a bearing on an individual's willingness to engage in healthcare behaviours associated with HIV/AIDS.

Goodall (2008) suggests that markers associated with HIV/AIDS across cultures are context specific as they reflect a shared meaning relating to HIV infection. Tulloch and Chapman (1992) maintain that markers (physical and nonphysical) are varying representations, communicated as a culturally specific narrative, which position people as a threatening 'other'.



## 2.4 Blame and HIV/AIDS

A fundamental component to HIV/AIDS stigma is blame. According to Deacon (2006) people being blamed for their own infection is a key component to the formulation of stigma. HIV/AIDS related stigma is often associated with other forms of stigma relating to behaviour such as homosexuality, prostitution, promiscuity and drug addiction which in many societies is already stigmatised. According to Maughan-Brown (2006, p. 178) HIV/AIDS related stigma is “strengthened by the association between HIV and AIDS and previously stigmatised minority or disliked groups”. This is particularly relevant if the condition is perceived as having been contracted through voluntary or avoidable behaviours that evoke social disapproval. In this sense, HIV infection is viewed as avoidable and needless. This relates to Deacon’s (2006) first component of the generation of stigma, that illness may be constructed as preventable and controllable. According to Nzioka (2000) HIV has become a metaphor for moral and physical contamination because it is primarily transmitted through sexual contact. It directly symbolises pollution and contamination and “consequently PLWHA have been associated with dirt and uncleanness” (Maughan-Brown, 2006, p. 168).

The association between HIV and socially unacceptable behaviours results in PLWHA acquiring a spoiled identity and thus being required to bear the burden of responsibility for infection as a result of the moralization of HIV/AIDS (Nzioka, 2000). This results in moralism and anger towards those with HIV. Maughan-Brown (2006) refers to this form of stigma as symbolic stigma. Symbolic stigma, relating to HIV/AIDS is based on “judgemental attitudes towards those perceived to have put themselves at risk of infection through immoral and/or irresponsible behaviours” (Stein, 2003, as cited in Maughan-Brown, 2006, p. 167). Stigmatisation is not only directed towards those who are HIV positive but may also be directed towards those suspected of having HIV. In the presence of behaviours identified as being high risk behaviours, this is especially relevant. Blame relating to HIV infection may be seen in intimate relationships, such as with spouses or sexual partners, as “sexual transmission of HIV is often evidence of infidelity” (Misovich, Fisher & Fisher, 1997 as cited in Geary et al., 2014, p. 1419).

According to Maughan-Brown (2006) symbolic stigma serves to protect the stigmatiser from fear and anxiety by situating the in group as safe from infection through assessing their own behaviour as moral and thus they distance themselves from the possibility of HIV transmission. Deacon (2006, p. 424) proposes that “blaming certain groups of people for having an illness provides stigmatisers with an opportunity to distance themselves and their in-groups from risk of infection”. It is for this reason that, according to Deacon (2006), stigma is reproduced in society. Furthermore Deacon (2005, p. 23) asserts that “individuals are active agents in creating stigma” given that stigma is fundamentally a social process related to blame.

## **2.5 Silence and HIV/AIDS related stigma**

The negative values attached to HIV and consequently those infected propels the secrecy surrounding HIV/AIDS. Skinner and Mfecane (2004) propose that keeping HIV hidden enables its perceived threat to be reduced. In this sense silence related to HIV/AIDS plays a protective role in enabling a distance to be Van der Riet, Hough and Killian (2011) suggest that HIV/AIDS related stigma has created a culture of silence which curtails discussion of this disease. This culture of silence surrounding HIV/AIDS is embedded in a fear of stigmatisation relating to HIV/AIDS (Duffy 2005, as cited in Naidoo et al., 2007). Both HIV positive and HIV negative individuals are susceptible to fear of HIV related stigma. Stigmatisation relating to HIV may not necessary be experienced directly, simply observing it may generate fear of stigmatisation. Skinner and Mfecane (2004) suggest that any association with HIV and PLWHA could be a basis for HIV/AIDS related stigma. With regard to HIV positive individuals, Lekganyane and du Plessis (2012) suggest that feelings of fear and shame relating to HIV infection may lead to secrecy and silence regarding individual’s health status as well as a self-imposed social isolation. The way in which individuals view themselves and are viewed by others is radically impacted by the discrediting social labels associated with stigma (Link & Phelan, 2001). Maughan-Brown (2006) highlights that for many HIV/AIDS is a ‘moral’ disease with beliefs about the moral conduct of those infected. HIV/AIDS is associated with socially deplorable behaviours and has served to signal contamination in this regard. According to Clark (2012) silence relating to HIV/AIDS enables people to avoid being implicated in the moral order that shapes the construction of HIV. Silence is a means of

evading the negative meanings attached to HIV/AIDS and the 'danger' HIV/AIDS represents. Thus "stigma promotes silence and silence in turn promotes the generation of stigma" (Goodall, 2008, p. 32).

### **2.5.1 Silence through renaming HIV/AIDS**

According to Alonzo and Reynolds (1995, as cited in Deacon, 2005, p. 15) "stigma is not merely an attribute, but represents a language of relationships, as labelling one person as deviant reaffirms the normalcy of the person doing the labelling". Language is a cultural resource which shapes the meaning of HIV/AIDS, the way it is constructed as well as how it is represented. Niehaus (2007) found that villagers in the South African Lowveld (Bushbuckridge) avoided making direct references to HIV/AIDS. Euphemisms were used when referring to HIV and AIDS. For example euphemisms such as 'the three letters', 'was on diet' or that a person 'owned a House In Vereeniging' were used to avoid mentioning the words HIV and AIDS directly. Fear of association with HIV/AIDS appears to promote the avoidance of the direct use of HIV/AIDS terms and this perpetuates the silence surrounding HIV/AIDS. This renaming of HIV and AIDS may serve to create a safe distance between the self and HIV/AIDS and those who are living with HIV/AIDS (Goodall, 2008). Cain (2007) supports this view and proposes that euphemisms may be used as a means of avoiding taboo topics and safely negotiating content that is experienced as threatening.

According to Niehaus (2007) the association between death and HIV is the driving force behind HIV related fear, silence and stigma. The use of euphemisms for HIV/AIDS is directly related to political, medical and religious discourses which situate people between life and death (Niehaus, 2007). Thus the construction of PLWHA as the 'dead before dying' is at the root of fear and silence relating to HIV/AIDS (Niehaus, 2007). This construction of HIV/AIDS as paralleled to death generates fear relating to HIV/AIDS. This fear is managed through the re-naming of HIV/AIDS which may serve a protective function in that it allows the speaker to create distance between the self and the perceived threat HIV/AIDS signifies.

According to Clark (2012) the use of coded references for HIV/AIDS rather than directly mentioning the actual world enables the speaker to avoid being implicated in the moral order that shapes HIV/AIDS and its negative associations. The use of codes enables the

individual to disassociate themselves from blame associated with a HIV positive status. According to Clark (2012) the naming of HIV/AIDS in its self is construed as aligning oneself with the stigmatised category through the implied knowledge of the object. In this sense direct references to HIV/AIDS may be viewed as complicit with all the negative values associated with stigmatised group. The fear of blame expressed in the 'unsayability' of HIV/AIDS has bearing on the silence surrounding this disease.

In addition to this, Clark (2012, p. 497) argues that "these rhetorical devices, in alluding to the 'unsayability' of HIV or AIDS, also imbue the unspoken word with meaning" and in this way "context and social relations inform the discursive resources that give meaning to HIV/AIDS and also implicate particular networks of social relation, and as such can be taken as commentary on much more than 'just' the disease". Therefore words may be coded as a result of their undesirable connotations in society and their association with perceived culpability with transgression (Clark, 2012). In this sense the avoidance of direct references to HIV/AIDS and thus the silence surround it both fosters and maintains stigma relating to HIV/AIDS.

### **2.5.2 Disclosure**

Geary, Parker, Rofers, Haney, Njihia, Haile and Walakira (2014) suggest that the fear aroused by stigmatisation relating to HIV/AIDS towards PLWHA is a barrier to HIV disclosure. Naidoo et al. (2007) proposes that silence and secrecy relating to disclosure may be related to self-stigmatisation, the cumulative result of HIV received stigma. Geary et al. (2014) supports this view stating that non-disclosure of HIV may be influenced by not only experienced stigma but internalized stigma. Internal stigma refers to the shame associated with HIV and AIDS and the fear experienced by PLWHA of being discriminated against. Disclosure has the common reaction of rejection which results in social isolation leaving the person with HIV alone (Maman et al. 2001 as cited in Skinner & Mfecane, 2004). Since HIV is associated with socially unacceptable behaviours and thus often includes blame, Deacon (2005) proposes that non-disclosure of HIV may be an attempt to reject stigmatising connotations.

## **2.6 HIV/AIDS related gossip**

Gossip has been cited as a stigmatising practice relating to HIV/AIDS (Parker, 2005). People who are infected with HIV as well as those who are believed to have HIV/AIDS are subject to rumour and gossip relating to this disease (Parker, 2005). According to Parker (2005) constructions of moral imperatives, including blame attribution are reiterated through HIV/AIDS related rumour and gossip. Gossip in this sense is a manifestation of blame relating to HIV/AIDS. According to Maughan-Brown (2006) this has a bearing on the willingness of people who are HIV positive to disclose their status to community members, perpetuating the silence surrounding HIV/AIDS. Fear of gossip relating to HIV/AIDS becomes a barrier not only to HIV/AIDS disclosure but to compliance with healthcare related behaviours which may signal the presence of HIV/AIDS (Niehaus, 2007).

## **2.7 HIV/AIDS and 'othering'**

As alluded to in previous sections, fear, blame and silence relating to HIV/AIDS may result in or reinforce a process of 'othering'. According to Joffe (1999, as cited in Deacon 2006, p. 420) stigma may be defined as "emerging from an individual psychological blaming and 'othering' response, a cognitive justification for an emotional reaction to fear". Deacon (2005) suggests that there are different forms of stigma. Broadly 'othering' refers to a process by which an 'other' is identified and marked as different from oneself. People's identities are therefore constructed in relation to others. This identification of an 'other' may be made through the use of HIV/AIDS related markers. In this sense the process of identifying markers relating to HIV is a function of constructing an 'other' (Goodall, 2008).

Blame may be considered an 'othering' response in that high risk behaviors are attributed to an out group and this enables them to be blamed for their condition (Nelkin & Gilman 1998 as cited in Petros, Airhihenbuwa, Simbayi, Ramlagan & Brown, 2006). According to Skinner and Mfecane (2004, p. 159) this is "psychologically reassuring as it divides society into 'us' and 'them'. The deployment of blame relating to HIV/AIDS is thus a means of distancing oneself from risk through associating it with characteristics of an out group (Deacon, 2005). Nelkin and Gilman (1988, as cited in Petros et al., 2006) propose that this process of othering through blame is a functional reaction that creates a sense of control. It is a means

by which anxiety may be alleviated in times of crisis or stress (Deacon, 2005). According to Campbell, Foulis, Maimane and Sibiyi (2005) the process of 'othering' provides comfort and feelings of invulnerability which would otherwise be overwhelming and in this way serves as an "identity-protective" function. This is in keeping with the notion that 'othering' is a reactive coping mechanism to an unconscious universal fear of collapse and chaos (Campbell et al., 2005, p. 808). 'Othering' may be understood in terms of the psychological defense mechanisms of 'splitting' and 'projection' (Deacon, 2005). According to Deacon (2005, p. 22) Klein identified splitting as a means of reducing anxiety in which 'good' and 'bad' are separated from one another, the 'bad' is rejected by "projecting in onto the 'other'". Joffe (1999, as cited in Deacon, 2005, p. 22) suggests that the use of splitting of the 'good' and 'bad' is a means in which to "forge 'protected' identities by projecting risk and deviance onto outgroups". Petros et al. (2006) asserts that the process of 'othering' is magnified as a result of fear of contracting a fatal disease, as is the case with HIV.

## **2.8 Knowledge and behavioral responses to HIV/AIDS**

According to UNAIDS (2008), a lack of HIV/AIDS related knowledge is the chief source of HIV/AIDS stigma. Furthermore it is asserted that an increased knowledge about HIV/AIDS and ways to protect oneself will result in positive preventative healthcare practices (UNAIDS, 2008). This notion that HIV/AIDS there is a direct correlation between HIV/AIDS related knowledge and behavioural responses to HIV/AIDS has been challenged. According to Van der Riet (2009) despite knowledge of HIV/AIDS, people do not change their behaviours; they continue to engage in practices that put them at risk of HIV infection. Maughan-Brown (2006, p. 168) suggests that "a person might 'know' how HIV is transmitted and therefore be aware that one cannot become infected via casual contact, but yet might nevertheless refrain from hugging PLWHA". This highlights the 'disconnect' between knowledge relating to HIV/AIDS and behavioral responses to PLWHA. Goodall (2008) found, in a study conducted in KwaZulu-Natal amongst children, that knowledge relating to the transmission and contagion of HIV as well as preventative health care behaviors did not determine positive behavioral responses in this regard. Rather the fear of labelling related to HIV/AIDS stigmatization was cited as influencing HIV/AIDS related behavioral responses in certain circumstances (Goodall, 2008). For example participants suggested that the use of a

condom was equated with an HIV positive status and that for this reason condom use may be rejected (Goodall, 2008). Parker (2005) asserts that the notion that knowledge is a precursor to behavioral responses to HIV fails to consider social constructions of HIV. According to Parker (2005) the assumed sequential linear relationship between knowledge and action does not account for social and contextual variables or emotional responses on individual action. Van der Riet (2009, p. 21) argues that most of the models which underpin the notion that knowledge directly impacts behaviour, are based on the conception of a “cognitivist-rationalist ‘self’ able to ‘choose’ to act in the way that they do”. The idea that an individual is able to ‘choose’ assumes “rational intentionality of agency” (Kelly et al., 2001 as cited in Van der Riet, 2009, p. 21). Kelly et al. (2001 as cited in Van der Riet, 2009) assert that there are numerous behaviours which are not performed as an intentional action. Furthermore these models adopt an “individualist and mentalist conception of behaviour” (Van der Riet, 2009 p. 22). This does not account for the role of ‘context’ in behaviour, including social factors (Van der Riet, 2009).

## **2.9 The impact of stigma**

According to Deacon (2006) the negative impacts of stigmatisation includes status loss, discrimination and a failure to take advantage of social, economic and healthcare opportunities as a result of fear of anticipated stigma and discrimination. Niehaus (2007) argues that, as a result of the terminal status of PLWHA and its related stigma, they may experience a social death. Stigmatisation, when internalised may lead to loss of status since the allocation of negative meanings is intrinsic to status loss (Deacon, 2005). This in turn may result in social isolation. This social isolation is physically and psychologically damaging as people are inherently social beings (Jenkins & Sarkar, 2007 as cited in UNAIDS, 2008).

Fear of stigma and discrimination remains a major deterrent to disclosure of a positive HIV status, HIV testing and accessing of treatment and care (UNAIDS, 2013). This includes people disclosing their status to their sexual partners. According to Herek (2002, p. 594) “being the target of stigma inflicts pain, isolation, and hardship on many people with HIV, seeking treatment, or practicing risk-reduction”. As a result of fear of stigmatisation denial is

employed as a means of delaying testing and accessing treatment as well as limiting the possibility of disclosure to potential sources of much needed support.

According to Skinner and Mfecane (2004, p. 162) “stigma drives HIV out of sight so reducing the need for behavioural change”. Deacon (2006) suggests that people may feel a sense of protection from HIV/AIDS due to the construction of the ‘other’ and therefore neglect to practice necessary preventative measures. Maughan-Brown (2006) supports this view and asserts that by individuals “assessing that their own (im) moral behaviour is not conducive to HIV transmission” they situate themselves “the ‘in-group’ as safe from infection”. This is evident in people’s reluctance to use safer sex practices. Furthermore as suggested above, protective behaviours, such as condom use, could be seen as a marker of HIV and thus these behaviours are rejected in order to avoid being stigmatised.

Resource-based stigma, in which the allocation of limited resources to PLWHA is resented or opposed, may result in PLWHA being blamed for financial difficulties experienced by their families as a result of the cost of caring for them as well as their economic contribution diminishing or ceasing altogether (Maughan-Brown, 2006).

### **2.10 Stigma via association with PLWHA**

According to Herek (2002) the family members, close friends and carers of those with HIV often experience what Goffman terms ‘courtesy stigma’. Wright et al. (2006, p. 445) suggest this courtesy stigma “is based on the symbolic contagion of HIV, and may produce the same types of perceived stigma effects for informal caregivers as it does for PLWHA”. Through the close association of caregivers, family members and close friends with people with HIV/AIDS, they may be stigmatised through being identified and labelled with negative characteristics associated with HIV/AIDS. According to UNAIDS (2008) discrimination may be encountered by the families, children and caregivers of PLWHA as a result of shame associated with HIV/AIDS. Courtesy stigma may result in social isolation for those closely associated with PLWHA. According to Wright et al. (2006) this form of stigma places a strain on relationships between caregivers and families of PLWHA. Caregivers may experience social distancing at a time when support is so critically needed (Wright et al., 2006).



## **2.11 The impact of stigmatisation on society**

Society is affected by stigmatisation in many ways including “creating disruptions in social functioning, increasing people’s vulnerability to infection and reducing the overall caring capacity of communities” (Skinner & Mfecane, 2004, p. 158). Skinner and Mfecane (2004, p. 161) propose that individuals’ and communities tendency to distance or create barriers “between those infected and the rest of the population” facilitate the above negative effects of stigmatisation. The result of this tendency is that HIV ‘disappears’ and a false sense of safety is created in the majority of the population (Skinner & Mfecane, 2004). This impacts on the willingness of people to engage with and care for HIV infected community members. Stigmatisation hampers behaviour change and is a barrier to the prevention and treatment of HIV. According to Petros et al. (2006), the silence and denial surrounding HIV/AIDS prevents people from accurately assessing their own personal risk of infection as well as reinforcing the notion that HIV and AIDS affect others with the exclusion of the self. Daniel et al. (2007) suggest that although a community may be aware of the prevalence of the disease, people learn to remain silent resulting in a culture of silence. This culture of silence is “based on deep-seated cultural taboos regarding adults talking to children about sex and death” (Daniel et al., 2007 p. 110). According to Cohen (2001 as cited in Daniel et al., 2007, p. 111), “One of the strongest reasons for silence at the cultural level, across the whole community or society, is that the group learns to keep silent about matters whose open discussion would threaten its self-image”. The association of HIV/AIDS with social stigma, sex and shame compounds this culture of silence.

According to Niehaus (2007) the reaction to HIV/AIDS in the village and township setting is one of silence and fatalism. Niehaus (2007, p. 850) argues that the responses of people in South African society to HIV/AIDS is an outcome of the way in which “medical, political and religious discourses have constructed AIDS as a liminal condition between life and death”. This has significant implications for PLWHA. UNAIDS (2013, p. 84) assert that the negative effects of HIV related stigma for PLWHA include “isolation from communities and inability to participate as a productive member of society as a result of their HIV status”.

Schoepf (2001, as cited in Goodall, 2008, p. 1) asserts that “AIDS has struck with particular severity in communities struggling under the burdens of poverty, inequality, economic crisis and war”. According to Skinner and Mfecane (2004) stigma has had particular implications for South Africa as a result of South Africa’s history of racism accompanied by other stigmatising beliefs. Petros et al. (2006, p. 75) asserts that “Apartheid ideology compounded pre-existing inequalities in health provision along race and class lines”. In the South African context much of the blame and othering of HIV/AIDS could be traced back to South Africa’s complex history in racism, patriarchy and homophobia (Petros et al., 2006). In this context the processes of othering in relation to HIV/AIDS facilitates a sense of security and a safe social space in which AIDS may be thought of in terms of being in other communities apart from one’s own.

## **2.12 Summation**

Stigmatisation in South Africa today is still a relevant contributor to the continuation of the HIV/AIDS epidemic and has not adequately been dealt with in the form of comprehensive interventions as HIV/AIDS still perpetuates. According to UNAIDS (2008) HIV/AIDS related stigma is promoted through fear, shame and silence relating to HIV/AIDS. HIV/AIDS is highly stigmatised as it is associated with behaviors which are deemed by society as immoral, such as “sexual promiscuity, sexual deviation, drug use, and personal irresponsibility” (Wright et al., 2006, p.445). HIV/AIDS stigma is highly correlated with blame as people living with HIV/AIDS are perceived as being responsible for their condition as their infection is constructed as being preventable (Deacon, 2006). A culture of silence has been cultivated surrounding HIV/AIDS as a result of this fear and shame, which further advances the construction of stigma (Daniel et al., 2007).

Stigmatisation involves a social process in which the identification and labeling of ‘other’ takes place in order to create and ‘us and them’. This social process is fashioned by political economy, social structures and culture (Schoepf, 2001). This allows for a distancing of oneself from HIV/AIDS and in this sense plays a protective function from the perceived threat HIV/AIDS represents. HIV/AIDS stigma has a far reaching impact not only on the individual but on the community, evident in the disruption of social functioning and the

caring capacity of communities as well as affecting health behaviors, such as risk reduction and impacting on the emotional, social and psychological wellbeing of PLWHA.

Maughan-Brown (2006) maintains that the development of effective responses to HIV/AIDS stigma is contingent on understanding both the social and psychological factors influencing stigma. An exploration of the ways in which HIV/AIDS is referenced and how stigma is constructed and maintained may facilitate an enhanced understanding of HIV/AIDS stigma related to the specific context of this research project. Deacon (2005, p. 29) proposes that stigma is constantly “re-enacted and re-created in different situations” and therefore the development of context specific understanding of stigma is essential in providing “effective local intervention programmes”. This study has focused on exploring references to HIV amongst women given that women are especially vulnerable to HIV infection (Parker, 2005). According to Parker (2005) socio-economic factors underpinning the HIV/AIDS epidemic include poverty and limited resources and services with regard to HIV prevention and treatment. Areas, such as the site for this study, which are under-resourced and characterized by economic difficulty have been most severely affected by the HIV/AIDS epidemic (UNAIDS, 2008). It is for this reason that this study has focused on a rural area in the Eastern Cape Province.

This chapter has considered stigma relating to HIV/AIDS. This has included an inspection of the terms used to reference HIV/AIDS and an examination of the social processes involved in the construction and perpetuation of HIV/AIDS related stigma. This has provided a framework through which the data has been analysed. The methodological features of this research project will be outlined in the following chapter.

## **Chapter 3: Methodology**

### **3.1 Research aims and rationale**

The HIV/AIDS pandemic continues with South Africa having an estimated overall prevalence rate of 11.2% of the total population infected with HIV (Statistics South Africa, 2015).

HIV/AIDS remains a major health and social concern in this country. HIV/AIDS related stigma has been cited as a primary reason people are reluctant to be tested for HIV, to engage in preventative healthcare behaviours and to seek treatment for HIV/AIDS (Deacon, 2005). As a result of HIV/AIDS related stigmatisation, PLWHA often experience social isolation and loss of status within their communities. Fear of stigma results in secrecy and silence surrounding HIV/AIDS. The effectiveness of public health interventions are undermined as a result of stigma (Maughan-Brown, 2006).

This study aimed to identify, explore and describe HIV/AIDS related stigma through consideration of the terms used to reference HIV/AIDS amongst women in a rural area of the Eastern Cape. This was achieved through investigating and describing the language used by people when referencing HIV/AIDS, exploring whether they were stigmatising and exploring and describing how they were stigmatising. Thus the ways in which HIV/AIDS related stigma is understood and constructed by women was explored.

### **3.2 Research questions**

The research questions were guided by a review of the literature relating to HIV/AIDS related stigma. The specified theories relating to the formulation of stigma provided a framework through which the data could be analysed and a starting point for the research questions. The process of data analysis is outlined in greater detail in section 3.4.4. The following research questions were considered:

1. What are the responses of women in a rural Eastern Cape setting to HIV/AIDS?
2. What terms and phrases are used when referring to HIV/AIDS?
3. Are references to HIV/AIDS stigmatised?
4. How are references to HIV/AIDS stigmatised?
5. How do women in this area make sense of HIV/AIDS?

### **3.3 Context of the study**

This study forms part of a broader NRF Thuthuka funded project conducted in a research site in the Eastern Cape Province given the pseudonym, *Ematyholweni*. This study was centred on sexual health, sexual risk behaviours and HIV. Since the data used in this study was drawn from the existing NRF project, it is considered secondary data.

### **3.4 Research design**

This study employed a qualitative research design. According to Babbie and Mouton (2005) qualitative research is identified by its interest in human experience, subjectivity and specificity in context. Unlike quantitative research, in a qualitative approach relationships being examined tend not to be definitely defined (Van der Riet, 2009). Terre Blanche, Kelly and Durrheim (2006) suggest that qualitative research makes open-ended and inductive exploration possible within a specific context. According to Van der Riet (2009, p. 77) “qualitative approaches go beyond a focus on causation, to try and explore the reason why a phenomenon is like it is, for example, what is the mechanism that leads to the relationship between x and y”. Thus attempts to understand phenomena and the meanings embedded in the human experience are fundamental to qualitative approaches.

This study attempts to describe reality from the participants’ perspective and is concerned with understanding meaning in relation to lived experience (Kvale, 1996). It aims to explore, describe and understand the perceptions of HIV/AIDS and whether they are stigmatising amongst women in a rural area of the Eastern Cape. As this project is aimed at understanding the participants’ own perceptions which are expressed in their own words, an in-depth qualitative study is befitting this study (Taylor & Bogdan, 1984).

In view of the fact that this study makes use of secondary data, methodological issues relating to the original study will be dealt with first, followed by a description of the current study.

### **3.4.1 The original study**

#### **3.4.1.1 The research site**

*Ematyholweni*, the research site for this project, is located in the Eastern Cape province of South Africa. This deep rural setting constituted a homeland during the previous dispensation according to the 'separate development' apartheid policy. The area has both a traditional leadership structure as well as a political dispensation. This area is under-resourced and has poor infrastructure. The sources of income in the area include state pensions, childcare grants and funds being sent to the occupants from family members working outside of the area, for example on the mines or in the domestic domain. This area is characterised by limited financial resources since opportunities for formal employment are scarce. HIV/AIDS and sexual health related programmes in this setting are limited to initiatives implemented by the government. This area is serviced by only one primary healthcare clinic and a single secondary school.

#### **3.4.1.2 Sample**

According to Babbie and Mouton (2005, p. 277) purposive sampling is used to "maximise the range of specific information that may be obtained from and about" a context according to the aims of the research. A subset of a larger population is selected based on the researcher's judgement regarding which units will be most representative (Babbie, 2006). The study made use of purposive sampling. The sample of participants included a wide age range (from 10 to 75+ years of age). Permission for the study was sought from the Chief of the area in which the sampling took place. The village Residents' Association Chairpersons were also consulted in this regard. A 'key informant' who was well known and respected in the area acted in an advisory capacity for the research. Each village in the area was visited and in consultation with the key informant and Residents' Association chairperson, participants were identified and recruited. After relevant information was explained, such as the purpose of the study, its intent and issues relating to confidentiality, participants were requested to participate in the study. With regard to the principle of autonomy, it was made clear to participants that it was entirely their choice whether or not they would like to participate in the study.

### **3.4.1.3 Data collection**

The original study was conducted from 2011 to 2013. It made use of semi-structured interviews and focus groups during data collection. The semi-structured interviews were conducted with the participants in order to “understand how they really think and feel” about issues relating to sexual health and sexual risk behaviours as well as HIV/AIDS (Terre Blanche et al., 2006, p. 297). One interview schedule was used across all the interviews conducted and another schedule across the focus groups. According to Terre Blanche et al. (2006, p. 304) “focus groups are often selected so as to reflect a heterogeneous cross-section of interests and attitudes within the parameters of whatever main criterion qualifies them for membership”. Inhabitants of the villages, across age categories, participated in focus groups in which their knowledge, attitudes and beliefs about HIV/AIDS and risk behaviours were explored. A total of 68 interviews and 20 focus groups were conducted with both male and female participants.

Interviews and focus groups were conducted in the mother tongue of the participants (*isiXhosa*). The four researchers who collected the data were first language *isiXhosa* speakers. The data was audio recorded and transcribed verbatim into English using a simplified version of Jeffersonian transcript conventions (Appendix 1). The anonymity of participants’ was ensured through the use of pseudonyms and codes.

An information sheet was given to the participants outlining information pertaining to the project, including what would be expected of the participants. This information was also communicated verbally during a briefing prior to the commencement of interviews and focus groups. Participants in the focus groups were required to sign a confidentiality pledge in addition to the informed consent form. Upon the request of those participating in the study during the data collection process, workshops were conducted in the area with the purpose of educating the community with regards to preventative healthcare behaviours and HIV/AIDS. This was done in addition to community meetings in which the findings of the study were communicated to members in the form of ‘report back’ sessions.

### **3.4.2 The current study**

#### **3.4.2.1 Sample**

As already mentioned, this study is making use of secondary data from a broader NRF project. The data set for this study is comprised of transcripts of both interviews and focus groups conducted with female participants, relating to the terms used to refer to HIV/AIDS. A purposive sampling technique was utilized in order to obtain cases which related to the research issues of this study.

#### **3.4.2.2 Sampling the data**

Prior to the commencement of the data sampling process, literature relating to the topic was reviewed in order to provide a framework for the research process. All the transcripts of female participants, across the age categories, were read and re-read in order for the researcher to immerse herself in the data. The age categories included 10 to 13 years of age, 14 to 17 years of age, 18 to 25 years of age, 25 to 34 years of age, 35 to 45 years of age and 46 to 60 years of age.

The process of sampling the data began with an appraisal of each transcript for all reference to HIV/AIDS. This was followed by looking for the following: terms used to reference HIV/AIDS; terms used to reference people with HIV; the ways in which HIV/AIDS is identified; attitudes towards people with HIV/AIDS and community response to HIV/AIDS and PLWHA. As other themes emerged, such as fear of death, they were included in the thematic framework.

Each transcript was reviewed for each theme. From the data base of 39 transcripts, only three were excluded from the data set as no themes relating to the research aim were found in these transcripts. A total of 36 transcripts were included in the data set. This resulted in a large data set. Three of the transcripts included in the data set were from self-disclosed HIV positive participants. The table below is a representation of the demographics of the data set.



Age range	Focus groups	Interviews
10-13 years of age	1	0
14-17 years of age	2	0
18 -25 years of age	3	7
26-34 years of age	2	9
35-45 years of age	1	8
46-60 years of age	1	2
<b>Total</b>	10	26

**Table 1: Demographics of the transcripts in the data set**

### **3.4.2.3 Data analysis**

This study made use of Terre Blanche, Kelly and Durrheim’s (2006) method of thematic analysis. The process of data analysis began during the data sampling process, given that the process involved in data sampling and data analysis cannot be distinctly separated (Terre Blanche et al., 2006). A review of the literature provided a starting point for the sampling of data and thus data analysis, however as themes emerged during the process of data analysis they were included into the thematic framework. According to Terre Blanche et al. (2006) thematic analysis is useful in identifying, analysing and reporting patterns within data. This is achieved through the identification of patterns and themes (both implicit and explicit) across the data set relevant to the research question. Thus aspects of the phenomena being studied are described, organised and interpreted. Boyatzis (1998) suggests that this is achieved through the identification and organisation of observable themes or recurrent ideas (both manifest and latent) from the data using explicit codes.

Terre Blanche et al. (2006) describe five steps as a means of operationalising the analysis process:

1. familiarisation and immersion
2. inducing themes
3. coding
4. elaboration

## 5. interpretation and checking

The researcher became immersed in the data through reading and re-reading the transcripts. This resulted in the researcher knowing the data “well enough to know more or less what kinds of things can be found where, as well as what kinds of interpretation are likely to be supported by the data and what are not” (Terre Blanche, et al., 2006, p. 323). As broad themes emerged, extracts were grouped together and thus the data began to be organised into ‘issues’ relating to HIV/AIDS stigma, for example extracts that illustrated HIV/AIDS related fear were grouped together. Terre Blanche et al. (2006, p. 323) advocates thinking “in terms of processes, functions, tensions, and contradictions” when analysing the data in this “bottom up approach”. Many themes covering a broad range of issues were identified in this process which allowed for the provision of a ‘thick description’ (Terre Blanche et al., 2006), for example issues relating HIV/AIDS knowledge, fear, blame, silence, gossip, disclosure, support, signs and symptoms of HIV/AIDS and healthcare behaviours. Themes were labelled and coded into meaningful pieces which were clustered in relation to other clusters (Terre Blanche et al., 2006). For example the code “this thing” was identified within the sub theme of indirect references to HIV/AIDS, related to the theme of silence surrounding HIV/AIDS.

Each transcript in the data set was then reviewed in relation to each theme and relevant codes. The researcher became very familiar with the data during this process. Themes were reviewed and explored more closely in order to “capture the finer nuances of meaning” within the data (Terre Blanche et al., 2006 p. 326). A journal was kept in which thoughts and ideas pertaining to the analysis were recorded. This was particularly useful in documenting the progression of the analysis while helping the researcher to be aware of possible areas of bias. The interpretation was carefully reviewed in an attempt to detect possible contradictions or over interpretation.

This study made use of the constant comparative method to data analysis proposed by Silverman (2005) as a means of increasing the validity of the study. This was achieved through examining and comparing all the data fragments that arose across cases. This required starting with a small part of the data and expanding the data corpus to test the hypothesis (Silverman, 2005). The researcher was clearly able to see which categories

emerged across the data set as opposed to being subjectively selected to fit the analytical argument (Silverman, 2005). An example of this was the theme of HIV/AIDS related knowledge versus practice which emerged during the analysis rather than being actively looked for. This meant that repeated inspections of themes across the data set was required in order to ensure that the “generalization is able to apply to every single gobblet of relevant data that you have collected” and all data is accounted for (Silverman, 2005, p. 180). In addition to this the researcher addressed deviant cases within the data as outlined in the results section. This process ensured that the problem of ‘anecdotalism’ was avoided (Silverman, 2005). These processes were particularly important in this study, given that a potential disadvantage of the use of secondary data relates to the production of “deliberate or unintentional bias” since data is selected with a specific purpose in mind (Stewart & Kamins, 1993, p. 6).

### **3.4.5 Ethical considerations**

The data pertaining to this study has been stored electronically in a password protected folder and will be deleted on completion of this project. An agreement was signed by the researcher (Appendix 2) in this regard. The anonymity of the participants was ensured through adherence to the use of the pseudonyms or codes utilized in the original study. At no point has the researcher had access to any data which may lead to the identification of participants. In addition to this a pseudonym was used for the research site in order to protect the identity of the community. This relates to respect for the persons involved in the study (Wassenaar, 2006).

Since sensitive issues were being discussed during interviews and focus groups, the broader project ensured psycho-social support was made available to participants through referral networks. The principle of nonmaleficence is maintained in the current study since no direct contact was made with participants. No direct or indirect harm will be experienced by the participants (Wassenaar, 2006). It is noteworthy that the participants who participated in the original study were specifically made aware that other researchers would be working with the data gathered from the study. This relates to the issue of informed consent for the project. With regard to the issues of justice, the broader project ensured fair selection of participants. Participants are required to benefit from their participation in research

projects in order for the ethical principal of beneficence to be realized (Wassenaar, 2006). Participants potentially benefited from the larger project by having the opportunity to discuss issues relating to sexual health, sexual risk behaviours and HIV. In addition to this workshops were held, at the request of the participants, to further explore these issues. Although participants may not have directly benefited from this study, the findings may help to inform future interventions aimed at the alleviation of HIV/AIDS stigma. This may add social value and in this way indirectly benefit the participants.

### **3.4.6 Credibility, dependability and transferability**

According to Van der Riet and Durrheim (2006, p. 90) validity is defined as the “the degree to which the research conclusions are sound”. In qualitative research this relates to issues of credibility, dependability and transferability, which were achieved in this study in the following ways. Sampling of as large a sample as possible was done in an attempt to ensure that the findings of this study are substantiated and are not a result of the researcher’s preconceived ideas and biases (Babbie & Mouton, 2005). As suggested above, comprehensive data treatment and the use of the constant comparative method to data analysis was aimed at enhancing the credibility of this study (Silverman, 2005). This included the use of explicit and consistent coding in order to avoid spurious correlations, aimed at enhancing the trustworthiness of the study. Rich detailed descriptions, illustrated in extracts from the transcripts, were presented in order to provide readers with “detailed accounts of the structures of meaning which develop in a specific context” (Van der Riet & Durrheim, 2006, p. 92). The aim of this study was to produce results that accurately reflected the participants’ responses to HIV/AIDS and PLWHA. These insights may then be transferred to new contexts in other studies, providing a framework from which to consider the new context (Van der Riet Durrheim, 2006).

## Chapter 4: Results

This chapter will present the results of the analysis of the data. Although themes have been separated into artificial categories in order to aid the process of analysis, it is important to note that they are complexly interrelated and therefore should not be viewed as definitive categories. The results suggest that the terms used by the participants to reference HIV/AIDS are stigmatising. In addition to this, the themes that emerged in the data are a reflection of how references to HIV/AIDS are stigmatising. The fear of death seems to propel HIV/AIDS related stigma. This fear might sensitize people to the signs and symptoms used as a means of identifying HIV infection in others. The identification of HIV/AIDS may result in blame relating to the construct of HIV in terms of 'uncleanliness' and 'dirt'. Being blamed for being the agent of infection was also found in the data. Fear of blame may contribute to the silence surrounding HIV/AIDS. This silence is seen in the use of indirect references when referring to HIV/AIDS and in peoples' reluctance to disclose their actual or hypothetical HIV positive status. Fear of HIV/AIDS gossip has a bearing on HIV disclosure as well as the willingness of people to engage in healthcare behaviours. Participants displayed a fair knowledge of HIV/AIDS related issues but often cited behaviours or attitudes incongruent with their expressed knowledge.

Thematic analysis was used to code and analyse the data collected from interviews and focus groups, as outlined in the data analysis section (section 3.4.4). Extracts from interview and focus group transcripts are presented to illustrate the above outlined themes. The transcripts were transcribed using a simplified version of Jeffersonian transcript conventions. Extracts have been presented precisely as they occur in the original transcript. Extracts will be notated in the following ways: age ranges for participants as well as whether the extract is from an interview or focus group will be indicated; P denotes participant; I denotes interviewer (interviews); F denotes facilitator (focus groups); P followed by a number (e.g. P2) denotes the code for different focus group participants; ... denoting that parts of the transcript have been excluded; the line numbering corresponds to the line numbering found in the original transcript from which extracts were taken; the code at the end of each transcript (e.g. A;B) corresponds with appendix 3 to show which transcript the extract was taken from.

Themes	
fear of death	silence surrounding HIV/AIDS
transmission of HIV as a response to fear of death	indirect references to HIV/AIDS
identifiable signs of HIV	disclosure
fear of blame	gossip
clean versus unclean	healthcare behaviours
agent of infection	support
HIV/AIDS knowledge versus practice	

**Table 2: Themes identified in the process of data analysis**

#### 4.1 Fear of death

The identification of HIV/AIDS as a killer or as a death sentence was found across the data set. The following extracts illustrate the conceptualization of HIV and AIDS in terms of death. The first extract is from an interview with a participant between the age of 26 and 34. In this extract in line 468, the participant comments that “it kills”.

466 I: mm alright (.) is there a person that you have spoken to about it, for sure you  
467 usually speak about it here what you usually talk about when you talk about it  
468 P: w:e usually talk about the fact that it kills and then a person needs to protect  
469 themselves. (A)

The second extract is from an interview with a participant between the age 35 and 45.

276 Participant: People would say hey this one is going to die (.) do you understand (B)

The extract below from an interview with a participant between the age of 35 and 45 also illustrates the construct of AIDS as ‘killing’ or a ‘killer’. This participant also references AIDS in terms of being a ‘destroyer’ (line 547) which she seems to closely associate with “AIDS kills” (line 549).

- 547 Participant: AIDS remember is a disease (.) that kills, that has also destroyed the whole world=  
548 Interviewer: =yes  
549 Participant: =here in the world, there is a lot, and AIDS kills (C)

In some cases HIV and death seemed to be viewed as a single entity. This is illustrated in the extract below from a focus group of participants between the ages 25 and 30. This participant suggests that HIV and death are the equivalent when she says “it’s the same like death mos”.

- 2316 P1:: death and HIV/AIDS are the same because you are going to say that you are afraid of  
2317 AIDS you don’t know how AIDS is going to treat you once you are infected by it. It’s the same  
2318 like death mos (.) you see. (D)

This construction of HIV/AIDS as a ‘destroyer’ and a death sentence seems to create fear. This is illustrated in the extract below taken from the transcript described above.

- 2329 P3: no shame I am afraid of it  
2330 P4:: no I don’t even want to lie  
2331 F: what makes you scared of it  
2332 P3: I think it wouldn’t sit well with me  
2333 P5: it would never  
2334 P3: it’s like I would die right now. (D)

Fear associated with HIV and death seemed to frequently manifest in a fear of contagion for HIV negative people. This is illustrated in the following extract from a focus group of participants between the ages of 46 and 60.

- 1088 P1: I mean that once people know that you are positive then they talk behind your back and you  
1089 see that they don’t really like you, you are no longer welcome amongst the people because you have  
1090 this virus.  
1091 P4: they are scared that you are going to infect them.  
1092 P1: then people get distressed and they even die because this thing is eating them, they are no

1093 longer accepted by other people. (E)

In the above extract social isolation by others is described in terms of “talk behind your back”, “they don’t really like you” and “you are no longer welcome”. The participant seems to directly attribute “no longer being welcome amongst the people” to a positive HIV status. A reason for this social rejection of individuals who are HIV positive is then given by another participant. She associates these behaviours with a fear of contagion when she says “they are scared you are going to infect them”. The phrase “this thing is eating them” may suggest that people become consumed and overwhelmed by the rejection of others due to their HIV positive status.

Despite participants citing accurate information regarding the various modes of transmission of HIV/AIDS, many of them seemed to fear contagion. This fear seemed to result in social isolation for the infected party. The first extract below is from an interview with a participant between the age of 35 and 45.

327 P: I had that thing↑ I would have that fear↑ () the way it was being spoken about,  
328 people saying that feet would fall off () I had that thing that () maybe I would be scared of them  
329 and have you seen that thing of hearing things here and there, I also had that thing that I would  
330 not even share something that they are eating or drinking. I had that thing of thinking I would  
331 say no thank you. You know that thing of not having full information about something. I would  
332 () I would not treat them the way that they should be treated, maybe because they would not  
333 be from my home. I didn’t have anyone like that in my immediate home. (F)

This participant references “fear” (line 327) of HIV and then she comments on being “scared of them” (line 328) referring to PLWHA. She seems to suggest that the way others reference HIV induces fear in her. The description of feet falling off may be representative of ‘loss’. The participant then goes on to describe her stigmatising behaviours towards PLWHA (line 330). She seems to associate her stigmatising behaviours with fear, firstly of HIV and then of HIV positive people. This participant implies that it is a lack of relevant knowledge that makes her fearful when she says “you know that thing of not having full information about something” (line 331).



The second extract from an interview with a participant between the age of 18 and 25 also illustrates behaviours associated with fear of contagion.

- 1610 P: no here with clothes there is a problem. Because that person is a person with rash maybe,  
you  
1611 know when you wear my jacket and then bring it back and I feel that hey. You know, that  
thing you  
1612 must first wash it. (G)

Although this participant is willing to lend her clothing to an HIV positive person, she seems to be reluctant to have it returned without being washed (line 1612). She seems to believe that she may contract something (such as a rash) from wearing clothing that an HIV positive person has worn without it first being washed. This may be linked to idea that HIV/AIDS represents 'dirt' and 'uncleanliness' outlined below.

It is noteworthy that although the above participants demonstrated a fair knowledge of issues relating to HIV/AIDS, they demonstrated behavioural responses to HIV and PLWHA that were inconsistent with this knowledge.

The construct of death and dying associated with HIV/AIDS was found to be connected with the identifiable signs and symptoms of HIV. Therefore if a person was identified as having HIV as the result of presenting with these signs and symptoms, they were labelled as 'dying'. This is illustrated in the extract below from an interview with a participant between the age of 35 and 45. This participant refers to being identified as HIV positive by people as a result of "weight" after which she says "people would say hey this one is going to die".

- 271 P: Because is able to look at you (.) let's say your weight (.) a person can look at  
272 your weight (.) even though you do not have HIV people will think you have HIV (.)  
273 I: Mmh  
...  
276 P: People would say hey this one is going to die (.) do you understand? (B)

It would seem that the fear of death may be related to issues surrounding the transmission of HIV.

#### **4.1.1 Transmission of HIV as a response to fear of death**

References were made by participants between the age of 18 and 24 to the deliberate transmission of HIV. This is illustrated in the extract below, taken from a focus group.

- 123 P1: maybe a person has HIV right?  
124 F: yes  
125 P1: so he or she wants to pass it to another person=  
...  
385 F: so now, do you think that really happens that people know they do have the virus  
386 they want to pass it on to others?  
387 P2: yes=  
388 P3: =those things happen  
...  
405 P3: knowing that no, [I am doing this because I want to pass it=  
406 P4: = [I keep on passing it; they say they don't want to die alone. (I)

These participants maintain that “he or she wants to pass it to another person” (line 125). This is suggestive of intentional transmission of HIV. This purposeful infection of others seems to be attributed to a fear of dying alone (line 406). Although this may be considered a deviant case in this study, it may suggest the presence of a fear of death in relation to HIV/AIDS, and/or the demonstration to the researchers of ‘bravado’ in the face of HIV/AIDS. No other transcripts in the data set referenced the deliberate transmission of HIV to others.

It seems that the association between death and HIV/AIDS and the fear this seems to generate might have a bearing on people’s awareness of the outward signs and symptoms seen to denote the presence of HIV.

## 4.2 Identifiable signs of HIV

Outward signs and/or symptoms were used by participants to denote the presence of HIV/AIDS. They seemed to be the means by which people living with HIV (PLWH) are identified by others. This is illustrated in the extract below from an interview with a participant between the age of 35 and 45.

- 271 P: Because is able to look at you (.) let's say your weight (.) a person can look at  
272 your weight (.) even though you do not have HIV people will think you have HIV (.)  
...  
227 I: Mmh mmh (.) you said (.) when a person looks at your weight 277 (.) how so maybe  
278 (.) °how would they look at you°?  
279 P: They'd look at how thin you are and say that you are sick  
280 I: O::h  
281 P: Yes (.) lets say you have a small body  
282 I: Mmh mmh  
283 P: But you are not sick (.) they look at that not knowing that no matter how big  
284 you are (.) you can still have HIV  
285 I: Mmh (.) But you are saying  
286 P: they take it as though a person who has HIV is one who has lost weight (B)

The use of outward signs and symptoms to signal the presence of HIV was present across the data set, irrespective of generational boundaries. The visible signs of HIV related to weight (weight loss, being thin, being an 'ironing board'), discoloration of the skin (navy skin, black skin, black spots, black splotches, pink mouth), hair loss (blotches of missing hair), sores (mouth sores, boils on face), fatigue (tired, walking slowly), dandruff and a cracked mouth. The symptoms of HIV related to the presence of diarrhoea, fever, cramps and feeling cold. The following extract from an interview with a participant between the ages of 26 and 34 illustrates the use of signs and symptoms as a means of identifying HIV.

- 241 Participant: I see it happening to people and you can see the person has this thing.  
242 Interviewer: Even though the person didn't say?  
243 Participant: Hum, yes.  
244 Interviewer: How do you see?

245 Participant: I maybe see them by being tired all the time whereas the child was very active.  
246 You can see that they are not the way they were before. And, the child used to be big and  
247 now they have lost so much weight to the extent that it is not the person that I was used to.  
248 Interviewer: Um.  
249 Participant: Even the hair falls off whereas before they had lots of hair.  
250 Interviewer: Ok=  
251 Participant: = And on the head thy have blotches of hair missing as well as sores.  
252 Interviewer: Ok -ok.  
253 Participant: And then you can conclude that it is it that is causing this. (J)

The basis of this identification of the presence of HIV/AIDS appears to be made through a socially shared conception of HIV/AIDS. In some cases participants indicated that PLWHA do disclose their status to others in their communities. In most cases participants referenced 'seeing' the disease 'in' an infected person, which was associated with the 'identifiable signs and symptoms' of HIV. This is illustrated in the following extract from a focus group of participants between the age of 14 and 17.

842 F: so people, are there people that you know of who have HIV?  
843 P1: there  
844 P3: there are lots of them  
845 P5: there are  
846 F: there are lots of them, how do you know that they have HIV/  
847 P5: others they tell us and others we can see the symptoms of HIV in them  
848 F: mm like how can you see them?  
849 P5: (unclear)  
850 P1: like even their lips they get sores  
851 P6: they get thin  
852 P1: they get thin  
853 P2: they get black spots on their bodies  
854 P5: their body, their hair. (K)

The identification of HIV through socially constructed signs and symptoms used to signal the presence of HIV could lead to blame associated with infection.

### 4.3 Fear of blame

The fear of blame was found predominantly in the transcripts of interviews and focus groups with women above the age of twenty five. No themes relating to blame were found in the transcripts of adolescent girls. They tended to be more concerned with issues relating to being identified as HIV positive through various markers and the consequent loss of status within their communities. The following interview with a participant between the age 35 of 45 illustrates the fear of blame.

292 P: The way it was spoken about, in such a bad way, and really even when it was first  
293 came it was said that you got it from being promiscuity, they have only just recently said  
that  
294 you are able to get it even if you have been conducting yourself well, like helping someone  
295 who- maybe they are now adjusting it. However in the end, elderly people, people still have  
296 that thing of impression that it is because of promiscuity, understand? So that is what I was  
297 scared of. (F)

This participant comments on how HIV is associated with promiscuity when she says “it was said that you got it from being promiscuity” (line 293). She maintains that elderly people still view HIV in this way despite new information regarding modes of transmission. She references being “scared of” (line 297) being perceived as promiscuous. This is suggestive of fear of blame as a result of HIV infection.

The following extract taken from an interview with a participant between the age of 18 and 25, illustrates blame relating to HIV.

289 P: I would tell people to take care of themselves. If maybe a person is at the tavern  
290 she must not just sleep with any man that she does not even know. She does not even know  
what that person  
291 has. (L)

In this extract blame seems to be implied by the participant attributing possible HIV infection to promiscuous behaviours. She says the person must “take care of themselves” (line 289) and “must not sleep with any man that she does not even know” (line 290). This suggests that this person is liable for possible infection of “of what that person has” (line 290). The phrase “does not even know” (line 290) may suggest disapproval.

Themes relating to blame surrounding HIV/AIDS seemed to be predominantly associated with socially unacceptable behaviours. These included promiscuity, adultery, and the consumption of alcohol, which was closely related with frequenting taverns. The extract below taken from an interview with a participant between the age of 35 and 45, illustrates the association between infection and “travelling” a word used for engaging in sexual behaviour with multiple partners.

- 256 I: Are there people that you talk to about HIV? And what is it that you talk about?  
257 P: In Johannesburg I used to tell all my friends just as I tell who like going out and  
258 travelling. I tell them that you will cry the day you find out that you have contracted HIV.  
259 “No we cannot follow that”, they would say.  
260 I: uh .hh  
261 P: And then I had another friend of mine from QQ we used to work together. I’d tell  
262 her every Friday “calm down with travelling. If you don’t do that you will eventually find out  
263 that you have HIV. Have you ever seen HIV written in people’s faces? One day you will see  
264 it. (M)

This participant seems to associate promiscuous behaviour with HIV/AIDS infection when she says “calm down with travelling” (line 262) and “if you don’t do that you will eventually find out that you have HIV” (line 262 -263). She seems to view HIV infection as the fault of the person who is “travelling”.

Another extract from an interview with a participant between the age of 26 and 34 also attributes blame for HIV infection to having multiple partners.

- 362 P: Not having one partner. If I have one partner then there are no outside things that  
363 come in. (N)

This participant directly attributes HIV infection to multiple partners. The implication here seems to be that a positive HIV status is indicative of promiscuous behaviour.

HIV/AIDS was frequently associated with people who ‘drink’ alcohol and who frequent taverns. This was also closely linked to promiscuous behaviour. This is illustrated in the following extract from a focus group with participants between the ages of 40 and 46.

- 1243 P1: I don't even want to lie to you. And the one thing that has contributed to the spread of HIV are
- 1244 these people that drink. They drink and then they do these things, that's how it spreads, because
- 1245 there are no condoms and that's how it spreads. (E)

This participant seems to be blaming the spread of HIV on people who drink and as a result engage in sexual intercourse without using protection.

Blame associated with HIV/AIDS seems to propel the view of PLWHA as being 'unclean'.

### **4.3.1 Clean verses unclean**

References to HIV/AIDS, in the context of finding out one's status were frequently made in terms of being found to be 'clean'. In other words people seem to be classified in terms of being clean or unclean i.e. HIV positive or negative.

The following extract is taken from an interview with a participant between the age of 46 and 60 who was discussing how she would advise her children regarding sexual relationships and HIV. This participant was suggesting that her child is clean i.e. HIV negative.

- 87 P:... Maybe you can see that you are clean
- 88 and I can see that you are clean... (P)

The extract below from an interview with a participant between the age of 35 and 45 illustrates the use of the term "uncleanliness" relating to HIV.

- 126 P4: He's
- 127 brought uncleanliness to me from the outside and then when you go and test you find that
- 128 you have these things, you see. (Q)

In addition to referencing HIV in terms of being 'unclean', this participant seems to associate this "uncleanliness" with adulterous behaviour by referring to infection being "brought from the outside".

In some instances when discussing romantic relationships participants made references to HIV/AIDS and sexually transmitted diseases as 'dirt'. The inference seems to be that people living with HIV/AIDS are perceived by others as 'unclean' or 'dirty' by virtue of being HIV positive. Promiscuous or adulterous behaviour was implicated in these contexts. This is illustrated in the following extract from an interview with a participant between the age of 18 and 25.

93 P: You do not know what that girl has, so you will take whatever dirt you get there and bring  
94 it to me. (R)

The following extract with an interview with a participant between the age of 46 and 60 also illustrates the use of the term 'dirt' in relation to HIV, linked with adulterous behaviour.

64 P: -talked about love and that he mustn't love me and like other people on the side maybe  
65 while he has other people on the side and maybe that person has dirt (infection) you know?  
66 I: uhm  
67 P: maybe he ends up bringing it to me, while I am looking at him you know?  
68 I: okay, okay  
69 P: you know? He ends up getting me infected too. (S)

This participant indicates that the term "dirt" refers to "infection" (line 65). She associates this with promiscuity when she says "while he has other people on the side" (line 65). She suggests that he may infect her with "dirt" contracted from his other sexual partners. Blaming another for being the agent of infection seemed also to be associated with immoral behaviour, i.e. adultery.

#### **4.3.2 Agent of infection**

Blaming someone for being the agent of infection was found in the data from women above the age of 35. In most instances this form of blame was associated with adulterous behaviour. It emerged in the context of a discussion about romantic relationships. Blame in this context was expressed by participants with regard to their own relationships as well as that of others in their community.



The extract below from an interview with participants between the ages of 35 and 45, illustrates blame in terms of responsibility for the transmission of HIV within the context of a relationship.

363 P: Yes, in other relationships usually the couple fight and one says to the other 'you  
364 brought me this thing'... (F)

The words "you brought me this thing" are suggestive of an accusation. Seemingly this participant is suggesting that the conflict is centred on blame as one partner accuses the other of infecting them with HIV.

The extract below from a focus group of women between the ages of 35 and 45 also illustrates blame in the context of HIV transmission, associated with adultery.

110 P1: and sometimes maybe he has a car you know mos that a car controls it'self and he will  
111 say that he has broken down on the way and so I slept in that town but that's not true. It's a  
112 chance for him to sleep out. So that being said even men do go out. And so you find that  
113 sometimes you even get real problems, you get sick  
114 P2: mm because of your husband's outing  
115 P1: you see. you find that you are sick now  
116 P3: and then the truth comes out  
117 P1: maybe you went to the clinic and you find that you've got HIV. Sometimes, you know  
118 we are married mos, we should go to the clinic and test together. And I know that I have  
119 had no affair. I will wonder where I got it from but the thing is that I got it from him. (Q)

These participants refer to men and then later "husband's" (line 144) having sexual relations with other partners outside of their committed relationships, the term used for this is "outing". Their husband's outing is given as the reason for their HIV infection. They suggest that the husband's 'outing' is accomplished through lying, for example when participant 2 says "and then the truth comes out" (line 116). Participant 1 says she knows that she has "had no affair" (line 119). This participant goes on to say that although she wonders where she "got it from but the thing is that I got it from him" (line 119) and blames the husband for

the wife's infection. It is unclear whether these participants are recounting their own experience or illustrating the experience of others within their community.

The following extract from an interview with a participant between the ages of 46 and 60 illustrates this form of blame by community members, rather than by one of the partners within the relationship.

- 182 P: then I speak out when I see it happening in another home  
183 I: in another house that's rights that's right  
184 P: it's sore when you see that happening because you see now the woman has  
185 brought this to the husband  
186 I: yes- yes  
187 P: you see things like that because that is not something right it's very hurtful  
188 I: Mmh  
189 P: because that man was not a promiscuous man  
190 I: yes  
191 P: so it's the woman that has brought this thing to him (P)

This participant's comment relating to her speaking "out when I see it happening in another home" (line 182) suggests that her comments relate to others in the community. This participant seems to be directly blaming the wife in this relationship for infecting her husband with HIV. This is associated with promiscuity when she says "because that man was not a promiscuous man" (line 189) implying that the wife therefore must have been promiscuous. It seems that HIV infection is viewed as exclusively the result of promiscuous behaviour. No other modes of transmission are considered. The wife is identified and blamed for being the agent of infection within this relationship.

A fear of blame related to HIV infection may contribute to the silence surrounding this disease.

#### 4.4 Silence surrounding HIV/AIDS

Themes relating to silence surrounding HIV/AIDS were found in most of the transcripts across generational boundaries. The following extract from a focus group with participants between the ages of 14 and 17 illustrates this silence.

- 824 Participant 1: No we do not speak about it at all.  
825 Participant 2: mm  
826 Participant 1: well at home we have never spoken about it.  
827 Participant 2 Mm mm, we never speak about it.  
828 Participant 3: Hayi even at home we do not speak about it. (K)

These participants suggest that HIV/AIDS is not spoken about “at all”. HIV/AIDS is seemingly surrounded by silence. It was found to be largely a taboo topic in many of the participant’s societal milieu. This is clearly illustrated in the extract below from an interview with a participant between the age of 26 and 34 who, on being asked whether there was someone to whom she spoke to about HIV replied “we don’t usually speak about those things” (line 221). This suggests that HIV is a taboo topic.

- 218 I: Is there someone you do speak to about HIV?  
219 P: No.  
220 I: Why?  
221 P: Because we don’t usually speak about those things... (V)

The extract below from an interview with a participant between the age of 18 and 25 suggests that silence surrounding HIV/AIDS may be an attempt to avoid HIV/AIDS altogether due the discomfort it induces.

- 127 P: Um some people they (.) um avoid anything to do with AIDS.  
128 I: Mm.  
129 P: They don’t like to talk about it. (W)

The conceptualization of HIV/AIDS as a killer and the fear this seems to generate may contribute to the silence surrounding HIV/AIDS. This is illustrated in the excerpt below from a focus group of participants between the age of 14 and 17.

810 P3: we don't speak about it

...

817 F: so so, because, why have you never spoken about it

818 P1: because we know that it kills (K)

These participants cite their knowing that HIV "kills" (line 818) as the reason for their reluctance to speak about HIV. This suggests that the construct of HIV as a 'killer' contributes to HIV/AIDS silence.

Fear of blame for infection, associated with socially unacceptable behaviours was also found to contribute to silence relating to HIV/AIDS. This is illustrated in the following extracts, taken from interviews with HIV positive participants. The extract below is from an interview with a participant between the age of 35 and 45.

401 Participant: ( ) .hh I don't feel good ( ) because when they- most of the time, when people talk

402 about it they criticise it- they criticise it. So when a person is going to talk about something that

403 you know you have- you also. Or you just shut your mouth because in the end, you – it feels as

404 if they are taunting you- understand? (X)

This participant is seemingly unable to disclose her status in the face of censure relating to HIV/AIDS. She seems to experience the manner in which people talk about HIV as deprecating (line 402 and 404) and as a result she remains silent when HIV is discussed (line 403). Fear of being viewed as being blamed for infection seems to foster silence relating to HIV/AIDS.

Silence surrounding HIV/AIDS seems to be manifest in a reluctance of people to name HIV/AIDS directly.

#### **4.4.1 Indirect references to HIV/AIDS**

Consistently throughout the data set the euphemism “this thing” was used by participants when referring to HIV/AIDS. In some cases it was referred to as “that thing”. In the few transcripts where HIV/AIDS was referred to directly, it tended to be by younger women rather than older women. This avoidance of the direct usage of HIV/AIDS was prevalent amongst both HIV positive and HIV negative women. Despite the interviewer or facilitator referring directly to HIV/AIDS during both individual interviews as well as focus groups, the participants tended to revert back to the use of “this thing” when discussing issues relating to HIV/AIDS. Likewise in instances where HIV/AIDS was named directly by participants, they frequently returned to use “this thing” when referring to HIV and AIDS.

The following excerpt, taken from a focus group of women between the ages of 14 and 17, demonstrates the use of “this thing” when referring to HIV/AIDS. Relationships were being discussed in general after the facilitator had asked participants what it means to them to have a boyfriend.

- 130 P6: uhm, because of this thing I see happening man, and its because I saw that girls are just  
being
- 131 played with, guys use girls and also because of the presence of this thing outside
- 132 F: mm mm. And when you say this thing outside what do you mean?
- 133 P6: HIV (K)

In the above extract, the participant has clearly indicated that the euphemism “this thing” refers to HIV. It is noteworthy that in the majority of the transcripts in which HIV/AIDS is referred to using these euphemisms, the participants have demonstrated a fair knowledge of HIV/AIDS. In most cases HIV/AIDS is acknowledged as a disease that is incurable but treatable with ARV's. Furthermore the various modes of HIV transmission were often

accurately cited. The following extract, taken from a focus group of women between the ages of 18 and 24, further demonstrates the use of “this thing” when referring to HIV/AIDS.

1586 P: Ja, and say that I have this thing... (Y)

This extract is a reflection of a trend across the majority of the data set in which participants believe that people with HIV and AIDS should be open regarding their HIV/AIDS status and yet seem reluctant to name HIV/AIDS themselves. This apparent reluctance to use the correct term for HIV/AIDS might be related to feeling threatened by the direct use of HIV/AIDS.

The following extract from a focus group of women between the ages of 46 and 60 demonstrates a reluctance to name HIV/AIDS directly in the context of a romantic relationship. The participant makes references to fear of being blamed for infidelity as a result of an HIV positive status.

511 P3: and I want to support what Six is saying. Most of the time it is the men who see  
themselves as  
512 clean, so if you have that thing as a woman you feel bad because you feel that maybe he is  
going to  
513 hit you, that where did you get this from. Maybe at the time he does not have the signs  
maybe you  
514 are the one that had the signs first. So when you tell him about this thing he hit's you, where  
are you  
515 getting this thing from because I don't have it. But this thing showed it'self on me and the  
thing that  
516 was needed was for him to go and get help so that it does not get worse for him. And he  
says you  
517 must tell him where you got it from. But most of the time it is the woman who is accused of  
518 cheating. And so you keep quite and endure because you are scared to say. You reckon that  
you are  
519 really not feeling what you are doing although you are feeling that something is wrong. (E)

The participant refers to feeling “bad” and being “scared” to disclose “this thing” as a result of possible blame of “cheating”. She suggests that men mostly view themselves as “clean”. This reference of HIV in terms of being clean may imply that a positive status makes one

unclean. Repeatedly she references “where you got it from”. At times this phrase is posed as a question, as if she is relaying a dialogue between herself and her partner and at other times a statement exposing her culpability. The participant maintains that “most of the time it is the women who is accused of cheating” (line 589). Here she directly references blame of HIV infection being associated with immoral behaviour.

It would seem that silence surrounding HIV/AIDS is closely connected to issues relating to the disclosure of a positive HIV status.

#### **4.5 Disclosure**

Most participants referenced secrecy with regard to disclosing one’s HIV positive status. Secrecy regarding an HIV positive status was referenced in terms of public disclosure within the community as well as in the context of disclosure to a sexual partner. This is illustrated in the extract below from an interview with a participant between the age of 35 and 45.

286 P: People in M that have HIV do not want to be known that they have HIV. They  
287 do not disclose themselves. (M)

Some of the data did suggest that some people reveal their status in order to access treatment for HIV/AIDS. Although most participants believed that HIV positive people should reveal their status, they frequently cited the negative consequences for doing so. The extract below from an interview with a participant between the age of 26 and 34 illustrates this.

129 I: Do you think a person who is HIV positive should disclose their status to other  
130 people?  
131 P: It is important to speak about it even though people will laugh at you. It is  
132 important to tell your family though. (Z)

This participant suggests that disclosing one's status will result in being laughed at. This is suggestive of ridicule which could result in loss of status for the person who discloses their status.

Some participants suggested that it was not possible to disclose one's HIV positive status because of the negative consequences of doing so. These negative consequences were found to include ridicule, gossip, loss of status and social isolation. The extract below from a focus group of participants between the ages of 26 and 34 also illustrates this.

- 632 F: uh. So, so, do you think that a person must tell other people when they are positive  
633 P1: when you are ready to  
634 P2: if you want to, but I don't think that you can tell other people because other people  
make  
635 fun of that  
636 P3:: mmm mm mm mm  
637 P1: if you tell here at home only  
638 P2: if you tell them at home, so that they know about it.  
639 P1: support  
640 P1: to get support  
641 P2: otherwise here outside you will be the laughing stock of the village  
642 F: so it won't be support if it's from outside, it's only support here at home  
632 P2: no, it's fine here at home  
644 P1: no, when you are ready you will tell someone that you trust from outside, you see. That  
645 person that you trust. Then as time goes, like maybe you attend support groups and you get  
646 counselling. Then you see that I am ready to face the world no matter what they can say  
647 F: ok, ok. So now what makes you say that, is it because people who have come out and  
648 said they are positive in the community, have they been-  
649 P1: others are not accepted. (AA)

In line 634 the participants says "but I don't think that you can tell other people because other people make fun of that". This suggests that the negative consequences, in this instance ridicule, associated with a HIV infection inhibit disclosure. In line 641 the participant comments "otherwise here outside you will be the laughing stock of the village".



This suggests that disclosure of an HIV positive status may result in loss of status. The comment made in line 649 “others are not accepted” suggests that disclosure may result in social isolation.

The extract below of a focus group of participants between the age of 10 and 13 illustrates reluctance to disclose an HIV positive status because of gossip and the associated loss of status and social isolation that seems to accompany it.

- 481 F: do you think that they should tell others, are they forced?  
482 P1: no  
483 F: they are not forced?  
484 P: yes  
485 F: why  
486 P: no man  
487 P2: maybe you tell your neighbour and they tell another person  
488 P3: and they advertise it and everyone in the village is talking about you  
489 P4: and they talk behind your back  
490 P3: this and that and this and that, yhu no man  
(U)

The phrase “and everyone in the village is taking about you” (line 488) and “they whisper about you behind your back” (line 489) is suggestive of loss of status and social isolation. The HIV positive person becomes in a sense ‘separate’ from other village members by becoming the target of gossip. It seems the negative consequences of disclosure are known to everybody in the community.

As suggested in the section regarding the silence surrounding HIV/AIDS (section 4.4), HIV positive people seem reluctant to disclose their positive status. This was illustrated in an extract taken from an interview with an HIV positive person. Seemingly this reluctance stems from a fear of blame because HIV is associated with immoral behaviours. The participant suggested that a HIV positive status was associated with promiscuity.

Seemingly HIV disclosure is influenced by a fear of gossip and its associated negative consequences.

## 4.6 Gossip

The theme of gossip relating to HIV/AIDS was found across the data set. Gossip appears to be constructed by participants as a form of scorn. This is illustrated in the extract below of a participant between the age of 35 and 45.

- 251 I: Oh! I hear you. What are the challenges faced by a person who is living HIV here in  
252 Ematyholweni?  
253 P: ... In the  
254 end you just have to deal with the fact that a person says what they say, in that place they  
say  
255 in- people don't speak nicely about an HIV positive person ( ) who lives with it-ehe.  
266 ( ) they do not support them. What I mean is there isn't anything they SAY  
267 there isn't anything they do about them either besides this thing that I am saying-that they  
just  
268 gossip about them.  
...  
287 ... There is still a lot of gossiping going on, there isn't that sense of support, and  
288 it's just gossip. (T)

This participant suggests that gossip relating to HIV is rife within her community. Seemingly gossip undermines a sense of support for HIV positive people (lines 266 and 287). The comment "people don't speak nicely about an HIV positive person" seems to suggest that people with HIV are spoken about negatively and are isolated.

Gossip seemed to be associated with the signs and symptoms used as a means to identify PLWHA. This is illustrated in this extract below taken from the same interview. The phrase "she live with it is written on you" suggests the physical signs associated with HIV/AIDS infection.

- 253 P: .hh ( ) well it is those that I mentioned earlier of gossiping mongers. You find that  
254 even when you are just going about your business, 'she lives with it' is written on you ... (T)

The fear of and possibility of gossip seems to promote silence surrounding HIV/AIDS through creating a context in which HIV is not discussed directly or openly with the relevant party.

This is illustrated in the extract below from an interview with a HIV positive participant between the age of 35 and 45.

421 P: There is just one thing that I have experience in, just one thing that. There was still  
422 that thing where if people have heard that you have it, you would be gossiped about but  
423 nobody would come to you.

...

453 P: So ke, I was upset because I realised that people are still getting judged. If someone  
454 hears or if someone suspects you, they gossip about it nobody comes to you straight. (F)

This participant suggests people gossip about a person with regard to their HIV infection but avoid the topic with the person concerned. This participant says “nobody comes to you straight” (line 454). She seems to link gossip and judgement to an HIV positive status (line 453-454). This tendency to avoid discussing HIV openly might perpetuate the silence surrounding HIV/AIDS.

The silence surrounding HIV/AIDS seems also to be impacted on by a fear of gossip which appears to adversely impact people’s willingness to disclose an HIV positive status. This is illustrated in the extract below from a focus group of participants between the age of 10 and 13.

491 F: so is that wrong for other people to know that someone is HIV positive or they  
492 have AIDS  
493 P2: its wrong because maybe you can tell the wrong person who is going to tell  
494 someone in the community and the whole community knows. So that when people see you  
495 they whisper about you behind your back, even though they are your friend

...

500 F: Like what do they say when they see that person?

501 P4: They gossip. (U)

Gossip was found to be related to blame in terms of HIV and AIDS being associated with socially immoral behaviours. This is illustrated in the excerpt below from an interview with a participant between the age of 35 and 45.

490 Participant: They usually criticise it (), they still criticize it because of that thing, as I said of  
491 criticising it. SHE HAS THIS THING, it becomes this thing and you find that a person is  
sneering  
492 upon it. It has not really been accepted, not really accepted, properly. And they still have  
that  
493 thing of- that someone who has it was all over the place, understand?(F)

This participant suggests that HIV is talked about in a disdainful manner (line 491). The participant seems to attribute HIV to not really have been “accepted” to its association with immoral behaviour. The term “been all over the place” (line 493) is suggestive of promiscuity. This association may result in loss of status for this person. Furthermore the phrase “not really accepted” (line 492) might suggest that this person is excluded and thus socially isolated.

Participants suggested that they would not access treatment for HIV infection due to a fear of gossip. This is illustrated in the extract below from a focus group of participants between the age of 18 and 25. These participants suggest they would not access treatment because this may result in their hypothetical status becoming known to “other people”.

1722 P1: I would not take it because of the fact that they tell other people.

...

1730 P3: Like maybe I haven't told my mom and she is going to hear about it on the bus that yhu  
xxx

1731 your child has AIDS. I haven't told her here at home that I have it.

1732 P4: Maybe someone is gossiping and that person doesn't know that it is your cousin you see,

1733 and you get shocked that hayi bo, so and so is like this? (G)

Gossip seems to have a bearing on the people's willingness to engage in health care behaviours.

#### 4.7 Healthcare behaviours

Most participants displayed a good knowledge of issues surrounding HIV/AIDS. This included issues relating to treatment and preventative healthcare behaviours. In addition to this, participants commented that they believed people with HIV/AIDS should engage in preventative health care behaviours and that they should seek treatment. Despite this, participants revealed behaviours contrary to this knowledge. These behaviours seemed to be associated with a fear of being labelled as HIV positive and the subsequent negative repercussions of this, such as gossip and loss of status. The extract below from an interview of a participant between the age of 35 and 45 illustrates the association between being seen at the clinic and an HIV positive status which results in gossip.

425 P: Yes, you are gossiped about behind your back, I am going to speak about myself  
426 mostly. Maybe there was- you know once you are seen here in the rural areas going  
regularly to  
427 the clinic, people have that thing that maybe you are going to get treatment. Once you are  
428 seen going to the clinic regularly, °<going to clinic again and again> °, they have that thing  
that  
429 you must be going to fetch treatment. And then of the treatment the one that most people  
go  
430 to get is this one for HIV. If they see you about three times, four times, that person who  
sees  
431 you, then it becomes known that you are positive... (F)

The extract below from a focus group of participants between the age of 18 and 24 illustrates an avoidance of preventative healthcare behaviours due to a fear of ridicule. These comments were made in the context of a discussion relating to discovering ones HIV positive status. The comment “they scared of being laughed at” is suggestive of fear of mockery. This ridicule might result in loss of status.

1045 Participant 2: =Males don't want to see a clinic.  
1046 Participant 1: you see?  
1047 Interviewer: what makes males don't want a clinic anyway?

- 1048 Participant 1: remember they just say they=  
1049 Participant 3: =they scared of being laughed at. (I)

The use of a condom in sexual relations was found to be associated with an HIV positive status. This is illustrated in the extract below taken from the same transcript as above. These participants suggest that a woman who is known to use a condom is thought by men to do so because she is aware of her positive HIV status (line 1273).

- 1271 F: Wait, girls, if a girl is known by guys that she doesn't do a mistake, she uses  
1272 condom, condom, condom, guys, and how do they think about such a girl?  
1273 Participants: Maybe they think, maybe she knows that it is HIV positive.  
1274 Interviewer: =Yes.  
1275 Participants: That's why she always wants a condom. (I)

The extract below from a focus group of women between the ages of 25 and 30 also illustrates the association between condom use and an HIV positive status. In this case it is suggested that men will think that the women who wants to use a condom during sexual relations is doing so because she believes that he is HIV positive.

- 2151 P1:: no but I want to use a condom but you reckon that-  
2152 P2:: how are you going to approach it  
2153 P1:: yhu this one *uyonqeneka* (reluctant) how will I even approach this. They are not even  
written in  
2154 the face  
2155 P2: and he is going to think (unclear) if you are going to say that to him?  
2156 F: mm  
2157 P3: they just think what is he going to say when I (unclear)  
2158 P1:: maybe he is going to think that hey this girl thinks I have HIV and AIDS, you see (D)

In addition to health care behaviours, the issue of support for HIV positive people comes to the fore.

## 4.8 Support

In most of the data, participants agree that a PLWHA should receive support and care from the community. Although they tended to state that PLWHA were treated well in the community, they frequently contradicted this idea by referencing stigmatising behaviours such as social isolation or loss of status as the result of ridicule. The contradictory points regarding the treatment of PLWHA within the community is illustrated in the following extract from an interview with a participant between the age of 26 and 34. These comments were made in the context of a discussion relating to whether people should disclose their HIV positive status.

315 P: I don't need to tell the community; else they will make fun of me. Just as long as

316 it is known here at home

317 I: Ok.

318 P: Because these days, people are making jokes about it.

319 I: Um ok. So: It is important to tell people when you do have it?

320 P: NO it is not necessary to tell other people, as long as it is known here at home.

321 There is no need to tell other people because people will make a laughing stock of it.

322 I: And it is a must to tell the people at home?

323 P: It is a must to tell them at home.

324 I: Oh ok- ok:: a:nd erm how are people with HIV treated by the community?

325 P: They are treated alright.

326 I: Ok.

327 P: and you tell the person that this is not the end of life, with this thing.

328 Interviewer: So they are living in peace?

329 P: They are living in peace. (O)

On the one hand references are made to stigmatising behaviours such as ridicule evidenced in the phrases "else they will make fun of me"(line 315) and "these days' people are making jokes about it" (line 389) and "people will make a laughing stock of it" (line 321). These phrases are suggestive of loss of status. On the other hand, after making the above comments, this participant suggests that HIV positive people are treated "alright" within the community. She goes on to say "they are living in peace" (line 392).

Some participants promoted disclosing one's status, suggesting that PLWH are treated with dignity while others advocated revealing ones status only to family members in order to gain support because of the stigmatising behaviours of community members. On the other hand, HIV positive participants related experiencing ridicule (such as being laughed at) and being fearful of stigmatising and discriminatory behaviours. This is illustrated in the extract below of an interview with a participant between the age of 35 and 45. This participant references "worries" and "fears" associated with how she will be treated in a job setting. She relates this to how in a job she might experience discriminatory behaviour such as not sharing drinking cups.

383 P: Mmh (.) Yes (.) you do get worried (.) you have some worries because you can

384 think (.) hey I wish I can get a job

385 I: Mh

386 P: But you think that (.) this job (.) at that house (.) some people have this thing

387 that when you drink with the same cup that someone else used (.)

388 I: Mmh

389 P: And then you think about how you will be treated in that house when I disclose

390 my status to them

391 I: Mmh °ok°

392 P: So you get such fears (B)

Furthermore stigmatising behaviours were frequently implied through references to the ways in which HIV infected people should be treated. This is illustrated in the following extract from a focus group with participants between the age of 46 and 60. After citing accurate information regarding HIV transmission one of the participants comment "you must not be disgusted by them" and "I can share the same spoon with them". This might suggest that these behaviours do occur.

998 P: This virus, firstly it is infectious, it infects people in relationships, through sex. To protect  
999 yourself from it you must use a condom. Sometimes you do not get it through sex only, but  
also

1000 through maybe there is a child who has it and they have a cut and I am trying to help them  
.Maybe



- 1001 while I am using my hands to help them I have a cut and then I contract it through their blood. And
- 1002 whoever has this virus, you must not be disgusted by them. I can share the same spoon with them,
- 1003 it's only blood, and no other way. Only through sex and through blood. (E)

The extract below from an interview with a participant between the age of 26 and 34 is also suggestive of stigmatising behaviours. This participant references how not to treat a HIV positive person when she says “not to treat them any differently” and “not be mean and act funny towards them”. This may suggest that people do behave in these ways towards PLWHA.

- 427 P: I would join a group. I don't know what I could do on my own. I do support
- 428 people with HIV though and do not treat them any differently, to show them love and not be
- 429 mean act funny towards them. I want to be a very understanding person. (H)

Seemingly the knowledge of HIV does not necessary inform behavioural responses to HIV.

#### **4.9 HIV/AIDS knowledge versus practice**

As has been suggested above, participants mostly demonstrated a good basic knowledge of HIV/AIDS. This includes knowledge of modes of transmission, treatment and healthcare behaviours. However, participants frequently seemed to contradict themselves during interviews. This trend is suggestive of a disjuncture between participants' professed HIV/AIDS knowledge and their practices. In response to a question pertaining to HIV/AIDS knowledge, they often demonstrated a sound basic understanding of HIV/AIDS and yet cited practices or views that were incongruous with their stated knowledge.

The following extract from a focus group with participants between the ages of 26 and 34, illustrates the disconnect between HIV knowledge and practice.

- 650 P1: like for example maybe she eats from this bowl, and I am like, who ate from this bowl?  
No
- 651 Lusanda ate from it. I don't even want to touch that bowl, I don't even want to touch that chair.

652 That's how some people interpret it. People who do not have knowledge about it. You see, they

653 interpret it another way. And you find that they are stigmatising her, they want to ostracize her.

654 F: and people who have knowledge about it?

655 P1: I am gonna put it like this, people that don't know about it are the ones who do that.

656 P2: those that do not have knowledge about it

657 P2: you will never stigmatise a person even though you have knowledge about it

...

723 P1: there is this girl that I was working with who was positive. I was very heart sore, cos I know

724 how she was when she first started working, but she just had a drop in weight and she got sick it's

725 very sore when you see someone that you know is positive

726 P3: when she is all spoilt now

727 P2: you become very heart sore. And you tend to not accept her, you the very same person

728 who knew her. (AA)

In the extract above references are made to other people “stigmatising” and “ostracizing” PLWHA as result of not having “knowledge about it”. When the facilitator asks the participants how people who do have knowledge respond to people with HIV, the participants suggest that those with knowledge do not stigmatise PLWHA. They seem to consider themselves in the category of people who are knowledgeable about HIV and who do not stigmatise HIV positive people. They then go on to reference firstly identifying HIV infection through signs and symptoms of HIV. Secondly they reference negative values to this person by saying “she is all spoilt now”. This is suggestive of loss of status. Thirdly references are made to tending “to not accept her” this suggests discriminatory behaviours. These participants’ referenced behaviours consistent with stigma after citing non stigmatising ideals.

In addition to the above, as has been alluded to and illustrated in excerpts throughout this chapter, these contradictions were found to include an expressed knowledge of modes of transmission followed by practices consistent with fear of contagion. Participants’

commented on behaviours that promote risk despite displaying a fairbasic knowledge of HIV/AIDS healthcare practices..

#### **4.10 Summation**

The themes that have emerged in the data analysis suggest that HIV/AIDS related stigma continues to be high in this area. Although the themes presented in this chapter have been separated into artificial categories for the purpose of clarity, they are complexly interrelated. The association between death and HIV/AIDS and the construction of HIV as a killer seems to engender fear. Fear relating to HIV/AIDS might have a bearing on people's awareness of the outward signs and symptoms that are used as a means of denoting the presence of HIV in others. The association between HIV infection and immoral behaviour seems to result in people being blamed for their infection. This blame seems to be manifest firstly, in a construction of PLWH as being 'unclean' and secondly in accusing someone for being the agent of transmission. The fear of blame this generates may reinforce the silence surrounding HIV/AIDS. HIV/AIDS seems to be a taboo topic which tends to be avoided. This is evident in the use of euphemisms when referring to HIV/AIDS rather than naming this disease directly and in the reluctance of people to disclosure their HIV positive status to others. The fear of HIV/AIDS related gossip, and subsequent loss of status and social isolation, seems to promote the silence surrounding HIV/AIDS and to adversely impact people's willingness to engage in healthcare behaviours. Engaging in healthcare behaviours seems to be a means of identifying HIV infection. A disconnect between peoples HIV knowledge and behaviours emerged during the analysis process. An example of this is how stigmatising practices would be cited in a transcript followed by comments relating to how well PLWH were cared for or treated. These themes are discussed in greater depth in the discussion chapter.

## Chapter 5: Discussion

In this chapter the results of the research are discussed. This project made use of secondary data from a larger NRF Thuthuka project on sexual health, sexual risk behaviours and HIV. It drew on the interviews and focus groups with women in the age range of 10 to 65. This project was aimed at examining the terms used to reference HIV/AIDS in order to ascertain whether or not they were stigmatising and to explore how they were stigmatising. In this chapter it will be argued that blame, HIV/AIDS related silence and gossip are a means of 'othering' in response to fear relating to HIV/AIDS. This process of 'othering' is understood to be a necessary defence mechanism in the face of the tremendous threat HIV/AIDS poses.

### 5.1 Blame as a means of 'othering'

HIV/AIDS was referenced in terms of a person being 'clean' or 'unclean' i.e. HIV negative or positive within the data. Terms such as "unclean", "uncleanliness" and "dirt" were used to refer to HIV/AIDS. These terms seemed to be linked with the association of HIV/AIDS with socially unacceptable behaviours. Maughan-Brown (2006, p. 168) suggests that HIV/AIDS directly symbolises pollution and contamination and "consequently PLWHA have been associated with dirt and uncleanliness". HIV positive participants referenced fear of blame for infection as a result of the association between HIV and immoral behaviours. This relates to Deacon's (2006, p. 421) model of stigma (first and fourth component), that "illness is constructed as preventable and controllable" and people are "blamed for their own infection". According to Maughan-Brown (2006) the process of blame includes the attribution of negative values to an HIV infected person. This forms the second component of the formulation of HIV/AIDS related stigma proposed by Maughan-Brown (2006). Participants frequently linked HIV infection with socially unacceptable behaviours such as "promiscuity", "travelling" (the term used to describe engaging in sexual relations with multiple partners) and "drink". As a result HIV positive people become the target of gossip which was suggested by participants to be related to the attribution of the above labels. For example participants commented that married women who were HIV positive were believed to have had an adulterous affair. This assignment of negative values to another is significant as it results in the devaluation of a person's reputation and their social standing in the community (Maughan-Brown, 2006). The participants suggested that people who are

believed to be HIV positive become a laughing stock and are ridiculed within the community. This is indicative of loss of social status.

The mechanism of blame is a means of separating oneself from the blamed 'other'. Similarly Deacon (2006, p. 421) proposes that "'immoral' behaviours are associated with 'carriers of the illness, drawing from existing social construction of the 'other'" and that "status loss is projected onto the 'other'". This process of 'othering' through blame is a means of creating a sense of control (Petros et al., 2006) by providing "stigmatisers with an opportunity to distance themselves and their in-groups from infection" (Deacon, 2006, p. 421). This places people as active agents in the creation of stigma (Deacon, 2005). An example of this in the data may be the individual who was blamed for infecting her partner with HIV because of her alleged adulterous behaviour. The notion of an 'other' may be created through the construction of the 'guilty' adulterous women (the immoral other) and the innocent victim, her spouse.

The mechanism of blame appears to contribute to HIV/AIDS related fear. The fear of blame coupled with a fear of death seems to propel HIV/AIDS related stigma.

## **5.2 HIV/AIDS related fear**

Niehaus (2007) proposes that HIV/AIDS related stigma is primarily generated as a result of the association between death and AIDS. The findings of this study supports this notion. Fear associated with HIV/AIDS was found to be manifest in two ways in the data of this study. Firstly fear was related to the tendency of participants to construct HIV/AIDS in terms of 'death'. HIV/AIDS was frequently conceptualized as a 'killer' and a 'death sentence'. In some cases death and HIV were conceptualised as a single entity. This supports the view proposed by Skinner and Mfecane (2004), that HIV is seen as being equivalent to death. This view of HIV/AIDS seemed to impact on the manner in which participants respond to the disease and those infected by it. A fear of contagion emerged in the data. This was linked to the notion that HIV "kills". Despite knowledge of the modes of transmission of HIV, participants commented on fear of contagion. This suggests that knowledge relating to HIV does not necessarily mitigate HIV/AIDS related fear. This is consistent with the findings of Goodall et al. (2011) study relating to HIV/AIDS stigma amongst children in KwaZulu-Natal, participants' fear of contagion was incongruent with their knowledge of the means of HIV

transmission. This was suggested to be an “indication of the irrational nature of fear” and the insufficiency of HIV/AIDS knowledge to “quell fear of this disease” (Goodall, 2008, p.38). An example of the irrationality of HIV/AIDS related fear was suggested by an HIV positive participant who commented that PLWHA are “no longer welcome amongst the people” because they fear being infected with HIV. This illustrates how people in this context continue to fear contagion despite information regarding the modes of HIV transmission.

Secondly fear was closely associated with blame. As suggested above, participants feared being blamed for the positive HIV status and commented on being “scared” of being associated with socially unacceptable behaviours as a result of HIV infection. Nzioka (2000) asserts that HIV/AIDS has become a metaphor for physical and moral contamination because of its association with various forms of stigma as a result of its means of transmission. It is for this reason that death as a result of AIDS is considered a ‘bad’ or ‘undignified’ death which is believed to be the responsibility of the individual (Nzioka, 2000).

Fear of blame combined with a fear of death may sensitize people to physical and nonphysical signs used as a means of identifying HIV infection in others.

### **5.3 The construction of an ‘other’ through markers of HIV/AIDS**

Participants referenced both physical markers of HIV/AIDS as well as behavioural markers as a means of identifying HIV infection in another. For example weight loss and fatigue were seen to signal the presence of HIV/AIDS. Likewise preventative healthcare behaviours, such as condom use, were used by participants to denote HIV infection. Skinner and Mfecane (2004) assert that the use of behavioural markers (associated with preventative health care behaviours or treatment) to signal HIV/AIDS often leads to stigmatisation. Participants suggested that people feared being labelled as being HIV positive as a result of physical and non-physical markers. Goffman (1963 as cited in Goodall et al., 2011) suggests that this process of labelling results in a spoilt identity for the stigmatised individual. Participants commented on being able to “see” HIV infection “in” others which may be understood to be the starting point of this process of labelling. According to Link and Phelan (2001), discrediting social labels drastically impact the way individual’s view themselves and are viewed by others. These labels may result in loss of status and social isolation for the stigmatised individual. For this reason it is understandable that participants suggested that

the fear of being identified or labelled as HIV positive resulted in the rejection or avoidance of preventative healthcare options. This supports the view of Skinner and Mfecane (2004) that the use of behavioural markers associated with health care behaviours may adversely affect the willingness of individuals to engage in vital health care behaviours.

Tulloch and Chapman (1992) assert that physical and nonphysical markers are changing representations that situate people as a threatening 'other'. Since markers provide a primary schema through which the carrier of the stigmatised marker may be understood, they are an effective means of protecting the self from the potential danger HIV/AIDS represents (Crocker, 1998 as cited in Dovidio et al., 2000). For example in the data of this study markers are used as a means to denote HIV infection and consequently, often a means of identifying the 'immoral' or 'contaminated' other. In this way the use of markers to signify HIV/AIDS may be considered to be a function of 'othering' in this context. This 'othering' is necessary defence from feelings of vulnerability which would otherwise be overwhelming (Campbell et al., 2005). The use of markers to identify (accurately or inaccurately) HIV/AIDS in others often leads to stigmatisation in the form of gossip.

#### **5.4 Gossip as a means of stigmatisation**

HIV/AIDS related gossip was cited as being aimed at both HIV infected people as well as people who were suspected of being infected. Gossip was associated with markers relating to HIV/AIDS as well as with socially immoral behaviours within the data of this study. This is consistent with the notion that constructions of moral imperatives, including blame attribution are reiterated through gossip and rumour relating to HIV/AIDS (Parker, 2005). In this sense, gossip may be considered a vehicle of HIV/AIDS related stigma. Participants suggested that HIV/AIDS related gossip may result in loss of status and social isolation for the person being gossiped about. Fear of gossip was cited by participants to adversely affect the willingness of people to disclose their HIV status, access treatment or engage in healthcare behaviours. This is consistent with the view of Niehaus (2007) who proposes that compliance with healthcare behaviours may signal the presence of HIV/AIDS, subjecting people to gossip. In addition to this participants suggested that people do not disclose their status because of fear of gossip, ridicule and subsequent loss of status and social isolation. It

is for this reason that HIV/AIDS related gossip is a barrier to HIV disclosure and the willingness of people to engage in healthcare behaviours (Niehaus, 2007).

Fear of stigmatisation promotes silence surrounding HIV/AIDS, which in turn results in the generation of further stigma through 'othering'.

### **5.5 HIV/AIDS related silence as a means of 'othering'**

Secrecy and silence surrounding HIV/AIDS consistently emerged in the data across age categories. HIV/AIDS seemed to be viewed by participants as a taboo topic that caused discomfort and as a result is mostly avoided within their context. The construct of HIV/AIDS as a disease that "kills" and the fear this generates was implicated by participants as a contributor to HIV/AIDS silence. In addition to this, fear of blame relating to the association of HIV with socially unacceptable behaviours was cited as being a reason for HIV/AIDS silence. This supports the idea that HIV/AIDS is a moral disease with beliefs concerning the moral conduct of people infected with HIV/AIDS (Maughan-Brown, 2006). The silence surrounding HIV/AIDS may be a means by which the participants in this study are able to avoid being implicated in the moral order that shapes the construction of HIV (Clark, 2012). Silence may be a means by which the participants are able to create distance between themselves and HIV/AIDS. In this way the perceived threat HIV/AIDS represents to them is reduced and managed (Skinner & Mfecane, 2004). Silence may therefore be a means of seeing HIV/AIDS as affecting others and not the self (Petros et al., 2006).

HIV/AIDS related silence is evidenced in the unwillingness of participants to name HIV/AIDS directly.

#### **5.5.1 The use of euphemistic terms for HIV/AIDS**

In most of the data set, participants used the term "this thing" to refer to HIV/AIDS. At times "that thing" would be used to refer to this disease. The tendency to avoid the direct use of HIV/AIDS was prevalent among HIV positive and HIV negative participants. Although participants demonstrated a fair understanding of HIV/AIDS and were able to talk about issues pertaining to this disease, they still used euphemistic terms when referring to HIV/AIDS. According to Clark (2012) the naming of HIV/AIDS is in itself construed as aligning



oneself with the stigmatised category through implied knowledge of the object. The participants in this study may therefore be avoiding the direct use of HIV/AIDS in order to circumvent being viewed as being complicit to the stigmatised group. Some participants referenced blame in relation to the use of “this thing”. Clark (2012) argues that the use of rhetorical devices which allude to the ‘unsayability’ of HIV or AIDS imbue the unspoken word with meaning. For the participants in this study, this may serve to increase fear associated with HIV/AIDS given that words may be coded as result of their undesirable connotations in society and their association with perceived culpability with transgression (Clark, 2012). In this sense fear of blame may be considered to be expressed in the ‘unsayability’ of HIV/AIDS. Therefore participant’s use of coded references for HIV/AIDS rather than naming it directly may enable them to avoid the moral imperatives and negative values associated with HIV and the fear this generates (Clark, 2012). In this sense the use of euphemisms for HIV may be means of dissociating the self from the fear of blame associated with HIV/AIDS.

Niehaus (20017) argues that the use of euphemism for HIV/AIDS is directly related to political, medical and religious discourses which position people between life and death. The construction of PLWH as the ‘dead before dying’ is at the root of HIV/AIDS related fear and silence. An example of this is the participant’s comment that once infected with HIV “it’s the same like death”. Participants fear generated by the construction of HIV/AIDS as equivalent to death may be managed through the renaming of HIV/AIDS by creating a sense of distance between the self and the threat HIV/AIDS signifies. This is suggestive of an ‘othering response’, a necessary coping mechanism to protect the self from perceived danger (Campbell et al., 2005).

Participants’ responses to HIV/AIDS frequently were incongruent with their expressed knowledge of issues relating to this disease.

## **5.6 The dichotomy between knowledge and practice**

A disjuncture between participants’ HIV/AIDS related knowledge and their responses to HIV/AIDS and PLWHA frequently emerged in the data. This dichotomy was seen firstly in participants’ reference to fear of contagion despite citing accurate information regarding HIV/AIDS including modes of transmission. Secondly participants commented on issues

relating to the appropriate treatment of PLWHA followed by behaviours consistent with stigma. Participants demonstrated a sound basic knowledge of HIV/AIDS healthcare practices and treatment protocols which were preceded by indicators of behaviours that promoted risk. UNAIDS (2008) cites a lack of HIV/AIDS related knowledge as being the primary source of HIV/AIDS stigma. In addition to this it is suggested that increased HIV/AIDS related knowledge, including ways to protect oneself, will result in positive preventative healthcare behaviours. The findings of this study do not support this notion. Rather the findings of this study are consistent with the view asserted by Parker (2005) who maintains that the sequential linear relationship assumed between knowledge and action does not account for social or contextual variables or emotional responses on individual action. Van der Riet (2008) argues that the notion that knowledge directly impacts behaviour does not account for the role of 'context' in behaviour. This is inclusive of social factors. This is opposed to the majority of models which underpin the notion that knowledge has direct bearing on behaviour which are suggestive of an "individualist and mentalist conception of behaviour" (Kelly et al., 2001 as cited in Van der Riet, 2009, p. 22) In addition to this, these models assume "rational intentionality of agency" since they are based on the conception of a "cognitivist rationalist self who is able to 'choose' behavioural action (Kelly et al., 2001 as cited in Van der Riet, 2009, p. 21). In contrast to this idea the participants in this study seldom seemed to respond to HIV/AIDS rationally. Issues relating to fear and blame were frequently referenced by participants in relation to their responses to HIV/AIDS. This is keeping with Goodall (2008) who proposed that fear of labelling related to stigmatisation influenced behavioural responses to HIV/AIDS. It may be argued that HIV/AIDS stigmatisation may not be effectively dealt with through intervention solely based on increasing HIV/AIDS knowledge in an attempt to effect behavioural change.

Fear generated as a result of the construct of HIV in terms of death combined with fear of blame appears to be at the root of HIV/AIDS stigmatisation.

### **5.7 HIV/AIDS stigma as a reaction to fear**

Fear has been found to be inherently related to blame, HIV/AIDS related silence (including the use of indirect reference for HIV/AIDS and gossip in the data of this study). Fear and HIV/AIDS stigma may be understood to be cyclical, fear of HIV/AIDS (fear of HIV/AIDS

related stigma and fear of the disease) generates further stigma which increases associated fear (Goodall, 2008). Fear has been implicated as being a driving force behind the psychological blaming and 'othering' response (Joffe, 1999, as cited in Deacon, 2006). Fear may therefore be reasoned to be instrumental in the promotion of HIV/AIDS 'othering' in this context. In order to defend against the fear and anxiety associated with HIV/AIDS, participants appear to employ the defence mechanism of splitting, in which 'good' and 'bad' are separated. The 'bad' is then projected onto the 'other' (Deacon, 2006). This process is considered to be unconscious psychological response (Campbell et al., 2005), which creates a safe distance from the self and the overwhelming fear and anxiety associated with HIV/AIDS (Deacon, 2006). In this way the process of 'othering' serves an "identity-protective function" through creating a sense of invulnerability and relief when confronted with perceived or actual overwhelming threat (Campbell et al., 2005 p. 808). It may be argued that 'othering' promoted by fear of HIV/AIDS, is a powerful determinate in the social construction and maintenance of HIV/AIDS related stigma. For the participants in this study the process of 'othering', implicated in the construction of stigma, is a necessary means of managing and defending against HIV/AIDS related fear, which may otherwise be too great to cope with. The lack of knowledge of HIV/AIDS as the primary source of stigma generation appears to be superseded by the process of 'othering' as a response to fear in the construction of HIV/AIDS related stigmatisation. In order to render HIV/AIDS interventions more effective, consideration of the role of fear and 'othering' in the generation and perpetuation of HIV/AIDS related stigma is necessary.

## **5.8 Summation**

The responsiveness of people toward preventative healthcare and treatment options may be impacted by a fear of stigmatisation. This is especially relevant given that stigma removes power from the stigmatised person, resulting in a reduction of self-worth and social status (Link & Phelan, 2001) and possibly discrimination and social isolation. In the context of this study, the process of 'othering' is understood to result in HIV/AIDS stigma. This 'othering' response, through mechanisms of blame, gossip and HIV/AIDS related silence, is argued to be primarily driven by fear. Fear of HIV/AIDS is generated as a result of blame associated with HIV/AIDS and the conceptualization of HIV/AIDS in terms of death. This is significant

since the majority of HIV/AIDS related interventions are aimed at increasing HIV/AIDS related knowledge in an attempt to deal with HIV/AIDS stigma (UNAIDS, 2008). The effectiveness of HIV/AIDS interventions may be limited by a failure to consider the psychological processes involved in the construction and perpetuation of HIV/AIDS stigma.

## Chapter 6: Conclusion

The terms used to reference HIV/AIDS and PLWHA by the participants in this study suggest that HIV/AIDS stigma perpetuates and remains an obstacle to prevention strategies. Participants used a wide range of terms to reference HIV/AIDS. They identified HIV infection in others through the use of physical and non-physical markers of HIV. Participants tended to construct HIV in terms of death, often viewing HIV as equivalent to death. This conceptualization of HIV seemed to promote fear of HIV/AIDS. The association between HIV and socially unacceptable behaviours resulted in people being blame for HIV infection. This additively contributed to fear of HIV/AIDS as participants' feared being associated with these negative values and the consequent social implications thereof. Fear of this disease seemed to promote the silence surrounding HIV/AIDS, evidenced in participants' indirect references to HIV/AIDS. The use of the euphemism "this thing" was frequently used by participants to refer to HIV.

Although participants were able to demonstrate a fair knowledge of HIV/AIDS related issues, they often did not respond to HIV in accordance with their expressed knowledge. A disjuncture between participant's HIV/AIDS knowledge and their behavioural responses to HIV as well as those infected with this disease was evident in the data. This may suggest that interventions in this context, which focus on the development of HIV/AIDS related knowledge in an attempt to effect behavioural change, are not sufficient to achieve this goal. This is in keeping with the view of Parker (2005), who asserts that interventions based on knowledge are limited by their neglect to account for contextual and social variables as well as emotional responses to HIV/AIDS. The majority of models, assuming a direct relationship between knowledge and behaviour, upon which many HIV/AIDS interventions are based, are underpinned by the notions of "rational intentionality of agency" and "individualistic and mentalist conceptions of behaviour" (Kelly, 2001 as cited in Van der Riet, 2009, p. 21-22). The findings of this study do not support this view. In the context of this study the generation and maintenance of stigma appears to be embedded in HIV/AIDS related fear which results in an 'othering' response. This 'othering' response, which divides society into 'us' and 'them' is psychologically reassuring and provides feelings of protection in the face of the significant perceived danger HIV/AIDS represents (Skinner & Mfecane, 2004). Consideration of these complex social and psychological processes related to HIV/AIDS fear and 'othering' may enhance the efficacy of HIV/AIDS interventions.

## **6.1 Limitations of the study**

The use of secondary data may be considered a limitation in that the interactional component of the data collection process is inaccessible to the researcher. Therefore the layers of interpretation, which present during data collection and are specific to the context, may be restricted. However the researchers involved in the original study were also available to discuss any issues relating to the original project. This enabled a greater understanding of the data collected in the original study.

A further constraint of the research process is that the data was not collected with the current study's research question in mind. This may have limited the scope of focus with regard to the topic of this study. Although this could be considered a limitation on the one hand, on the other hand the emergence of the themes relating to the focus of this study may be a more accurate reflection of the participants' responses to HIV/AIDS and therefore HIV/AIDS related, stigma since they emerged in the context of a different research focus.

## **6.2 The value of the study**

In a context where participants maintain that HIV/AIDS and PLWHA are no longer stigmatised, the results of this study suggest that this is in fact not the case. Fear of HIV/AIDS related stigma continues to be a major barrier to HIV/AIDS prevention. This is significant in light of many years of HIV/AIDS intervention initiatives in this country and has implications for ongoing HIV/AIDS management. As mentioned above the majority of HIV/AIDS prevention strategies in South Africa are aimed at increasing HIV/AIDS knowledge in an attempt to effect HIV/AIDS behavioural change. The findings of this study suggest that this may not be sufficient to deal with the complex social and psychological processes involved in the generation and perpetuation of HIV/AIDS related stigma. Interventions aimed at addressing fear of HIV/AIDS appear to be needed.

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## Appendix 1

### Simplified version of Jeffersonian transcript conventions

(.)	Just noticeable pause
(.3), (2.6)	Examples of timed pauses
↑ word, ↓ word	Onset of noticeable pitch rise or fall ( <i>can be difficult to use reliably</i> )
word [word [word	Square brackets aligned across adjacent lines denote the start of overlapping talk. Some transcribers also use "]" brackets to show where the overlap stops
.hh, hh	in-breath (note the preceding full stop) and out-breath respectively.
wo(h)rd	(h) is a try at showing that the word has "laughter" bubbling within it
wor-	A dash shows a sharp cut-off
wo:rd	Colons show that the speaker has stretched the preceding sound.
(words)	A guess at what might have been said if unclear
( )	Unclear talk. Some transcribers like to represent each syllable of unclear talk with a dash
word= =word	The equals sign shows that there is no discernible pause between two speakers' turns or, if put between two sounds within a single speaker's turn, shows that they run together
word, WORD	Underlined sounds are louder, capitals louder still
°word°	material between "degree signs" is quiet
>word word< <word word>	Inwards arrows show faster speech, outward slower
(( <i>sniff</i> ))	Analyst's signal of a significant line Transcriber's effort at representing something hard, or impossible, to write phonetically

## Appendix 2

### MEMORANDUM OF AGREEMENT REGARDING RESEARCH, THESES, PUBLICATIONS and PRESENTATIONS

I, (student/intern's name) JULIE SUTHERLAND understand and agree that all raw data (audio, digital files and electronic and hard copy transcriptions; interviews and focus groups) remains the property of Dr Mary van der Riet (Psychology, School of Applied Human Sciences, UKZN) and the NRF Thuthuka project 'Activity theory and behaviour change'.

I agree to return all data given to me in any form (pdf documents, audio transcripts, MS word files) on the completion of my thesis/publication. I undertake to delete all electronic versions of the data on completion of my thesis/publication.

In my use of the data for research, theses, publications and/or presentations, I undertake to uphold the confidentiality agreements within the research process viz. I agree not identify individual participants by name, or by place identifiers.

I will take all reasonable steps to ensure that other people do not have access to digital voice files, and transcripts to ensure the confidentiality of the research participants. I will advise Dr Mary van der Riet should I become aware of a possible breach, e.g. a stolen laptop.

Furthermore, I agree to acknowledge my affiliation to the NRF Thuthuka project<sup>1</sup>, and the University of KwaZulu-Natal in all published research, and presentations that might proceed from this work.

I agree to submit my intention to publish or present results related to this data, with an abstract specifying the target journal and proposed authorship, and/or target audience (conference/seminar series etc) timeously to Dr Mary van der Riet for approval.

I understand that co-publication, on the basis of actual contributions, with Dr Mary van der Riet and researchers on the *Activity Theory and behaviour change team* is strongly favoured, along with any others who have contributed intellectually to the project.

Should I not publish research arising from this work, Dr Mary van der Riet and the research team have a right to initiate publication and will invite you and your academic supervisor(s) to contribute as co-authors.

Signed: J. Sutherland Student/Intern Date: 25/02/2014

Signed: M. van der Riet Dr Mary van der Riet (PI Activity theory and behaviour change project)

Date: 25/2/2014

<sup>1</sup> There is a standard statement which needs to be inserted in all publications related to the NRF Thuthuka funded project.

### Appendix 3

<b>Transcript:</b>	<b>Code:</b>
20120616_26-34_F_OJ_Z	A
20130604_H_F2(2)_OJ_R	B
20120612_35-45_F-DS_T	C
20130607_25-30_FG_F_OJ_Z	D
20120616_46-60_FG_F_OJ_DZ_Z	E
20130529_H_F1(1)_OJ_S	F
20120614_18_18-25_FG_F_OJ_Z	G
20120618_26-34_F_OJ_S_(E)	H
20130317_18-24_FG_F_OJ_Z	I
20120613_26-34_F_DS_7_(E)	J
20120614_14-17_FG_F_DS_K_(E)	K
20120513_18-25_F_PS_S_(E)	L
20120617_35-45_F_OJ_S_(E)	M
20120616_26-34_F_DS_Z	N
20120613_26-34_F_DS_T_(F)	O
20120614_46-60_F_DZ_T	P
20120618_30-45_FG_F_DS_OJ_R	Q
20120513_18-25_F_DZ_T	R
20120618_46-60_E_DS_S	S
20130606_H_F1(2)_OJ	T
20120509_10-13_FG_F_DS_V_(E)	U
20120616_26-34_F_PS_Z	V
20120511_18-25_F_OJ_S	W
20130606_H_F1(2)_OJ_S	X
20130530_FG_F_18-24_OJ	Y
20120617_26-34_F_DZ_Z_(E)	Z
20120510_26-34_FG_F_DS_T	AA

## Appendix 4



24 April 2014

Mrs Julie Sutherland (214588837)  
School of Applied Human Sciences - Psychology  
Pietermaritzburg Campus

Protocol reference number: HSS/0272/014M (linked to HSS/0695/031)  
Project title: An exploration of stigmatisation relating to HIV and AIDS among women in a rural area in the Eastern Cape

Dear Mrs Sutherland,

### Full Approval – Expedited

In response to your application dated 04 April 2014, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol have been granted FULL APPROVAL.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

**PLEASE NOTE:** Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 5 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Dr Shumila Naidoo (Deputy Chair)

/ms

cc: Supervisor: Dr Mary van der Riet  
cc: Academic Leader Research: Professor Doug Wassenaar  
cc: School Administrator: Mr Siboniso Duma

### Humanities & Social Sciences Research Ethics Committee

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