Naming and labelling HIV and AIDS: Responses to HIV in a rural setting in the Eastern Cape

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Declaration

I hereby declare that this exploratory study on *Naming and labelling of HIV and AIDS: Responses to HIV in a rural area in the Eastern Cape* is my own work and all the resources that I have used or cited have been indicated and acknowledged by means of complete references. As far as my belief and knowledge, none of the present work has been previously submitted for any degree or examination at any other institution of higher learning.

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Dedication

To **_Professor Velile Notshulwana._** It only makes sense that I dedicate my first academic work to you, for you saw potential in me and believed in my capabilities as a prospective social scientist.

I would also like to dedicate this to the people of _Ematyholweni._ My wish for you is that one day you live in an HIV stigma-free community.

Abstract

In the next year, South Africa hopes to reduce HIV infections and stigma by 50%. With HIV stigma being a significant cause of the difficulties experienced with the management of HIV in the country, research resources have focussed on how to understand and reduce HIV. Although much attention has been given to HIV-prevention intitiatives, HIV stigma is still evident. Examining the issue of 'talk' around HIV and AIDS could help in gaining some insights into stigma as one of the ways HIV and AIDS stigma manifests is through language.

This primary aim of this qualitative study was to explore the names and labels currently used in a rural area of the Eastern Cape to talk about HIV. Furthermore, the aim of this study was to examine whether these names are stigmatising or not. A total of 30 interviews and 11 focus groups discussions were purposively sampled from an already existing data set of 95 transcripts. Out of the 30 interviews, 16 were sampled from men and 14 from women and the participants were between the ages of 18 to 70 years. There were five focus groups with male participants and six with female participants. Focus groups had participants ranging in age between 10 to 70 years, with participants of the same age group assembled together in a group.

The study used thematic analysis where six themes were identified. These were: misuse or conflation of the terms HIV and AIDS; metaphorical labels; 'collecting death'; 'that thing'; 'clean blood', as well as a discussion of attempts to describe the disease. The study then used social construction theory and a fear and blame stigma model to understand results in this study.

This research shows that even though HIV/AIDS has been in our communities for over 30 years, stigma is still rife in *Ematyholweni* and this is reflected through the names people used to refer to the disease. This research also recognises that these names play different functions in communicating

about HIV, but at the core, they are negative, stigmatising and as a result, they have led to negative

responses to the disease in the research site.

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Chapter 1: Introduction

It is nearly over three decades since the arrival of the Human Immunodeficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS) in South Africa. Throughout the years, the South African government has dedicated its resources to the management of the disease. However, even with a capable social infrastructure used in managing HIV and AIDS compared to other African countries (Ajobola, 2009), South Africa's HIV infection trends continue to show an increase in the number of HIV-positive people. To date there are approximately 6, 4 million living with HIV, a number that has increased by 1,4 million from the 2008 survey done in the country (Shisana et al., 2014). Besides the successful provision of Antiretrovirals (ARVs) in the country, which has seen people living longer with HIV compared to previous years (Shisana et al., 2014), stigma has been cited as the greatest obstacle in tackling HIV and AIDS in South Africa (Shisana et al., 2014; WHO, 2000). This is because stigma can impede access to HIV-prevention and care services, among other negative outcomes.

HIV-related stigma is widely researched through qualitative and quantitative measurements of people's discriminating attitudes towards those who are HIV positive (Ajobola, 2009). However, literature shows that stigma is not only present in the discriminating behaviour towards HIV-positive people, but that the terms used to talk about HIV and AIDS have been shown to be stigmatising. According to Mbwambo (2003), when it comes to HIV and AIDS, words have been found to be a powerful means to stigmatise.

The purpose of the current qualitative study was to explore how people in a rural area (*Ematyholweni*) in the Eastern Cape name and label HIV and AIDS. This exploration was not only to examine the names and labels used, but to assess whether the ways in which HIV and AIDS are labelled or named in this rural context is stigmatising or non-stigmatising. This was achieved by thematically analysing the terms used to talk about HIV and AIDS in 30 in-depth interviews and 11

focus groups with men and women between the ages of 10-70 years. According to Brandt (1988), the social construction of AIDS has a powerful impact on choices people make in responding to the disease. Clark (2006, p. 461) also adds that:

> Language is at the core of the network of resources that we draw on in describing the world and relating to others, and as such HIV/AIDS cannot be separated from the ways in which we think about it, talk about it, and act on it.

Therefore, studying HIV labels used in this context assisted in not only understanding the HIV terminology present in Ematyholweni, but provided insight into how people in this area have responded, or continue to respond, to HIV and AIDS. Stigma has been reported to be hard to define and measure (Ogden & Nyblade, 2005) and so this study used the blame and fear stigma model to assess the stigmatising nature of names and labels used in *Ematyholweni*. Conducting a study that delves into the possible stigmatising use of HIV-related terms potentially informs policy makers and health programme interventions about areas where HIV-learning programs about stigma need to be directed.

Much research on naming and labelling of HIV and AIDS has been conducted all over the world. For instance, in 2004, Mawadza conducted a study on *'Stigma and HIV/AIDS discourse in Zimbambwe'*, where references used by participants were found to be stigmatising. Mathangwane (2011) also did a study on *'People's perceptions of HIV/AIDS as portrayed by their labels of the disease: The case of Botswana'*. In 2003, Wallis and Nerlish conducted a study titled *'Disease metaphors in new epidemics: The UK media framing of the 2003 SARS Epidemics'*, a study which focused on how HIV is labelled. More recently, a qualitative study by Mupenda et al. (2014) on the '*Terms used for people living with HIV in the Democratic Republic of the Congo'* was conducted.

The way people perceive and name HIV and AIDS differs in each society and is informed by how people in that society construct the disease (Clark, 2006). In South Africa, studies exploring terms used to refer to HIV and AIDS have been conducted in different provinces (Campbell, Nair,

Maimane & Nicholson, 2007; Squire, 2007). Ogden and Nyblade (2005) state that HIV stigma has been found by many policy makers to be too cultural, context specific and too sensitive to be addressed meaningfully. Thus, in order to successfully explore and address HIV stigma, research should be context based. In addition to this, because language use differs from one area to another, an exploration of the naming and labelling of HIV in the rural context of *Ematyholweni* is useful.

This thesis takes on the following structure: Chapter Two looks at the history of HIV terminology. This chapter moves on to discuss a theory behind the need to make sense of HIV and AIDS. After this, the chapter discusses the theoretical framework of the study as well as the current terms used to talk about HIV around the continent. The chapter ends with the rationale, aims and the objectives of the study. Chapter Three provides the methodology of both the broader study from which the data was drawn and the current study. It outlines the study design, sampling, data collection, data analysis and ethical consideration of both the main and the current study. Chapter Four presents the results of the study. In this chapter, six themes are reported using extracts from the data to discuss the findings. Chapter Five discusses the results using the blame and fear model of stigma and relevant literature. Chapter Six presents the conclusion, strengths, limitations as well as the recommendations of the study.

Chapter 2: Literature review

2.1 Introduction

There has been a steady increase in research conducted on naming and labelling HIV and AIDS, with the most recent research being done in the Congo by Mupenda et al. (2014) on '*The language that people use to describe people living with HIV and AIDS*'. The purpose of this chapter is to provide a review of existing literature on naming and labelling HIV and AIDS. In reference to the current study, labelling and naming HIV refers to the labels people use to talk about HIV and AIDS. These terms will be used interchangeably throughout the chapter.

This chapter starts by exploring the history of naming HIV and AIDS. This brief history covers a global as well as a South African journey related to the technical invention of the terms used to speak about the epidemic. This is followed by an examination of the current vocabulary created and used across the continent to talk about the epidemic. The chapter moves on to discuss HIV and AIDS terminology in relation to HIV stigma. Following this is a discussion of the theory behind the creation of diverse terms used to refer to HIV and AIDS. Towards the end of the chapter, two theoretical frameworks are outlined. The first one, social constructionism, aims at discussing how diseases are constructed through use of language, while the second one, the blaming and fear model of stigma, links the current HIV terminology to stigma. The chapter ends by providing the rationale, aims and objectives, and the research questions of the study.

2.2 Brief history of HIV and AIDS terminology

The epidemic we now know and refer to as HIV and AIDS was once nameless (Treichler, 1999). As a result, some of the early responses to HIV and AIDS involved debates about naming of the disease. The naming of HIV and AIDS has a long and a complex history. Current literature documents the

disease as a phenomenon that has been constructed through language and the current study aims to contribute to this argument. However, before a discussion of the sociolinguistic and discourse analysis of HIV-related terms, it is important to give a brief history of the naming of HIV and AIDS from a technical viewpoint.

At a technical level, the process of naming of HIV and AIDS dates back to 1981. The term WOGS ('Wrath of God Syndrome') is amongst the first of many names that were informally created by health officials to name the AIDS disease at that time. This name was informally adopted by a New York hospital after a noticeable number of cases of young homosexual men died from a 'nameless' disease in the 1970's (Treichler, 1999). Soon after, the term GRID ('Gay-Related Immunodeficiency') was adopted and used to refer to the epidemic, only to be later replaced with AIDS ('Acquired Immune Deficiency Syndrome') (Treichler, 1999). AIDS as a term was believed to be reasonably descriptive and not as pejorative as GRID (Black, 1986).

The disease that was once nameless now had a name, AIDS, but there were still concerns about finding a name for its virus. Treichler (1999) writes that it was only in 1986 that the Human Retrovirus Subcommittee of the International Committee on the Taxonomy of Virus held debates on an appropriate name for the virus that causes AIDS, and a year later, the term Human Immunodeficiency Virus (HIV) was proposed and accepted as the name for the virus. The epidemic could now be referred to as HIV and AIDS.

In the following paragraphs, I discuss how in South Africa the epidemic went from only having the terms HIV and AIDS to carrying a variety of other significant terms. This discussion focuses on the process of translation that the South African government undertook in creating official labels for HIV and AIDS in the other ten South African languages.

2.2.1 HIV labelling and naming in South Africa

In South Africa, HIV moved from being almost unmentionable to being spoken about all over the country, especially on television and radio shows (Squire, 2007). The very first communication about HIV and AIDS in South African media depicted the epidemic as a 'killing disease' (Webb, 1997). The earliest South African television campaign illustrated a coffin and a funeral along with the slogan 'the new killer disease is here' (Joffe, 1995). This was after a number of deaths occurred in the country in 1985 (Webb, 1997). Consequently, from early on in the epidemic the language used by the South African government to talk about HIV and AIDS to the public was that of 'warning' people about the 'killing disease' (Webb, 1997). Webb (1997) argues that such messages left people confused and, as a result, ways to enhance understanding about HIV and AIDS had to be adopted.

Adedeji (2002) and Ndimande (2002) argue that health officials played a role in transferring HIV and AIDS knowledge to the public and this developed the public's understanding of the disease. It is at this stage that the epidemic moved from being the 'unmentionable to the most talked about', as previously mentioned by Squire (2007). The attempts to engage in open discourse about HIV and AIDS faced various challenges, especially from the language perspective. For instance, with the HIV-related information being produced and consumed at multiple levels, the epidemic reproduced its own vernacular in the country (Patton, 1990). Inherently related to the production of a substantial vernacular were issues with poor translation of the terms 'HIV' and 'AIDS' into local languages, which created problems particularly for the country's health officials.

Health officials in Southern Africa used metaphoric terms in an attempt to communicate the disease to people using local languages (Mabachi, 2009). Adedeji (2002) and Ndimande (2002) argue that the use of metaphors, narratives or proverbs could be explained by the African oral tradition that tends to use story-telling and metaphors in its discourse about disease. These two authors add that the translation discrepancies which arose in metaphor use were more significant

in rural populations as the language barriers to the use of English are more prominent in that context. For instance, for people whose first language is not English, there might be mispronunciation of some English words, due to unfamiliarity with the language. The terms used to refer to HIV and AIDS listed below (Dowling, 2002) illustrate metaphors that were unofficially adopted by the country's health officials early on in the epidemic to communicate about HIV and AIDS, and were intended to encourage a better understanding of the seriousness of the disease.

- *uMabulalabhuqe* - the indiscriminate killer (*isiZulu*)

- *uBhubhane* - plague *(isiXhosa)*

- *uDubul'egeqa* - the one who shoots to kill (*isiZulu*)

- *uQedisizwe* - the destroyer of the Nation (*isiZulu*)

- *uMashayabhuqe* - the beater-up of people (*isiZulu*)

The terms above highlight how HIV and AIDS was perceived as a deadly disease. They convey the idea that once one gets infected, there is no chance of survival. Communicating about HIV using these terms served the deliberate purpose of South African health officials warning people about the disease and in turn preventing transmission. This type of framing of the disease continues to overwhelm discourse about HIV and AIDS in some parts of the country and, according to Staiano (1992), this is because these terms carry a killing aspect which is absent in the terms HIV or AIDS.

2.2.1.1 The eleven official terms for HIV and AIDS in South Africa

As years passed, progress could be noted regarding the advancement of HIV-related information in the country. South Africa was progressing towards the creation of official local terms that could be used to talk about the epidemic instead of the actual acronyms (HIV or AIDS) (Adedeji, 2002; Ndimande, 2002). The years 1999-2000 were a critical period in the country regarding the creation of vernacular terms for HIV and AIDS. According to the Department of Arts and Culture (2012), this

period was marked by consultative workshops on HIV and AIDS terms that would be equivalent in the other ten official languages.

A list of 749 terms was proposed as a way to improve the communication about HIV and AIDS between the health care professions and the general public. These terms were verified by the Terminology Technical Committee of the National Language Bodies (NLBs), which was created by the Pan South African Language Board (PanSALB). The terms can be found in the 2012 Department of Arts and Culture document: *Multilingual HIV and AIDS terminology*. Below is a tabulation of the terms in 11 South African official languages.

Official names for HIV and AIDS in 11 South African languages		
Language	**Human Immunodeficiency Virus (HIV)**	**Acquired Immune Deficiency Syndrome (AIDS)**
English	➢ Human Immunodeficiency Virus (Full form) ➢ HIV (Acronym)	➢ Acquired Immune Deficiency Syndrome (Full form) ➢ AIDS (Acronym)
Afrikaans	➢ *Menslike Immuniteitsgebreks-virus* (Full form). ➢ *Menslike Immunogebreks Virus* (Full form) ➢ *MIV* (Acronym)	➢ *Verworwe immuniteits-gebreksindroom* ➢ *VIGS* (Acronym)
IsiZulu	➢ *Igciwane lesandulelangculazi*	➢ *Ingculazi* ➢ *I-eyidzi*
IsiXhosa	➢ *Intsholongwane kaGawulayo* ➢ *Itshayivi*	➢ *UGawulayo*
Siswati	➢ *Sandvulelangculazi*	➢ *Ingculazi*
IsiNdebele	➢ *Umbulalasihlangu obangela intumbantonga*	➢ *Intumbantonga*
Setswana	➢ *Lebolelamading* HIV ➢ *Mogare -tlhaelotshouto ya motho*	➢ *Phate* ➢ *Segopalwetse-tlhaelotshouto*
Sepedi	➢ *Kokwanatlhoko ya* AIDS ➢ *Kokwanatlhoko ya go fokotša mašole a mmele mo mothong* ➢ *Baerase ya phamokate*	➢ *Bolwetsi bja* AIDS ➢ *Phamokate* ➢ *Sephamola*
Sesotho	➢ *Tshwaetso e hlaselang tshireletso*	➢ *Phamokate* ➢ *Tshwaetso e Hlaselang Tshireletso*
Tshivenda	➢ *Vairasi i kulaho nungo dza maswole* ➢ *Tshitzhili tsha Eidzi*	➢ *Eidzi* ➢ *Ndongondela*
Xitsonga	➢ *XIMPASA* ➢ *Xitsongwatsong-wanampalansawuto*	➢ *Xipalansawuto*

Table 1: Official names for HIV and AIDS in 10 South African languages (Department of Arts and Culture, 2012, p. 24)

The labels tabulated above were accepted as official local terms for HIV and AIDS in South Africa, yet some of these terms are metaphors and still carried a 'warning' message, as previously highlighted (Webb, 1997). For the purpose of this study, only one metaphoric term from the above table will be discussed - *uGawulayo*. This is done later on in this chapter, under AIDS metaphors.

In addition to the list of official terms discussed above, South Africans use a variety of other terms when talking about the epidemic. These include terms such as *amagama-amane* ('four words') when talking about AIDS, and HIV as *amagama-amathathu* or 'three words' (Dowling, 2002). The references 'four words' and 'three words' have been the most common ways to talk indirectly about HIV and AIDS. Other terms which originate from South African popular culture are 'lotto' and '*unyathele icable*' meaning contracting HIV is like stepping on a live wire (Integrated Regional Information Networks [IRIN], 2008). In addition to these terms, terms such as 'Z3', 'Ace', 'TKZee' and others have also been reported in the country (Dowling, 2002). Names such as these are taken from everyday objects and activities such as gambling (the reference to the lotto). Dowling (2002, p. 5), explains the relationship between lotto and HIV as follows:

> When people play the lotto they know they only stand a tiny chance of winning, which is if you have AIDS you only have a tiny chance of living. The risk of losing your money by taking part in the lottery is high - as is the risk of dying from AIDS. I also think that it is somehow less scary to talk about lotto than AIDS or *Umbulalazwe* (nation killer) because it does not refer directly to death, but rather to living at risk.

The use of terms such as Z3, which refers to a fast BMW car model, is also common in referring to HIV and AIDS. Z3 is an attributional term which refers to HIV as a virus that infects people who lead a 'fast' life, that is, those who engage with sex with multiple partners (Dowling, 2002). Other terms such as ACE or TKZee refer to organisations with three letters in their acronym, such as BMW (Dowling, 2002) and they are used to talk about the 'three-words' virus, HIV, as highlighted above.

2.3 Naming or labelling of HIV and AIDS in the African continent

Even with the provision of official local terms to refer to HIV and AIDS, conversations about HIV and AIDS often do not mention the disease by name at all (Dilger, 2003). In addition to this, people have created their own terms to talk about the epidemic. This section provides an overview of the vocabulary that has been created to talk about HIV and AIDS in South Africa and a few other African countries, drawn from an article by IRIN that was titled *AFRICA: Mind your language: A short guide to HIV and AIDS slang* (2008).

In Angola, where most people speak Portuguese, the term *pisarna mina* was used, which means contracting HIV is like stepping on a landmine. In an attempt to come to terms with HIV in Nigeria, people referred to HIV as the 'sickness of this generation' and some called it *oria obirinaajaocha,* which can be translated into a 'sickness that leads to death'. Here, HIV is also referred to as *eedi,* which means a curse. In Zimbabwe, where citizens speak Shona and Ndebele, HIV is talked about as *shuramatongo,* meaning a bad omen for relatives. Zimbabweans also talk about HIV as *zvirwerezvemazuvano,* which means the 'current disease'. Some euphemisms observed in Zimbabwe include the term 'boarding pass' and this implies that HIV is a boarding pass to death. Ugandans speak of HIV as *Ka-onde-onde* and this means 'that thing that makes you thinner and thinner'. In Tanzania, people refer to HIV as *mdudu* - the bug. Lastly, in his study, Iliffe (2006) observed that HIV and AIDS was referred to as 'slim' by people of Uganda, because weight loss was the most common and visible symptom in those infected by the disease.

The above outline of HIV terms provides a sense of some of the names that people use to refer to HIV and AIDS. It also shows that people have at their disposal a wide range of names they have created to use when talking about HIV and AIDS. The section below provides an overview of why people have created their own language to talk about HIV and AIDS.

2.4 The creation and use of various HIV-related terms

The history of naming HIV and AIDS discussed above shows HIV-related terms as medical and political labels provided to us by science and scientific naming practices. However, the language people are using to talk about HIV and AIDS is not a medical one, but rather a vernacular which reflects diverse cultural, social and linguistic conceptualisations of the disease (Treichler, 1991). Mawadza (2004) links this to the notion that people label emerging diseases based on what they experience instead of using scientific terms in talking about the disease. A major reason for this is that diseases are more than biological entities; they are socially constructed phenomena, hence the diverse conceptualisations (Crystal & Jackson, 1992). Nevertheless, scientists, physicians and public health authorities still contend that AIDS is 'just' an epidemic of infections and nothing more (Treichler, 1999). Yet, three decades into the epidemic, people are still trying to create their own meanings of the disease.

According to Brandt (1988), attempts to make sense of HIV and AIDS are based on the destruction and the behaviours that the disease brings with it. Like some chronic diseases, for example cancer, AIDS is debilitating in nature and can lead to a deterioration of the body. However, unlike other chronic diseases, HIV and AIDS have had the extra burden of not being as easily accepted. For instance, in a study that was conducted in the United States by Westbrook, Legge and Pennay (1993) which investigated the degree of stigma attached to twenty different diseases and disabilities across six cultural groups in the country, it was found that compared to asthma, diabetes, heart disease and arthritis, HIV and AIDS was the most stigmatised condition across all cultures. One explanation for this difference is the fact that HIV is a sexually transmitted disease which is associated with intravenous drug use, sexual promiscuity, and homosexuality, behaviours that in themselves are seen to be deviant and are subject to disapproval by the society (Crandall, Glor & Britt, 1997; Herek & Capitanio, 1999; Herek & Glunt, 1988).

The medical definition of HIV helps to make the disease intelligible, but Treichler (1999) maintains that the epidemic is still viewed as frightening, complicated and unpredictable. Efforts to try to live with a disease of this nature initially included making sense of the disease. The theory of social representation by Moscovici (1984) helps in understanding why the arrival of HIV led to the need to 'make sense' of the disease.

Moscovici (1984) maintains that people's attempts to make sense of the disease may be attributed to unfamiliarity with the disease, which compels them to make sense of it through naming it. This theory identifies two processes in which this happens: anchoring and objectification.

Anchoring refers to a process of taking something foreign and comparing it to a paradigm or a category which we think is suitable. The process of anchoring helps people to classify and name things, because things that are unnamed and unclassified are seen as non-existent or alien, and sometimes threatening. Thus the threatening, unpredictable nature of the epidemic led people to develop their own meanings about the disease. This was particularly the case in South Africa where HIV terminology was constructed based on what people witnessed and felt. Objectification, on the other hand, is a process of reproducing a concept in terms of an image. In the context of HIV and AIDS metaphors, the process of objectification is evident in many of the terms, for example, using an image of slim people to refer to the disease.

The creation of different terms to talk about HIV and AIDS in South Africa was not only a means to make sense of the disease but was also a result of the HIV stigma people encountered. In the early 1990's, South Africa not only faced the challenge of a high HIV infection rate but also the accompanying stigma. This had an influence on the creation of names for HIV and AIDS. According to Peters, Kambewa and Walker (2010), naming and labelling of HIV and AIDS was also a means by which people attempted to normalise the disease in order to bring it back under control. Thus, it was a means through which people lived with and managed the disease. As a disease that carried a lot of stigma, the creation of names, or the avoidance of naming the disease directly, was a way for

relatives and friends to protect the sufferer from the public stigmatisation of the disease, or ways in which those who had the disease could talk about it in a subtle, 'disguised' manner (Peters et al., 2010).

Encounters with HIV led people to name it and through meaning-making, labels emerged. Thus, the initial creation of terms came from health officials as the disease entered the country, followed by lay people's interpretation of the causes of the disease, and terms then developed as the mortality rate associated with the disease increased.

2.5 Theoretical framework

There are two theoretical frameworks that underpin this study. These are the social constructionist theory and the blaming model of stigma; they are discussed below.

2.5.1 Social constructionist theory

Crystal and Jackson (1992) state that diseases are socially constructed. Accordingly, a social constructionist approach will be used to understand the construction of the disease through the names and labels used to refer to HIV and AIDS in *Ematyholweni*. According to social constructionism, what people perceive as reality has been shaped through a system of social, cultural and interpersonal processes (Villanueva, 1997). The author adds that the construction of knowledge happens only through the interaction of sociocultural processes with the intrapersonal self, that is, one's ideas, beliefs and history. Thus, people are constructors of knowledge in their lives, assisted by the prevalent discourses in their societies and cultures, and their own life experiences (Villanueva, 1997).

Gergen (1985) maintains that there are four assumptions made by social constructionists, but for the purpose of this study, only three of these are discussed:

a) The concepts and categories we use vary considerably in their meanings and connotations over time and across cultures. These concepts are assumed to relate to permanent human experiences or functions. This means that how HIV and AIDS are currently labelled might be unique in *Ematyholweni*, based on the community's current experience and knowledge of HIV and AIDS.

b) The popularity or persistence of a particular concept, category, or method depends more on its usefulness than on its validity. For example, the names and labels found in the context of HIV and AIDS serve a purpose in terms of warning people about the disease.

c) Descriptions and explanations of the world are themselves forms of social action and have consequences. Thus, the language we use can inform the way we respond to social issues or diseases like HIV.

2.5.2 The blaming model of stigma

Given the fact that HIV-related terms carry specific meanings, this section examines the blaming model of stigma to explore how talking about HIV and AIDS may or may not be stigmatising, based on the meaning the terms carry. Deacon (2005) argues that stigma is considered to be the result of blame and fear, and understanding stigma should begin with an understanding of the primary contexts within which this blame and fear are expressed. The section starts by discussing the blaming model of stigma, and then it discusses fear and stigma.

When it comes to HIV stigma theories, social psychologists have been at the forefront of stigma conceptualisation. They have used the insights of the social-cognitive approach to understand how people construct categories and link these categories to stereotyped beliefs, and this has helped in advancing the understanding of stigma processes (Link & Phelan, 2001). However, these cognitive approaches focus on individual-level drivers of stigma such as lack of knowledge or negative attitudes, with inadequate attention paid to the social influences on these individual-level phenomena (Parker & Aggleton, 2003). Furthermore, they pay no attention to the role of

unconscious factors as the vehicle of stigma (Joffe, 1999). With that said, the social-cognitive approach can be credited for giving birth to a few frameworks used to understand stigma. One of these is the blaming model of stigma.

The blaming model of stigma is applicable in this study because it provides insight into the role the terms (whether stigmatising or not) play when used in making references to HIV. This model appears mostly in the work of two social scientists, Joffe (1999) and Deacon (2005). According to the blaming model of stigma, HIV stigma transpires a social activity by which people utilise shared social representations to separate themselves and their in-group from the possibility of contracting a disease. They do this by constructing the disease as escapable, identifying 'immoral' behaviours causing the disease, connecting these behaviours with individuals from the other groups who are infected with the disease, blaming them for their own infection and justifying corrective action against them (Deacon, 2005).

This model further suggests that people attach negative meanings to disease, and the people who contract it, in order to dispel anxiety about risk of infection (Crawford, 1994; Gilman, 1985; Joffe, 1999). According to this model, stigma is a necessary emotional response to danger that helps others feel safer by projecting manageable risk by putting blame onto the out-groups (Deacon, 2005). Stigmatisation thus helps to create a sense of control and immunity from danger at an individual and a group level (Deacon, 2005). According to these authors (Crawford, 1994; Foege, 1988; Nelkin & Gilman, 1988), blaming of other groups often happens in discourse about disease (Deacon, 2005). Foege (1988) states that, through blaming, people create an identity where the disease is not 'for them' but for other people. Furthermore, by talking about individuals or groups as 'other', or even the disease as 'for others', one magnifies and reinforces projections of apparent difference from oneself.

In most literature, the term 'othering' has been used to understand the process of blaming. Othering can be understood as a particular cultural process of people creating relations between

the disease and specific groups (for example, lesbian women) or with behaviours already labelled as abnormal or taboo (for example, transactional relationships, same sex marriage) (Deacon, 2005). Deacon (2005) further states that othering manifests in different ways. She states that it can manifest through othering the disease based on cultural associations. This could involve associating the disease with other historically stigmatised diseases, such as syphilis, leprosy or tuberculosis (Deacon, 2005). This means that othering of HIV could merely mean labelling the disease using the terms of other stigmatised illnesses.

Othering can also manifest through the culturally mediated assessments of the epidemiological nature of a specific epidemic (origin identified in certain groups, its differential prevalence in certain groups, its severity) (Deacon, 2005). Thus, HIV references which link the disease to certain individuals, behaviours or origins reflect acts of blaming. For instance, at times people refer to a person's type or number of sexual partners as the reason for their HIV-positive status; this is blaming the person for being 'careless' and getting infected with HIV.

2.5.2 Stigma and fear

For the purpose of this study, the blaming model will be paired with the 'fear' construct to understand naming and labelling HIV and AIDS. Joffe (1999), who has written on blaming, also believes in studying 'disease fear' as it counts as one of the intra-psychic drivers of stigma. Joffe (1999) argues for the existence of a universal unconscious human fear of collapse and chaos. She adds that this fear becomes intensified in the presence of a particular risk or danger, such as a widespread HIV and AIDS epidemic (Campbell et al., 2010). Additionally, Joffe (1999) states that in such cases, people may cope with fears by constructing negative representations of the disease or people with the disease, and subjecting them to stigma as a way of distancing themselves from the threat. Calling HIV a 'death sentence' disease is one example of people constructing a negative representation of the disease. According to this theory, the inclusion of these terms by people in

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the discourse around HIV has served as a warning to others and in some cases to oneself, to guard against HIV infections. The following section discusses literature on HIV stigma and terminology.

2.6 HIV-related stigma

Initially, HIV-related stigma research primarily featured research done in the United States. This was due to heavy stigmatisation of homosexuals upon the emergence of HIV in the 1970's (Deacon, 2005). With the disease now being widespread and becoming a challenge in African countries as well, HIV-related stigma has taken a central focus in South Africa in terms of research to measure stigma. A recently conducted study in the country has shown HIV stigma to be quite high, with 36% of those living with HIV in South Africa reporting to have experienced HIV stigma from their communities (South African National Aids Council [SANAC], 2014). HIV and AIDS stigma appears in many forms, as shown by research, and below is a definition of stigma and different forms of its manifestation.

2.6.1 Definition of HIV-related stigma

Stigma definitions lack common ground; this means that the definitions show wide variation (Link & Phelan, 2001). The modern understanding of disease stigma is from the work of Goffman (1963), who suggested that people who possess a characteristic defined as socially undesirable (HIV or AIDS, in this case) acquire a 'spoiled identity' which then leads to social devaluation and discrimination. As an extension of Goffman's interpretation of stigma, Herek (2002) defines HIV and AIDS stigma as an enduring attribute of an individual infected with HIV, who is negatively valued by society, and this thus disadvantages people living with HIV.

In addition to these definitions, UNAIDS (2004, p. 126) describes HIV-related stigma as a "process of devaluation" of people either living with or associated with HIV and AIDS. This stigma

often stems from the underlying stigmatisation of sex and intravenous drug use, which are two of the primary routes of HIV infection (UNAIDS, 2004)

In many definitions that have been given for HIV stigma, researchers have argued that stigma can only be called stigma if it results in discrimination. In support of this, the sociological tradition adopts the view that stigma is defined by its discriminatory result (Deacon, 2005). In contrast to this, Deacon (2005) states that HIV stigma definition should not be limited to something that results in discrimination, but should be defined as an ideology that recognises and links the existence of a biological disease agent to negatively defined behaviours of a group in society. In short, HIV stigma can be defined as the negative things, such as fear of contagion, death, etc. that people believe about HIV (Deacon, 2005).

Such stigma can be 'felt' or 'enacted' (Hasan et al., 2012). Felt stigma or internalised stigma is defined by Brouard and Wills (2006) as the product of the internalisation of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV positive. This form of HIV stigma, internalised stigma, negatively affects the well-being of those who are HIV positive because it prevents them from participating in most community and social activities, and sometimes from getting treatment (Hasan et al., 2012). On the other hand, enacted or external stigma stimply refers to the actual experience of discrimination (Hasan et al., 2012).

For the purpose of this research, Deacon's (2005) definition of stigma is going to be adopted because it is centred on beliefs with no links to prejudice or discrimination. The negative beliefs stated in Deacon's (2005) definition of HIV stigma could manifest in two stigmatising ways: (a) instrumental AIDS stigma and (b) symbolic AIDS stigma (Herek, 1998). Instrumental AIDS stigma occurs when the disease is widely perceived to be unalterable and fatal. This form of stigma is expressed in the form of blame, which stems from the fact that HIV is mainly transmitted through sexual intercourse. Symbolic AIDS stigma encompasses the social meanings attached to AIDS. It is based on the metaphoric social meaning attached to AIDS (Herek, 2002). The two ways in which

stigma could manifest are highlighted because the names and labels for HIV and AIDS are sometimes metaphoric and communicate blame. This will be discussed in more detail in Chapter Five.

When it comes to the issue of disease stigma, unlike other chronic diseases, HIV is unfortunately linked to stigmatisation (Westbrook et al., 1993). Goffman (1963) and Sontag (1978) argue that this is because aspects of the illness itself, for example, the transmission through sexual intercourse or potential for contagion and death, contribute to the stigmatisation of HIV and AIDS. Herek (2002) adds that HIV is stigmatised because being infected with the disease is understood to be the bearer's responsibility. Goffman (1963) and Sontag (1978) also argue that, as a serious illness, HIV is likely to assume a symbolic meaning that goes far beyond the biological status of the virus. The metaphors and terms used to talk about the disease reflect these symbolic meanings. The section below explores how HIV terminology may be stigmatising.

2.6.2 HIV-related stigma and the HIV and AIDS terminology

There has been extensive research conducted in the area of naming and labelling HIV especially on the African continent. However, most research conducted on this topic has been centred in linguistics with little focus on the use of these terms in relation to HIV stigma. Additionally, research conducted on talk around HIV and stigma focuses on hostile words people have uttered to those with HIV and sees these as a form of stereotyping, prejudice and discrimination. Examining HIV-related stigma in this manner has been important in HIV-related stigma management, but there seems to be a lack of research on the general use of terms to refer to HIV, as well as how these terms might be related to stigma. The paucity of literature on HIV-related stigma and HIV terminology highlights the importance of the exploration of the presence and extent of stigma in the terms given to the disease.

When unpacking HIV and AIDS terminology and stigma, one will notice that even the very first names that were used to describe HIV and AIDS in the beginning of this epidemic reflected society's stigmatisation of it. This was through the use of names such as gay-related immune disease, and gay bowel syndrome (Huber & Gillaspy, 1998). Looking back at the use of these terms, it is easy to see that HIV and AIDS has been burdened with negative language. Mawadza (2004), who has spent much time studying HIV language and stigma, argues that one way that the language used to talk about HIV and AIDS can be stigmatising is in the use of pejorative references to those with HIV and AIDS. This author adds that negative terms used to refer to HIV are strong and common forms of stigma. This statement is coherent with Deacon's (2005) definition of stigma. This is supported by Jones (1997) who believes that there is a widespread gloom in the discourse of HIV and AIDS.

There are very few African scholars who have explored the discourse that Jones (1997) describes. One of the few scholars who has done research on naming and labelling HIV and stigma, Mathangwane (2011), conducted a study on this topic in Botswana and found that labels that had negative projections contributed to the stigma associated with HIV and AIDS. Most research done in the world on this topic also makes note of these negative projections and how they encourage HIV stigma. Scholars such as Herek (2002); Stein (2003); Wolf (2002), who have focused on this topic highlight the association of HIV with death, the use of metaphors to talk about HIV, avoidance of naming the disease and the use of other terms to refer to HIV and AIDS indirectly, as ways in which the disease has been stigmatised from a terminology perspective. An example of this is from a study by Uys et al. (2005) which looked at five countries (one of which was South Africa) and identified a total of 290 references to words or phrases used to describe the disease or people living with the disease (Uys et al., 2005). Their qualitative report found that these references could be classified into seven categories, which were (from most to least common): attributional, neutral, death related, physical feature related, factual statements, lingering illness related and common illness

related. These descriptions showed many negative labels and beliefs (Uys et al., 2005) as will be discussed below.

2.6.2.1 HIV and death-related terms

The constructions of HIV and AIDS have often been negative, especially in societies where people witness HIV in its final stages, giving them negative experiences and consequently perceiving HIV though a fatalistic lens. Concerning the popular terms which make reference to HIV and death, there seems to be a conflict in the use of these terms. One way this is expressed is through the question of whether one can justifiably label HIV and AIDS as a 'killing' disease or whether this will perpetuate stigma of the disease. Herek (2002) maintains that referring to HIV as 'death' or a 'killing/killer' disease tends to stigmatise the disease. This is because the language used to talk about HIV and AIDS that focuses on people dying from AIDS rather than on people living with HIV (Crystal & Jackson, 1992) alone creates stigma and a sense of hopelessness. Stigmatising attitudes towards HIV and AIDS have developed mainly due to the fact that the infection can lead to death as there is currently no cure for it. In practice, it is not merely the death-related terms which are a source of stigma, but the extent to which the terms are used, which leads to hopelessness and fear which then causes stigma.

Niehaus (2007) concurs with Herek (2002) and Crystal and Jackson (1992) and maintains that the common association of AIDS with death is likely to be the source of its stigma; this also illuminates many aspects of people's responses to stigma. One of these responses is the lack of motivation to be tested since the person sees no benefit when the diagnosis of HIV is seen as equivalent to death, and they are furthermore likely to experience discrimination (Abdool-Karim, Tarantola, Sy & Moodie, 1992). Findings by Abdool-Karim et al. (2009) concur with a study done in the United States of America by Fortenberry et al. (2002) where stigma was associated with a

decreased likelihood of being tested for HIV. Abdool-Karim et al. (2009) maintain that this impacts on the management of HIV and AIDS.

In a country like South Africa, where much has been done in terms of shifting people away from viewing HIV as death, studying the names used to label HIV helps us to gain insight into people's current beliefs about this epidemic, especially when the country has been able to increase the number of people on ARV's, an achievement which has seen the country's AIDS mortality going down and life expectancy rising (Johnson et al., 2013).

2.6.2.2 AIDS metaphors

Despite the biological characteristics of its signs and symptoms, HIV also carries a second reality which is expressed in cultural images and metaphors (Wood & Lambert, 2008). The use of metaphors in the HIVAIDS context is known as "the use of indirect linguistic forms that are embedded with meaningful and agonising messages on the source, the physical symptoms and the tragic impact of HIV and AIDS on the individual, the family, community and the nation" (Mashiri, Mawomo & Tom, 2002, p. 225). Studies conducted on the African continent on HIV language and stigma have focused on the use of metaphors in labelling and talking about HIV and AIDS. An example of this is a study presented by Wolf (2002) at the Botswana AIDS and Literature Conference entitled '*War, movement and food. The use of metaphors in discourses about AIDS*'. In this paper, Wolf (2002) argued that in Malawi and Kenya, people came up with metaphors using food, war and movement as references. For example, in this study, phrases such as 'you do not eat sweets in a package' were found.

Also presented in this conference was a study by Page (2002) on '*The metaphorical nature of HIV and AIDS: An analysis of the coverage of HIV and AIDS in four Zimbabwean newspapers*'. This study discovered that, in Zimbabwe, there were six dominant metaphors present in the newspapers analysed: HIV and AIDS is a war to be fought); HIV and AIDS is a disaster (to be curbed); HIV and

AIDS is a risk (to be avoided); HIV and AIDS is a secret (to be opened); HIV and AIDS is a business (to be managed); and HIV and AIDS is a social problem (to be controlled).

Sontag (1978, 1989) was one of the first people who wrote on this subject; she states that even though naming this phenomenon 'HIV/AIDS' made it comprehensive, people still used metaphoric words to refer to the disease. African society's use of metaphoric terms or labels for HIV/AIDS may be accounted for by the fact that African people often create their own terms to talk about private or sensitive issues (Brandt, 1988). Reasons for this differ from culture to culture, but the main reason as identified by Mutembei, Emmelin, Lugalla and Dahlgren (2002) is that when a new phenomenon turns up, people feel the need to identify it, understand and cope with it, sometimes through the use of metaphoric terms.

Mashiri et al. (2002) give another perspective and state that because issues regarding death, sex and sexuality are still largely taboo, they end up assuming a metaphoric vocabulary. Also, according to Mashiri et al. (2002), HIV and AIDS is normally fatal and often sexually transmitted disease and metaphors, euphemisms, colloquial expressions and slang end up being adopted as a means of communicating about the disease.

Nyandiba and Anyonje (2013) maintain that the use of local metaphors makes it easy for people to relate to the target domain inherent in the metaphors. Furthermore, metaphors mean that people can easily identify with and help in the conceptualisation of the 'world' of HIV and AIDS. Also, the use of metaphors plays a crucial role in disseminating messages that would otherwise be seen as taboo if expressed in plain language (Nyandiba & Anyonje, 2013). These authors argue that metaphors perform crucial roles such as information, caution, persuasion, justification, comprehension and even threat.

AIDS metaphors thus provide a means to facilitate a smooth discourse about the disease on the African continent. However, Todoli (2007) warns that metaphors should not be accepted uncritically. Mawadza (2004) adds that this is because metaphors have a suggestive power and

often carry an element of dread and fear. For example, the metaphoric terms found in the literature to refer to HIV and AIDS have been identified mostly as stigmatising.

Mawadza (2004) conducted a study involving 35 Shona-speaking men and women between the ages of 20 and 30 years. This study involved randomly selecting participants and asking them to list words or phrases they use to refer to HIV and AIDS. The following metaphors were noted when referring to HIV and AIDS: *manje manje masofa panze* which literally means 'very soon sofas or couches will be outside' which suggests the day of the funeral; *yakabuda* which means that 'the disease is now showing'. The author maintains that the term *yakabuda* is a stigmatising term to refer to HIV and AIDS symptoms once they show. Other metaphoric terms used suggested that HIV is a foreign disease, a modern disease or *tsono* (lethal). Mawadza (2004) states that the HIV and AIDS metaphors used by participants associated the disease with death and denial, and blame and stigma were found in all of these associations.

The most recent study conducted by Nyandiba and Anyonje (2013) in Kenya analysed the meaning of HIV-related utterances made by various *AbaGusii* (Kenyan Bantu languages) as they occur in their natural social context. Data collection involved listening to HIV and AIDS education vernacular programmes aired on six radio stations. Metaphors such as *enyamokirimbi eye yacha* (a new plague), *okemura* (disease for boys) and *enyamoreo* (thinning disease) were amongst the many metaphors identified in this study. Nyandiba and Anyonje (2013) state that the metaphors used to talk about HIV and AIDS portrayed the disease as a plague, a contamination and a new disease that has befallen humanity.

Of the few studies on naming and labelling of HIV and AIDS conducted in South Africa, none refers to the use of metaphoric terms for HIV and AIDS. This study explores all the terms, including metaphors, used to refer to HIV and AIDS by participants from *Ematyholweni*. Below is a discussion of the metaphor *uGawulayo,* which is currently used at an official and grassroots level by *isiXhosa*-speaking people in the country.

From an official and technical viewpoint, *uGawulayo* is a South African *isiXhosa* term for AIDS, as indicated in Table 1 above. The term also carries a metaphoric narrative. Vokwana (2014, p. 9) states that "*uGawulayo* is a *Xhosa* noun deriving from the root verb -*gawula* meaning to hack (shrubs), axe down a tree or clear up a vegetated area".

Dowling (2002) expands on this definition and writes that by saying *uGawulayo*, one is coining the act of *ukugawula* (chopping) a person. Dowling (2002) adds that the personification of HIV and AIDS in this reference can be linked to the use of *ukuhlonipha* (a cultural form of respect) which is prevalent in many tribal groups in South Africa. *Ukuhlonipha* is used in place of the actual name when referring to something or someone who is respected or feared or taboo (Dowling, 2002). According to Vokwana (2014), the strength of the name *uGawulayo* for HIV and AIDS lies in its imagery and semantic weight which suggests a degree of destruction or annihilation. The use of the term suggests that once one is infected by the disease, one is left with no chance of surviving as the disease has no mercy in its act of destruction. This is a source of stigma as Herek (2002, p. 3) maintains that "greater stigma is associated with conditions that are lethal and incurable"

2.6.2.3 References to HIV and avoidance

Another way in which stigma is manifested in people's responses to HIV and AIDS is through avoidance of using the terms HIV or AIDS. This often leads to use of phrases such as 'that thing' as a means of the speaker avoiding mention of the terms HIV or AIDS. Skinner and Mfecane (2004) maintain that such acts mean that the disease remains hidden. Bryceson, Fonseca and Kadzandira (2004) state that some authors have described this avoidance of direct reference to the illness as AIDS as denial and note that this denial is a manifestation of stigma. Petros, Airhihenbuwa, Simbayi, Ramlagan and Brown (2006) add that denial reinforces the belief that HIV and AIDS is a disease of others and not of the self.

Mathangwane (2011) conducted a study about perceptions of HIV and AIDS inherent in the labels used to refer to the disease. In this study, people used labels such as 'the radio disease', and

'disease of those in town'. Mathangwana (2011) argues that this shows denial and distancing, which Petros et al. (2006) label as a manifestation of stigma. Several studies conducted in South Africa have also noted the avoidance references that people use in conversations about HIV.

Campbell et al. (2007) conducted a study in a rural community in KwaZulu-Natal. This study revealed that people mostly used indirect references such as 'new disease', 'that illness…you know', to refer to HIV and AIDS. Even the participants who acknowledged the existence of HIV and AIDS often avoided referring to AIDS by name.

It is important to note that referring to HIV in indirect terms has not been exclusive to people who are not living with HIV. A study done by Squire (2007) in a township in Cape Town shows that those who live with KHIV also used indirect terms to talk about HIV. These included calling HIV 'our thing', 'this torturing thing', 'this awful disease' or simply 'this thing'. This distancing of self from HIV and AIDS enhances stigma.

Stein (2003) cites another study that was conducted inthe Western Cape Province by Morgan (2003) in which HIV and AIDS was just called *ulwazi* which means 'that thing'. Morgan (2003, in Stein, 2003) argues that this suggests that HIV and AIDS is seen, not only as a disease that has no cure, but as one which is so stigmatised, it cannot even be referred to by name.

In reference to a study that was done in rural and urban settings in KwaZulu-Natal, Clark (2006) states that 20 *isiZulu*-speaking middle-aged women used 'coded references' to HIV and AIDS. According to Clark (2006), this illustrated the conscious intention of the speaker not to mention the actual word but instead frame it as the referent. Clark (2006) adds that this can be explained in terms of the stigmatisation of HIV and AIDS. Clark (2006) further explains that naming the disease 'HIV and AIDS' implies knowledge of the disease, hence the use of coded language as a means of distancing oneself from the disease.

According to Skinner and Mfecane (2004), those who acknowledge the disease by being direct when talking about it or by even mentioning it are at a risk of being excluded from society,

which then means that the disease is not only distanced but denied as well. Furthermore, when HIV is hidden as a result of being denied, its perceived threat is reduced (Skinner & Mfecane, 2004). It is clear that this avoidance of mentioning HIV has fuelled stigma when it comes to HIV as it leads to denial and distancing and, seeing that stigma impacts on the HIV infection, it needs to be reduced. Stigma can be reduced by focussing on a 'communication' perspective. Young et al. (2011) conducted a study in China where it was found that the way people talk about HIV and AIDS, particulary using direct and open communication about the disease, has been as being able to reduce HIV-related stigma and change community norms.

2.6.2.4 HIV and other 'warning' terms

From the beginning, the language used to talk about HIV and AIDS has been that of warning people against HIV and AIDS as it is 'dangerous' and 'deforming'. Herek (2002) believes that regarding HIV as highly dangerous, contagious and deforming has contributed significantly to the stigma currently embedded in the disease. Most studies on the naming of HIV and AIDS have highlighted the negative connotation related to talk about HIV. For example, Mathangwane (2011) notes that in Botswana people used the word *segajaja* which means 'a disaster of immense magnitude' to talk about the disease. Mathangwana (2011) states that the name carries negative connotations which are meant to instil fear and this fear contributed to stigma associated with HIV and AIDS. Some of the metaphors and death-related terms discussed above have an element of warning people against being infected with HIV. Mashiri et al. (2002), on the other hand, found warning terms to have a pragmatic function - to positively awaken people's consciousness and lead them to assume responsibility to protect themselves against HIV infection. Therefore, warning terms are known to have negative and positive funtions, depending on their nature and use.

2.6.2.5 Misuse of the terms HIV and AIDS

The misuse of the term 'HIV and AIDS' seems not to have been explored in many studies. Crystal and Jackson (1992) have, however, paid special attention to it. They argue that the terminology commonly used to describe the experience of HIV and AIDS often makes use of the synecdoche AIDS, even when people mean to talk about HIV (Crystal & Jackson, 1992). This means that when talking about HIV, some people tend to refer only to aspects of AIDS and the same goes when talking about AIDS. Crystal and Jackson (1992) warn that the use of AIDS even when HIV is meant has meaningful consequences. They comment that this sociolinguistic construction of HIV and AIDS tends to focus on the terminal, debilitating and stigmatising consequences of the condition.

2.6.2.6 Use of the words 'dirty' and 'clean' to talk about HIV status

The use of the words 'dirty' or 'clean' to refer to a positive HIV status and a negative status, respectively, dates back to the 1990's. Lawless, Kippax and Crawford (1996) found that HIV-positive women were using the phrase 'dirty blood' in speaking about HIV status. Most recently, Grov, Agyeman, Ventuneac and Breslow (2013) conducted a qualitative pilot study on condom use and HIV status disclosure. In this study, the researchers report that participants used the term 'clean' when describing HIV and STI's. These authors further noted that this term had an underlying connotation that implied that those who are HIV positive are dirty, that is, 'not clean'.

Although little research has been conducted on this 'dirty or clean' HIV discourse, in social media and non-academic literature the use of term clean to refer to being HIV negative is prevalent. A report by Morrison and Baker (2014) documented HIV-positive and HIV-negative gay men talking about HIV. In this study the participants talked about how they use the word clean to talk about HIV status. These participants noted how talk about HIV has moved from "have you got HIV" to just "are you clean". Another online magazine from the United Kindom conducted an online survey with over 250 HIV-positive participants. Results from this study revealed that being HIV positive was often

associated with being 'dirty' (Haggas, 2014). Online talk platforms such as blogs also report numerous cases where people often use the word clean to refer to an HIV negative status.

The implication that one has 'dirty blood' if one is HIV positive reveals just how much the disease is framed in a negative manner. Due to negative connotations like these, those who are infected might experience internalised stigma along with internalised shame, blame, hopelessness, and guilt, amongst other things (Brouard & Wills, 2006). Internalised stigma negatively affects the well-being of those who are HIV positive and this is because it prevents them from participating in most community and social activities and sometimes from getting treatment (Hasan et al., 2012).

It is well documented that getting treatment is one of the main strategies for HIV management; however, with the fear or anticipated shame of being labelled dirty resulting from internalised stigma, those who are HIV positive are prevented from not only taking treatment, but from accepting their status, modifying their behaviour or even disclosing their status (Farquhar et al., 2001). Disclosure is regarded as a vital part of behaviour modification (Farquhar et al., 2001); this is because HIV status disclosure benefits those who are living with HIV psychologically, emotionally and with receiving material support from family and other community members as well as the freedom to use ARV medications (Bennetts et al., 1999; Ko et al., 2007; Norman, Chopra & Kadiyala, 2007). An addition, chances of HIV transmission between partners is reduced (Farquhar et al., 2001). The following section examines how the HIV language discussed above contributes to the stigma associated with HIV and AIDS.

2.7 The stigmatising nature of the terms used

It is clear that people's negative response to HIV and AIDS can strengthen stigma of the disease. For instance, even though there is general consensus amongst scholars that avoidance of the terms HIV and AIDS is stigmatising, some authors have expressed scepticism about the pervasiveness of such

stigma and find little evidence of it (Chimwaza & Watkins, 2004; Chirwa & Chizimbi, 2007; Kaler, 2004; Smith, 2003; Whiteside, Mattes, Willan & Manning, 2002). For example, according to Dowling (2002) and Wood and Lambert (2008), the indirectness of the mention of AIDS stems from the idea of *ukuhlonipha* as a customary system of respect based largely on linguistic avoidance that underpins good social relations and, according to these authors, this cannot be thought of as stigmatising.

Wood and Lambert (2008) add that indirectness should be thought of as a way of respecting things that are sacred or feared. In support of this statement, Duffy (2005) also maintains that less-than-exact terms are used by people to name AIDS, not as a way of denying the existence of the disease but to avoid insensitivity to culturally sensitive issues.

In a study that was conducted by Peters et al. (2010) in Malawi, little evidence of stigma was found in people's multiple responses to HIV and AIDS. Results from this study show that people's use of labels when referring to HIV and AIDS was a way of glossing over a wide range of responses such as shame, fear, suspicion, confusion, reluctance, blame, avoidance, anxiety and grief. However, this could be because at this time, people in Malawi were dealing with a disease (*kanyera*) that was similar to HIV and AIDS; therefore, HIV and AIDS was viewed as less threatening and thus less stigmatised by local people (Peters et al., 2010). This suggests that diseases are perceived based on how much of an epidemic the disease is in relation to others.

The review of literature shows that people's responses to HIV and AIDS are sometimes stigmatising and sometimes not. Mathangwane (2011) states that the way people label HIV and AIDS reflects the beliefs and perceptions societies and communities hold and they sometimes form the basis of stigma. Not only do these labels reflect how HIV and AIDS are perceived, they also illustrate how language can contribute to, and maintain, HIV- and AIDS-related stigma.

Thomas (2005) warns us that context matters when studying this phenomenon. He further states that the nature and intensity of AIDS stigma are shaped by the social construction of the

epidemic in different locales. Therefore, understanding how HIV and AIDS is constructed through different terms in a rural Eastern Cape setting will enable an understanding of how it could be stigmatising or not stigmatising in that context. The literature review provided an outline of how talk about HIV in various communities around Africa has shaped how HIV has been perceived, thought about and made sense of. Seeing that the HIV and AIDS language is contextually embedded, when studying whether certain terms are stigmatising or not, it is important to study each country, community or village separately.

The current study argues that by examining the issue of talk around HIV and AIDS, some insights into stigma and HIV and AIDS could be gained. Vast amounts of research and campaigning have been conducted in the area of HIV, but the numbers of those infected continues to rise even though people are informed about HIV and AIDS. Mabachi (2009) writes that, because of this, there is a call by African scholars to engage in qualitative studies and intervention-based research that will lead to a better understanding of why the current HIV programs in Africa are failing to produce the desired results. This is especially true in South Africa. Based on the review of literature, language is seen as a way in which HIV and AIDS stigma has manifested. Seeing that stigma has been a major barrier for management of HIV, this study aims to gain insight about how stigma can manifest in people's reference to the disease.

2.8 Summation

This chapter demonstrated that there are names and labels other than 'HIV' or 'AIDS', that people use to refer to the disease. The naming and labelling of HIV has been extensively explored, but with substantial focus on the metaphors used to name the disease. The names ranged from official names to casual use of metaphors and slang, to totally refraining from calling the epidemic by its 'proper' name. From this review, it emerges that the HIV-related labels people use indicate negative

inferences about HIV and AIDS. There also seems to be little change from the initially negative view of HIV; instead, throughout the years there has been an accumulation of these negative words, mostly coming from indigenous or local languages. Research across countries seems to illustrate that the terms used inform the stigmatisation of the disease. However, it is also demonstrated that to make conclusions on the stigmatisation of the terms, research on HIV labels has to be localised because terms that carry stigma in one context could be non-stigmatising in another. The chapter discussed the blaming and stigma theory of stigma as a framework that could assist in understanding howHIV names and labels relate to stigma.

2.9 Aim and rationale

Communities have responded uniquely to HIV and AIDS and this can be seen from the different names that have been used to communicate about this pandemic. Researchers who have explored the issue of labelling and naming HIV and AIDS argue that the names given to HIV and AIDS reflect the beliefs and perceptions of societies and communities. These labels are important to study as they assist in understanding how people make meaning of the disease, and they generate a picture of the discourse about HIV and AIDS which exists in particular settings. Studying these terms not only informs scholars about how HIV is perceived in societies but also indicates where and how education needs to be directed when creating awareness about acceptable discourses about HIV and AIDS. Thus, for any insight on beliefs about HIV, the issue of naming and labelling HIV and AIDS needs to be explored. A contextual study might translate into meaningful locally relevant HIV education in the research area.

It is theorised that the terminology used to talk about HIV and AIDS sometimes forms the basis of stigma (Mathangwane, 2011). Studying the names used by the people of *Ematyholweni* will help in unpacking HIV-related stigma in this rural area. These labels are an important study focus as

they assist in understanding how people make meaning of the disease, and they generate a picture of the discourse about HIV and AIDS which exists in particular settings.

This study has the following research objectives and it aimed at answering the questions below.

2.9.1 Objectives of the study

1. To examine how people in a rural setting in the Eastern Cape respond to HIV and AIDS in their naming and labelling of the disease.

2. To assess whether the labels or names used to describe HIV and AIDS are stigmatising, neutral or non-stigmatising.

2.9.2 Research Questions

1. How do people in a rural setting in the Eastern Cape name and label HIV and AIDS?

2. How are the labels or names used by people in this context stigmatising, neutral or non-stigmatising?

This study draws on data from an NRF-funded qualitative research study on 'Activity theory and behaviour change', which was conducted in a rural area (*Ematyholweni*) in the Eastern Cape. The focus of the study was on sexual activity and risk in response to HIV and AIDS. The current study aims to examine terms used to refer to HIV and AIDS. This process of conducting the study is discussed in depth in Chapter Three below.

Chapter 3: Methodology

This chapter presents the research methodology that was employed to perform this study. This includes an outline of the research design, sampling strategies, sample size, study setting, data collection, data analysis, trustworthiness and rigour, as well as ethical considerations. The chapter will discuss both the methodology of the main study, from which the data for the current study was obtained, and the methodology of the current study.

3.1 Research design

This is a qualitative study of an exploratory nature. The aim of exploratory research is to make a preliminary examination into a topic that is lightly researched or unknown (Durrheim, 2006), that is, to unearth the social meaning people attribute to their experiences, circumstances and situations, as well as the meanings people embed into texts and other objects (Gravetter & Forzano, 2009). Choosing to do this study using a qualitative-exploratory approach is informed by the need to get acquainted with how people in a rural area of the Eastern Cape respond to HIV as portrayed by how they name and label HIV and AIDS. To fulfill this purpose, an open, flexible and inductive approach to research such as qualitative exploratory approach is advantageous (Durrheim, 2006). Holstein and Gubrium (2008) also state that this approach helps in answering questions about how social realities are produced, assembled and maintained.

3.2 Sampling

3.2.1 The main study

3.2.1.1 Sample

The data for this study on 'Naming and labelling HIV and AIDS' was obtained from a National Research Foundation (NRF) *Thuthuka*-funded study on 'Activity theory and behaviour change'. One of the aims of this main study was to look at how participants respond to HIV and AIDS. This data was collected in a rural area, *Ematyholweni* (a pseudonym for the research site), in the Eastern Cape between 2011 and 2013, under the supervision of Dr. Mary van der Riet. The two methods that were used in collecting this data were individual interviews and focus groups.

The sample for the main project included black, *isiXhosa*-speaking men and women from 14 villages which make up *Ematyholweni*. The composition of this sample was based on the fact that the study was in a rural setting, dominated by *isiXhosa*-speaking residents. The participants were sampled in the following age ranges 10-13; 14-17; 18-25; 26-34; 35-45 and 46-70 years. Additionally, the sample was made up of married and single participants, pensioners, teenagers, youth, young adults, traditional healers, as well as HIV-positive individuals. Data was collected from 20 focus groups and 75 individual interviews. The data from this broader study was made available to me for my study.

3.2.1.2 Sample recruitment steps

The supervisor of the main study has a longstanding relationship with the research site, which facilitated access. Initially, permission to conduct research in the setting was granted by the chief of the area (see Appendix 1 for the letter seeking permission and 1A for the *Xhosa* version of the letter). Additional permission had to be obtained from the chairperson of the Resident's Association in each of the 14 villages that made up the research site. The chairpersons, who also acted as key

informants of the study, assisted the research team in identifying the potential participants of the study. After potential participants were identified, researchers visited them, told them about the study (see study's information sheet in Appendix 4) and requested that they take part in the study. This process was repeated in all 14 villages. In addition to the use of key informants to recruit participants, the research team visited social gatherings such as soccer tournaments and choir practices and took details of potential participants. This was particularly useful in recruitment of the youth.

3.2.1.3 Sampling strategies used

The two non-probability sampling strategies that were used to select participants were purposive sampling and convenience sampling. Purposive sampling permits one to choose cases which illustrate some features or processes in which one is interested (Silverman, 2013). In this study, participants had to be between the ages of 10 and 70. Both men and women had to be selected, as well as married and single individuals. Finally, each participant had to be from the one of the 14 villages of *Ematyholweni*. Convenience sampling was the second strategy; this means that participants were selected based on their availability (Gravetter & Forzano, 2009). Participants who took part in the main study were those who when approached through the key informants, and the research team, and after the research process was explained to them, willingly availed themselves for the study.

3.2.2 The current study

3.2.2.1 Sample

The data used in this study was sampled from the 95 data transcripts from the main study. Data from the main study covered topics on sexual behaviour, sexual relationships and HIV and AIDS. In this study, the data that addressed the names and labels used in *Ematyholweni* to refer to HIV and

AIDS formed the focus. Studying responses to HIV and AIDS in the area is useful as *Ematyholweni* forms part of a district in the Eastern Cape with a high prevalence (30, 6%) of people with HIV (Eastern Cape AIDS Council, 2011).

The process of sampling data from the broader data set occurred as follows: I had access to the transcripts of all the interviews and focus groups for the main study. I read through all of these transcripts, looking for sections in the transcripts that referred to how people construct HIV and AIDS through the names and labels they use to refer to it. For example, I selected all interviews and group discussions where the participants at any point of the conversation used terms to refer to HIV and AIDS. This meant excluding interviews or focus groups where the direct acronyms HIV or AIDS were the only terms used and done so correctly. Purposive sampling was thus a procedure I used to sample the data, as I chose transcripts that illustrated some features in the data in which I was interested (Silverman, 2013).

After this selection of transcripts, I ended up with 41 transcripts as the sample which Kcontained various labels used to talk about HIV and AIDS. Eleven transcripts came from focus groups and 30 from interviews. Both men and women were represented. All the age groups, thus 10-13; 14-17; 18-25; 26-34; 35-45; 46-70 for focus groups and 18-25; 26-34; 35-45; 46-70 for interviews formed part of the sample. The characteristics for the sample in this study are presented in Table 2 and Table 3 below. In some transcripts the age of the participant was not available and this is indicated with 'unknown'.

Table 2: Sample demographics for focus groups

SOURCE	AGE	MALES	FEMALES	TOTAL
Focus group	10-13	1	-	1
Focus group	14-17	1	1	2
Focus group	18-25	1	1	2
Focus group	26-34	1	2	3
Focus group	35-45	1	1	2
Focus group	46-70	-	1	1
TOTAL		**5**	**6**	**11**

Table 3: Sample demographics for interviews

SOURCE	AGE	MALES	FEMALES	TOTAL
Interview	18-25	2	2	4
Interview	26-34	6	8	14
Interview	35-45	2	-	2
Interview	46-70	5	1	6
Interview	Unknown	1	3	4
TOTAL		**16**	**14**	**30**

3.3 Data collection

3.3.1 The main study

The main study used individual semi-structured interviews and focus group discussions for the data collection process. These two methods were chosen because of the nature of the research focus on sexual activity and risk in response to HIV and AIDS. As a data collection method, interviews are useful in gaining a more detailed picture of the participant's beliefs about, or perceptions of a particular topic (Greeff, 2011), and their personal experiences. This data collection method allowed participants flexibility and freedom in giving personal accounts. The data collection process was guided by an interview schedule and this helped in ensuring that all the topics were covered and the data collection process had structure. The interview schedule was designed differently for married participants (see Appendix 2) and single participants (see Appendix 3). The motivation behind this was that issues of sexual activity, relationships and perceptions about risk and condom use might differ depending on one's marital status. Each participant signed an informed consent form before participating in the interview (see Appendix 5) and this consent was accompanied by a form giving consent to record the interview (see Appendix 6).

Data was also collected from a variety of focus groups, across specific age ranges and from the 14 villages of *Ematyholweni*. These groups were made up of 5-6 participants and each group consisted of participants of the same sex. This grouping of participants of the same sex facilitated

free and open discussions on the topic at hand. Focus groups helped in gaining in-depth information through participants' interaction with each other and the researcher. The guiding questions for the group discussions were the same for both men and women, with a few alterations based on the age group of participants (see Appendix 7 for guiding questions). In each group, participants signed consent forms (Appendix 8) and were sworn to confidentiality (see Appendix 9 for confidentiality pledge). Focus groups, by definition, are carefully planned discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment (De Vos, Strydom, Fouche & Delport, 2011).

The data collection was conducted in *isiXhosa*, the language of the participants. If a non-*isiXhosa* speaker was involved in the data collection process, a translator was present. All of the inK2terviews and focus groups were audio-recorded. This audio data was transcribed and translated by the research team using a simplified version of Jeffersonian transcription conventions (see Appendix 10). In order to ensure validity and quality of the data, back-translation was done by two independent researchers who were fluent in *isiXhosa*. Chen and Boore (2009) describe back-translation as a process where two independent translators translate the same transcript. This means one translator translates the original version of the transcripts into the target language (which in this case was from *isiXhosa* to English). The other translator then translates the same transcript back to the original language, thus from English to *isiXhosa.* This process helps to check for discrepancies in the data (Chen & Boore, 2009).

3.3.2 The current study

As stated above, the data used for the current study was collected using interviews and focus group discussions. These data collection tools were useful in the sense that engagements with participants meant that the data was generated from people's own perspectives and experiences. Such data

allowed me to examine the participants' constructions of HIV and AIDS and the way in which they name and label the disease.

Because I was not involved in the original data collection process, data collection for this study involved a review of the English transcripts. In all, out of the 95 transcripts which I read and examined, 41became my sample. Collecting data that related specifically to the labels and names used to refer to HIV and AIDS was a bit challenging. This is due to the fact that I had access to already transcribed and translated transcripts, and there seemed to be some discrepancies in the translations. For example labels such as *uGawulayo,* which is *isiXhosa*, were translated as 'AIDS' in the transcripts. To clarify some terms and phrases I went back to the original *isiXhosa* audio files. I am a first-language *isiXhosa* speaker and by listening to the audio files and checking their consistency with the transcripts, I noticed that there were instances where utterances such as *uGawulayo* were transcribed as 'HIV' and not AIDS, and this occurred often. I translated and re-transcribed the sections of the audio files which I thought were inaccurate. These translations were then checked in consultation with my supervisor and one of the main researchers in the broader project who is *isiXhosa* speaking.

To ensure that I did not miss other references to HIV and AIDS as a result of the transcription process, I briefly listened to the 30 sampled interviews audio files, but not those for the focus groups as I had no access to these. In conclusion, the data collection method used meant sampling extracts from the transcripts and documenting new data that emerged from the audio files.

3.4 Data analysis

3.4.1 The current study

I had access to 95 qualitative data transcripts of audio files from interviews and focus groups, but analysed the 41 sampled transcripts. The analysis process began with the reading and rereading of transcripts; this helped in becoming intimately familiar with the data. Since the main research study did not have a specific question asking about how participants 'name and label HIV and AIDS in *Ematyholweni*', I had to read through each transcript to find out how HIV and AIDS were referred to by the participants. From this process I could already highlight the general labels people were using to talk about HIV and AIDS. Some of these labels were: 'it/this/that thing', 'killer', 'death', 'lotto', '*umbulalazwe*', 'danger', 'clean blood', etc. This informal manual analysis of the transcripts was followed by importing all of the transcripts into the qualitative analysis software programme, NVivo version 10.

Using NVivo, I then did text searching using the key terms informed by the labels manually identified. These key terms were: 'kills', 'killer', 'HIV', 'AIDS', 'death', 'clean blood', 'dangerous', 'danger', 'misfortune', 'lotto', 'that thing', 'it', 'this thing', 'cable' and 'big'. Other references to HIV and AIDS could not be identified by only using key term searching on Nvivo; therefore, I reviewed all trancripts again thoroughly on Nvivo and performed open coding, and through this process, more code such as 'misuse and conflation of HIV and AIDS' emerged. De Vos et al. (2011) define open coding as a means of going through the content of the data and finding codes. These codes can be in the form of a sentence, one word or a phrase. This initial analysis was discussed with the research supervisor, and one of the researchers from the broader project.

After identifying a variety of names and labels used to refer to HIV and AIDS through this open coding process, these were further organised into themes using thematic analysis. The

purpose of thematic analysis is to identify themes salient in a text at different levels (Attride-Stirling, 2001). According to Braun and Clarke (2006), during thematic analysis one should be guided by six principles. As briefly mentioned above, thematic analysis firstly requires familiarisation with the data and this is achieved by reading and re-reading the data and noting ideas or patterns (Braun & Clarke, 2006). The second phase involves generating the initial codes by identifying where and how patterns occur. In this study, this meant identification of terms used to refer to HIV and AIDS. Thirdly, the codes are collated into themes that accurately depict the data. This means that labels relavant to each theme are collated; for instance, in this study labels such as lotto and *uGawulayo* were collated to a 'metaphoric labels' theme and this was applied throughout the labels. The fourth phase includes reviewing themes to check if the themes make sense and account for all the coded extracts and the entire data set. In this way, a thematic 'map' of analysis will be generated in the fifth phase, which involves defining and naming each theme (Braun & Clarke, 2006). The final phase of analysis includes producing a final report. Guided by the principles of thematic analysis, six themes were identified inductively from the transcripts and deductively from the research questions.

3.5 Trustworthiness and rigour

In the qualitative research process, the researcher needs to ensure rigour and trustworthiness. According to Lincoln and Guba (1985), trustworthiness is comprised of four epistemological K2standards: true value; applicability; consistency; and neutrality. These standards are evaluated through the credibility, transferability, dependability and conformability of the study, respectively (Lincoln & Guba, 1985). The four components are discussed in reference to this research in the paragraphs below.

3.5.1 Credibility

CrK2edibility of this study was firstly achieved by ensuring prolonged engagement in the field, where a team of researchers in the main study conducted several interviews and focus group discussions. For this study, I engaged for many months with the 95 transcripts, reading and consulting with a few audio recordings to judge for consistency across these two versions. In some cases, I re-transcribed sections of the audio files. After this prolonged engagement with the data, I constantly checked the accuracy of my coding with the research team and research supervisor through peer debriefing.

The use of different data collection methods in the main study (interviews and focus group discussion) assisted in producing "convincing and believable" results as stated by (Van der Riet & Durrheim, 2006, p. 91). This triangulation of methods meant that the study did not only rely on one method of collecting data and this helped in ensuring credibility of the main study.

The data from which I sampled the data for the current study comprised both interviews as well as focus group discussions which had been translated by various individuals who were fluent in the language in which the research was conducted (*isiXhosa*). The back-translations meant that the data I had access to was verified and thus of quality. Although I had to re-translate few extracts for accuracy. This also enhanced credibility of the data I was working with.

Credibility in this study was also achieved by being true to the data and not only including cases that agreed with my research focus. For instances, HIV terms that were only present in one interview transcript out of 41 transcripts were included as part of the terms people in *Ematyholweni* use to talk about HIV and AIDS. Thus, my analysis also included an assessment of deviant cases or discrepant information.

3.5.2 Transferability

Transferability is concerned about producing a rich description of the studied phenomenon (Van der Riet & Durrheim, 2006). To strengthen transferability, a purposive sampling method was used both in the main and the current study. For this study, the sampled transcipts had specific characteristics related to the focus of the study, that is, they discussed HIV and AIDS and used varyious labels to refer to the disease, which allowed me to collect the richest data possible.

The methodology section of this document has given a full and accurate description of how the research was carried out. This was done by giving a description of the main study process and giving a detailed description of how the current study was conducted, including the sampling strategies, data collection, data analysis and data interpretation, as well as the context of the study. This K2all helped to confirm transferability of the study. Given the accurate, thorough description of how the research was carried out, other reseachers should be able to assess if the results are tranferable to other contexts..

3.5.3 Dependability

Dependability is the alternative to the more positivistic term of reliability'; dependability is "the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions" (Hammersley, 1992 p. 67). To strengthen the dependability of the study, researchers in the main study ensured that the process of sampling was carried out uniformly. This means that a level of consistency in the characteristics of people sampled from each village that formed part of this study was maintained. Athough the main study included participants with different genders, ages and marital status, during data collection the same questions were asked of all participants as the researchers saw fit, except for some small differences between the interviews with single and married participants.

For this study, dependability was enhanced in the analytic process by using a qualitative data processing software programme, NVivo (10). Using this software, I could search for the same key words across all transcripts in the search across the extracts that I was interested in. In addition to this, Nvivo allowed for the process through which data was analysed to be applied in the same way to all of the transcripts. This helped in ensuring the dependability of the analysis of the data in this study. Data analysed by the researcher was checked by the team of researchers working on this aspect of the NRF study. This increased inter-rater and inter-coder reliability, thus strengthening dependability.

3.6.4 Confirmability

Confirmability is concerned with providing evidence that the data analysis and the resulting findings and conclusions can be verified as reflective of and grounded in the participants' perceptions. In essence, confirmability can be expressed as the degree to which the results of the study are based on the research purpose and not altered due to researcher bias (Given, 2008). To strengthen confirmability, a coding framework, informed by theory, was developed at the beginning of the data analysis process. Miles and Huberman (1984, as cited in Silverman, 2013) argue for the importance of data display. This is an organised assembly of information that permits conclusion drawing and action. To increase confirmability, I have included the display of data in the form of extracts from the transcripts. Both *isiXhosa* and English extracts are displayed in the results section to show the readers the raw data which was used for the analysis. The codes of each of the extracts showing how they are related to the broader project data set are also included in the appendices in this document (see Appendix 14).

3.6 Ethical considerations

Data used in this study had already been collected. Ethical clearance for the broader study was granted in 2011 (Reference: HSS/0695/011, see Appendix 11). The current study was granted ethical clearance (Reference: HSS/0266/014M) in March 2014 by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal (Appendix 12).

I also signed an agreement with Dr. Mary van der Riet that allowed me access to and use of the data, and ensures that the current study adheres to the ethical standards established in the broader study, such as maintaining the confidentiality of the participants' identities in all accounts of the study (see attached agreement in Appendix 13).

Ethical issues that this research considered are respect for people, non-maleficence, beneficence and justice. These are discussed below.

3.6.1 Respect for people

Respect for people requires one to maintain anonymity and/or confidentiality and/or ensure that participants' privacy is not violated (De Vos et al., 2011). The identity of the participants in the main study was protected through the use of pseudonyms for the names of the participants. This anonymity was maintained in my study as I only had access to the transcripts which were labelled using the gender and the age of the participants. In addition, a pseudonym was used for the research site, as well as a code for each village.

3.6.2 Non-maleficence

Babbie (2007, cited in De Vos et al., 2011) states that the fundamental ethical rule of social research is that it must not bring harm to the participants. This harm may be emotional or physical. I had no direct contact with the participants; however, because the main study discussed sensitive topics such as HIV and AIDS, the researchers had measures in place for unforeseeable distress. These

measures were described in the information sheet (see Appendix 4) which contained information about referral to counselling and HIV and AIDS support services

3.6.3 Beneficence

The ethical issue of non-maleficence discusses harm that participants might experience as part of the research process and how they should be protected from this. Beneficence, on the other hand, highlights the benefits of participating in a research study. Monette et al. (2005, cited in De Vos et al., 2011) point out that a research project may have positive benefits, even though this may take years to be seen. The short-term benefits of participation included an opportunity to discuss issues pertaining to relationships, risks in sexual activity, and HIV and AIDS. In the broader study, there were also workshops conducted through a form of participatory research, where participants discussed the findings of the study. As an indirect benefit of the study, the results of the broader NRF study could inform educational and policy initiatives that could benefit the people of *Ematyholweni.*

Furthermore, results of this current study could bring awareness to the people of *Ematyholwen*i about the stigmatisation of HIV and AIDS through the way people construct and thus name the disease. Such awareness might help in combatting HIV stigma in this rural area and other areas.

3.6.4 Justice

Social research should have social value. The current research falls under a broader study that addresses the problem of HIV and AIDS in Ematyholweni. Data obtained during the broader project also showed evidence of stigma related to HIV and AIDS in the research site. This study has taken up that focus and explored the way in which references to HIV and AIDS in the site might be

stigmatising. This will also help in identifying HIV-related stigma and thus inform interventions that might be developed to address stigma and discrimination in rural contexts.

3.7 Data storage and the dissemination of results

The data for the broader study has been kept securely by the project supervisor (Dr. Mary van der Riet). I signed a contract with the project supervisor to use and discard all the data on completion of this thesis. During the main study, participants were notified that the results could be used for conference presentations and publications and that students might use the data for their dissertations. However, because the data remains the property of Dr. Mary van der Riet, I am to consult her should I plan to publish or do any presentations from the results of this study.

The next chapter presents the results of the data analysis of the study.

Chapter 4: Results

This chapter presents the results of the process of data analysis. It focusses on presenting the names and labels used in *Ematyholweni* to refer to HIV and AIDS. These terms, which emerged when searching for participants' references to HIV and AIDS from a set of qualitative data, are arranged into six different themes. In this chapter, each of these themes is described along with illustrations extracted from the original data. The description of themes moves from direct to K2indirect references to the disease. The chapter starts by presenting participants' misuse and conflation of the two terms 'HIV' and 'AIDS'. This is followed by a description of several themes, namely: metaphorical labels; 'collecting death'; 'that thing'; 'clean blood', as well as attempts to describe the disease.

As discussed in the methodology chapter, the data set for this study consisted of transcriptions of individual interviews and focus group discussions. During data collection in the broader study, HIV and AIDS were core topics, and participants and interviewers kept referring to the disease. It became apparent during this data collection that HIV and AIDS were referred to using both of these terms. It is important to note that no direct question was posed to the participants about how they name, label or talk about HIV and AIDS, so the analysis is not of their direct responses to this question. However, the current study examinedhow participants named and labelled HIV and AIDS at different points during the interviews or discussion.

Finally, although the data was collected using *isiXhosa*, due to the transcripts being translated into English, the HIV references presented here are in English. However, I have decided to present some terms in their original form, that is, in *isiXhosa*, especially where the depth and context of the term might have been lost due to translation. For example, terms such as *uGawulayo* for AIDS are presented in their original form. In instances where the two versions of the extracts are

given, the *isiXhosa* version is presented first followed by the English version of the same extract. In some extracts, the area of focus is underlined for easy reading.

In the extracts and the discussion of the findings, the research site name and the participants' names are all pseudonyms. The gender, age, and source of the extract is indicated by F for female and M for male, the age or age range, and I for interview, and FG for focus group. The line numbering in all of the extracts is from the original transcriptions and indicates where the extract has been drawn from in the original interview or focus group discussion. The data set codes of the transcripts from which the extracts in this section were obtained are included in Appendix 14. Below is adiscussion of the themes with the names or labels they encompass.

4.1 Misuse and conflation of the terms HIV and AIDS

The analysis revealed that people in *Ematyholweni* tend to misuse and conflate the two terms HIV and AIDS. Instead of labelling the disease 'HIV and AIDS' or 'HIV' or 'AIDS' where appropriate, participants mostly used 'AIDS' to refer to any characteristic of HIV and AIDS. For example, 'AIDS' was used in all talk about the disease even when 'HIV' would have been a more suitable term. This way of referencing HIV and AIDS is significant because it highlights how the disease is seen and known in the area. This provides a basis from which to understand some of the other labels used by the participants.

This misuse or conflation of the terms HIV and AIDS was present in most interviews and across all age groups, and was only correct in some instances. It is important to emphasise that the term AIDS was regularly misused by participants, but that the HIV label was correctly applied most of the time. This is illustrated in extract 1 which is from an interview with a female participant between the ages of 18 and 25.

Extract 1

78   Participant: It's important because we are scared that AIDS is transmittable.

79   Interviewer: Ok, so it's AIDS. Preventing [AIDS

80   Participant: [Preventing AIDS] Ummm preventing AIDS with this condom.

The participant in extract 1 talks of AIDS as being "transmittable", and that it is therefore necessary to condomise. Such statements (line 78) are usually correct when talking about HIV. This is because the HI virus is transmittable and is not AIDS; but in this interview, the participant uses the term AIDS instead. This is also seen later on in the interview (see extract 2) when the participant seems to be aware that HIV is transmitted by having unprotected sex with an HIV-positive individual. However, in line 165, she talks about someone 'getting AIDS' when they have sex without a condom.

Extract 2

162   Interviewer: Please tell me the knowledge you have on it.

163   Participant: I know that HIV is transmittable.

164   Interviewer: Ok

165   Participant: By having sex without a condom, you may get AIDS.

In this interview, some aspects of HIV are erroneously communicated as those of AIDS. One does not get AIDS when one sleeps with an HIV-positive person; one gets HIV which eventually progresses to AIDS if one's immune system is compromised. This inaccurate use of the term AIDS happens throughout the interview with this participant.

In extract 3, the 24-year-old male interviewed is asked a question particularly about AIDS and in his response he talks about getting tested for HIV, but the term he uses is AIDS and not HIV.

For instance, in line 653 as he talks about the HIV testing tool detecting his HIV status ("been caught by the machine"), he mentions the test reading as saying "you have AIDS".

Extract 3

648 INTERVIEWER: Mmh okay okay, so (.4) so is there anything that you would like to

649 know, maybe a question that you have for me regarding Aids?

650 Respondent: (.3) J;ah about Aids I would like know something, let's say I get tested

651 at the clinic…in fact you have a partner (.1) but sometimes when you go for testing

652 you don't go with your partner. So↑ if you find out that you have been caught by the

653 machine and they say you have AIDS, so (.2) in terms of advice what do you sa:y

654 to your partner?

655 INTERVIEWER: Mmmh

656 Respondent: ((sniff)) And let's say your partner has been negative all along, my

657 question now is or should I say how would advise me to say to my partner upon 658 finding

that I have been caught by the machine…

659 INTERVIEWER: Okay Ja

660 Respondent: What would you advise me to say to her would you say I should lie to

661 her or just tell her straight that I have AIDS.

This misuse of the term AIDS is the same as that identified in the previous two extracts, where

participants talk about the HIV phase of the disease but incorrectly use the word AIDS. Towards the

end of the extract, as the participant continues to seek advice from the interviewer, he asks advice

about disclosing to his girlfriend after discovering that 'he has AIDS'. The term AIDS is once again

preferred here and throughout the whole interview.

This conflation of HIV and AIDS when naming the disease was common in the interviews and

focus groups across all age groups in the research site. Extracts 4 and 5 are both from an individual

interview with a man in the 46-60 age group. In extract 4, he talks about getting tested for HIV and goes on to demonstrate his knowledge about the symptoms of people with AIDS. However, he incorrectly uses the term AIDS when naming the disease he gets tested for at the clinic (line 11: "I test for AIDS").

Extract 4

1   Participant: Listen here, I am saying to you that I ((name)), I went to the clinic today. I also

2   checked- I was going to fetch treatment. I tested for AIDS; it was shown that I do not have it

3   because I usually test. The people whom I have seen to have Aids are thin, emaciated,

4   finished, they do not eat and so on and have diarrhoea because they themselves have seen that

5   they have not gone to the clinic in time where they could have gotten help. I will stop there

6   ((cell phone ringing)) ((interruption))

7   Interviewer: Now, you were still telling me, what made you decide to go and get tested?

8   Participant: Me?

9   Interviewer: Yes

10   Participant: The reason that I decided to test for AIDS-I am a person who   takes treatment

11   for a mental illness-I test for Aids and diabetes regularly (.2) I didn't feel anything but the

12   fact is that I usually see people that have AIDS (.)

Throughout the interview, the participant labels the disease AIDS and only mentions HIV twice when led by the interviewer. For example in extract 5 below, line 196, he used the term AIDS when he seems to be talking about the epidemic of HIV and AIDS. This shows that he prefers the term AIDS when talking about the disease and this can be found throughout the interview. The conflation of HIV and AIDS is shown again, where he talks about being tested for AIDS and not HIV at the clinic (see lines 197-198).

Extract 5

196 Participant: they say, listen man, you see with this thing of AIDS, they say you must test

197 yourself, and after a few months go there again. There is a machine there at the clinic that

198 tests you for AIDS. The results come out right there and then. You her> and then if you do

199 have it only the nurse that was testing you knows about it, and you and then they tell you at

200 the clinic that man, don't trouble yourself, you have been infected.

Extracts 6, 7 and 8 below are from an individual interview with a male participant who is also between the ages of 46 and 60. Every time the participant talked about HIV and AIDS in the interview, he used the term AIDS.

Extract 6

124 Interviewer: uh -uh, uh what is that condom meant for?

125 Participant: it's made so that this AIDS thing doesn't go in ((laughs)) I am really saying it

Most of the time this term was misused; for example, in extract 6, he states that "this AIDS thing …goes in" when one does not use protection, whereas it is actually the HI virus which gets transmitted (in the case of sleeping with a HIV-infected person). This is similar to what the participant in extract 2 said about the disease.

  The preferred use of the term AIDS even when HIV would have been more appropriate can be understood from what the participant demonstrates in extract 7.

Extract 7

399   Interviewer: so could you please tell me what you know about HIV

400   Participant: HIV ((pronounces it Jiving))

401   Interviewer: yes

402   Participant: no I don't have Jiving

403   Interviewer: so could you please tell me about what you know about it, or AIDS

Here, when asked about his knowledge of HIV, the participant refers to HIV as "jiving". From the audio recording it can be detected that the participant struggles to speak English and thus has great difficulty in pronouncing terms such as HIV, which the interviewer uses, hence the use of 'jiving' to mean HIV. In line 402, he states he does not have 'jiving', that is, HIV. The incorrect pronunciation of HIV and the preferred use of the term AIDS is explained by the participant in extract 8 where the participant comments that he was unaware of 'HIV' until the interviewer brought it up. However, how he refers to HIV as 'jive' or 'jiving' seems to have little to do with the participant's knowledge about the virus, but more to do with him struggling to say this unfamiliar abbreviation.

Extract 8

480   Interviewer: so is there anyone you know of who has HIV

481   Participant: hey you see I haven't heard of anyone who was said to have this Jive. It's my
482   first time hearing about this Jiving. I didn't know about this Jiving, I know about this one that
483   they were saying is there

484   Interviewer: AIDS?

485   Participant: the first one that they say is there, this second one I don't know, I haven't heard
486   of this Jiving I only know of this first one

487   Interviewer: the one they call AIDS?

488   Participant: mm

The analyses revealed that there was a common use of the term AIDS when referring to any attributes of HIV and AIDS. For instance, every time the participants talked about transmission and testing for HIV, they would use the term AIDS. Some participants said that they were only familiar with AIDS and not HIV, hence the misuse of the term. The misuse and conflation of HIV and AIDS has many implications, one of which reflects how the disease is known and thus named in *Ematyholweni*.

4.2 Metaphorical labels

There were a few metaphoric labels used by participants to refer to HIV and AIDs. For example, some related to the official translation of the terms: *intsholongwane kaGawulayo kunye noGawulayo* (HIV and AIDS), and others made references to danger such as *ubanjwa nguGesi* (being held by electricity), and risk taking, such as '*lotto*'. *Intsholongwane kaGawulayo* is the official *isiXhosa* name for referring to HIV. *Intsholongwanwe* means 'a virus', while *uGawulayo* refers to AIDS. Thus, the term means a virus that advances to become AIDS. Although the terms are official names for the disease and used appropriately in the study, the word *uGawulayo* found in both of the terms is a metaphor, hence the inclusion of the terms as an example of the metaphorical labelling of the disease by participants.

The metaphors discussed here were generally more evident in the individual interviews than in the focus group discussions. There is a significant difference in the metaphors used relating to the different age groups in the study. For instance, the metaphor lotto was only found in an interview with a participant in the 26-34 age group. The use of *intsholongwane kaGawulayo* and *uGawulayo* was present across all of the data , except for the younger focus groups (from 14 to 17 years of age)

which did not use any metaphors and only referred to the virus and the disease as 'HIV' or 'AIDS', respectively. This is discussed in detail below.

4.2.1 *Intsholongwane kaGawulayo kunye noGawulayo* (HIV and AIDS)

UGawulayo refers to an act of 'chopping something mercilessly'. In the case of HIV and AIDS, this means that AIDS is labelled as a disease that chops one's body down once infected with HIV. Thus the term communicates the debilitating nature of AIDS. The full term normally used for AIDS in *isiXhosa* is *isifo* (a disease) *sikaGawulayo*, but the members of the general population usually shorten it to *uGawulayo*. This was also the case in this study.

The limitation of having this term shortened is that it is never clear whether one is referring to HIV or AIDS as both of these terms, when translated into *isiXhosa,* have the word *uGawulayo* as part of the term. However, when listening to the audio files, I detected consistency in the manner in which the interviewers (the researchers) and the participants used these *isiXhosa* terms. In all the relevant audio files, the terms were correctly used, meaning the term *uGawulayo* was used for AIDS and the term *intsholongwane kaGawulayo* for HIV, therefore this eliminated confusion and thus the misinterpretation of the terms. The *isiXhosa* term *intsholongwane ka Gawulawo* which is used for HIV can be loosely translated as 'the AIDS virus*',* with *intsholongwane* known as 'the virus' and *uGawulayo* as 'AIDS'. For a clear illustration of the use of these terms, each extract below is presented in *isiXhosa* first, followed by an English translation.

Extract 9

98 Interviewer: Mmh…ungandichazela↑ kancinci nje malunga nolwazi onalo

99 ngentsholongwane kaGawulayo okanye uGawulayo?

100 Participant: Mmh (0.2) endiyaziyo ngentsholongwane kaGawulayo uyifumana xa uthe

101 wadibana nomntu, wabelana naye ngesondo naye abe enayo. Ubanayo naxa

102 usonga lomntu then ube une cut onayo then uye uyifumane

103 Interviewer: Mmh okay (0.4) ukhona mhlawumbi umntu owakhe waxoxa naye

104 ngalentsholongwane okanye uGawulayo↓.

Extract 9.1

98 Interviewer: Mmh…could↑ you tell me in short about your knowledge of HIV or AIDS?

99 Participant: Mmh (0.2) the knowledge I have about HIV is that you get through unprotected

100 sex with an infected person. You get it when you are nursing an infected person and

101 you have a cut then you get also it.

102 Interviewer: mmmh…okay (0.4) is there any person you have spoken to about the virus or

AIDS↓?

Extract 9/9.1 is from an individual interview with a female participant between the ages of 26 and

34. The extract begins with the interviewer asking the participant about her knowledge of

intsholongwane kaGawulayo (HIV) or *uGawulayo* (AIDS) and this is the first time the virus or the

disease is mentioned in the interview. The participant gives a response in relation to HIV by

speaking of *intsholongwane ka Gawulayo*. In this instance, the interviewer introduces the *isiXhosa*

terms and the participant takes one of them up (*intsholongwane ka Gawulayo*). As the interview

progresses and throughout, the interviewer only uses the *isiXhosa* terms for both the disease and

the virus, and the participant adopts these. Extract 10/10.1 shares some similarities with extract 9

discussed above.

Extract 10

3 Interviewer: Bendicela ngokufutshane undichazele ngolwazi onalo malunga ne

4 ntsholongwane kaGawulayo (HIV).

5 Traditional Healer 2:   Intsholongwane kaGawulayo (HIV) izindidi ngeendidi kuba sisifo

6 (disease) nje esingasaziyo ukuba sivelaphi kwaye senziwa yintoni kuba ngelinye ixesha

7 umntu utyebile ufana nam…

Extract 10.1

3 Interviewer: Could you please tell me in short about your knowledge of HIV?

4 Traditional Healer 2: There are different types of HIV, because it is a disease that we just

5 don't know, where it comes, what causes it because sometimes a person is fat and looks just

6 like me…

This extract is from an interview with a female traditional healer. When the interviewer asks about the participant's knowledge of the virus, she uses *isiXhosa* terms to refer to the disease. The participant also responds using the same *isiXhosa* term (*intsholongwane ka Gawulayo*). Throughout this interview, both the participant and the interviewer use the terms HIV and *intsholongwane kaGawulayo* interchangeably, and they do the same for the terms AIDS and *isifo sikaGawulayo;* thus, there is exclusive use of English or isiXhosa terms.

In some interviews, the terms were neither introduced nor used by the interviewer at any point in the interview, but brought up by participants. Extracts 11 and 12 provide such examples. Extract 11 is from a section where the interviewer and the participant (a man from the 46-60 age group) were talking about condom use. In this interview, the participant uses the term AIDS to talk about HIV and AIDS, which is sometimes inaccurate (as discussed in the theme 'conflation and misuse of the terms HIV and AIDS'), but in this section he changes from using the term AIDS to using

the *Xhosa* term *uGawulayo*. As the conversation about condom uses continues, the term

uGawulayo appears once again as he states that he uses the condom to run away from *uGawulayo*

(see line 126). The participant referred to AIDS as *uGawulayo* several times. Thus, only the term

AIDS is used by the participant in the interview, and the *uGawulayo* label is used even when

references are about *intsholongwane kaGawulayo* (HIV).

Extract 11

114 Interviewer: Oh…uzama ukunqanda ntoni ngale condom?

115 Respondent: ISIFO↑ esi se AIDS, uGawulayo

                        […]

121 Interviewer: Ugqibele nini kengoku ukuyisebenzisa?

122 Respondent: Intoni?

123 Interviewer: Icondom…

124 Respondent: Kuleveli ingapha kwale iphelileyo

125 Interviewer: Kwakutheni uze uyisebenzise, kwakutheni?

126 Respondent: NDIBALEK'UGAWULAYO…

Extract 11.1

114 Interviewer: Oh… what are you trying to prevent with this condom?

115 Respondent: This AIDS… DISEASE↑, AIDS…

                        […]

121 Interviewer: When last did you use it…?

122 Respondent: What?

123 Interviewer: Condom.

124 Respondent: A week before last.

125 Interviewer: Why did you use it, what happened?

126 Respondent: I WAS RUNNING AWAY FROM AIDS…

The following extract is taken from an individual interview with a 24-year-old man. As in most of the extracts discussed so far, the participant used the term AIDS to talk about the disease. Extract 12 reveals one of the few times where the participant takes up the term *uGawulayo* (see line 590 from the *isiXhosa* extract) to describe the status of people with HIV.

Extract 12

589 Respondent: So baye bahambe iclinic (HIV positive people) kuye kufumaniseke into
590 yokuba kengoku, N:O ufunyenwe ngu Gawulayo
591 Interviewer: Mmh...

Extract 12.1

589 Respondent: So they (HIV positive people) go to the clinic and then they are discovered to
590 have AIDS
591 Interviewer: Mmh...

The terms discussed in the extracts above: *intsholongwane kaGawulayo* and *isifo sikaGawulayo*, are *isiXhosa* words for HIV and AIDS. Unlike other references to HIV and AIDS, these terms were not used as indirect means of referring to the disease (as will be seen in the following themes), but these are the official terms for HIV and AIDS as discussed above.

4.2.2 *Ubanjwa nguGesi*

Another metaphor that was used to refer to HIV is that of being held by electricity (*ubanjwa ngugesi*). *Ugesi* is an *isiZulu* word for electricity which is also used by *isiXhosa* speakers. When using this metaphor, the reference being made is to the fact that an electric shock harms or even kills one. Therefore, referring to HIV using this metaphor implies that HIV is seen as a virus that once it infects someone they have little chance of surviving. The term was only used in an individual

61

interview by one male participant between 35 and 45 years of age. Below is the original *isiXhosa* interview with its translation.

The section in this extract (extract 13/13.1) is in response to a question posed by the interviewer about disclosure of HIV status. The participant mentions that he would reveal his status to his siblings once he gets diagnosed with HIV. He uses the metaphor *ndibanjwe ngugesi* to refer to HIV. The text illustrating this term is underlined.

Extract 13

267 Participant: Mmh... xandicinga mna, kwaba ndihlala nabo bakamama nabakatata...mandenze
268 umzekelo ngam. Xakunothi kuhambeke ndithi xandisithi <u>ndibanjwe nguGesi</u>, ndingabachazela
269 abasekhaya uba <u>undibambile ugesi.</u>

Extract 13.1

267 Participant: Mmh... personally I think I would share it with my siblings... let me make an example
268 about me. If as the time goes by, I would discover that I have been <u>held by electricity,</u> I would tell
269 my siblings that <u>I have been held by electricity.</u>

4.2.3 'Lotto'

Just like the term *ubanjwa ngugesi*, 'lotto' is a metaphor used to describe HIV. The word lotto comes from a television game show where one pays a small amount to select numbers that might be chosen to win a much larger prize. The reference to 'winning the lotto' is an inversion of the outcome of the real game where one would win money. People generally use this HIV metaphor to imply that if one gambles and takes a chance with one's life (have unprotected sex with an HIV-infected person), one might be (un)lucky and get HIV. Based on this explanation, the label 'lotto' is

used to attribute being infected with HIV to a certain lifestyle, that of 'taking a risk and sleeping with an HIV-infected person'. In this study, the 'lotto' reference to HIV appeared only in the interview of one male participant who was between the ages of 26 and 34, as discussed below.

Extract 14

498　Interviewer: so people talk

499　Participant: because if you are a person who is suspected that hey so and so has gotten the
500　lotto they call it the lotto mos

501　Interviewer: uh they call it the lotto

502　Participant: mm they call it the lotto, it seems like they got the lotto. A person is going to
503　want to provoke that person like as we are all sitting together they are going to be busy
504　talking about this thing

The conversation in extract 14 continues from a dialogue about 'how people in the research site treat people with HIV'. When responding, the participant firstly refers to HIV as 'the lotto' and quickly tries to explain this by saying that it is others who call it the lotto. This suggests that the term lotto is a common social reference to HIV. The use of the phrase the lotto was not dominant in the data, but this may relate to the fact that the participant who used the term rarely stays in the research site, but visited during holidays.

The metaphors used by participants assisted in communicating about the disease while avoiding the use of direct terms, but in most cases the disease was talked about without the use of metaphors. For example, one way of talking about the disease was with the use of the word 'death'.

4.3 'Collecting death'

One of the ways in which HIV and AIDS was referred to by the participants in the study was by associating it with death. This was the most common way of referring to HIV and AIDS in the research site. From the analysis of the data it was clear that in *Ematyholweni*, HIV and AIDS are viewed as a synonym for death. Most of the participants expressed their knowledge of the disease through using terms such as 'death', 'destroyer of the world/nation' and 'killer'. This was the case for both men and women, and across all age groups, when specifically asked about the disease and when the disease was generally discussed. Importantly, in *Ematyholweni*, both HIV and AIDS were referred to as death. Below is a discussion of this theme with extracts as illustrations.

The link between death and HIV and AIDS was so significant that some participants not only referred to it as a 'disease that kills', but simply called it 'death'. This is illustrated in extract 15 from a focus group with men between the ages of 18 and 25. During a prior discussion about condoms, the participants speak of condoms as a means of protection from a 'killing' disease, AIDS. In the opening line of extract 15, Azania is commenting on the culture of condom use among men (meaning older male youth who have been through the initiation rite).

Extract 15

141   Azania: even with us people who are men there are some of us who do not want to use it,
142   and says hayi suka, I have never used this thing I will never throw my children into the
143   toilet's, kanti that's not children those, he is welcoming death by doing that you see

Azania states that men do not want to use a condom as they will have to remove it after sexual intercourse and throw it away, which will mean throwing their sperm, and potential children, into the toilet. The extract ends with Azania suggesting that by not using a condom due to fear of throwing one's sperm away, one is "welcoming death". Unfortunately the phrase "welcoming

death" is not further probed or clarified in the interview, but based on the group's previous

discussion about HIV, AIDS and condom use, the phrase likely refers to 'welcoming HIV/AIDS'. That

this participant conceptualises HIV and AIDS as death is also reflected in extract 16.

Extract 16

243   Azania: you know, there is nothing more hurtful then go to a person and you don't know
244   that she has it, and then you find out that she has it and now that you have been messing
245   around with her for a long while. It's better if you go to a person and you know that this one
246   has it even if I am messing around <u>I have come to collect this death for myself</u>, rather than a
247   person not tell you that this is death that you are coming to. She just opens and shuts you

Extract 16 illustrates a different part of the same focus group as the one presented above (extract

15). The extract sees the same participant, Azania, referring to HIV and AIDS as death. In this

extract, Azania speaks about the disadvantageof having unprotected sex ("messing around" in lines

244-246) with a partner when he is unaware of her status. In line 246, he argues that he prefers

being aware of the HIV status of the person he sleeps with so that even if he decides not to engage

in safe sex, he is aware that he has "come to collect death" for himself. This statement suggests that

HIV or AIDS is not viewed merely as a disease, but something inherently connected to mortality.

Many participants in the study seemed to see HIV and AIDS as a killer/death/destroyer.

HIV and AIDS were also portrayed as the killer or destroyer of a world or nation. In extract

17, the male participant from an individual interview, who is between the ages of 26 and 34, labels

HIV and AIDS as "*umbulalazwe*". This can be loosely translated as 'the killer of the nation'.

Extract 17

357   Interviewer: uh, maybe can you tell me a bit about what you know about HIV and AIDS

358   Participant: <with regards to HIV:>

359   Interviewer: about what you know about it, what is it, or, you know all of that

360   Participant: no I would say that my knowledge is with regards to this thing that it is
361   *umbulalazwe* (pandemic)

The initial translator and transcriber of the interview had described this as 'pandemic' (see words in brackets in line 361) which is correct except that the participant phrases the disease as something that kills, as well as a disease that is widespread around world. He does this by referring to the disease as *'umbulal'"* (killer)-*'zwe'* (nation).

This is not the only instance where HIV was labelled in this manner. For example, in extract 18, from a different individual interview with a female participant between the ages of 35 and 45, the participant does not only say the disease is prevalent but says as a 'killing' disease it has "destroyed" the world. In line 549 she refers to AIDS as a pandemic (which is the case) but she also adds that AIDS kills.

Extract 18

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

550   Interviewer: okay

Extracts 19-21 also illustrate HIV or AIDS being referred to as a killer. In all of these extracts, when participants are asked about their knowledge of AIDS or HIV, they clearly and confidently state that "it kills". However, there is also inconsistency in the data in the labelling of HIV and AIDS as a killer.

Some of the participants state that HIV kills while most state AIDS kills. Extract 19 is from an interview with a man between the ages of 18 and 25. Extract 20 is from an interview with a woman between the ages of 26 and 34, while extract 21 is from a focus group discussion with boys in the 14-17 age group.

Extract 19

14   Interviewer: ( ) So please briefly tell me about AIDS, the information that you have

15   Respondent: The knowledge that I have ( ) is that it kills

Extract 20

163   Participant: AIDS is a disease yes. And it kills.

Extract 21

1012   Interviewer: was anyone going to say something else?

1013   Nkosi: no I was going to say HIV is an incurable disease that kills that is not acceptable to
1014   people (.1)

Extract 22 is from an individual interview with a female participant who is between the ages of 26 and 34. Before the dialogue shown in this extract, the interviewer was probing about HIV specifically and the participant shared accurate knowledge of the virus. As the conversation about HIV continues and she is probed about what she discusses with others about the virus, she mentions how she and others refer to HIV as a killer.

Extract 22

466   Interviewer: 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   Participant: w:e usually talk about the fact that it kills and then a person needs to protect

469   themselves

Just like in extract 22, in extract 23 a male participant in the 46-60 year age group shared some accurate information about HIV and AIDS where he stated that once infected with HIV, a person gets exposed to other diseases (see line 232). The participant also emphasises that HIV kills and that he labels it so because it can be seen killing people (see line 231).

Extract 23

226   Interviewer: mmm. ((coughing))and so could you tell me a bit about HIV what you know

227   about it

228   Participant: like what about it?

229   Interviewer: what do you know about it?

230   Participant: uh, Uh HIV the first thing is that when you hear that you have HIV,its not just it

231   is HIV it kills. We used to think that it was just something. We can see it in people that it

232   kills. It kills you in the sense that a person has diseases and diseases. Others you find that

Extracts 22 and 23 illustrate that conversations about HIV and AIDS in this community usually construct the virus and the disease as being fatal and some justify this association with death with the fact that they have seen it killing people.

In extract 24 from a focus group discussion with young girls between the ages of 14 and 17, HIV is portrayed as a killer. Just as in extracts 21 and 22 above, when participants speak about what they know about HIV they all refer to it as a disease that kills.

Extract 24

797   Beyonce: like maybe we talk about like maybe as we are friends like maybe someone says hey me I
798   use a condom and maybe someone asks wat makes yo use a condom and then maybe she says that
799   no man HIV is not a disease for dogs it also infects people so that is why you must use a condom and
800   we say that HIV it kills mmos

801   Interviewer: okay okay

802   Lindi: we talk like hey my friend, when you are still a girl and you are dating you must use a condom
803   because there is this AIDS man and AIDS is this uncurable disease and when you get it there is no
804   medicine that you can use it to cure it but you can manage it

805   Interviewer: okay okay so you all speak about it

806   Lebo: no we have never spoken about it

807   Tamia: no we don't ever speak about it

808   Thembi: we don't know about it

809   Interviewer: so you don't speak about it

810   Thembi: we don't speak about it

811   Participant: (unclear)

812   Lebo: hayi we have never heard you speak about it

813   Participants: ((laughter))

814   Interviewer: ((laughing)) she s(h)ays th(h)at they have never heard you speak about it nj(h)e

815   Lebo: ((laughing)) we have ne(h)v(h)er re(h)all(h)y heard you speak about it

816   Tamia: no really we have never heard her speak about it

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

818   Lebo: because we know that it kills

819   Interviewer: because it kills

The whole discussion in extract 24 is about whether participants engage in conversations about the disease. The extract starts with Beyonce mentioning that when she is with her peers, they discuss how no human is immune from getting HIV once exposed to the disease (line 799: "HIV is not a disease for dogs; it also affects people"). At the end of her statement (see line 800), she comments that the importance of a condom is linked to the fact that HIV 'kills'.

The discussion about what participants share when they talk about HIV and AIDS continues, with most participants saying they do not talk about the disease. When probed further about their silence around the issue of HIV and AIDS, in line 817 they mention the fact that "it kills". In the same focus group discussion, when the interviewer asked about whether participants discuss the disease at home with their parents, different responses emerged. One of them was that parents usually talk about AIDS being a killer when advising their children about relationships (see extract 25). This suggests that social conversation about HIV or AIDS usually involves portraying the disease as death. This might explain why HIV or AIDS is labelled as death, killer, and destroyer.

Extract 25

829   Interviewer: okay so Thembi at home you do not speak about it, Tamia, Lebo? What do they say?

830   Lindi: no my mom speaks about it and say my child AIDS kills and you must not date too many men

There were some instances in the data where, in a different focus group discussion, male participants in the 26-34 age group provided another picture of HIV and AIDS. In extract 26 (line 1418), Bobo speaks of HIV/AIDS as a disease that can be managed (with ARV treatment and through counselling) and emphasises the 'living with HIV' component rather than the 'dying from the disease' that has been prevalent throughout the data. However, these more positive perspectives on HIV and AIDS were not common in the data.

Extract 26

1412   Interviewer: okay so what do you know about HIV

1413   SMINDLOZ: AIDS

1414   Interviewer: HIV, both rather

1415   SMINDLOZ: it's a virus man

1416   Asavela: that is spread through sex

1417   SMINDLOZ: it's incurable and it kills doesn't it.

1418   Bobo: but ja sure it kills but it doesn't mean that once you have it you can't live, like you got a death
1419   sentence you can die any minute. There is treatment ARVs are there is counselling

1420   SMINDLOZ: counselling

1421   Bobo: that thing needs counselling it needs support.

The death-related labels discussed in this section illustrate instances where participants were direct in naming the disease. The following section provides examples where references to HIV were mostly indirect.

4.4 'This thing'

In dealing with a difficult topic such as HIV and AIDs, there were occasions when the participants seemed to try to avoid directly naming the disease. Unlike the themes discussed above, where the disease was given alternative labels or referred to metaphorically, in many instances participants simply avoided naming HIV or AIDS and instead referred to the disease as 'it' or 'this thing'. In the translation and transcription process, this was the way the words *'i-nto'*, and *'le-nto'* were translated. The labels 'it' and 'this thing' were the most commonly occurring labels in the data when participants were talking about HIV and AIDS. There were even examples in the interviews where these labels were used throughout the discussions, with no use of the words HIV or AIDS at all.

Extract 27 below from an interview with man between the ages of 26 and 34, illustrates how one participant in *Ematyholweni* tries to avoid referring to HIV or AIDS.

Extract 27

256   Interviewee: Because she says that she is protecting other people as well. I saw that because
257   even when I was trying to bring myself close to her she told me that she has this thing. So I
258   thought that this is one of the reasons why you are living with this thing because you do not
259   hide it, and she said that she does not hide it because this is something that is in a person, a
260   virus

261   Interviewer: Mm, so how are people treated when they reveal that they have the disease?

262   Interviewee: You see my brother I like your question and I am going to answer it well. People
263   are silly out there you see

264   Interviewer: Mm

265   Interviewee: Especially when they know your status that you have this thing.

266   Interviewer: Mm

267   Interviewee: And even when the sister told me that she has this thing I did not just go around
268   telling people

269   Interviewer: Mm

In the first section of extract 27, the participant narrates an experience where he was attracted to a woman who had HIV. In the whole extract, he keeps referring to HIV as 'it' and 'this thing'. The interviewer does not ask for clarity on what is meant by 'this thing' or 'it', perhaps because he understands that this refers to the disease. There are instances in the interview where the participant mentions HIV, but even then he refers to it as 'this HIV thing', which suggests his discomfort at saying the word HIV.

In extract 28, the interviewer is having a conversation with an older man who is between the ages of 46 and 60, about whether he has spoken to anyone with HIV.

Extract 28

244   Interviewer: and you have never spoken to anyone about HIV?

245   Participant :< mostly> the ones that had it, in fact there isn't there is a child from the (says
246   name) who had and in fact she would have been very happy if she was here. She is a child
247   that does not even hide that, she's a girl but now she has gone to (unclear) but she was
248   always there. She was a person that always spoke about it that no this is something that I
249   have and she used to say that you see HIV if you ever heard that you have it don't ever be
250   scared of that

251   Interviewer: mmm

252   Participant: because a disease if it comes to you then it's come to you. BUT you are going to
253   be told at the clinic what you must do. That you must accept this thing

254   Interviewer: and besides the people that have this, the ones that do not have this do you
255   ever talk to them?

256   Participant: yes we do talk to them, the ones that do not have it because we see the ones
257   who have it and we reckon you this thing we were not taking it serious but this thing, it's not
258   something to be taken lightly

259   Interviewer: eh

In response to the interviewer's question, in lines 245-250 the man shares a story about a girl (he refers to her as a child in line 245 due to the fact that he is her elder, but he does not mean that she is literally a 'child') who used to share her HIV status with others. In line 248, the participant talks about the fact that the girl "always spoke about it". Just as in extract 27, the participant is talking about HIV but uses 'it' to avoid saying HIV. From lines 252-253, it is not clear if the participant is continuing to use the girl's words, but even here, he still refers to the disease as "this thing". In line 254, the interviewer also adopts the participant's avoidance of referring to the disease and does not mention the dynamic. The extract ends with the participant still referring to HIV and AIDS as "it" and "this thing".

In one interview from which extracts 29 and 30 are taken, the female participant who is between the ages of 26 and 34 generally avoids using the terms HIV or AIDS when speaking about the disease.

Extract 29

504   Participant: they don't=I mean they don't uh (.) talk about it, but have you seen when there

505   are these things of groups you do sometimes see some people there at the clinic

506   Interviewer: oh alright

507   Participant: and sometimes you see them being given that porridge there, that those people

508   that have this thing get given

In extract 29, when asked if people in *Ematyholweni* talk about HIV and AIDS, she states that in this area, conversations "about it" (HIV and AIDS) are almost non-existent (see line 504). She comments that she has only seen people with the disease at the clinic. In the last line of this extract (line 507) she talks about seeing people who have HIV or AIDS being given the porridge that "people who have this thing get given". She avoids mentioning the disease altogether and, despite the interviewer using the terms, the participant does not take them up at all throughout the interview

In extract 31, which is from an interview with a man between 46 and 60 years of age, HIV or AIDS is not mentioned at all, although both the participant and the interviewer are having a dialogue about the disease and the virus.

Extract 31

727   Interviewer: I see that. What do you think could be done about HIV/AIDS here in the

728   community because it is such a problem? What could be done, what could we do to help

729   solve the problem of HIV/AIDS?

730   Participant: if there could be age groups, age groups where they keep on talking about this

731   thing I think that people would really realize that it is something that kills this thing

Extract 32, from the same discussion, begins with the interviewer taking up the avoidance terms used by the participant. In the whole extract, although he has had close contact with HIV and AIDS (through a family member dying of AIDS), this participant (male between the ages of 35 and 45) still referred to the disease using indirect terms such as "this thing".

Extract 32

328   Interviewer: like I am thinking what is usually the reason for you guys to talk about this
329   thing?

330   Participant: like maybe when you have thought of a person who had this thing and you
331   reckon that ey, so and so had this thing

332   Interviewer: ok

333   Participant: like my sister in law, there is my wife's younger sister who also died of this thing

334   Interviewer: ok- ok

The indirect terms such as 'it' and 'this thing' emerged in focus group discussions as well. The assumption may have been that everyone in the group would understand what was being discussed. One example is a focus group comprised of men between the ages of 46 and 60. Johane (see extract 33) comments that he knows of an HIV-positive woman and this woman still looks healthy (he uses the term "fresh"). In reponding to the interviewer about dating this girl, Johane refers to the fact that she is beautiful (which makes her attractive). In the same line (line 957), Johane talks about how people should accept "that thing" in order to live longer. In talking about acceptance of HIV and AIDS, he does not mention the disease by its name; he simply uses 'it' and 'that thing'.

Extract 33

951   Johane: yes it is like that. I have stayed in Port Elizabeth, more than 31 years. There is this girl who
952   has this thing. But she is still fresh even now.

953   Interviewer: she is still fresh even now

954   Johane: yes

955   Interviewer: that is because you know her because otherwise if I did not know even I would go and
956   throw myself at her

957   Johane: yes because you are seeing a beautiful girl uh, they say you must accept that thing. If you
958   accept it then you will live for years

959   Interviewer: you will live for years without it being visible

960   Johane: the one who is killed the fastest by that thing is the one who has not accepted it

961   Interviewer: it quickly shows itself and then it takes him

962   Johane: yes because you are busy stressing, then it takes

963   Interviewer: has anyone here ever spoken to a person who has it? (.3)

The avoidance labels used to talk about HIV and AIDS reveal how participants in *Ematyholweni* are uncomfortable with using the words HIV and AIDS and prefer using indirect references such as 'it' and 'that thing'.

Just as in the avoidance theme, participants also opted for physical descriptions to refer to the disease. In this case they used the example of 'clean blood' to refer to one's HIV status.

4.5 'Clean blood'

In *Ematyholweni*, people used the words 'clean blood' or just 'clean' to talk about the HIV-free body. This occurred in the interviews with participants across all age groups and across both genders in the study. The following extracts illustrate this theme. In extract 34, a young woman who is between the ages of 26 and 34 talks about her HIV-testing experience

Extract 34

> 240   Participant: = I was scared yo; I was so scared I couldn't sleep. Then I got the results from
> 241   the doctors and they said my blood is clean.

Here the participant refers to 'clean blood' to refer to her HIV-negative status. This can be seen in line 241. However, it is not clear whether it is the doctor (or nurses) who said her "blood is clean", or whether she is referring to reading the results herself and concluding that her "blood is clean".

    In the following extract (extract 35) from a male participant who is also within the age range of 26-34, the word "clean" is used to label HIV. Being HIV negative is once again referred to as having clean blood.

Extract 35

> 86   Interviewer: Mm okay (.) so in your knowledge are there any other ways of practising safe
> 87   sex without using a condom?
>
> 88   Interviewee: Yes there but I do not know how safe it is. That would be to go get tested first if
> 89   ever we do not want to use a condom
>
> 90   Interviewer: Okay
>
> 91   Interviewee: We could go get tested to see if she clean and I am clean. Even with that we
> 92   cannot just test once we have to at least go again
>
> 93   Interviewer: So after you get tested for the second time and the results come out negative
>
> 94   Interviewee: And they come out saying we are clean

In line 93, the interviewer poses a question and specifically refers to the HIV results as being negative. In line 94, the participant uses the phrase "they come out saying we are clean" and, unlike in extract 34, here it is clear that the participant is himself referring to the results. This emphasises that this participant labels being HIV negative or being HIV positive in terms of the cleanliness of one's blood.

Extract 36 comes from a focus group of young boys who are between the ages of 14-17, discussing HIV and AIDS.

Extract 36

249	Nkosi: ehh with what he is saying, others they are lucky I mean other fathers yes they do
250	allow that maybe he was lucky and he got someone who is right someone who is clean
251	maybe his son is going to go to someone who is HIV positive and he will be afraid to come
252	out in the public and say he has HIV and then end up taking pills and maybe he doesn't even
253	follow those pill and what ends up happening? He ((clicks tongue)) dies because he is shy of
254	taking his treatment

This group of young boys are discussing aspects of dating and parental advice. In the discussion, the participants' fathers are portrayed as people who are usually more flexible than mothers about allowing their children to date. Nkosi, who is a participant, agrees with this statement (see line 249), but he goes on to imply that one should be wary of taking advice from one's father as he might have been lucky while dating and "got someone who is right", while the recipient of the advice might not be that lucky. The comparison between cleanliness and dirtiness is also made in this discussion where Nkosi labels someone who is HIV negative as being "clean" (line 250). The implication is that someone who is HIV positive is 'dirty'.

The theme 'clean blood' highlighted participants' use of physical descriptions to talks about HIV. Just like in this theme, the following theme looks at other terms that emerged as participants tried to construct the meaning of HIV and AIDS.

4.6 Attempts to describe the disease

Some responses to HIV and AIDS showed participants' attempts to describe the severity and enormity of the disease. These responses included describing HIV as 'big' or 'massive', 'dangerous' and as a 'misfortune'. Responses such as these were not as common as the terms discussed in the sectionKs above. However, these references were still noteworthy as they highlight participants' responses to HIV and AIDS. Each of the four labels will be discussed below.

4.6.1 Big or massive disease

When some participants were asked what they know about HIV, they referred to it as this "big disease". Extract 37 illustrates this.

Extract 37

170   Participant: HIV...I do not know, ok HIV is a big disease and (unclear) you see

171   Interviewer: YA

172   Participant: it is just a big disease you see, and you must watch the ways that it can infect you, you
173   see

174   Interviewer: YA

175   Participant: HIV my bra is something that we respect as people, me too, I respect it

176   Interviewer: YA

177   Participant: I know mos it is a disease that kills

In an individual interview with a man in the age group 18-25, the participant twice speaks of HIV as a "big disease" (lines 170 and 172). This reference to HIV in relation to magnitude and scope, as well as his reference to respecting the disease, suggest that he is in awe of it, and perhaps overwhelmed by it. His comment in line 172 that it needs to be watched reinforces this sense of being in awe of HIV, and respecting the power of the disease to end life.

4.6.2 HIV as 'dangerous'

In some of the references to HIV, participants commented on how dangerous the disease is. They labelled it a "dangerous" disease. Extracts 38 and 39 contain references to this danger. Extract 38 comes from an interview with a man who is between the ages of 26 and 34. Here, the participant highlights the need to be constantly alert to this danger

Extract 38

335   Participant: and so we will be discussing this thing that hey, this thing is dangerous

336   Interviewer: yes- yes, this thing is dangerous

337   Participant: mm

338   Interviewer: mm –mm- mm- mm

339   Participant: it's dangerous this thing

340   Interviewer: it needs to be carefully watched

341   Participant: you have to watch it

The participant in extract 38 is talking about conversations with his peers about HIV. Throughout the extract, he talks about HIV as a dangerous disease. Even though the participant avoids directly naming it as HIV and AIDS , the interviwer is aware that he referring to HIV.

In the extract below (extract 39), the woman interviewed (who is between the ages of 26 and 34) shows her knowledge of HIV by comparing it to a different disease. She refers to HIV as "dangerous" because it is not like diabetes, which is "bearable" (lines 240-241) and not transmittable. She argues that the disease of HIV can become "unbearable" (line 241) .

Extract 39

238   Interviewer: Ok. So I'm going to ask you general questions on HIV and about you. Please tell

239   me -in short your knowledge on HIV and AIDS?

240   Respondent: (.4) I would say it's a disease that is transmittable and is dangerous. It is not like

241   diabetes because it is bearable. With this disease there are stages where it can be unbearable

242   (.) So it is that type of disease.

4.6.3 HIV as 'misfortune'

The term 'misfortune' was found in an interview with a male participant who was between 35 and

45 years of age. In the first two lines of the extracts below (extracts 40/40.1), he expresses his

unhappiness about people gossiping about those who have had the "misfortune" of being

diagnosed with HIV. The exact utterance is "*elolishwa*" (line 284, *Xhosa* extract 40). By using the

word *elolishwa* (misfortune) he implies that it is not necessarily their fault (it is important to note

that he is specifically referring to a woman when he states that it is not necessarily their fault).

Although, like any other diseases HIV can cause problems, labelling it as *ilishwa* illustrates that he

perceives a person who gets HIV as a victim.

Extract 40

283 Participant: Mmh… into endiye ndingakholiseki kuyo, abantu bayathetha, i-worse apha

284 Ematyholweni. Apha into eyenzekayo uye umntu xa ethe <u>wafumana elolishwa,</u> kwafumaniseka uba

285 unale ntsholongwane…

Extract 40.1

283 Participant: Mmh…what I don't like here is that people talk… it's worse here at Ematyholweni. Here

284 what happens is that when a person <u>has had that misfortune</u> and they are discovered to have the

285 virus…

4.7 Summary of results

Although people in *Ematyholweni* refer to HIV and AIDS by its name, what is significant is the variety of names that were used when referring to HIV and AIDS. This study explored how people in *Ematyholweni* respond to HIV and AIDS by looking at the labels they use to refer to the disease. This chapter discussed six themes and these themes encompass the references used by participants to talk about HIV and AIDS during the interviews and focus groups.

The issue of the misuse of, and conflation of, the terms HIV and AIDS was discussed first. It was clear that the term AIDS was popular in the area when talking about the disease. It was also clear that although the term is used correctly in some cases, most of the time participants misused the term by using it to refer to aspects that relate to HIV instead. Preference for the term AIDS over HIV was evident in all age groups across the data. This formed the basis of examining how participants in this community respond to HIV.

The chapter followed with a discussion of metaphorical labels. These were *uGawulayo* (AIDS), *ubanjwa ngu gesi* (being held by electricity) and the lotto. The use of lotto and *ubanjwa ngu gesi* was evident in the interviews and focus groups with the youth of the community. These two metaphors were also indirect references to HIV. *UGawulayo* is an official *isiXhosa* word for AIDS and when translated, it means 'to chop something mercilessly'. Unlike other labels, the term was not used to avoid naming HIV and AIDS but it was used as an *isiXhosa* name for referring to the disease.

What the results also showed is the fact that, HIV and AIDS is a synonym for death. Participants labelled the disease as a killer. There was no difference in how HIV or AIDS were labelled in this regard; both the virus and the disease were simply labelled as killers. The reference to HIV and AIDS as a killer also came up every time participants were asked what they knew about the disease.

The chapter also discussed how the terms HIV and AIDS are avoided The words 'it' and 'this thing' were the main labels used by participants to avoid referring to HIV and AIDS, even though these indirect references were labels themselves. Some participants seemed to use the indirect references because they were uncomfortable with the terms HIV and AIDS.

HIV was also labelled according to cleanliness of the blood. Results showed that participants use the label 'clean blood' to talk about the HIV-negative status. Talking about HIV in this way was quite common amongst the participants.

The last section of the chapter reported how participants attempted to describe HIV and AIDS. Within this theme were sub-themes such as HIV being big or massive, HIV being dangerous, as well as HIV being a misfortune. These three subthemes highlighted how HIV andAIDS as a disease is viewed as overwhelming and something that should be feared. In addition, this emphasised how participants viewed the disease negatively. The next chapter discusses these findings.

Chapter 5: Discussion

5.1 Introduction

HIV and AIDS have been known to South Africa for over 30 years now, yet the disease is still subject to major stigma. HIV stigma is carried in many forms. This study explored this stigmatisation through the lens of language, by looking at the names and labels used to refer to the disease and how they contribute to possible stigmatisation. The literature and the results chapters in this thesis provided an overview of existing HIV and AIDS terminology around the world and in *Ematyholweni.* The two main questions that this chapter will attempt to answer are: "Are the labels analysed in the data stigmatising or *non-stigmatising?*" and "What do these names and labels communicate about how the people in the research site *respond* to HIV and AIDS?" The purpose of this chapter is thus to unpack the implications of the HIV-related terms used by people of *Ematyholweni* to refer to HIV and AIDS, using the blame and fear model of stigma. Additionally, the chapter aims to discuss the general response to HIV and AIDS by people of *Ematyholweni* based on their construction of the epidemic through the names and labels found in the area.

Unlike most research conducted on the labeling and naming of HIV, which shows a wide range of terms to construct HIV, this study did not find a wide range of names used to talk about HIV and AIDS. However, the analysis of the terms used in the site provides rich insight into how HIV is constructed in *Ematyholweni*. Also, unlike with most studies in this area of research, the terms gathered in this study were not responses to a direct question on how HIV and AIDS is named, but rather terms that emerged as participants spoke about the disease. This is an interesting approach to the phenomenon as it might be that these terms were thus more authentic, rather than deliberately called up by the participants.

The terms were organised into six themes: Misuse and conflation of the terms HIV and AIDS; metaphoric terms; death-related terms; avoidance; the 'clean blood' narrative; and, attempts to

describe the disease. There was generally no difference between genders in the research site with regard to the use of terms. There were, however, slight differences relating to age and the use of some of the terms. The metaphors of lotto and *ubanjwa nguGesi* were only present in the language of the youth (18-35 years), and *uGawulayo* was significantly absent in the vocabulary of participants between the ages of 14 and 17. Nevertheless, the use of specific terms remained broadly the same across all participants. This is highlighted in the discussion below.

The chapter begins by discussing the references to HIV and AIDS in *Ematyholweni* and stigma, where direct and indirect references to HIV and AIDS are discussed separately. The second part of the discussion adresses responses to HIV and AIDS in the area.

5.2 References to HIV and AIDS in *Ematyholweni* and stigma

References to HIV and AIDS in *Ematyholweni* range from direct (official) to indirect (unofficial) reference. The direct references used here are the official terms: 'HIV' and 'AIDS' or '*intsholongwane kaGawulayo' kunye 'noGawulayo'*. On the other hand participants mostly named the disease using other terms and descriptions or opted not to mention the disease at all.

5.2.1 Direct (official) reference to HIV and AIDS

5.2.1.1 Misuse and conflation of the terms 'HIV' and 'AIDS'

This use of direct references in the research site to the pandemic is problematic. The official and acceptable terms or acronyms ('HIV' and 'AIDS') used to talk about the disease were mostly misused, particularly the term AIDS. In this study, the term AIDS and *uGawulayo* were incorrectly used, where participants seemed to prefer these terms to talk about any aspect of the disease, even where the term HIV or *intsholongwane kaGawulayo* would apply. In addition to the misuse and conflation of the terms HIV and AIDS, the study found that the pandemic in *Ematyholweni* is

commonly referred to as AIDS or *uGawulayo* (where the local language is used) meaning that participants barely use the comprehensive name 'HIV and AIDS' to communicate about the disease but rather prefer the term AIDS. There were even instances in the study where participants indicated that they preferred referring to HIV and AIDS as just AIDS.

In this study, the conflation and misuse of the terms was mostly present amongst participants between the ages of 45 and 60, that is, the older participants in the study. Although the reasons for preference for the term AIDS are unknown, it might be that it relates to an incomplete and inaccurate understanding of HIV in this particular group. This is not surprising as HIV information tends to be directed at the younger population in South Africa via sex education in schools and various other youth programmes. This might then relate to the lack of in-depth knowledge demonstrated by older participants in this study. Knowledge of HIV and AIDS in areas similar to *Ematyholweni* has previously been reported to be lower compared to other six sites studied in the country (Kelly, Ntlabathi, Oyosi, van der Riet & Parker, 2002), and this seems to still be the case, especially for older residents. Also, there are no HIV/AIDS educational programs in place at *Ematyholweni* for either younger or older people, other than what is provided at the local clinic, thus leading to lack of access to relevant information about HIV and AIDS, and lack of renewal of what information is known.

The common use and strong preference for the term AIDS, even where the term HIV is appropriate, has powerful implications. Crystal and Jackson (1992) state that the how the term AIDS is used, even when HIV should be used, leads to disease stigmatisation. This is firstly due to the fact that each term carries a different weight. To unpack this statement, living with the HI virus can be maintained through medication, whilst AIDS signifies the final stage of the disease where death is almost inevitable. Thus by naming the pandemic as AIDS, one is communicating or depicting the disease in its final stage, that of being terminal and incurable (Crystal & Jackson, 1992). Herek (2002) warns us that conditions that are terminal and incurable are greatly stigmatised because of

how they disrupt human lives. Preferring the use of the label AIDS means that the disease is set up negatively. Once infected, the assumption is that death is next, as the term AIDS is associated with its disabling nature and, as Herek (2002) states, this may lead to HIV stigma.

The common use of the term AIDS in *Ematyholweni* might not be to deliberately stigmatise the disease, but rather might relate to confusion people have about the detailed aspects of the disease. However, the use of the term in an area where the disease is already overwhelmed with stigma is problematic. This is because communicating about a chronic disease through a label which suggests its terminal state rather than its chronic nature might lead to the manifestation of stigma and hopelessness amongst those who are already infected with HIV and those who are yet to check their status. Misuse and conflation of the terms HIV or AIDS has not been reported in studies focusing on HIV and AIDS terminology; in addition, it rarely features in literature on the language of HIV and AIDS. This study highlights this aspect of labelling HIV and AIDS and its implication in terms of HIV and AIDS discourse.

5.2.1.2 *UGawulayo*

Participants in the study used the terms HIV and AIDS interchangeably, that is *intsholongwane kaGawulayo* or *uGawulayo*, respectively. The use of the *isiXhosa* terms was particularly popular among participants between the ages of 46 and 70, but was also noticeable among those who were 26-34 years, whereas the youngest participants (14-17) who formed part of the study did not use the terms at all. The different use of the *isiXhosa* terms based on the age of the participants might be related to the fact that the older generation residing in rural areas prefer to use their own language, which is *isiXhosa*, rather than English, whereas the youth, through exposure to formal schooling, as well as social media and television, are more familiar with English.

As stated in the *Multilingual for HIV and AIDS terminology* (2002) document from the South African Department of Arts and Culture, HIV was translated into *IsiXhosa* as *intsholongwane*

kaGawulayo and AIDS as *uGawulayo*. This translation process indicates a phase for South Africa, that of making sense of the disease. According to Moscovici (1984), images and objects had to be used in order to reproduce the term (in this case *uGawulayo*) that communicates the nature of the disease and this was done in order to make sense of the disease. As much as the name *uGawulayo* assisted in making sense of the disease, it is unfortunate that it suggests 'the one who chops or kills', a phrase which communicates a 'personified and merciless destroyer'. It is these rather unfortunate phrases, which potentially generate a negative image of the disease, which have been adopted by *isiXhosa*-speaking people in this research site.

It is important to note that the construction of AIDS as a form of destruction through the use of the term *uGawulayo* is not actively done by the participants in the research site as they are merely using the term which is used in formal communication about HIV and AIDS in South Africa. This means that, although this term is official, it cannot be linked exclusively to the responses to HIV of people in *Ematyholweni* to HIV. However, using this term as part of daily discourse around HIV and AIDS is problematic as it emphasises the fact that the disease kills. The weight of the term *uGawulayo* and what is suggested are likely to generate dread and fear.

Fear as an important determinant of stigmatisation of diseases is explained in Joffe's (1999) fear model of stigma. Joffe (1999) states that fear of a disease allows people to intensify the risk of stigmatisation. In the case of this study, the use of a term which implies that AIDS destroys potentially creates more fear around HIV and AIDS. Joffe (1999) states that such fear leads people to distance themselves from the disease for fear of infection. Further, distancing opens the disease to being stigmatised (Joffe, 1999). Thus, Joffe (1999) maintains that that negative constructions of HIV and AIDS as lethal and destructive (for example, through the use of terms such as *uGawulayo)* perpetuates the fear of the disease and as a result, increases the stigmatisation of the disease. Based on Joffe's (1999) model of fear, it can be stated that the use of the term *uGawulayo* in *Ematyholweni*, although official, reinforces stigmatisation of the disease. For a place like

Ematyholweni where people already experience HIV stigma, using this term not only reinforces stigma but helps in maintaining it.

A great deal has been documented on metaphors, especially those constructed by people, but there is a paucity of research conducted on official terms for HIV and AIDS, which also tend to be metaphoric in their own right. Exploring the terms used for HIV and AIDS in *Ematyholweni* has exposed this phenomenon.

5.2.2 Indirect (unofficial) references to HIV and AIDS

There are many unofficial terms related to HIV and AIDS which are used by people as a means of making sense of the disease. Researchers generally concur that this act of making sense of HIV and AIDS is influenced by the need to try and live with the frightening, complicated and unpredictable nature of the pandemic (Treichler, 1999). The result of this has been the creation of a wide variety of indirect terms which conceptualise and reflect how people experience the disease. In this study, a number of indirect references to HIV and AIDS were identified. Most of these references have also been reported in other studies in different contexts from that of the research site.

5.2.2.1 Death-related labels

People of *Ematyholweni* know HIV as a synonym for death. This is true for both young and old people in this area. When asked what they knew about HIV and AIDS, many referred to it as a 'killer', 'death' or '*umbulalazwe*' (pandemic-world killer). One of the participants even commented that by having unprotected sex one is "collecting death". This signals how HIV and AIDS is known to be a fatal disease and perceived as a death sentence. Not only did participants refer to HIV and AIDS as a killing disease, but they also spoke of how the disease is labelled as a killer when spoken about in social gatherings, and in discussions with their parents about the risks of sex. Scholars state that

even years into the epidemic with better education, awareness and availability of ARV's, the killer metaphor is still used but not as often (Ajobola, 2009).

However, in *Ematyholweni* a term such as killer was the most frequently used label when referring to HIV and AIDS. This shows that language around HIV and AIDS in *Ematyholweni* is centred on the knowledge that the disease is lethal. Although it has been years since the negative images of HIV/AIDS disappeared from the media, which led to a vast negative vocabulary about the disease (Webb, 1997), people in *Ematyholweni* still report cases where they have seen community members and family slowly dying from the disease. Thus, personal encounters with HIV in this area have been negative ones, which has led to the negative construction of the disease (or the maintainance of a negative construction) via the labels identified in this study. According to Herek (1998), by labelling HIV as something that is lethal people are manifesting what is called instrumental AIDS stigma. Stigma and use of these labels is discussed below.

Literature on the medical characteristics of HIV and AIDS states that HIV is a virus that can be managed through treatment and AIDS is a disease where death is almost inevitable (Herek, 1986; Herek, 2002). In this study, participants referred as much to HIV as a 'killer' as they did to AIDS. This is related to the conflation of the two terms which is possibly linked to a lack of detailed knowledge about HIV and AIDS, as highlighted above. The construction of HIV as a deadly disease could be linked to how people have experienced the disease in this area. Most participants in the study had some knowledge of a person in the research site who had suffered or died due to HIV and AIDS. For instance, one participant said that the disease had been viewed like any ordinary disease but due to seeing people die from it, he had since referred to it as a 'killer'.

Mawadza (2004) states that this act of constructing the disease based on one's experience of it is quite common, especially in African communities. Although the use of the words 'death', 'destroyer' or 'killer disease' might be justified by how participants in the research site have experienced (and/or continue to experience or perceive) HIV and AIDS, the UNESCO guidelines on

language and content in HIV- and AIDS-related material (UNESCO, 2006) clearly state that referring to AIDS as deadly should be avoided at all times as this is sensational language that creates fear and increases stigma and discrimination. With regard to the stigmatisation associated with death-related terms, Herek (2002) and Niehaus (2007) point out that terms that describe HIV as fatal tend to reinforce stigma. Therefore, the use of such terms in *Ematyholweni* accentuates the fear that exists in the area about HIV and AIDS as generally expressed by participants in the study, and this further maintains HIV stigma in the research site.

5.2.2.2 'Big', 'massive' and 'dangerous'

Labels such as 'big', 'massive', 'dangerous' and 'misfortune' emerged in this study; however, they were not common. Participants used these labels perhaps in recognition that the disease ought to be respected. As an epidemic, HIV and AIDS is one of the 'biggest' diseases in human history and, labels such as 'big' and 'massive' are likely to be part of people's HIV and AIDS language. However, literature has shown that as much as these labels are used to describe the state of the disease, they are usually used to 'warn' people about the disease. For example, Dowling (2002) argues that by using such names (big disease), people have found ways to warn others to respect the disease. Through the use of terms such as big, the warning and the respect narratives position HIV as a virus that is powerful and likely to defeat one once one is infected with it. Thus, by saying that the disease should be respected due to its nature, participants in this area were perhaps communicating their fear and awe of HIV and AIDS.

The conceptualisations of HIV and AIDS, especially those related to the 'danger' of contracting HIV, are cited in many studies on the naming of HIV and AIDS. For example, in one study conducted in Botswana by Mathangwane (2011), people labelled HIV and AIDS as a 'disaster of immense magnitude'. In this study, Mathangwane (2011), found that use of labels such as 'danger' were meant to instil a fear of the disease like the use of 'big' or 'massive' mentioned above. In this

study, the 'danger' terms were seen to have contributed to stigma around the disease. Herek (2002) explains that regarding HIV as highly dangerous has contributed significantly to the stigma currently embedded in the disease. This is because labels which aim to instil fear are viewed as labels people use to cope with and distance themselves from the disease or anyone who has it (Joffe, 1999).

This study showed that fear of the disease has led people to perceive HIV and AIDS as a powerful disease that should be respected. The implication of this is that through the act of respect one will distance oneself from the disease. This fear and distancing communicates the extent to which the disease is stigmatised. The construction of names related to HIV and AIDS that aim at warning and instilling fear reveal the stigma of the disease.

The label 'misfortune' used in one interview in this study has not been reported in other studies, even though metaphors which imply the misfortune of contracting HIV are documented in other African countries. The term 'misfortune' is a negative term because it implies that by being HIV positive one has been a victim of bad luck; HIV in this case is viewed as bad luck. According to the HIV stigma definition by Deacon (2004), any negative belief about HIV can be defined as HIV stigma. Thus, this study revealed that by labelling HIV as misfortune, HIV is stigmatised in *Ematyholweni*. Mawadza (2004) argues that such a pejorative view of the disease (misfortune, in this instance) indicates stigma around the disease.

5.2.2.3 Avoidance ('this thing'; 'it')

When HIV and AIDS were spoken of by the participants, indirect terms such as 'this thing' or 'it' were used, thus avoiding naming the disease, with the assumption that the interviewer knew what was meant. Even though the interviewers constantly referred to the disease by its name, most participants (young and old) referred to it as 'it/that/this thing'. In some interviews, participants talked about the disease without mentioning its name at all and simply used 'it/that/this thing'. South African studies have reported the same findings, where participants used similar labels as a means of avoiding referring to the epidemic by its name, HIV and AIDS. For example, a qualitative

study that was conducted by Campbell et al. (2007) in a rural community in KwaZulu-Natal revealed that most people used references such as 'that illness…you know' to refer to HIV and AIDS. In another study by Squire (2007) in a township in Cape Town, people referred to HIV as 'this thing'.

Although all participants used these terms, such avoidance terms were most commonly used by participants in the research site between the ages of 45 and 60. This suggests that older participants were the most uncomfortable with using direct terms. Being uncomfortable in this case could be explained by the fact that HIV is linked to sexual activity, an act that is seen as taboo by the society (Crandall, Glor & Britt, 1997; Herek & Capitanio, 1999; Herek & Glunt, 1988) and unlikely to be directly spoken about, especially by older people. Duffy (2005) confirms this and states that the use of such terms as done by older participants in *Ematyholweni* might not be a way of denying the disease, but a way of avoiding talking about culturally sensitive issues (a sexually transmitted disease, HIV, in this case).

Also, the culture of *ukuhlonipha* which is mostly practiced by older people in rural areas might relate to the use of avoidance terms by older participants; according to this practice, feared and sacred things are unmentioned or given indirect terms (Wood & Lambert, 2008) as means of maintaining respect for them. Because HIV and AIDS is personalised as a 'big' killer in the area, indirect terms are likely to be used for those who are in awe of the disease. The use of these terms in *Ematyholweni* seemed also to relate to denial and distancing.

Bryceson et al. (2004) state that avoiding mentioning the name of the disease communicates denial and distancing of oneself from the disease. On the issue of denialism, participants acknowledged the existence of HIV and AIDS, but demonstrated denialism and distancing language practices when the topic was about them. A simple illustration is a participant who referred to the disease by its name throughout the interview, but avoided mentioning the disease by name when the questions shifted from being general to personally focusing on him. Such responses to HIV and AIDS indicate that the disease is for others and not of the self (Petros et al., 2006). Bryceson et al.

(2004) point out that the acts of denialism and distancing tend to be prevalent when the disease carries stigma, which seems to be the case in the research site.

5.2.2.4 Metaphors ('lotto'; *'ubanjwa nguGesi'*)

Mashiri et al. (2002, p. 22) state that in the context of HIV and AIDS, metaphors are "indirect linguistic forms of expression that are imbued with meaningful and agonising messages about the source, the physical symptoms and the tragic impact of HIV and AIDS on the individual, the family, community and the nation". The literature reviewed in this study, showed that in the African context metaphors are commonly used to talk about HIV and AIDS. This is, however, not the case in South Africa and has also not been the case in the area of *Ematyholweni*. In this research site, only a few metaphoric terms were found: *uGawulayo* (which has already been discussed), 'lotto' and 'being held by electricity' (*ubanjwa ngugesi*). The latter two terms were the least-used terms and were only used by the youth (18-35 years old) in the research site. The finding on the terms used and the age group relates to the fact that 'lotto' and '*ubanjwa ngugesi'* are slang and, linguistically, slang is likely to be more popular amongst younger people rather than older people, as they tend to be more willing to experiment with language.

The term 'lotto' has been reported in many South African HIV terminology documents. For example, IRIN (2008) compiled a list of slang terms used to talk about HIV and the term 'lotto' was listed. This shows that, like other terms found in this study, the term is widely used in other contexts. Although the term 'lotto' is popular, in this study it was the least-used term, used by only one participant. This deviance was accounted for by the fact that the participant spends much of his time in towns outside this rural area and only comes to *Ematyholweni* during the December holidays. Therefore it cannot be concluded that the term 'lotto' generally forms part of the discourse about HIV and AIDS in this research site. Even though the use of the term was 'lotto' was reported the least in this study, its meaning makes it crucial for discussion.

As a term, 'lotto' is loaded with othering, an action which Joffe (1999) and Deacon (2005) comment on in relation to HIV stigma. The term 'lotto' implies that HIV infection is something that one should be 'in control' of or else one is 'gambling' with one's life. Joffe (1999) and Deacon (2005) make us understand that the use of the term 'lotto' positions the disease as preventable or controllable and the individual's 'immoral' behaviour is seen as a cause of the disease. Deacon (2005) calls this process the culturally-mediated assessment of the epidemiological nature of the disease. This defines it as a process of 'othering', where links between the disease to certain individuals, behaviours or origins are made. Joffe (1999) and Deacon (2002) concur that the act of blaming and othering reflects stigmatising. This is because according to this blaming model of stigma, by using social representations (such as having many partners, and thus 'gambling' with one's life) people get to distance themselves by associating the behaviours of the 'gamblers' with getting infected, and blaming these individuals or groups for their own infection. Using the term 'lotto' thus potentially contributes to the stigma that currently burdens HIV and AIDS.

Participants in this study used the *isiZulu* phrase '*ubanjwa ngugesi*' which implies that being infected with HIV means instant death, such as when one is shocked by electricity. The *isiXhosa* phrase *'unyathele icable'* which has the same meaning as the *isiZulu* one has been noted by the Humanitarian News and Analysis Newspaper (IRIN, 2008) as slang used in the country to talk about HIV and AIDS. The social meaning attached to HIV (that of being shocked by electricity) is a process which Herek (1998) believes to be a manifestation of symbolic AIDS stigma. Symbolic AIDS stigma is defined as the use of metaphors to make meaning about HIV and AIDS (Herek, 2002). Although such symbolic metaphors are used as a means to make meaning of HIV and AIDS, their use in this research site indicates that in *Ematyholweni* those who are infected by HIV are not seen as living with HIV but rather as dying from AIDS. Any HIV language which focuses on people dying from AIDS rather than on people living with HIV manifests negative thoughts especially for those who are

affected and infected with the disease (Crystal & Jackson, 1992). Stigma is also created therby, as diseases which are seen as deadly suffer from stigmatisation (Herek, 2002).

5.2.2.5 'Clean blood'

The phrase 'clean blood' was used to refer to an HIV-free body. The term was used across all age groups to identity the HIV-negative status of the person. Instead of using the phrase 'HIV negative', participants referred to this status as having 'clean blood', implying that an HIV-positive status means that one has 'dirty blood'. This supports the findings of Grov et al.'s (2013) study where participants used the term 'clean', implying that those who were HIV positive were dirty. The use of this term in *Ematyholweni* also confirmed that people often opt for this term as a way of stating one's status, as reported by Morrison and Baker (2014). This also shows that this use of language and the construction of HIV in this manner is not something unique in *Ematyholweni* but is part of daily HIV discourse worldwide. Participants reported the phrase 'clean blood' as used by health workers, whilst in many cases, the label was found to be used by participants as they spoke to the interviewer.

Although the label 'clean' is used innocently, the implications of its use are negative especially when used in the presence of those with HIV. In the context of HIV, society's use of the phrase 'clean/dirty blood' to refer to one's HIV status labels people as 'good' or 'bad', both in terms of health and behaviour. Thus, the language of "I am clean" as reported in *Ematyholweni* and other countries serves as a vehicle to divide. Grov et al. (2013) argue that language such as 'clean' and 'dirty' creates a 'them and us' situation. In *Ematyholweni*, very few people openly discuss their HIV-positive status. The construction of HIV using the 'clean/dirty' narrative might be a contributing factor to this, as people do not want to be labelled as having 'acted badly and gotten 'dirty' in the process when they disclose their status. The use of terms such as 'clean' show just how much particular constructions of HIV and AIDS contribute to the negative perception of the disease.

According to Deacon (2005), the exact negative constructions of HIV (for instance, that an HIV-positive status means being 'dirty') indicate the stigmatisation of the disease and such use of language may cause someone who is HIV positive to become stigmatised in the society (Ajobola, 2009).

5.4 Responses to HIV and AIDS in *Ematyholweni*

Of all the references to HIV and AIDS which were found in this study, none communicated a positive image of the disease and no terms seemed to be neutral. This trend has been seen in other studies, where HIV terminology, particularly indirect terminology, is gloomy (Jones, 1997). Using the blame and fear model of stigma, the HIV names and labels identified in this study were found to be stigmatising. However, besides the stigmatisation of HIV found in these terms, it is important to note that the construction or usage of the terms revealed already existing HIV stigma in *Ematyholweni.* Thus, the terms used show that HIV and AIDS is so stigmatised that people in the area are using labels that carry stigma to speak about the disease.

Brandt (1988) argues that how diseases are constructed has a powerful effect on the choices people make in responding to these diseases. The way participants have constructed HIV and AIDS in this study seems to be linked to how they have responded to the disease. The fact that in the research site HIV and AIDS is viewed as a disease that others should be 'respectful' of due to the fact that 'it kills', it is 'dangerous' and means one is 'dirty' etc., has seen many people in the research site afraid to openly discuss the disease. There were instances where participants stated that they do not speak about HIV and some said this was because they feared being 'insulted' or be seen as 'insulting' others. This not only reveals a lack of open discussion about the disease in the area, but it also shows how the disease is stigmatised.

The inability of people in the research site to speak about HIV openly was also evident in the way they avoided even saying the terms 'HIV' or 'AIDS' or *'uGawulayo'* but rather used 'it/that thing' to talk about HIV and AIDS. Breaking the silence and speaking openly about HIV has been a theme of many HIV-reduction campaigns. Young et al. (2011) state that this is because when people can engage in open and direct discussion about HIV, stigma gets reduced. According to the above statement, the silence around HIV in the area of *Ematyholweni* is likely to cause the opposite, that is, to elevate and maintain stigma.

The use of stigmatising terms like 'clean' (which then implies that someone is 'dirty' if they are HIV positive) has implications for those living with HIV in the research site. During data collection, it was found that few people have disclosed their status publicly in *Ematyholweni*. This is not suprising as the use of othering and shaming HIV labels like 'dirty' leads to silence, especially for people who still need acceptance. In one interview, a parent stated that "as long as her child is 'clean', then she is happy with that". Such expressions imply that that being 'dirty', and having an HIV positive status, would bring unhappiness to the family. Such attitudes from significant others potentially discourage people from testing for HIV for fear of finding out that they are also 'dirty' and therefore might be not be accepted. Non-disclosure might also be the choice for those who fear that disclosure might mean being labelled negatively or even excluded from familial love and acceptance. Mupenda et al. (2014) revealed that being labeled sometimes made youth suffer in silence, afraid to disclose their status, or avoid performing actions in public, preferring to let others do them. Skinner and Mfecane (2012) also maintain that association of HIV with things like being 'dirty' can be a basis for people being excluded from their community, which then means that HIV is denied. Moreover, when HIV remains hidden, its perceived threat is reduced (Skinner & Mfecane, 2001). This then hinders the likelihood of people in *Ematyholweni* facing and managing HIV and AIDS.

Skinner and Mfecane (2012) state that when people are seen as dirty, they are likely to be silent due to feelings of shame and to protect themselves from being stigmatised. Research has shown the benefits of disclosing one's status in the context of HIV. Norman et al. (2007), Ko et al. (2007) and Bennetts et al. (1999) argue that HIV status disclosure allows people living with HIV to receive support from family and the community, whilst it also benefits them psychologically and emotionally, and provides them with freedom to access and use their treatment. Farquhar et al. (2001) adds that disclosure of HIV status is a vital part of behaviour modification such as timely access to care and treatment services. Furthermore, chances of HIV transmission between partners is reduced (Farquhar et al., 2001). The discussion above suggests that the construction of HIV in terms of 'clean vs dirty' will have contributed negatively to the way people of *Ematyholweni* have responded to HIV and AIDS.

Other constructions of HIV and AIDS which communicate fear (like 'killer', 'dangerous', etc.) also have negative consequences for the management of HIV. These negative consequences include a lack of motivation to be tested, since the person sees no benefit when the diagnosis of HIV is seen as equivalent to death, and they are likely to experience discrimination (Abdool-Karim et al., 1992). From this, it can be concluded that denial, silence and fear as responses to HIV, are harmful in terms of ensuring an HIV-free generation in the research site. This is because stigmatisation resulting in silence, secrecy, denial and fear not only affects care and treatment but has serious implications for prevention which are critical in a disease with such a long subclinical phase (Skinner & Mfecane, 2012).

'Lotto' was another term found in this study which, according to the blame and fear model of stigma, puts the blame on those infected with HIV and AIDS and also has an impact on how those who are HIV positive feel. This is because labels that communicate blame as part of the HIV and AIDS discourse imply that the disease is the bearer's responsibility (Herek, 2002). The end result of this is what is known as internalised stigma (Brouard & Wills, 2006). Negative effects of internalised

stigma inhibit people with HIV from participating in most community and social activities, and sometimes from getting treatment. From this definition of internalised stigma, it can be seen that the use in *Ematyholweni* of blaming HIV-related labels might hinder those who are affected with HIV from living well with HIV, and accepting their HIV status and taking their treatment. Acceptance and behavioural modification such as eating more healthily, exercising and safe sex, amongst others, are advocated in order to live longer with HIV (Farquhar et al., 2001). However, if people are made to feel that they are to blame for their HIV-positive status via the discourse that is dominant in the community, this might lead to internalised stigma and failure to act in ways that support their health.

5.4 Summation

There is little difference between the names and labels used in *Ematyholweni* to refer to HIV and AIDS and those found in other contexts in South Africa and in other African countries. This means that this study did not discover new terms in relation to how the disease is labelled in *Ematyholweni*. However, the labels used highlighted how the disease is known and perceived in the area. The analysis also illustrates how language can contribute to, and maintain, HIV- and AIDS-related stigma (Mathangwana, 2011). Analysis of these terms and how they are used revealed that HIV and AIDS in the research site carries a great deal of stigma. Most terms reflected HIV stigma already in the area whilst analysis of other terms showed an undertone of stigma; this means that through continued use of the terms, HIV stigma is likely to be perpetuated as these terms carry negatives meaning relating to HIV and AIDS. In conclusion, the construction of HIV in *Ematyholweni* is linked to how people have responded to the disease. Responses such as silence, denial and fear were found in people's perceptions of HIV and AIDS. Such responses have adverse implication in

terms of managing HIV and AIDS through testing for HIV, gaining access to treatment and adhering

to treatment regimes.

Chapter 6: Conclusion

Through its health policies, South Africa has managed to increase the number of people on ARV's which has led to a decrease in AIDS mortality and an increase in life expectancy (Johnson et al., 2013). However, perceptions such as 'HIV and AIDS is death' are still very prevalent in *Ematyholweni*. This suggests that, even with great strides taken by the country in managing the disease, many people in communities such as *Ematyholweni* still view the epidemic in the same negative light as it was viewed three decades ago.

The first question that this study aimed to answer relates to the names or labels used in *Ematyholweni* to refer to HIV and AIDS. The labels which were identified in this study were: 'lotto', '*ubanjwa ngugesi*', 'clean blood', 'killer/*umbulalazwe*/kills', '*uGawulayo*', 'misfortune', 'big/dangerous/massive disease' and avoidance labels such as 'it/this/that thing'. The second question that this study asked is whether the terms listed above were stigmatising or non-stigmatising. To answer this question the blame and fear model of stigma was applied. Using this model, the labels and names used to refer to HIV in this site were found to generate fear, blame and even denial, and are thefore stigmatising. This finding seems to concur with Mwambo's (2003) statement that in the HIV and AIDS context words can be stigmatising.

The blame and fear model of stigma assisted in potentially understanding the HIV stigma that is manifesting in *Ematyholweni.* Understanding stigma as a problem of fear and blame instead of ignorance can help in positively addressing HIV stigma. For example, most people in the research site are still in awe of and overwhelmed by HIV. If this fear is addressed, names or labels that communicate this fear might be eradicated. Also, the othering terms such as 'lotto' could be used less if people understand that HIV is a societal problem rather than only an individual problem.

The overall conclusion that can be drawn from this study is that stigma is present in the research site. This stigma needs to be addressed, as it has been found to be the ultimate burden

when it comes to fighting HIV and AIDS in the country (Shisana et al., 2014; WHO, 2000). In support

of Shisana et al. (2014) and (WHO, 2000), this study also showed that the stigmatisation of HIV in

the research site led to negative responses to the disease as discussed below.

Stigma has not only led to the use of stigmatising words but it has also led to a negative

response to the disease. This potentially holds people back from dealing effectively with HIV. In a

stigma-free society, people would be more willing to go for testing (Farquhar et al. 2001) as

opposed to when stigma is present, as confirmed in Fortenberry et al.'s (2002) findings, where the

presence of HIV stigma led to people not getting tested for HIV. Also, less stigma would mean that

people would gain early access to treatment, thus living longer with HIV (Farquhar et al. 2001).

This means that, with a high number of HIV-positive people enrolled in ARV treatment

programmes, people in *Ematyholweni* would experience HIV and AIDS differently; that is, they

would encounter fewer HIV death as a result of people living longer. Consequently, the epidemic

would be constructed more positively or neutrally, and labels such as 'killer', '*uGawulayo*',

'destroyer', 'danger' etc., might be less common. Thus, there is an urgent need for reducing stigma

in *Ematyholweni* so that people can be more willing to test, enroll on treatment, etc.

Stigma can potentially be addressed if studies like these are conducted, where the basis of

stigma is understood by studying people's use of language. This is because language forms a major

part in social constructiions of disease (Clark, 2006). Approaching stigma from the language

viewpoint also has a potential of revealing areas of focus for policy makers concerning HIV stigma

intervention and education.

Below is a discussion of the strengths and limitationof this study, as well as an outline of

recommendations based on the findings of this study.

6.1 Strengths and limitations of the study

There were a few challenges in conducting this study. These relate more to the methodology applied in the study. However, before I discuss these, I will first mention the strength of having a large sample (95 transcripts) which allowed me to have access to a variety of names and labels used in the site to talk about HIV and AIDS. It also allowed me to collect data until saturation point was reached. This helped in ensuring the credibility of the study, as I could draw my data from a large pool of participants.

The data collection methods used in the main study, interviews and focus groups meant that I had access to in-depth detailed data. Using two different data collection methods to document people's conversation helped strenghthen the credibility of the study.

The first limitation of this study was that I was not part of the research team which conducted the study; thus, I relied on transcripts and audio files for the data of this study. However, I had meetings with the research team where the study's methodology was explained to me in detail.

The study was conducted in *IsiXhosa*, but I only had access to the transcribed data in English. Due to transcription discrepancies, it is possible that some HIV labels and terms were not included in the final transcripts. This means that I had no control over whether I gathered all of the labels and names used to refer to HIV and AIDS in the study area. However, the data I used was translated by fluent *IsiXhosa*-speaking researchers with back-translations done as well; thus, I used data that was of quality and verified. I addition to this, I had meetings with the research team to discuss and read the data together. I also had access to all audio files and I speak *isiXhosa*; therefore, I listened to some of the original audio files. My prolonged engagement with the data and checks for verification purposes, both with the team and alone, helped to strengthen the credibility of this study.

Another limitation of this study is that the aim of the main study was not to explore names and labels used in *Ematyholweni*; this means that the current study included names that emerged at random times during data collection. However, the strength of this is that the HIV references which emerged occurred naturally in the discussion related to relationships, risks and sexual activity and this helped to reveal the actual HIV discourse present in the study setting.

Lastly, the findings of this study cannot be generalised as this is a qualitative study with just a sample size of 41. However, this study gave a full and detailed description of the methodology employed and thus the findings of this study can be transferrable to people with similar demographics, and in contexts which are similar to *Ematyholweni*.

6.2 Recommendations

A study to explore names and labels used in *Ematyholweni*, with a direct question about which terms are used, is needed in order to gather more terms used in reference to HIV and AIDS. This will provide an opportunity to properly address the HIV stigma embedded in references to the disease. In addition to this, there is a great need for stigma to be addressed at a community level in *Ematyholweni.* From a social science perspective, in order for this to occur, qualitative researchers could use the findings of this study to engage in participatory interventions to change and develop the people's understanding of stigma and stigmatising terms. Thus, interventions aimed at tackling HIV and AIDS, should have stigma as a primary focus in the research site.

Greater attention needs to be paid to how the terms HIV and AIDS are used and what they are understood to mean. This could happen in HIV counseling sessions in the local clinic, and or in educational interventions in schools, or other interventions by the Department of Health. For the people of Ematyholweni, such actions could address and correct (amongst other things) the misuse

of the terms HIV and AIDS in this area. This is the first step that will help the people of *Ematyholweni* to view the disease like any chronic disease and not as a fatal disease.

This study showed that there is a need to review the HIV terminology guide as terms such *uGawulayo* carry negative metaphoric meanings. Such term should be replaced with more accurate but neutral *isiXhosa* terms. Although the use of *isiXhosa* is easy in the area as it is a rural area dominated by *isiXhosa* speakers, it might help for the people in *Ematyholweni* to use more acceptable names outlined in the United Nations HIV-related language policy guide. In this guide the terms or acronyms HIV or AIDS are advocated as the terms to be used when referring to the virus or the disease respectively (The United Nations Development Programme, 2006), as the English terms comprehend HIV without carrying the fatal aspect (Staiano, 1992), found in other names such as *uGawulayo*.

Finally, although the results in this study correspond to those conducted in a few other provinces in the country, more studies need to be conducted in different South African communities (urban, semi-urban and rural) on HIV-related terms and the way they potentially construct stigmatisation. In this way, stigma can be addressed using language-related interventions that are embedded in those communities, as language use differs across all communities in the country.

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Appendix 1A: Letter to the chief

8 December 2011

Dear Nkosi XXXXXXXXX

I have worked in *Ematyholweni* with various research projects since 1990. In 2000-2003 we conducted research about HIV/AIDS, youth, relationships and sexual health. I would like to consult with you, and seek your permission to continue the research in *Ematyholweni*, over the next few years.

The focus of the research would be on seeing how responses to HIV and AIDS have changed in *Ematyholweni*. It would look at what people know about HIV and AIDS, what they think about it and how they are responding to it. The team of people working on the project are from the University of KwaZulu-Natal, in Pietermaritzburg, and also staff and students from Fort Hare University.

The research would involve interviews and focus groups with young people, parents, church groups, traditional leaders, traditional educators, traditional healers, and the clinic staff. It would also involve workshops at which information collected in interviews and focus groups will be presented and discussed. The process of the research project is meant to include the residents of *Ematyholweni* in understanding and analyzing this information. It might happen that because we are all discussing the research process and the information together, changes will come out of the workshop process.

We would like to work in a few villages in *Ematyholweni*. Unfortunately because of time constraints it will not be possible to work in all of the villages. The project data collection would start in 2012, and might continue until the end of 2013.

The interviews and focus groups will be recorded so that the researchers can accurately capture what it is that people have said, and translate it into English. The workshop process will be filmed using a video camera, also to accurately record what people discuss. This information will then be transcribed (or written down) from the video recording. The names of all of the people who participate in the interviews and focus groups will be kept confidential and known only by the research team. Each participant will be given a code number so that their views will remain private. The information collected in the research process will also be used to write research articles, and to present at conferences so that other people may learn from the experience of our research. Some of the students and lecturers conducting the research will be using the research project to study for their degrees.

I will be happy to answer any questions that you have about the project.

Yours sincerely

Dr Mary van der Riet

Senior Lecturer

School of Psychology

Appendix 1B: Letter to the chief *IsiXhosa* version

8 December 2011
Nkosi XXXXXXXX othandekayo
Ndike ndasebenza e-Ematyholweni ndisenza iinkqubo zophando ezininzi ukusukela ngo 1990. Ngo 2000-2003 senza uphando ngentsholongwane nesifo sikagawulayo, ulutsha, ezobudlelwane kunye nempilo ekwabelaneni ngesondo. Ndingathanda ukuba sidibane, ukuzo cela imvume yakho yokuba siqhubeke noluphando e-Ematyholweni kuleminyaka embalwa elandelayo.

Ingqwalasela yoluphando kukubona ukuba iimpendulo malungelana nesifo sikagawulayo sezatshintsha na e-Ematyholweni. Oluphando lizakujonga ulwazi labantu ngentsholongwane nesifo sikagaqulayo, iingcinga zabantu ngesisifo kunye nokuba bapendula/bayibona kanjani lemeko. Iqela labantu abasebenza koluphando basuka e Yunivesithi yaKwaZulu-Natal, eMgungundlovu (Pietermaritzburg), kunye nabasebenzi, nabafundi abasukae Yunivesithi yaseFort Hare.

Oluphando luquka, udliwano-ndlebe kunye nengxoxiswano nolutsha, abazali, amabandla, inkokheli zesintu, iingcibi, abanyangi/izangoma kunye nabasebenzi base kliniki. Oluphando luzoquka/bandakanya iimfundiso/imihlangano apho ulwazi oluqokelelwe kudliwano-ndlebe nakwiingxoxiswano, lizokwandlalwa khona. Lenkqubo yoluphando yenzelwe ukuba abahlali base Ematyholweni babe nesabelo ekuqondeni nasekucalucaleni olulwazi. Kungezeka ukuba ngenxa yokuba sixoxisana sisonke kulenqubo yophando kunye nakwi ncukacha, utshintsho lungavela emhlanganweni. Singathanda ukuqhuba oluphando kwiilali ezimbalwa zaseEmatyholweni. Kodwa ngenxa yokuba ixesha esinalo lufutshane, asizukwazi ukuba sisebenze kuzo zonke iilali. Uqokelelo-lwazi loluphando luzokuqala ngonyaka ka 2012 futhi lungaqhubeka kude kuyophela unyaka ka 2013.

Iindliwano-ndlebe kunye nengxoxiswano zizoshicilelwa ukwenzela ukuba abaphandi babambe ngononophelo oko abantu abakuthethileyo, bakutolikele kwisingesi. Inkqubo yemfundiso/yomhlangano izoshicilelwa kusetyenziswa i-video camera, kushicilelwe nyanisekileyo oko abantu abakuxoxileyo. Olulwazi luzokubhalwa phantsi lusuka/lusukela kushicilelo lwe-video.

Onke amagama abantu abazobe behlomla/bethatha ingxaxheba kudliwano-dlebe nakwi ngxoxiswano azogcinwa efihlakele azokwaziwa liqela lophando kuphela. Wonke umntu ezoba ehlomla uzonikwa inombolo ukuze izimvo zabo zihlale zifihlakele.
Ezi nkcukacha ziqokelelwe kule nkqubo yophando zisosetyenziswa ukubhala amanqaku azokwaziswa/bhengezwa kwi nkonfa ukwenzela ukuba abantu bafunde kumava oluphando. Abanye babafundi nabafundisi-ntsapho abaqhuba oluphando bazokusebenzisa lenkqubo yophando ukufezekisa/ukugqibezela izifundo zabo. Ndingathanda ukuphendula yonke imibuzo mayelana noluphando.

Ozithobileyo
Dr. Mary van der Riet
Senior Lecturer, School of Psychology

Appendix 2A: Interview questions 18+ Parents, married people

Process:

Introduction of the research process

Sign consent documents

Obtain permission for audio-recording

Complete demographic information sheet

RELATIONSHIPS

1. How long have you been married?

2. Tell me a bit about how you met your husband/wife?

3. Do you have children?

a. What are their ages?

4. Do you talk to your children about sex?

a. If yes, at what age did you/do you talk to them? Can you tell me briefly what you say?

b. Do you talk to them about the risks in sex?

i. What kinds of risks?

ii. What can they do about these risks

c. If no, why do you not talk to them?

5. Have you been in a relationship before?

`

HEALTH RISKS

6. As married people, have you discussed the risks of sex? Why/why not?

a. If yes, what risks have you discussed Who raised the question of the risks?

b. What was said in the discussion?

c. Did anything change because of the discussion?

7. Do you think it is important to worry about safe sex in your marriage? Why/why not

a. Do you think it is important to practice safe sex in your marriage? Why/why not?

8. Have you discussed with your wife/husband how to prevent getting a sexually transmitted infection?

a. Please tell me briefly about that discussion (why did it come up? What was the worry/concern? Who raised it?) If no, why have you not discussed this?

9. Can you discuss sex freely with your partner? Why, why not?

CONDOM USE

10. Have you ever used a condom in your marriage?

a. If yes, can you explain when and why? Do you always use a condom? If no, why not?

b. How do you feel about getting a condom? Why? Where would you get a condom? Are there problems with getting condoms? Elaborate

11. Are there other ways of practicing safe sex without using a condom? Please explain.

12. Can you freely suggest using a condom to your husband/wife? Why/why not?

a. What would his/her reaction be if you suggested using a condom? How would you feel if your husband/wife suggested using a condom?

13. Do you carry a condom with you? Why/why not?

a. What do you think about a woman carrying a condom around with her What do you think about a man carrying a condom around with him

14. The last time you had sex, did you and your husband/wife talk about condom use? Can you tell me what happened?

15. The last time you had sex did you use a condom? Can you tell me what happened?

HIV QUESTIONS

16. Can you tell me briefly what you know about HIV/AIDS(Please note I do not want to know your status, you do not have to tell me anything about whether you are positive or negative).

17. Have you ever talked to anyone about HIV and AIDS?

a. If yes, please elaborate?

b. If no, why not? What stops you from talking about HIV?

18. Is there anything you would like to know about HIV? Do you know anyone in Ematyholweni who is HIV positive? (please do NOT tell me their names)

a. How do you know they are HIV positive?

19. If someone is HIV positive should they tell others? Why/why not

a. Do you know of anyone who is HIV positive? How are people who are HIV positive treated in the *Ematyholweni*? Should this change? Why/why not

TESTING

20. What do you know about HIV testing

a. What do you think about it? Is it a good/bad thing? Why?

21. Do you know your own HIV status? (PLEASE DON'T TELL ME YOUR STATUS, ONLY WHETHER OR NOT YOU KNOW YOUR STATUS) Did you check your husband/wife's HIV status before getting married? Why/why not? Have you ever been for an HIV test?

a. If yes,

i. Why did you go?

ii. What did you feel about going for the test? Where did you go?

iii. What was it like? Have you been again? How often do you go?

iv. Would you go again? Why/why not?
b. If no, why have you not gone?
i. What would need to change for you to go? (under what conditions would you go for a test?)
22. If you have a husband/wife do you know his or her HIV status?
a. If yes, how did you find out? (did your partner tell you? Did you go for a test?) If no, why not?
i. Do you want to know?
23. Have you discussed going for a test with your husband/wife? Why/ Why not?

TREATMENT
24. Can HIV be treated?
a. If yes, how?

b. If no, why not?

c. If you had HIV, how would you treat it?

d. Where would you go in Ematyholweni for treatment?
25. What do you know about anti-retroviral treatment (ARV's)? (What is it, what does it look like, how does it work?)
26. Would you take ARV's if you needed to? Why/why not?
a. If yes, where would you go to get them?

b. If no, what would stop you from taking them?

GENERAL
27. What can be done about HIV and AIDS in the Ematyholweni? What can YOU personally do about HIV and AIDS in Ematyholweni?

Appendix 2B: Interview questions 18+ Parents, married people *IsiXhosa* version

Process:
Introduction of the research process
Sign consent documents
Obtain permission for audio-recording
Complete demographic information sheet

RELATIONSHIPS

1. Lingakani ixesha seleutshatile?

2. Bendicela undichazele kancinci ukuba nadibana kanjani nomyeni wakho/nonkosikazi wakho?

3. Unabo na abantwana?
a. Mingaphi iminyaka yabo?
4. Uyathetha na nabo ngokuthandana nentlobano zesini?
a. Waqala nini ukuthetha nabo ngezizinto?

b. Bendicela undixelele kancinci ukuba uthini kubo?

c. Uyathetha na nabo ngeengozi zentlobano zesini?
i. Uthetha ngeziziphi iintlobo zenengozi?

ii. Yintoni abanokuyenza bona ngezizingozi?
d. Ukuba awuthethi nabo, kutheni ungathethi nabo?
5. Wena wake wanaye Umntu othandana naye?

HEALTH RISKS
6. Njengabantu abatshatile, niyaxoxa na ngengozi zeentlobano zesisni?
a. Ukuba kunjalo, zeziphi iingozi enizixoxayo?

b. Ngubani owavusa lombandela wezizingozi?

c. Kwathiwani kulengxoxo?

d. Khona uthsintsho owalibona ngenxayalengxoxo phakathi kwenu?
7. Xa ucinga, kubalulekile ukuba kuthethwe ngokulalana okukhuselekile emthsatweni?
a. Xa ucinga, kubalulekile ukuba nizikhusele xanilala emtshatweni wenu?
8. Wakewaxoxa nomkakho/nomyeni wakho ngezifo ezigqithiselwa ngokulala?
a. Bendicela undichazele kancinci ngalengxoxo?

b. Ukuba akunjalo, kutheni?
9. Uyaxoxa ngokukhuleka ngentlobano zesini nomyeni/nomkakho?

CONDOM USE

10. Niyazisebenzisa na iicondom emtshatweni wenu?

a. Ukuba kunjalo Bendicela undixelel ukuba wazisebenzisa nini, kutheni?

b. Niyisebenzisa njalo na icondom?

c. Ukuba akunjalongo, kungoba kutheni?

d. Uziva kanjani xakufuneka uyofumana icondom? Ngoba?

e. Uyfumanaphi icondom, zikhona ingxaki ojamelana nazo xaufuna icondom? Bendicela uchaze

11. Zikhona na ezinye iindlela zokuzikusela ungayisebenzisanga icondom? Ndicela undichazele

12. Uyakwazi na ukumcela umyeni wakho/umkakho ukuba manisebenzise icondom ukhululekile?

a. Uye athini xausenza esisicelo?

b. Ungaziva kanjani ukuba umkakho/umnyeni wakho angakucela ukuba nisebenzise icondom?

13. Uyayiphatha na wena icondom? Ngoba?

a. Ucinga ntoni ngabafazi abaphatha iicondom?

b. Ucinga ntoni ngendoda ehamba iphethe icondom?

14. Nathetha na ngokusebenzisa icondom? Bendicela undichazele ukuba kwenzeka ntoni?

15. Ukugqibela kwakho ukulala nomntu wakho, nayisebenzisa na icondom?

HIV QUESTIONS

16. Bendicela undixelele kancinci ngolwazi onalo ngentsholongwane ka gawulayo?

Please note I do not want to know your status, you do not have to tell me anything about whether you are positive or negative. Andifuni kwazi ukuba upositive na

17. Ukhona umntu owake wathetha naye nge AIDS

a. Bendicea undichazele

b. Ukuba akekho, kutheni engekho?

18. Kukhona na into oralela ukuyazi ngesisifo?

19. Kukhona na Umntu apha e Ematyholweni omaziyo ukuba upositive?

a. Wazikanjani ukuba upositive lomntu?

20. Ukuba Umntu uneHIV okanye iAIDS, kufanele na abazise abanye abantu? Ngoba?

a. Ukhona na Umntu omaziyo oHIV positive?

b. Baphathwa kanjani abantu abanentsholongwane apha eEmatyholweni?

c. Kufuneka itshintshe na lento?

TESTING

21. Loluphi ulwazi onalo ngokuhlolwa kwentsholongwane kagawulayo?
a. Ucinga ntoni ngayo,yinto entle okanye ayintlanga? Ngoba?
22. isimo sakho seHIV uyasazi na? ndicela ungandixeleli ukuba sithini

23. Umyeni wakho, umkakho wamhlola na intsholongwane ngaphambilokuba nitshate?

24. Wena wake wayihlolelwa iHIV?
a. Ukuba kunjalo
i. Kwakutheni uzeuye

ii. Wawuziva kanjani ngelixeshauyohlolwa?

iii. Wahlolwa phi

iv. Kwakunjani?

v. Selekewaphinda, kangaphi?

vi. Ungaphinda futhi uyohlolwa? Ngoba?
b. Ukuba zange uphinde, kutheni?
i. yintoni ekunofuneka itshintshe ukuze uphinde?
25. Ukuba unaye umfazi/inkosikazi, uyasazi na isimo seHIV sakhe?
a. ukuba uyasazi, usazi kanjani?

b. Ukuba awusazi, kutheni ungasazi?
i. Uyafuna na ukusazi?
26. Nakenaxoxan nomkakho/nomyeni wakho ngokuyohlolwa?

TREATMENT
27. Iyatritwa na iHIV?
a. Ukuba kunjalo, kanjani?

b. Ukuba akunjalongo, kanjani?

c. Ukuba uneHIV uyitrita kanjani?

d. Ungayaphi eEmatyholweni xaufuna itritment
28. Uyazazi iARVs?

29. Ungazithatha na xakunesidingo sokuba uzithathe? ngoba?
a. Ungayozithatha phi?

b. Yintoni enokunqanda ukuba ungazithathi?

GENERAL
30. Yintoni enokwenziwa ngeHIV eEmatyholweni?

31. Yintoni onokuyenza ngeHIV wena apha eEmatyholweni?

Appendix 3A: Interview questions 18+ (unmarried people who have been in/or are in relationships).

Process:
Introduction of the research process
Sign consent documents
Obtain permission for audio-recording
Complete demographic information sheet

RELATIONSHIPS
If not in a relationship currently, questions are about what happened in the last relationship

1. Have you been in a relationship before?

2. Are you in a relationship at the moment? Are you married?
a. Is it with someone in the area?
3. Tell me a bit about the relationship
a. How did it start?

b. How old is your partner?

c. How long has it been going on for? How long have you been married?

HEALTH RISKS
If not in a relationship currently, questions are about what happened in the last relationship
4. In your relationship, have you discussed the risks of sex? Why/ why not?
a. If yes, what risks have you discussed?

b. Who raised the question of the risks?

c. What was said in the discussion? Did anything change because of the discussion?
5. Do you think it is important to worry about safe sex in your kind of relationship? Why/why not?
a. Do you think it is important to practice safe sex in your kind of relationship? Why/why not?
6. Have you discussed with your partner how to prevent getting a sexually transmitted infection?

a. Please tell me briefly about that discussion (why did it come up? What was the worry/concern? Who raised it?)

7. If no, why have you not discussed this?

8. Can you discuss sex freely with your partner? Why, why not?

CONDOM USE

9. Have you ever used a condom in your relationship?

a. If yes, can you explain when and why? Do you always use a condom?

b. If no, why not?

c. How do you feel about getting a condom? Why?

d. Where would you get a condom? Are there problems with getting condoms? Elaborate

10. Are there other ways of practicing safe sex without using a condom? Please explain

11. Can you freely suggest using a condom to your partner? Why/why not?

a. What would his/her reaction be if you suggested using a condom

b. How would you feel if your partner suggested using a condom

12. Do you carry a condom with you? Why/why not?

a. What do you think about a woman carrying a condom around with her what do you think about a man carrying a condom around with him?

13. The last time you had sex, did you and your partner talk about condom use? Can you tell me what happened?

14. The last time you had sex did you use a condom? Can you tell me what happened?

HIV QUESTIONS

15. Can you tell me briefly what you know about HIV/AIDS? (Please note I do not want to know your status, you do not have to tell me anything about whether you are positive or negative).

16. Have you ever talked to anyone about HIV and AIDS?

a. If yes, please elaborate? If no, why not? What stops you from talking about HIV?

17. Is there anything you would like to know about HIV? Do you know anyone in *Ematyholweni* who is HIV positive? (please do NOT tell me their names)

a. How do you know they are HIV positive?

18. If someone is HIV positive should they tell others? Why/why not?

a. Do you know of anyone who is HIV positive? How are people who are HIV positive treated in the AB? Should this change? Why/why not?

TESTING

19. What do you know about HIV testing?

a. What do you think about it? Is it a good/bad thing? Why?

20. Do you know your own HIV status? (PLEASE DON'T TELL ME YOUR STATUS, ONLY WHETHER OR NOT YOU KNOW YOUR STATUS)

21. Did you check your partner's HIV status before getting into the relationship? Why/why not?

22. Have you ever been for an HIV test?

a. If yes,

i. Why did you go? What did you feel about going for the test ? Where did you go? What was it like? Have you been again? How often do you go?

ii. Would you go again? Why/why not?

b. If no, why have you not gone?

i. What would need to change for you to go? (Under what conditions would you go for a test?)

23. If you have a partner do you know his or her HIV status?

a. If yes, how did you find out? (Did your partner tell you? Did you go for a test?)

b. If no, why not?

i. Do you want to know?

24. Have you discussed going for a test with your partner? Why/ Why not?

TREATMENT

25. Can HIV be treated?

a. If yes, how?

b. If no, why not?

c. If you had HIV, how would you treat it?

d. Where would you go in *Ematyholweni* for treatment?

26. What do you know about anti-retroviral treatment (ARV's)? (What is it, what does it look like, how does it work?)

27. Would you take ARV's if you needed to? Why/why not?

a. If yes, where would you go to get them? If no, what would stop you from taking them?

GENERAL

28. What can be done about HIV and AIDS in the *Ematyholweni*? What can YOU personally do about HIV and AIDS in *Ematyholweni*?

Appendix 3B: Interview questions 18+ (unmarried people who have been in/or are in relationships). *IsiXhosa* version.

Process:
Introduction of the research process
Sign consent documents
Obtain permission for audio-recording
Complete demographic information sheet

RELATIONSHIPS
◻ If not in a relationship currently, questions are about what happened in the last relationship

1. Wakhe wathandana na?

2. Ukhona Umntu othandana naye ngoku?
a. Ngumntu walapha?
3. Bendicela undixelele kancinci ngobubudlelwane benu?
a. Iqale kanjani?

b. Uneminyaka emingaphi?

c. Lixesha elingakanani?

HEALTH RISKS
 If not in a relationship currently, questions are about what happened in the last relationship

4. Kobubudlelwane benu niyaxoxa na ngentlobano zesini neengozi ezichaphazela impilo?
a. Zeziphi iingozi enizixoxayo?

b. Zivuswa Ngubani ezingxoxo?

c. Nathetha ngantoni kulengxoxo?

d. Lukhona utshintsho olubonayo ngenxayale ngxoxo?
5. Kubalulekile na ukuba nizikhathaze ngengozi ezichaphazela impilo kwiintlobano zesini?
a. Kubalulekile na ukuba nizikhusele xanisenza isini?
6. Nakenaxoxa na nomntu wakho ngokuzikhusela kwizifo ezigqithiswa ngesini?
a. Ndicela undichazele ngalongxoxo?
7. Ukuba zange nixoxe, kutheni?
a. Ungaxoxa ngokuzikhusela ngokukhululekileyo na nomntu wakho? Ngoba?

CONDOM USE
8. Nake nayisebenzisa na icondom?
a. Bendicela undichazele?

b. Uyisebenzisa njalo na icondom?

c. Ukuba hayi, ngoba?

d. Uziva kanjani xakufuneka ufemene icondom? Ngoba?

e. Ungayifumanaphi icondom xa uyifuna? Zikhona ingxaki ojongana nazo xaufuna icondom?

9. Zikhona na ezinye iindlela zokuzikhusela ungayisebenzisanga icondom xa uzolala nomntu?

10. ngokukhululeka na umntu wakho ukuba makasebenzise icondom?
a. Angathini?

b. Ungathini wena ukuba umntu wakho angatsho lonto kuwe?

11. Icondom uyayiphatha na kuwe? Ngoba?
a. Ucinga ntoni ngabafazi/amantombazane aphatha iicondom?

b. Ucinga ntoni ngamadoda/amakhwenkwe aphatha iicondom?

12. Ukugqibela kwakho ukulala nomntu wakho, naxoxa na ngokusebenzisa icondom? Bendicela undichazelel ukuba kwenzeka ntoni?

13. Ukugqibela kwakho ukulala nomntu wakho, nayisebenzisa na icondom?

HIV QUESTIONS

14. Bendicela undixelele ulwazi onalo ngeHIV/AIDS?

(Please note I do not want to know your status, you do not have to tell me anything about whether you are positive or negative). Ungandixeleli isimo sakho sentsholongwane, andifuni ukusazi sona

15. Ukhona Umntu owakhe waxoxa naye nge ntsholongwane iHIV ne AIDS?
a. Ukuba Ukhona, Bendicela undichazele?

b. Ukuba akekho, kutheni, yintoni ekwenza ungathethi ngayo?

16. Ikhona na into ofuna ukuyazi ngeHIV/AIDS?

17. Ukhona na Umntu omaziyo apha eEmatyholweni onentsholongwane kagawulayo?
a. Wazikanjani ukuba unentsholongwane kagawulayo?

18. Kuyafuneka na ukuba axelele abanye abantu na Umntu oneHIV ukuba unayo? Ngoba?
a. Unaye na wena umntu omaziyo oneHIV?

b. Baphathwa kanjani abantu abane HIV aphe e*Ematyholweni*?

c. Kufanele kutshintshe na oku? Ngoba?

TESTING

19. Wazintoni ngokuhlolwa kweHIV?
a. Yinto entle okanye embi?

20. (PLEASE DON'T TELL ME YOUR STATUS, ONLY WHETHER OR NOT YOU KNOW YOUR STATUS) isimo sakho seHIV uyasazi na?

21. Umntuwakho wasihlola na isimo sakhe sentsholongwane ngaphambi kokuba nithandane?

22. Wakewahlolwa na
a. If yes,
i. Wasiwa yintoni?

ii. Waziva kanjani xausiyakuhlola?

iii. Wayaphi?

iv. Kwakunjani?

v. Wakhe waphinda futhi? Kangaphi?

vi. Uyozeuphinde na? Ngoba?
b. Ukuba hayi, kutheni ungaphindanga waya khona?
i. yintoni ekunofuneka itshintshe ukuze uphinde?
23. Ukuba unaye umntu onaye, Ingaba uyasazi na isimo sakhe se HIV?
a. Ukuba uyasazi, wasazi kanjani?

b. Ukuba akunjalo kutheni?
i. Uyafuna na ukusazi?
24. Nakenaxoxa na nomkakho/nomyeni wakho ngokuyohlolwa?

TREATMENT
25. Iyatritwa na iHIV?
a. Ukuba iyatritwa itritwa kanjani?

b. Ukuba akunjalongo, kanjani?

c. Ukuba uneHIV uyitrita kanjani?

d. Ungayaphi eEmatyholweni xaufuna itritment?
26. Zisebenza kanjani? ziyintoni?

27. Ungazithatha na iARVs xakukho isidingo sokuba uzithathe? ngoba?
a. Ungazithatha phi?

b. intoni enokunqanda ukuba ungazithathi?

GENERAL
28. Yintoni enokwenziwa ngeHIV eEmatyholweni?
29. Yintoni onokuyenza ngeHIV wena apha eEmatyholweni?

Appendix 4A: Information sheet

INFORMATION SHEET ABOUT THE RESEARCH PROJECT

Dear resident of *Ematyholweni*

You may know that I have conducted research here in *Ematyholweni* before. That research was about HIV and AIDS and what you as residents of *Ematyholweni* think about HIV and AIDS, and how you respond to HIV and AIDS. In that research we spoke to youth and parents about relationships, about sex, about sexual health, and about the risk of HIV and AIDS.

In this research project we want to show you some of the things that we found in that research, and find out what you think about those findings. We would like to hold a few workshops where we talk about the findings of that research. It has been a number of years since that research project, and perhaps things have changed in *Ematyholweni* . We would therefore also like to conduct more interviews, and focus group discussions with traditional leaders, young people, parents, traditional educators, traditional healers, church members and the clinic staff. In these interviews and focus group discussions we would ask you to talk about relationships, sexual health practices, and what you think about HIV and AIDS.

The interviews and focus groups will be recorded so that the researchers can accurately capture what it is that people have said, and translate it into English, so that all of the researchers can understand it.

Once we have held the interviews and focus groups, we will take the information, and make it confidential. Each person who participates will be given a code number, so that his or her name is not used. This means that you will not be able to know who said what in the interviews or focus groups.

This information will then be used in another workshop, where we can all discuss what people say about relationships, and sexual health. In this way, we hope to see what people in *Ematyholweni* feel about the problem of HIV and AIDS, and what you feel can be done about it. The workshop process will be filmed using a video camera, also to accurately record what people discuss. This information will then be transcribed (or written down) from the video recording.

Mary van der Riet, who you know has conducted research in *Ematyholweni* before, is the leader of the project. She is now living in KwaZulu-Natal and is a lecturer at the University of KwaZulu-Natal. There will also be a few students and lecturers from the University of KwaZulu-Natal, and some from the University of Fort Hare, who are helping her with the research. Some of these people may do the interviews and focus groups, and they will be at the workshops. We will introduce all of these people to you.

The information collected in the research process will also be used to write research articles, and to present at conferences so that other people may learn from the experience of our research. Some of the students and lecturers conducting the research will be using the research project to study for their degrees.

We would like to do this research process in a few villages in *Ematyholweni*. It depends on how much time we have. The project data collection would start in 2012, and might continue until the end of 2013.

We would like to invite you to participate in the research project. The more people who participate, the more different views we have of the problem. If you have any questions, then please let us know. You can talk to us directly, or you can call Mary on XXX XXXXXXX.

This project has been approved by the Ethics committee of the University of KwaZulu-Natal. If you have any questions about the ethical issues in this project, then you can contact Ms Carol Mitchell on XXX XXXXXXX, or Ms Carol Mitchell, School of Psychology, University of KwaZulu-Natal, Private Bag X01, Scottsville, Pietermaritzburg, 3201 or email XXXX@XXXXXXXX.

Yours faithfully

Dr Mary van der Riet

Senior Lecturer, Psychology, UKZN

Appendix 4B: Information sheet *IsiXhosa* version

Icwecwe lencukacha mayelana nenkqubo yophando

Mhlaliwase *Ematyholweni* othandekayo.

Nisenokwazi ukuba ndakendenza inkqubo yophando apha *Ematyholweni* ngaphambili.Olophando lwalumayelana nentsholongwane kunye nesifo sikagawulayo, nokuba nina ningabahlali base *Ematyholweni* nicingantoni na ngentsholongwane kunye nesifo sikagawulayo, nokuba nisithatha/Nicinga ntoni ngesisifo. Kolophando, saathetha nolutsha, kunyenabazali mayelana nobudlelwane, ukwabelana ngosondo/iintlobano zesini, kunyenobungozi bentsholongwane nesifo sikagawulayo.

Kulenqubo yophando, sifuna ukunibonisa ezinye izinto esazifumana kolwaphando futhi sive ukuba nina nicingantoni ngezozinto. Singathanda ukubamba imihlangano, embalwa apho sizothetha ngezinto esazifumana kolwaphando.

Seyadlula iminyaka, emva kwalanqubo yophando, mhlawumbi nezinto sezatshintsha *Ematyholweni*. Singathanda ukuqhuba olunye udliwano-ndlebe kunye neengxoxiswano, neenkokheli zesintu, abantu abatsha, abazali, iingcibi,abanyangi, abezenkolo kunye nabasebenzi base kliniki. Kwezodliwano-ndlebe kunye neengxoxiswano, singathanda ukuba nithethe ngobudlelwane, indlela ezikhuselekileyo zesondo, nokubanicingantonina ngentsholongwane nesifo sikagawulayo.

Udliwano-ndlebe kunye neengxoxiswano zizokushicilelwa ukwenzela ukuba abaphandi babambenyanisekileyo oko abantu abakutshileyo/abakuthethileyo futhi bakutolikele kwisingesi ukwenzela ukuba bonke abaphandi bakuqonde/bakuve.

Emvakokuba sesilubambile udliwano-ndlebe kunye neengxoxiswano, sizothatha iingcombolo/inkcazelo/inkcukacha sizenze imfihlo. Wonke umntu othatha umnxeba uzokunikwa inombolo ukwenzela ukuba igamalakhe lingasetyenziswa. Oku kuchaza ukuba angekewazi ukuba ubani utshontoni kwindliwano-ndlebe neengxoxiswano.

Ezingcombolo/olulwazi, luzokusetyenziswa nakweminye imihlangano, apho sizoxoxa ukuba abantu bathini nangezobudlelwane, kunye nezempilongesondo. Ngalendlela, sithemba ukubona ukuba abantu base *Ematyholweni* bazivakanjani ngalengxaki yentsholongwane nesifo sikagawulayo nokuba bacinga ukubayintoni enokwenziwa ngaso. Le nkqubo yemihlangano izoshicilelwa kusetyenziswa I video camera ukwenzela ukuba kushicilelwe nyanisekileyo oko abantu abakuxoxayo. Ezingcombolo zizokubhalwa phantsi zithathwakwi video recorder.

UMary Van der Riet, enimaziyo, owakewenza uphando apha *Ematyholweni* ngaphambili, nguye umkhokheli wale nkqubo. Ngoku sengumhlali waKwaZulu-Natal futhi ungumfundisi- ntsapho eyunivesithi yakwaZulu-Natal. Kuzobekukho abafundi abambalwa kunye nabafundisi-ntsapho abaphuma eyunivesithi yakwaZulu-Natal, nabanye abasuka eyunivesithi yase Fort Hare, abancedisa ngophando. Abanye baba bantu bangenza iindliwano-ndlebe kunye neengxoxiswano, futhi bazobe bekhona kwiimfundiso/kwimihlangano. Sizokubazisa bonke ababantu kuni. Ezinkcukacha ziqokelelwe kulenkqubo yophando zizosetyenziswa ukubhala amanqaku azokwaziswa/bhengezwa kwinkonfa ukwenzela ukuba abantu bafunde kumava oluphando. Abanye babafundi nabafundisi-ntsapho abaqhuba oluphando bazokusebenzisa lenkqubo yophando ukufezekisa/ukugqibezela izifundozabo.

Singathanda ukwenza le nkqubo yophando kwiilali ezimbalwa zase *Ematyholweni*. Kuzokuxhomekeka ukubasinexesha elingakanini na. Uqokelelo lwencukacha luzoqala ngo 2012 futhi kungenzeka ukuba luqhubeke ukufikela ekupheleni kuka 2013.

Singathanda ukunimema ukuba nithathe inxhaxheba kulenkqubo yophando. Ukubanabantu abaninzi abathatha inxhaxheba kuzonceda ukuba kubekho imibono emininzi eyahlukeneyo ngalengxaki. Ukuba unemibuzo, sicela uqhagamshelane no Mary kulenomboro xxx xxxxxxx.

Ukhuseleko lwabathathinxaxheba kulenkqubo yophando beselijongwe lavunywa yikomiti yezophando yaseYunivesithi yaKwaZulu Natal. Kodwa ukuba unemibuzo ungathintana no Ms Carol Mitchell kulenombolo xxx xxxxxx okanye Ms Carol Mitchell, School of Psychology, Private Bag X01 Scottsville, 3201 okanye email: xxxxxx@xxxxxxx.

Ozithobileyo
Dr Mary van der Riet
Senior Lecturer, Psychology, UKZN

Appendix 5A: Consent form for individual interviews

Consent form Interviews
Dear Participant
In this interview we will ask you some questions about relationships, sexual health and the risk of HIV and AIDS. We would like to find out what your experience is, and what you think about these things.

The interview will take about 1 hour.
Once we have held the interviews and focus groups, we will take the information, and make it confidential. This means that you will be given a code number, so that your name is not used and not linked to the statements that you make.

We would then like to use the information we get from all of the interviews and also from the focus groups in workshops with more people. Then we can all discuss what people say about relationships, and sexual health. In this way, we hope to see what people in the *Ematyholweni* feel about the problem of HIV and AIDS, and what you feel can be done about it. The information collected in the research process will also be used to write research articles, and to present at conferences so that other people may learn from the experience of our research. Some of the students and lecturers conducting the research will be using the research project to study for their degrees.

If you participate in the interview, your views will help us to have a different perspective on the problem of HIV and AIDS.
If you agree to participate, but then at a later time you feel that you would like to withdraw from the interview, or not participate any more, that is fine. You can say so and we will stop the interview.

If you have any questions, then please let us know. You can talk to us directly, or you can call
Dumisa Sofika on xxx xxxxxxx or Mary on xxx xxxxxxx
Yours faithfully, Mary van der Riet and Dumisa Sofika

CONCENT TO PARTICIPATE

I agree to participate in this research

- I have had an opportunity to read and understand the information sheet given to me.
- The purpose of the study has been explained to me. I understand what is expected of me in terms of my participation in this study and the time commitment I am making to participate in this study.
- I understand that my participation is voluntary and I know that I may withdraw from the study at any point, without negative consequences.
- I understand that the information collected in this interview will be kept safe

- I understand that my identity will remain confidential
- I understand that the information collected may be used for student studies, for future research, for conference presentations and for journal articles. I understand that in all of this my name will not be mentioned and that my participation in this research will be completely confidential. I understand that no identifying information about me will be published.
- I have the contact details of the researcher should I have any more questions about the research.

_____   _____

Participant's signature   Date

Appendix 5B: Consent form for individual interviews *IsiXhosa* version

Ucwecwe lemvume yokuthabatha inxeba kudliwanondlebe

Kulodliwanondlebe sizokubuza imibuzo edibene nokuthandana, intlobano zesini kunye negozi ezidibene neHIV ne AIDS. Sufuna ukwazi kuwe ukuba ucinga ntoni ngezizinto.

Udliwanondlebe uzokuthatha iyure enye

Emvakodliwanondlebe nengxoxiswano sizokuthatha iincukacha sizenze imfimfihlo. Uzokinikwa inomboro eyiyikodi ukwenzela ukuba igama lakho lingaveli, kwaye nezinto ozithethile.

Sizosebenzisa ezoncukacha zalodliwanondlebe kwingxoxo nabanye abantu. Sifuna ukuxoxisana ngezinto ezifana nokuthandana nezinto ezichaphazela impilo. Sifuna ukuva ngani ukuba Nicinga ntoni ngezizinto nokuba Nicinga ukuba kungathiwani ngazo

Iincukacha ezivela kwezingxoxo esizozibambha zizokusetyenziswa ekubhaleni amaphepha azobhengezwa kwinkomfi naphambi kwabanye abantu nabaphandi. Abanye abafundi bazosebenzisa lenqubo ukuze bafumane iidigri zabo.

Ukuthabatha inxeba kwakho kulenqubo kuzonceda ukuba sifumane amava ahlukene ngalengxaki yentsholongwane kagawulayo nesifo sikagawulayo.

Ukuba uyavuma ukuba lilunga lalenqubo, kodwa mhawumbe uphinde uzivekungathi awusafuni ukuthabatha inxeba kulenqubo uvumelekile ukuba uziroxise kulenqubo. Ukuba sisinqweno sakho ukuziroxisa sizokuyekisa.

Ukuba unemibuzo ngalenqubo ungatsalela umnxeba ku Dumisa Sofika kule nomboro xxx xxx xxxx okanye u Mary kule nomboro xxx xxx xxxx

Mary van der Riet

Dumisa Sofika

Imvume yokuthabatha inxeba kudliwanondlebe

- Ndiyavuma ukuthabatha inxeba kulenqubo

- Ndilifumene ithuba lokufunda ucwecwe lencukacha zalenqubo futhi ndiyaziqonda

- Ndiyichazelwe intloso yalenqubo. Ndinalo ulwazi lokuba kudingwa ntoni kum futhi ndiyazibophelela ukwenza ezozinto ezicelwe kum.

- Ndiyaqonda ukuba akunyanzelekanga ukuba ndithabathe inxeba kulenqubo, futhi ndingayeka nanini apho ndithande ukuyeka khona.

- Ndiyaqonda ukuba zonke incikacha eziqokelelwe kulenqubo zizogcinakala ziyimfihle

- Ndiyaqonda futhi ukuba ndizogcinakala ndikhuselekile kulenqubo

- Ndiyaqonda ukuba incukacha ezivela kwezingxoxo esizozibambha zizokusetyenziswa ekubhaleni amaphepha azobhengezwa kwinkomfi naphambi kwabanye abantu nabaphandi. Abanye abafundi bazosebenzisa lenqubo ukuze bafumane iidigri zabo. Ndiyaqonda ukuba kuyyonke lenqubo, igama lam lizohlala likhuselekile.

- Ndinazo iincukacha zabaphandi kulenqubo kwaye ndingabatsalela umnxeba nanini ukuze ndicaciselwe ngemibuzo endinayo nangezinto endingaziqondi.

_____   _____

Appendix 6A: Consent for audio recording

Consent to audio record interview/focus group

In order to be able to understand clearly what you have said in this interview/focus group, and to remember it, we would like to record the discussion on this small digital recorder. We will then listen to the recording and write it down (transcribe it). It will also be translated into English. After we have written the information down, we will then delete the recording on the digital recorder.

We assure you that your name will not be linked to the recording, or the written information from the recording. We will give you a code name, using numbers, for example Participant 1_Interview 3. Or Focus group 3.
Do you agree that we can record the discussion?

If yes, then please sign here _____ Date_____

Appendix 6B: Consent for audio recording *IsiXhosa* version

Ucwecwe lemvume yokuqopha udliwanondlebe
Ukuze sikuqonde kakuhle, futhi sikukhumbule okuxoxwe apha sifuna ukuteypa ingxoxo yethu nge rekoda. Sizophinde siyimamele lengxoxo kulerekoda sibhale phantsi iincukacha zalengxoxo. Ingxoxo izotolikwa ukuze iviwe ngabanye abaphandi. Ukuqhiba kwethu ukwenza lonto sizokuyicima yonke into ekwi rekoda.

ukuba igama lakho alizukuvela kwi rekoda nakwizinto ezibhaliwe ephepheni. Igama lakho sizokuligcina liyimfihlo ngokulinika inomboro.
Uyavuma na ukuba siyiqophe ingxoxo?

Ukuba uyavuma, ndicela ubhale igama lakho apha _____
umhla_____

Appendix 7A: Focus group questions for 18+ (young people, unmarried, married, parents, older people).

Process: Introduction of the research using info sheet
Signing of consent documents
Obtain permission for audio-recording
GET demographic information on SHEET
QUESTIONS ABOUT RELATIONSHIPS

- Use YOUNG If under 30 and unmarried

- Use MARRIED if married participants

1. Do (young/married) people in *Ematyholweni* have boyfriends or girlfriends?
a. What is it called when they do this? (is it dating?/what is dating) Are there different ways of having a boyfriend or a girlfriend? (What kinds of relationships do young/married people in the *Ematyholweni* engage in
i. Can you describe them?

ii. What words do they use to describe these relationships?
2. What kinds of activity do boyfriends and girlfriends engage in? When do young people in *Ematyholweni* have a chance to meet? Can you give examples? Do people sometimes have relationships with people who are much older/younger than them?
a. What do you think about this? (Is this a problem? Why/why not?)
3. Are people sometimes forced to have relationships? Why? Do young/married people in relationships have sex?
a. Why do they have sex? What do you think they want from sex? If they don't have sex, why not?

RISKS IN SEX
4. Are there risks in having sex? What are these risks?
a. Do people in relationships discuss the risks in sex?
i. Can you give me an example of this discussion? (who started it, what was said, what happened after the discussion?) Who usually raises the issue of health risks in relationships?
5. How do people having sex protect themselves from these risks?
a. If they protect themselves, can you explain how they do it+? If they don't do anything, why not? Do they discuss the risks with their partners? Do men and women worry about for these risks in the same way? Do men and women take responsibility for these risks in the same way?

6. Do you think people in long term relationships are concerned with the risks in sex?
a. Do you think they should be concerned?

b. What does safe sex mean for a couple who has been going out for a long time?
7. Do people use condoms?
a. If they don't use condoms, why not? If they use condoms:
i. When do condoms get used? Who raises the issue of using a condom? Why this person?

ii. Where do they get them from? What are problems with getting condoms?
8. Do people in marriages use condoms? Why/Why not? Should married couples, or couples in long-term relationships use condoms? Why? Why not? What do you think if a woman carries a condom with her**?**

9. What do you think if a man carries a condom with him? Do people in relationships have more than one partner? Why
a. Is this the same for men and women? Why?
10. Do married people have more than one partner? Why?
a. Is this the same for men and women? Why?
11. Do women talk about sex? Why, why not? Who do they talk to?

12. Do men talk about sex? Why, why not? Who do they talk to?
Additional questions for PARENTS
a. Do parents talk to their children about sex? If yes, at what age does this happen?
i. Can you tell me briefly what is said?
b. If no, why not?

HIV QUESTONS
a. Can you tell me briefly what you know about HIV/AIDS? ***NB I do not want to know about your status so you do not need to tell me if you are positive or negative.*** What is HIV/AIDS? How do people get HIV/AIDS Can you tell if someone has HIV/AIDS? How? Do you think AIDS is curable? Please elaborate. Have you ever talked to anyone about HIV/AIDS?
i. If yes, whom did you talk to?

ii. What did you talk about?

iii. If no, why not? What prevents you from talking about HIV and AIDS?
b. What would you like to know about HIV and AIDS?

13. Do you know of anyone who has HIV/AIDS? /Are there HIV positive people in *Ematyholweni*?

a. How do you know that they are HIV positive?

b. How do you feel around that person?

c. How are people who are HIV positive treated in the *Ematyholweni*?

d. Do you think this should change? Why/why not?

14. If people are HIV positive, do they tell others? Why/why not?

a. Should they tell others? Why/why not?

15. Do people in the *Ematyholweni* get themselves tested for HIV?

a. If yes, why do they go?

b. If yes, where do they go?

c. If no, what prevents people from going?

d. What would need to change for people to go for testing?

16. Do people in relationships have discussions about HIV testing?

a. If no why not?

b. If yes, what kinds of things are discussed?

17. Do people in relationships encourage each other to know their HIV status?

a. If yes, why?

b. If no, why not?

18. Do men and women go for testing?

19. What types of treatments are there for HIV positive people?

a. Where do they go for that treatment?

b. If there is medication, what do you know about it? (where do you get it, what does it look like, how much does it cost?)

c. If there is medication, how does it work?

d. What do you know about anti-retroviral treatment (ARV's).

e. Do people take ARVs' if they need to?

f. How do they do this? Where do they go?

g. If they don't take them, what stops them from taking them?

h. Do you think that people should get treatment for HIV?

That is all the questions we wanted to ask you. Do you have any questions about the research process, or about what we have been discussing? Thank you for participating in this focus group.

Appendix 7B: Focus group questions for 18+ (young people, unmarried, married, parents, older people). IsiXhosa version.

Process: Introduction of the research using info sheet
Signing of consent documents
Obtain permission for audio-recording
GET demographic information on SHEET
QUESTIONS ABOUT RELATIONSHIPS

- Use YOUNG If under 30 and unmarried

- Use MARRIED if married participants

1. Ingabe abantu abatsha/abatshatileyo bayajola na apha eEmatyholweni?
a. Ibizwa ngantoni/kuthiwa yintoni xa besenza lonto? (kuyathandanwa?/yintoni ukujola?)
b. Ingabe kukhona iindlela ezihlukile zokuthandana? (zeziphi ezikhoyo iindlela zokuthandana apha eEmatyholweni?)
i. Bendicela nindichazele ngezizindlela?
ii. Ngawaphi amagama asetyenziswayo xakuthethwa ngoluhlobo lokuthandana/abathandana ngalo?
2. Abantu abajolayo zeziphi izinto abazenzayo?

3. Ulutsha luwafumana nini amathuba okudibana? Bendicela nindiphe umzekelo

4. Kuyenzeka na ukuba abantu bathandane nabantu abadala/abancinci kakhulu kunabo?
a. Nina ngokubona kwenu nithini ngalento? (niyibona iyingxaki, ingeyiyo ingxaki?)
5. Abantu banyanzelekile ukuba babenabantu ngamanyane amaxesha? Ngoba?
6. Ulutsha/abantu abatshatileyo abathandanayo bayazenza intlobano zesini
a. Bazenzelani intlobano zesini? Ngokubona kwenu, yintoni abafuna ukuyifumana kwintlobano zesini?
b. Yintoni eyenza abanye abantu bakhethe ukungazenzi intlobano zesini?

RISKS IN SEX
7. Ingaba ikhona imiphumo emibi okanye iingozi ekubeni nentlobano zesini? Yeyiphi lemiphumo emibi?
a. Ingaba abantu xa bethandana bayaxoxa ngengozi eziphathelene nokuba neentlobano zesini ?

i. Ningandenzela imizekhelo yezingxoxo (Ngubani oyiqalayo lengxoxo, uye athini, kwenzekani emva koko ?)
ii. ngubani umntu ovusa umbandela wokuzikhusela kwingozi ezichaphazela impilo kwizithandani?
8. Bazikhusela kanjani abantu abenza iintlobano zesini kwezi ngozi?
a. Ukuba bayazikhusela, bazikhusela kanjani (cacisa)?
b. Ukuba abazikhuseli, yintoni eyenza ukuba bangazikhuseli?
c. Bayathetha na ngengozi nabantu babo?
d. Abantu abangomama notata bazikhathaza ngendlela efanayo ngizingozi?
e. Kungabe abantu abangomama no tata bathatha inxaxheba yokuzikhusela kwezingozi ngendlela efanayo?
9. Kungabe abantu abasebekunye ixesha elide bayazikhathaza na ngeengozi zentlobano zesini?
a. Xa nicinga, kufanele na bazikhathaze ngalonto?

b. Kuthetha ntoni xabezikhusela kwintlobano yesini abantu abasebekunye ixesha elide?

10. Bayazisebenzisa na iicondom abantu?

a. Ukuba abazisenbenzisi, yintoni eyenza ukuba bangaziseenzisi?

b. ukuba ziyasetyenziswa iicondoms

i. Zisetyenziswa nini?

ii. Ngubani ekuba nguye ovusa indaba yecondoms xakuzolalwa? Kutheni ingulomntu?

iii. Bazifumana phi ezicondoms?

iv. Zeziphi iingxaki ezikhoyo ekufumaneni iicondoms?

11. Bayazisebenzisa na iicondoms abantu abasemtshatweni? Bazisebenzisela ntoni/kutheni bengazisebenzisi?

12. Abantu abasebetshate ixesha elide kufanele bazisebenzise na iicondoms?

13. Nicinga ntoni ngomtu ongumama/ngentombi ephatha iicondom kuyo?

14. Umntu ongutata ophatha icondom kuye nicinga ntoni ngaye?

15. Umntu onaye umntu anaye kuyenzeka ukuba abe nabantu abaninzi ajola nabo? Kwenziwa yintoni?
a. Kuyafana ko mama no tata?
16. Abantu abatshatile kuyenzeka ukuba babenaye abantu babebaninzi?
a. Kuyafana na ko mama no tata?
17. Bayathetha na abantu abangomama ngetlobano zesini? Kwenziwa yintoni? Bathetha nobani?

18. Amadoda ayathetha na ngentlobano zesini? Ngoba? Bathetha nobani?

Additional questions for PARENTS
19. Abazali bayathetha nabantwana babo ngentlobano zesini?

c. Bathetha nabo xasebe neminyaka emingaphi?
i. Bendicela nindixelele kancinci ukuba kuthethwa ngantoni?
d. Ukuba akunjalongo kwenziwa yintoni?

HIV QUESTONS

20. Bendicela nindixelele kancinci ngolwazi eninalo ngeHIV/AIDS?

NB I do not want to know about your status so you do not need to tell me if you are positive or negative. Andifuni kukwazi ukuba umntu upositive okanye negative na

a. Yintoni iHIV/AIDS?

b. Ifumaneka kanjani iHIV/AIDS?

c. Uyabonakala na umntu oneHIV/AIDS? Ubonakala njani?

d. .Xanicinga iyanyangeka iAIDS? Bendicela nindichazele.

e. Ukhona umntu owake wathetha naye ngeAIDS?

iv. Kwakungubani lomntu?/ngubani umntu ongathetha naye ngeAIDS

v. Nathetha ngantoni? Yintoni eningayixoxa nalomntu?

vi. Ukuba akheko umntu ongathetha naye kutheni kunjalo?

f. Loluphi ulwazi onothanda ukubanalo ngeHIV/AIDS?

21. Ukhona umntu omaziyo oneHIV/AIDS? Bakhona na abantu abaneHIV/AIDS apha eEmatyholweni?

e. Nazi kanjani ukuba bapositive?

f. Uzivanjani xa uphambi kwalomntu?

g. Abantu abanengculaza baphathwa kanjani apha eEmatyholweni?

h. Xanicinga kufanele itshintshe lento? Ngoba?

22. Ukuba abantu bapositive, kukhona abantu ababaxelelayo? Ngoba?

b. Kunyanzelekile na baxelele abanye abantu? Ngoba?

23. Abahlali balapha eEmatyholwenibayayixilongelwa na iHIV/AIDS?

e. Bazixilongela ntoni?

f. Baxilongelwa phi?

g. Yintoni ebavimba ukuba bangayi kuyoxilongwa?

h. Yintoni ekunofuneka ukuba itshintshe ukuze abantu bazise ukuyoxilongwa?

24. Bayaxoxa na abantu abathandanayo ngokuzixilongela iHIV/AIDS?

c. Ngoba?

d. Zeziphi izinto abazixoxayo ngokuxilongwa?

25. abantu abathandanayo bayacebisana ukuba mabasazi isimo seHIV/AIDS sabo?

c. Ukuba ewe, ngoba?

d. Ukuba hayi, ngoba?

26. Ingaba amadoda nabafazi bayaya na ukuyoxilongelwa iHIV/AIDS?

Appendix 8A: Consent form Focus groups

Dear Participant

In this focus group we will ask you some questions about relationships, sexual health and the risk of HIV and AIDS. We would like to find out what your experience is, and what you think about these things. The focus group discussion will take about 90 minutes. Once we have held the focus groups, we will take the information, and make it confidential. This means that all of you who participate in the discussion will be given a code number, so that your name is not used and not linked to the statements that you make.

As a member of this group we will also ask you to sign a confidentiality pledge. This means that you will not tell other people outside of this discussion in this room what was said by other group participants. This will help all of you to feel that you can speak more freely. We would then like to use the information we get from all of the focus groups and also the interviews in workshops with more people. Then we can all discuss what people say about relationships, and sexual health. In this way, we hope to see what people in the *Ematyholweni* feel about the problem of HIV and AIDS, and what you feel can be done about it.

The information collected in the research process will also be used to write research articles, and to present at conferences so that other people may learn from the experience of our research. Some of the students and lecturers conducting the research will be using the research project to study for their degrees.

If you participate in the focus group, your views will help us to have a different perspective on the problem of HIV and AIDS.
If you agree to participate, but then at a later time you feel that you would like to withdraw from the interview, or not participate any more, that is fine. You can say so and we will stop the interview.

If you have any questions, then please let us know. You can talk to us directly, or you can call Mary on xxx xxx xxxx
Yours faithfully
Mary van der Riet

CONSENT TO BE INTERVIEWED
- I agree to participate in this research
- I have had an opportunity to read and understand the information sheet given to me.
- The purpose of the study has been explained to me. I understand what is expected of me in terms of my participation in this study and the time commitment I am making to participate in this study.
- I understand that my participation is voluntary and I know that I may withdraw from the study at any point, without negative consequences.
- I understand that the information collected in this interview will be kept safe
- I understand that my identity will remain confidential

- I understand that the information collected may be used for student studies, for future research, for conference presentations and for journal articles. I understand that in all of this my name will not be mentioned and that my participation in this research will be completely confidential. I understand that no identifying information about me will be published.
- I have the contact details of the researcher should I have any more questions about the research.

_____   _____

Signature of Participant   Date

Appendix 8B: Consent form Focus groups *IsiXhosa* version

Ucwecwe lemvume yengxoxiswano
Kulengxoxiswano sifuna ukukubuza imibuzo ngobudlelwane bokuthandana, iintlobano zesini nentsholongwane nesifo sikagawulayo. Sifuna ukuva ukuba ucinga ntoni ngezizinto. Ingxoxiswano izothatha ixesha elingangeyure ezimbini. Emvakodliwanondlebe nengxoxiswano sizokuthatha iincukacha sizenze imfimfihlo. Uzokinikwa inomboro eyiyikodi ukwenzela ukuba igama lakho lingaveli, kwaye nezinto ozithethile.

Njengane lunga leliqela labantu abakulengxoxiswano, sizokucela ukuba usayine incwadi eyisibophelelo semfihlo. Ukusayina kwakho eliphepha kuthetha ukuba awuzukuzithetha izinto esizixoxe kweligumbi, okanye ezithethwe ngabanye abantu ngaphandle kwalamagumbi, kwabanye abantu. Kodwa, asinasiqiniseko sokuba abantu abazukuzithetha ezizinto ngaphandle kwalamagumbi. Sicela nilumke ukuba igenzeka lento. Mhlawumbi endaweni yokuba uchaze izinto ngawe, ungenza umzekelo ngezinto ezenziwa ngabanye abantu.

Emvakoko, sifuna ukusebenzisa ezincukacha eziqokelelwe kulenqubo kwezinye ingxoxiswano, phambi kwabanye abantu. Kwezongxoxiswano kulapho esingathetha khona, sive ukuba abanye abantu bacinga ntoni ngezizinto, nokuba bacinga ntoni ngeHIV neAIDS nokuba ingathiwani. Iincukacha eziqokelelwe kulenqubo zizosetyenziswa ngabafundi ukubhala amaphepha wabo we research, nokufumana iidigri zabo, futhi zizokubhengezwa kwiikomfa phambi kwabanye abantu ukubazisa ngalenqubo yoluphando. Ukuba uthabatha umnxeba kulengxoxiswano esiyibambayo, amava wakho azosinceda ukuba sibenemibono emininzi ngalenxaki yeHIV ne AIDS
Ukuba uyavuma ukuba lilunga lalenqubo, kodwa mlawumbe emvakwexesha uphinde uzive ufuna ukuroxisa inxeba yakho kulomba, kulungile. Kufuneka ukhululeke usixelele, sizokuroxisa.
Ukuba unemibuzo ofuna ukuyibuza ungatsalela umnxeba kuMary kule nomboro xxx xxx xxxx
Mary van der Riet

Ucwecwe lwemvume yokuthabatha inxeba kwingxoxiswano
- Ndiyavuma ukuthabatha inxeba kulenqubo
- Ndilifumene ithuba lokufunda ucwecwe lencukacha zalenqubo futhi ndiyaziqonda
- Ndiyichazelwe intloso yalenqubo. Ndinalo ulwazi lokuba kudingwa ntoni kum futhi ndiyazibophelela ukwenza ezozinto ezicelwe kum.
- Ndiyaqonda ukuba akunyanzelekanga ukuba ndithabathe inxeba kulenqubo, futhi ndingayeka nanini apho ndithande ukuyeka khona.
- Ndiyaqonda ukuba zonke incikacha eziqokelelwe kulenqubo zizogcinakala ziyimfihle
- Ndiyaqonda futhi ukuba ndizogcinakala ndikhuselekile kulenqubo
- Ndiyaqonda ukuba incukacha ezivela kwezingxoxo esizozibambha zizokusetyenziswa ekubhaleni amaphepha azobhengezwa kwinkomfi naphambi kwabanye abantu nabaphandi. Abanye abafundi bazosebenzisa lenqubo ukuze bafumane iidigri zabo. Ndiyaqonda ukuba kuyyonke lenqubo, igama lam lizohlala likhuselekile.
- Ndinazo iincukacha zabaphandi kulenqubo kwaye ndingabatsalela umnxeba nanini ukuze ndicaciselwe ngemibuzo endinayo nangezinto endingaziqondi.

_____   _____
Isityikityo   Umhla

Appendix 9A: Confidentiality pledge

Confidentiality Pledge

As a member of this Focus Group, I promise not to repeat what was discussed in this focus group with any person outside of the focus group. This means that I will not tell anyone what was said in this group.

By doing this I am promising to keep the comments made by the other focus group members confidential.

Signed _____ Date: _____

Appendix 9B: Confidentiality pledge *IsiXhosa* version

Isibophelelo sokugcina ingxoxiswano iyimfihlo
Njengelunga labantu abakulengxoxiswano, ndiyathembisa ukuba andizukithetha ngaphandle kwalamagumbi izinto esizixoxe namhlanje.

Andizukuzithetha namntu izinto esizixoxe apha.
Izinto ezithethwe ngabanye abantu zizohlala ziyimfihlo.
Igama _____ Umhla: _____

Appendix 10: Verbatim transcription conventions

	(.)	Just noticeable pause
	(.3), (2.6)	Examples of timed pauses
	↑word, ↓word	Onset of noticeable pitch rise or fall *(can be difficult to use reliably)*
A: B:	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 fullstop) 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
A: B:	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
→		Analyst's signal of a significant line
	((sniff))	Transcriber's effort at representing something hard, or impossible, to write phonetically

Appendix 11: Ethical clearance letter for broader study

UNIVERSITY OF KWAZULU-NATAL

INYUVESI YAKWAZULU-NATALI

Research Office, Govan Mbeki Centre
Westville Campus
Private Bag x54001
DURBAN, 4000
Tel No: +27 31 260 3587
Fax No: +27 31 260 4609
Ximbap@ukzn.ac.za

8 November 2011

Dr M van der Riet (24839)
School of Psychology

Dear Dr van der Riet

PROTOCOL REFERENCE NUMBER: HSS/0695/011
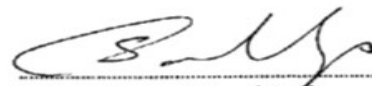**PROJECT TITLE: Activity theory and behavior change**

FULL APPROVAL NOTIFICATION – COMMITTEE REVIEWED PROTOCOL

This letter serves to notify you that your application in connection with the above was reviewed by the Humanities & Social Sciences Research Ethics Committee, has now been granted **Full Approval** following your responses to queries previously raised:

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study. PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

Best wishes for the successful completion of your research protocol

Yours faithfully

Professor Steven Collings (Chair)
Humanities & Social Sciences Research Ethics Committee

Appendix 12: Ethical clearance letter for this study

UNIVERSITY OF ™
KWAZULU-NATAL

INYUVESI
YAKWAZULU-NATALI

14 April 2014

Miss Ngcwalisa Amanda Jama 214581493
School of Applied Human Sciences
Howard College Campus

Dear Miss Jama

Protocol reference number: HSS/0266/014M
Project title: Naming and labelling HIV and AIDS: Responses to HIV in a rural setting in the Eastern Cape

NO-RISK APPROVAL

In response to your application, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has 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 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

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

Yours faithfully

Dr Shenuka Singh (Chair)
Humanities & Social Science Research Ethics Committee

/pm

cc Supervisor: Dr Mary van der Riet
cc Academic Leader: Prof DP McCracken
cc School Admin: Ms Ausie Luthuli

Appendix 13: Agreement to use data

MEMORANDUM OF AGREEMENT REGARDING RESEARCH, THESES, PUBLICATIONS and PRESENTATIONS

I, (student/intern's name) ……………………………………… 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[1], 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: _____Student/Intern Date: April 2014
Signed: _____ Dr Mary van der Riet (PI Activity theory and behaviour change project)

Date: _____

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[1]There is a standard statement which needs to inserted in all publications related to this NRF Thuthuka funded project.

Appendix 14: Extract codes

EXTRACTS CODES	
EXTRACT NUMBER	**INTERVIEW/ FOCUS GROUP CODE**
Extract 1	20120511_18-25_F_DS_Y_(E)
Extract 2	20120511_18-25_F_DS_Y_(E)
Extract 3	20120512_18-25_M_DS_24
Extract 4	20120509_46-60_M_DS_V
Extract 5	20120509_46-60_M_DS_V
Extract 6	20120620_46-60_M_DS_Y
Extract 7	20120620_46-60_M_DS_Y
Extract 8	20120620_46-60_M_DS_Y
Extract 9	20120617_26-34_F_DZ_Z_(E)
Extract 9.1	20120617_26-34_F_DZ_Z_(E)
Extract 10	20120615_TH_F_OJ_V
Extract 10.1	20120615_TH_F_OJ_V
Extract 11	20120509_46-60_M_DS_V
Extract 11.1	20120509_46-60_M_DS_V
Extract 12	20120512_18-25_M_DS_24
Extract 12.1	20120512_18-25_M_DS_24
Extract 13	20120617_35-45_M_DZ_X (E)
Extract 13.1	20120617_35-45_M_DZ_X (E)
Extract 14	20120615_26-34_M_DZ_V
Extract 15	20120202_18-25_M_FG_DS_Z_(E)
Extract 16	20120202_18-25_M_FG_DS_Z_(E)
Extract 17	20120615_26-34_M_DZ_V
Extract 18	20120612_35-45_F_DS_T
Extract 19	20120512_18-25_M_DS_S
Extract 20	20120510_26-34_F_DS_S_(E)
Extract 21	20120614_14-17_FG_M_OJ_K
Extract 22	20120616_26-34-F_OJ_Z
Extract 23	20120511_46-60_M_DS_S
Extract 24	20120614_14-17_FG_F_DS_K_(E)
Extract 25	20120614_14-17_FG_F_DS_K_(E)
Extract 26	20120617_26-34_FG_M_DS_OJ_R_(E)
Extract 27	20120512_26-34_M_DS_S_(E)
Extract 28	20120511_46-60_M_DS_S
Extract 29	20120616_26-34_F_OJ_Z
Extract 30	20120616_26-34_F_OJ_Z
Extract 31	20120511_46-60_M_DS_S
Extract 32	20120511_46-60_M_DS_S
Extract 33	20120617_46-60_FG_M_DZ_S

Extract 34	20120510_26-34_F_DS_S_(E)
Extract 35	20120512_26-34_M_DS_S_(E)
Extract 36	20120614_14-17_FG_M_OJ_K
Extract 37	20120510_18-25_M_DS_S
Extract 38	20120512_26-34_M_DS_S_(E)
Extract 39	20120618_26-34_F_OJ_S_(E)
Extract 40	20120617_35-45_M_DZ_X_(E)
Extract 40.1	20120617_35-45_M_DZ_X_(E)