

UNIVERSITY OF KWAZULU-NATAL

**AN EXPLORATORY STUDY TOWARDS DISCLOSURE OF STATUS
AND REDUCTION OF STIGMA FOR PEOPLE LIVING WITH
HIV/AIDS IN A LOW INCOME COMMUNITY: THE DEVELOPMENT
OF A COMMUNITY-BASED FRAMEWORK**

AYISHA RAZAK

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AND REDUCTION OF STIGMA FOR PEOPLE LIVING WITH HIV/AIDS
IN A LOW INCOME COMMUNITY: THE DEVELOPMENT OF A
COMMUNITY-BASED FRAMEWORK**

BY

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DEDICATION

This thesis is dedicated to my children, Shabnam, Gulshan and Mohammed Ishruth, my son-in-law, Ahmed Mahomed Cassoo and my adorable grandson, Talha for their love, encouragement and support through this journey.

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My children, Shabnam, Gulshan and Mohammed Ishruth for their love, support, understanding and perseverance.

DECLARATION

I Ayisha Razak, declare that this thesis titled “An exploratory study towards disclosure of status and reduction of stigma for people living with HIV/AIDS in a low income community” is my original work and has not been submitted to any other university except the University of Kwazulu-Natal (Durban). The sources of information that I have used in this work have been acknowledged in a complete reference list.

Student's Signature

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Supervisor

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Co-supervisor

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ABSTRACT

Introduction: Stigma associated with HIV/AIDS creates a barrier to prevention, care and treatment of HIV/AIDS. It further restricts PLWHA from learning about their status, disclosing their status, adopting safe behaviour and accessing services such as antiretroviral treatment. Disclosure of HIV status and a reduction in stigma may contribute to the decrease in new HIV cases.

Purpose: The purpose of the study was to develop a community-based framework that would encourage people living with HIV/AIDS to disclose their HIV status and reduce the stigma associated with the disease.

Method: This study used the action research method to explore the experiences of stigma and disclosure of HIV status and to develop a community based framework with PLWHA who encouraged disclosure and promoted the reduction of stigma in a community-based setting. The research setting was Bhambayi, an informal settlement in the district of Inanda. Non-probability purposive sampling was used. In-depth interviews with PLWHA that had disclosed their HIV status and focus group discussions with family members, adult children and community members were conducted.

Findings: The data was analyzed manually and the following categories and subcategories emerged. The categories were experience of disclosure, stigmatizing reactions, lifestyle changes after disclosure and supports to reduce stigma. Some of the sub-categories were ‘opens out the illness’, gossiping and pointing fingers, discrimination against PLWHA by family and community, changes in relationships, community awareness and formation of support groups. The findings revealed that PLWHA that had disclosed their HIV status had changed their

lifestyles. Recommendations were made on the need for nurses to develop community engagement projects and establish partnerships in order to reach out to communities regarding HIV/AIDS. Incorporate HIV/AIDS stigma and discrimination into the current nurses' curriculum. The need for research is expressed on the evaluation of the framework and conducting similar research in larger communities.

Conclusion: PLWHA who had disclosed their HIV-status shared their experience of being HIV-positive and encouraged other people to get tested. The community-based framework to facilitate disclosure and reduce stigma among PLWHA can be operationalised in other informal community-settings.

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LIST OF ACRONYMS

AIDS	:	Acquired Immune Deficiency Syndrome
ARRM	:	AIDS Risk reduction Model
ART	:	Antiretroviral Treatment
ARV	:	Antiretroviral
BRDC	:	Bhambayi Reconstruction and Development Committee
CBD	:	Central Business district
CCG	:	Community Caregivers
GIPA	:	Greater Involvement in People Living with HIV/AIDS
HAART	:	Highly Active Antiretroviral Treatment
HCT	:	HIV Counselling and Testing
HIV	:	Human Immuno Deficiency Virus
ICHC	:	Integrated Community-Based Home-Care
ICRW	:	International Centre for Research on Women
NGO	:	Non Governmental Organisation
NIH	:	National Institute of Public Health
PLWHA	:	People Living with HIV/AIDS
PMTCT	:	Prevention of Mother to Child Transmission
SLT	:	Social Learning Theory
TB	:	Tuberculosis
UNAIDS	:	United Nations Joint Programme on HIV/AIDS
UNHCR	:	United Nations High Commissioner for Refugees
UNICEF	:	United Nations Children's Fund
USA	:	United States of America

USAID : United States Agency of International Development
VCT : Voluntary Counselling and Testing
WHO : World Health Organisation

CHAPTER 1

INTRODUCTION

1.1 Background to the Study

According to an epidemiological survey conducted in 2007, Human Immunodeficiency Virus (HIV) and the associated Acquired Immune Deficiency Syndrome (AIDS) remain a public health challenge in South Africa (National Department of Health of South Africa, 2008). Since the onset of the HIV epidemic more than 60 million people have been infected and 30 million have died from HIV-related causes (UNAIDS Global Report, 2010a). HIV/AIDS continues to be a worldwide public health burden with an estimated 33.3 million people living with HIV in 2009 in comparison to 26.2 million in 2004. Across the world mortality from AIDS-related deaths stood at 1.8 million in 2009, a decrease from 2.1 million in 2004 (UNAIDS Global Report, 2010a). The trend is that more adult women aged 15 years and older are now living with HIV. There were 17.7 million women living with HIV in 2006, an increase of one million in comparison to 2004 (UNAIDS, 2006). The global incidence of HIV has declined from 3.1 million in 1999 to 2.6 million in 2009 (UNAIDS Global Report, 2010a). New HIV infections have declined by more than 25% between 2001 and 2009 in 33 countries, 22 of which are in sub-Saharan Africa (AIDS Scorecards, 2010).

Africa is the epicentre of the AIDS pandemic with an estimated 22.5 million adults and children living with HIV in sub-Saharan Africa at the end of 2009. This figure accounts for 68% of the

world's HIV infected population and 75% of AIDS deaths in the world (UNAIDS Global Report, 2010b). The Southern Africa region has some of the highest HIV infection rates in Africa estimated at 25.9%, while Botswana stands at 23.9%, Lesotho at 23.2% and Namibia at 15.3%.

Based on the 2009 National Antenatal Prevalence Study the HIV prevalence in South Africa is presented in Table 1.1.

Table 1.1 HIV Prevalence in South Africa

Year	Age Group	Prevalence
2009	Women aged between: 15 and 49 years	29.4%
	Women aged: 20 – 24 years	21%
	Men aged: 20-24 years	7%
	Adults Aged: 15 – 49years	17%

(Department of Health, 2010; UNAIDS Global Report, 2010b)

KwaZulu-Natal continues to report an increase in HIV prevalence from 38.7% in 2008 to 39.5% in 2009 (Department of Health, 2010). There has been a steady decline in the HIV prevalence trends in the 15-19 years age group from 16.1% in 2004 to 15.9% in 2005 and then to 13.7% in 2006 and to 12.9% in 2007 (National Department of Health South Africa, 2008). However, there has been an increase of 6% in the HIV prevalence in the older age of group 35-39 years in the last four years. These figures range from 29.3% in 2006 to 32.4% in 2008 and 35.4% in 2009

(Department of Health, 2010). The total number of people living with HIV in South Africa was estimated at 5.6 million in 2009 (UNAIDS Global Report, 2010b). This figure includes 184,680 children in the age group 0-14 years (National Department of Health of South Africa, 2008).

Dr. Des Martin of the South African HIV Clinicians' Society describes the epidemic as follows: "South Africa is host to a burgeoning HIV epidemic of catastrophic proportions" (UNAIDS, 2006:8). HIV/AIDS in South Africa is a complex social issue underpinned by issues of poverty, lack of empowerment of women, gender violence and the legacy of the apartheid era (UNAIDS 2006). Other factors that contribute to the epidemic are related to sexual behaviour and exposure to high risk groups such as truck drivers, prisoners and mining communities (National Department of Health of South Africa, 2008).

The AIDS pandemic has a profound impact on many nations, negatively affecting their economic growth, with the burden of the disease and workplace stress compounding the problem. Dr. Martin, of the South African HIV Clinicians' Society highlights the fact that the epidemic has discriminated against and stigmatised those who suffer from HIV/AIDS (UNAIDS, 2006). Individuals, households and communities are equally affected by the impact of HIV/AIDS (Kates and Wilson-Leggoe, 2005). The working population is hardest hit in sub-Saharan African countries as skilled workers are lost to the epidemic and the impact of AIDS in the education sector has contributed to serious shortages of educators in several African countries (Kates and Wilson-Leggoe, 2005). The enormous demand for health care services in many developing countries impacts negatively on the overall public health infrastructure. A large number of health care workers are also lost due to AIDS. As a consequence the labour force could be as

much as 35% smaller in some sub-Saharan African countries by 2020 (Kates and Wilson-Leggoe, 2005).

The increase in new HIV infections and AIDS related deaths worldwide has prompted the global community to scale up available prevention strategies in 125 low and middle income countries. According to the global figures, an estimated two million life years were gained through the expanded provision of antiretroviral (ARV) treatment since 2002 in low and middle income countries. The life expectancies in several highly-affected countries could drop to below 40 years in 2010 (Kates and Wilson-Leggoe, 2005). The South African average life expectancy at birth in 2008 was 52 years (UNICEF-South African Statistics, 2010) and according to the South African mid-year 2010 population statistics, the life expectancy of South Africans was estimated at 53.3 years for males and 55.2 years for females (Statistics South Africa, 2010). The increase in the life expectancy from the estimate of 50.7 years in 2006 (Knight, 2006) to 52 years in 2008 and may be attributed to the increased availability of antiretroviral treatment. The latest UNAIDS/WHO '3 by 5' data indicate that from June 2006 more than 1.6 million people living with HIV have been receiving ARV therapy in low and middle income countries. The coverage of antiretroviral therapy in low and middle income countries increased from 7% in 2003 to 24% in June 2006 (UNAIDS, 2006).

The most significant problems for people living with HIV/AIDS include the stigma attached to the disease, fear of disclosure and the delays in testing (HRSA Care Action, 2003). HIV/AIDS stigma is a global phenomenon and people have been stigmatised since the diagnosis of the first cases of HIV/AIDS in the United States of America (USA). People living with HIV/AIDS

(PLWHA) were discriminated against in the workplace, in social settings and even when attempting to secure safe housing (HRSA Care Action, 2003). The stigma of HIV/AIDS severely affected PLWHA in most communities with people being punished for simply revealing their HIV status (HRSA Care Action, 2003).

‘Stigma’ has been defined as a discrediting attribute that examines the insider’s view as the ‘emic’ and the outsiders view as the ‘etic’ perspective (Goffman, 1963 cited in Holzemer et al. 2007). PLWHA are affected both by cultural and personal perceptions, as well as by the perceptions of others who are observers. AIDS stigma is further categorised by Project Siyamkela [2003] as received stigma, internal stigma and associated stigma. ‘Received stigma’ is described as stigmatising behaviour experienced by PLWHA that is categorised as neglect, fear of contagion, rejection, labeling, abuse and gossip. ‘Internal stigma’ arises from the person’s negative thoughts and perceptions about ‘self’ based on their HIV status. It is categorised as perception of self, social withdrawal, self-exclusion and fear of disclosure. ‘Associated’ stigma results from a person’s association with HIV positive people either living with them or working with them. ‘Etic’ stigma relates to received and associated stigma while ‘emic’ stigma relates to internal stigma (Holzemer et al., 2007). An important strategy in the eradication of HIV/AIDS stigma may be HIV/AIDS education (Holzemer et al., 2007).

Stigma and discrimination are closely aligned because discrimination constitutes the acts in which the content of stigma is applied on an individual, community, or society level. Discrimination against illness has a history in society in general: people with mental illness as well as physical disorders such as cancer, tuberculosis, sexually transmitted infections and

leprosy are often victims of discrimination. AIDS stigma and discrimination is based on associations with and presumptions about race, gender, homosexuality, drug use and promiscuity. Communities that are affected by HIV are discriminated against due to skin colour, gender, sexual orientation, type of work (such as prostitution), or geography such as the entire continent of Africa or sub-Saharan Africa (Skinner and Mfecane, 2004).

The fear of rejection and feelings of dependence or shame discouraged HIV positive people from disclosing their status. A sense of moral responsibility manifests as a need for disclosure, a need for support and concerns about the individual's health. When individuals are no longer in a position to keep their health status a secret, they then disclose to family and friends. Individuals that are on highly active antiretroviral treatment (HAART) have the choice of selective disclosure. The therapeutic effect of HAART impedes or delays disclosure, thereby allowing individuals to appear healthy and avoid the stigmatising signs of advanced AIDS (Klitzman et al., 2004).

HIV positive people who disclose their status risk exposing themselves to ridicule, rejection, ostracism and alienation from their families and communities (Harrison, 2006). HIV positive men are blamed for their promiscuous behaviour and are often victims of the perception that contracting the disease is a 'just punishment' for their choices. Women experience gender bias, moral judgment and the cultural perception that they are responsible for spreading the disease. People living with HIV are also blamed for a host of social misfortunes. Out of fear therefore, they do not disclose their HIV status. Many people who have disclosed their HIV positive status

have been forced out of their homes; have experienced loss of emotional and financial support and/or verbal and physical abuse (Harrison, 2006).

The HIV-positive person has the choice to disclose or conceal his/her status. The fear of disclosure is associated with the risk of being stigmatised or overtly rejected by people who subtly distance themselves from people with the disease. The advantages of disclosure are access to voluntary counselling and testing as well as support from family and friends. The disadvantages are social isolation and diminished access to health and social services due to the fear of being stigmatised. Disclosure has a negative impact on a person's family and personal relationships, as well as their educational, occupational and financial opportunities (Greeff et al., 2008). The need to seek help is crucial in improving the care, quality of life and emotional health of PLWHA. Interventions directed at reducing HIV related stigma help in the reduction of new HIV infections (HRSA Care Action, 2003).

HIV/AIDS has a strong association associated with poverty. A study by Tladi (2006) established and explained the link between HIV/AIDS and poverty using the South African Demographic and Health Survey data. In a study by Booysen (2004) cited in Tladi (2006) poorer women engaged in more risky sexual behaviour, lacked control over their decisions regarding financial issues and lacked knowledge about the use of condoms. Households which have a monthly income of less than R1000 per household cannot bear the cost of caring for an HIV/AIDS family member (Tladi, 2006).

A number of incidents of stigma and discrimination have been reported worldwide. In South Africa, Skinner and Mfecane, (2004), cite the murder of Gugu Dlamini in Durban in December 1998 for openly stating that she was HIV positive. Mpho Mtloung and her mother were murdered by her husband in the year 2000 for the same reason. In 2004, Lorna Mlofane was raped and later murdered by her three rapists after they learned that she was HIV positive. In many cases HIV positive children have been denied admission into schools, the best known of these was Nkosi Johnson in Johannesburg. The practices of exclusions extend to the workplace, within the military, in homes, communities and rejection from families (Skinner and Mfecane, 2004). In Kenya, a woman was deprived of her inheritance after her husband died of an AIDS-related illness and she was blamed by her in-laws for bringing HIV into the household (USAIDS, 2006). Health care workers in Ukraine coerced a pregnant woman into being sterilised after they discovered her HIV positive status during delivery (USAIDS, 2006). When monks started providing support to AIDS orphans in Cambodia, community members avoided the local temple. In Vietnam, HIV positive injection drug users were denied access to antiretroviral therapy. In Mexico, a man was fired after being diagnosed with tuberculosis because his fellow workers feared that he may be HIV positive (USAIDS, 2006).

Stigma associated with HIV acts as a barrier to the prevention, care and treatment of HIV and AIDS (ICRW HIV/AIDS Stigma, 2006). Any attempt at reducing stigma may help to reduce new HIV cases (HRSA Care Action, 2003). Research studies in Ethiopia, Tanzania, Vietnam and Zambia relating to HIV/AIDS stigma led to the development of an HIV stigma-reduction toolkit that people in communities can use to combat stigma. These interventions in stigma research have made the provision of a holistic and effective way of combating stigma. The

outcomes of these interventions have impacted on improving both the quality of HIV/AIDS programmes and the lives of people living with HIV and AIDS (ICRW HIV/AIDS Stigma, 2006).

1.2 Problem Statement

Stigma arguably remains the biggest challenge to HIV reduction programmes. Stigma restricts people from learning about their HIV status, disclosing their status, adopting safe behaviour, accessing services and caring for people living with HIV/AIDS. It further creates barriers for women accessing services (eg, PMTCT) and intensifies the pain and suffering of PLWHA and their families. Ultimately, stigma fuels the spread of HIV (Hogan, 2003). According to the UNAIDS Global Report (2010a), more than 90% of governments had included stigma and discrimination reduction in their HIV programmes but less than 50% had budgeted for such programmes.

According to Kehler (2006), policies to address HIV-related stigma have been minimal. The reason for this slow response is that stigma could not be meaningfully addressed because it was believed to be cultural, context-specific, and a sensitive issue (Kehler, 2006). Stigma and the fear of discrimination restrict PLWHA in the choices they make. The impact of stigma on the health care system results in barriers that HIV positive individuals encounter in accessing health care. Health care providers' fear of contagion and death can have a negative impact on their attitudes toward and treatment of HIV positive patients. Providers of ancillary and support services to people living with HIV/AIDS fear stigmatisation themselves because of their work with HIV positive patients (HRSA Care Action, 2003).

Stigma discourages people from disclosing their HIV positive status to their spouses or others because of the fear of discrimination (ICRW HIV/AIDS Stigma, 2006). Society expects women to uphold its moral traditions. Women tend to be more stigmatised for having ‘failed’ as proper women or are blamed for ‘bringing’ HIV into the family or marriage (ICRW HIV/AIDS Stigma, 2006). HIV/AIDS stigma is thus a barrier to disclosure. Disclosure of HIV status is a complex issue but is viewed as an important step in breaking the silence of HIV/AIDS. HIV-positive people who disclose their positive status are in a strong position to increase awareness of the disease, extend their support to other HIV-positive people, and encourage others to take preventive measures so that they do not get infected. This could be possible if an enabling environment was created which encouraged HIV-positive people to disclose without increasing their vulnerability (Harrison, 2006). The problems that HIV-positive people encounter are the social realities and complex issues that restrict their ability to make decisions about disclosing their status (Harrison, 2006). According to Harrison (2006:3) “there is a conspiracy of silence in South Africa where ignorance and lack of understanding are the source of much prejudice and discrimination”.

PLWHA fear the negative consequences of disclosure and do not negotiate safe sex or access available prevention methods. They do not disclose their HIV-status, nor do they seek available treatment, support and care (Kehler, 2006). Disclosure of HIV status is an important aspect in creating awareness and openness about the disease and may lead to de-stigmatisation of HIV/AIDS (Ncama, 2007). Disclosure removes the mystery surrounding HIV. Disclosure of HIV-status to family or friends also increases the awareness of the disease and prepares

individuals to take the necessary precautions to protect themselves from being infected (Harrison, 2006). PLWHA who disclose their status experience an improvement in their mental and physical health through increased acceptance of their condition, and a reduction in the stress of having to cope with their illness in secrecy (Harrison, 2006). An increase in the number of PLWHA disclosing their HIV status will reduce the stigma, discrimination and denial that surround HIV/AIDS (Linch, 2004).

In the South African context, the issue of stigma and disclosure recurred as a common theme in the Integrated Community-based Home Care (ICHC) model. In the ICHC model, staff felt that it was essential that people with AIDS disclose their status so that teaching can be directed at individuals, families and the community at large (Uys, 2001). Models that were developed in the past have not paid special attention to what needed to be incorporated in the models that would facilitate disclosure of status among the PLWHA. The models did not give special attention to the aspects of stigma reduction that have been shown to be related to status disclosure (Uys, 2001). In view of the above discussion, it is clear that the challenge for this study is to explore the development of a community-based framework for people living with HIV/AIDS which will help them to disclose their status and as a result, experience a reduction in HIV-related stigma in the community.

The study was conceived from the observations made while working in the Bhambayi Settlement Project where it was found that not all of those diagnosed with HIV/AIDS had disclosed their HIV status to their significant others. The Bhambayi Settlement Project coordinator identified 177 patients from clinic records of Newtown C clinic for the period February 2004 to July 2004.

These clinic statistics indicated a 28.6% morbidity rate of people from Bhambayi who attended the Newtown C clinic. The disease profile of the people from Bhambayi who attended the clinic has been summarised from the data obtained at the clinic. There were a total of 177 patients. Most of the patients were diagnosed with tuberculosis, followed by HIV/AIDS while the lowest numbers were those with pneumonia, cancer and shingles. The results are presented in

Table 1. 2.

**Table 1.2 Disease Profiles of People from Bhambayi at Newtown C Clinic
(February-July 2004)**

Tuberculosis (TB)	79 (44.6%)	Asthma	8 (4.5%)
HIV/AIDS	74 (41.8%)	Diarrhoea	7 (3.9%)
Arthritis	18 (10.1%)	Sores	4 (2.2%)
Epilepsy	9 (5%)	Mental Illness	3 (1.6%)
Diabetes Mellitus	10 (5.6%)	Pneumonia	2 (1.1%)
Hypertension	13 (7.3%)	Cancer	2 (1.1%)
Stroke	12 (6.7%)	Shingles	1 (0.5%)

(Newtown C Clinic Records 2004 – extracted by researcher)

The clinic statistics show that only 74 patients had HIV/AIDS and this raises concern about disclosure of HIV status among these patients. The issues pertaining to stigma and disclosure of

HIV status of people in the community were discussed at great length with key community members present at the meeting. This discussion was an important step towards raising awareness among community leaders about the extent of the problem of the HIV/AIDS stigma.

1.3 Purpose of Study

The purpose of the study is to develop a community-based framework that would encourage people living with HIV/AIDS to disclose their HIV status and reduce the stigma associated with the disease.

1.4 Research Objectives

The objectives of the study are to:

- Describe the experiences of PLWHA who have disclosed their HIV status within the community
- Describe PLWHA's experiences of stigma in relation to their HIV status within the community
- Explore the factors that would encourage disclosure of HIV/AIDS status within the community
- Explore the factors that promote the reduction of stigma within the community and
- Develop a community-based care framework that would encourage disclosure and reduce HIV/AIDS stigma.

1.5 Research Questions

The research questions are:

- What are the experiences of disclosure among HIV positive people within the community?
- What are the experiences of stigma among HIV positive people within the community?
- What are the factors that would encourage PLWHA to disclose their HIV positive status within the community?
- What are the factors that would promote the reduction of stigma among PLWHA within the community?
- What community-based framework would encourage the disclosure of HIV-positive status and promote the reduction of stigma?

1.6 Significance of the Study

The increase in disclosure and the reduction of stigma are of fundamental importance to the reduction of new HIV infections in South Africa. PLWHA are in a position to set up programmes that would encourage disclosure of HIV status and reduce stigma associated with HIV. The reduction of stigma cannot be achieved without changing or/modifying behaviour at an individual and societal level. HIV prevention strategies have empowered individuals to make informed choices about behavioural changes (Kehler, 2006). The researcher intends to solicit the support of key role players in the community in supporting the efforts of PLWHA who have disclosed their status, with a view to reducing stigma.

This study contributes to the current body of knowledge by developing a community-based framework that encourages PLWHA to disclose their HIV status and therefore reduce stigma. Currently the greatest health priority is the prevention of new HIV- infections (Harrison, 2006) and it is believed that this could be better achieved through the disclosure of HIV status, the adoption of preventive behaviour, and the education and awareness about HIV/AIDS. This framework could be a useful guide for nursing practice in relation to examining the factors that contribute to the decision to disclose, the process of disclosure and its impact on HIV positive people (Chandra et al., 2003).

The contribution to education would be to inform the nursing curriculum with reference to the inclusion of disclosure and HIV/AIDS stigma and discrimination. Patients' concerns regarding disclosure to health care professionals centre around the fear of loss of confidentiality; the difficulty in obtaining health insurance and the delay in seeking health care among HIV-infected individuals (Chandra et al., 2003).

This study could inform policy formulation and implementation by incorporating the community-based framework into the health care system as an extension of services at community level, including administrators, managers and other health care professionals.

Future research in the area of disclosure of HIV status and the reduction of HIV/AIDS stigma should test the community-based framework and its feasibility in other settings with similar

characteristics in order to inform evidence-based practice in order to improve the quality of care for PLWHA.

1.7 Operational Definitions

The key concepts are defined to indicate their meaning in the context of this study.

1.7.1 Disclosure of HIV Status

Disclosure of HIV status means revealing one's HIV positive status either to one's sexual partner, family member/s, children, public or significant others.

1.7.2 Stigma

Stigma is an undesirable or discrediting attribute that reduces an individual's status in the eyes of society. Society attaches labels to people by calling them names and conveying a social identity that is devalued in a particular social context (Monjok et al., 2009)

1.7.3 Community-based Approach

A community-based approach is a fundamental mechanism to stimulate communities to gain their support to deal with HIV/AIDS. It reinforces the dignity and self-esteem of people to work together and to support members of the community in exercising their human rights (Alam, 2010; UNHCR, 2007).

1.8 Conclusion

This chapter presents the background to the study, the problem statement, purpose of the study, research objectives, research questions, significance of the study and the operational definitions.

In Chapter Two the literature is examined within the context of the extent of the problem of HIV/AIDS, disclosure of HIV status, stigma, HIV/AIDS stigma, discrimination and stigma reduction. Models and theories of behaviour change are examined with the intention of selecting a conceptual framework that will guide the study.

Chapter Three addresses the methodology that is used in this study and Chapter Four presents a descriptive analysis of the findings and the integration of the Stages of Change model with the Action Research. Chapter Five examines the stages of change model and presents cycle four and five as discussion of reflections by the researcher, conclusions from the findings, the development of an intervention in cycle five is the development of a framework for the disclosure of HIV status and the reduction of stigma, framework for the facilitation of disclosure of HIV status and the reduction of stigma, recommendations and limitations of the study.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter describes the magnitude of HIV/AIDS, disclosure of HIV status, stigma, impact of stigma and HIV/AIDS, discrimination against HIV and stigma reduction regarding HIV. The support systems such as social support, support groups, community caregivers, voluntary counselling and testing, antiretroviral treatment and community interventions are discussed as these are issues that have a bearing on the disclosure of the HIV status and the reduction of stigma. The models and theories of behaviour change are described in order to support the choice of a model/theory for behaviour change that is used as a conceptual framework in this study. The theories that precede the conceptual framework are the Social Learning Theory, Theory of Reasoned Action/Theory of Planned Behaviour, Health Belief Model, AIDS Risk Reduction Model (ARRM) and the Stages of Change/Transtheoretical Model. The Stages of Change/Transtheoretical Model is used as a conceptual framework for this study.

The literature review helps to provide background information and an understanding of the research topic. It also provides an overview of existing evidence on the problem being researched (Moule and Goodman, 2009). Information from the literature is used to compare findings from the present study to determine similarities and differences from prior research. *Google Scholar* was used to search for literature using the key words ‘stigma’, ‘disclosure’ and ‘HIV/AIDS’. Relevant literature pertaining to HIV/AIDS, stigma and disclosure were

downloaded from international agencies such as the United Nations Joint Programme on HIV/AIDS (UNAIDS), International Center for Research on Women (ICRW), United States Agency of International Development (USAID) and UNICEF. Other data-bases that were used to retrieve literature include PubMed/Medline, Sabinet, AIDS South Africa, Statistics South Africa, AIDS Care, National Institute of Public Health (NIH) Public Access, HRSA Care Action, HIV/AIDS Statistics South Africa, Department of Health, Pathfinder, Horizons, Department of Social Development and the Health Systems Trust. Some online journals were retrieved from publishers such as Emerald, American Sociological Association, Taylor and Francis Health Sciences, Edward Arnold, Routledge, The Guild for Press, AIDS Legal Network and the British Medical Journal.

The conceptual framework was used to design the structure of the literature review as well as the questions for the interview guides. Some of the questions in the guide for PLWHA were directly linked to the action and maintenance stages of the conceptual framework together with the processes of change. The questions focused on one's disclosure of HIV status to family members, the feelings experienced after disclosure and lifestyle changes. The action stage explored the changes that occurred after disclosing one's HIV status and modifying behaviour by engaging in a monogamous relationship and using condoms. The maintenance stage examined how PLWHA adopted the new model of behaviour such as settling into a monogamous relationship or abstaining from sexual intercourse or using condoms for periods exceeding six months. The process of dramatic relief underpins the feelings experienced after disclosure and the knowledge of one's HIV status. The processes of consciousness raising, self re-evaluation, stimulus control and helping relationship follow modifying behaviour. The adoption of the new

behaviour to replace current problem behaviours is linked to the processes of counter-conditioning, reinforcement management and self-liberation.

The stages and the processes of the conceptual framework emerged alongside the findings in the categories and sub-categories. The Action Stage (disclosure of HIV status/modify behaviour) includes the processes of consciousness raising, dramatic relief and self re-evaluation. The Maintenance Stage incorporates the processes of counter-conditioning, reinforcement management and self-liberation. The application of the action and maintenance stages shows the use of the conceptual framework in the discussion of the study findings. The integrative nature of the conceptual framework is applicable to individuals, families and communities so people's intention to change their behaviour impacts on families and communities. The changes evolving from action research are systematically integrated into the life of the individuals, families and communities. The research participants who will engage significantly in the processes of change, experience an improved quality of life thereby effecting a change in communities (Stringer, 2007).

Qualitative researchers do not generally conduct literature reviews prior to conducting the research study. Some qualitative researchers have different viewpoints on accepting a cursory review of the literature that may assist with the focus of the study. The rationale for not conducting the literature review at the outset is to reduce any biases, suppositions or preconceived notions that the researcher may develop about the topic. Qualitative researchers find it essential to conduct the literature review after data analysis in order to place the study in the context of existing knowledge. The purpose of the literature review at this stage is to inform

the reader how the findings fit phenomenon that is in existence (Speziale and Carpenter, 2003; Nieswiadomy, 2008).

According to Speziale and Carpenter (2003:265), “review of the literature is an activity that takes place throughout the study”. However, the literature review forms part of informing the planned change or action in line with data collection. In action research, the focus is on local problems, “the literature review most likely will not yield directly applicable information” (Speziale and Carpenter, 2003:265).

In qualitative research, any viewpoints regarding the extent to which literature is used prior to data collection to guide qualitative research may be based on the philosophical underpinning. In the current study literature was reviewed prior to data collection in order to be selective about the literature that is relevant for the study. The critical content analysis assists the researcher in deriving explanations from previous research results and then using these to substantiate the results or prevailing theories. The topics for discussion are also identified from the literature that relates to the field of research. Literature reviews also allow the researcher to identify problems in a mutually collaborative manner (Morse and Field, 2002).

The processes of social liberation and self-liberation are akin to action research, among other processes in the conceptual framework. The process of social liberation increases social opportunities for deprived and oppressed people. The upliftment of impoverished people is an outcome of action research which focuses on oppressed communities and gives them a voice

(Speziale and Carpenter, 2003). Social liberation also increases opportunities for behaviour change in under-resourced communities (Velicer et al., 1998). Action research implements action or changes in behaviour, develop action plans to resist change, empowers participants and develops local theory (Speziale and Carpenter, 2003). The fundamental characteristic of empowerment and giving people a voice features in both action research and the conceptual framework (Velicer et al., 1998; Speziale and Carpenter, 2003).

The argument that the conceptual framework and action research approach is contradictory can be refuted because behaviour change in the conceptual framework focuses on individuals and the purpose of action research is to bring about change in groups or organizations targeting individuals (Velicer et al., 1998; Speziale and Carpenter, 2003). According to Speziale and Carpenter (2003) the potential to drastically change the life experiences of many individuals lies within the realms of action research. Munhall (2007) refers to change in action research as an outcome and process and this concurs with behaviour change in the Stages of Change Model/Transtheoretical Model (Velicer et al., 1998). The similarities in both approaches lie in their focus on change, and the fact that something that is problematic is studied by the people who experience it. The people involved are responsible for the actions taken as they are the stakeholders and the voice in decision making (Munhall, 2007; Velicer et al., 1998).

Corbett et al. (2007) explored the relationship between participatory action research (PAR) and feminist theory with the premise that both philosophical premises share a common goal that informs and is informed by critical social theory. The feminist approach is chosen as a suitable methodology for changing practice. The central tenets of feminism embrace empowerment, self-

determination and the facilitation of agreed change that guides the research process. The difference between action research and PAR is that action research engages with people who have power and control and PAR is developed and utilized with disempowered people. It can be argued that “PAR arose as a separate research methodology within the critical paradigm out of action research” (Corbett et al., 2007:82). The feminist approach to PAR is firmly situated within the larger paradigm to human inquiry which is part of the emancipatory approach that encourages the less powerful and voiceless people to act boldly (Corbett et al., 2007).

Froggatt and Hockley (2011) described PAR including its origins, principles and its relationship with evaluations frameworks. The evaluation in their study focused on the impact of the intervention, the process of action research using the Aldrevast Sjuharad (AVS) Model to evaluate participation in a peer education programme for advance care planning among older adults. Action research is situated within the participatory research paradigm. The action research methodology bridges the gap between theory and practice through a cyclical process that involves action and reflection (evaluation). The use of a conceptual framework to structure an evaluation method within PAR studies is presented to illustrate the use of different evaluative methods in palliative care (Froggatt and Hockley, 2011). The action research case study incorporated a participatory framework based on critical theory that extended for a period of five years. The researcher worked collaboratively with the staff through reflective de-briefing sessions (RDBSs) on death and dying (Froggatt and Hockley, 2011).

In action research a conceptual framework serves a dual purpose, firstly to guide the data gathering and analysis process, and secondly it is embedded in an action research approach. The

more utilitarian, functionalist framework is usually compatible and follows from a technical knowledge interest. The more constructivist interactionist framework follows from a practical knowledge interest and an emancipatory knowledge interest leads to a neo-Marxist, feminist and critical race theories. Action research is aligned to organizational development which is a combination of a technical and practical knowledge interest as opposed to PAR which has an emancipatory knowledge interest (Herr and Anderson, 2005).

The literature that is drawn from the study allows the researcher to develop an in-depth understanding of the issues under study within the cycles of plan-act-observe-reflect. The body of literature sheds light on the findings with the result that data analysis is pursued by relevant literature through the contribution of this action research. Action research is seen as contributing solely to local knowledge and practices rather than to the knowledge bases of other disciplines (Herr and Anderson, 2005).

2.2 Magnitude of HIV/AIDS

Globally, HIV still remains a health problem with more than 60 million HIV infected people and an estimated 30 million deaths in the past 30 years (UNAIDS Global Report, 2010a). Although the estimated rate of deaths from AIDS has declined globally due to the success in expanding access to antiretroviral drugs in resource-limited settings, the incidence of HIV is still on the increase with a ratio of 2:1. In other words, for every two new infections, one person commences ARV treatment. An estimated 37% of adults and children in sub-Saharan Africa received antiretroviral treatment in 2009 and the result was a 20% decrease in AIDS-related deaths. In

Kenya, AIDS-related deaths declined by 29% between 2002 and 2007 (UNAIDS Global Report, 2010b). The percentage of people living with HIV has stabilised since 2000, with a global reduction of nearly 20% in new infections in the past decade (UNAIDS Global Report, 2010a). In addition the number of new infections globally outnumbered the number of AIDS-related deaths annually (UNAIDS/WHO Report, 2008).

Sub-Saharan Africa shouldered 68% of the global burden of HIV (UNAIDS Global Report, 2010b), 35% of HIV infections and 38% of AIDS deaths that occurred in 2007 (UNAIDS/WHO Report, 2008). The incidence of HIV has stabilised globally except in some regions of the world, such as sub-Saharan Africa. An estimated 45% of new infections occurred in young people aged 15-24 years. The number of children worldwide under 15 years old living with HIV has increased from 1.6 million in 2001 to 2.0 million in 2007. In 2007, an estimated 270 000 HIV infected children under 15 years of age died of AIDS and more than 90% of these live in sub-Saharan Africa (UNAIDS/WHO Report, 2008).

Sub-Saharan Africa is home to two-thirds (68%) of the global total of 32.9 million people living with HIV (UNAIDS/WHO Report, 2008). The reductions in HIV prevalence in Southern Africa is especially striking in Zimbabwe, where HIV prevalence in pregnant women attending antenatal clinics decreased from 26% in 2002 to 18% in 2006. In Botswana, a drop in HIV prevalence among pregnant women aged 15-19 years is noted from 25% in 2001 to 18% in 2006. Malawi and Zambia also show signs of the decreasing HIV prevalence among women attending antenatal services. These are indications of the epidemic stabilising in these countries (UNAIDS/WHO Report, 2008).

HIV prevalence trends in the provinces of South Africa indicate that the epidemic has progressed at a different pace in the different provinces. The Western Cape, Northern Cape and Limpopo have consistently lower levels, while KwaZulu-Natal has the highest HIV prevalence in the country with a rate of 39.5% in 2009 (Department of Health, 2010). HIV prevalence trends in the age group 15-19 years showed a decline nationally from 16.1% in 2004, to 15.9% in 2005, 13.7% in 2006, and 12.9% in 2007. A decline in HIV prevalence serves as a good indicator of the impact of intervention programmes (National Department of Health, 2008).

2.3 Disclosure of HIV Status

Disclosure of HIV status refers to verbally revealing one's HIV status to a sexual partner, family member, or friend (Gobach et al., 2004). Disclosure is the first step in breaking down AIDS related stigma and discrimination. Disclosure is described in many forms such as voluntary, partial, full, involuntary, non-disclosure, and shared confidentiality including managed disclosure. Voluntary disclosure is when an HIV-positive person shares his/her HIV status with other people without coercion and with a positive, desirable effect. Sharing of emotions and HIV-related information forms part of the process of coping with the illness. Voluntary disclosure is when the HIV positive person does not have a choice but to disclose, especially to family and friends who are there to support them (Chandra et al., 2003). Full disclosure is when an HIV-positive person publicly reveals his/her HIV status to another person or organization, a family member, friend, support group or to the media. Partial disclosure is when the HIV-positive person chooses the people he/she wants to tell, whether it is the spouse, a relative, a friend or counsellor. Involuntary disclosure refers to a situation where someone else other than the HIV-positive person reveals the HIV status to the third person without the knowledge or

approval of the HIV-positive person concerned. Non-disclosure means non revelation of one's HIV status to anyone. Shared confidentiality is when a person gives permission to another person to disclose his/her status on their behalf either to family, friends or significant others (Hope, 2004; Greeff et al., 2008). Managed disclosure refers to the ability of PLWHA to control the decision to disclose. In cases where the HIV-positive person has lost control over the decision to disclose, this is referred to as mismanaged disclosure (Greeff et al., 2008).

Disclosure without consent occurs when health professionals reveal test results to family and friends without consulting the HIV positive person (Chandra et al., 2003). In Chandra et al.'s (2003) study, the reasons for non-disclosure included stigma, disgrace to self and family and fear of discrimination. The reason for disclosure in this study is categorised as either being self-focused or for other-focused reasons. A self-focused reason is to elicit emotions and financial support from family and friends. The other-focused reason for disclosure is that the HIV-positive person feels that it is his/her responsibility to disclose so that the partners can be tested (Chandra et al., 2003).

The concept of disclosure is complex and may be potentially associated with significant anxiety, stigma and shame, leading to isolation and threats of personal safety. The reasons for non-disclosure to parents and siblings may be due to personal, health and family concerns, including the emotional needs of children, family finances and associated stresses (Klitzman et al., 2004). The study by Sowell et al., (2003) showed that the majority of women disclosed to their sex partners, close family members and friends and health care providers. Since disclosure of HIV serostatus is a sensitive issue for a woman, the process needs to be supported by health education

and counselling (Sowell et al., 2003). Community leaders and prominent members of society play a major role in promoting the visibility of HIV-positive people by publicly disclosing their status and breaking the silence and fear surrounding HIV/AIDS. HIV-positive people who are leading a successful, productive life can be an inspiration to those affected by the epidemic. Disclosure is regarded as a process of allowing individuals to come to terms with their new status, and fully understanding its implications when they disclose their status to others (USAIDS, 2006).

HIV status disclosure among school children and adolescents is strongly recommended by the American Academy of Paediatrics. Seventy percent of the HIV infected youth reported feelings of normalcy six months post-disclosure (Blasini et al., 2004). Patients (58%) and caregivers (59%) also report improved adherence to therapy after disclosure. Disclosure as a positive event for themselves and their families is expressed by 87% of youth and 97% of the caregivers (Blasini et al., 2004). Disclosure of one's seropositive status to children is problematic, since AIDS is perceived as a death sentence among most Africans. PLWHA who have disclosed their HIV status to their children find life generally less stressful, since undisclosed family secrets are unhealthy and destructive to family members. Children are less confused and anxious because they are aware of their parent's illness and take this opportunity to ask questions about HIV/AIDS and overcome their fears. The reason for non-disclosure to younger children is the fear of traumatising them and the uncertainty of how to answer questions from children about HIV (Moore et al., 2008). In a study by Olley et al. (2004) on self-disclosure of HIV serostatus, it is suggested that interventions to increase the extent of self-disclosure should include helping

PLWHA to alleviate the fear of negative consequences of self-disclosure and working with communities to de-stigmatise HIV/AIDS.

Public health researchers have identified non-disclosure of HIV-positive status to sexual partners as a critical issue in AIDS prevention. HIV positive individuals who know their HIV status and continue to adopt risky sexual behaviour by having unprotected sex could infect a series of unsuspecting partners. Of particular significance to public health is the non-disclosure of HIV status in relation to the prevalence of the disease, risky sexual behaviour and the extent to which unprotected sex is practiced between sero-discordant partners. AIDS intervention programmes should be directed at promoting sexual responsibility and increasing the rates of consistent safer sex among HIV-positive persons (Ciccarone et al., 2003).

2.3.1 Negative Factors and the Impact on Disclosure

The negative factors that influence an HIV-positive person's decision to disclose include the fear of discrimination and the break-up of relationships. The decision about non-disclosure at the workplace relates to fear of discrimination, harassment and anxiety about losing their health benefits. The consequences of disclosure include breaks in intimate relationships, divorce, denial of employment, denial of leadership positions and access to financial resources. Other factors that may influence a person's decision to disclose are stigma, confidentiality, timing, and access to group therapy, involvement in preventive initiatives and participation in support groups (Greeff et al., 2008).

2.3.2 Barriers to Disclosure

The barriers to disclosure in African countries that result in low rates of disclosure are stigma and discrimination, which is very high in many African cultures and leads to low rates of disclosure and access to antiretroviral therapy. Verbal and physical abuse and being chased out of their homes also create barriers to disclosure (Greeff et al., 2008). PLWHA feared the negative reactions from the family and community, of being denied parental and family care, being regarded as promiscuous, rejection, labelling, discriminating and community or family members being violent towards them.

The concern regarding insurance benefits and employment, protection of oneself and others emotionally from physical and verbal abuse also influences disclosure. The rate of disclosure varied among HIV-positive people from the time of diagnosis to disclosure. It is rare for HIV-positive people to disclose immediately after diagnosis as most people need time to come to terms with their illness and talk through their fears with a counsellor. According to Greeff et al. (2008), the average time between diagnosis and disclosure is 2.6 years.

2.3.3 Benefits of Disclosure

The benefits of disclosure extend to the household by creating awareness of the disease so that other members can take precautions to protect themselves (Harrison, 2006). An enabling, supportive environment promotes disclosure of one's HIV status and is beneficial to PLWHA and their families. The benefits of disclosure are the formation and participation in support

groups that encourage people to disclose their status and share their experiences and go for VCT (Greeff et al., 2008).

2.4 Stigma

Stigma and discrimination are attributes that are interrelated and common in all walks of life. The realm of attitudes and perceptions refer to stigma and discrimination in relation to action and behaviour (USAIDS, 2006). Goffman (1963) defines stigma as “an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one” (cited in Hogan, 2003:4). HIV stigma is also defined as a “dynamic process, socially constructed, a form of social control that occurs at all levels of society and in all of us as individuals, often layered on pre-existing stigmas” (Hogan, 2003:4). The USAIDS report (2006) on stigma refers to the negative responses such as rejection, denial, discrediting and social isolation that PLWHA experience from individuals, communities and society. The severity of the stigma is so intense that it leads to discrimination such as racism, homophobia and violation of human rights (USAIDS, 2006). HIV/AIDS related stigma is a powerful combination of shame and fear. Shame is the result of HIV either being transmitted sexually or as a result of intravenous drug usage. These two behaviours are surrounded by taboo and moral judgment. Fear is associated with death because AIDS is generally considered fatal (Anderson, 2004). The attitude and actions of people, even though these may sometimes be unconscious, can be stigmatizing. Other factors associated with HIV related stigma are sex, morality, gender equity and death (Hogan, 2003).

The individuals that are stigmatized have an attribute that is devalued in a particular social context. Stigma is the relationship between an attribute and a stereotype (Link and Phelan, 2004). The attribute is a 'mark' that links a person to an undesirable characteristic, that is, the stereotype (Link and Phelan, 2004). Stigma is conceptualised within these interrelated components that:

- people label others based on distinct differences;
- negative stereotypes and undesirable characteristics are linked to labelled persons;
- the separation of 'us' from 'them' places labelled persons distinctly into categories; and
- loss of status and discrimination results in unequal outcomes (Link and Phelan, 2004).

Stigma associated with HIV could be categorised as pre-existing stigma, HIV-specific stigma and enacted stigma (USAID, 2006). Pre-existing stigma is based on a negative attitude towards sex, the illicit use of drugs, as well as questions of gender, race, sexual orientation and class or economic status. HIV-specific stigma is based on immorality, imminent death and an exaggerated sense of danger. External or enacted stigma is described as a process that moves beyond perceptions and attitudes into actions. Examples of external stigma are testing followed by breach of confidentiality; labelling of PLWHA; avoidance; isolation or segregation and differential treatment. Internal stigma is the manifestation of feelings, emotions and reactions that affect one's sense of self, as well as external physical influences (USAID (a), 2006).

Stigmatisation leads to labelling, devaluing, rejection and exclusion as a result of status loss and discrimination. People with mental illness are discriminated against, labelled as dangerous and devalued. These perceptions have serious negative consequences for a person's worldview that

may result in strained and uncomfortable social interactions with potential stigmatisers. Stigmatisation results in more constricted social networks, a compromised quality of life, low self-esteem, depressive symptoms, unemployment and a loss of income (Link and Phelan, 2004). Stigma with its individualistic focus refers to something in the person rather than a designation that others fix to a person (Link and Phelan, 2004). Stigmatised people respond to self-stigmatisation (that is, internalisation of stigma) especially when PLWHA are in agreement with the social perception of themselves as being devalued. Stigma, discrimination and internal stigma are conceptualised as part of a cyclical continuum. The cyclical continuum describes stigma as a cause of discrimination, discrimination leads to internal stigma, internal stigma in turn reinforces and legitimises stigma (USAIDS, 2006). Stigma associated with HIV is categorised as pre-existing stigma, HIV-specific stigma, and enacted or tangible stigma (USAIDS, 2006). Pre-existing stigma is characterised by the negative attitudes toward sex and illicit use of drugs, gender bias, race and sexual orientation, deviation from the norm and feelings of inferiority. HIV-specific stigma includes the illness that is associated with HIV/AIDS, imminent death and an exaggerated sense of danger from the sometimes violent reactions of society. Enacted stigma is a process that describes a three-step pattern of identifying those that are infected, creating a distance between oneself and “them” and restricting and excluding ‘them’ (USAIDS, 2006).

Internal stigma is also conceptualised as a cycle with three distinct categories: the experiences of context, self-perception and protective action. The experience of context relates to the physical and environmental situations that impact on people living with HIV/AIDS, leading to denigration and negative prejudices, anxiety about losing a job, difficulty in accessing treatment and physical deterioration of one’s health. In the self-perception phase, the extremely common elements are

shame, deep-seated fears of dying, hurting or infecting others, being discovered, fears of causing pain, disappointment, or suffering to family members. The self-protective actions adopted by people living with HIV are non-disclosure avoidance and self-exclusion, subterfuge and denial, hiding or misleading about one's serostatus, sexual orientation or livelihood (USAIDS, 2006).

Stigma associated with diseases, objects, practices and also HIV/AIDS can be referred to as secondary stigma. Courtesy stigma is the stigmatisation of family members of PLWHA, orphans and vulnerable children whose parents have AIDS and health care workers who work with people living with HIV/AIDS (Deacon and Stephney, 2007). HIV/AIDS stigma is aligned to existing forms of social marginalization such as poverty, sexism and racism (Deacon and Stephney, 2007). Stigma affects individuals and groups such as gay men, black people, prostitutes and drug users. Factors that contribute to the development of stigma and discrimination are morality, anger and a fear of HIV-positive or HIV-negative people (Skinner and Mfecane, 2004). In order to understand the impact of stigma, one needs to distinguish between the ideology and discrimination of the practice of stigma. The cumulative effects of stigma can reduce the quality of life in infected and affected people (Deacon and Stephney, 2007).

Stigma is symbolic in its association with HIV/AIDS and sex. People believe that if you have AIDS, then you acquired it through sexual intercourse. Stigma and HIV/AIDS are associated with homosexuality, death, drug use and ethnic minorities. Sex, sin and immorality are factors that supported the stigmatisation of HIV/AIDS. AIDS is closely associated with pre-existing stigma and is considered 'dirty'. The perception of society (eg. Mexican) that relate to 'lifestyle

and risk' is evident when they came up with this equation: "AIDS=homosexuality=bad=death" (USAIDS, 2006:5). The main contributor of the symbolic ammunition sustaining this link is the church. The church has played an important role "in sanctioning and sustaining unequal relationships between men and women and between adults and young people, postulating a strong link between the moral order of the church and the sexuality of its members" (Campbell et al., 2005:813). The HIV epidemic highlights the loss of the church's moral authority which is vigorously linked to sexual transgressions, immorality and sometimes even the end of the world (Campbell et al., 2005).

2.5 Impact of Stigma and HIV/AIDS

A central problem in the control of the HIV pandemic relates to stigma. HIV/AIDS stigma limits PLWHA's access to testing for HIV, as well to treatment and care. The ability of PLWHA to lead a positive lifestyle is compromised by discrimination, rejection and secrecy. HIV/AIDS stigma has been widely studied in developed countries rather than in developing countries (Uys et al., 2005). In developing countries, HIV/AIDS stigma studies show that stigma exists at individual and community level, as well as in the private and public sector. Religious beliefs perpetuate the stigma of HIV/AIDS and, at the same time, it is the religious and faith-based organisations that have attempted to de-stigmatize the illness. PLWHA experience differential treatment, gossip, loss of identity and loss of access to resources due to stigma (Uys et al., 2005). The two types of stigma that people are exposed to are external and internal stigma. The characteristics of external stigma are described as avoidance, rejection, passing moral judgment, unwillingness to invest in PLWHA, discrimination and abuse. Internal stigma is characterised

by fear of disclosure and its consequences such as withdrawal from society and services, over-compensation and poor self-image (Uys et al., 2005).

Stigma and discrimination have impacted significantly on the HIV epidemic, affecting not only individuals infected with HIV but also extending into society, disrupting the functioning of communities and complicating the prevention of HIV infection and treatment of HIV-positive people (Skinner and Mfecane, 2004). According to Jonathan Mann (cited in Skinner and Mfecane, 2004), discrimination is recognised as the third phase of the epidemic following HIV and then AIDS. The implications at individual, community and national levels impact on voluntary testing and counselling, access to treatment and care and shortening of the lives of HIV-positive people (Skinner and Mfecane, 2004; Holzemer and Uys, 2004). A universal phenomenon of HIV/AIDS stigma is that it is in existence throughout the world (Kohi et al., 2006). HIV positive individuals that are discriminated against on the basis of their HIV positive status experience a violation of their human rights. HIV positive people are often victims of physical and verbal abuse, scolding, ridicule and neglect. These individuals are deprived of food by family members, denied opportunities to access loans or a chance to produce food (Kohi et al., 2006).

Dlamini et al. (2007) described the experiences of women in Swaziland who are sexually exploited by men. In the United States, studies by Eiseman et al. (2003) cited in Dlamini et al. (2007), showed that HIV-positive people have reported incidents of physical violence and victimization within their relationships as well as poor access to health care. The Siyam'kela Project (2003) in South Africa reported a range of abuse from name-calling in the community, to

being labelled as ‘Satan’s people’ by church members and physical abuse of women by their intimate partners, to being referred to as ‘scum of society with social evils that were cursed’ by some community members (Dlamini et al., 2007). Women have succumbed to rape by their HIV-positive husbands and in India (Dlamini et al., 2007 citing Majumdar 2004) women have endured rape and forced prostitution by their partners (Dlamini et al., 2007). In Africa, the cultural traditions positively and negatively influence the development of stigma and abuse. The practice of polygamy in many countries and the extended family system in the African culture expose HIV-positive people to greater risks of abuse within the family setting. This negatively impacts on the individual’s decision to disclose their HIV status or to be tested for HIV (Dlamini et al., 2007).

2.5.1 Discrimination in HIV

Discrimination refers to the people who distinguish themselves from the people who are affected by HIV/AIDS (Link and Phelan, 2004). Hogan (2003) perceives discrimination as the violation of human rights which results in actions such as isolation, violence and sanctions. People have been discriminated against on the basis of race, gender, sexual orientation, physical deformity, religion and age. Discrimination is attached to mental illness and physical disorders such as cancer, tuberculosis, sexually transmitted infections and leprosy. Stigma and discrimination are social processes that favour the powerful, while individual or groups which are not regarded as powerful are being victimised in the process. Stigma is used as a tool to protect the powerful, while impacting directly on recipients who blame themselves for being discriminated against (Skinner and Mfecane, 2004).

As a judgmental discourse, discrimination distinguishes the ‘innocent’ from the ‘guilty’. The innocent are those people who contract HIV via blood transfusion, children of HIV positive women and women whose partners are unfaithful. However, orphans and vulnerable children are often at risk of discrimination, especially at schools and in the community where they face verbal and physical discrimination. This discrimination excludes them from resources and support since they are identified as a major security threat for the future (Skinner and Mfecane, 2004). The impact of discrimination is well-established when it forces people who are HIV-positive to push the epidemic underground and have no association with the disease (Skinner and Mfecane, 2004).

Discrimination is differentiated from enacted stigma because “of its severity and in relation to international accords, laws, and policies” (USAIDS, 2006:5). The laws and policies of countries such as South Africa and Mexico form a solid base for combating discrimination via their Constitutions, as well as through international treaties and accords. Human rights of people living with HIV can be promoted based on the legal system of a country (USAIDS, 2006). According to the United Nations Commission for Human Rights, existing human rights standards prohibit any form of discrimination against HIV/AIDS (Kohi et al., 2006).

2.5.2 Stigma Reduction regarding HIV

The key obstacle in the prevention of HIV/AIDS lies with stigmatising PLWHA (Campbell et al., 2005). Any effort to reduce stigma should form an integral part of all HIV/AIDS prevention programmes. According to existing literature, the strategies for the reduction of stigma are as follows:

- Programmes which are designed to create awareness and provide information about HIV/AIDS in order to reduce ignorance about HIV and AIDS;
- The enactment or enforcement of anti-discrimination legislation;
- The participation of community members in supporting efforts to reduce stigma in their community.
- Initiatives that promote debate and dialogue within groups of people about HIV/AIDS (Campbell et al., 2005).

In the South African context, stigmatisation of HIV positive people is rife and cuts across all ages. Family members are in denial that their loved ones have died of AIDS so the cause of death is generally stated as tuberculosis. Family members have been known to deprive their sick relative of access to health care by hiding them at home in case people find out the truth about their illness. Some go to the extent of disowning their dead relatives by not even collecting their corpses from the mortuary (Campbell et al., 2005). PLWHA often only disclose their status when they are close to death. In such cases, family members announce the dead person's HIV status at funerals. These family members are then berated by friends and relatives for dishonouring the dead person's name. Stigmatisation by family members impacts negatively on HIV prevention programmes (Campbell et al., 2005).

2.6 Support Systems

The support systems outlined by Gwyther (2003) include those that offer psychological, social, and spiritual support.

Support systems have to be in place to allow PLWHA to disclose their HIV status to a close friend or family member, let alone on public platforms (Campbell et al, 2005). Psychological support must be provided to young people who experience stigma and rejection and to affected family members that have lost loved ones and need bereavement counselling. The support also deals with confidentiality/secretcy, fears of having HIV, its effect on their body image and the need for support groups. Social support is directed at people who need identification documents to access social grants, have no income, need assistance in the preparation of a will and help with the costs of treatment and care for the AIDS patient, the care of orphans, funeral arrangements and death certificates (Gwyther, 2003). Spiritual support works in cooperation with the person's faith and counsellors from that faith will help with decisions relating to cultural rituals regarding death and dying (Gwyther, 2003).

Support groups assist individuals with personal growth, building self-esteem and self-worth. In the support groups PLWHA have the opportunity to share their experiences, convey information and offer practical advice on a range of HIV wellness and treatment options. Support groups boost the individual's social confidence and improve their social capital by helping them to be involved in social organisations and allow them feel that they are able to connect with their community. As members of a support group, they influence social processes and develop a sense of trust in social institutions and authorities (USAIDS, 2006). In the traditional Zulu culture, rural women always worked in groups to protect one another, whether while working on the communal gardens, or collecting wood or water. The support is therefore of a physical, social and emotional nature. The support groups in the Western culture provide more emotional support where people have the opportunity to express their feelings and emotions by speaking

freely about their problems. When support groups are formed, the facilitator needs to be gender and age sensitive, especially in the context of the African culture since men are not comfortable speaking about their problems in the presence of women. It is disrespectful in the African culture for young adults or children to speak in the presence of elders.

Support groups perform the following duties:

- Organise meetings for PLWHA to give them an opportunity to express their feelings, talk about common problems and equip them with coping mechanisms.
- Provide emotional support to families to help them cope.
- Teach people about the disease, and discuss symptoms, treatment and how to care for them.
- Help people survive by organising some form of relief, for example food parcels.
- Organise social events where people relax and talk about their status.
- Organise talks and presentations by experts.
- Get PLWHA to join organizations that work for them.
- Assist with accessing government grants.
- Refer them to services and projects that could help them, for example home-based care (AIDS Family-Care, 2007).

2.7 Community Caregivers

The community caregivers (CCG) are trained in providing basic home-based care and counselling to PLWHA. Their training is extended to incorporate crisis counselling and care,

health promotion, and preventing the spread of HIV. The CCG works very closely with PLWHA, their families and the community, targeting traditional healers and community leaders, social systems and support groups. The complexity of the HIV/AIDS epidemic has challenged various health care agencies and organisations to establish partnerships in both the formal and informal sectors in order to provide optimal care for PLWHA. A support system for the caregivers would include adequate training, supervision and support, dealing with burnout due to the stressful demands of the job, and coping with losses (Gwyther, 2003).

The CCG provide emotional support to families of PLWHA. They advocate on behalf of PLWHA with the family. The family needs support systems to deal with the disclosure of the disease and come to terms with the illness. According to Gwyther (2003), when dealing with families one needs to be culturally sensitive and deliver care within the domains of the patient's culture. The language, respect for other cultures, awareness of cultural rituals regarding death, dying and funeral arrangements are aspects which need to be considered. Community caregivers work closely with cultural organisations, traditional healers and community leaders in shaping the attitudes and values regarding HIV, gender and sexual orientation. Intervention strategies target community-based organizations to clarify their values, dispel myths, get new information, and actively support the development of a positive self-image in PLWHA (USAIDS, 2006).

2.8 Voluntary Counselling and Testing (VCT)

A positive reason for VCT is so that people can know their HIV status long before they become ill and can take the necessary precautions to reduce HIV infection of their partners. VCT

services are offered free in many countries in sub-Saharan Africa. VCT services may be set up in hospitals, clinics or other settings that offer a wide range of support and support groups that may be linked to VCT centres. It is essential for people to know their HIV status in order to protect themselves and others from infection, to improve their health care and to plan for the future. In South Africa, VCT services are often offered in state hospitals. Unfortunately the environment in these hospitals is not conducive to establishing relationships or encouraging openness about sensitive or taboo subjects. Therefore, clients are reluctant to have VCT due to stigmatisation and a lack of privacy. A serious problem regarding VCT is the lack of follow up and support services after diagnosis. This is detrimental to a person's physical and mental well-being and can lead to feelings of fatalism and depression (van Dyk and van Dyk, 2003). Stigma and discrimination have impacted negatively on individuals who have experienced significant barriers to testing and access to treatment. PLWHA are afraid of being judged by both health care workers and family members. The fear of disclosure prevents them from accessing voluntary counselling and testing services (USAIDS, 2006).

Although VCT is rated as a top priority in the Government's five year HIV/AIDS plan, some of the barriers are logistical, a lack of incentives, confidentiality issues, attitudes and behaviour regarding VCT. The high client turnover and the low counsellor-to-client ratio are cause for concern, especially due to the heavy client load and the long waiting period for clients. A study by Masuku (2001), cited in Van Dyk and Van Dyk (2003), found that 80% of the clients did not go back for their test results because they were poor and did not have the money for transport. Another reason for not returning was their fear of being told that they were HIV positive. Hospitals do not provide a suitable environment for HIV counselling. They have special rooms

demarcated for HIV counselling. These demarcations contributed to stigmatisation, a lack of privacy and the risk of being labelled as HIV positive (Van Dyk and Van Dyk, 2003). In principle, clients are not against VCT, but have serious issues regarding confidentiality. The fears expressed by clients in relation to a breach of confidentiality are:

- disclosure of their serostatus by health care professionals without their permission;
- reactions of their sex partners;
- reactions of health care professionals;
- widespread fears that maternity staff might refuse to assist them to deliver their babies;
- rumours that medical staff intentionally kill HIV positive patients; and
- stigmatisation and embarrassment (Van Dyk and Van Dyk, 2003).

The culture of HIV Counselling and Testing (HCT) was established in South Africa in 2010. The government has taken a stance to conduct the biggest HIV counselling and testing campaign in the world. The new approach to the HCT campaign includes changes to the HIV treatment regimens. The theme of the HCT campaign is for every individual to be responsible, get tested, know their status and be proactive in adopting healthy lifestyles, irrespective of their HIV status (Department of Health, 2010).

2.9 Antiretroviral Treatment (ART)

According to the USAIDS report on stigma scale-up and treatment governance, “the delivery of effective ARV treatment can be imagined as the most powerful instrument currently available to combat stigma and discrimination. It enabled people living with HIV and their families to re-

enter the mainstream of social and economic activities and relations” (USAIDS, 2006:1). PLWHA who have not disclosed their status to families deny themselves access to health care and the introduction of ARVs that could considerably extend their lives. In cases where families accept and support PLWHA and openly acknowledge the benefits of testing, this could lead to minor behaviour modifications such as using a condom or having a monogamous relationship that can improve their lives (Skinner and Mfecane, 2004).

PLWHA who have not disclosed their status and delay seeking treatment until they become symptomatic with an AIDS defining illness, limit the efficacy of ARV treatment. In Malawi, antiretrovirals are free for pregnant women but women still choose not to undergo HIV testing because of the social stigma attached to HIV/AIDS. Women fear disclosing their status to their husbands and therefore have to hide their pills from them and do not attend clinic regularly. Families caring for PLWHA are profoundly affected by the stigma and discrimination. In Vietnam, some families support their relatives who are living with AIDS, while others find the shame of HIV an insurmountable barrier to accessing HIV treatment and services. Injection drug users have experienced profound difficulties in accessing and using HIV services. Even in the United States, more than 40% of the people who are eligible for antiretrovirals are not accessing treatment because they are reluctant to get tested for HIV. The most powerful instrument that addresses stigma and discrimination is the effective delivery of antiretroviral treatment (USAIDS, 2006).

2.10 Community Intervention

Community development and participation is a key component for improving the health of disadvantaged groups and communities. There has been a paradigm shift from the biomedical and behaviourally-oriented interventions to a community development perspective in health promotion activities. The involvement of grassroots communities in planning and implementing health interventions impacts positively on communities (Campbell, 2003). People living with HIV/AIDS are afforded an opportunity for self-development by community-based organisations. For example, the Siyam'kela Project (2003) trains their members in leadership skills so that they can involve them in community development projects (USAIDS, 2006).

The issues pertaining to community participation revolve around arguments raised regarding the recognition of local communities in the strategic and operational decisions about health service design and delivery. The factors that undermine the level of health service of marginalised communities are differential access, cultural differences, racism and communication difficulties (Campbell, 2003). On the issue of health-enhancing behaviour, it can be argued that local community groups should participate in the design and implementation of campaigns to promote behavioural change. It is anticipated that people follow the example of their peers and are more likely to change their behaviour because they trust their peers (Campbell, 2003). Health promoters have recognized the need for involvement in 'community-strengthening programmes' and seek to create 'health-enabling communities'. These relationships are based on trust, mutual support and involvement in local community projects. Multi-sectoral collaboration and partnerships are key components in strengthening communities and creating health-enhancing environments (Campbell, 2003).

According to Paulo Freire (cited in Campbell et al., 2005:814) “an important step toward mobilizing people with AIDS would involve initiatives that work toward facilitating the participation of local community groups in critical thinking programmes”. These programmes aim to expose the practices that sustain the stigma and undermine individuals who challenge these programmes. Critical thinking programmes are directed at marginalized communities, young people and women, the denial of young people’s sexuality, and the denial of the sexual activities of women. These programmes explore ways in which social institutions such as the church, family and traditional leadership system do or do not contribute to the marginalization of those infected and affected by HIV and AIDS. Community participation, alongside education and legislation are powerful weapons against stigma. The key role of community-participation is to promote all forms of critical consciousness that threaten to expose the unequal social relations sustained by stigma (Campbell et al., 2005).

2.11 Theoretical Underpinning

HIV/AIDS is associated with sexual behaviours that expose individuals to the risk of infection. The challenges that confront South Africans are the initiatives directed at reducing sexual risk behaviour in order to curb the epidemic (Karim and Karim, 2005). In order to address the issues relating to the disclosure of HIV status and HIV and AIDS stigma, certain theories/models will be reviewed to identify the most appropriate one for the conceptual framework of this study. Concepts such as attitudes, self-efficacy, intention to change and social influences underpin theories and models of behaviour change. An individual’s attitude, social influences and self-expectations constitute the belief system that determines their intention to perform certain behaviour. The demographic, sociological and personality factors also influence a person’s

intention to change their behaviour by influencing their attitudinal, social and self-efficacy expectations. The concept of 'self-efficacy' expectation relates to an individual's beliefs about his/her capabilities of performing a specific behaviour in specific situations. For example, 'I can use a condom' or 'I am not sure whether I am ready to use a condom' (De Vries, 1997).

2.11.1 Social Learning Theory (SLT)

Theories attempt to identify human behaviour and the intervening mechanisms responsible for change. Behaviour is evoked through a stimulus and is maintained by reinforcing conditions (Bandura, 1977). Behavioural responses are generally attributed to inner causes that can be induced, eliminated and reinstated or reinforced by external forces. Researchers have concluded that determinants of behaviour do not reside within the organism but are influenced by environmental forces (Bandura, 1977). The major determinants of behaviour in the Social Learning Theory are expectancies and incentives. The Stimulus Response Theory and the Social Cognitive Theory are the two approaches reflected in the general theory. Stimulus Response Theory relates to the belief that individuals are conditioned by the environment that influences their behaviour. Behaviour change is initiated and maintained through feedback and rewards, thereby reinforcing positive behaviour (Gorin and Arnold, 1997).

Self-efficacy is a central concept and both efficacy and outcome are critical to behaviour change including disclosure of HIV status. Individuals who are high in self-efficacy have a better chance of maintaining behavioural changes (Gorin and Arnold, 1997). The self-efficacy expectations reflect the individual's capability of considering behaviour change. People generally achieve an approximation of new behaviour from learning on a daily basis. This

change is brought about through self-corrective adjustments as a result of information feedback from performance (Bandura, 1977). The perception of social learning theorists is that change is mediated through cognitive processes. Cognitive events, on the other hand, are induced and altered through experiences that are mastered from successful performance (Bandura, 1977).

The SLT is not an appropriate choice as a framework based on these aspects. In SLT the focus is on personal, behavioural and environmental influences which impact on behaviour change and the ability of a person to:

- acquire behaviour through skills training and maintain it through support networks;
- change their behaviour, which is the consequence of their own actions;
- build on their self-confidence by having the ability to successfully perform a specific action; and
- develop a level of self-confidence to change behaviour.

The self-satisfaction of behaviour change is reinforced with rewards and incentives. A decrease in rewards can deter positive behaviour changes. The major limitation of the SLT is that individuals have to be motivated to achieve the target behaviour.

2.11.2 Theory of Reasoned Action/Theory of Planned Behaviour

Theory of Reasoned Action views a person's intention to enact behaviour as the immediate determinant of action. A person's intention operates on two basic determinants. One is personal in nature and the other reflects social influence. The personal factor is the positive or negative evaluation of an individual performing the behaviour and is termed 'attitude towards the behaviour'. The intention relies on the person's judgment to perform or not to perform the

behaviour, whether good or bad. An individual's perceived perception of social pressures to perform or not to perform behaviour is termed 'subjective norms'. According to the Theory of Reasoned Action, attitudes are a function of beliefs and beliefs underpin a person's attitude toward behaviour and are termed 'behavioural beliefs'. The beliefs that underpin a person's subjective norms are termed normative beliefs (Ajzen and Fishbein, 1980). The Theory of Reasoned Action examines behavioural intentions rather than attitudes as predictors of behaviour. This theory of behaviour change is directed at the individual's belief system because volitional behaviour can be predicted by beliefs, attitudes and intentions. The changes to the beliefs underlying a person's attitudes or norms can lead to changes in their behavioural intentions and, ultimately their behaviour (Gorin and Arnold, 1997). The central construct in this theory is the behavioural intention that indicates the extent and degree to which people make an effort to perform the behaviour. The three components that influence behavioural change are the person's attitude, perceived social pressure (subjective norms) and perceived behavioural control (Gorin and Arnold, 1997).

This theory is not chosen as a conceptual framework to guide this study based on the assumptions of Ajzen and Fishbein (1980) that behaviour change is the ultimate outcome of changes in belief. In order to influence behaviour change, people have to be exposed to information that could change their beliefs. A change in beliefs could lead to a change in attitude or subjective norm. A change in behaviour is an unrealistic expectation if neither the attitude nor the subjective norm changes (Ajzen and Fishbein, 1980).

2.11.3 Health Belief Model

The Health Belief Model was developed to explain preventive behaviour. This model deals with the behaviour of individuals who are healthy or free from disabling diseases and who adopt measures to avoid these diseases/illnesses. The constructs in the Health Belief Model are an individual's perception of susceptibility, seriousness, the benefits of taking action and barriers to taking action and one's cues to action (Rosenstock, 1974). Perceived susceptibility is an individual's personal perception of susceptibility to a disease or condition and it varies from the one extreme where the individual denies the possibility of contracting the disease to the other extreme when a person admits to the real danger of contracting the disease (Rosenstock, 1974).

Perceived seriousness of a disease varies from person-to-person. The severity of the condition is judged by the degree of emotional arousal and the problems and difficulties surrounding that disease. A person's perception of the seriousness of the disease may be described in terms of its medical and clinical consequences. The perception that the disease is fatal, or will reduce his/her mental and physical functioning and cause permanent disability will have a negative impact on the individual. The implication is much broader for an individual and includes his job, family life and social relationships (Rosenstock, 1974).

Perceived benefits of taking action are an individual's acceptance of his/her susceptibility to a serious disease which acts as a force leading to action. An individual may have the belief that a given action will reduce the threat of the disease but is reluctant to engage in the exercise due to the inconvenience, expense and unpleasant or painful experience. The barriers to preventive

action are the negative aspects that give rise to conflicting motives of avoidance (Rosenstock, 1974).

A cue or trigger to appropriate action serves as an important factor in the Health Belief Model. The susceptibility and severity provides the impetus to act and the perception of the benefits is a path of action. Cues to action in the health sector may be internal or external. Internal cues are described as in the perception of bodily states. External cues are in interpersonal interactions, impact of mass media campaigns, advice from others, or the receipt of a reminder postcard from a physician or dentist or the illness of family member or friend (Rosenstock, 1974). The aim of the Health Belief Model is to determine why some people who are illness-free take action to avoid illness, while others failed to take protective action (Gorin and Arnold, 1997).

The Health Belief Model encapsulates the belief systems of SLT and the Theory of Reasoned Action and is used in health promotion initiatives. The Health Belief Model is inappropriate as a conceptual framework for this study because it focuses on the individual's decision to adopt preventive behaviour based on the threat of illness and the behavioural response to that threat. The threat of the illness relates to the individual's perceived susceptibility to an illness. The behavioural response evaluates the benefits and the costs of risk reduction behaviours in order to reduce the threat of the disease (Bennet and Murphy, 1997). This model focused on healthy individuals taking precautions to prevent an illness while those who failed to take protective action contracted the disease (Bennet and Murphy, 1997).

2.11.4 AIDS Risk-Reduction Model (ARRM)

AIDS risk-reduction model (ARRM) explains people's efforts to avoid contracting HIV through sexual contact. People are at high risk for HIV infection if they exhibit high risk sexual behaviour. The labelling of one's behaviour as high-risk for HIV infections does not lead to behavioural change unless there is a strong commitment on the part of the individual to change their activities. The commitment process is dependent on the decision of whether or not behaviour can be modified and whether or not the benefits outweigh the costs. Individuals also resort to self-help, informal support or professional help in order to obtain solutions. In order to enact solutions, individuals or couples need to engage in complex negotiations with sexual partners who may not have the same degree of commitment to change (Catania et al., 1990).

The central constructs of ARRM and the factors that influence goal achievement are reviewed within and across stages. According to this model 'AIDS knowledge' and social factors influence multiple roles over the change process. This model explores the movement from stage to stage in order to achieve the goals of prior stages.

Stage one is problem perception, which is described as when high risk sexual behaviour exhibited by individuals is perceived and labelled as problematic. The labelling of behaviour as problematic begins when a person finds out that HIV is sexually transmitted, examines his/her sexual behaviour, labels the behaviour as risky and then becomes anxious about the susceptibility of contracting HIV (Catania et al., 1990). Stage two is the commitment to change. This next step in the process of changing high risk behaviour is reflected in making a firm commitment to

behavioural change. The decision is to remain committed in a sexual relationship and make changes to high-risk behaviours such as unprotected sex, having multiple partners, douching and the use of sex toys (Catania et al., 1990). The construct 'response efficacy' relates to reducing risky behaviour and adopting preventive actions under conditions of high self-efficacy. A high degree of self-efficacy is dependent on people believing in their own abilities to reduce high risk and increase low risk behaviours (Catania et al., 1990). Stage three involves taking action with the goal of achieving behavioural change, followed by the commitment of reducing high-risk sexual behaviour. The three phases that effect behavioural change are information-seeking, obtaining remedies and enacting solutions (Catania et al., 1990).

ARRM did not serve the purpose of a conceptual framework for this study even though the study focused on HIV/AIDS. The reason for not choosing this model is that the people have to identify their own risky behaviour as problematic, remain committed to changing the high risk behaviour to low-risk behaviour and, most importantly, they need to have good communication skills. In most cases, behaviour change is determined by a strong personal commitment to changing high-risk sexual behaviour to low-risk sexual behaviour which is not obvious in HIV positive people (Catania et al., 1990). The conceptual framework for this study is the Stages of Change/Transtheoretical Model.

2.12 Conceptual Framework – Stages of Change/Transtheoretical Model

The Stages of Change/ Transtheoretical Model is used as a conceptual framework for this study because of its integrative nature and its application to individuals, families and communities.

The Stages of Change/Transtheoretical Model is one of the first models proposed by Prochaska and Di Clemente in 1984 (Bennet and Murphy, 1997). It encompasses other models of behaviour change such as the Health Belief Model, Social Cognitive Theory and Stages of Change propositions and is directed towards behaviour change in individuals and groups (Gorin and Arnold, 1997). The self-efficacy construct from Bandura's (1977) Self- Efficacy Theory represents the situation specific confidence of people. It is self-efficacy that relates to the confidence people have of coping with high risk situations without relapsing into their unhealthy high risk behaviour (Velicer et al., 1998).

The assumption is that individuals move through a series of predictable stages towards behavioural change. These stages are pre-contemplation, contemplation, preparation, action, maintenance and termination/relapse. The Stages of Change/Transtheoretical Model is an integrative model of behaviour change with five stages and ten processes. The assumption is that individuals move through a series of predictable stages towards behavioural change. The five stages and ten processes are depicted in Figure 2.1 which is designed by the researcher.

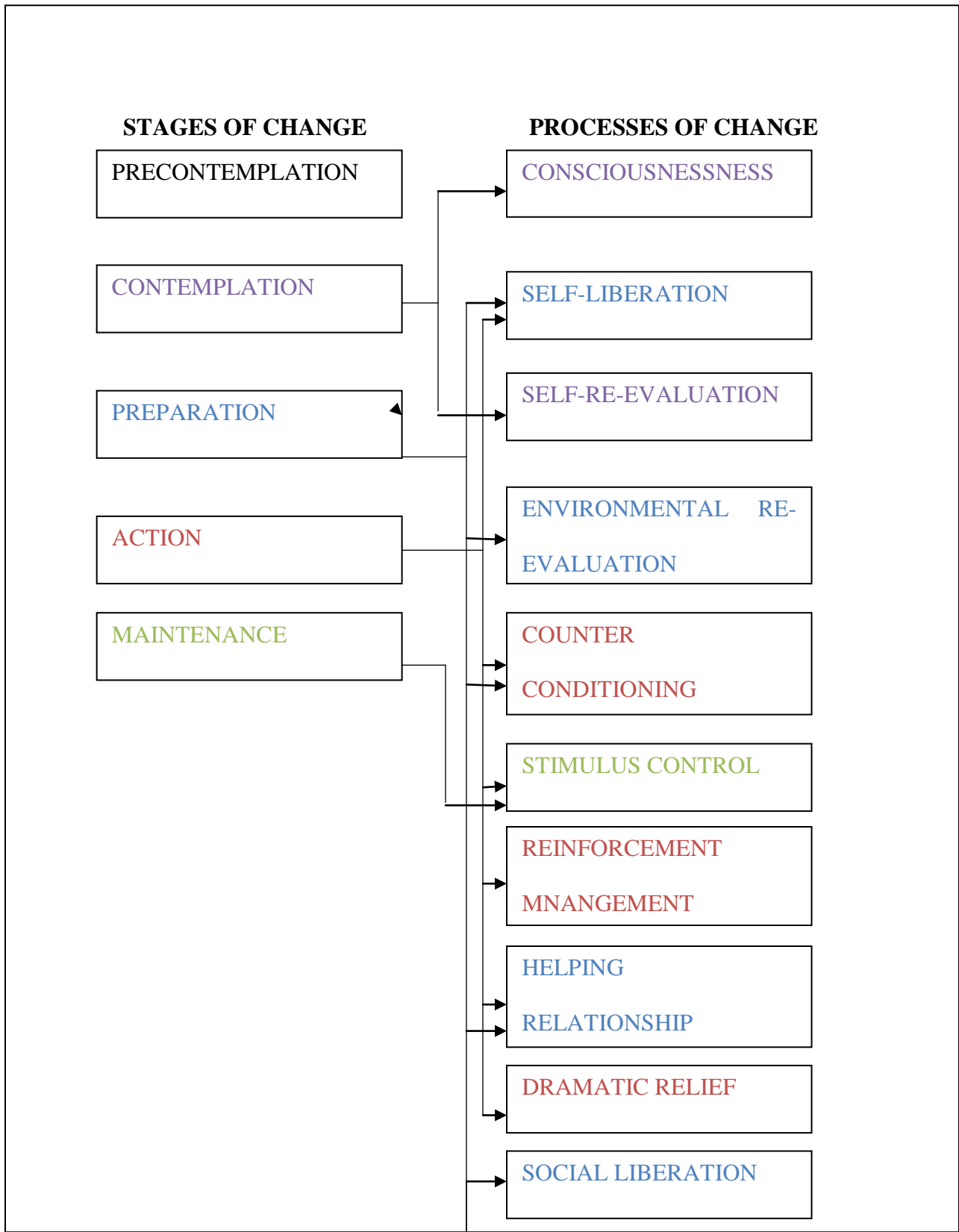


Figure 2.1 An outline for the development of the conceptual framework

2.12.1 Pre-contemplation

This is a stage in which people are in denial and do not want to accept the fact that they have a problem. They have no intention of disclosing their HIV status in the foreseeable future. These people are uninformed of the consequences of their behaviour and the possible benefits of changing their behaviour. They have no intention of disclosing their status to others because of the fear of discrimination and physical violence associated with the stigma of HIV/AIDS (Velicer et al., 1998).

2.12.2 Contemplation

People consider changing their behaviour at this stage or give some thought to whether they should or should not change. They acknowledge that they have a problem and weigh the pros and cons of changing their behaviour against the possible negative consequences of changing. People remain at this stage much longer than anticipated due to the ambivalence between the benefits of changing their target behaviour and the relative value assigned to influence the decision about behaviour change and the subsequent benefits thereof (Gorin and Arnold, 1997). They are not prepared for the traditional action oriented approaches to change. They contemplated disclosing their status in the foreseeable future (Velicer et al., 1998). The process of consciousness raising involves increasing people's awareness about the causes, risks and consequences of unsafe behaviour through awareness campaigns, information distribution and media campaigns. It has been shown, however, that increasing knowledge does not necessarily change risky behaviour (Velicer et al., 1998; Sullivan, 1998). The process of self-re-evaluation gives an individual the opportunity to re-appraise their self-image and evaluate the kind of person they want to be under the circumstances (Velicer et al., 1998).

2.12.3 Preparation

People at this stage are fully aware of the benefits of changing their behaviour for themselves and its effects on others (Velicer et al., 1998). They perceive greater benefits and fewer barriers to change at this stage (Sullivan, 1998). Therefore, they intend disclosing their status within a short space of time and plan on adopting preventive behaviour, such as consulting a counsellor, talking to a physician, buying a self-help book or relying on a self-change approach (Velicer et al., 1998).

The processes aligned to preparation are counter-conditioning, self-liberation, and social liberation, environmental re-evaluation and helping relationships. Counter-conditioning is a process of learning new behaviours to replace the current problem behaviours. The benefits of behaviour change are weighed against the costs of behaviour change and the outcome favours positive behaviour change. Self-liberation is the belief that the individual has of making a firm commitment to a new positive lifestyle and having the ability to remain committed to that lifestyle. The willpower that an individual has to make a public statement about his /her HIV status and having multiple choices enhances self-liberation. Social liberation allows people who are deprived or oppressed to increase their social opportunities and uplift themselves. This leads to the empowerment of impoverished people and increases the chances of behaviour change. Environmental re-evaluation refers to the situation in which people reflect on the consequences of their behaviour on people close to them and its impact on societal norms. Social appraisal is a combination of affective and cognitive assessments of one's personal behaviour and its impact on the social environment (Velicer et al., 1998). The stigma associated with homosexuality, drug use and sexual promiscuity impacts negatively on both HIV positive and HIV negative persons.

Individuals who internalise society's negative views are vulnerable to self-hatred (Lee et al., 2002). A 'helping relationship' incorporates acceptance, openness, caring, trust and support for positive behaviour change. The social support includes peer support, buddy systems and rapport building that support change. The support groups for PLWHA may include family, friends and community members (Velicer et al., 1998).

2.12.4 Action

This stage is marked by a conscious effort to modify behaviour. Behaviour change at this stage requires an intense effort to modify both the behaviour and the environment in which the behaviour occurs. Action leads to developing strategies to cope with the barriers in the environment. Behaviour change is usually equated with action aimed specifically at lifestyle changes such as disclosing their HIV status, settling in a monogamous relationship and using condoms. People who have modified their behaviour and changed their lifestyles within the past six months are ready for the maintenance stage (Sullivan, 1998; Velicer et al., 1998). The processes of dramatic relief, reinforcement management and helping relationship fall in line with the action stage. Dramatic relief arouses the individual's experiences emotionally and the techniques used to achieve this are psychodrama, role play grieving, personal testimonies and media campaigns.

Dramatic relief is also referred to as emotional arousal, which fosters increasing emotional experiences followed by a reduced effect of appropriate action (Velicer et al., 1998). Emotional arousal often occurs after experiencing the personal testimonies and media campaigns of people who have disclosed their status (Sullivan, 1998). The individual has come to terms with his or

her status and has disclosed to family or friends. Individuals have an opportunity of building support networks after the disclosure of their HIV status. HIV-positive people who choose to disclose to others may be vulnerable to both positive and negative reactions from people (Lee et al., 2002).

Reinforcement management includes a system of rewards and punishments, change depends more on rewards more than punishment. The positive responses to reinforcement management are positive self statements, group recognition, overt and covert reinforcements. The probability is that healthier and more appropriate behaviours are repeated and maintained. The sources of social support in the helping relationship are rapport building, therapeutic alliance, counsellor calls and buddy systems (Velicer et al., 1998).

2.12.5 Maintenance

The modified behaviour persists for longer than anticipated and some vigilance is required to avoid relapses into the previous behaviour. There is a possibility for individuals to slip back from any stage to an earlier stage. As they continue with their new behaviour, the person's confidence level increases leaving very little chance for relapse (Velicer et al., 1998). It is at this stage when people who have changed their lifestyles, and disclosed their HIV/AIDS status, settle in a monogamous relationship and use condoms for periods exceeding six months (Sullivan, 1998; Velicer et al., 1998). The process of stimulus control is appropriate for this stage because it focuses on removing cues for unhealthy behaviour and creating cues for health behaviour. In stimulus control the healthier alternatives are directed self-help groups that support change and reduce relapse. Stimulus control involves the removal of cues for unhealthy behaviour and

creating cues for healthy behaviours. Avoiding of multiple partners and joining support groups could provide a stimulus that supports change and reduces the risk of relapse (Velicer et al., 1998).

The Stages of Change/Transtheoretical Model has been used extensively in programmes such as smoking cessation, weight control, alcohol abuse, and condom use for HIV transmission/prevention, organizational change and stress management, to promote optimal health by promoting behavioural change. The unique feature of this model is the recognition that behaviour unfolds through a series of stages and is a process and not an event. The choice of this model in relation to other models is that it targets behavioural change and has been used extensively in the past decade (De Vries, 1997).

2.13 Conclusion

In this chapter, literature relating to the magnitude of the HIV/AIDS stigma is explored together with the concepts ‘disclosure of HIV status, stigma, impact of stigma and HIV/AIDS, discrimination in HIV, stigma reduction regarding HIV’. The support systems for PLWHA include community caregivers, voluntary counselling and testing, antiretroviral treatment and community interventions. In order to identify a suitable conceptual framework for this study’ various theories and models are described starting from Social Learning Theory, Theory of Reasoned Action/Theory of Planned Behaviour, Health Belief Model, AIDS Risk Reduction Model, and the Stages of Change Model. The Stages of Change Model/Transtheoretical Model was used as a conceptual framework for this study.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter discusses the methodology chosen for this study. Qualitative research approaches are distinct modes of inquiry towards understanding the unique nature of human thoughts and behaviours under different sets of historical and environmental circumstances (Munhall, 2007). Qualitative research is a philosophical approach that encompasses phenomenology, grounded theory, ethnography, case study, historical research, narrative enquiry and action research. Action research is situated within the realms of the qualitative research tradition that reflects beliefs, values and assumptions about the interaction between the nature of human beings and the nature of the environment (Munhall, 2007). According to Creswell (1998:15) qualitative research is:

“an inquiry process of understanding based on distinct methodological traditions of inquiry that explore social or human problems. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting”.

Qualitative inquiry demands that the researcher commits to spending lengthy periods of time in a natural setting. The researcher operates as the key instrument and collects extensive data. Data is collected as words or pictures and the outcome of the research is reported as a process rather than a product. The researcher faces challenges such as gaining access, establishing rapport and

having the advantage of an “insider’s” perspective of the phenomenon under study. The researcher is involved in complex, time-consuming process of data analysis by means of reducing the data into categories or themes. A detailed report is then written using expressive language, showing evidence of the participants’ perspective and substantiating the claims with supporting literature (Creswell, 2007). The characteristics of the qualitative approach are embedded in the tradition of inquiry, the assumptions, rigorous approach to data collection, data analysis and report writing. The narrative is presented as a detailed description, theory or abstract model using criteria such as rigour, the philosophical assumptions, methods approaches, and persuasive and engaging writing (Creswell, 2007).

Greenwood and Levin (2007) argued that action research is not limited to ‘qualitative’ research but may incorporate qualitative, quantitative and/or mixed method approaches. The central characteristic of action research is the focus on practical problems. Action research focuses on specific contexts and demands that theory and action operate in unison. The test of any theory and its capacity to resolve problems in real life situations lies within the paradigm of action research (Greenwood and Levin, 2007). Action research is a systematic process that aims to establish what is going on, identify a problem, think of possible solutions, implement the plan of action, monitor actions by gathering data, evaluate the progress and make judgements, test the validity and modify practice based on the evaluations (Mc Niff and Whitehead, 2011). “Action research has always been understood as people taking action to improve their personal and social situations, and offering explanations for why they do so” (McNiff and Whitehead, 2011:14). In order to ensure the quality of the relationships in action research, and for it to be sustainable the individual researcher accepts responsibility in the interest of others above their own. Therefore

action research undertaken by individuals is always participative and collaborative and not individualistic (McNiff and Whitehead, 2011). In the conceptual framework (Stages of Change Model) the focus of change is individualistic but the impact of change affects the group at large, that is, the family or community. The common feature between the conceptual framework and the action research approach is change and the integrative nature that is applicable to individuals, families and communities. Both these approaches look at people with problems but target the resolution of problems at group or organizational level (Velicer et al., 1998; McNiff and Whitehead, 2011).

According to Holter and Schwartz-Barcott (1993), researchers and practitioners in action research collaboratively diagnose problems, design action plans and implement these action plans. This chapter further explores the philosophical underpinning of action research, the action research approach, phases in action research, research setting, study population, sampling, data collection guides, data collection processes, data analysis, trustworthiness and ethical considerations.

3.2 Philosophical Underpinning

In the 1940s, Kurt Lewin was seen as the pioneer of action research. Action research derives its relevance from a set of scientific ideas and concepts that stem from the General Systems Theory (Holter and Schwartz-Barcott, 1993; Greenwood and Levin, 2007). According to Coghlan and Brannick (2010:95) “systems thinking and the action research cycles play complimentary roles”.

The general systems theorists holistically perceive the world as a composition of interacting systems responsible for the production of basic matter of the universe. It is through these interacting systems, the production of various processes differently and the integration thereof that we encounter as the world of experience (Greenwood and Levin, 2007). The systems approach underlies action research since both approaches rely heavily on the interconnectedness and holistic view of the world. Humans exist within social systems in which structures and processes dynamically interact within material boundaries and are capable of transforming material living conditions (Greenwood and Levin, 2007). The action researcher seeks insights into the systematic patterns of thinking and acting in a system and into the constructs and meanings that the researcher brings to the inquiry process (Coghlan and Brannick, 2010).

3.2.1 Pragmatic Philosophy and Action Research

Dewey's pragmatic philosophy outlines an action approach to science as a form of human inquiry with its inherent connections aligned to democracy (Dewey, 1991). The essential components of a democratic society are diversity and conflict. Dewey also believed in democracy as "an ongoing, collective process of social improvement in which all levels of society had to participate" (Greenwood, and Levin, 2007:60). It was his belief that all humans were capable of scientific judgement and an improvement in society could be achieved through increasing capacities among all of society's members. Scientific research, democratic social action and scientific knowledge were the products of continuous cycles of action and reflection. The solutions achieved with the materials at hand are embedded in his philosophy of pragmatism (Greenwood and Levin, 2007).

3.2.2 Epistemological Foundation of Action Research

The aim of action research is to find solutions to pertinent problems of major importance to the local people. This is achieved through a collaborative process between the researcher and the participants (Greenwood and Levin, 2007). The core characteristics of action research stem from General Systems Theory. The characteristics of action research are described as:

- Holistically addressing real-life problems which are context-bound;
- Researchers and participants collaboratively inquiring and co-generating knowledge and ensuring that all the participants' contributions are considered seriously;
- The diversity of experiences and capacities within a local group are treated as an opportunity for the enrichment of the research-action process;
- In the inquiry process, meanings that lead to social action are constructed and these reflections on action lead to the construction of new meanings; and
- In action research, credibility and validity are measured against participants' actions to solve problems and increase control over their own situations (Greenwood and Levin, 2007).

The epistemological assumption is that knowledge is uncertain, and it is up to the people's ability to create answers through negotiations and if that is not possible people learn to live with the situation. Knowledge is the property of individuals which assumes a subjective and biased nature. The subjective and biased nature of action researchers arises from the assumptions that knowledge is the property of individuals and that the individuals have to negotiate their meanings with other individuals (Mc Niff and Whitehead, 2011). Epistemological perspectives

adopted by action researchers relate to their own distinctive way of doing research and determine what they consider as a valid, legitimate contribution to knowledge or theory (Coghlan and Brannick, 2010). Epistemology accepts the notion of a possible theory-neutral language to access the external world objectively and a subjective view that denies the possibility of a theory-neutral language (Coghlan and Brannick, 2010).

The questions that emerge in relation to the conceptualisation of action research are based on the logic of inquiries; reasonable criteria for judging knowledge as credible; and the strength of context-bound knowledge which can be effectively communicated to academics and other recipient groups. An epistemological position that supports the arguments for the value of action research is as follows:

Action research enables people to systematically investigate their problems and issues, formulate detailed accounts of their situation and construct plans to deal with the problems (Munhall, 2007). An inquiry into the participants' problems would determine the degree of importance and the impact of the problem on their daily lives. The inquiry process precedes actions that are linked to acquiring knowledge and these actions are designed to resolve pertinent issues. Reflections are developed based on experiences drawn from prior actions that add new meaning to the construction of a theory. In this study, the pragmatic philosophy was directly connected to the participants resolving their own problems and the process is judged in terms of workability. Workability refers to whether or not a solution is identified as a solution to the initial problem or a revision or redesign of the actions. The outcomes of collective social action are the result of collective judgement by knowledgeable participants (Greenwood and Levin, 2007).

Action research as a democratic process supports the creation of new knowledge which is liberating. This inquiry process aims to solve problems which are important to local participants. This increases their potential to have control over their own situations, thereby liberating them. The knowledge that emerges must be used to support the enhancement of participants. The logic of inquiry relates to a positively controlled inquiry process in which action and reflection are directly linked. The researcher, as an outsider, becomes a participant with the insiders. In action research the researcher's involvement raises important challenges of integrity and critical reflection (Greenwood and Levin, 2007).

In any action research process, balancing active involvement with integrity and critical reflection is fundamental. The involvement of a diverse group of co-researchers and participants exposes them to a broader set of experiences and attitudes that the participants contribute towards developing creative solutions. The argument to sustain diversity is equally important because action research gains strength from the creative potential in the diversity of the group (Greenwood and Levin, 2007).

In the inquiry process, mutual learning is established by combining insiders and outsiders in an enabling communication mechanism. Mutually understandable discourse was achieved through living together, sharing experiences and taking actions together. In action research, new knowledge that emerges from an action-reflection process creates a shared language between insiders and outsiders that "identifies meaning constructed through the inquiry process" (Greenwood and Levin, 2007:66). Epistemological discussions on knowledge development are directed towards more humanistic forms of inquiry. The prevailing paradigm for nursing had its

origins in the natural sciences within an Anglo-American tradition. The argument that the foundation of nursing science lies within the paradigm of natural sciences does not correspond to the nature of knowledge needed for nursing. A possible alternative is within the paradigm of the humanistic sciences (Holter and Schwartz-Barcott, 1993).

3.3 Action Research Approaches

Action research attempts to bridge the gap between theory, research and practice (Holter and Schwartz-Barcott, 1993). The hallmark of the action research process is the interaction between researchers and participants that creates the action which empowers people to act on their own behalf to solve real problems and bring about change (Speziale and Carpenter, 2003). Action research is an ongoing process that concentrates on solving problems with the intention of improving the quality of life for people. According to Ferrance (2000), the term ‘action research’ was used to describe the investigation and the action needed to solve the problems as parallel processes that operate in unison to find solutions to problems. “Action research is a collaborative approach to inquiry or investigation that provides people with the means to take systematic action and to resolve specific problems” (Stringer, 2007: 8). The purpose of all action research is primarily to contribute to the body of knowledge or develop emancipatory theory. Each inquiry contributes directly to the upliftment of people and their communities (Coghlan and Brannick, 2010).

The four characteristics that remain central to all forms of action research are “collaboration between researcher and practitioner, solution of practical problems, change in practice and

development of theory” (Holter and Schwartz-Barcott, 1993:299). Action research as a method of inquiry postulates that research is context bound. There is full engagement between the researcher and participants. The process is truly collaborative and attention is paid to how it impacts on the lives of others. An action or change is the focal point in the process. The decision to implement the action or change rests with the stakeholders (Speziale and Carpenter, 2003). The approaches to action research are many and varied, from the technical collaborative to mutual collaborative, enhancement, cooperative inquiry, participatory, community-based and action science or action inquiry.

3.3.1 Technical Collaborative Approach

For the purpose of this study, the technical collaborative approach was adopted. In action research, collaboration is a key principle in the interaction between the researcher and the research team. The collaboration between the researcher and the practitioners is technical and facilitatory. Collaboration exists between the researcher, who enters the field with expertise in theory and research, and the practitioners, who are seen as experts in a given situation or setting. The nature of the problem relates to action or change (Holter and Schwartz-Barcott, 1993). Collaboration is at the root of the emancipatory research process in which the researcher and participants engage as equal partners. The researcher facilitates the process but does not control it. Participants are empowered to implement an action or change. This action is achieved through the process of dismantling a problem. An outcome which is acceptable to all depends on the degree of collaboration, and the power to act resides exclusively in the hands of the participants to implement the action. Any final or subsequent actions to be taken must reflect the

collective thinking of the group and must not be determined by an outsider (researcher) or insider (practitioner) (Speziale and Carpenter, 2003).

In insider action research, the questions are formulated based on issues that practitioners have been struggling with and the practitioners engage in a systematic inquiry to find solutions to their problems. The practitioner wants to gain a deeper insight about issues in order to have a better understanding and the questions become part of a general attitude of inquiry (Herr and Anderson, 2005). In outsider action research, the research question is generated by an outsider. One person may instigate the inquiry (process) which is set in motion with the team of interested people or stakeholders. Another approach is to extend an invitation to an outsider with research expertise to collaborate on the inquiry (Herr and Anderson, 2005).

The degree of participation in problem identification impacts on the change process. The researcher enters the collaboration with an identified problem and a specific intervention (Holter and Schwartz-Barcott, 1993). The problem for this study is the disclosure of HIV status and the reduction of stigma for people living with HIV/AIDS. The researcher secures the interest of the practitioners in the research by gaining their assistance in facilitating the research. This approach results in efficient and immediate change. The technical approach generates knowledge that is predictive. The major thrust is validation and the refinement of existing theory which adopts a deductive approach (Holter and Schwartz-Barcott, 1993).

The research team for this study comprised the secretary of the Bhambayi Reconstruction and Development Committee (BRDC), a community care giver who worked under the auspices of the Bhambayi Settlement Project, community leader (Sangoma), a BRDC committee member and the researcher. The researcher created an opportunity for intervention ahead of time or in collaboration with the practitioners. The final goal in action research is the development of theory based on the generation of additional knowledge, general knowledge and local knowledge that may be developed in the process of finding solutions to practical problems (Holter and Schwartz-Barcott, 1993).

3.3.2 Mutual Collaborative Approach

The mutual collaborative approach engages both the researcher and the participants. The researcher and practitioner enter into a dialogue that leads to the identification of potential problems, their underlying causes and possible interventions (Holter and Schwartz-Barcott, 1993). The outcome of such a dialogue results in the researcher and the practitioner arriving at a new common understanding of the problem, as well as the causes of the problem and plans for initiating a change process. A mutual collaborative approach generates knowledge that is descriptive, leads towards the development of new theory and adopts an inductive approach (Holter and Schwartz-Barcott, 1993).

3.3.3 Enhancement Approach

In the enhancement approach the participants work together by progressing beyond the collaborative approach to engage in critical dialogue to raise group consciousness (Speziale and

Carpenter, 2003). The enhancement approach is grounded in two underlying goals. Firstly, to increase the closeness between the actual problems encountered by the participants and the kind of theory used to explain and resolve these problems. Secondly, the approach assisted practitioners in identifying and making fundamental problems explicit. This was achieved by raising their collective consciousness. The knowledge that emerges is collaborative, descriptive and predictive (Holter and Schwartz-Barcott, 1993).

3.3.4 Co-operative Inquiry

Cooperative inquiry is an approach that values the full participation of individuals in action research. In the implementation of cooperative inquiry, both researchers and informants cooperate to derive new knowledge (Speziale and Carpenter, 2003). Cooperative inquiry focuses on individuals who are self-determining and engage in research with their full participation (Speziale and Carpenter, 2003). The research outcomes in cooperative inquiry are well-grounded, taken through many cycles, by as many members with as much individual diversity and collective unity of approach as possible. Cooperative inquiry and research cycling relate to prolonged engagement in the field and involves a more dialectical, dynamic engagement with participants (Herr and Anderson, 2005).

3.3.5 Participatory Action Research (PAR)

Participatory research is a process that attempts to empower deprived, disenfranchised people with the research skill that equips them to identify their problems and find solutions to their problems to the best of their abilities, thereby transforming their lives (de Vos et al., 2011). It

increases people's confidence and enables them to develop new knowledge and skills or build on existing ones (Speziale and Carpenter 2003). Participatory action research focuses on relinquishing control, learning through mutual interaction between researcher and participants and giving a voice to oppressed people (Speziale and Carpenter, 2003). PAR lends itself to collaboration between researchers and study participants in defining the problem, selecting a research method and analysing the data and the findings appropriately (Bloomberg and Volpe, 2008). The ultimate goal of PAR is to empower communities so that they become independent and able to assist their members to overcome impairments through the process of constructing and using the knowledge (de Vos et al., 2011; Bloomberg and Volpe, 2008).

3.3.6 Community-based Action Research

Community-based action research focuses on efforts to improve the quality of peoples' lives in an organisation, community or family level. In community-based action research, researchers engage subjects as full and equal partners (Speziale and Carpenter, 2003). Community-based action research commences with an interest in the problems of a group, a community, or an organization. The purpose of community-based is to assist people in understanding the situation, confronting their problems and then resolving their problems. The process on inquiry in community-based research is rigorous in that stakeholders participate in acquiring information (collecting data), reflecting on the information (analyzing) and transforming their understanding of the nature of the problem (theorizing) (Stringer, 2007).

3.3.7 Action Science or Action Inquiry

The last approach in action research is action science or action inquiry. Action science or action inquiry is inquiry into practice that leads to systematic change within an organisation. Action inquiry encompasses the empowerment of participants, collaboration through participation, the acquisition of knowledge and social change (Ferrance, 2000). In action science, “the emphasis is on identifying theories of action that guide behaviour” (Speziale and Carpenter, 2003:255). The ultimate reflection in action leads to a fuller understanding of how theory guides practice (Speziale and Carpenter, 2003).

3.4 Action Reflection Cycle

The action reflection cycle is a process of observe – reflect – act – evaluate – modify – and move in new directions. The process begins by identifying a particular concern, reflecting on what was happening, thinking of possible solutions as in the way forward, evaluate progress by establishing any new understandings with others, modify practice in the light of evaluation, and move in new directions (McNiff and Whitehead, 2011). According to Reason and Bradbury (2008:390) “the iterative cycles of action and reflection, provide a robust model to increase our understanding of complex situations, while designing and monitoring interventions”. Stringer (2007) refers to the action research routine as ‘look, think and reflect’ which is presented as a spiral of activity, that is, plan, act observe, reflect. The ‘look’ process incorporates gathering information and describing a situation; ‘think’ refers to exploring and analyzing, interpreting and explaining the situation and ‘act’ incorporates planning, implementing and evaluation. The participants in action research work through the details of their activities by means of a constant process of observation, reflection and action. At the end of each activity the participants will

review (look again), reflect (reanalyse), and re-act (modify their actions) (Stringer, 2007). The phases of inquiry in the action research cycle are the identification of a problem area, collection and organization of data, interpretation of data, action based on data and reflection. Figure 3.1 is an illustration of the action reflection cycle.

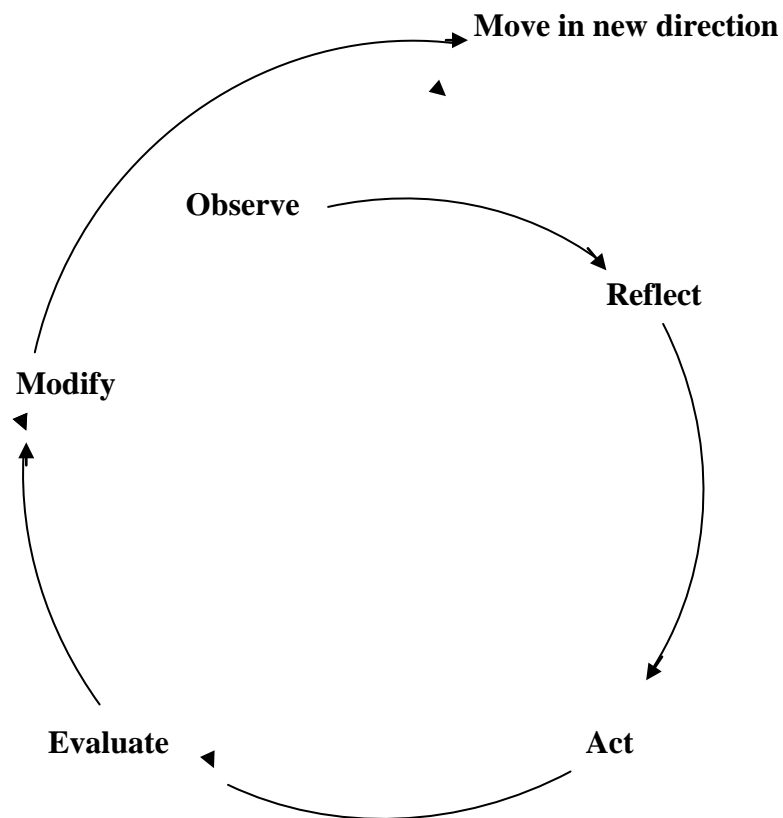


Figure 3.1 Action Reflection Cycle

3.4.1 Identification of a Problem Area

The initiative for an action research project ideally would be expressed by a community or group that was experiencing a problem (Bless and Higson-Smith, 1995). The community or group would seek the insights of individuals with research expertise to resolve the problem (Speziale and Carpenter, 2003). The researcher was involved in a home-based care project in the community and the community caregivers brought the problem of stigma and discrimination of PLWHA to the attention of the researcher.

3.4.2 Gather Data

In action research, data collection does not require any specific method (Holter and Schwartz, 1993). Although data collection is a significant step, it determines what action needs to be taken. The researcher needs to ensure that the most appropriate data for the issue being researched was selected (Ferrance, 2000). According to Stringer (2007) the 'look' stage of the action research process focuses on gathering information about the participants' experiences. It is important to ensure that the information which is gained is directly from the participants and not tainted by biases and experiences of the research facilitator. Data collection can follow a process of allowing people to talk about their experiences, gaining clarity and greater understanding of the realities of the situation (Stringer, 2007). In the current study data was collected using in-depth interviews and focus group discussions.

3.4.3 Interpret Data

The process of analysis and interpretation entails two important steps: categorizing and coding, and the analysis and selection of key experiences that illuminate the nature of the experiences (Stringer, 2007). Interpretations and explanations of data were offered to participants within the context of the study. The participants most accurately reflected the context (Speziale and Carpenter, 2003). The research team engages in dialogue and debate about the findings and reach consensus in the analysis of the outcome. The researcher's primary responsibility is to lead the data analysis phase. The final conclusions are drawn by the team of participants who attend the meeting (Speziale and Carpenter, 2003).

3.4.4 Act on Evidence

On completion of the data analysis the team of participants on completion of the data analysis makes a firm decision on the action or change that needs to take place (Speziale and Carpenter, 2003). Changes occur because their need induces transformation (Smith, Pyrch and Lizardi, 1993). Reflection in the action phase process is an important aspect of change. Data recorded during reflection adds significance to the study and contributes to the theory that emerges (Speziale and Carpenter, 2003). Action plans are recorded, clearly indicating how the team of participants will achieve their goals based on the outcome statements which describe what is actually going to be done (Stringer, 2007).

3.4.5 Evaluate Results

Evaluation at the end of the study assesses the effects of the intervention to determine the extent of improvement achieved. The researcher guides the evaluation process (Speziale and Carpenter, 2003). Evaluation is conducted to formulate joint stakeholder descriptions and interpretations in which individuals or groups “place their claims, concerns, and issues, review information from interviews and focus group discussions, resolve claims, issues, and concerns, and prioritize unresolved items” (Stringer, 2007:141). The actions are identified in the action phase of the research project, questions are raised on the data and plans for additional improvements are implemented. The unresolved issues are modified and moved in new directions of the cycle for continued action (Stringer, 2007; Ferrance, 2000).

3.4.6 Move in New Directions

The cyclical nature of action research allows for feedback to participants and modifications to any innovations being introduced. The researcher reformulates the issues and negotiates any points of disagreements so that consensus is reached to move in new directions (Stringer, 2007). Participants examine their own practices (review), identify any deficiencies (reflect) and change them to improve the situation (modify their actions). These changes are only achieved through collaboration between the researcher and participants who systematically take action to resolve specific problems (Stringer, 2007).

Data collection follows the processes of community mobilization and collaboration, collective selection of participants and sharing of knowledge.

3.4.7 Community Mobilisation and Collaboration

The measures adopted to improve health and other needs of the community are implemented through community mobilization. “Community mobilization builds capacity in communities for sustained, responsive and locally owned programmes and services” (International HIV/AIDS Alliance, 2012:2). The PLWHA, communities and households are most severely affected by the impact of HIV/AIDS. The challenge is for communities to mobilize support for HIV education and ensure better health for all the people by establishing links for community action with essential health and social services. Communities need to address the barriers which undermine good HIV treatment, care and prevention strategies (International HIV/AIDS Alliance, 2012). A community based strategic plan to combat this vulnerability to HIV/AIDS should be comprehensive, consistent, coordinated, constructive, consequence oriented and committed to the community (Alam, 2010).

A collaborative approach in action research seeks to build a positive working relationship. The process of collaboration is intent on developing a harmonious and productive relationship among disparate groups of people to achieve set goals. The assumption is that cooperation and consensus should be the primary focus of the research activity. Herr and Anderson (2005) refer to insiders initiating collaboration with outsiders, such as community members contracting or inviting outsiders to collaborate on the research. Collaboration links groups that are in conflict to attain viable, sustainable and effective solutions to problems that affect the lives of people in the community through dialogue and negotiation (Stringer, 2007). The research participants have the capacity to engage in research that is sustainable and enables people to maintain the momentum of their activity over a prolonged period of time (Stringer, 2007).

3.4.8 Collective Selection of Participants

The research facilitator needs to identify and communicate with people in a position of authority in the community and gain their permission to work in their community. Opinion leaders or gatekeepers are also included in the early stages of the research process. Participants are invited to participate in the study. The research facilitator ensures that the participants in the study are drawn from groups or individuals with different experiences and perspectives (Stringer, 2007).

3.4.9 Sharing of Knowledge with the Community

The participants or the members of the research team share their concerns with the community in order to build consensus for social/behaviour change. The mutual sharing of ideas and concerns and having knowledge of the community's cultural norms and languages are critical to the success of the research project (Choudhry et al., 2002). According to Reason and Bradbury (2008:208) "action researchers have sought out innovative ways of making the results of their efforts both more accessible and more useful to their community partners".

3.5 Research Setting

Bhambayi is an informal settlement located in the district of Inanda, in the province of KwaZulu Natal, South Africa. Bhambayi used to be a peri-urban area north-west of Durban and is now incorporated within the boundaries of the eThekweni municipality. This community has been riddled with crime, violence and political instability since the 1980's but has stabilised since the second democratic election in 1999. The geographical area of the planning unit is 0.9km². Bhambayi is situated 18 kilometres from the central business district (CBD) of Durban and

Verulam is the closest major commercial centre, about 10 kilometres away. Phoenix is four kilometres away and is the main transport node for the inhabitants in Bhambayi. The health-care facilities that the people can access are Inanda C and Newtown C clinics which are both a kilometre from Bhambayi. Mahatma Ghandi Hospital is a level-one hospital three kilometres away from Bhambayi. Being an informal settlement, the area lacks the infrastructure of piped water, sanitation, and housing and refuse disposal. The Bhambayi Reconstruction and Development Committee (BRDC) is responsible for co-ordinating all development projects in the community. The projects in progress since 2001 include the provision of low cost government housing, development of roads, supply of piped water at focal points, the provision of mobile chemical latrines, and refuse disposal facilities.

The Bhambayi Settlement Trust situated at the Drop-in-centre in Bhambayi, is a non-profit organisation (NPO) run under the auspices of the Department of Welfare. The project has identified ninety four children that are affected with HIV/AIDS and provides them with food. The feeding scheme makes provision for sandwiches in the morning and school lunches. This project also provides home-based care services for terminally ill AIDS patients and food hampers for PLWHA who are on antiretroviral treatment (Bhambayi Settlement Project Coordinator, 2004). This community was chosen for the study because the researcher had been in contact with this community since 2003, working on a project for home-based care.

The office of the Bhambayi Reconstruction and Development Committee (BRDC) is centrally situated in the informal settlement. The building is a white brick building surrounded by dense bush. There is a security fence around the building with a gate that is locked at all times. Access to the office was arranged by appointment with the secretary of the BRDC. A pre-fabricated

building situated alongside the office is used by the community for meetings and church gatherings. In front of the offices is a green chemical latrine close to the fence. There are public telephone booths at the entrance opposite the building alongside the road is a standpipe where people collect water and wash their clothes. The main roads in Bhambayi have been tarred since 2004. A drop-in-centre which caters for PLWHA and orphans is situated fifty metres from the office of the BRDC. Ghandi Settlement, a historical site and tourist attraction, is situated in Bhambayi. Figure 3.2 is a site map of Bhambayi.

Planning Unit Profiles - Bhambayi

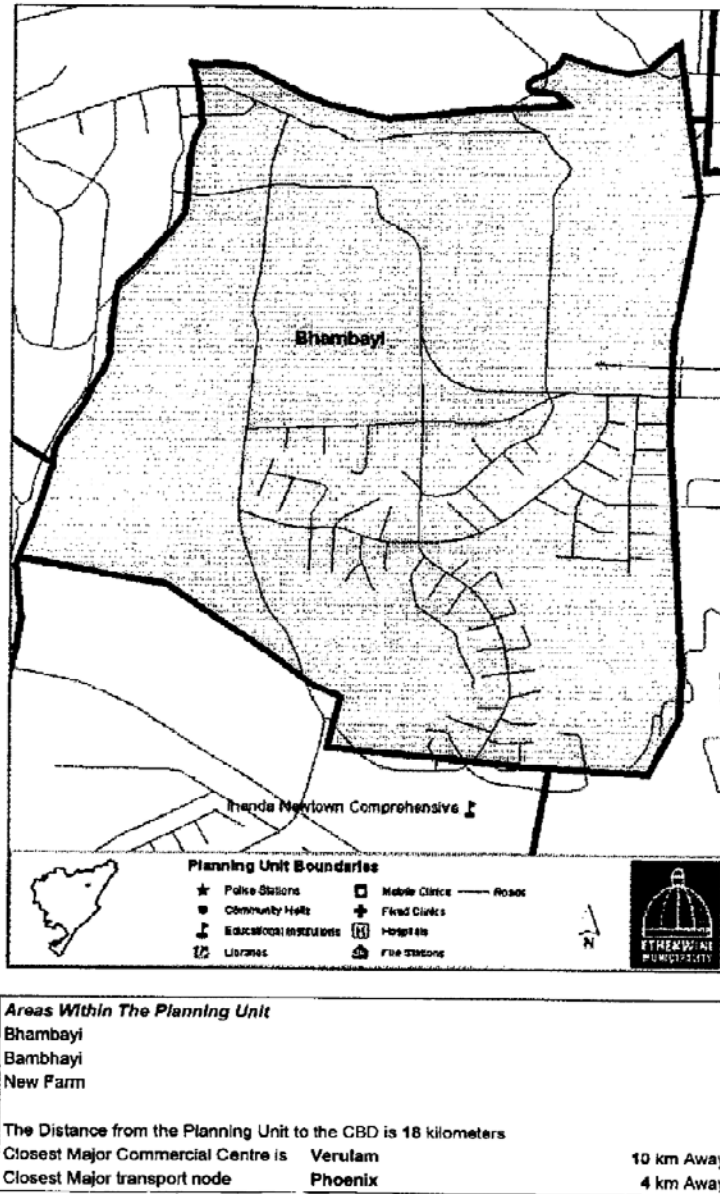


Figure 3.2 Site map of Bhambayi

3.6 Study Population

The Bhambayi community constitutes the study population and the statistics were captured from the eThekweni Planning Unit Profiles for Bhambayi at the time of investigation. The population of Bhambayi was 6713 and there were 2401 households. The population comprised 99% Blacks, and 1% Indian. The ratio of males to females was 46%:54% (Planning Unit Profiles, 2009).

The community under study is a low-income community. The figures for 2009 indicate that 36% of the people were unemployed, 15% employed and 19% not economically active. The dependency ratio was 7:1. Due to the high rate of unemployment the annual household income ranged from no income in 53% of the population up to R38 400 in 6% of the people. The household income per annum in 9% of the population ranged from R1 – R4 800. Seventeen per cent of the population earned between R48 01 – R9 600 and 12% ranged from R9 601 – R19 200 (Planning Unit Profiles-Accessed - 2/9/2009). The target population comprises all the people who are HIV positive. The accessible population is the PLWHA that have disclosed their HIV status.

3.7 Sampling

In qualitative studies, researchers choose purposive sampling which is directed at groups, settings and individuals where the phenomenon being studied is present or likely to occur. Purposive sampling means selecting participants based on their relevance to the study, research questions and the theoretical positioning of the study (Silverman, 2010). From the seventy four HIV-positive people who were identified by the project coordinator of the Bhambayi Settlement Project, the researcher purposively selected the participants who had disclosed their HIV status. Prior to the researcher purposively selecting the participants the community caregiver had

approached twenty five PLWHA who had disclosed their HIV status and were willing to participate in the study. Participants are deliberately selected because they had already lived through the experience or were undergoing the experience. The quality of the participant determines the quality of the data and the participant had to be willing to talk and share the experience with the researcher. Participants can either volunteer to participate in the study or are self-identified by an advert or recruited by a third person as was the case in the current study (Silverman, 2010). The research team comprised the BRDC secretary, community caregiver, community leader (Sangoma), and a BRDC committee member. The research team was responsible for their active participation in action research. The research team identified the participants and then approached them and asked them to participate in the study. In order to ensure that data was obtained from a variety of different perspectives, PLWHA, community members, family members and adult children of HIV/AIDS people were also approached to participate in the study.

The BRDC committee member initially recruited six community members who were willing to participate in the study and seven members each for the second and third focus group discussions. Five family members willingly participated in the study. PLWHA who had disclosed their HIV status also made requests to their children above the age of 18 years to participate in the focus group interviews. Six adult children were identified and one (aged sixteen) was not eligible to participate in the study. In qualitative research, participant selection is based on people who are willing and more likely to give descriptive rich data (Morse and Field, 2002). The focus group comprised a minimum of five and a maximum of seven members.

3.7.1 Inclusion Criteria

The inclusion criteria comprised all the PLWHA who had disclosed their HIV status to a family member or friend. Family members were approached by the PLWHA to participate in the study. Children above the age of 18 years were also approached by their parents to participate in the study.

3.7.2 Exclusion Criteria

Children below the age of 18 were excluded and PLWHA who had not disclosed their HIV status were excluded from the study.

Data sources were self-reports which emanated from the in-depth interviews with PLWHA who had disclosed their HIV-status and focus group discussions with community members, family members and adult children (aged 18 and above). The number of people living with HIV/AIDS and the disease profile of the community were captured from the database of the Bhambayi Settlement Project. The researcher engaged in informal meetings with the secretary of the BRDC and the Ward Councillor regarding employment opportunities for single parents and assistance with securing identification documents respectively. Figure 3.3 is an illustration of the data sources.

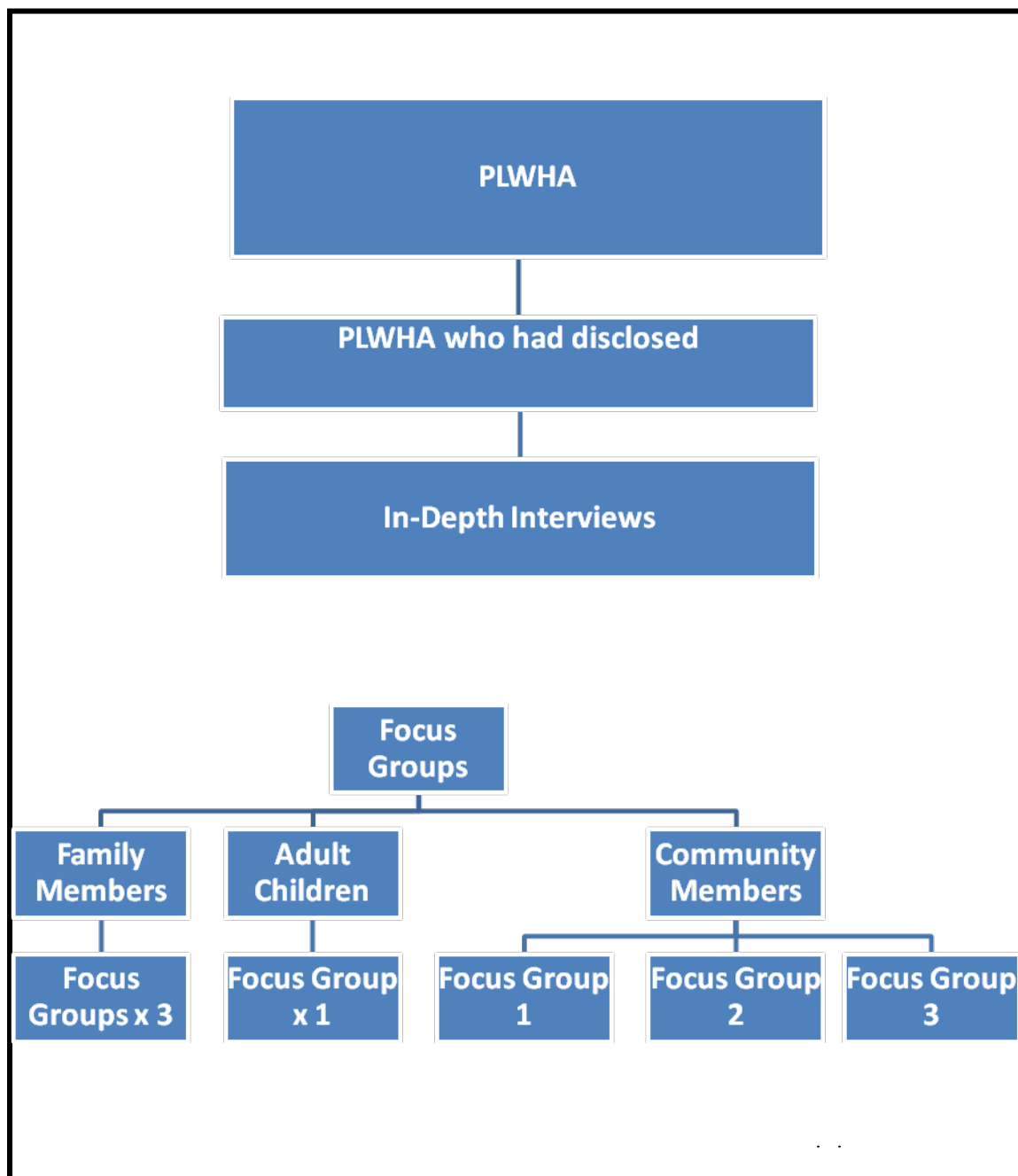


Figure 3.3 Data Sources

3.8 Data Collection Guides

The interview guides for in-depth interviews and focus group discussions were developed by the researcher based on the research questions. Literature underpinning the study, the conceptual

framework and the action research design guided the structure of the questions. Due to the sensitive nature of the topic, questions exploring the details about their sexual relationships were changed or re-phrased. This was achieved with the guidance of a nursing expert in HIV/AIDS research. Annexure 1 is a focus group guide for community members. The questions looked at views on stigma related to HIV, views on HIV positive people disclosing their status, assistance to PLWHA to disclose their status, importance of disclosure, and support from community leaders for PLWHA who have disclosed. Issues pertaining to stigma, conditions that would allow PLWHA to experience a reduction in stigma, conditions that would lead to a reduction in stigma in the community and community leaders support to PLWHA to experience a reduction in stigma. Annexure 3 is a focus group guide for family members and adult children and it focused on issues attached to HIV, sharing of family member's status with other community members, experiences of living with a family member who has HIV/AIDS and change to their status in the community.

The interview guide for PLWHA is Annexure 2 which focused on specific questions pertaining to their demographic status of age, gender, marital status, number of children, religious affiliation, and knowledge of HIV status and disclosure of HIV status to family members. The semi-structured open-ended questions targeted the participants' experiences of stigma, experiences of disclosure and lifestyle changes. In action research, action precedes intervention

and this may not necessitate the pre-testing of instruments because of the follow up interviews (Munhall, 2007).

In the current study three focus group sessions were held with community members and family members. One focus group session was held with adult children. The reason for one focus group discussion with adult children was the problem in organising mutually convenient times to conduct the focus group discussions.

3.9 Data collection process

The data collection processes included interviews with PLWHA who had disclosed their HIV status to a family member or friends in the comfort of their homes. The focus group discussions were held with family members, adult children and community members at the offices of the BRDC.

3.9.1 PLWHA

At each interview the researcher introduced herself and the community caregiver to the participant. Each participant received a detailed explanation of the purpose and objectives of the study which was interpreted by the community caregiver. An information sheet (Annexure 4) outlining the nature of the study and an informed consent form (Annexure 5) were handed to each participant prior to the commencement of the interview. The information sheet and informed consent forms were translated to isiZulu. The informed consent forms were signed (Annexure 6) to confirm their willingness to participate in the study.

After the initial introduction the researcher requested permission from each participant prior to the interview to use the tape recorder. Participants refused to allow the use of the tape recorder because of the sensitive nature of the topic and they felt they could not express their views freely if the tape recorder was used. The researcher had to resort to note taking. Although the researcher had a very good understanding of the Zulu language, it was the community caregiver that asked each participant the questions in isiZulu. The researcher followed the responses of the participants and wrote these responses down as the participants spoke, taking care to write as much detail as accurately as possible. The community caregiver assisted with the translation of the responses into English after each participant had completed a statement. The interview was conducted according to the interview guide Annexure 2.

The time for the in-depth interviews varied from forty-five minutes to an hour, depending on the condition of the participants. The researcher, with the assistance of the community caregiver, encouraged participants to talk freely, bearing in mind that the participant may be perceived as an expert on the subject (de Vos et al., 2011). Participants were provided with a packet of biscuits and a litre of juice at the end of each interview as token of appreciation.

3.9.2 Focus Groups

PLWHA nominated one or preferably two family members and adult children to participate in the focus group discussions. A community representative from the BRDC was appointed by the members of the BRDC to approach community members who were willing to participate in the study. The researcher selected community members on the basis of their willingness to

participate in the focus group discussions. The group size comprised five to seven members in each group, affording each member the opportunity to make a valuable contribution. The community members had six members in the first group and seven members in the second and third focus group sessions. There were five family members and adult children each in their focus group discussions. The difference in the group size in the first and subsequent sessions was dependent on the availability and willingness of the participants to be part of the study. The group dynamics were managed quite successfully by encouraging people to express and clarify their views (Burns and Grove, 2009).

A focus group strategy deliberately encourages participants to remember their experiences and to compare their experiences with those of others. Questions on the interview guide were used to guide the discussions. The advantage of focus group discussions is that they generate dialogue (Burns and Grove, 2009). The office of the BRDC was used as the venue for the focus group interviews of community members, family members and adult children. Participants were familiar with its location. The researcher had already established a trust relationship due to her engagement with the community since 2003. The researcher encouraged the participants to respond, remained neutral to the comments and monitored their verbal and non-verbal behaviour. Participants were allowed to interact with one another and this led to more synergistic exchanges. The researcher had to be astute and know when and how to probe and guide the community caregiver in order to gather specific details on personal experience which would improve the credibility and general quality of data. Since this study was conducted during the period of transformation and this was a disadvantaged community, the researcher dispelled ideas of change in the political arena and concentrated on lifestyle changes (de Vos et al., 2011).

The researcher introduced herself and the nature of the meeting prior to the commencement of each focus group discussion. All the focus groups, with the exception of the adult children, were held in isiZulu and the community caregiver translated for the researcher. He explained the purpose and objectives of the study. Information sheets (Annexure 4) and informed consent forms (Annexure5) were distributed to each member. The participants were asked to sign if they were willing to participate in the study. They read the document and signed the informed consent form (Annexure 6).

The researcher welcomed the members to this study and the community caregiver repeated the welcome in isiZulu for the benefit of the members. The community caregiver was the facilitator in the focus group discussions. The researcher coached the community caregiver on the method of questioning. Participants were assured of confidentiality and their right to withdraw from the interview or stop it at any time. The facilitator asked the questions according to the interview guide in isiZulu and directed the questions from general to specific. It was necessary to carefully plan the focus group discussions, keeping in mind the group dynamics for accessing rich information. Participants that are fairly homogenous and share similar backgrounds feel sufficiently at ease to express their views (Moule and Goodman, 2009). The ideal group size is six to twelve. The setting for the group discussion should be neutral and not aligned to any values or expected behaviours. The setting must be easily accessible, comfortable and not intimidating. The facilitator must ensure that all the group members contribute to the discussions and must not let a few people to dominate the discussion (Moule and Goodman, 2009).

In the focus group discussions, the facilitator encouraged clear lines of communication among the participants, creating a non-threatening environment that facilitated trust (Moule and Goodman, 2009). The process of communication acts as a link between the worlds of the researcher and the participants. Focus groups have a tendency of producing self-disclosure. Therefore, participants were encouraged to share their ideas, perceptions and personal experiences (de Vos et al., 2011; Morse and Field, 2002). At each focus group discussion the participants responded in isiZulu. The researcher wrote detailed notes as accurately as possible as the discussion progressed. After every response to a question, the facilitator translated what had been discussed so that the researcher could check her notes for accuracy. At the end of the discussion the researcher was guided by the group in summarising the main points for clarity and correctness of information (Moule and Goodman, 2009). Focus group discussions with community members and family members lasted for between one and one and a half hours and with the adult children for forty five minutes. An estimated thirty five hours were spent in interviews and focus group discussions. At the end of each focus group discussion refreshments were provided in the form of juice and biscuits (Moule and Goodman, 2009).

3.10 Data Analysis

Qualitative data analysis begins with a general review of information. The researcher reads through the information to get a sense of the overall data, writing memos and reflective notes in the initial sorting out process or summarising field notes (Creswell 2007). The researcher takes the information back to the participants to obtain feedback which also assists with the verification of findings at a later stage. It is at this point that the researcher closely examines the words used by the participants such as metaphors or translates the participants' ideas into

meaningful units. The data is further reduced to develop codes or categories that are matched to a text segment (Creswell, 2007). The researcher assesses the quality of the information and recruits new participants. This was done in the current study for the period 2008 – 2009. A transcript of an interview with a HIV positive person who had disclosed to family is presented as Annexure 13. The researcher conducted three focus group discussions with family and community members in order to establish saturation and verification of data. Data “saturation means that no new information is being obtained from participants” (Nieswiadomy, 2008:63). The researcher stopped data collection when saturation was reached and no new information was obtained.

The qualitative data analysis process conforms to the general contour which is represented in a data analysis spiral. In the first loop of the spiral data management refers to organising the data into files and notes. The files are then converted into appropriate text units for analysis. This can be done manually or by using a computer software programme. The second loop progresses from reading to memoing, that is, writing notes in the margins of field notes to the next loop of the spiral, describing, classifying and interpreting. The researcher describes the data in detail, develops a classification system and interprets the data based on their own views or the viewpoints of other authors in the literature (Creswell, 2007).

Classification of qualitative data means taking the data apart into segments or units of meaningful data, labelling the unit of meaning in a single word and matching the categories and sub-categories (Bloomberg and Volpe, 2008; de Vos et al., 2011). Interpretation of the data relates to making sense of the data, and adding meaning to the data in relation to what is

happening in the actual situations. In the last phase of the spiral the researcher presents the data in a text and tabular format. The inductive analysis in qualitative studies begins with raw data from multiple sources, broadens to specific categories and sub-categories and then onto the general theme (Creswell, 2007). Figure 3.4 is an illustration of the data analysis spiral.

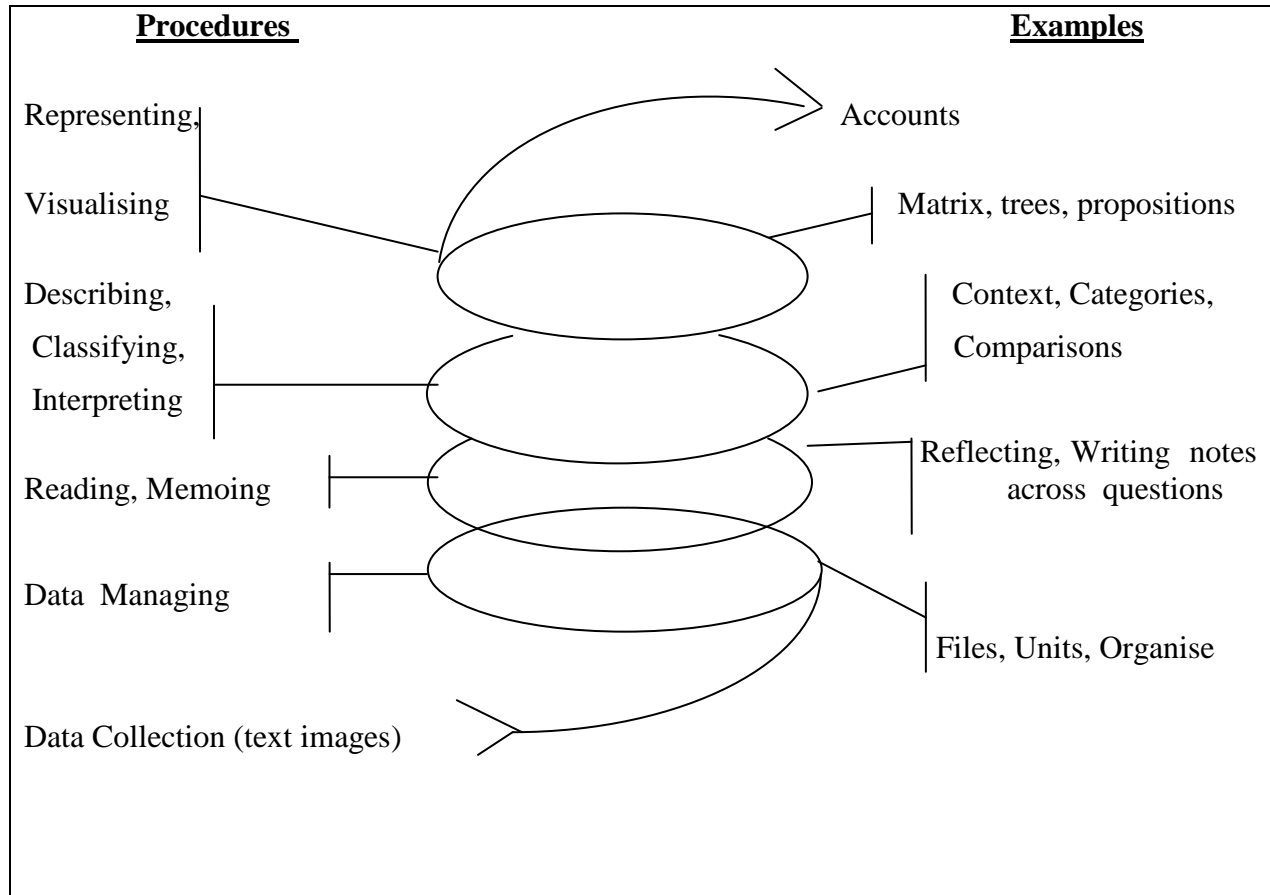


Figure 3.4 Data Analysis Spiral

The researcher in this study examined the data by reading it several times and making sense of it. This process of reading the data constantly forces the researcher to become well acquainted with the data as a whole before taking it apart. When re-reading the data the researcher writes short

phrases, ideas or key concepts that occur in the margins of the field notes (Bloomberg and Volpe, 2008; Creswell, 1998; de Vos et al., 2011). This process forces the researcher to become well-acquainted with the data, and to perform minor editing to make the field notes manageable. The researcher closely reviewed the field notes and reflected on the major thoughts presented in the data that leads to the formulation of the initial categories. The evidence and the multiple perspectives to support the categories were sub-categories (Creswell, 2007).

The researcher wrote detailed descriptions of the experiences that related to the topic. During the process of synthesis the researcher was able to link, examine the relationships and verify the findings (Moule and Goodman, 2009). These findings were checked by more experienced researchers and with the research team. The demographic data from interview schedules were analysed manually because the sample was relatively small. Qualitative data was also analysed manually using the open coding system. Data was transcribed and read, highlighting units of meaning with different colours. These segments were written on chart paper followed by labelling units into single words. Then, the possible groupings of codes were done followed by categorising the codes into categories and sub-categories, thereby ensuring coherence of the text. For example, there was 'exposure of disclosure' as a category and 'important to disclose' as a sub-category. These were checked by more experienced researchers (Henning et al. 2004; Moule and Goodman, 2009). The ultimate goal of qualitative data analysis is the development of a community-based framework which is achieved through re-contextualisation. The results were supported by literature which claimed a unique contribution in the context of established knowledge (Bloomberg and Volpe, 2008; Moule and Goodman, 2009).

3.11 Trustworthiness

Rigour or trustworthiness is a means of establishing credibility and integrity in qualitative data (Moule and Goodman, 2009). Trustworthiness of a qualitative inquiry was established against the four criteria used as a gold standard by qualitative researchers (Bloomberg and Volpe, 2008).

When appraising qualitative research, rigour is classified as rigour in documentation, procedural rigour and ethical rigour. Procedural rigour incorporates appropriate and precise data collection techniques that attempt to reduce bias and misinterpretation. The application of ethical principles throughout the study confirms ethical rigour (Moule and Goodman, 2009). Qualitative researchers use four criteria to establish trustworthiness, that is, credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985). The positivist's paradigm uses concepts of validity and reliability as opposed to the naturalistic investigators that incorporated the four criteria outlined by Lincoln and Guba (1985). These four criteria are equivalent to the conventional concepts of validity and reliability.

Lincoln and Guba's (1985) views on trustworthiness affords the naturalistic inquirers an opportunity of comparing validity, reliability and generalisability to correspond with the four criteria establishing trustworthiness. Credibility corresponded to internal validity, transferability to external validity/ generalisability, dependability to reliability and confirmability to objectivity and neutrality (Shenton, 2004; Tobin and Begley, 2004).

3.11.1 Credibility

Credibility refers to confidence in the truth of the data. Prior to the study, the researcher had gained an in-depth understanding of the community, their culture, language and the views of the people, thereby establishing a rapport and a trust relationship with the community (Bloomberg and Volpe, 2008). Credibility was achieved through prolonged engagement with the community during data collection over a period of three years.

The researcher used member checks as the technique for establishing credibility. The data was checked 'on the spot' with the informants at the end of each interview and focus group discussion. The researcher read the notes in English and the community caregiver translated the information into isiZulu to ensure that what had transpired had been captured correctly. This process also gives the respondents an opportunity to correct errors, restate incorrect interpretations, summarise the findings and assess the overall adequacy of data points (Lincoln and Guba, 1985). The researcher presented the categories and subcategories to the research team to establish the accuracy of the data which had been captured. In the final analysis, data member checks also involved the verification of findings and the emergent conceptual framework. A detailed description of the research setting and detailed description of experiences were important contributions for the promotion of credibility (Shenton, 2004).

Triangulation enhances credibility and this was achieved through the different perspectives of the individuals, family and the community. Data triangulation involves the collection of data from several sources and a wide range of informants whose viewpoints and experiences can be

verified against others in a comparable position (Shenton, 2004; Burns and Grove, 2009). In the current study data was collected from PLWHA, family members, adult children and community members. The researcher then closely examines the experiences of different individuals, groups of people or communities in relation to the phenomenon under study for the purpose of validation. In methodological triangulation the researcher uses two or more methods either at the design stage or the data collection stage (Burns and Grove, 2009). Data collection method used in the current study was in-depth interviews and focus group discussions.

Participants who were genuinely willing to participate in the study offered data freely without any reservations. They were made aware of their right to withdraw from the study at any point (Shenton, 2004). The frequent debriefing sessions between the researchers and the supervisors afforded the researcher an opportunity to review the analysis of data into categories and sub-categories. The questions that emerged were addressed in the interpretation of data. The supervisors, with their wide experience, identified flaws in the study, which were brought to the attention of the researcher so that corrective action could be taken. Probing by the supervisors on issues pertaining to the phenomenon afforded the researcher opportunities to reflect on the findings of the study (Shenton, 2004).

The researcher's reflective diary was used to record the initial impressions of each data collection session. According to some writers, this recording could be considered critical in establishing credibility because it monitors the researcher's progressive subjectivity (Shenton, 2004). Reflective critique is relative to the person that claims that the facts are true. People reflect on issues and processes and make implicit judgements based on their interpretations,

biases, assumptions and concerns. Dialectical critique focuses on the social reality of the phenomenon under study. A dialogue is pursued between the research team and the participants in order to create opportunities for change, for example, prominent leaders making public disclosures and members of the community following them. The involvement of PLWHA regarding disclosure of HIV status and the reduction of stigma is a useful contribution. The principle of collaborative resource was achieved through the verification of the findings which were interpreted into categories and sub-categories and presented to the research team for their input (O'Brien, 1998).

The background, qualification and experience of the researcher enhanced credibility. The funding of the study by a recognised organisation (National Research Foundation-Thuthuka Programme and the Durban University of Technology) and permission to undertake the study as authorised by the University and the stakeholders in the community continue to emphasise the need and credibility of the study (Shenton, 2004).

3.11.2 Transferability

Transferability does not allow for the generalisation of the findings but the researchers can apply the methods in other similar settings. The detailed description of the research included the setting and the study population together with the sufficiently detailed description of the phenomenon that was researched. The detailed description of the findings enables the researcher to compare the phenomenon with the report on the findings to other similar situations. It can be argued that, since qualitative research confines itself to small numbers of individuals in particular

environments, it is impossible to make generalisations (Shenton, 2004). Lincoln and Guba (1985) present a similar argument but suggest that it is up to the researcher to provide detailed descriptions that enable the reader to have a clear understanding of the phenomenon, embrace it and compare it to other situations (Shenton, 2004). The transferability of the findings to similar settings and contexts could be assessed based on the phenomena under study that may manifest in similar settings. Transferability is the ability of the researcher to see that it can be transferred to fit their own context (Polit and Beck, 2010).

3.11.3 Dependability

Dependability overlaps with credibility because the techniques outlined to measure credibility were also applicable to dependability. The overlapping methods used to achieve the close ties between dependability and credibility were methods such as focus groups and individual interviews (Shenton, 2004). The argument against this practice is that, to establish dependability in practice, an inquiry audit could be adopted to establish confirmability of the data (Lincoln and Guba, 1985). Dependability was attained through an inquiry audit and supporting documents were scrutinised by external reviewers. The inquiry audits that established the dependability of the data refer to the provision of detailed accounts of the data collection and interpretation processes (Bloomberg and Volpe, 2008). The detailed reporting of the processes within the study addresses the issue of dependability. This enables future researchers to repeat the study and examine the extent of the proper research practices that were adopted in the study (Shenton, 2004).

3.11.4 Confirmability

Confirmability in qualitative research corresponds to objectivity in quantitative design. The researcher ensured that the findings of the study detailed the experiences and ideas of the participants and not the preferences of the researcher (Shenton, 2004). Confirmability was established by ensuring that the research findings were the results of the experiences and the ideas of the informants. Confirmability was enhanced by at least two independent people reviewing and agreeing with the data's relevance or meaning by checking the transcribed data. An inquiry of the product, that is, data findings, interpretations and recommendations supported by data establishes confirmability (Lincoln and Guba, 1985).

3.12 Ethical Considerations

The ethical considerations for this study were based on the ethical framework, principles and benchmarks that guide clinical research (Emanuel, Wendler, Killen and Grady, 2004).

3.12.1 Independent Review

The researcher obtained ethical clearance for the study from the Biomedical Research Ethics Committee at the University of KwaZulu Natal on the 31st August 2005 (Annexure 7). The chairman of the Bhambayi Reconstruction and Development Forum granted the researcher permission to conduct the study on the 02nd August 2004 (Annexure 8). The new committee of the Bhambayi Reconstruction Development Committee granted the researcher permission to conduct the study on 2nd April 2005 (Annexure 9). A request for permission to conduct the research study at NIP Site-Bhambayi was sought through the District Manager, Inanda District

Office (Annexure10). The Acting Superintendent-General, Department of Social Welfare and Population Development authorised the researcher's request for permission on the 29th April 2005 (Annexure 11).

3.12.2 Informed Consent

The researcher invited the participants to be part of the research study and they were selected based on their willingness to participate (Munhall, 2007). The participants were reassured that the data collected would not cause emotional, physical or psychological harm (Moule and Goodman, 2009). Informed consent to participate in the study (Annexure 6) was obtained from the participants after the objectives and the purpose of the study had been explained to them in a language they understood. The participants who were illiterate endorsed the consent forms with a thumb print. Participants must be in their right frame of mind psychologically and legally to give consent or to refuse. They were made aware that they were at liberty to withdraw from the study at any time (Moule and Goodman, 2009).

3.12.3 Respect for Recruited Participants and Communities

The researcher respected the rights of every individual to make autonomous decisions. The individual had the right to question issues, to refuse to contribute on issues that caused discomfort or to terminate their participation (Moule and Goodman, 2009). Information provided by the participants would not be publicly reported in a manner that would lead to their identification (Moule and Goodman, 2009). The researcher assured the participants of confidentiality and the obligation of members of the research organizations who have access to

information to respect it (Moule and Goodman, 2009). The need to maintain confidentiality was strictly negotiated with the HIV counsellor and the caregiver. They were aware of the principle of confidentiality because they were directly involved with PLWHA. The community caregiver fulfilled the role of interpreter as well and was sworn to secrecy in order to maintain confidentiality. Therefore, the researcher did not need an expert to translate the interviews and focus group interviews.

3.12.4 Favourable Risk-Benefit Ratio

The researcher ensured that there was no undue distress to the study participants due to the sensitive nature of the topic of HIV/AIDS (Moule and Goodman, 2009). The researcher had training in community and mental health and therefore was qualified to provide counselling, support and advice and had knowledge of resources that would resolve their concerns and overcome their difficulties. The supportive nature of the researcher was her ability to listen carefully to what was said by the participants 'off the record', thereby establishing a valuable bond (Munhall, 2007).

3.12.5 Data Management

The management of qualitative data was an important issue that needed consideration. All the data was carefully labelled and dated according to date of collection. Data was usually stored in a safe and secure place under lock and key. The researcher used a password controlled computer to store data, with back-up files on a separate machine. Since the analysis was done manually, the written notes and charts were stored separately from other field notes and journals

which are usually kept by the researcher (Munhall, 2007). The ownership of the data was negotiated with the research team prior to commencing the study. Data was only accessible to the researcher and promoters.

3.13 Conclusion

The philosophical paradigm for action research was explored with the idea of ensuring its relevance to the current study. The epistemological discussion of action research and its significance to nursing was explained. The various approaches to action research were presented, indicating a choice of the technical collaborative approach for this study. This approach is commonly used in nursing. The action research reflection cycle was discussed as a process of observe-reflect-act-evaluate-modify- and move in new directions. The phases of inquiry in the action research cycle were described as identification of a problem, collection, organization, and interpretation of data and action based on reflection. The aspects that were described in the study were the research setting, study population, sampling, data collection guides, and data collection processes and data analysis. The four criteria that establish trustworthiness were explored in order to reflect the truth. Finally, the chapter concludes with ethical considerations and data management.

CHAPTER 4

FINDINGS

4.1 Introduction

This chapter presents the results from interviews with PLWHA and focus group discussions of community members, family members and adult children of PLWHA who have disclosed their status. The questions asked in the interview guides were formulated around the research questions and were guided by the conceptual framework. The data was analyzed by categories and subcategories and the voice of the participants was included. The researcher had planned to use a tape recorder for the purpose of data collection and planned to have the data from the isiZulu interviews transcribed verbatim by an isiZulu-speaking language expert and then translated into English for analysis. PLWHA were asked if a tape recorder could be used to record the interviews. The participants preferred that a tape recorder not be used due to the sensitive nature of the topic. Since the participants did not agree to the use of a tape recorder, the researcher recorded the interviews in writing with the help of the interpreter.

The action research cycles in this chapter relate to community mobilisation in cycle one. The key features in this cycle are community entry, establishing the need for research and setting up a research team. Cycle two focuses on data generation and collection among PLWHA, family members, adult children and community members. The features in this cycle for each group of participants focused on the setting and participants, data collection, data analysis and findings. Cycle three follows up on verification of findings in relation to PLWHA, family members, adult

children and community members. Cycle four explores the reflections of the researcher and cycle five relates to the development of an intervention which is the development of a framework to facilitate disclosure and reduce stigma among PLWHA

The community caregiver assisted the researcher in interpreting the information given by the participants during the interviews. The researcher has a working knowledge of the isiZulu language. During the interviews, the researcher was present and recorded the responses of the participants in English. During and after the interviews, the community caregiver verified that the information which had been recorded by the researcher was a true reflection of what had transpired during the course of the interviews. Data from the in-depth interviews and focus group discussions were typed up from the hand written notes by the researcher at the end of each interview or focus group discussion. This process was a little time consuming but no alternative could be found. The researcher took comprehensive notes during the interviews to ensure that data was not lost.

4.2 Cycle 1: Community Mobilisation and Collaboration

PLWHA play an active and influential role in community mobilisation since they are the people who are mostly affected by HIV. The members of the community also take responsibility for addressing issues pertaining to HIV/AIDS with the support of key community members. In essence, community mobilisation is a capacity building process through which individuals, groups or organisations plan, carry out and evaluate activities to improve health and other needs. Communities make decisions jointly with all the relevant role players and stakeholders. The

community takes responsibility for transforming and changing their lives. The principle of community mobilisation builds on the capacity for the sustainability of projects or services (International AIDS Alliance, 2010). Collaboration and consensus building with key community members is essential for the effective management of a project (Choudhry et al., 2002).

4.2.1 Community Entry

The researcher engaged in a dialogue with community members to gain entry in order to conduct research for academic purposes and also to inform, empowering and conscientise the community (Annexure 8 and 9). The conscientising process makes the participants aware of their situation, as well as the problem, challenges and potential from different perspective (Seedat, Duncan and Lazarus, 2001). Community entry is vital and an integral component of the research process. Its importance is emphasized, particularly when collaborating with ethnically diverse communities and when exploring sensitive topics (Moorlaf et al., 2008). Community entry is a gradual process and an essential step in community participation. The researcher must establish a rapport with the people in the community. The initial step in the entry process is critical and sets the tone for the success or failure of the research project (Moorlaf et al., 2008).

The researcher was introduced to this community in 2003 with the intention of developing this community as a training facility for community nursing students. The community was defined as an informal community with different political factions in an area which had a very high incidence of crime. It was during the provision of home-based care for PLWHA that the extent of the problem of HIV /AIDS stigma was identified by the researcher. The researcher then

approached the secretary of the Bhambayi Reconstruction and Development Committee (BRDC) in July 2004 and shared her idea of conducting a study in the community. The secretary discussed the researcher's idea with the BRDC committee and the researcher was invited to a meeting of the BRDC in Bhambayi. The BRDC scheduled meetings every Saturday at 10h00. The researcher presented the proposed research topic and asked whether there would be support for the research. The committee members questioned the scope of the research and its proposed impact on the community.

The members of the BRDC agreed to the researcher proceeding with the study and supported the project. The BRDC members advised the researcher to contact the Project Co-ordinator of the Bhambayi Settlement Project in order to proceed further with the research. After many phone calls, the researcher managed to set up a meeting with the Project Co-ordinator who was a retired nurse. She was enthusiastic about the study and offered her support. She advised the researcher to put forward a request in writing to conduct the research study in Bhambayi.

The Project Coordinator of the Bhambayi Settlement Trust invited the researcher to their Christmas party in order to meet the members of the Trust. The District Manager also invited the researcher to a meeting of the regional coordinators in order to engage with them on projects that would benefit the proposed study. The researcher had a meeting with the Project Co-ordinator and requested permission to conduct her research. This request for permission was forwarded by the Project Coordinator to the District Manager and to the Regional Office. The Acting-Superintendent General: Department of Social Welfare and Population Development approved the study. The researcher established and maintained a very good working relationship with the

Project Coordinator and the secretary of the BRDC, who were subsequently involved in the study as members of the research team.

The researcher established a rapport with the community and maintained a trust relationship throughout the study as members of the research team. The community's residents were reluctant to accept any projects or programmes that were designed by 'outsiders'. Therefore, the researcher ensured that the community took ownership of the project, supported the project and were encouraged to change it as the need arose. Networks with community representatives, who were the members of the Bhambayi Reconstruction and Development Committee (BRDC) had already been established. The BRDC is the gatekeeper of the community and played a major role in coordinating the needs of the community, interpreting these needs and negotiating with governmental and non-governmental organizations for resources.

4.2.2 Establishing the Need for Research

The burden of HIV/AIDS has affected communities, households and individuals living with HIV/AIDS. The Bhambayi community was equally affected with more and more people suffering from AIDS. Families and communities presently do not have the resources to care for people with AIDS and are unable to cope with the burden of the disease (Health Systems Trust, 2000). With an increase in the disease profile of the community, the households and community did not have the capacity to care for PLWHA. The need for home-based care was expressed by the community at an open meeting of representatives from social welfare, health, the tertiary institution that the researcher was employed at and members of the community, in 2003. The

Bhambayi Settlement Trust, under the auspices of the department of health and social welfare, established home-based care services for terminally ill people with AIDS. PLWHA in the community expressed concern to the community caregivers about being stigmatised because they were infected and affected by the disease. It was at a debriefing session of community caregivers with the project coordinator of the Bhambayi Settlement Trust and the researcher that this concern was raised by the community caregivers. The researcher asked PLWHA that were being counselled by the HIV counsellor whether there was a need for a study on stigma and disclosure. They expressed a need and stated that they would support the research. The researcher seized the opportunity and approached the Bhambayi Reconstruction and Development Committee (BRDC) with a topic for the study on the disclosure of HIV status and the reduction of stigma in PLWHA in Bhambayi. The community was aware of the problem of stigma and disclosure and did not make any changes or modify the initial research idea in any way. They fully supported the idea of the research project on HIV/AIDS stigma and disclosure.

4.2.3 Setting up the Research Team

According to Speziale and Carpenter (2003:261), it is "important in the initial stage of action research to identify as many stakeholders" as possible and engage in discourse about the problem. Greenwood and Levin (2007), in their Co-generative Action Research Model, recommend communication arenas which are described as spaces that allow participants and researchers to come together for mutual learning. Arenas are designed to match the specific needs of communities. Communication between insiders and outsiders aims at producing learning such as information sharing, team building, the need for large group, small group, one-

on- one meetings or spaces for reflection (Speziale and Carpenter, 2003; Greenwood and Levin, 2007).

As an outsider, the researcher makes decisions at the outset and teaches and trains local participants on the topic that they share a common interest in. It is the responsibility of the researcher to encourage insiders to take control of the developmental process (Greenwood and Levin, 2007). The action research process was collaborative and sought the full attention of the researcher and the participants in implementing action or change. The focal point of the process was change and it rested in the hands of the participants or the research team who act as change agent. It was the research team that mobilized the change and continued with their involvement in the project (Speziale and Carpenter, 2003). The researcher's ability to let go of the project can become problematic if the local participants have not achieved the capabilities to control and direct the project on their own (Greenwood and Levin, 2007). The researcher carefully selected the members of the research team from a group meeting, one-on-one interviews and from an organization (the BRDC). The researcher was aware of the dynamics of community engagement and the need to gain the support and co-operation of key people within a community in order to start a project or continue with it (Choudhry et al., 2002).

The first person that the researcher contacted was the project co-ordinator of the Bhambayi Settlement Trust because this project targeted PLWHA. At the first meeting, the need for the study was established based on the statistics and the disease profile of the community. It was the project coordinator of the Bhambayi Settlement Trust who introduced the researcher to the HIV counsellor and the community caregiver. The community caregiver established the link between

the researcher and the secretary of the BRDC to approach the community leaders. In view of the nature of the Bhambayi community, the decision makers at that time were the Bhambayi Reconstruction Committee. All matters regarding the community had to be dealt with by them. The BRDC nominated a representative from their committee to be a member of the research team. Although the researcher had previously contacted the project coordinator of the Bhambayi Settlement Trust, the BRDC also advised the researcher that she would be the best person to identify participants for the study. The sangoma (trained traditional healer who uses bones or connects with the spirits that assist with diagnosis and treatment) was introduced to the researcher by the community caregiver as a parent of a person living with HIV/AIDS. The sangoma advised and treated young girls that sought her advice on HIV. The research team comprised the researcher, the secretary of the Bhambayi Reconstruction and Development Committee (BRDC), a community member, the sangoma and a community caregiver. The researcher has a Public Health Nursing background with thirty seven years of experience in community health nursing. The researcher fulfilled various roles as educator, advisor, counsellor, resource person and facilitator within her field of work.

The researcher engaged in informal meetings with the secretary of the BRDC and the ward councillor which took approximately thirty minutes to an hour. The secretary of the BRDC was in charge of the day care centre in the community. The community caregiver was trained in home-based care and HIV counselling prior to the research, and worked under the auspices of the Bhambayi Settlement Trust. The sangoma and community member were well known people in the community. The community member was involved in the housing project in the community. The researcher fulfilled an advisory role in addressing the many and varied problems of people

living in an informal settlement. The secretary of the BRDC was the link between the researcher and the BRDC. She arranged meetings with the BRDC, acted as a spokesperson on their behalf and assisted with matters pertaining to PLWHA, BRDC and the community. The researcher fulfilled the role of coordinator in the research project. The community caregiver assisted the researcher with the identification of PLWHA who were willing to participate in the study. He accompanied the researcher to interview PLWHA who had disclosed their HIV status. He also fulfilled the role of interpreter in the project.

The sangoma was a prominent member of the community and a number of HIV-positive people had consulted her for the services that she provided. She was aware of the signs and symptoms of HIV. She advised young girls that had not disclosed their status to family members to do so and, most importantly, to get tested and seek treatment for their condition. She also provided health education to the people who visited her, advising them about accessing antiretroviral treatment at a hospital or clinic for HIV/AIDS. The sangoma's advisory role met the needs of the research team in educating and creating awareness about HIV/ AIDS.

The community member was the key person who acted as a liaison between the community and the research team. She was also the key informant in matters relating to the community. PLWHA who did not have identity documents were unable to access grants if their CD 4 cell count was below 200 μ /ml. The community was aware of the problem of stigma and disclosure. This allowed the researcher to set up a research team comprising influential members of the community and proceed to the next cycle of exploring the experiences of participants regarding disclosure and stigma. Together with the members of the research team, the researcher

approached PLWHA, family members, adult children, and community members for their involvement in the study. The participants that willingly participated shared their experiences regarding disclosure and stigma in the community.

4.3 Cycle 2: Data generation and collection

Data was generated through interviews with PLWHA and focus group discussions with family members, adult children and community members. In action research, the data collection processes include participant observation, reflective diaries and journals and field notes to monitor the process of change. The data was interpreted by the participants as a collaborative process to the analysis and drawing of valid conclusions (Moule and Goodman, 2009).

4.3.1 PLWHA

The PLWHA were the participants who have disclosed their HIV status to a family member, friend or partners and participated in the study.

4.3.1.1 Setting and participants

The setting for the research was a low income community which is an informal settlement as described in Chapter 3. The in-depth interviews were conducted in the privacy of the homes of PLWHA. The reason for the private interviews was that the PLWHA had disclosed their status to their close relatives and friends, but they had not necessarily disclosed their status to the public.

Since the researcher had approached the community with the topic, PLWHA were the primary focus for the study. The project coordinator of the Bhambayi Settlement Trust suggested that a community caregiver assist the researcher in approaching PLWHA who were willing to participate in the study as all the caregivers visited them daily for the provision of home-based care or meals. The researcher trained the community caregiver beforehand regarding the conducting of interviews and how to look out for any signs of fatigue or distress during an interview so that it could be halted. It was the community caregiver who approached PLWHA who had disclosed their HIV status to family members and others close to them to ask them to participate in the study. The community caregiver also suggested the most appropriate times and days of the week to visit PLWHA. Due to the sensitive nature of the research, it was important for the community caregiver to prepare the participants and to choose appropriate and comfortable settings for the interview. The community caregiver told them about the research and the need for consent prior to the researcher coming in for the interview. He helped to forge links for the researcher, and also to establish a comfortable environment for the interview. On arrival the researcher explained the research topic again in English and obtained their consent. This explanation was translated by the community caregiver into isiZulu. Twenty five PLWHA willingly signed informed consent forms and participated in in-depth interviews. Two out of the twenty-five participants died within three months and ten days of being interviewed.

4.3.1.2 Data Collection

An interview guide in English and isiZulu was used for the in-depth interviews. In-depth interviews with PLWHA were conducted in the privacy of their homes (informal shacks). The

community caregiver asked the questions in isiZulu and the researcher used the English version of the guide to follow the line of questioning. The participants responded by speaking slowly and the researcher was able to take comprehensive notes as they spoke. The community caregiver translated the responses of the participants, thus allowing the researcher to check the notes to ensure that all the information had been captured. The recorded notes were read aloud by the researcher, and the community caregiver translated this for the benefit of the participants. The participants either agreed or disagreed with the recorded information or clarified any issues that were not captured. Although it was time consuming, this exercise ensured accuracy. A similar system was adopted for the focus group discussions.

The inability to use a tape recorder was a significant limitation as it prolonged the information gathering process. This was overcome by asking the participants to speak slowly, which they generally did. The other means adopted to overcome these limitations included recorded notes; translation of responses; and the checking and reading aloud of the notes in isiZulu for the benefit of the participants. This process allowed the participants to verify the data immediately.

The data collection period extended over three years. This prolonged engagement afforded the researcher an opportunity to get to know the participants and aided in establishing a rapport with them. The participants felt comfortable enough with the researcher to disclose their status. They spoke freely about their experiences regarding the use of condoms and engaging in monogamous relationships or not. The length of time for the in-depth interviews varied between forty five minutes and an hour depending on how long the participants were comfortable to continue with the interview. Due to the sensitive nature of the topic and the physical condition of the

participants, the researcher looked out for signs of fatigue or distress during the interview. She kept checking if the participants would like her to continue with the interview or stop and return at a more convenient time. The participants were given the time and space to gather their thoughts and get mentally prepared for the interview. For example, a thirty year-old participant chatted with the researcher on her first visit and then set an appointment to continue with the interview. Another participant was very ill and requested that the researcher revisit her for the interview.

4.3.1.3 Data Analysis

Qualitative data was analysed manually by transcribing the written notes. The entire text was read and re-read thereby deriving units of meaning, identifying codes or groupings of codes. These groupings of codes led to the emergence of categories and subcategories.

4.3.1.4 Findings

The findings and discussions are presented according to the characteristics of PLWHA and their experiences in relation to disclosure and stigmatising reactions. Lifestyle changes after disclosure and suggestions on support strategies to reduce stigma are also presented.

(i) Demographic Data of People Living with HIV/AIDS (PLWHA)

Demographic data of age, gender and marital status, number of children, religion and knowledge of status was generated to describe the twenty five PLWHA who participated in this study. PLWHA who participated in in-depth individual interviews were HIV positive people either in

good health, acutely ill, chronically ill or people in the advanced stages of AIDS. There were two participants in the advanced stages of the disease at the time of the interviews. Fifteen participants were on antiretroviral treatment or prophylactic treatment for opportunistic infections, including tuberculosis. Three out of the fifteen were acutely ill when they were interviewed. Of the twenty five participants, ten indicated that their CD 4 cell counts ranged from 41cells/ μ l to 652 cells/ μ l and the others did not know their CD 4 cell counts. Table 4.1 shows the CD 4 cell counts of participants from lowest to highest. For the purpose of anonymity participants are allocated numbers.

Table 4.1 CD 4 Cell counts of ten participants

Participant Number	CD 4 Cell Count / μ l
21	41
23	137
24	190
12	245
16	257
22	263
18	266
17	272
25	290
15	652

(ii) Age

The inclusion criterion was PLWHA who had disclosed their HIV status to relatives or friends, irrespective of age, but the age of the participants ranged from 17 to 49 years. Twelve participants were between the ages of 20 to 30 years, eight between 31 to 40 years and four between 41 to 49 years and one aged 17 years participated with the consent of her grandmother.

(iii) Gender

Of the total of twenty five PLWHA who participated in the study, twenty two (88%) were females and three (12%) were males.

(iv) Marital Status

Twenty four (96%) participants were single and one (4%) was married. Although the participants were classified as 'single', they were living with boyfriends and partners. Four out of the twenty four participants had indicated that they had been in a long-term relationship for five, ten, twelve or fifteen years. Ten participants had no partners.

(v) Number of Children

Out of the twenty five participants seven had one child each, five had two children, three had four and five each and one participant had six children.

(vi) Religion

Religion was classified as Christian, Islam, Hindu and Traditional African. All the participants were Traditional African following the different faiths. Nine participants were affiliated to the Zionist faith, four Nazarene, three each to Apostolic and Roman Catholic, one each to Mpumelelo Holy Practice Church, Church of Christ, Universal, Twelve Apostles and Christian Church.

(vii) Knowledge of HIV status

The participants' knowledge about their HIV positive status occurred between 1995 to 2006. Eight (38%) out of the twenty five were informed about their HIV status in 2005, six in 2004, five in 2003, two in 2000 and 2006, one each in 1999 and 1995 respectively.

(viii) Disclosure of HIV Status to Family Members and Others

PLWHA disclosed their HIV status to their family members, friends, mothers, grandmother, sisters, boyfriend, daughter, children and owners' of the house in which they shared some living space. Twenty eight per cent disclosed their status to family members, 16% to friends, 16% to mothers, 16% to children, 8% to their sisters, 8% to boyfriends and 8% to owners of the house with whom their shared some living space.

(ix) Experiences of PLWHA

Four categories and eight subcategories emerged regarding disclosure, stigmatizing reactions, sexual lifestyle changes and support to reduce stigma.

The categories and sub-categories from the participants' responses are presented in Table 4.2.

Table 4.2 Experiences of PLWHA

Categories	Sub-categories
Experience of disclosure	'Opens out the illness' and feeling relieved
Stigmatizing reactions	Gossiping and pointing fingers Discrimination by family and community
Lifestyle changes after disclosure	Changes in relationship Healthy lifestyle
Support to reduce stigma	Community awareness Disclosure to the community Formation of support groups

Category 1: Experience of Disclosure

PLWHA related their feelings and experiences after disclosing their HIV status and this had one subcategory namely, opens out the illness and feeling relieved.

(a) Subcategory: 'Opens Out the Illness' and Feeling Relieved

According to the participants, HIV/AIDS was just like any other disease and the participants likened it to leprosy. Leprosy is one of the diseases mentioned in the Bible which describes in detail how people with leprosy were treated in ancient times. Leprosy was also a highly

stigmatised disease and lepers were shunned by society. The PLWHA were treated in a similar manner. Tuberculosis was another disease that was stigmatised because it was contagious. PLWHA were treated in a manner similar to that of people who were infected with tuberculosis. The more people spoke openly about their HIV status and the more that PLWHA explained their experiences, the easier it would be for the community to accept these people and for them not to be stigmatized. The participants explained that if they told people about the illness and explained their HIV status, this would help the community to learn about the disease. This is how participants expressed their feelings.

“Relieved from just talking about it [HIV/AIDS], it opens out the illness. Openness about the disease, I know that AIDS is not curable and to talk about it [HIV/AIDS] and to get to know more about it” (Participant 6).

“I felt good and relieved. It [disclosure of HIV status] has helped me a lot I am not worried that everybody knows. I can drink from the same cup and use everything in the home” (Participant 11).

“I feel relieved talking to my friends and neighbours and get their support. I am happy to tell people my HIV status” (Participant 8).

PLWHA were relieved after disclosure. By disclosing their HIV status, PLWHA experienced a change in their condition and felt much better. These are some of the responses of the participants who felt relieved.

“I am 100% I don’t feel anything. I spoke to the bishop and all the people at the church. No stress. My boyfriend is now on ARVs” (Participant 18).

“Felt relieved talking to my boyfriend. He did not worry and is going to get tested. My boyfriend is a security guard” (Participant 10).

The participants who disclosed their HIV status to their children felt free and happy because their children still respected them and cared for them. These were the responses of participants after disclosing to their children:

“I am happy that I told my daughter that I was HIV positive. She did not say anything about how she felt” (Participant 12).

“I feel free after disclosing, they don’t trouble me, I get respect from my children and they care for me” (Participant 2).

“No problem telling the children. I was relieved after disclosing to my children. Ngakhululeka (felt good and free)” (Participant 24).

Category 2: Stigmatising Reactions

Stigmatising reactions was a category developed from the responses of PLWHA. The two sub-categories that emerged from this category were (a) gossiping and pointing fingers and (b) discrimination by family and community.

(a) Subcategory: Gossiping and Pointing Fingers

The informal idle talk among members of the community about HIV positive people troubled the PLWHA. Some people in the community ridiculed PLWHA to the extent that they were made the laughing stock of the community. PLWHA felt that the knowledge of their HIV status was safe within the family, but if the community or neighbours knew about it, then they would gossip endlessly. This was the response of participants who explained the reactions of people after he/she disclosed his/her status:

“People gossiped about me and neighbours end up gossiping” (Participant 2).

“People talk too much and point fingers at people who get tested” (Participant 10).

PLWHA felt that people in the community were talking about HIV positive people and pointing fingers at them. They were against being made fun of, ridiculed and laughed at.

“Other people can gossip about you, point fingers at you” (Participant 13).

“People are laughing. Don’t use the cup, don’t use the spoon. People are laughing at you. Sometimes they are sick and they are laughing. They are laughing at other people and they did not go to check their status” (Participant 15).

(b) Subcategory: Discrimination by Family and Community

PLWHA feared being discriminated against by their family and community. The participants that were discriminated against were not allowed to use the same cutlery and crockery in their home and would be served food last. According to the participants, the reason for being served last was to prevent the food from being contaminated. Tuberculosis was a highly stigmatised disease and people's perceptions have changed. When people had tuberculosis, they were served with separate utensils because the disease was highly contagious. HIV is also a contagious disease but the mode of spread differs from that of tuberculosis. Some families placed restrictions on PLWHA in the belief that this would prevent other members of the family from getting infected. PLWHA also had their own utensils and some even had the experience of being locked in a room. This was the practiced by families of people with contagious diseases or any physical or mental disability to avoid being shunned by the community. HIV/AIDS is a contagious disease but the community has limited knowledge about its mode of spread, therefore they treated it like any other contagious disease. Some participants were very angry because they were infected and they did not get any support from their families. PLWHA who participated in the study were from an informal community and it was easier for them to disclose to their friends. The participants felt that their image was tainted and that they were worthless. The anger they felt was so intense that they felt they could possibly kill somebody for isolating and ridiculing them. This was the expression of one participant.

“I want to kill somebody. I am the laughing stock of the community. My family did not allow me to drink from the same cup. They locked me in a room” (Participant 23).

“My sister does not worry about me. They don’t believe me. My mother discriminated against me after disclosure” (Participant 5).

Category 3: Lifestyle Changes after Disclosure

The category 'lifestyle changes after disclosure of HIV status' was based on the changes in relationship and a healthy lifestyle. Lifestyle changes after disclosure had two sub-categories, namely: (a) changes in relationships which incorporated abstinence and 'powerlessness' and (b) healthy lifestyle which included diet, exercise and work.

(a) Subcategory: Changes in Relationship

The decision to engage in a single long term relationship or choose not to have a sexual partner was based on the knowledge of their HIV status and the severity of their illness. Participants who previously had multiple sexual partners settled into a monogamous relationship. These were some of the responses of the participants.

“I am with this boyfriend for 12 years. My present boyfriend is the father of my 6 year old son who died of AIDS in 2005” (Participant 13).

“I am in a relationship with one man for 5 years” (Participant 3).

“I am with the same woman for 15 years” (Participant 20).

Some of the female participants rejected men due to their illness and said that they needed to concentrate on their health and their children. They felt that men used them for sex and there

was no emotional attachment or trust in their relationship. Therefore the expression of anger and being 'fed up' came across very strongly.

“Don’t want boyfriend anymore, manje impilo yami (now I must worry about my illness), I don’t want to think of a boyfriend, I am really angry and fed-up with men” (Participant 14).

“No more boyfriends. No more using me for sex. I have nobody to care for my kids” (Participant 25).

The participants who were in long term monogamous relationships advised their partners to get tested and insisted that they use condoms. The challenge that HIV positive women faced was in convincing their partners to use condoms, something which goes against their traditional or cultural practices. The aim of developing trust in their long term relationship and the thought of improving their health were the key factors that determined the use of condoms. Women who were assertive, insisted on their partners getting tested and using condoms. A participant’s partner was angry when she asked him to use a condom. He left her for three months but later changed his behaviour and is now using condoms.

“At the beginning he did not use condoms. ...He [boyfriend] was angry for about three months. After three months he visited me and then started using condoms” (Participant 9).

“I left my boyfriend because he did not want to use a condom” (Participant 17).

In the case of Participant 9, the partner was reluctant to use condoms at the beginning. It is important to note the behaviour change in the above example from anger and denial to

acceptance in the use of condoms and staying in the relationship. The partners of three participants tested negative for HIV (Participants 5, 7 and 13). They stayed in the relationship and continued to use condoms. PLWHA felt very strongly that their boyfriends must use condoms because of the high risk of infection. The participants who had partners who tested negative were afraid of infecting them and insisted that they use condoms to protect themselves. These were the responses of the participants.

“My boyfriend was not sleeping without a condom, I told my boyfriend to have himself tested and he tested negative” (Participant 7).

“My boyfriend uses condoms. He tested twice for HIV and is negative. It is important to use condoms” (Participant 5).

The changes in sexual practices were in the areas of abstinence and 'powerlessness'. The reason for abstaining from sexual intercourse for periods of one to two years was the death of partners or husband.

“I made a big change by abstaining from sexual intercourse for 1 year. I am controlling my sexual desires because I want to get better and go to work” (Participant 22).

“I had no boyfriends; I lived with my husband in Bhambayi. He died of AIDS in 1999 and no other man after he died” (Participant 12).

The participants who were powerless did not make any changes to sexual practices and felt that their partners should be equally responsible in supporting them to make changes, especially in

the use of condoms. Some women were in a relationship where they were powerless and therefore unable to make any changes. The men exercised their authority by threatening to kill them. These were the responses of participants who did not make any lifestyle changes.

“I tried to change. They don’t want to use a condom. Others you can tell they will kill you”
(Participant 11).

“I showed my boyfriend the results. He swore at me. He does not use a condom. He abuses me and told me that I must give the condoms to my mother” **(Participant 16).**

(b) Subcategory: Healthy Lifestyle

PLWHA adopted healthy lifestyles so that there was an improvement in their health and they could go back to work. PLWHA involved in the gardening project benefitted by having food at the end of the harvest time and were able to work. A young participant who wanted to get a job and go back to school responded as follows:

“I know that I am HIV positive but I want to get a job and go back to school” **(Participant 4).**

“I made a big change by abstaining from sexual intercourse for 1 year. I am controlling my sexual desires because I want to get better and go to work” **(Participant 22).**

Category 4: Support to Reduce Stigma

The actions of HIV positive people were examined in relation to the reduction of stigma.

One category that emerged was ‘support to reduce stigma’. This category had three sub-categories, namely: (a) community awareness, (b) disclosure to the community, and (c) the formation of support groups.

(a) Subcategory: Community Awareness

Community awareness was directed at dispelling the myths and misconceptions about HIV. According to the participants, the community believed that HIV positive people were bewitched. They associated witchcraft with the illness instead of accepting the fact that they were HIV positive. HIV positive people must have an opportunity to explain their status and talk about their experiences of the disease. The following is the views of participants on how an HIV-positive person can reduce stigma:

“I must talk about it. I must have an awareness campaign. Have community awareness to dispel misconceptions, myths about HIV and witchcraft. The myth is that the people believe that HIV is caused through witchcraft. The more the community learns about, it the better it is” (Participant 6).

“I talk to people to go for HIV test. I encouraged my sister to go for a HIV test. I advise all the young people that visit me to go and get tested” (Participant 7).

Participants felt very strongly about the community being educated on living positively with HIV/AIDS. The more HIV-positive people talked about their illness, the better the chances were for the community to think positively about HIV. The assumption was that if HIV positive

people think positively, their health would improve and subsequently would lead to living positively with HIV/AIDS. Their responses were expressed in the following excerpts:

“Call the people and educate the community. Some people can understand when I explain my status” (Participant 23).

“Encourage people to get tested and know their status and get treatment. I have spoken to many friends to go and get checked. They went and got themselves tested and told me their status” (Participant 9).

The participants' involvement in community awareness addressed issues of counselling, prevention and treatment. They advised their children to abstain from sexual intercourse in order to prevent HIV infection. The participants are trying to educate the family and the community about children who are sexually active. The children must be educated that if they are sexually active, then they must use condoms and have a single relationship.

“I advised my daughter to stay away from boyfriends. I don't want her to get the disease like me. I will speak to my son when he is older” (Participant 14).

“I advised my daughter to use condoms. I talk to her about how dangerous AIDS is and how they must behave” (Participant 2).

(b) Subcategory: Disclosure to the Community

On the issue of disclosure, the participants responded in the affirmative about disclosing their status to the community. They were prepared to talk about their HIV/AIDS status from being very ill to actually getting better and experiencing an improvement in their health. This would allay the fears of people in the community who believed that once you had HIV you were going to die. The participants encouraged people to get tested and know their status and by doing so, more and more people would get tested, thus reducing the stigma of HIV. They were of the viewpoint that if HIV was treated like any other disease, the stigma would be reduced. The more the community knows about the disease, the better it will be for PLWHA. They felt that HIV/AIDS was just like any other disease and people had to be open about it in order to support the reduction of stigma. These are responses from participants:

“I can disclose to the community that I have a problem. Explain my experience from being very ill to improving my health status” (Participant 22).

“A lot of my friends and neighbours know about the disease. I talk to my friends and ask them to go and get tested” (Participant 17).

Participants expressed their thoughts about people in the community speaking about HIV because according to their perception, the community was full of HIV positive people. This was the response of one participant.

“People don’t want to talk about it or go to the clinic. People in Bhambayi must speak about it because Bhambayi is full of HIV positive people. The more the community learns about it, the better it is” (Participant 6).

(c) Subcategory: Formation of Support Groups

The formation of support groups for PLWHA within the community was strongly recommended by the participants as a measure to reduce stigma. However there were two participants in particular who said that they did not join the support groups at the hospital and clinic in particular because they felt like outsiders. The first participant was not comfortable with the support group at the hospital. She collected her antiretroviral treatment at this hospital and because all these people were from different communities, she felt that she did not belong there. In her community there would be a sense of belonging and togetherness because her friends also had the disease. The second participant attended the local clinic in the vicinity and felt that their own support group from their own community would be better than sitting with strangers at a clinic. The third participant felt that the best way to reduce stigma was to form a support group in Bhambayi. This issue came up again at a meeting of all the participants who disclosed their status to formalise a support group. They can share their experiences and support one another. These were the responses of the participants:

“Kuyangidabukisa (I feel sorry) that I cannot speak openly when I am alone but I am prepared to talk in a group. I do not know about others. The people speak about other illness but not HIV”

(Participant 20).

“I am willing to get involved in the support group and share my experience of having HIV/AIDS”

(Participant 8).

PLWHA highlighted the problems they experienced and expressed the need for physical and psychological support from the group. The one essential need was food for survival since most of them were unemployed. Psychological support in the form of post-test counselling and assisting with the grieving process when there was a death in the family was also needed. Some of the PLWHA who were on antiretroviral treatment had meals supplied to them twice a day through the feeding scheme under the auspices of the Bhambayi Settlement Trust. The Bhambayi Settlement Trust also provided home-based care for terminally ill PLWHA and a feeding scheme for HIV/AIDS orphans. The Bhambayi Settlement Trust was responsible for the training of caregivers in home-based care and HIV counselling. Knowing that the disease was fatal deterred PLWHA from accessing antiretroviral treatment.

The community caregiver explained to the PLWHA that the Bahmbayi Settlement Trust provided meals for PLWHA who were on antiretroviral treatment and not for all the PLWHA. The twenty five PLWHA who disclosed their status were of the opinion that the criteria used for the distribution of meals to PLWHA was not right and that all the PLWHA were entitled to meals due to the high rate of unemployment in that community. PLWHA who participated in the study expressed a need regarding the formation of a support group. The Siyakhula Support Group was formalized in August 2006. The interpretation of the data was done in collaboration with the research team and led to the conclusion that some action or change needs to take place.

The cyclical nature of action research allows for feedback, thus leading the members to seek the support of the community in developing skills in gardening. The community supported this project by sending the members of the Gardening Project on a workshop in gardening. The

secretary of the BRDC, in collaboration with an agricultural officer from the provincial department organized a training programme. The change that was occurring was shown by the gardening project group. The members of the Siyakula Support Group suggested additional projects that the members could engage in. These were bead work, sewing and making grass mats to sustain a livelihood.

4.3.2 Family Members of PLWHA

Family members of PLWHA who had disclosed their HIV status also participated in the study.

4.3.2.1 Setting and Participants

The Bhambayi Reconstruction and Development Committee offered the use of their premises for the focus group discussions. PLWHA who had disclosed their HIV status also made a request for one or two family members to participate in the focus groups. Only five family members consented to participate in the focus group discussions on behalf of the twenty five PLWHA who had disclosed their HIV status.

4.3.2.2 Data Collection

The data was collected in focus group discussions. Focus group discussions were conducted at the offices of the Bhambayi Reconstruction and Development Committee (BRDC), which is centrally situated in the informal settlement. The focus group discussions were facilitated by the researcher in collaboration with the community caregiver. The researcher was mentally prepared with a positive attitude, was relaxed and friendly and encouraged participants to talk about themselves. The researcher engaged in small talk with the participants prior to the group

discussions, thereby showing an interest in the participants and putting them at ease by creating a warm, friendly environment. The facilitator had to ensure that she remained a facilitator and not a participant (de Vos et al., 2011). An information sheet and consent form in isiZulu was handed to the participants. The researcher explained the nature of the study and the importance of obtaining their consent. This information was translated into isiZulu by the community caregiver. The participants were assured that they could withdraw from the study at any time. The researcher requested that the participants provide their contact details for distribution amongst the participants for future contact prior to focus group discussions (de Vos et al., 2011). The community caregiver asked the questions from the interview guide in isiZulu and the researcher took notes as the dialogue progressed. The community caregiver translated the responses into English for the benefit of the researcher. The researcher guided the community caregiver in encouraging the participants to express their opinions, to be more specific in their responses and explore the reasoning underpinning their viewpoints (de Vos et al., 2011).

The researcher sought the permission of the group to tape record the discussions. The group was not amenable to this request due to the sensitive nature of the study. This problem was overcome by the researcher taking copious notes of the discussions in English. Although the discussions were held in isiZulu, the researcher had a good working knowledge of the language and could follow the discussions. After each question, the responses to the discussions were summarised in isiZulu by the community caregiver for the participants and in English for the researcher. The researcher recorded the data as the discussion progressed. At the end of each discussion point, the researcher cross-checked the information that was summarised by the community caregiver against the written notes. The findings were verified in collaboration with the community

caregiver and the participants. The researcher read out the findings and the community caregiver translated the information for the benefit of the participants. They then agreed or disagreed, corrected or clarified what was recorded. The community caregiver facilitated the flow of the discussion ensuring that the discussion was not dominated by one or two persons. It was the researcher who dealt with the dynamics of group discussions by looking out for changes in behaviour and attitudes for and against the viewpoint under discussion. The challenges facing opposing viewpoints were handled by the researcher who captured the emotional responses of the participants. The time taken for each focus group discussion was between one and one and half hours.

The family members engaged in three focus group discussions. The first focus group was initiated by the researcher, the second by the family members who felt that there were pertinent issues that needed discussion. The third focus group was set up by the researcher to inform the participants of the discussions that had transpired in the first two focus group discussions and for verification of the findings.

4.3.2.3 Data Analysis

Qualitative data was analysed manually by transcribing the written notes. The entire text was read and re-read to derive units of meaning and identify codes or groupings of codes. These groupings of codes led to the emergence of categories and subcategories.

(a) Subcategory: Challenges of Living with an HIV/AIDS Person

The physical burden encountered by family members was most severe during the process of caring for a person with AIDS in their terminal stage. The necessity for the provision of care in bathing, giving of medication, feeding and accompanying them to the hospital/ clinic was taxing for a single member of a family. The families of the two participants who were in the terminal stages of the disease had the unpleasant task of cleaning, bathing and changing them after their bouts of diarrhoea. Although they experienced difficulties in the physical care of the family member with HIV/AIDS, they did not express any concern of becoming infected. If these tasks were shared by other members of the family, it would reduce the burden of caring being assigned to one person. Some HIV positive people were angry and violent towards family members.

“When my daughter is angry with me she kicks everything. I must always do everything in my power to care for her” (Focus Group 3).

Psychological support for families that had lost their loved ones to AIDS was crucial. In the case of the mother that lost her 30 year-old daughter to AIDS, she acknowledged that her daughter had suffered from excruciating headaches and had died of tuberculosis meningitis. It was a very painful experience for the mother because she watched her daughter wasting away under her care and she felt powerless. This was the response of the mother:

“She was discharged from hospital, always tired, she had TB meningitis. The doctor left the needle for the lumber puncture that caused the sore. Very sore and painful to lose a big child, as the days go it is very hard and difficult” (Focus Group 1).

The researcher visited the mother prior to the funeral to pay her respects and sympathize with the mother. After the funeral, the researcher visited the families of the two participants who had died in order to provide psychological support in the form of bereavement counselling.

A male participant in the focus group was worried about his status, although he had tested negative on several occasions since 2003, 2004, 2005 and 2006. He knew his partner's HIV status and questioned her being infected prior to their relationship. The big worry was who had infected her and was she cheating on him? The question of mistrust often arises in a relationship where one of the partners is HIV positive and the other negative. The doubt in their relationship is expressed in the following excerpt.

“I am still worried about my status. It is imperative to know what happened, who came with the disease from the beginning? My partner is infected, who infected her? How did she get infected” (Focus Group 2)?

Category 2: Fears of Disclosing to the Community

The sharing of a family member's HIV status was a very sensitive issue. The category 'fears of disclosing to the community' had two subcategories: (a) more protective because we are directly affected, and (b) the community ridicules PLWHA.

(a) Subcategory: More Protective because we are Directly Affected

The reason for not sharing a family member's HIV status was that the person must be respected for what they are and must not be degraded. The family members felt that they were directly

affected by having an HIV- positive family member. By disclosing their HIV status they would be taking their dignity away, creating problems in marriages and a breach of trust in a relationship.

“No. I would not want to go about talking and taking her dignity away. She is human, I respect her for that. If I speak about her status it can lead to problems in marriage, no trust in the relationship” (Focus Group 2).

The family members responded negatively to the disclosure of family members’ HIV status to other members of the community, except for one mother who experienced the death of her daughter aged 30. She told the people at the church about her daughter’s HIV status.

“Yes, I told the people at the church about my daughter’s status” (Focus Group 1).

The family members had noticed that their neighbours were estranged. The neighbours apologized to the family for ignoring them and were very supportive after they were made aware of the diagnosis. The family members had not disclosed to other community members, believing that they would be isolated by the community.

“No, they will isolate you in the community. Look at you differently” (Focus Group 1).

(b) Subcategory: Community Ridicules PLWHA

There were people in the community who ridicule other people with HIV/AIDS. They treated it as a joke and laughed at PLWHA.

“There must be a way to explain because other people take it as a joke and make a fool of you”

(Focus Group 3).

People in the community perceived thin people as having HIV, and cannot say the same for fat people. Their knowledge of people with HIV/AIDS in the community was based entirely on the external appearance of individuals. Family members felt that even though they did not share the HIV status of a family member the community was aware of the people with HIV/AIDS.

The following is an excerpt from the focus group discussion:

“You cannot see the signs and symptoms on some because they are fat. Only the thin ones you see the signs” **(Focus Group 3).**

Category 3: Stigma Reduction

Stigma reduction had two subcategories namely: (a) dissemination of information and (b) support group for family members.

(a) Subcategory: Dissemination of information

One method to reduce the stigma surrounding the disease is by means of community awareness campaigns to educate the community about HIV/AIDS. The dissemination of information to family members and the general community would inform people, get them to change their behaviour and broaden their understanding of HIV/AIDS resulting in a reduction of stigma. An excerpt from the focus group discussion highlights this practice:

“You as family are prepared to disseminate information from clinic/ health worker and pass it on to other families. Call a meeting of the community and explain about the disease. Then we get people to understand about the disease and reduce stigma” (Focus Group 2).

(b) Subcategory: Support Group for Family

Families ostracized those that were ill because of their attitude and expressions of anger. The establishment of support groups would allow people infected and affected by HIV/AIDS to talk about their illness or experiences, thereby alerting the community to the seriousness of the disease. This was expressed in an excerpt from the focus group discussion:

“To have a support group, talk about the disease then we can get the people to change. Teach the people about the disease. Sitting together gives information about getting tested before you get sick” (Focus Group 2).

Affected families need support for themselves and also to provide support to PLWHA. The family members advised the community on having an HIV test prior to the onset of diarrhoea and vomiting. This action would ease the use of antiretroviral treatment, which has its own side effects. The process of stigma reduction would result from the dissemination of information to family members and the community in order to get people to change their behaviour and broaden their understanding of HIV/AIDS. Their advice was expressed as follows:

“Go and get tested before you get sick. When my sister had diarrhoea then she went for a test. Visit the family of the one that is affected. Talk to the family” (Focus Group 2).

Family members were affected by having a member infected with HIV. A few families still ostracised family members that were HIV positive because of their attitude and expression of anger. Some families disclosed their family member’s HIV status to the community at their funeral or memorial service. The families that lost their young adults to AIDS were devastated. The impact of having a family member infected with HIV/AIDS on the family was severe. There is no future for PLWHA as the disease is fatal. This is an excerpt from the focus group discussions:

“Very sore painful “gubage isugu”, very hard, difficult. Before my daughter died she had meningitis. I did not have a problem because she did not want others to know. The disease is not affecting her in anyway. Think of the children, two in the family died of HIV they had glands.

Two brothers died with HIV, 45 yrs old and 30 yrs old. My sons died of HIV and my daughters also have HIV” (Focus Group 1).

The interpretation of the data resulted in open dialogue on coping with a family member with HIV/AIDS and the consequences for the family. Counselling of PLWHA and family members was viewed as a mechanism to equip them to work through the emotions of having to deal with a terminal illness and the thought of losing a loved one.

The family members appreciated the support from the researcher and the community caregiver. The families who were affected by having family members living with HIV/AIDS expressed the need for a support group for family members as well. The researcher, in collaboration with the community caregiver, planned on working with families to start their own support group. The family members felt that expressing their feelings and emotions of living with an HIV/AIDS person in a support group would relieve them of the stress of keeping their family member’s HIV status a secret. The collaboration between the research team and the family members would precipitate further changes to the action research cycle, depending on the needs of family members.

4.3.3 Adult Children

Adult children of PLWHA who had disclosed their HIV status participated in the study.

4.3.3.1 Setting and Participants

The offices of the Bhambayi Reconstruction and Development Committee were used for the focus group. Only five children consented to participate in the focus group interviews on behalf of the twenty five PLWHA who had disclosed their HIV status.

4.3.3.2 Data Collection

Data was collected during the focus group discussions with the five adult children. They had one focus group discussion because the children were at school during the day and were occupied during the weekends. The focus group with the children was held in the late afternoon, taking cognisance of the safety of the researcher in this high risk, crime ridden community.

The focus group discussion was facilitated by the researcher in collaboration with the community caregiver and was conducted in English. The researcher engaged in small talk with the participants prior to the group discussions, thereby showing an interest in the participants and putting them at ease by creating a warm, friendly environment (de Vos et al., 2011).

Information sheets and consent forms in isiZulu and English were handed to the participants. The researcher explained the nature of the study and the importance of obtaining their consent. The participants were assured that they could withdraw from the study at any time (de Vos et al., 2011). The community caregiver asked the questions from the interview guide. The researcher took notes as the discussion progressed. The community caregiver facilitated the flow of the discussion, ensuring that the discussion was not dominated by one or two people. Again the researcher dealt with the dynamics of group discussions, looking out for changes in behaviour

and attitudes for and against the viewpoint under discussions. The challenges facing opposing viewpoints were handled by the researcher, who captured the emotional responses of the participants (de Vos et al., 2011). The time taken for the focus group discussion was approximately one hour.

The researcher sought the permission of the group to tape record the discussions. Once again, the group was not amenable due to the sensitive nature of the study. This problem was overcome by the researcher taking comprehensive notes of the discussions in English. After each question, the responses to the discussions were summarised by the community caregiver in isiZulu for the participants and in English for the researcher. The researcher recorded the data as the discussion progressed. At the end of each discussion point, the researcher checked the information that was summarised by the community caregiver against the written notes. The findings were verified in collaboration with the community caregiver, researcher and the participants. The researcher read out the findings for the benefit of the participants and they agreed with or clarified what was recorded.

4.3.3.3 Data Analysis

Qualitative data was analysed manually by transcribing the written notes. The entire text was read and re-read, deriving units of meaning and identifying codes or groupings of codes. These groupings of codes led to the emergence of categories and subcategories.

4.3.3.4 Findings

Adult children were questioned on similar issues as family members. Since HIV/AIDS stigma and disclosure were sensitive issues, the children did not respond spontaneously to the questions but showed signs of reservations in their responses, unlike the community members and family members who responded spontaneously without any reservations. They carefully thought about the questions and then expressed their views. The male participant in the group would not comment unless questioned directly on his views regarding the issues being discussed.

The data of adult children focused on addressing the issue of stigma reduction, sharing of family member's status with other community members, their experience of living with a family that had HIV/AIDS and changes in his/her relationship with the community since the diagnosis. Three categories and five sub-categories emerged. The categories and sub-categories that emerged from the adult children's responses are presented in Table 4.4.

Table 4.4 Adult Children of PLWHA

Categories	Sub-categories
Living with an HIV positive family member	Feeling ashamed Psychological support Changes in own behaviour
Disclosure to the community	Keeping a family secret
Stigma reduction	Education and awareness of the community

Category 1: Living with a HIV Positive Family Member.

The category living with an HIV positive family member incorporated three subcategories namely: (a) feeling ashamed, (b) psychological support and (c) changes in own behaviour.

(a) Subcategory: Feeling Ashamed

The issue of having a family member living with HIV/AIDS depended on how that particular individual perceived themselves. The adult children's perception of the illness was to a large extent, influenced by the way in which it was perceived by the PLWHA. These views were expressed by adult children:

“Depends on how my mother treats herself. If she is ashamed then I am ashamed. If she accepts then I accept” (Focus Group 1).

“I feel ashamed. I feel ashamed but I can accept the fact that my mother has the disease” (Focus Group 1).

(b) Sub-category: Psychological Support

The adult children felt that it was a painful experience and they had to be strong to support their family member. They were aware that the disease was fatal and feared their parent's death. The idea of being left as orphans or having to take care of their siblings and still continue with school was daunting. In cases where the family member acknowledged that they had the disease, the children also accepted their decision but felt sorry for them. An adult child expressed his/her view as follows:

“It is painful and I have to be strong for her and support her” (Focus Group 1).

“I feel sad I accepted her illness but feel sad as well” (Focus Group 1).

(c) Subcategory: Changes in own Behaviour

The adult children who were not sexually active did not see the need to change their behaviour, although they had an HIV- positive family member. They talked about conflicting feelings and being in a difficult situation where they saw the PLWHA and also the problem of HIV/AIDS. But if they were to change or do anything differently, the community would react and wonder why there was a change or what triggered the change? They were in a dilemma and did not know what to do. They were aware of preventative measures like abstaining from sexual intercourse or using a condom if they were sexually active. This was a response of a participant in the focus group:

“I will use a condom, protect myself by abstaining from sex” (Focus Group 1).

One participant in the focus group was afraid of the people’s reaction because she was sexually active and wanted to get tested. This was her response:

“I want to be tested but I am afraid of people’s reaction” (Focus Group 1).

Category 2: Disclosure to the Community

The category 'disclosure to the community' had one subcategory: keeping a family secret.

(a) Subcategory: Keeping a family secret

Four adult children had kept a family secret by not disclosing the family member's HIV status to other people in the community. One adult child did share her family member's HIV status with a friend because she was afraid that the family member was going to die. This excerpt supports their view:

"I don't have the right to disclose somebody's status. It is hard to talk about it" **(Focus Group 1)**.

The adult children felt that the people in the community would gossip and they would be isolated from the community if the family member's HIV status was known. The community regarded their HIV infected parents as prostitutes since they had many partners.

"You got HIV because you have many partners. Think you are a prostitute. You deserve to be positive or you have something different" **(Focus Group 1)**.

It was a family secret and as children they did not have the right to disclose anybody's status. Parents who had disclosed their status trusted them and did not expect them to discuss their status with others in the community. This excerpt expresses their view:

"My mother disclosed her status to me because she trusted me and does not expect me to talk to others" **(Focus Group 1)**.

The participants did not experience any change in their relationship in the community since the family member's diagnosis of HIV/AIDS. Their friends supported them and, as affected individuals, they supported one another. This excerpt explains their response:

“No change in the relationship with the community. Friends support you. We, as children, support one another” (Focus Group 1).

Category 3: Stigma Reduction

The category 'stigma reduction' had one subcategory and that was 'education and awareness of the community'.

(a) Subcategory: Education and Awareness of the Community

The adult children expressed their views on stigma reduction. They felt that people needed education about HIV/AIDS and how to protect themselves by using condoms or abstaining from sexual activity. Men were uncomfortable expressing their views on HIV/AIDS and experienced difficulty talking about the disease. This was the response of the adult male child in the group:

“It is difficult for me to talk about HIV. I do not feel comfortable to express my views” (Focus Group 1).

The adult children felt that the people must be taught about the disease and given an opportunity to express their views freely about the disease. Education of the community about the disease and creating awareness was crucial to stigma reduction. The people must be taught about HIV/AIDS and how to protect themselves by using condoms or abstaining from sexual activity.

“Teach people about HIV/AIDS. How to protect themselves. Use condoms and abstain” (Focus Group 1).

“Talk about the disease freely” (Focus Group 1).

The adult children were aware of the seriousness of the disease through education in schools and awareness programmes on television. Except for one participant in the group that was sexually active, the others pledged to abstain from sexual intercourse as long as possible or to use condoms. The adult children supported their parents despite the community’s perception of their parents as prostitutes. Their views on stigma reduction related to education and the creation of awareness within the community.

4.3.4 Community Members

The community members willingly participated in the study.

4.3.4.1 Setting and participants

The office of the Bhambayi Reconstruction and Development Committee was used for the focus group discussions of community members. The community representative, who was a member of the research team, approached members of the community who were willing to participate in the focus group discussions. Six community members willingly participated in the first focus group discussion and seven in each of the second and third discussions. Some community members held leadership positions in the community for example a traditional healer, a principal of a preschool or the manager of the housing project. The rest were lay members in the community.

There were different people in each focus group and the same questions were asked in each focus group.

4.3.4.2 Data Collection

Data was collected during the focus group discussions with community members. The focus group discussion was facilitated by the researcher in collaboration with the community caregiver. The researcher was mentally prepared with a positive, relaxed, friendly attitude and this encouraged participants to talk about themselves. The researcher engaged in small talk with the participants in isiZulu prior to the group discussions, thereby showing an interest in the participants and putting them at ease by creating a warm, friendly environment. The facilitator had to ensure that she remained a facilitator and not a participant, to guard against the tendency of facilitators to overpower the participants (de Vos et al., 2011).

The information sheet and consent form in isiZulu were handed to the participants. The researcher explained the nature of the study and the importance of obtaining their consent. This information was translated into isiZulu by the community caregiver. The participants were assured that they could withdraw from the study at any time. The researcher requested that the participants write their contact details for distribution and for future contact with other participants prior to focus group discussions (de Vos et al., 2011). The community caregiver asked the questions from the interview guide which was in isiZulu. The researcher took notes as the discussion progressed. The researcher guided the community caregiver in encouraging the

participants to express their opinions, to be more specific in their responses and to explore the reasoning underpinning their viewpoints (de Vos et al., 2011).

The community caregiver facilitated the flow of the discussion, ensuring that the discussion was not dominated by just one or two people. The researcher dealt with the dynamics of group discussions by looking out for changes in behaviour and attitudes for and against the viewpoint under discussions. The challenges facing opposing viewpoints were handled by the researcher, who captured the emotional responses of the participants. The time taken for each focus group discussion was approximately one to one and a half hours. The community members engaged in three focus group discussions. The researcher sought the permission of the group to tape record the discussions. The response was not favourable due to the sensitive nature of the study. This problem was overcome by the researcher taking comprehensive notes of the discussions in English. Although the discussions were held in isiZulu, the researcher had a very good working knowledge of the language. After each question, the responses to the discussions were summarised by the community caregiver into isiZulu for the participants and in English for the researcher. The researcher recorded the data as the discussion progressed. At the end of each discussion point, the researcher checked the information that was summarised by the community caregiver with the written notes. The findings were verified in collaboration with the community caregiver and the participants. The researcher read out the findings and the community caregiver translated them into isiZulu for the benefit of the participants and they agreed with or clarified what was recorded. Three focus group discussions were held with community members until data saturation point was reached.

4.3.4.3 Data Analysis

Qualitative data was analysed manually by transcribing the written notes. The entire text was read and re-read deriving units of meaning, identifying codes or groupings of codes. These groupings of codes led to the emergence of categories and subcategories.

4.3.4.4 Findings

The community members expressed their views on their experiences of disclosure and stigma, assistance with disclosure and support to reduce stigma. Four categories and five sub-categories emerged from their responses during the focus group interviews. The categories and sub-categories that emerged from the community members' responses are presented in Table 4.5.

Table 4.5 **Community Members**

Categories	Sub-categories
Exposure of disclosure	Important to disclose
Experience of stigma	Stigma associated with HIV
Support to assist with disclosure	Education and awareness Talking freely to people you trust
Support to reduce stigma	Support groups

Category 1: Exposure of Disclosure

There was one subcategory, 'important to disclose' that emerged from the category exposure of disclosure.

(a) Subcategory: Important to Disclose

In this subcategory, community members' thoughts on the importance for PLWHA disclosing their HIV status and the reason for disclosure were explored. The thoughts that community members expressed were in the affirmative. The community asserted that PLWHA did not disclose their HIV status because of their fear of being discriminated against and were disadvantaged. It was important for PLWHA to disclose their status so that they could be supported by their families, friends and the community. Most importantly, they could freely access antiretroviral treatment. PLWHA could disclose to the sangoma, close friend or family.

“It is important for them to disclose so that they can be helped” (Focus Group 3).

“PLWHA find out that they are positive and hide their card. People that are positive have headaches and stomach ache. Have treatment and vitamins” (Focus Group1).

“CD 4 count 200 PLWHA must get treatment and payment” (Focus Group 1).

“Proud of yourself that you know your status and can get treatment and prevent AIDS” (Focus Group 1).

Once PLWHA had disclosed their status openly, there was no need for confidentiality. Counselling in churches for HIV positive people and for the youth in the community was proposed by members of the community. A need for counselling and support was essential especially with the knowledge that the disease was fatal.

“We must help them by counselling. Counselling others about the disease being fatal” (Focus Group 1).

“Counsellors to counsel patients. Counselling then they know their status. Community needs to be counselled as well” (Focus Group 1).

PLWHA who disclosed, lived freely without the stress of hiding the illness. It was when they did not disclose their status that it was like an 'ulcer eating them inside'.

“We feel it is better to disclose than eating them inside when they hide it” (Focus Group 2).

The reasons expressed by community members for the importance of PLWHA disclosing were that they felt emotionally better, healthier and free. PLWHA should be encouraged to disclose so that they have a will to live.

“Encourage people so they have the will to live” (Focus Group 2).

Category 2: Experience of Stigma

The category 'experience of stigma' had one subcategory: 'stigma associated with HIV'.

(a) Subcategory: Stigma Associated with HIV

Ridicule and discrimination by the community should be addressed so that people could be made aware of these issues. The community needs to be educated about the stigma associated with HIV and its implications. Mothers who had children who were affected and infected by HIV/AIDS were provided with information about resources that they could access for the care of their children. This would allow PLWHA to get the proper care and compassion from the community, thereby leading to a reduction of stigma. The education about HIV was directed at individuals and the community so that everybody would have an understanding of the disease. The community members expressed their understanding in the following excerpt:

“Everybody understands the disease and learns about the disease. They are those that are infected and all are affected” (Focus Group 3).

The community members expressed their viewpoint that AIDS was like any other illness, except for the problem of stigma. Other diseases like leprosy and tuberculosis were also stigmatised. Their perceptions were that prostitutes were the carriers of HIV. Couples that were dishonest with one another were afraid to disclose their status to their partners. The community ridiculed and discriminated against PLWHA and made them feel inferior. This was the response from one focus group interview:

“AIDS is not like any other illness. ...Maybe the problem is the stigma. Only prostitutes are carriers. Husband and wife are not honest, afraid to tell others. They will laugh and if they don't laugh then they discriminate. They make PLWHA feel inferior” (Focus Group 2).

PLWHA do not get the love and support from their families. Young adults have a tendency to label PLWHA by calling them names like ATM, OMO, SMS and MTN. According to the explanation by a member of the focus group that these three letter words depict a three legged pot and HIV was linked to the number three that denotes bad luck. Two focus groups agreed with this statement:

“People call PLWHA by labels – ATM, OMO, SMS, KOC (Vodacom)” (Focus Group 1).

“Don’t call them names. Three letter words like MTN. OMO, QOX, or three legged pot, ATM, SMS. By calling them names they are discriminated and undermining them. Mostly the young people are calling people names” (Focus group 2).

Category 3: Support to assist with Disclosure

The category 'support to assist with disclosure' had two subcategories namely: (a) education and awareness and (b) talking freely to people you trust.

(a) Subcategory: Education and Awareness

AIDS awareness campaigns and programmes on television did assist PLWHA to disclose their status. PLWHA should be invited to a public audience to express their views about HIV/AIDS. PLWHA that have disclosed their status publicly must be treated with love and care. Organizations like the Treatment Action Campaign worked closely with HIV- infected people, supporting their disclosure. The community members expressed their support by visiting and talking to PLWHA. The community members felt that it was important for PLWHA to disclose

their status so that they could be supported when they needed help. This was an excerpt from a focus group:

“Treatment Action Campaign (TAC) is doing a lot for the people. AIDS awareness day will help people disclose” (Focus Group 2).

“Tell the sangoma. Tell the friend and family. Talk only to very close friends” (Focus Group 3).

PLWHA who are very ill and who had visible sores from the disease are cared for by the community caregiver or the sangoma. They get their supply of gloves from the nurse at a Level 1 hospital or a pharmacist in the area. This was the response of the sangoma:

“When you work with people, a nurse at the hospital guides you what to do? ...Need gloves to care for them. Get gloves from nurse at clinic and at the chemist” (Focus Group 3).

It was suggested by community members that prominent people in the community that were HIV positive should reveal their status. The community members felt that HIV/AIDS counsellors should be visible in the community so that PLWHA could have easy access to counselling services.

“If there are counsellors they should be visible in the community. Prominent people should reveal their status and quote them to make it easy for people to reveal their status.... (Focus Group 2).

(b) Subcategory: Talking Freely to People you Trust

PLWHA disclosed their status to friends and family that they trusted. They also disclosed to people who were open and approachable whom they trusted. PLWHA developed a trust relationship with community members, affording them an opportunity to disclose their status without any inhibitions. This was the response of the group:

“Visit and talk to the person. Help them to trust (thembeke) the person. Now you can tell the people and there is no confidentiality” (Focus Group 1).

PLWHA who have disclosed can access grants depending on their CD4 cell counts being below 200u/m. According to the community, the delays in processing of grants was problematic for PLWHA because some people would get their grants very late while others had died by the time the grant was approved. The group expressed their views as follows:

“They need a grant but this comes too late or does not come at all. There are delays in getting a grant and by the time they get it, they are dead. CD 4 count must be below 200 to qualify for a grant” (Focus Group 3).

Category 4: Support to reduce Stigma

The category ‘support to reduce stigma’ had one subcategory: support groups.

(a) Subcategory: Support Group

PLWHA need the love and support of communities to help them overcome their fears and improve their health. The fears experienced by PLWHA were the threat of being exposed and

the consequences of being undermined. The community members proposed that workshops and the formation of support groups would assist PLWHA to experience a reduction in stigma.

“When people are afraid, they must not be afraid and they must love themselves. Talk to them, they need the love and support, then they improve” (Focus Group 3).

The community members proposed the removal of labels as a measure that would allow PLWHA to experience a reduction in stigma. Discrimination against PLWHA led to feelings of being inferior and useless, thereby inhibiting them from disclosing their status. The suggestions of PLWHA were to stop the community from name calling, talking to the youth and counselling them about the disease, especially in churches.

“Counselling in the church. Counselling of youth and stage plays and drama to create awareness like Soul City” (Focus Group 2).

The community leaders’ acceptance of PLWHA would be the driving force behind the community’s acceptance of PLWHA. This acceptance would result in the reduction of stigma. Community leaders’ participation in support groups for PLWHA and their visibility in caring for PLWHA would help to reduce the stigma. The community must be educated about HIV/AIDS so that they stop labelling PLWHA. The development of youth and adults in the community must be supported by community structures such as the Community Policing Forum, Non-Governmental Organizations (NGOs) and counsellors trained by churches. The community members expressed their views in the following excerpt:

“Support groups from community leaders. ... Visibility of community leaders to visit people that are affected to show you care about them. Use the Community Policing Forum (CPF) in the development of youth and adult. Youth structures from different organizations, counsellors trained by churches and NGOs” (Focus group 2).

The findings of the participants were verified by the research team in cycle three.

4.4 Cycle 3: Verification of findings

The verification of the data was based on the categories and sub-categories that emerged from the previous in-depth interviews and focus group discussions. The researcher contacted the secretary of the BRDC and the community caregiver telephonically to set up a meeting with the research team to verify the findings. The research team members present were the secretary of the BRDC, community caregiver, sangoma, community member, an HIV-positive person who had disclosed her status and the researcher. An attendance register was signed and the secretary of the BRDC volunteered to translate the findings for the group.

4.4.1 PLWHA

The researcher explained the findings on the categories and sub-categories pertaining to PLWHA. Each section of the presentation was translated by the secretary of the BRDC so that the research team had a clear understanding of the findings. The researcher requested that the team pose questions regarding the findings or make any comments. They agreed with the findings that were presented and made additional comments. Comments were made regarding children being stigmatised. For example, a child at the drop-in-centre was teased about the food

that they were getting. The food was for HIV/AIDS children. The child questioned the grandmother on this issue. This child was teased, ridiculed and stigmatised by other children. The child stopped attending the drop-in-centre for meals.

The sangoma questioned the issue of “how is it possible for PLWHA to reveal their status”? The HIV-positive person in the team responded by stating that you disclose your HIV status to the people you trust. It would not be possible to tell everybody in the community but only the people who are close to you and who you can trust. Another point of discussion was the perpetual problem of HIV-positive people not having identity documents and not being in a position to access the government’s disability grants. The team proposed that this matter be brought to the attention of the BRDC at Ward level. The community representative on the team would submit this issue as an item on their agenda. Even though the disability grants were reviewed every three months, the problem still persisted when the grants were discontinued. PLWHA complained about not having food to eat.

4.4.2 Family Members

The team verified the findings after the researcher presented each category and sub-category.

The issues raised by the team related to the volunteers who were in a dilemma about whose responsibility it was to disclose a child’s HIV status to the mother. In their practice as volunteers, they came across a child with a CD 4 count of 6. The mother was not aware of the child’s condition because she was hospitalised for tuberculosis. Most mothers have very ill

children but are in denial about their children's HIV status. The volunteers find it difficult to approach these mothers.

4.4.3 Adult Children

The categories were similar to those of family members but the sub-categories were different. These findings were verified by the team. Comments by the team related to a lack of interest among youth regarding HIV/AIDS education. The adults from the community would attend HIV/AIDS education workshops but experienced difficulties in explaining the disease to their children because of the stigma. A case was reported of a child who was infected and the whole family was affected because the family was afraid of being infected.

4.4.4 Community Members

The research team agreed with the findings presented by the researcher. It was then emphasized by the HIV positive person in the team that there was a lack of knowledge among members of the community about HIV/AIDS and the mode of transmission of the disease. The challenges facing the community were that more and more people were infected. Their silence compounded the problem of not being tested and treated. The sangoma was able to detect the signs and symptoms of HIV among the orphans under her care.

Finally, the community caregiver at this meeting explained the process of applying for birth certificates, identity documents and accessing grants. The secretary of the BRDC requested a copy of the findings that the community member could present at the Health and Welfare

Committee at Ward Level. The duration of this meeting was one and a half hours. The involvement of other stakeholders in the project is indicative of the community's participation in action research.

4.5 Conclusion

The findings were presented in cycles in line with action research. The three cycles were community mobilization; data generation; and the collection and verification of findings. This study targeted PLWHA, community members, family members and adult children of PLWHA who had disclosed their HIV status. PLWHA engaged in in-depth interviews while family members, adult children and community members participated in focus group discussions. The findings presented in this chapter can be broken down as follows:

- Cycle 1: mobilization and collaboration which explains community entry, establishing a need for research and setting up the research team.
- Cycle 2: elaborates on data generation and collection from PLWHA, exploring the demographic data, knowledge of HIV status, disclosure of HIV status and experiences of PLWHA, family, adult children and the community.
- Cycle 3: explained the verification of findings with the research team.
- Cycle 4: reflections comprise discussions of findings, conclusions, verification and recommendations.
- Cycle 5: development of an intervention

The findings are presented in this section under Setting and Participants, Data Collection, Data Analysis and Findings. The findings on PLWHA explored the demographic variables of age, gender, marital status, number of children, religion, knowledge of status and disclosure of their status to family members and others.

The experiences of PLWHA explored their experience of disclosure, stigmatising reactions, lifestyle changes after disclosure and support to reduce stigma. The experiences of family members concentrated on living with HIV positive family member, fears of disclosing to the community and stigma reduction. Areas similar to those of family members were explored for the adult children. The community members' views on exposure of disclosure, experience of stigma, support and assistance with disclosure and support to reduce stigma were captured in their categories and subcategories. This chapter concludes with verification of findings in cycle 3. Cycles 4 and 5 will be discussed in Chapter 5.

CHAPTER 5

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

In this chapter, the researcher presents the discussions, conclusions and recommendations from the findings that led to the development of a community-based framework. The purpose of the study was to develop a community-based framework that would encourage people living with HIV/AIDS to disclose their status and reduce the stigma associated with the disease. The objectives of the study were to describe PLWHA's experiences of stigma in relation to their HIV status, PLWHA's experiences of disclosing their HIV status, the factors that would encourage disclosure and finally the factors that would promote the reduction of stigma.

The study focused on PLWHA who had disclosed their HIV status and were at different levels of the Stages of Change/Transtheoretical Model regarding changing their behaviour. Since the study targeted PLWHA who had disclosed their HIV status, they were placed at the action phase. The three stages of pre-contemplation, contemplation and preparation are therefore not included in this study. The integration of the Stages of Change Model/Transtheoretical Model with the Action Research cycles culminated in the presentation of findings, discussions and conclusions into five cycles. In Chapter 4, three cycles were accommodated, namely:

- community mobilisation and collaboration;
- data generation and collection ;
- verification of findings.

The reflections by the researcher are presented as discussions in Cycle 4, drawing conclusions from the discussions followed by the development of an intervention that is a framework for the disclosure of HIV status and the reduction of stigma in Cycle 5 and making recommendations from the findings.

5.2 Cycle 4: Discussion - Reflections

The researcher's reflections of the findings are captured as discussions in Cycle 4. The researcher reflects on and discusses the findings in the context of the conceptual framework and related literature.

5.2.1 Disclosure - a Sense of Relief

PLWHA were the central figures in instituting change by disclosing their HIV status, talking freely about the disease and contributing to the reduction of stigma. They needed the support of the family and the community in bringing about this change. Their expressions of feeling relieved, free, good, and happy and "a hundred percent" post disclosure was indicative of their improved emotional state brought about by disclosure. These emotional experiences are equated to 'dramatic relief as a result of disclosure'. PLWHA were relieved after disclosing to family members, friends and neighbours because their HIV status was no longer a secret. They had easier access to health care as they did not have to hide their HIV status and could take their ARVs in the open.

In the current study, PLWHA disclosed to family members and caregivers when they were extremely ill so that people living with them could take precautionary measures against being infected. In a study by Ncama (2007), it was found that PLWHA disclosed their HIV status when they were very ill in order to seek medical care. PLWHA who were symptomatic were more likely to disclose their HIV status than those who were asymptomatic, as the latter were secretive about their HIV status (Ncama, 2007). Self-disclosure of HIV in Britain was highest to partners, followed by friends and lowest for families. In India, disclosure of HIV was higher to family members who were the primary support system (Chandra et al., 2003). Hutchinson et al.'s 2007 study in Soweto found that 90% of the study sample disclosed to at least one person and 62% disclosed to their current sexual partner. These findings concur with the study by Harrison (2006) on disclosure of HIV status, where PLWHA were in a position to get medical, emotional, social and spiritual support within the social context as well as support from the family.

The positive aspect of disclosure is the decrease in stress by not keeping one's HIV status a secret. As much as the family members were directly affected by having a HIV positive family member, they were reluctant to disclose their HIV status to the community. The family protected their HIV positive member from the loss of dignity or other problems by not disclosing their HIV status to the community.

The community expressed the importance of disclosure so that PLWHA could be supported by their family, friends and the community. The community members reported that if community leaders disclosed publicly, then more people in the community would make public disclosure,

thereby breaking the silence and fear surrounding HIV/AIDS. They also proposed AIDS awareness campaigns and programmes on television that assisted PLWHA to disclose their status. The idea of public disclosures was supported by the community where PLWHA should be invited to a public audience to express their views about HIV/AIDS. The community supported the idea that the PLWHA who had disclosed their status publicly must be treated with love and care. They were aware of organizations like the Treatment Action Campaign that worked closely with HIV infected people, supporting them after disclosure. Once conscientised, communities can mobilise resources and relevant stakeholders in order to physically and psychologically support PLWHA to disclose and live positively with HIV. This implies that PLWHA will be in a position to access health services, antiretroviral treatment, grants and food supplies. According to Harrison (2006), disclosing one's HIV status was beneficial to PLWHA, their families and the community. For people to disclose there would have to be an enabling, supportive and safe environment (Hutchinson et al., 2007). In order to disclose, their status, environment around the PLWHA must be conducive and must include trust, confidentiality and the support of the family, community and support groups for PLWHA.

5.2.2 Disclosure to Trusted Persons

According to the PLWHA who participated in the study, disclosure of HIV status was based on a relationship of trust with family and friends. When the family, friends and significant others were supportive, this made it easier for PLWHA to develop a trusting relationship with them.

This was also found in a study by Chandra et al. (2003), in which the subjects reported disclosure to nuclear and extended family members. Twenty five HIV positive people were at the Action stage of the Stages of Change/Transtheoretical Model because they had disclosed their HIV

status to family members and friends living with them. In a study by Greeff et al. (2008), it was found that the people to whom PLWHA disclose, vary from partners to children and parents, family, friends, health care professionals, employers, colleagues and the community at large. PLWHA often disclosed their HIV status to someone close to them who was supportive, while others overtly reject or subtly distance themselves from HIV- positive people. The family and the community caregivers provided a caring, trusting environment that allowed PLWHA to be open about their HIV status, and to be accepted as well as supported for their behavioural changes. The establishment of a trust relationship within the community would allow PLWHA to disclose their HIV status in a safe and secure environment.

The trust relationship is aligned to the Helping Relationship in the process of change, which is a combination of caring, trust, openness, and acceptance, as well as support for behavioural change. The support system for PLWHA included family, friends and community caregivers.

5.2.3 Support for PLWHA

The PLWHA need the physical and psychological support of the family and community. This finding is similar to the assumption made by Harrison (2006) that in a supportive family and social context PLWHA would be able to access medical, emotional, social and spiritual assistance to deal with the challenges of living with HIV. Lekganyane and du Plessis's study (2011) found that female family members were a rich source of support for women who live with HIV and access ART. The family members enabled support by actively searching for information on how to become supportive (Lekganyane and du Plessis, 2011). The physical support in the current study involved caring for PLWHA in their terminal stages. The families' involvement in the dissemination of HIV information, and counselling and supporting family

members to change their behaviour would aid in the prevention of the disease or would restrict infection of people with the disease.

According to Harrison (2006) disclosure of one's HIV status to one's household expands their awareness of the disease, thus allowing family members to take precautions to protect themselves from being infected. PLWHA need the support from the family to encourage disclosure and reduce stigma. An individual's decision to make a public disclosure enhances self-liberation (Velicer et al., 1998). The community members felt that HIV/AIDS counsellors must be visible in the community for PLWHA to have access to counselling services. It is up to the counsellors, educators, healthcare professionals, churches and communities to create a loving and supportive environment in which PLWHA feel safe and secure to disclose their HIV status (Harrison, 2006). PLWHA were motivated to disclose their HIV status after engaging in AIDS awareness campaigns and watching programmes on television. This finding is supported by Hutchinson et al.'s 2007 study which explored the efforts of mass media to inform and educate people about HIV/AIDS and Harrison (2006) who promotes HIV disclosure as the 'norm' for the creation of awareness about the disease that leads to support for PLWHA. The community felt that public disclosure would result in the reduction of the stigma associated with HIV/AIDS.

5.2.4 Benefits of Disclosure

In the current study, PLWHA reported that disclosing their HIV status "opened out" the illness. PLWHA could speak openly about their HIV status, thereby decreasing their psychological stress of keeping their HIV status a secret. Disclosure of their HIV status was an indication that

the PLWHA had progressed from a state of denial to one of acceptance and were modifying their thinking, feeling or behaviour in the process of change which is incorporated in the Stages of Change Model. According to Ncama (2007), acceptance of one's HIV positive diagnosis is a result of the disclosure of one's status. These findings are further supported by Ncama (2007), who found that disclosure was important in creating awareness and openness about HIV/AIDS and could lead to de-stigmatisation of the disease. PLWHA in the current study were relieved after disclosing to their children who still respected them. The feelings of relief are similar to dramatic relief or emotional arousal in the process of change where PLWHA have come to terms with their HIV status and have disclosed to family or friends. PLWHA felt that disclosure of HIV status to the community would allay their fears of death. The benefits of disclosure were easy access to antiretroviral treatment, counselling and support, and not having to hide the illness because of the fear of discrimination.

PLWHA in the current study experienced an improvement in their condition once they started taking antiretroviral treatment, although the side effects of the antiretroviral treatments were severe and traumatic. It took PLWHA some time to overcome these side effects. Similar findings were reported in studies by Emlet (2006) and Greeff et al. (2008) where HIV positive people experienced an improvement in their health and were prepared to make public disclosure. According to the USAIDS report (2006), the effective use of ARV treatment enables PLWHA to re-enter mainstream social and economic activities. Hutchinson et al. (2007) also reported on the recent improvements in the availability and affordability of ARV treatment in South Africa. By telling family members about their HIV status, they would be able to take their antiretroviral treatment publicly without having to hide. PLWHA are in the process of self re-evaluation once

they accept that HIV/AIDS is a chronic disease, with subsequent improvement in their health and their quality of life. In the USAIDS (2006) report, some families in Vietnam supported their relatives who were living with AIDS while others were ashamed and created a barrier to accessing antiretroviral treatment (USAIDS, 2006). Of the twenty five participants in this study, fifteen were on antiretroviral treatment. This finding of PLWHA having access to antiretroviral treatment was supported by literature on the delivery of effective ARV treatment, which is a powerful instrument/tool currently available to help to combat stigma and discrimination (USAIDS, 2006).

5.2.5 Stigma

In the current study, it was found that PLWHA were affected by the ridicule and gossip they encountered in the community. The idle talk among community members and being made a laughing stock by the community troubled the PLWHA. These findings are similar to the Lekganyane and duPlessis's (2011) study where clerks at the pharmacy laughed at people because they were referred from the ARV clinic. PLWHA in the current study were intensely angry due to their exposure to abuse, discrimination, ostracism and a sense of worthlessness.

In the ICRW (2006) study, gossip was reported as one of the most significant forms of stigma. According to Skinner and Mfecane (2004), anger and fear both in HIV positive and HIV negative people contributed to the development of discrimination. Religious groups discriminated against PLWHA by making explicit or implicit judgments (Skinner and Mfecane, 2004). In the Kohi et al. (2006) study, it was found that churches discriminated against PLWHA by not allowing them to serve in the church. The reason was that they were considered not worthy to spread God's word. A religious leader in Zambia made a moral judgment to the effect

that people who are promiscuous and careless are being punished by God for being disobedient (ICRW, 2006). PLWHA in the current study emphasized the importance of having an HIV test, having knowledge of their HIV status and explaining their HIV status to their children.

The findings in the current study showed that PLWHA were isolated in their homes by their families. The isolation of PLWHA in the current study is also supported by the findings of a study in Ethiopia where people feared transmission of HIV through casual contact like kissing, shaking hands, sleeping in the same room and eating together (ICRW HIV/AIDS Stigma, 2006). A study in Cape Town found that discrimination included not sharing a meal or sleeping in the same room (Hutchinson et al., 2007). These findings are similar to the ICRW HIV/AIDS Stigma (2006) study in which eating food prepared by an HIV positive person, sharing clothing, bedding and eating utensils was taboo. People who have not been tested agreed that PLWHA are dirty, should feel ashamed and guilty and should not be allowed to work with children (Hutchinson et al., 2007). The family members had a tendency of protecting their HIV positive family member from the stigma imposed by the community for fear of isolation, gossip and ridicule. However, some of the families ostracised their HIV positive family members themselves. These negative experiences encountered by PLWHA intensified their fears and inhibitions about HIV. The people in the community ridiculed PLWHA and were ignorant of their own HIV status. According to Campbell et al., (2005), stigmatising reactions by family members have impacted negatively on HIV prevention programmes.

According to the community members in the current study, HIV/AIDS was a disease that was stigmatized along with other diseases such as leprosy, tuberculosis, cancer, mental illness and

physical disabilities. The community members' viewpoint was that AIDS was like any other illness, except for the problem of stigma and name calling. The stigmatising reactions that PLWHA endured indicated that their stigma status had changed from being discreditable which is covert to a discredited state that is overt. This finding is supported by the ICRW HIV/AIDS Stigma (2006) study which reported widespread isolation in the four study countries. The isolation extended from within the home to out in the community and also in places such as markets, places of worship, schools, workplaces and hospitals. People would not sit next to a person with HIV in a public place like the bus. PLWHA may also be publicly excluded from eating from a common platter (ICRW HIV/AIDS Stigma, 2006). The community members had pointed out that young people in the community have a tendency to use hurtful labels and name calling for PLWHA. The finding about being ridiculed and discriminated against is supported by Uys et al. (2005) in their study on stigma in which PLWHA experienced differential treatment, gossip, loss of identity and loss of access to resources. Link and Phelan (2004) support the findings that people label others based on distinct differences. The HIV/AIDS Stigma-Siyamkela Project (2003) in South Africa also reported a range of abuse from name-calling to PLWHA referred to as 'Satan's people' to physical abuse by intimate partners (Dlamini et al., 2006). According to Lekganyane and du Plessis (2011), participants in their study who experienced HIV-related stigma expressed a sense of loss, feelings of fear and shame, loss of dignity, fears of death and discrimination.

The outcomes of discrimination in South Africa resulted in the murder of Gugu Dlamini, the rape and murder of Lorna Mlofane and the murder of Mpho Mtloung and her mother by her husband who subsequently committed suicide (Skinner and Mfecane, 2004). Discriminatory actions and

abusive behaviour include verbal and physical abuse. In a Tanzanian study during the period 2004 - 2005, more than 65% of the general population surveyed agreed that HIV/AIDS is a punishment for bad behaviour (ICRW HIV/AIDS Stigma, 2006). HIV stigma is associated with gender discrimination against women for spreading the epidemic. The fears of discrimination reported in the study by Chandra et al. (2003) cited cases of PLWHA being thrown out of their homes with their children. People would not interact with them or even have coffee with them. Discrimination based on gender and racism assigned blame to women and black people. In a study by Skinner and Mfecane (2004), it was found that people with HIV felt isolated and guilty, experienced feelings of shame, fear, anger, mental strain and self-loathing which forms part of the person's identity (Skinner and Mfecane, 2004; Emlet, 2006).

The psychological strain that the family endured was the fear of death of their loved one and the fear of isolation and discrimination by the community. Accompanying sick HIV/AIDS family member to the clinic or hospital for their treatment added to the strain of caring for them. The community members vowed to address the issues of ridicule and discrimination in the community in order to reduce the stigma of HIV/AIDS. PLWHA would receive the necessary compassion and care from the community, thereby reducing the stigma.

5.2.6 Reduction of Stigma

The actions of PLWHA in the reduction of stigma was expressed as consciousness raising, that is, creating a platform for community awareness, disclosure to the community and the formation of support groups. In an effort to challenge HIV-related stigma within the general public, Logie

and Gadalla (2009) proposed social marketing to promote compassion towards PLWHA and education to reduce fear of HIV contagion. Hutchinson et al. (2007:490) found that “substantial efforts have been expended through mass media to inform and to educate people about HIV/AIDS” in South Africa. Since the community believed that HIV positive people were bewitched, their awareness programme was directed at dispelling this myth along with the formation of support groups. The findings of the current study are similar to that of the Kalichman et al. (2006) study in which efforts to increase AIDS knowledge and dispel myths and misconceptions were reported. The family members’ responses towards supporting the reduction of stigma were that they felt very strongly about people speaking about the disease in the community. The benefit would be that people infected and affected would not have to keep their HIV status a secret and the family would not have to isolate their HIV positive family member. The Provider-Initiated HIV Counselling and Testing programme in Mozambique has shown an increase in the number of facilities offering HCT to all patients and hiring people exclusively dedicated to providing counselling and testing. The provision of HCT to all patients and the integration of services have proven to reduce stigma and discrimination and increase HIV diagnosis (USAID HIV/AIDS, 2010). Hutchinson et al. (2007) suggest community-participation as a means of stigma reduction. The adult children in the research study expressed the view that people needed education about HIV/AIDS and how to protect themselves by using condoms or abstaining from sexual intercourse because they were seeing the results first hand. The PLWHA felt that men were uncomfortable about expressing their views on HIV/AIDS and experienced difficulty talking about the disease. The community members proposed the removal of labels, which was a positive step towards the reduction of stigma. The negative responses of

discrimination against PLWHA resulted in their feelings of being inferior and useless, thereby inhibiting them from disclosing their status.

In many African countries, the community perceives people living with HIV/AIDS in a negative, derogatory and harmful manner (Uys et al., 2005). The community's effort in the current study was directed at putting a stop to name calling by talking to the youth and counselling them about the disease, especially in churches. In a study by Uys et al. (2005), it was found that name calling was also practiced in the Tswana community of South Africa. The measures that are common and are mentioned by all four groups in the current study were community awareness and education, the formation of support groups and talking freely about HIV as a means to reduce the stigma of the disease.

In the current study, the acceptance of PLWHA by community leaders would help the community in accepting them as well. The need to educate the community about the disease was the primary tool in the reduction of stigma. Youth and adults in the community are supported by community structures such as the Community Policing Forum that attempts to curb the crime in the community; Non-Governmental Organizations (NGOs) such as the AIDS Helpline; and the AIDS Support and Care Services that provide social welfare and support services in the community and HIV/AIDS counsellors. The mobilisation of community structures such as the Health and Welfare Committee at Ward level and the Bhambayi Settlement Project would be utilized in the efforts of the community to support the reduction of the HIV/AIDS stigma. These findings concur with the ICRW HIV/AIDS Stigma (2006) study, where efforts to integrate stigma reduction into the activities of community-based organizations had materialized. The

benefits of these collaborative efforts with local partners were seen in Tanzania in the Kimara Stigma Reduction Programme (ICRW HIV/AIDS Stigma, 2006). The outcome of this programme was that more people attended counselling and received HIV/AIDS tests and joined group counselling sessions. In Mozambique, the ICRW HIV/AIDS Stigma Initiative incorporated stigma reduction into a CORE initiative project that integrated tuberculosis (TB) and HIV diagnosis and care (ICRW HIV/AIDS Stigma, 2006). HIV and tuberculosis care programmes in Cambodia, India and east and southern Africa, under the auspices of the International HIV/AIDS Alliance, found stigma and discrimination to be significant barriers in the efforts to improve HIV and TB services (Holzemer and Uys, 2004).

5.2.7 Action and Maintenance

The Action stage was marked by conscientising the communities about HIV/AIDS stigma and disclosure, encouraging PLWHA to disclose their HIV status, the formation of support groups, lifestyle changes and behaviour modification.

5.2.7.1 Community Awareness and Education

In the current study, it was found that community awareness was directed at educating the community about living positively with HIV/AIDS. PLWHA felt strongly that HIV/AIDS was like any other chronic disease and that people should speak openly about HIV in order to reduce stigma. Consciousness raising was what PLWHA are proposing to reduce stigma. These findings are supported by the Makoae et al. (2008) study. This study found that talking to people allows them to build social networks, which in turn provides platforms for PLWHA to tell their

stories, share the pain, chat and develop friendships. It is the responsibility of governments and community leaders to take up the challenges of reducing stigma and discrimination, thereby decreasing HIV transmission and improving the quality of life of PLWHA and those affected by HIV/AIDS (USAID, 2006). In Kenya, AIDS education awareness has been in place for a number of years. The results of a national population-based survey showed that nearly all adults aged between 15 and 64 years had heard about AIDS. In the same survey 90% knew that a healthy-looking person could be infected, 75% of the women were aware of the need to use condoms and 81% of the men were aware that condoms reduced the risk of HIV infection (HIV and AIDS in Kenya, 2011).

Consciousness-raising as a process of change is pivotal in the education of the individual, family and community. Children (from the age of 15 years or from the onset of menarche) who are sexually active are advised to use condoms and be faithful to one partner. PLWHA are willing to share their experiences of being close to death and recovering from the illness. More and more people are encouraged to get tested, know their status and reduce the HIV /AIDS stigma. The adult children in the current study expressed the need for education in the community. Education initiatives should teach people in the community about protecting themselves with the use of condoms or abstaining from sexual intercourse. This finding is supported by an education initiative in Nigeria such as community-based HCT. This initiative includes both counsellors and health care workers who provide clients with information, tools and access to interventions which enable them to protect themselves from acquiring or transmitting the virus (USAID HIV/AIDS, 2010). The community-based HCT campaign in Nigeria is referred to as the Global HIV/AIDS Initiative Nigeria (GHAIN). The purpose of this campaign is to enhance access to

HCT for hard-to-reach populations such as youth, orphans and vulnerable children, sex workers and transport workers (USAID HIV/AIDS, 2010). According to the adult children, prevention and creating awareness is critical to stigma reduction. These findings concur with the measures to reduce stigma that were proposed in the HRSA Care Action (2003) study that focused on information distribution through lecture presentations, brochures, advertisements and information packs for community awareness and education. The approach adopted included a factual description of the disease, details about the modes of transmission and methods of risk reduction (HRSA Care Action, 2003).

The current study found that family members are willing to distribute information about HIV/AIDS and encourage people to change their behaviour by starting with their children and extending to the community. Their actions would lead to an improvement of the community's understanding of HIV/AIDS, thus resulting in the reduction of stigma. These findings are in line with strategies for reducing stigma as outlined by Holzemer and Uys (2004), who suggest that, when assessing, it is necessary to determine the support of the family, partner and friends; community support and legal issues; the strength of the person to cope with the negative attitudes from others, mental health including depression, fear and suicidal tendency and readiness for participation in HIV care, including antiretroviral treatment (ART).

Community awareness targeted issues such as education, distribution of pamphlets, information sharing, prevention of HIV infection and educating the family and the community on giving advice to children about their sexual behaviour. The message to the people was to get tested and know their status, thereby supporting the reduction of stigma. These findings are similar to the

suggestions of the ICRW HIV/AIDS Stigma (2006) study that revealed the need to improve the content of the messages pertaining to HIV, providing information on how HIV is transmitted and how it is not transmitted. Once people understand and internalize this fact they are less likely to stigmatize HIV/AIDS affected people through avoidance and isolation (ICRW HIV/AIDS Stigma, 2006). The significant changes reported by PLWHA who had disclosed were having a monogamous relationship, their insistence on the partner using condoms, staying in a long-term relationship and abstaining from sexual intercourse.

5.2.7.2 Formation of Support Groups

It was at a meeting of all the PLWHA that had disclosed their HIV status that the suggestion to form a support group for PLWHA was established. The community provided the information about what would help or assist them. This finding concurs with the USAID report on community-based organisations which established support groups for PLWHA and also extended their services to orphans and vulnerable children at community level (USAID HIV/AIDS, 2010). The formation of support groups was suggested by PLWHA and family members as a measure to reduce stigma. In support groups, PLWHA have a common platform to share their experiences and support one another. The support group for family members would afford them an opportunity to exchange their views and experiences about living with PLWHA. This support group would alert the community about the seriousness of the disease and also support families in bereavement. Traditionally, rural women in Zulu culture always worked in groups. They collected wood, fetched water, did their laundry at the riverside, cared for the elderly and raised their children together. The women accompanied one another in groups to collect water or wood

to protect each other from any danger they would encounter from strangers or stray animals (Zulu Culture, 2010).

The research team supported the formation of the Siyakhula Support group. The members of the Siyakhula group showed an interest in gardening. In order to initiate the gardening project, the researcher sought written permission (Annexure 12) from the BRDC for the use of a vacant plot of land next to the crèche for gardening. Five members of the Siyakhula Support group got involved in the gardening project. The participants suggested the formation of these groups to help PLWHA show the community that they were capable of working. Prior to the commencement of the gardening project, second-hand clothes were sold by a member of the Siyakhula Support Group. The proceeds from the sale of second-hand clothes were used to purchase garden tools. As a member of the research team, the secretary of the BRDC reported on the progress made by the group in the gardening project and identified members who lacked skills in gardening. The lack of skills in the techniques of gardening was resolved by sending two out of the five people on a skills development workshop, thereby achieving a solution to practical problems. This workshop was held at Inanda C clinic in September 2007. The members that showed a keen interest in gardening were chosen to be part of the project, even though they lacked the skills. The community supported the Gardening Project by granting them permission to use the land which was fenced off. The secretary of the BRDC organized the training programme with an agricultural officer from the provincial department.

5.2.7.3 Benefits of a Support Group

The main aim of the support group was to give PLWHA a platform to share their experiences of having HIV/AIDS, provide physical care and psychological support. The support group for family members would afford them an opportunity to exchange their views and experiences about living with PLWHA and to care for them in their terminal stages of the disease. The establishment of support groups would allow people infected and affected by HIV/AIDS to talk about their illness or experiences, thereby educating and sensitising the community about the seriousness of the disease. The advice on having HIV tests prior to the onset of diarrhoea and vomiting would ease the use of antiretroviral treatment. The psychosocial support for PLWHA and their families was for post-test counselling and assistance with grieving families that have experienced the death of a loved from AIDS-related illnesses. The provision of counselling and support was essential for PLWHA to feel emotionally better and healthier. These findings are supported by Holzemer and Uys's (2004) study that adequacy of social support and an environment for managing stigma should be evaluated, especially in the care of PLWHA.

5.2.7.4 Lifestyle Changes / Behaviour Modification

The majority of PLWHA who participated in the study had multiple sexual partners from the time they became sexually active during their teenage years and adult life. PLWHA acknowledged that knowing their HIV status could lead to minor behaviour modifications such as the use of condoms and engaging in a monogamous relationship that could improve their life. According to Skinner and Mfecane (2004), families accepted and supported PLWHA and acknowledged the benefits of testing. The behaviour modifications alluded to by Skinner and Mfecane (2004) were aligned to a change in practice in PLWHA who had disclosed. The change

in sexual practices of PLWHA after disclosure of their HIV status was dependent on their relationship with their sexual partners. PLWHA appraised their sexual behaviour and its impact on societal norms (Velicer et al., 1998). One participant who reported having five children from five different partners, subsequently settled in a monogamous relationship. Post-disclosure the PLWHA in the current study established monogamous relationships or resorted to staying without a partner. These findings concur with the findings of the Hutchinson et al. (2007) study in the Eastern Cape Province of South Africa, in which social influence and social learning have influenced the adoption of preventive methods including abstinence, being faithful to a single partner and consistent condom usage. The argument against this finding could be that, in some communities, for a man to have multiple partners was seen as an indicator of success or manhood (Skinner and Mfecane, 2004). Ten participants had abstained from sexual contact by reporting that they had no boyfriends. The changes in sexual practices of PLWHA were abstinence, the use of condoms and maintaining a monogamous relationship. In a study by Meursing (1999) in Zimbabwe, similar findings were presented regarding the reduction in the number of sexual partners, temporarily abstaining from sex for some time and the use of condoms as measures used to prevent the spread of HIV. PLWHA in the current study felt that more people should be encouraged to disclose their status and get tested, thus facilitating HIV Counselling and Testing (HCT). This finding is supported by Greef et al.'s (2008) study on disclosure of HIV status, in which voluntary counselling and testing was stated as an advantage of disclosure.

The findings of this study showed that PLWHA have made a conscious decision either to settle in a long term monogamous relationship or not have a partner. Four PLWHA in the current

study reported that they were in a long term relationship for five, ten, twelve and fifteen years. Six had no partners, therefore placing them at the Maintenance stage of the model. The PLWHA who were in long term relationships and women who were assertive insisted that their partners get tested and use condoms. Four participants abstained from sexual intercourse after being diagnosed as HIV-positive for periods longer than one year and five participants used condoms. The act of abstaining from sexual intercourse for over a year placed them at the Maintenance stage of the model. The change in behaviour in the use of condoms progressed from anger to denial to acceptance. The partners who had tested for HIV stayed in the relationship and continued with the consistent use of condoms, placing them at the Maintenance stage of the model. The reason for abstaining from sexual intercourse was the death of a partner or husband. Two participants in the study felt that they needed the support of their partners to make any changes to their sexual practices. Their partners threatened to kill them if they insisted on the use of condoms. They were powerless and had not made any changes. The PLWHA who had not disclosed their HIV status were thus placed at the stage of Preparation. According to Hutchinson et al. (2007), the influence of behavioural theories emphasises the social nature of HIV/AIDS.

The findings of the current study are supported by Low-Beer and Stoneburner's (2003) study in Uganda that found a wide range of sexual behavioural changes. These ranged from reducing sexual partners, abstinence, faithfulness, marriage and increased condom use. The Masaka study in Uganda showed a decline in casual sex from 35% to 15% with a subsequent decline in the incidence of HIV throughout 1990 (Low-Beer and Stoneburner, 2003). The most frequent response among all age groups in the study, except among young men aged 15-19 years, was to

be committed to one partner. The level of abstinence was slightly higher in older women over 45 years than in young women aged 15-19 years. The response of adults across African countries regarding the most important aspect of AIDS was the reduction in casual sex and the fact that abstinence was more highly recommended than condom use. In contrast, Thailand had a 100% success in the condom policy among sex workers. In the Thailand study (Low-Beer and Stoneburner, 2003), a behavioural process of risk avoidance was apparent. There was a 55% decrease in the number of men visiting sex workers and a decrease from 28% to 15% of non-regular partners. The consistent use of condoms among sex workers rose from 36% to 71%. A decline in the visits to sex workers correlated with a decline in the incidence and prevalence of HIV. The behaviour change in Zambia and the resultant decline in HIV prevalence included a decrease in multiple partners and an increase in condom usage (Low-Beer and Stoneburner, 2003).

PLWHA in the current study acknowledged that having HIV/AIDS made them reconsider their relationships and adopt preventive measures such as abstinence, being faithful to a single partner and the consistent use of condoms. PLWHA are empowered by the knowledge of their HIV status to make conscious decisions about behaviour change and informed choices about HIV prevention. This is the process of self-liberation. The PLWHA who are self-liberated and committed to a positive lifestyle, increase the move towards stigma reduction. This was demonstrated by PLWHA's acceptance of their HIV positive status, settling into a monogamous long-term relationship, abstinence, and the consistent use of condoms. These findings are supported by Makoae et al.'s (2008) study that referred to 'changing lifestyle' as changing their behaviour and lifestyle. The participants' responses to changes in lifestyle were making a

conscious decision about living with HIV and starting a new life. Another participant reported having made a conscious decision to not become further infected and to rather lead a healthy lifestyle by watching her diet and never sleeping with her husband again (Makoae et al., 2008). It is the society's responsibility to allow individuals to make these informed choices about behavioural changes because it takes a long time and is not a quick intervention (Kehler, 2006). The research team identified problems that were not directly related to the study but affected the PLWHA in the community and are presented as spin off cycles.

5.2.8 Spin-off Cycle

The spin-off cycle that emerged was not directly related to the study. It was that of young unemployed women who had no identification documents and experienced delays in accessing social welfare grants and physical and psychosocial support available for PLWHA. The issue of unemployed young women experiencing difficulty in securing jobs was raised with the secretary of the BRDC at their meeting. Young women who were not in possession of identification documents were also unable to access the government's Child Care grants. The research team engaged in a dialogue with community members, bringing into perspective the issues identified by them so that the community leaders could act on resolving these issues. The action or change that occurred in this group led to the upliftment of these young girls. The research team's attempt at conscientising the community was demonstrated in the advice given for the application of identification documents for young women. Single parents without identification documents were not in a position to access Child Care grants. It was the researcher, in collaboration with the research team, who informed the Ward Councillor about people in the community's need to apply for identity documents especially PLWHA who were not in

possession of identity documents. The Ward Councillor in the area was advised to draw up lists of names of people without identification documents and submit it to the Department of Home Affairs. He had to arrange a date with the Department of Home Affairs to allow members of the Bhambayi community to have their applications for identification documents processed.

PLWHA can access social welfare grants if their CD 4 cell count is below 200 μ /m. The social support is part of the Helping Relationship in the processes of change. The problem PLWHA encountered was the delays in the processing of their grant applications. By the time the grants were approved, some people had died. In the management of PLWHA, the idea was to link them with social support including support groups for PLWHA. PLWHA need assistance with their medication and an ongoing relationship should be established in the care of PLWHA (Holsmer and Uys, 2004). PLWHA preferred their own support groups within the community and were unhappy to join support groups at the nearby clinic and hospital. The physical care was directed at fulfilling a need for survival that is, having food to eat. This was achieved by five members of the Siyakula Support Group who engaged in a self-help gardening project. People with very low CD 4 cell counts and on antiretroviral treatment received two meals a day from the Bhambayi Settlement Trust, a non-profit organization. PLWHA are of the opinion that all the PLWHA in the community should have meals supplied to them due to the high rate of unemployment in that community. These findings differ with the HRSA (2003) study that found the strategy for support groups for PLWHA should include social reinforcement for positive attitudes, behaviour change and maintenance of safe behaviours.

5.3 Conclusions from the Findings

In conclusion the following statements emerge from the discussion and reflections of the findings and form the basis of the concepts which are conceptualized as a framework of the study:

- PLWHA talking freely about the disease, thereby supporting the reduction of stigma;
- Community awareness and education;
- Formation of support groups for PLWHA;
- Public disclosures by community leaders so that PLWHA could follow their example;
- Supportive conducive environment for disclosure of HIV status.

5.3.1 Cycle 5: Development of an Intervention: Development of a Framework for the Disclosure of HIV status and the reduction of stigma

The concepts that emerged in the findings led to the conceptualization of a framework to aid in the disclosure of HIV status and to reduce stigma in the community. PLWHA function in a social system supported by their family and community. The knowledge of their HIV status allowed PLWHA to disclose their HIV status, change or modify their behaviour and get involved in the education of individuals, family and the community about HIV/AIDS. The aim of this framework is to graphically represent factors that would encourage people living with HIV to disclose their status and reduce stigma. It is the responsibility of the family and the community to create an environment that is nurturing and supportive in order to increase disclosure and reduce stigma. According Moore, Kalanzi, and Amey (2008) social support from the family has decreased depressive symptoms and improves psychological functioning among PLWHA after

they have disclosed their seropositive status. Studies in Africa and Asia Pacific region show that disclosure has helped PLWHA in improving and increasing their productivity and well-being (Moore, Kalanzi and Amey, 2008). PLWHA highlight the need to disclose their HIV status without the fear of stigmatisation or discrimination. According to the participants in the study, the reduction of stigma would be achieved through community awareness and education and the formation of support groups. The benefits of disclosure relate to “opens out the illness” makes access to ARVs easier and brings a sense of self-liberation. The benefits of decreased stigma are public disclosures, more people getting tested (HCT) and acceptance.

The framework for this study was developed from the data based on the six criteria recommended by Chin and Kramer (2004) for the development of a framework. These six criteria are the purpose, concepts, definition of concepts, relationship statements, structure of framework and the assumptions. There are six concepts and eleven sub-concepts described in this chapter. PLWHA, stigma, and disclosure are the major concepts in the framework. The concepts of family and community are structures represented by the pillars of the fulcrum that support PLWHA. A safe and secure environment which promotes disclosure forms the border of the framework. The benefits of increasing disclosure and reducing stigma have sub-concepts. The benefits of reducing stigma are public disclosures, more people getting tested and then the acceptance of the disease. The benefits of increasing disclosure are “opens out the illness”, easy access to ARVs and self-liberation. The sub-concepts that facilitate disclosure are support, trust and acceptance. The sub-concepts that decrease stigma are community awareness and education and formation of support groups. The nature of relationships describes the interrelatedness of the

concepts. The functional nature of the framework outlines the structure, description and assumptions.

A theory, as described by Chinn and Kramer (2004:91), is “a creative and rigorous structuring of ideas that project a tentative, purposeful and systematic view of phenomena”. A grand theory or macro- theory attempts to describe and explain large segments of the human experience (Polit and Beck, 2010), as opposed to middle-range theories that are less abstract, narrow in scope and closely linked to clinical practice and research. Macro theories are the most abstract, cover a broad area within a discipline and are often complex and not easily understood (Chinn and Kramer, 2004; Fawcett, 1984). Middle-range theories originate from a continuum of theories ranging from ‘most abstract’ to ‘most concrete’ and are located midway between the two (Fawcett, 1984). Micro-theories are classified as precise, concrete, narrow in scope and related to a particular situation or a set of circumstances in nursing practice. The concepts that make up micro-theories are readily measurable, objective and applicable to a specific population or practice setting (Fawcett, 1984).

The theory is usually created to draw several different aspects together in order to describe, explain, predict and control that phenomenon (Chinn and Kramer, 2004). According to Stringer (2007:188) “theories are embedded in a set of concepts, assumptions, and views of reality that make sense only within a particular context”. A model is a symbolic representation of concepts which demonstrate theoretical relationships. This can take the form of a pictorial or graphic diagram of empirical experience in words (Fawcett, 1984; Chinn and Kramer, 2004). A framework is a “logical grouping of related concepts... that is relevant to a complex situation

such as a practice setting” (Chinn and Kramer, 2004:268). Frameworks are usually applied to different kinds of nursing situations and are often referred to as ‘conceptual frameworks’.

Action research is grounded in actual practice situations and allows for modification and refinements of basic knowledge that is linked to practice (Holter and Schwartz-Barcott, 1993). Theories can inform practice and out of this process of enlightenment new practices may emerge (Stringer, 2007). In the phenomenon under study, PLWHA who have disclosed their status need the support of the family and community and a conducive environment in order to facilitate the reduction of HIV/AIDS stigma. The framework provides clarity and understanding about the way participants enact processes of inquiry in order to achieve the effective outcomes (Stringer, 2007). The substantive concepts are defined and conceptualized in a particular framework in a relatively associative manner in order to bring about understanding of how a community-based framework would facilitate PLWHA in disclosing their HIV status and reduce stigma (Mtshali, 2003).

5.3.2 Framework for the facilitation of disclosure of HIV status and the reduction of stigma

The purpose of a framework reflects the context and the situation in which the framework is applied. The concepts of the framework are identified by listing key ideas and questioning how the relationships and structure emerge in the framework. The nature of relationships describes the links between concepts and focuses on various relationship statements that give structure to the framework. The structure of the framework addresses the overall form of the conceptual

relationships within the framework. The structure of the framework consists of assumptions on which the framework is built. The assumptions are ideas, values, beliefs asserted as truths and accepted with little or no evidence to underlie theoretical reasoning. The explanation of concepts in a framework conveys explicit meanings and clarifies the nature of the construct (Chin and Kramer, 2004).

5.3.2.1 Purpose

PLWHA are often subjected to stigma and this prevents them from disclosing their condition. This was reported in the study in terms of stigma and discrimination. The purpose of the framework is to assist the PLWHA to disclose their HIV status to their family or community in an environment that is conducive, for example in a community-based setting. PLWHA need the support of the family and the community in order to facilitate disclosure and reduce stigma.

5.3.2.2 Concepts

Concepts are images or symbolic representations of an abstract idea and are used in the description of phenomena. The basic element of a framework is a concept and the two terms closely related to concept are 'construct' which is an abstract and a 'variable' which is concrete. A concept that has a very high level of abstraction is referred to as a 'construct'. A variable is more specific and is measurable. The numerical values vary from one to another, therefore the term 'variable' (Fawcett, 1984). PLWHA are the main concept in the study. The core concepts linked to PLWHA are the disclosure of HIV status and the reduction of HIV/AIDS stigma. The concepts that emerged as a phenomenon of interest in the study are family support, community

support and the environment. The decrease in stigma would be achieved by the sub-concepts of community awareness and the formation of support groups. The benefits of reducing stigma are presented as public disclosures, more people getting tested (HCT) and acceptance. The benefits of increasing disclosure are related to the sub-concepts 'opens out the illness', easy access to ARVs, stress free lives and self-liberation. Disclosure of HIV status to partners who have not tested increases awareness of risks of HIV infection which leads to greater uptake of voluntary HIV counselling and testing (Medley et al, 2004). Concepts are given a structural form to clarify their relationship by means of a symbolic representation. In order to follow the reasoning of the development of this framework, the nature of their relationships, the nature of its structure and the process description of the framework as depicted in Figure 5.1 will be presented. The nature of relationships, structure of the framework and assumptions precedes the explanation of the concepts.

5.3.2.3 Nature of Relationships

The linkages between and among concepts are expressed as relationship statements of a theory (Chinn and Kramer, 2004). Concepts can be interrelated in one, two or many ways. The nature of the relationships that emerge is presented as clues to the theoretical purposes and assumptions on which the framework is based (Chinn and Kramer, 2004). The interrelationships of the concepts PLWHA, environment, family and community as shown in Figure 5.1 indicate the functional nature of the framework within the community (Chinn and Kramer, 2004). Stigma and disclosure are on either side of the fulcrum, with PLWHA located centrally. The symmetrical relationship between disclosure and stigma influences the deterministic nature in that an increase in disclosure probably has a direct consequence in the decrease of stigma and

vice versa. A decrease in stigma denotes a sequential relationship, resulting in the probable reduction of stigma by creating community awareness and education and the formation of support groups. The decrease in stigma is linked to public disclosures, with more people getting tested and acceptance. In studies on outcomes of HIV status disclosure among women in developing countries, women reported receiving kindness, understanding and acceptance following disclosure in only three out of ten studies (Medley et al, 2004). There is a concurrent relationship between an increase in disclosure and the benefits of disclosure as in speaking openly about HIV/AIDS, having easier access to antiretroviral treatment and self-liberation by making public disclosures and informed choices about HIV prevention. The increase in disclosure relates directly to developing a relationship of trust and acceptance (McKenna, 1997).

5.3.2.4 Structure of the Framework

The structure emerges from the relationship of the concepts in the framework. Structural forms clarify the relationships by means of symbolic representation (Chin and Kramer, 2004) as depicted in Figure 5.1. The concept of PLWHA is central to the framework and represented in a circle with double arrowheads on a horizontal plain in the centre of the framework. The arrowhead on the right points to the increase in disclosure from the empirical perspective that is directly related to experiences which are abstract and more mentally constructed (Chin and Kramer, 2004). From the concept PLWHA, the arrowhead on the left points to the decrease in stigma which is abstract and encompasses the sub-concepts of community awareness and the formation of support groups. Disclosure of HIV status is a relatively empirical concept and stigma is an abstract concept. The concept of 'disclosure' encompasses the sub-concepts of support, trust and acceptance. The family and the community are represented as pillars of support

for PLWHA within the framework. The environment contextualizes the relationships of PLWHA, family, community and supports the increase in disclosure and the decrease in stigma within the framework. The core concepts of 'stigma and disclosure', benefits of reduced stigma and the benefits of increased disclosure all feature within the framework.

PLWHA are the central structure located on the fulcrum at the apex, supported by the pillars (representing the family on the left and the community on the right) that effect change. The core concepts of stigma and disclosure (shown by a broad single-headed arrow) are represented on the left and right side of the central concept. The concept benefits of reduced stigma (as shown in a rectangle) is interrelated with the reduction of stigma (depicted by a single arrowhead) which includes the sub-concepts of public disclosure, more people getting tested and acceptance. The concept 'disclosure' is directly related to the benefits of disclosure (shown by a single broad arrow pointing upwards from disclosure towards benefits of disclosure) with sub-concepts (depicted in the rectangle) such as opens out the illness, easy access to antiretroviral treatment and self-liberation.

The schematic representation of the framework explains the arrows and the shapes that make up the framework. The arrows denote direction from one concept to the next. For example, an increase in disclosure leads to a decrease in stigma and vice versa. The rectangular border of the framework depicted by broken lines represents the environment as dynamic, constantly changing and conducive for the disclosure of HIV status and a reduction of stigma. The two rectangles in the right upper quadrant and left lower quadrant denote the benefits of increasing disclosure and the benefits of reducing stigma which are inside the box (Tague, 2005). The double arrow with

arrowheads at both ends emerges from the PLWHA at the centre and points towards stigma and disclosure, indicating a reciprocal relationship (McKenna, 1997). The nature of the structure PLWHA forms the basis of a necessary relationship, with stigma on the left and disclosure on the right side depicted by a double pointer with two arrowheads. The concept 'stigma' is represented inside a broad arrow with a single arrowhead. Inside the single broad arrowhead are measures that decrease stigma, that is, community awareness and education and formation of support groups. The single arrowhead denotes an asymmetrical relationship with the benefits of reducing stigma. Disclosure is represented inside a broad arrow with a single arrowhead. The three sub-concepts of support, trust and acceptance are measures that increase disclosure and are located within the arrowhead. The single arrowhead denotes an asymmetrical relationship with the benefits of disclosure.

The description of the framework begins from the central structure of PLWHA. PLWHA are centralised to emphasize the significance in the actual operation of the framework. PLWHA are depicted in a circle on a fulcrum that is dependent on the family and community within a safe and secure environment for the optimal functioning in the community. PLWHA as a phenomenon of interest in this study directly influence the two major concepts: increase in disclosure of HIV status on the right and decrease of stigma on the left. These prepositional statements declare that only if PLWHA disclose their HIV status will there be a decrease in stigma (Mc Kenna, 1997).

The family is represented as the left pillar of the fulcrum and forms the support system that PLWHA depend on in the community. Families are prepared to get involved in the dissemination of HIV information, counselling and support of family members to change their

behaviour. One of the outcomes that increase disclosure relates to the family's acceptance of PLWHA and support to facilitate disclosure. As a primary resource, the family fulfils a pivotal role in the treatment and care of PLWHA (USAID, 2006). The families' involvement in community awareness is directed at informing people of the importance of changing their behaviour and their understanding of HIV/AIDS. It is the family that has to promote the acceptance of PLWHA and inspire other family members to overcome the ostracism of family members.

The right pillar of the fulcrum in the framework denotes the nature of community. Community support as a phenomenon in this study refers to community leaders making public disclosures; acceptance of PLWHA; participation in support groups; support of efforts to assist with disclosure of HIV status and the reduction of stigma. The participation of community leaders in support groups for PLWHA and family members contributes to the disclosure of HIV status and the reduction of stigma. According to the USAID report (2006:9), "disclosure of HIV status by prominent members of society can play an important role in promoting visibility of HIV-positive people and breaking down some of the silence and fear surrounding HIV". The community's role in shaping attitudes and values related to HIV lies within cultural organizations, initiation schools, traditional healers and community leaders. It is the responsibility of these community-based leaders to clarify their values, demystify myths, update information and support the development of a positive self-image of PLWHA (USAID, 2006).

The environment has to be safe, secure, comfortable and friendly for PLWHA to disclose their HIV status without any fear of discrimination. The environment denotes safety and security that promotes disclosure for the optimal functioning of the framework. In Nigeria, the Couples HCT

programme is part of the community-based HCT programme, which creates a safe environment for couples to discuss their concerns and provides information on HIV prevention, transmission and treatment, eases the tension and reduces blame (USAID HIV/AIDS, 2010).

Disclosure as the core concept in the framework denotes the PLWHA who have disclosed their HIV status. The sub-concept 'support' relates to PLWHA who have the support of their families to disclose their HIV status. They also have the support of the community, including access to health services. They are motivated to adopt positive lifestyles change and/or modify their behaviour. This finding is supported by the Couples HCT programme in Nigeria in which

“effective couples HCT encourages and supports the couple to adopt preventive , facilitates disclosure, and also aims to mitigate harmful relationship dynamics and reduce potential HIV-related stigma and blame” (USAID HIV/AIDS, 2010:3).

In a study by Meursing (1999) PLWHA adopted measures to prevent HIV spread by reducing the number of sexual partners, abstaining from sex or condom use. PLWHA are more likely to disclose their HIV status to people they trust. Once PLWHA have established a trusting relationship within the community, they are in a position to make public disclosures. The sub-concept 'trust' emanates from PLWHA and their level of trust in the people close to them to disclose their HIV status. Disclosure of HIV status is based on a trust relationship that PLWHA have with family or friends. PLWHA encourage their HIV positive friends and family members to disclose their status. The idea was that the more the community was informed about HIV/AIDS, the more PLWHA would benefit. The sub-concept acceptance relates to PLWHA

accepting their HIV-positive status. The family's acceptance of their HIV- positive family member allowed them open access to antiretroviral treatment.

The disclosure of HIV status also contributed to a culture of open dialogue in which HIV-positive people instead of being demonized were accepted and aided rather than being discriminated against. According to Greeff et al. (2008), the positive aspects of disclosure, for PLWHA was their participation in support groups thereby encouraging others to disclose their HIV status, share their experiences and provide psychological support during their meetings. PLWHA also experienced a heightened sense of self understanding, healing, empowerment, relief from the burdens of secrecy and rumours, and ease of further disclosure and support (Greeff et al., 2008).

The benefits of increasing disclosure include the sub-concepts 'opens out the illness', 'easy access to ARVs' and 'self-liberation'. 'Opens out the illness' was how PLWHA felt after disclosure. PLWHA related their experiences of being HIV-positive and were relieved at no longer being secretive about the disease. PLWHA who have disclosed their HIV status were relieved of the burden of keeping their illness a secret. The sub-concept 'easy access to antiretroviral treatment' revived the PLWHA's will to live. PLWHA are 'free' to use ARVs and do not have to hide it or keep it a secret from the family. The use of antiretroviral was essential in the treatment of HIV/AIDS to prolong people's lives. According to Ware, Wyatt and Tugenberg (2006) adherence to antiretrovirals in a social context can be problematic for PLWHA who experience barriers to medication taking in the case of non disclosure. The sub-

concept 'self-liberation' entails PLWHA making public disclosures and choices regarding behaviour modification.

The core concept 'stigma' relates to PLWHA being stigmatised and discriminated against. The sub-concepts of stigma are 'community awareness and education' and 'the formation of support groups'. The community awareness and education campaigns target individuals, family and the community, encouraging them to adopt positive lifestyles and change their behaviour as measures to reduce stigma. Education is directed at the dissemination of HIV information and creating a platform for PLWHA to disclose their status. Hutchinson, Mahlalela, Yukich (2007) allude to the extensive campaigns in South Africa to educate and inform people through mass media about HIV/AIDS and mechanisms for transmission and prevention. The education programmes include the availability of treatment and the need for compassion and care for PLWHA. The family that is affected by having a loved one with HIV was relieved of the burden of hiding their HIV positive family member from relatives, friends,

PLWHA suggested the formation of support groups for themselves and their families as a measure to reduce stigma. The support group meetings for PLWHA were a form of group therapy which allowed them the opportunity of sharing their experience, conveying information and giving advice on a range of HIV treatment options. Counselling and support assisted PLWHA to improve their personal growth, boost their self-esteem and self-worth and develop a sense of trust (USAID, 2006). The support group for families focused on sharing information, demystifying beliefs, clarifying values and making resources available in order to decrease the burden on the family. Support groups gave PLWHA an opportunity of sharing their experiences

of being HIV positive, venting their feelings of being discriminated against and asking for physical assistance and psychological support (USAID, 2006).

The benefits of reducing stigma are represented by the sub-concepts ‘public disclosures, more people getting tested and acceptance’. The sub-concept ‘public disclosure’ relates to PLWHA making public disclosure and choices regarding behaviour modification. The phenomenon of interest in this study related to PLWHA who shared their experience of being HIV-positive and encouraged other people to get tested. PLWHA also advised their partners to get tested and insisted on the use of condoms. The intervention strategies to reduce stigma, as stated in the HRSA Care Action (2003) literature, refers to information distribution in the form of a factual description of the disease, details regarding modes of transmission and methods of risk reduction. The strategy on counselling provided social reinforcement for positive attitudes, behaviour change and the maintenance of safe behaviours. The stigma reduction interventions targeted change in attitudes, change in behaviour and their sustainability over time.

5.3.2.5 Assumptions

These are the assumptions of the Community-based Framework to Facilitate Disclosure and Reduce Stigma among PLWHA:

- HIV-positive people need the trust and support of the family and the community to disclose their HIV status.
- The provision of a conducive environment encourages disclosure of a HIV positive person.

- Disclosure of one's HIV-positive status relieves the burden of secrecy among PLWHA.
- Disclosure by an HIV -positive person encourages utilisation of relevant support services.
- Disclosure of HIV-positive people may promote a reduction in stigma.
- Reduction in stigma could in turn promote/enhance disclosure.

COMMUNITY-BASED FRAMEWORK TO FACILITATE DISCLOSURE AND REDUCE STIGMA AMONG PLWHA

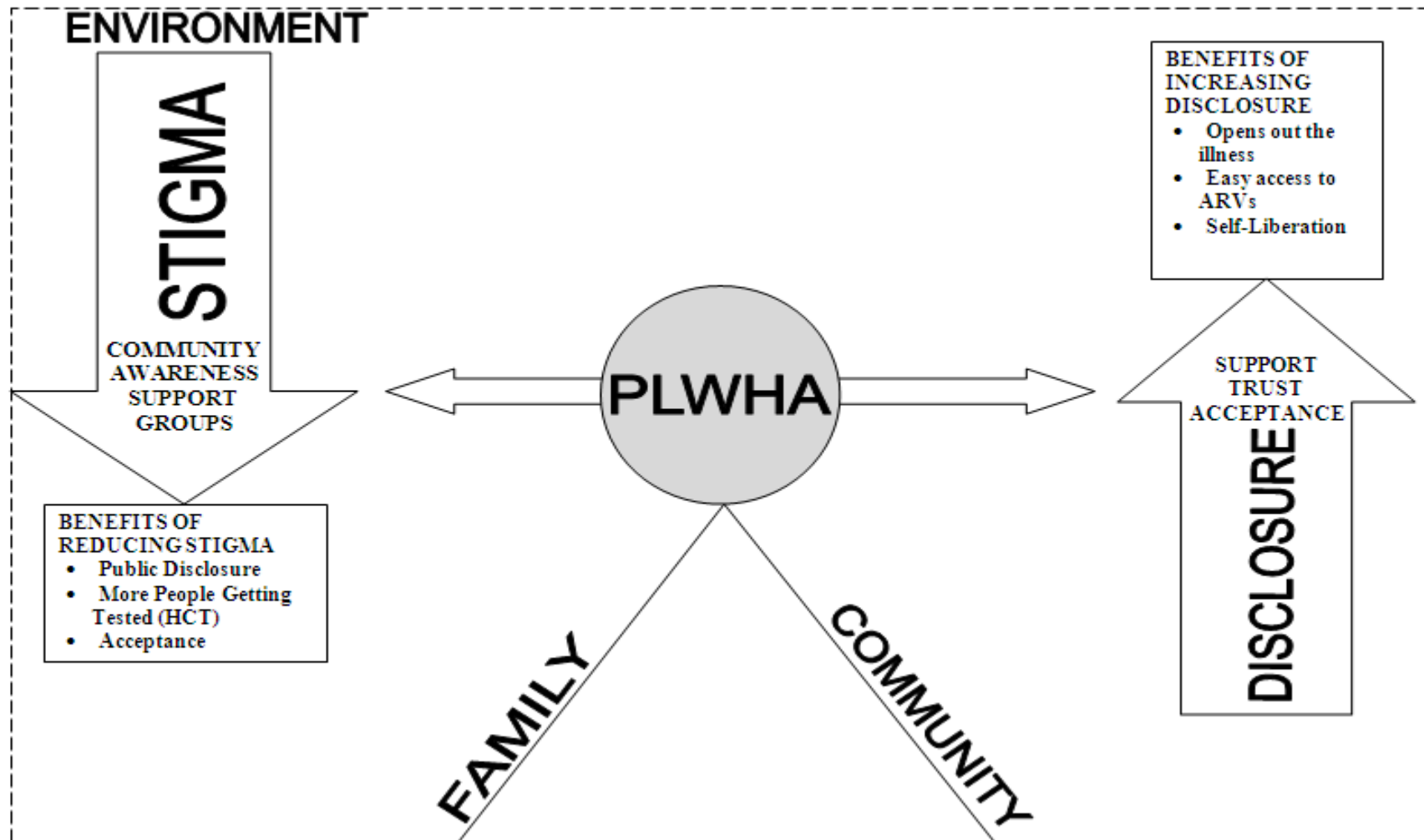


FIGURE 5.1: Community-Based Framework to Facilitate Disclosure and Reduce Stigma among PLWHA

5.3.2.6 Explanation of Concepts

A conceptual definition is more comprehensive and differs from a dictionary definition of a word. Conceptual definitions are clear, accurate explanations of statements within a framework (Fawcett, 1984). Concepts are defined according to their theoretical structure, that is, definitions and assumptions and can be implied in the context of the research study (Chin and Kramer, 2004).

(i) PLWHA

In the context of this study PLWHA are categorized as HIV positive and people who have the advanced clinical signs of the disease and have disclosed their HIV status. An HIV-positive person can be described as healthy with a CD 4 count above 300cells/ μ l and WHO stage 3 classifications (South African HIV Clinicians Society and UNHCR, 2007). People in the advanced stage of the disease are symptomatic with a severe AIDS defining illnesses or a low CD 4 count of < 50 cells/ μ l (USAID, 2006; Southern African HIV Clinicians Society and UNHCR, 2007). In the context of this study, all the above mentioned categories are included in the framework.

(ii) Disclosure of HIV Status

Disclosure means telling people that you are HIV positive. These people maybe your sexual partner, family members, children, significant others and/or the public. PLWHA have control over the decision to disclose and choose disclosure styles ranging from 'selective' to 'full disclosure' (Greeff et al., 2008). The process of disclosure is inherently stressful and is influenced by the negative factors which include fear of discrimination; an anticipated disruption

of relationship, 'concern about insurance benefits and employment', a desire to protect one-self and others emotionally and the possibility of verbal and physical abuse (Greeff et al., 2008). Disclosure is characterized by people taking time to accept a positive HIV diagnosis. Their feelings about disclosure may change over time as they encounter challenges with disclosure, HIV/AIDS knowledge, silence and denial, media images of PLWHA, HIV/AIDS related discrimination and HIV/ AIDS stigma including external and internal stigma (HIV/AIDS Stigma-Siyamkela Project, 2003). The increased chance of disclosure is related to an environment in which there is a relationship of trust and acceptance.

(iii) Relationship of trust

Disclosure of HIV status by PLWHA was based on trust. Relationships of trust existed with people who were physically close to them or living in the same house. PLWHA disclosed their HIV status to people who they trusted, such as family and friends. It was the family and friends who provided a caring, trusting environment that enabled PLWHA to be open about their HIV status and disclose their status.

(iv) Acceptance

Acceptance meant that the PLWHA had come to terms with their illness and had accepted the fact that they were HIV positive. The family's acceptance of PLWHA was a positive response to families which overtly rejected or subtly distance themselves from HIV-positive people. The acceptance and support from family and friends also helped them to make changes to their behaviour. The family's acceptance of PLWHA allows for open access to antiretroviral treatment.

Benefits of disclosure are ‘opens out the illness’, easy access to treatment and self-liberation.

(v) ‘Opens out the illness’

‘Opens out the illness’ is an expression of how PLWHA felt after disclosure of their HIV status. Since their HIV status was no longer a secret, they could speak freely and openly about HIV/AIDS. PLWHA experienced relief from the burden of secrecy about their HIV status. The measure to reduce stigma was based on creating awareness and openness about HIV/AIDS. PLWHA felt emotionally better and healthier after disclosure and were relieved after disclosure. The burden of a fatal disease was removed by disclosing their HIV status.

(vi) Easy access to ARVs

The easy access to antiretroviral treatment gave PLWHA a new lease on life. PLWHA’s perception of HIV/AIDS was that it is a fatal disease. Having antiretroviral treatment changed their perception of the disease. PLWHA experienced an improvement in their health after taking ARV treatment. After disclosing to family and friends and experiencing an improvement in their health, they were prepared to talk about how they did not have to hide that they are sick or taking their medication.

(vii) Self-liberation

Disclosure of HIV status was self-liberating. Public disclosure to the community also alleviated the fears of death. PLWHA who have made a conscious decision about their behaviour and informed choices about HIV prevention are self-liberated.

(viii) Stigma

Stigma in HIV positive people is the consequence of labelling, name calling and ostracism. The measures to reduce stigma are dependent on the degree of involvement of HIV-positive people in prevention, treatment and self-care. A comprehensive response to the reduction of stigma is for the inclusion of support organizations of PLWHA as real partners. It is HIV-positive people who initiate activities to support and educate communities affected by HIV to actively address stigma and discrimination. The principle of the Greater Involvement of People Living with HIV/AIDS (GIPA) was established eleven years ago and is kept alive through the work of HIV-positive individuals and communities around the world (USAID, 2006). In countries like Vietnam, the increase in support and involvement of PLWHA rests with the creation of an enabling environment for improved HIV prevention, treatment and care. The GIPA strategies must operate in unison to strengthen treatment governance (USAID, 2006). The reduction of stigma and the involvement of PLWHA in the prevention and treatment activities are critical to upscale the prevention efforts in the reduction of stigma (USAID, 2006).

(ix) Community Awareness and Education

Community awareness is a system of creating awareness in the community and educating the people about HIV/AIDS. It includes PLWHA, the family and the community attempting to educate the community about HIV/AIDS. PLWHA who have disclosed their HIV status are prepared to speak openly about their experiences of living with HIV/AIDS, provided that they have a conducive environment in which to do so. The education and awareness targets individuals, the family and the community and encourages them to adopt positive lifestyles and change their behaviour as a means of reducing HIV/AIDS stigma. Education and awareness of

the community incorporates creating a platform for PLWHA to disclose their status. Education is also directed at post-test counselling and counselling of PLWHA to deal with a fatal disease.

(x) Support Groups

Support groups are a forum for PLWHA to find a common ground to discuss their problems and experiences of HIV/AIDS. Support groups were advocated for PLWHA and family members as a measure to reduce stigma. The support group for family members would afford them an opportunity to exchange their views and experiences about living with people with HIV/AIDS. This support group would alert the community about the seriousness of the disease and assist families in bereavement counselling. “Support groups facilitate a sharing of experiences; convey information and give practical advice on a range of HIV wellness and treatment options” (USAID, 2006:11). The support of families and communities has stimulated the creation of several self-help and support groups. Some of the positive impacts of support groups were the reduction in the levels of felt stigma and discrimination in the community and an increase in access to essential services (USAID, 2006). In the African culture, community support and caring is marked in the tradition of ‘ilimo’ where a farmer invites neighbours to assist with ploughing the fields and their support is acknowledged by giving them traditional beer and food (Foundation Report on Giving, 2009/10). The community organizes an ‘ilimo’ by inviting different households to participate in communal gardening projects, thereby allowing the whole community to work on one’s field. They are compensated when the harvest is ready for consumption. Health professionals facilitate self-help income generating projects for their survival and contribution to the economy (Xulu, 2007).

The concepts that benefit the reduction of stigma are public disclosures, more people getting tested and acceptance.

(xi) Public disclosures

PLWHA make an announcement in a public forum that they are HIV positive. The community members strongly supported the idea that community leaders should make public disclosures so that other people in the community will follow their example of disclosing their HIV status. If the community decreases stigma, then people are more likely to talk publicly regarding themselves which further increases disclosure and reduces stigma.

(xii) HIV Counselling and Testing

PLWHA are willing to encourage more people to get tested, know their status and reduce HIV/AIDS stigma. HIV counselling and testing (HCT) campaigns are the new approach adopted in the HIV Treatment programme. HCT campaigns could be extended to shopping centres. The idea behind the campaign is to mobilize people to know their status and seek treatment, care and support. The campaign also advocates encouraging people to take proactive steps towards living a healthy lifestyle, irrespective of their HIV or TB status (Department of Health, 2010). If stigma is removed, then people are more likely to go and get tested.

(xiii) Family

The family fulfills a central role for PLWHA and is the pillar of support. Support from the family includes acceptance after disclosure to facilitate the reduction of stigma. Families need

counselling in order to support their HIV-positive family member and give them time to process their thoughts and emotions. Support groups for families provide assistance in demystifying beliefs, clarifying values and accessing resources to lessen the burden on the family (USAID, 2006).

(xiv) Community

The community is also a pillar of support for PLWHA by providing strength and support. The community leaders' involvement is essential for the effective management of any programme designed to encourage disclosure and reduce stigma. There is a need for the involvement of HIV-positive people in community strengthening programmes that seek to create healthy, enabling communities. The relationship in community involvement projects is based on trust, mutual support and involvement in local community projects (Campbell, 2003).

(xv) Environment

A safe and secure environment encourages PLWHA to disclose their HIV status. Generally, the family provides a supportive, stable environment in which members of the family feel safe, secure and comfortable. In under-resourced communities, the need is even greater for the provision of a conducive environment in families where HIV is prevalent and they are experiencing difficulties. The family should maintain the dignity and confidentiality of PLWHA who have disclosed their status.

5.4 Recommendations

The findings of the study provide the basis for the recommendations that address the tensions in the findings. The recommendations from this study are described below:

Research

The need for future research on the evaluation of the framework is recommended. This was not done in the current study due to time constraints. Further research studies can be conducted in larger communities with similar profiles. Research in the areas such as labelling and stereotyping at the individual level, public disclosure by prominent members in the community and implementation of awareness and education campaigns should be explored.

Nursing Practice

There is a need for nurses to develop community engagement projects and establish partnership in order to address the issues regarding HIV/AIDS. The development of a safe, secure and conducive environment to disclose their HIV status in the home, hospital or community with the support of the family and the health service provider is recommended. This is essential to ensure that more people get tested, know their HIV status and disclose their HIV status in order to prevent further spread of the disease.

Education

Effective strategies to measure the impact of education on HIV/AIDS stigma and discrimination should be explored. The extent of the reduction of stigma among PLWHA, their families, the community and professionals must be established through the development of Health Promotion Programmes.

Management

The development of policies to curb HIV/AIDS stigma should be strengthened in order to address issues pertaining to HIV/AIDS stigma for the benefit of individuals, families and the community.

5.5 Limitations

One of the major limitations of the study was not being able to tape record the interviews and the focus group discussions due to the sensitive nature of the topic. The researcher had requested permission from the participants to tape record their sessions and they had declined that request. The researcher then had to resort to transcribing during the interviews/focus group discussions so valuable information could have been lost in this process. Information could also have been lost in the translation from isiZulu to English.

5.6 Conclusion

PLWHA emphasised the importance of having an HIV test and knowing their status in order to prevent further spread of the disease. Having knowledge of their HIV status and the severity of

the illness allowed them access to free antiretroviral treatment. PLWHA encouraged other people to get tested and disclose their HIV status, thus promoting HIV Counselling and Testing. PLWHA who are aware of their HIV status are in a position to prevent the spread of the disease by using condoms and having a monogamous sexual relationship.

PLWHA are willing to talk about their HIV status and share the experiences of their illness so that the community has a better understanding of the disease and accepts them. The viewpoint of the PLWHA was that the more people speak openly about their HIV status, the easier it would be for the community to accept them. The process of consciousness-raising involves creating awareness which PLWHA are willing to undertake to increase the community's knowledge and understanding about HIV/AIDS. PLWHA are prepared to dispel myths and misconceptions about HIV by creating community awareness and accepting the fact that they are HIV positive and are not bewitched (having an evil spell cast over you) as is often perceived by the community.

The discussions are captured in the Stages of Change Model/Transtheoretical Model. Three of the action research cycles were presented in Chapter 4 and two in Chapter 5. Cycle 4 of action research concentrated on discussion of the reflections of the researcher. The cycle on discussion-reflection was inclusive of disclosure a sense of relief, disclosure to trusted persons, support for PLWHA and benefits of disclosure, stigma and reduction of stigma. The last two stages of action and maintenance of the Stages of Change Model/Transtheoretical Model focused on conscientising communities, forming support groups, modifying lifestyle and behaviour and other factors that were spin-off cycles not directly related to the study. The recommendations

and limitations conclude this chapter. The final analysis of this discussion culminates in the development of a framework for community-based care.

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Annexure 1

FOCUS GROUP INTERVIEW GUIDE FOR COMMUNITY MEMBERS

Research questions 1 and 2

What are the requirements in a CBC for PLWHA to enable them disclose their status without fear?

What are the requirements in a CBC for PLWHA to enable them experience reduction in stigma attached to HIV/AIDS?

INTRODUCTION

The researcher will:

- introduce herself and the nature of the organization that she is representing.
 - explain the purpose and the nature of the study.
 - give an explanation about the necessity for tape recording and the note taking.
-
1. What are your views on stigma related to HIV?
 2. What are your views on HIV positive people disclosing their HIV status
 3. What are the needs of PLWHA in the community?
 4. How can you assist PLWHA to disclose their HIV status?
 5. How can you make it easy for PLWHA to disclose their status without the fear of being discriminated?
 6. Do you think it is important for PLWHA to disclose their HIV status?
 7. Why is it important for PLWHA to disclose their status?
 8. Would the community leaders provide support for PLWHA that have disclosed their status?
 9. How would you address the issue of stigma towards HIV/AIDS?
 10. What are the conditions that would allow PLWHA to experience a reduction in stigma?
 11. What are the conditions that would lead to reduction of stigma in the community?
 12. What are the things that you as community leaders can do assist PLWHA experience reduction in stigma?

Annexure1

UHLAKA LWENGXOXO YEQEMBU LAMALUNGU OMPHAKATHI.

Imibuzo yocwaningo 1 kanye no 2

Yiziphi izidingo kuCBC ze PLWHA ezenza bakwazi ukudalula izimo zabo ngaphandle kokwesaba?

Yiziphi izidingo kuCBC zePLWHA ezenza bakwazi ukwehlisa isinembekezero nesandulela ngculazi kanye nengculazi.

ISINGENISO

Umcwaningi uzo:

- Zethula yena nemvelaphi yehlangano ayimele
- Chaza izinhloso nemvelaphi yesifundo
- Nikeza izincazelo ngezidingo zokuqopha kanye nokuthatha amanothi

1. Yimiphi imibono yakho ngesinembekezero esikusandulela ngculazi?
2. Yimiphi imibono yakho ngabantu abanesandulela ngculazi abazidalula ngezimo zabo zokuba nesandulela ngculazi?
3. Yiziphi izidingo zePLWHA emphakathini?
4. Ungamsiza kanjani uPLWHA ukuthi adalule izimo zobo zesandulela ngculazi?
5. Ungakwenza kanjani kube lula kuPLWHA ukudalula izimo zabo ngaphandle kokwesabela ukuba babandlululwe?
6. Ucabanga ukuthi kubalulekile ukuthi uPLWHA azidalula izimo zabo zesandulela ngculazi?
7. Kungani kubalulekile kwi PLWHA ukuzidalula ngezimo zabo?
8. Kungaba abaholi bomphakathi bangalunika yini usizo ku PLWHA kulabo asebedalule izimo zabo?
9. Ungakwazi ukulandisa ngesinembekezero maqondana nesandulela ngculazi /nengculazi?
10. Yiziphi izimo ezingavumela i IPLWHA ukuthi yehlise isinembekezero?
11. Yiziphi izimo ezingaholela ekutheni kwehliswe isinembekezero emphakathini?
12. Yiziphi izinto eningazenza nina njengabaholi bomphakathi ukusiza ekwehliseni isinembekezero?

Annexure 2

IN-DEPTH INTERVIEW GUIDE FOR PLWHA

Research questions 3 and 4

What are the factors that would promote reduction of stigma among PLWHA in community-based care?
What framework for community-based care would promote reduction of stigma and encourage disclosure of HIV positive status?

INTRODUCTION

The researcher will:

- introduce herself and the nature of the organization she is representing;
- explain the purpose and the objectives of the study;
- give an explanation about the necessity for tape recording and note taking.

1. Age: _____

2. Gender:

MALE	
FEMALE	

3. Marital Status

SINGLE	
MARRIED	
WIDOW	
DIVORCED	

4. Number of minor children: _____

5. State your religious affiliation: _____

6. When did you come to know about your HIV status?

6.i. State month: _____ year: _____

7. Have you disclosed your HIV status to any family member?
8. How do you feel after disclosing your status?
9. Have you had any experience of stigma?
10. What changes have you made to your lifestyle?
11. What can you do as a HIV person to reduce stigma?
12. Do you think disclosing your HIV status has reduced experience of stigma?

If yes:

- What makes you think so?
- How has it been reduced?

Annexure 2

In-depth interview guide for PLWA

Imininingwane yemibuzo yabantu abaphila negciwane lengculazi (PLWA)

Imibuzo 3 no 4

Ngabe inhloso yenzelwe iCBC ukunciphisa ukubandlululeka kwabantu abaphila negciwane lengculaza endaweni yase Bhambayi?

Ngabe inhloso yenzelwe iCBC ukugquzela abantu abaphila nengculaza endaweni yaseBhambayi ukuthi baphumele obala mayelana nesifo abaphila naso?

Isingeniso

Umcwaningi uzo:

- zazisa yena kanye nenhlangano aqhamuka kuyona
- achaze inhloso yocwaningo
- anike incazelo mayelana nokuqopha kanye nokuthatha amanothi.

1. Iminyaka _____

2. Ubulili

Owesilisa	
Owesifazane	

3. Mayelana nesimo somshado

Angishadile	
Ngishadile	
Umfelokazi	
Sesahlukanisa	

4. Inani lezingane _____

5. Ngabe usonta kuphi _____

6. Ngabe wazi nini ngesimo sakho sesandulela ngculaza?

6.1 Yiphi inyanga: _____ Unyaka: _____

7. Ngabe ukhona emndenini wakho owamazisa ngesimo sakho sesandulela ngculaza?

8. Uma ucabanga ukuphumela kwakho obala mayelana nesifo sakho kukusizile ukunciphisa imizwa yakho ngokubandlululeka?

9. Emva kokuba usuwazi ngesandulela ngculaza, ngabe ushintshile ngesimo sokuphila kwakho?

10. Uma ucabanga yini ongayenza njengoba unesandulela ngculaza ukunciphisa ukubandlululeka?

NGIYABONGA UKUBAMBA KWAKHO IQHAZA KULOLUCWANINGO.

Annexure 3

FOCUS GROUP INTERVIEWS FOR FAMILY MEMBERS OF HIV POSITIVE PEOPLE

Research questions 3 and 4

Is a purposely developed CBC towards reduction of stigma capable of achieving reduced experience of stigma among the PLWHA in Bhambayi?

Is a purposely developed CBC towards increased disclosure of HIV/AIDS status capable of achieving increased disclosure of status among PLWHA in the Bhambayi community?

INTRODUCTION

The researcher will:

- introduce herself and the nature of the organization she is representing;
- explain the purpose and the objectives of the study;
- give an explanation about the necessity for tape recording and note taking.

1. How would you address the issue of stigma attached to HIV/AIDS in your community?

2. Have you shared your family member's status with other community members?

If yes:

What was their reaction?

If no:

Why not?

3. What is it like to have a family member living with HIV/AIDS?

4. How has your status in the community changed since your family member has been diagnosed with HIV/AIDS?

Annexure 3

Uhlelo lwemibuzo yemindeni yabantu abaphila negciwane lesandulela ngculaza Imibuzo 3 no 4

Ngabe inhloso yenzelwe iCBC ukunciphisa ukubandlululeka kwabantu abaphila negciwane lengculaza endaweni yase Bhambayi?

Ingabe inhloso yenzelwe iCBC ukunyusa amathuba okuba abantu baphumele obala mayelana nesimo sengculaza eBhambayi?

Isingeniso

Umcwaningi uzo:

- Zazisa yena kanye nenhlangano aqhamuka kuyo.
 - Achaze inhloso nezinto azoziphumelelisa kulolucwaningo.
 - Anike incazelo ngokusebenzisa i-tape recorder kanye nokuthatha amanothi.
1. Ngabe ungakuchaza kanjani ukubandlululeka endaweni yangakini okubangwa i-HIV?
 2. Ingabe ukhona endaweni osuke wamazisa ngesimo sengculaza soyilunga lomndeni wakho? Uma ekhona:
Ngabe wathuka/bathuka?
Cha: Yini indaba bengathukanga?
 3. Uzizwa unjani ukuba nelunga lomndeni elinesifo sengculaza?
 4. Ngabe umphakathi washintsha kanjani emva kokuzwa ukuthi ilunga lomndeni wakho linegciwane lengculaza?

Annexure 4

INFORMATION DOCUMENT

Study title: An exploratory study towards disclosure of status and reduction of stigma for people living with HIV/AIDS in a low income community.

Greeting: Welcome to this study.

Introduction:

I am doing this research on disclosure of HIV status and reduction of stigma so that I can get a higher qualification. The study will also benefit the community because if more people are willing to disclose their status and go for treatment thereby helping in the reduction of stigma.

Invitation to participate: You are kindly requested to take part in this study. I know that the topic is very sensitive and you can say "No" and not take part in the study. I would also like for you (ie, people that have disclosed), to pick one / two members of your family and one / two children that over the age of 19 years.

What is involved in the study – I will have an interview that would take about an hour with people that have disclosed their status. There will be a focus group discussion for about one/one and half hours with the family members, adult children, community members, and family members of people that have died of AIDS. The people that are going to take part in this study are all members of this community. Each focus group will have a minimum of five and a maximum of seven participants. The numbers will depend on how many people are willing to take part in the study.

Risks: There are no risks anticipated in this study since it is not a clinical study. Due to the sensitive nature of the topic the necessary precautions will be taken not to cause any distress or harm (eg. In the case of emotional stress not to continue probing or prying but to be sensitive and stop).

Benefits: This study would benefit the both people living with HIV/AIDS, their families and the community. The people that have disclosed their HIV status can seek treatment, their families can accept them and take care of them and the community can assist in the reduction of stigma.

The subject will be given pertinent information on the study while involved in the project and after the results are available.

Annexure 4

UMQULU WOLWAZI

Isihloko sesifundo: Isifundo esihlola maqondana nokudalulwa kwesimo kanye nokwehlisa isinembekezele kubantu abaphila nesandulela ngculazi/ nengculazi emphakathi othola iholo elincane.

Ukubingelela: Siyanamukela kulesi sifundo.

Isingeniso:

Ngenza lolu cwaningo lokudalula isimo sesandulela ngculazi kanye nokwesinembekezele khona ngizothola iziqu eziphakeme. Isifundo sizohlomulisa umphakathi ngoba uma abantu abaningi befisa ukuzidalula izimo zabo kanye nokuthola ukwelashwa lokho kuyosiza ukwehlisa isinembekezele.

Isimemo sokubamba iqhaza: Uyacelwa ukubamba iqhaza kulesi sifundo. Ngiyazi ukuthi sinozwelo futhi ungasho ukuthi “cha” futhi ungalibamba iqhaza esifundweni. Ngingathanda futhi (ukusho abantu abazidalulile), ukuthatha oyedwa/amabili abangamalunga omndeni wakho kanye noyedwa /ababili abantwana abangaphezulu kweminyaka eyi 19.

Yini ebandekanyekayo esifundweni –Ngiyoba nengxoxo ezothatha ihora nalabo bantu abazidalula isimo sabo. Kuyoba neqembu elixoxa isikhathi esilinganiselwe ihora elilodwa/ ihora nohafu namalungu omndeni, Abasayizingane, amalungu omphakathi, kanye namalungu emindeni yabantu abafa ngengculazi. Abantu abayobamba iqhaza kulesi sifundo kuyoba amalungu onke omphakathi. Iqembu ngalinye liyoba namalungu angaphansi kwesihlanu kanye nangaphezu kwesikhombisa abambe iqhaza. Izinombolo ziyoya ngokuthi bangakhi abantu abayothanda ukubamba iqhaza kulesi sifundo.

Ubungozi: Abukho ubungozi obungaba khona kulesi sifundo njengoba kungesona sekilini. Ngenxa yesimo semvelo ngesihloko izinyathelo ezifanelekile zokuthi kungabi khona nhlupheko noma ubungozi ziyothathwa, (isib.)Esimweni sokucabanga kakhulu akufanele uqhubeke nokubuzisa imibuzo kodwa kufanele ube nozwelo ume.

Imihlomulo: Lesi sifundo siyohlomulisa bobabili abantu abaphila nesandulela ngculazi/ nengculazi, imindeni yabo kanye nomphakathi. Abantu abazozidalula ngezimo zabo zesandulela ngculazi bangathola ukwelapheka, imindeni yabo ingabamukela bese ibanakekela futhi nomphakathi ungabasiza ukwehlisa isimo sesinembekezele.

Isifundo siyonikeza ukuqonda kombiko ngesifundo ngesikhathi somsebenzi womphakathi ngemumva komphumela oyobakhona.

Annexure 5

INFORMATION DOCUMENT AND INFORMED CONSENT

You are kindly requested to take part in this study on disclosure of HIV status and reduction of stigma. The study is towards a higher degree. I know that the topic of HIV/AIDS is very sensitive and you can say “No” and not take part in this study. At the end of this study you will be informed about the results of this study. All the information in this study is confidential.

What I am trying to achieve in this study is for people living with HIV/AIDS (PLWHA):

1. To disclose their HIV status so as to reduce the stigma.
2. To disclose so that they can get treatment.
3. To disclose so that their families can accept them and take care of them.

REFRESHMENTS

You will be provided with refreshments at each meeting.

CONTACT

My contact details are:

Name : Ayisha Razak

Telephone : Work: 031 - 373 2748

Home: 031 - 269 1322

Cell: 083 786 7282

Place of work : Durban University of Technology

Your participation in this research is voluntary and you may withdraw at any time.

If you agree to participate, you will be given a signed copy of this document and the participation information sheet, which is a written summary of the research.

The research study and information has been explained to me orally, I understand what my involvement in this study means and I voluntarily agree to participate.

Signature of Participant

Date

Signature of Witness

Date

Signature of Translator

Date

Annexure 6

INFORMATION DOCUMENT AND INFORMED CONSENT

Uyacelwa ukuthi ubambe iqhaza kuldu ewani – ngo olumayelana nokuvesa isimo sakho sengculuza konye nokugedwa kokubandlululeka. Lolugwamingo lwenzelwa imfundo ephakeme (higher degree).

Ngiyazi ukuthi isihloko esikhuluma nge HIV/AIDS sinzima futhi unelungelo lokunqaba ukubamba iqhaza kulolucwaningo.

Yonke imininingwane esizokhuluma ngayo iyimfihlo, akekho oyokwaziswa ngayo, futhi uyokwaziswa ngemiphumela yocwaningo.

Engifuna ukukuphumelelisa kubantu abaphila nesifo sengculuza:

- (1) Ukuphumela obala ukuthi kunciphe ukubandlululeka mayelana nesifo sengculuza.
- (2) Baphumele obala ukuze bathole ukwelashwa.
- (3) Baphumele obala emindenini yabo ukuze ibanakekele.

Refreshments

Kuzobe kutholakala okokuphuza ngesikhathi nisehlanganweni.

Contact details

Ungangithinta kulemininingwane engezansi:

Igama :Ayisha Razak
Ucingo :Lomsebenzi 031-204 2748
Lwasekhaya 031-269 1322
Cell 083 786 7282

Indawo yokusebenza :Durban Institute of Technology

Ukubamba iqhaza kulolucwaningo kusothandweni lwakho futhi ungayeka ukuqhubeka nalolucwaning noma nini.

Uma uvuma ukubamba iqhaza uzonikwa icopy ozoyisayina kanye necopy eneminingwane efinqiwe yalolucwaningo.

Imininingwane mayelana nalolucwaningo luchaziwe kimina, ngiyayiqonda ngokubamba iqhaza lami kulolucwaning futhi ngivumile ukubamba iqhaza lami kulesi-study.

 Sayina obamba iqhaza	<u>24.10.2005</u> Usuku
+ M F Sayina owufakazi	<u>24.10.2005</u> Usuku
 Sayina oyi-translator	<u>24.10.2005</u> Usuku

Annexure 7



RESEARCH OFFICE (GOVAN MBEKI CENTRE)
WESTVILLE CAMPUS
TELEPHONE NO.: 031 – 2603587
EMAIL: ximbap@ukzn.ac.za

31 AUGUST 2005

MRS. A RAZAK (961115145)
NURSING

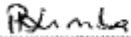
Dear Mrs. Razak

ETHICAL CLEARANCE NUMBER: HSS/05057A

I wish to confirm that ethical clearance has been granted for the following project:

“An exploratory study towards disclosure of status and reduction of stigma for people living with HIV/AIDS low income community”

Yours faithfully


.....
MS. PHUMELELE XIMBA
RESEARCH OFFICE

PS: The following general condition is applicable to all projects that have been granted ethical clearance:

THE RELEVANT AUTHORITIES SHOULD BE CONTACTED IN ORDER TO OBTAIN THE NECESSARY APPROVAL SHOULD THE RESEARCH INVOLVE UTILIZATION OF SPACE AND/OR FACILITIES AT OTHER INSTITUTIONS/ORGANISATIONS. WHERE QUESTIONNAIRES ARE USED IN THE PROJECT, THE RESEARCHER SHOULD ENSURE THAT THE QUESTIONNAIRE INCLUDES A SECTION AT THE END WHICH SHOULD BE COMPLETED BY THE PARTICIPANT (PRIOR TO THE COMPLETION OF THE QUESTIONNAIRE) INDICATING THAT HE/SHE WAS INFORMED OF THE NATURE AND PURPOSE OF THE PROJECT AND THAT THE INFORMATION GIVEN WILL BE KEPT CONFIDENTIAL.

cc. Faculty Officer
cc. Supervisor (Prof. O Adejumo)

Annexure 8

Parks Dept Chatsworth.

PHONE NO: 401352

April 08 2005 10:15AM F

ATTN: ANISHA KAZAK

BHAMBANI RECONSTRUCTION AND
DEVELOPMENT FORUM

P.O INAMBH

4310 02-08-2004

FROM :-

CHAIRPERSON

S.D. MBAMASE

ITS A PLEASURE TO ME TO GET THIS OPPORTUNITY
REPLY OR RESPOND TO YOUR WRITTEN REQUEST &
YOUR WILLINGNESS TO UNDERTAKE RESEARCH STUDY
OF THIS EPIDEMIC IN OUR AREA. WE APPRECIATE
BRAVENSNESS OF PUSHING ASIDE THE UNBECOMING HISTORY
OF OUR AREA WHICH MAKES LOT OF PROFESSIONALS
IGNORING IT, WHILE THE H.I.V. & AIDS IS BEING WIDESPREAD
TO OUR COMMUNITY.

SO ANISHA, WE ARE GIVING YOUR REQUEST A BIG
AND WE PROMISE YOU WITH OUR UNRESERVED SUPPORT
IN ALL SPHERES OF PRACTICALITY, SPIRITUALITY AND
EMOTIONALITY

THANK YOU

YOURS FAITHFULLY

S.D. MBAMASE (CHAIRPERSON - B.R.D.F.)



Annexure 9

Bhambayi Reconstruction and Development Committee
Bhambayi

April-2, 2005

Dear Ayisha *FAX 031-204-2039*

REQUEST TO CONDUCT RESEARCH IN BHAMBAYI

We the chairman and members of the Reconstruction and Development grant you permission to conduct research in our committee. We will support you in your venture but will not take any responsibility for the research you intend undertaking.

We look forward to working closely with you in our community.

NAMES	SIGNATURES
1 <i>Lillian Molealle</i>	<i>[Signature]</i>
2 <i>DATACIA Madaba</i>	<i>[Signature]</i>
3 <i>Wesley Makize</i>	<i>[Signature]</i>
4 <i>Bulus Mbulu</i>	<i>[Signature]</i>
5 <i>Mombiluthi Namuni</i>	<i>[Signature]</i>
6 <i>Muel E. Mhlonso</i>	<i>[Signature]</i>
7 <i>SANISANI GANTHWA</i>	<i>[Signature]</i>
8 <i>Sibusiso SITHALA</i>	<i>[Signature]</i>
9 <i>Mphahlele - Madaba</i>	<i>[Signature]</i>
10 <i>T.R. Zwane</i>	<i>[Signature]</i>
11 <i>G. Mkhomo</i>	<i>[Signature]</i>
12 <i>Khondiso Gantsho</i>	<i>[Signature]</i>
13	
14	
15	

Yours sincerely

Molealle (0132443835)

Chairman / Secretary

To: AYISHA KAZAK

Annexure 10

Inanda District Office

To : Ayisha Razak
From : Mrs M.M.M Mkhize
Topic : Request

The request for doing/ conducting of research at Bhambayi N.I.P. Site.
Your request has been forwarded to the Regional Office Directorate to formalize his agreement.
There is no objection to have you undertake this research.

Yours truly,



M.M.M. Mkhize

DISTRICT MANAGER

**PROVINCE OF KWAZULU-NATAL
DEPARTMENT OF SOCIAL WELFARE AND POPULATION DEVELOPMENT**

ADMINISTRATION : DURBAN REGION

**SUBJECT: TO REQUEST FOR PERMISSION TO CONDUCT RESEARCH
STUDY AT NIP SITE – BHAMBAYI : MS AYESHA RAZAK**

21 April 2005

The Acting Superintendent-General
Department of Social Welfare
and Population Development
Private Bag X27
ULUNDI
3838

ATTENTION : MR W MAGWAZA

1. BACKGROUND

Ms Ayesha Razak is a student at the University of KwaZulu Natal but currently employed as a Senior Lecturer in the Department of Post Graduate Nursing at the Durban Institute of Technology.

Ms Razak is provisionally registered for a doctoral degree. The title of the Project is:

"An exploratory/descriptive study of disclosure and stigma for family members people living with HIV/AIDS in a low income community".

The Region sees the benefit of her conducting the study in Bhambayi since it will help deal with the issue of stigma and disclosure amongst the people of Bhambayi who are already stigmatising the NIP Site.

We also hope that the result of the study will inform us on the number of infected people who wish to access services available but due to stigma remain silent and fear rejection by family members.

The study will benefit the community where people will disclose and be able to access proper medication which will prolong their lifespan and be productive citizens.

2. RECOMMENDATION

It is recommended that the student Ms Ayesha Razak be granted permission to conduct her study in Bhambayi NIP Site.

N Gumele 26/04/05
N GUMEDE
DIRECTOR : SOCIAL SERVICES

RECOMMENDED / NOT RECOMMENDED

COMMENTS

E.T. Mhlongo
ET MHLONGO
CHIEF DIRECTOR : SOCIAL SERVICES
DATE : 26/4/05

APPROVED / NOT APPROVED

APPROVED / NOT APPROVED / APPROVED AS AMENDED
[Signature]
ACTING SUPERINTENDENT-GENERAL
DEPARTMENT OF SOCIAL WELFARE
AND POPULATION DEVELOPMENT
DATE : 29.04.2005

PPS/sub.ayesha/137/fr

Annexure 12

45 Booth Avenue
Overport
Durban
4091

April 2, 2005

The Chairman & Members
Bhambayi Reconstruction and Development Committee
Bhambayi

Dear Madam/Sir

REQUEST TO CONDUCT RESEARCH IN YOUR COMMUNITY

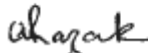
I am provisionally registered for a doctoral degree at the University of Kwazulu Natal. I am employed as a Senior Lecturer in the Department of Postgraduate Nursing at the Durban Institute of Technology.

The title of my project is:

An exploratory study of disclosure and stigma for family members and people living with HIV/AIDS in a low-income community.

Your favourable response is greatly appreciated.

Yours truly,


Ayisha Razak
Student Number 91115145

1. Age: 34 years
2. Gender: Female
3. Marital status: Single
4. No. Of children: 2 boys. Age 4 years & 2years
5. Religion: Zionist
6. 16 December 2005. CD 4 count was 23 and I was 3 months pregnant.
7. Disclosed to boyfriend, family-grandmother, aunties & sister, in-laws & community.
8. Feel free – Before I got sick and pregnant for 3 months afraid of losing the baby. I am going to die. My friends and family did not believe that I had HIV. They felt it was a ‘muti’ thing because I was working with the men as chairperson of BRDC. At Prince Mshiyeni Hospital I came to my status. Dec. 16 2005 felt sick in the taxi. Went to doctor baby in critical condition. Went to Addington Hospital there was no bed then I went to prince Mshiyeni Hospital. They found that it was not the baby but I was sick. Prince Mshiyeni was also full remembering it is 16 December 2005. My boyfriend’s sister was working there then I got admitted. I was hospitalized for 3 months. I was afraid that I could lose the baby and that is why I had to stay in hospital for so long. That was my first son. My second son was born in 2008. I have the same boyfriend that is the father of my two children. After I tell everybody what is going on with me and I am on treatment and I feel free.
9. No experience of stigma because my family was very supportive, my boyfriend and my in-laws.
10. My lifestyle has changed use condoms, eat proper food. I am working my boyfriend is not working he was fired in July 2010. He used to work at Prospecton. He was sick for 2 weeks and when he got back there was no work for him. He was a contract worker. Started ARVs HIV positive started treatment and was ill for 2 weeks then he got fired. Children are both negative gave AZT with Nevarapine gave babies Nevarapine syrup for 2 weeks checked and found he was negative. They did that for both the children and they are negative. To be tested 6/12, 18/12, 24/12 and then 5 years. Eldest child is 4 years and second 2 years. They attend crèche in Bhambayi. I am happy I know my status. I can tell everybody to go to clinic.

11. I think workshops will help because people are afraid to talk about HIV. Support groups for HIV positive people and people without HIV should meet and talk. In my work I talk to people HIV positive. Counsel him to start treatment and carry on with treatment and it is for life. When they see viral load is low and CD 4 count high then they stop their treatment. I visit HIV positive people in the community, encourage them, give them hope, encourage them to take their treatment on time. As part of my I visit people in the community that have been diagnosed as HIV positive. Defaulters from Bhambayi phone them why they have left. Trace them and follow them about especially pregnant women. Especially pregnant women that are pregnant and don't attend clinic then I follow them up. The people in the community respect me. They know my status and I am still alive. I am with this boyfriend for 10 years.
12. Yes let's say if I take my medication and drink it. I go to the farm I drink my medication family reminds me if I took my medication makes life easier. I keep it (medication) in front everybody sees my pill box and medication kept in my lounge not in my bedroom. Stigma it is not like before if you talk about it they talk about it. Before HIV positive nobody came to your house. Everybody hates you. They think you are the carrier and you kill the people. There is a change in the people because they go to the clinic and talk about it. They don't have a problem now to talk about their illness. There are lots of people with HIV. HIV positive people because of poverty, using drugs, alcohol women sleep with different boyfriends because they need money. Older women that are rich sleep with young boys because of poverty. Young girls not go to school and sleep around. Young girls age 13 years. Mother has died and no money, no ID and they sleep around for money. Community tried to help because there is no income they leave the program. Lillian (BRDC Secretary) tried to help with food parcel, get donation to send them to school. Some children go to school. Drop-in-center some people get help some don't. From last year only children get 2 meals after 2 months they get food parcel or every 3 months or 6 months. I had a friend with 13 children without food, no birth certificate. Six children sisters and the other ones hers, one 14 year old left school. Social worker help her out to try and get ID/birth certificates but they don't get it. Adults also don't have ID and that is the problem for the children to get ID documents. In 2005, 2006, 2007 they had AIDs awareness day in the community. Now HIV positive people

go to Newtown C to celebrate AIDS awareness. May go to Amouti, Ghandi's Hospital. My family thought I was bewitched. They did not understand that I was HIV positive it took them time. I collect medication every month. CD 4 count 680 and viral load undetectable. I have good support in my boyfriend, remind me to take medication if I am late and rush to work. My boyfriend is also on ARVs. No more children. I had ligation. Getting married maybe next year June 2011. June 15 elder son's birthday and second son 17 may 2008.

Annexure 13

1. Age: 34 yrs

2. Gender: Female

3. Martial Status: Single(Engaged)

4. Number of Children: 2

5. Religious Affiliation: Christian-Zionist

6. Ngithole ngonyaka ka 2005 ukuthi ngiphila negciwane lengculazi, bengikhulelwe , I CD4 iww 23. Bengikhulelwe sihambe nesoka lami ngo Dec 16 siya edolophini ngabe seniqalwa isusu etekisini, saya kudokotela owathi ingane engiyikhulelwe isenkingeni kungcono siye esibhedlela e Addington, ngeshwa imibhede yayigwele kwazise u December sabe sesidlulela e Prince Mshiyeni.Nakhona kwakugwele kuchichima ngenhlanhla u dadewabo wesoka lami usebenza khona ngawuthola kanjalo umbhede ngale kwalokho ngabe nakhona ngaphindiselwa emuva

6.1. Month:December Year 2005

7. Umndeni wami,ugogo, uanti, kanye nodadewethu.Ngaphumela obla nakumndeni wengoduso yami, abangani bmi kanye nomphakathi wase Bombay lapho ngihlala khona.

8. Ngizizwa ngikhululekile , ngenkathi ngikhulelwe ngangisaba ukuthi umntwana uzoshona ngoba I CD4 yayiphansi iwu 23. Umndeni kanye nabangani babethi ngithakathiwe ngoba ngangisebenza nendoda ehhovisi futhi ngiwusihlalo.

9. Cha angikaze, wonke umunu ube ngakimi umndeniwami, isoka lami kanye nomndeni

10.Manje nginesoka elilodwa ingoduso yami sesineminyaka eyishumi sindawonye, sinezingane ezimbili abafana omunye uneninyaka emine omunye emibili.Sisebenzuisa ikhondomu .Sidla ukudla okunomsoco, ngiyasenza, isoka lami lona balixosha emsebenzini ngo June kulonyaka ngoba lagula amasonto amabilli uma liqala amaARV, lathi maliphindela emsebenzini lathola ukuthi sebethathe omunye umuntu ngoba liyitoho

Ngigqugquzela nomphakathi ukuthi uteste khona uzozazi ukuthi umephi

11. Ngicabanga ukuthi ama “workshop” kanye nama “support group” njalo emasontweni amabili. Lapho umphakathi uhlengana khona baxoxe abaphila negciwane leHIV kanye nalabo abengenalo kungakwehlisa ukucwasana

Emsebenzini?

Ngenza I post test Counselling. Ngikhuluma kakhulu ngokubaluleka kokdla amaphilidi noma ngabe uzizwa sewungcono kakhulu “Adherence”. Abantu abaningi kuye kuthi uma ICD4 isinyuile ne gciwane lingasabonakali egazini bese beyawayeka amaphilisi. Mina ke indima yami ukuqinisekisa ukuhi bayazi ukuthi imishanguzo idliwa implo yakho yonke uma usuqalile uze uphunyuzwe ukufa zonke izinsuku futhi ngesikhathi esifanayo.

Emphakathini?

Umphakathi uyangihlonipha kakhulu ungoba uyazi ukuthi ngiphila negciwane futhi ngingusihlala

Ngiyabavahashela ngesikhathi somsebenzi ngibanike ithemba ukuthi baphuze amaphilisi ngesikhathi.

Ikakhulukazi laba abasanda kuthola ukuthi ba”positive”

Ama”defaulters” siyawafuna awalapha eBombay besinike incazelo yokuthi bawayekeleni amaphilisi, bese ke siyabagququzela ukuthi baqhubeke namaphilisi

Sinenkinga enkulu yomama abakhulelwe okuthi uma sebethole ukuthi ba’positive’ bese bengaphinde babuye , siyabalandela senzela ikakhulukazi ingane engakazalwa ukuze ikwazi ukuthola usizo

12. Yebo

Uma sinezivakashifuthi sekuyisikhathi samaphilisi ngiyasukuma phambi kwaso ngiphuze amaphilisi. Umndeni wami uyangikhumbuzauma sekuyisikhathi lokho kwenza implilo ibe lula. Mina amaphilisi angiwafihli ngiwabeka obola papho wonke umuntu ongenayo ezowabona

Nomphakathi futhi usuyakhuluma nge HIV, akusafani nakuqala nomphakathi usuyangibuza

Ngaphambili umphakathi wawukuzonda uma uositive, bengangeni emzini wakho, bengakukhulumisingoba becabanga ukuthi uzobathelela ubabulale

Ebombay lukhona kakhulu ushintsho ngoba umphakathi awusesabi ukza kwami emini uma udinga usizo. Ngaphambili babeza ebusuku besaba ukubonakala bekhuluma nami ngoba anantu abababonayo bazobona ukuthi nabo ba positive uma bengivakashela besaba ukucwswa

Baningi kakhulu anantu abapositive la. Into engenza ngisho kanjalo

Ububha-amantombazane amancane kusukela ku minyaka eyi 13 alala nobaba abadala ukuze athole imali yokondla imindeni yawo ikakhululukazi ngoba ayizintandane futhi asebeheke imindeni

Kanjalo nomama abadala abanemali balala nabafana abancane bebanike imali

Inkinga yezidakamizwa futhi indlondlobalisa I HIV

Inkinga yokuthi abantu abadala nabancane abanawo ama ID, kwenza ukuthi bengalutholi usizo lokuxhaswa uhulumeni, izingae nezalukazi ezondla imindeni azulutholi uxhaso yikho ke ziyeka isikole zilale namdoda amafidala ukuze zikwazi ukondla imindeni yabo

Umphakathi ayikho into osiza ngayo kuqala babethola ama ‘food parcel’ manje awasekho eza kanye emva kwezinyanga ezithanthu

Izintandane ezazithola ukudla akusafani nakuqala, minaje nginomngani onezingane eziwe13, eziyisithupha ezikasisi wakhe owashona bese kuthi eziyisikhombisa ezakhe. Inkinga abhekene nayo ukuthi azinawo amaID, Uunonhlalakahle selokhu aqala ngo2006 ukuzama ukubasiza kodwa lutho.

World Aids day ngo 2008 no 2009 ayizange ibekhona la eBombay yagcina ngo 2007 Ngiya kanye ngenyanga eclinic Icd4 yami manje ithi 680. Iviral load ayisabonakali. Isoka lami liyanginakekela , uma ngiphuthuma mhlawumbesengikhohlwe amaphilisi liyangikhumbuza ukuthi ngithathe amaphilisi. Sengivalile manje ngeke ngisathola ezinye izingane

