

# **FACING HIV AND AIDS: UNDERSTANDING FAMILY SUPPORT WITHIN A RURAL KWAZULU-NATAL COMMUNITY**

By

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## **ABSTRACT**

This study on, 'Facing HIV and AIDS: Understanding family support within a rural Kwazulu-Natal community' aimed to explore how an HIV/AIDS diagnosis affects the family as a whole and to determine the role of the family as a primary support system. Although HIV and AIDS infects individuals, it also affects entire families. The researcher employed a qualitative research design to gain in-depth and rich data, and to hear the stories of all participants. The study is grounded in the systems theory and the risk and resilience theory framework. For purposes of clarity, much of the work was divided into the different levels of the systems theory. Risk and resilience aspects were identified in relation to the various themes. It was necessary to explore this topic, not only from the perspective of individuals living with HIV and AIDS, but also from the perspective of their family and community. Three sets of data were therefore utilised: interviews with individuals living with HIV and AIDS, interviews with family members of an individual living with HIV and AIDS, and a once-off focus group discussion to gain the perspective of community members. This helped to ensure sample and instrument triangulation.

The type and amount of support that was offered affected the stigma experienced; and affected individual fears and goals, willingness to disclose and the utilisation of available services in the community. It was clear that receiving support reciprocally affected individuals, family and the community. The experience of not being supported resulted in aspects of risk – for example, being more vulnerable in the face of stigma and discrimination. The importance of family support was thus found to be vital in facing the HIV and AIDS journey with resilience.

Recommendations are provided at micro, mezzo and macro levels. This study also hopes to assist service providers to provide the necessary services.

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## DECLARATION OF ORIGINALITY

I declare that this dissertation is my original work. All references to the work of others has been appropriately acknowledged and referenced in accordance with university requirements.

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## **ABBREVIATIONS**

AIDS - Acquired Immune Deficiency Syndrome

HIV - Human Immunodeficiency Virus

NGO - Non-Governmental Organisation

UNAIDS - United Nations – AIDS

ARV – Antiretroviral

# **CHAPTER 1**

## **INTRODUCTION**

### **1.1 INTRODUCTION**

According to Makoe (as quoted in Iwelunmor, Airhihenbuwa, Okoror, Brown, & BeLue, 2006, p. 321), "HIV and AIDS in sub-Saharan Africa has grown to become an epidemic that affects the family as a functioning system, threatening its supportive capacity, and redefining the manner of coping and adapting to the burden of a disease. Research has shown that living with HIV and AIDS poses tremendous physical and psychological challenges for those who are infected, as well as for their families."

There are 34 million people living with HIV globally, with sub-Saharan Africa accounting for 69% of this total; almost one in every 20 adults is living with HIV in this region (Global report UNAIDS, 2012, p. 8).

HIV and AIDS does not exist in isolation. Many other factors impact communities and can worsen the effects of HIV and AIDS. "The impact of HIV and AIDS on children and families is compounded by the fact that many families live in communities which are already disadvantaged by poverty, poor infrastructure, and limited access to basic services" (Foster & Williamson, 2000, p. 280). These contributing factors include poverty, alcohol and drug abuse, mental illness and the lack of a good support system. Yadav (2010, p. 158) states that Durkheim laid the foundation for the concept of social support in the 19<sup>th</sup> century when he established "the link between diminishing social ties and an increase in suicide." This demonstrates the strong impact that support or non-support can have on an individual.

Van Dyk (2008) highlights the need for support for individuals living with HIV and AIDS. She adds that such support can be offered by partners, friends, families, support groups, the church, professionals and the community. This study aimed to determine the role of the family as a primary support system. It is known that HIV and AIDS does not only affect the individual who is infected; entire families and communities are affected. There is also the threat of “multiple stigmatisation” where a person living with HIV/AIDS could experience more than one form of stigma and so feel more burdened than if they were only living with HIV (Gilore & Somerville, as quoted in Skinner & Mfecane, 2004).

An example of such stigma is someone living with HIV who is also physically or mentally disabled. Families in South Africa have had to find ways to become resilient and cope with HIV and AIDS alongside other compounding factors.

Bor et al, as quoted in Brown, BeLue and Airhihenbuwa (2010, p. 5) observe that, “the family unit in South Africa is often a strong source of social support. It remains the strongest source of support for caring for those who are living with HIV or AIDS.” The researcher sought to determine the importance of this family support and how feeling safe within a family system helps individuals living with HIV and AIDS to live a healthy and happy life.

Ilebani and Fabusoro (2011) concur, that physical, emotional and financial support from the family is more important than community support for individuals living with AIDS. The researcher has observed that this is true for some families, where family members support their loved ones living with HIV and AIDS in all spheres. However, for others, such support is not so easy. Some families battle to provide holistic support; for example, they may not be able to provide financially for the person living with HIV and AIDS. Unemployment in the family, a breadwinner living with HIV, or one grant being shared among family members all undermine the level of support a family is

able to offer. Furthermore, family members may be in denial regarding the diagnosis or they may stigmatise family members living with HIV.

AVERT (n.d.) states that families are the primary caregivers in the event of illness in the majority of developing countries and that they play a vital role in the support and care of individuals living with HIV and AIDS. Unfortunately, this care and support does not exist within all family support systems. A survey completed by Stutterheim et al in the Netherlands revealed that stigma within a family, e.g. avoidance, exaggerated kindness or being told to hide one's status caused significant psychological stress on the part of individuals living with HIV and AIDS (AVERT, n.d.).

Family support is essential for individuals living with HIV and AIDS. In an ideal situation, an individual living with HIV/AIDS would receive holistic family support and not have to worry about being stigmatised and discriminated against within their own family. Families would also receive support from the community, and would not have to be anxious about their loved one's status being disclosed. The researcher agrees with AVERT in that families are, or at least should be, the primary caregivers in support of individuals living with HIV/AIDS. However other factors impact the ability to provide such support, including other family members living with the virus, family members having passed away due to the virus and the individual having to find support within other structures. Some families may simply not want to support a family member who is living with HIV.

Skinner and Mfecane (2004, p. 158) describe stigma as “a deeply discrediting attitude that reduces a person to someone who is in some way tainted and can therefore be denigrated” and discrimination as “acts or omissions in which the content of the stigma is applied, either at an individual or social/community level.” In the early years, when HIV and AIDS was still a relatively ‘unknown’

disease and there was not much research, awareness or education, stigma was rife among communities in South Africa and at the global level. Individuals were ostracised by their families and communities and treated in extremely negative and inhumane ways; stigma took on a horrible form during apartheid (Skinner & Mfecane, 2004). Stigma around HIV and AIDS still exists today, despite an increase in awareness and education around HIV and AIDS.

Link and Phelan describe the effect that stigma can have on an individual: “Stigma removes power from the stigmatised person, enhancing differences and reducing the stigmatised group or person’s social status and self-worth” (as quoted in Skinner & Mfecane, 2004, p.158). The researcher believes that stigma hampers individuals from testing for the virus, disclosing their status and receiving support from their families and communities. “Stigma also introduces a desire not to know one’s own status, thus delaying testing and accessing treatment” (Skinner & Mfecane, 2004, p.157). Research conducted in KwaZulu-Natal revealed that youth did not want to know if they were infected or not (Skinner & Mfecane, 2004). This could lead to ignorance, whether desired or not, and impact on the level of support that an individual living with HIV/AIDS may be able to receive.

The following statement by the Prime Minister of Tanzania emphasises the importance of acceptance and not judging people living with HIV and AIDS. “We should focus our attention on understanding what causes us as a society to react in this way to people living with HIV/AIDS – people who are suffering enough, either physically or mentally to be challenged yet again by the judgement of others, by the very people who yesterday were their neighbours and who should be reaching out to them today” (Skinner & Mfecane, 2004, p.158).

Many communities within KwaZulu-Natal have been proactive, with non-governmental organisations (NGOs) stepping up to the plate to provide services to individuals living with HIV and AIDS. NGOs known by the community under study include the Place of Hope, Howick Hospice and Ithembeni. Part of this research involved exploring the availability and effectiveness of the services available to individuals living with HIV/AIDS and their families in this community. As noted earlier, support is needed both for the infected and the affected.

As previously discussed, HIV may *infect* one person, but it *affects* entire families. Family members have had to take on the role of supporting their loved ones, with or without resources and support from external sources. “Obviously, AIDS places an enormous strain on family systems. Families are called on to respond and manage an unpredictable illness while managing other chronic and acute stressors, often with little or no specialised training, guidance, or support. Given the scope and uncertainty of the challenges they face, families affected by AIDS need flexible coping skills that can be applied to a variety of circumstances” (Pequegnat & Szapocznik, 2000, p. 17). This statement highlights the burden that an HIV diagnosis can place on a family.

An exploratory and descriptive qualitative study was undertaken by the researcher in order to understand the concept of family support and its importance for people living with HIV and AIDS. In order to receive support from one’s family, disclosure of one’s status is vital. Disclosure enables people to accept their status, access services and medication, practice safe sex and promote responsibility (Van Dyk, 2008). Van Dyk identifies two types of disclosure; full disclosure (public revealing of one’s status) or partial disclosure (telling only certain people e.g. family members) (2008, p. 280). Disclosure may have negative effects such as stigma and discrimination. The researcher explored both forms of disclosure and the positive and negative effects of each. These will be discussed in more detail later in this study.

Serovich, Craft and Yoon described HIV/AIDS disclosure as a sensitive issue; due to the prejudice and discrimination surrounding HIV/AIDS, partners, friends or family members who would usually be a source of support often withdraw support when they discover an individual's status (2007, p. 970). Disclosing one's status therefore carries the risk of altering family relationships. This issue is also explored later in this study.

The researcher hopes that this study will provide a way forward in terms of how individuals living with HIV and AIDS could be empowered by family support. Services that may help families to cope and care for members living with HIV and AIDS are also explored.

## **1.2 RATIONALE FOR THE STUDY**

HIV and AIDS is a significant problem and a growing concern in South Africa. Many aspects of this epidemic have been, and need to be studied further to gain a holistic understanding of HIV and AIDS. As HIV and AIDS do not exist in isolation, but involves the whole family system, there is a need for studies that focus on the family. Davey, Foster, Milton and Duncan (2009, p. 50) note that one of the limitations of their study was that while they gained an understanding of patients' perceptions of family relationships and support, they did not interview family members themselves. This prevented them from gaining a holistic view of the family support under study. Bor, du Plessis and Russell (2004, p. 169) note that, "several studies have been concerned with the impact of social support from the perspective of the recipient who is unwell. However, there have been few studies that have examined the nature of the experience from the perspective of the caregiver." This underlines the need to include family members in a study of this kind.



According to Collins (1988, p. 446), “although many people think of the family as their major support system, at times whole families need support.” Families need support in order to support one another. The researcher believes that the long-term solution would be to facilitate support and thus equip and emotionally prepare family members to support one another. In this regard, Kulzer et al state that “if one family member is HIV infected, the entire family is affected and has to cope with the physical, emotional, social and economic consequences of HIV” (2012, p. 2).

While research is needed on many aspects relating to HIV/AIDS Boyd-Franklin, Steiner and Boland (1995, p. 297) identify “research concerning the family as a whole” and “research concerning psychosocial/behavioural interventions or strategies to help children and families” as gaps in the literature. The present study sought to broaden and build on research that already exists in relation to families in the field of HIV and AIDS. While many studies have been conducted on individuals living with HIV/AIDS, this study explores how their families are coping with it alongside them and how they provide support to their loved one.

Through this study, the researcher aimed to gain an understanding of the role of the family in dealing with HIV/AIDS and explore how family support impacts an individual living with HIV/AIDS. The researcher also sought to assess gaps at societal level in addressing HIV/AIDS that prevent families from supporting their HIV positive members. In this vein, Palattiyil and Chakrabarti (2008, p. 885) state that “there is an on-going need for long-term commitment and capacity building for family carers in the fight against HIV/AIDS. Understanding how they cope and what they need to do more effectively, may help to bring about the changes necessary to support this key resource in the fight against HIV/AIDS.”

The researcher has witnessed how families are impacted by the HIV/AIDS diagnosis of a loved one on an emotional, physical and spiritual level. “HIV and

AIDS continue to affect entire family systems in South Africa so much so that when a family member is diagnosed with HIV and AIDS, the impact radiates across the entire family system” (Bor, Miller, & Goldman as quoted in Iwelunmor et al, 2006, p. 5).

### **1.3 SIGNIFICANCE OF THE STUDY**

The potential outcomes and benefits of this study include assessing existing services and inspiring new service ideas, based on what the research participants shared. These services would work with the infected and the affected, as well as promote awareness and education in the community.

This study also sought to understand the importance of family support through the eyes of individuals living with HIV and AIDS as well as the family’s perspective. The researcher hoped to gain a deeper understanding by listening to the stories of both groups. A once off focus group discussion was also facilitated in order to gain the community’s perspective and thoughts on this topic.

### **1.4 AIMS AND OBJECTIVES OF THE STUDY**

The main aim of this study was to explore how an HIV/AIDS diagnosis in a family affects the family as a whole and to determine the role of the family as a major support system.

Kirst-Ashman and Hull define objectives as “behaviourally specific regarding what is to be achieved and how success will be measured.” (2006, p. 189). Objectives help to achieve the aim/s of a project and should be realistic and measurable.

The objectives that follow from the aim of this study are as follows:

- To explore the family’s understanding, perceptions, attitudes and beliefs about HIV/AIDS and to understand if there have been any changes in these since learning of the diagnosis.
- To explore the support system and the resilience of the family in dealing with HIV/AIDS – both support to the individual living with HIV/AIDS as well as the support they are getting as a family.
- To understand how the individual living with HIV/AIDS perceives the support they are getting from their family and community.
- To determine the challenges experienced regarding support in the midst of an HIV diagnosis.
- To explore available or needed services in the community relating to HIV and AIDS that could aid support.

## **1.5 RESEARCH QUESTIONS**

Research questions are important as “everything we do in the remainder of the research process will be aimed at answering that research question” (De Vos, Strydom, Fouche & Delport (2005, p. 100).

The following main research questions will guide the researcher in completing this study:

1. What are individuals living with HIV/AIDS perceptions of their family's reaction and behaviour towards them being HIV positive?
2. What are families' perceptions regarding HIV/AIDS in general and how did these perceptions change when they discovered that their loved one was HIV positive?
3. What challenges have individuals and families faced in dealing with an HIV diagnosis?
4. What are the barriers to support?
5. What support systems are in place in the community, both for individuals living with HIV/AIDS and families affected by HIV/AIDS?

## **1.6 THEORETICAL FRAMEWORK**

While there are several appropriate theoretical frameworks, for the purposes of this study, the systems theory was utilised.

The systems perspective assisted the researcher to gain an understanding of the support system at a holistic level. As discussed earlier, HIV/AIDS does not only affect the individual living with HIV/AIDS but extends to family, friends and the community. The systems perspective also helped the researcher to explore systems in the community that are or could be in place to empower families confronted by HIV/AIDS in some way.

Kirst-Ashman and Hull (2006, p. 9) define a system as “a set of elements that are orderly and interrelated to make a functional whole”; the system theory “guides social workers to look beyond a seemingly simplistic presenting problem” and to see systems as dynamic and interactive.

According to Goldenberg and Goldenberg, (as quoted in Kirst-Ashman & Hull, p. 2006), the systems perspective enables an understanding of family interrelationships and functioning rather than individual needs and pathology. Embedded in the systems theory is the notion that any event affecting one family member will affect all family members (Kirst-Ashman & Hull, 2006). In this case, being diagnosed with HIV, is not, or should not, therefore be an individual burden. Family members will all be affected by the diagnosis, whether in the emotional, physical or financial sense.

The risk and resilience theory was included under the umbrella of the systems theory as it was used to explore risk and resilience at micro, mezzo and macro levels. Elements of both risk and resilience were found in family support. This model is crucial in exploring the challenges and vulnerabilities confronting both the individual and his/her family (risks) as well as their coping strategies and focus on well-being and survival (resilience). According to the National Network for Family Resiliency (n.d. p. 3), “resiliency is the family’s ability to cultivate strengths to positively meet the challenges of life”; it is “the ability to bounce back from stress and crisis.” The researcher has used this model as a guide and not as a sole method in this study as this might limit the research.

A more detailed discussion of the relevance of the selected theoretical frameworks is provided in chapter 2.

## **1.7 RESEARCH APPROACH AND METHODOLOGY**

It is important for any research study to employ specific approaches and methods in order to create order and to know what to work towards. This section discusses the research design, the samples, sampling method and data

collection method as well as the method of data analysis used by the researcher.

### **1.7.1 Design of Study**

The research design and methodology that the researcher utilised is discussed briefly here and in more detail in chapter 3. A qualitative approach was deemed appropriate as there was a need to hear the stories of individuals living with HIV/AIDS and their families in order to gain an in-depth and holistic view of the research topic. Answers cannot be fixed as each participant's situation and emotions are different. De Vos et al state that the qualitative research design does not normally follow a specific plan or set of questions as a quantitative research design would, but is more flexible (2005, p. 167). The researcher was flexible in using a semi-structured interview plan so that the interviews could flow naturally and analysis could be completed from the narratives.

The study employed an exploratory and descriptive research design. Exploratory research is "conducted to gain insight into a situation, phenomenon, community or individual" (Bless & Higson-Smith as quoted in De Vos et al, 2005, p. 106). Neuman as cited in De Vos, Strydom, Fouche and Delport (2005, p. 106) note that descriptive research is designed to present a picture "of the specific details of a situation, social setting or relationship, and focuses on 'how' and 'why' questions." It leads to a more thorough and intense study in order to gain a deep description (De Vos et al, 2005, p. 106). The researcher used open-ended questions, and allowed the interviews to flow naturally. She explored different aspects of the participants' lives with them that related to the support that they received.

### **1.7.2 Samples, Sampling method and Data Collection Method**

The sample for this study involved three different categories of people. Firstly, twelve adults (individuals over the age of 18) living with HIV and AIDS were interviewed. Convenient and purposive sampling was used. The researcher gained entry into a rural community where she had access to a centre for disabled individuals. Through the manager, she was able to obtain contacts for her sample. The research sample was convenient and purposive as the individuals and family members interviewed met the criteria set for the study's target group. Participants were either interviewed at the centre or in their homes. The researcher hired two interpreters/translators for the duration of the study.

The researcher also interviewed seven family members related to and living with individuals living with HIV and AIDS, either by blood or marriage. Kulzer et al (2012, p. 167) note that, "Therapists who work with families affected by illness should first learn from the patient who he or she defines as a 'family'". According to Kirst-Ashman (2003, p. 113), "social work with families combines micro and mezzo practice because it involves a small group (i.e., the family) linked by ties of an intimate nature." Family members were also interviewed when their family member living with HIV and AIDS was not able, or did not want to participate in the study, and vice versa.

In exploring how families cope with HIV/AIDS, it was important to define a family in the right context for this study. Family structures in South Africa are diverse and complex. For the purposes of this study, the researcher defined family members as those who were related by blood or marriage to the individual living with HIV/AIDS. This extended to cousins, grandparents and step-parents, as in the South African context, families are rarely nuclear. The researcher used purposive and snowball sampling for this group of interviewees. Again, it was

purposive as the researcher needed to meet the criteria for the defined sample. Furthermore, snowball sampling was used since interviewees could recommend families that were available and willing to be interviewed. “Snowballing involves approaching a single case that is involved in the phenomenon to be investigated in order to gain information on other similar persons... In turn, this person is requested to identify further people who could make up the sample” (De Vos et al, 2005, p. 203).

Finally, a once-off focus group discussion was held with nine community members. It was important to gain their perspectives of family support and to bridge any gaps that may have been left by individual and family participants. The manager of the centre invited community members who were not necessarily directly infected or affected by HIV and AIDS to attend this meeting; in this way, this was convenient and purposive sampling.

The researcher employed a semi-structured interview guide for all three categories of participants.

### **1.7.3 Data Analysis Methods**

According to De Vos et al, data analysis is the process of “bringing order, structure and meaning to the mass of collected data” (2005, p. 333). De Vos, et al (2005) identified the following process for analysing data that the researcher adopted:

1. Planning for recording data
2. Data collection and preliminary analysis
3. Organising the data



4. Reading and writing memos
5. Generating categories, themes and patterns
6. Coding the data
7. Testing the emerging understandings

## **1.8 ETHICAL CONSIDERATIONS**

Social work ethics focus on what is 'right and correct' and values focus on a "commitment to human welfare, social justice, and individual dignity" (Kirst-Ashman & Hull: 2006, p. 14). Social workers are bound by a code of ethics and the researcher made every effort to ensure that these were upheld during the study and that the worth and dignity of the participants were maintained at all times.

The researcher understood that there were ethical considerations to be aware of when conducting this research as the target group was vulnerable to stigma, discrimination and trauma. Study participants chose to participate of their own free will, had knowledge of the research process and were informed that they could withdraw from the study at any point in time. The researcher made plans to counsel and refer the participants – individuals living with HIV/AIDS as well as their families – at any point in the study. Painful issues that emerged from the study were addressed by the researcher who is a trained professional social worker, but were also referred to another social worker in the area for follow-up where this was deemed necessary. Confidentiality was of the utmost importance in order to protect all participants.

Due to the nature of this study, participants were exposed to questions which may have triggered memories or negative emotions. In order to minimize any potential stress, the researcher was sensitive and ensured that the participants

knew that they could stop or slow the interview down at any point. The researcher ensured that any participants who were in need of counselling received it, either by her or through referral. The researcher understood the sensitive nature of this study and made every effort to ensure that participants were not exposed to stress.

## **1.9 DEFINITION OF KEY TERMS**

### **HIV**

HIV is the acronym for the Human Immunodeficiency Virus. “The defenders of our immune systems (the CD4 or T helper cells) have no way of defending us against the HI virus” (Van Dyk, 2008, p. 10). HIV is transmitted through blood (sharing needles etc), body fluids (unprotected sex) and mother-to-child transmission: either to the baby during pregnancy through the placenta, during birth via blood or through breastfeeding (Van Dyk, 2008).

### **AIDS**

Van Dyk (2008, p. 4) notes that AIDS is the acronym for the Acquired Immune Deficiency Syndrome, which is caused by the HI Virus.

### **SUPPORT**

Van Dyk lists a number of things that are important for the supporter to do. These include helping the patient access his/her medication and take it on time, building trust with the patient, maintaining confidentiality, being responsible and reliable and accompanying the patient to the clinic (2008).

## **1.10 OUTLINE OF THE DISSERTATION**

This dissertation is structured as follows:

### Chapter 1: Introduction

This chapter introduced the study and outlined its aims and objectives and rationale as well as providing a brief introduction to data analysis and the theoretical framework.

### Chapter 2: Theoretical Framework and Literature Review

This chapter presents the theoretical framework that the researcher used for the purposes of this study. A full literature review is also undertaken in this chapter.

### Chapter 3: Research Methodology

This chapter provides an in-depth discussion of the research methodology (research design and methods).

### Chapter 4: Results and Discussion

The data analysis and the findings that emerged from the interviews for this study are presented in this chapter.

### Chapter 5: Conclusions and Recommendations

This chapter summarises the main points of the study and presents recommendations. It also makes suggestions for further research.

## **CHAPTER 2**

### **THEORETICAL FRAMEWORK AND LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

This chapter discusses the theoretical framework utilised for the study and provides a review of related literature. The researcher chose to combine these aspects of the study in one chapter, as the theoretical framework forms the umbrella for the literature review. The purpose of including the literature review in this chapter was also to show how it links with the systems theory and the risk and resilience theory that underpinned the study. The theoretical framework will be discussed first, and then the literature review will be presented under the headings from the systems theory – micro, mezzo and macro. This relates to the principles of the systems theory, which is interactive and relational.

#### **2.2 THEORETICAL FRAMEWORK**

The researcher employed the systems theory as well as the risk and resilience theory to provide a theoretical framework for the study. The purpose of using two theoretical frameworks was that they complement each other, allowing for holistic exploration of the research questions.

The systems framework was employed to organise the theory in which to discuss the risk and resilience model; in this sense, it was the umbrella framework. Captured in the systems theory is the risk and resilience theory which assisted the researcher to understand the specifics behind the topic and to process data that emerged from the study. The researcher therefore

discusses concepts relating to the systems theory less than the risk and resilience theory, as the latter narrows down the former and examines the specifics.

### **2.2.1 Systems Theory**

The “systems theory does not specify particular theoretical frameworks for understanding problems, and it does not direct the social worker to specific intervention strategies. Rather, it serves as an organising conceptual framework or meta-theory for understanding” (Meyer, as quoted in Friedman & Allen, n.d., p. 3). As noted earlier, this is part of the rationale for using the systems theory as a base from which to work; as Meyer states, it is an “organising conceptual framework or metatheory”.

“Systems theories focus on the dynamics among and interactions of people in their environment”, and “a system is a set of elements that are orderly and interrelated to make a function whole” (Kirst-Ashman, 2003, p. 17). The systems theory is a holistic approach which views systems as inter-linked and constantly interacting. It is an important approach when assessing the person-in-environment and considering all spheres that they might interact with.

The systems theory is understood in relation to micro, mezzo, and macro levels of intervention. The researcher is aware that the exo system is also applied in some contexts and used by some authors. However, for the purposes of this study, the exo system has not been targeted in line with how Kirst-Ashman and Friedman and Allen cited above, define the systems theory.

Friedman and Allen assign individuals and couples to micro systems, groups and extended families to mezzo systems and communities and organisations to macro systems (n.d., p. 7). As Kirst-Ashman suggests, due to their sensitive nature, families lie in between the micro and mezzo systems (2003, p. 17). Therefore, the researcher worked with individuals as the micro system, families as part of the mezzo system and communities falling under the macro system.

The systems theory assisted the researcher to organise the research and view the micro, mezzo and macro levels as inter-linked. The individual living with HIV/AIDS would affect and/or be affected by family members, and the support offered between the two was explored. The services and resources available in the community to support individuals living with HIV and AIDS and their affected families, as well as gaps within them were explored with participants. This demonstrates that all levels within the systems theory were engaged in this study, therefore examining the research topic in a holistic manner, while remembering that all systems are linked and have an influence on one another. Research questions based on all levels of the systems theory were formulated to guide and provide structure to the research topic.

Included in the systems theory is the idea of the ecological environment and that “human development cannot be seen in isolation but must be viewed within the context of the individual’s relationship with the environment” (Friedman & Allen, n.d., p. 9). The researcher chose to interview individuals living with HIV/AIDS, as well as their families and community members in order to ensure that individuals were not viewed in isolation, but rather perceived as part of a system – interacting with their families and the community. For this reason, participants consisted of individuals living with HIV/AIDS and their family members as well as community members. The support offered by the community was also explored. This enabled an objective, in-depth study to be conducted.

The systems theory allowed the researcher to connect individuals, families and the community as a whole and thus gain a holistic picture.

### **2.2.2 Risk and Resilience Theory**

The researcher explored risk and resilience concepts that related to this study that fell within the micro, mezzo and macro levels of the systems theory discussed earlier.

Silberberg and Walsh, as quoted in Greene (2007, p. 30), state that

*“risk and resilience theory has helped to move the field of family therapy from a focus on family problems to a focus on the processes that emphasise family strengths, such as family assets and community resources that can enhance family functioning.”*

This emphasises the importance of looking beyond family problems (in this case, exploring the gaps in family support and the services available to individuals and families), and focusing on positive support for both individuals and families living with HIV and AIDS. Exploring the support that families provide for their loved ones living with HIV and determining what is helpful in terms of family and community support is important in order to determine the strengths and weaknesses of these systems.

According to Greene (2007, p. 44), risk is “a concept that examines the probability that a person who has experienced a critical life event will encounter future difficulties. *Risk factors* may be internal biological conditions, such as low-birth-weight, or external environmental factors, such as poverty.” Greene adds that, in practice, “risk factors contribute to client stress and lessen coping strategies” (Greene, 2007, p. 45). In terms of this study, individuals living with

HIV/AIDS are at risk due to their diagnosis and their vulnerability to other factors as a result of this diagnosis such as stigma, poverty, ill health etc. This risk may be increased by factors such as those listed by Greene, or by the absence of family and/or community support.

Greene also notes that, resilience refers to “people’s internalised capacities and the associated behaviours that enable them to maintain a sense of integration in the face of adversities” (2007, p. 45). Resilience can take three forms (Greene, 2007, p. 45). These are:

1. “Recovering from trauma following adverse effects”;
2. “Overcoming the odds or negotiating life transitions with competence”;
3. “Overcoming life stress, or successfully handling events that are perceived as harmful”.

Germain and Gitterman define resilience as, “the tendency to rebound or recoil, to return to prior state, to spring back” (2008, p. 66). Resilience is essential in order for individuals and their families to not only cope with adversity, but also to recover and be competent to face challenges and deal with stress, as noted by Greene (2007). Resilience means not giving up when faced with hardship and adversity, but rather using adversity as an opportunity for growth.

Stress is one result of being at risk. Greene states that, “stress may be acute as in a sudden event, or it may be chronic as in the wear and tear of the difficulties of everyday life” (2007, p. 47). Given the implications of the disease, individuals diagnosed with HIV/AIDS and their families are likely to experience some form of stress.



Richardson's resiliency model, as quoted in Greene, states that, resilience occurs when a person "has adapted physically, mentally, and spiritually to a set of circumstances whether good or bad". However, Greene notes that when stress occurs, it can affect the balance that Richardson's model refers to, and present challenges as well as opportunities (2007). Greene does not believe that stress only creates challenges and obstacles, but is of the view that it also has the potential to promote growth and future opportunities.

Greene also emphasises that resilience is a process, from the time when a person identifies a stressor to when they are motivated to set goals and move forward (2007). It takes time to build resilience. In the researcher's experience, every individual copes with adversity differently and at the same time, has different levels of resilience. Individuals, who were diagnosed with HIV many years ago, may have an increased resilience level as they have had time to adjust and become resilient; as Greene observes, resilience is a process.

Greene states that:

*"the assessment of social functioning following adverse effects centres on how well an individual forms relationships with others as well as the extent of his or her support systems. Social supports may be tangible – offering food, shelter, transportation, or child care – or intangible – giving a word of encouragement or advice. A client's self-perception of his or her social supports is among the most critical aspects of assessment. Social workers will want to know whom clients perceive as available and what they may provide" (2007, p. 53).*

Support systems were explored in this study and the factors of risk and resilience were enmeshed in this. This included support offered by family members as well as support measures that were perhaps limited or not functioning.

Greene lists basic human assumptions about the risk and resilience theory (2007, p. 58). Included in this list, which tie in with this study, are the following:

Risk and resilience:

- Focuses on an individual's capabilities in the midst of difficulties
- Looks at stress in the individual's life and what can be done to alleviate it
- Seeks to understand behaviour at the *micro*, *mezzo* and *macro levels*
- Explores an individual's coping mechanisms in the past
- Is a holistic approach
- Considers the individual as striving towards growth
- Views spirituality as an important aspect contributing to resiliency
- "Attends to the systemic, resilient properties of family, school, community, and society."

This demonstrates that the risk and resilience theory was appropriate for this study. In line with Greene's basic human assumptions, the researcher explored support structures at a micro, mezzo and macro level, and examined the strengths of the family and community. It is important to note that it is difficult for individuals to receive support from their families and the community if they are not open to it. In order for their families to be motivated and empowered to support them, they themselves, as well as their families, need be resilient. Family and community support may also relieve the individual (and family) living with HIV/AIDS from some of the stress and burdens that they carry.

The link between resilience and family support is also important; Greene observes that the risk and resilience theory "centres on the relationship between resilience and people's attachment to others as well as to their support systems" (2007, p. 58). It would therefore appear that resilience is not a purely individual matter, and that family and the community play a major role in supporting and encouraging one to be resilient.

Greene notes the importance of community support for an individual or family that is facing adversity and adds that, without community support and interventions, intervention with the individual and the family is much more difficult (2007, p. 61). The researcher concurs and cannot overemphasise the importance of the community backing the individual or family that is facing difficulties. While the family can support an individual living with HIV and AIDS to a certain extent, the community can provide resources and services and support them. Stigma is debilitating and can hamper family and community support. It needs to be replaced with support and acceptance from both the family and the community.

The researcher chose the risk and resilience model as it was appropriate and applied to the context of this particular study. The 'risk' in the model could be support structures for the individual and/or the family that are missing, or not complete. The 'resilience' refers to how the individual and family are coping with HIV and AIDS; the support and coping mechanisms they have to help them during this adversity.

Risk, in this study, featured as gaps in the support that the family was providing for individuals living with HIV and AIDS, as well as gaps in resources and services available to individuals and families affected by HIV and AIDS. An example of risk is families not being able to support their loved ones living with HIV/AIDS on an emotional level and discriminating against them. This would place the individual at risk, as emotional support and acceptance of a diagnosis is important; without it, individuals may become disheartened or experience negative emotions, thereby decreasing their coping abilities and resilience.

Resilience can be found in individuals living with HIV/AIDS as well as in families affected by HIV. Support systems play a major role in the resilience of

individuals living with HIV and AIDS, and the community can assist both individuals and families in this way.

## **2.3 CONCLUSION**

The systems theory and the risk and resilience theory are both useful theoretical frameworks for this study. It was necessary to employ both theories as they build on each other. These theories have been linked and the connections between them have been demonstrated. The systems theory was used to organise the study, while the risk and resilience theory looked at the specifics of this theory.

## **2.4 LITERATURE REVIEW**

The purpose of a literature review is to gain a clear understanding of the nature and meaning of the problem that is being studied (De Vos et al, 2005). Neuman, as quoted in De Vos et al, states that “a good literature review places a research project in context – it shows the path of prior research and how the current project is linked to the former” (2005, p. 125). The researcher consulted the relevant literature in order to gain a deeper understanding of the topic, explore gaps in the literature, some of which this study addresses, and compare the findings of the study with previous studies.

The literature is explored under the headings of the micro, mezzo and macro levels. While a fourth level, the exo system could be included in the systems theory, for the purposes of this study, risk and resilience concepts were explored through the micro, mezzo and macro systems. Different levels may

intersect at times and this will be noted when it occurs. The purpose of compiling the literature in such a way is to clearly show how the theoretical frameworks that the researcher used interlink with the theoretical concepts that are relevant to the study.

## **2.5 HIV/AIDS IN SOUTH AFRICA**

In 2008, 15.8% of the KwaZulu-Natal population was HIV positive; a 2010 survey showed that HIV and AIDS infection is higher among pregnant women in KwaZulu-Natal (39.5%) than any other province in the country (HIV/AIDS in South African Townships, 2012). Ndinga-Muvumba and Pharoah (2008, p. 3) state that in 2004, KwaZulu-Natal had the highest HIV/AIDS prevalence in South Africa. These statistics illustrate the need for continued research in this field. This study was conducted in a rural community in KwaZulu-Natal.

According to the Global Report for UNAIDS (2012), 2.5 million people were infected with HIV in 2011, and in the same year, approximately 1.7 million died from AIDS-related illnesses worldwide – a decrease from 2005. In 2011, 34 million people were living with AIDS (Global Report UNAIDS, 2012).

“South Africa has experienced one of the most rapid growths in HIV infections in the world,” (Baxen & Breidlid, 2009, p. 100); hence ongoing research is required to explore different aspects of the epidemic. Such research will enable individuals, families, communities and the state to keep up-to-date on current issues surrounding HIV and AIDS.

Baxen and Breidlid observe that,

*“The reasons for the rapid spread of HIV in South Africa are many and complex. They include high levels of poverty and income inequality, high levels of other sexually transmitted infections (STIs), a predominant patriarchal system that ascribes a low status to women, sexual activity at early ages, multiple sexual partners, unprotected sex, sexual violence, and lack of communication about sexuality between parents and children” (2009, p. 100).*

Baxen and Breidlid also discuss the impact of HIV and AIDS in South Africa:

*“where six million people (out of a population of 46 million) are HIV-positive, where life expectancy has dropped to 52 years, where more than half of all public hospital admissions are AIDS related and more than a quarter of the national health budget is going towards the disease, this country cannot afford ineffective and inefficient strategies and responses” (2009, p. 117).*

As the statistics demonstrate, while HIV and AIDS is a global challenge, prevalence rates are particularly high in Southern Africa and in KwaZulu-Natal specifically. HIV and AIDS is a global epidemic, and there are many different aspects of this epidemic that can be studied.

The South African Department of Health reported that between January and October 1989, 64 cases of HIV/AIDS were officially diagnosed in South Africa; by 2007, more than five million South Africans were living with HIV/AIDS, with an estimated 1 400 people becoming infected each day (Ndinga-Muvumba & Pharoah, 2008, p. 63).

## **2.6 MICRO SYSTEMS**

### **2.6.1 HIV and AIDS**

According to Pequegnat and Szapocznik, AIDS mainly affects people between the ages of 25 and 44; individuals in their most productive years who have a long life ahead of them.

*“Africa best illustrates the devastation of AIDS for families and economies when people in their most productive years are struck down. In some African villages, there are primarily grandparents and children because the parent generation has died of AIDS” (2000, p. 4).*

Individuals living with HIV/AIDS and their families face challenges in their lives over and above that of the virus, including unemployment, poverty, discrimination, crime and alcohol abuse (Brincks, Feaster & Mitrani, 2010, p. 525).

### **2.6.2 Disclosure**

Serovich, Craft and Yoon (2007, p. 970) describe HIV disclosure as a sensitive issue which often causes stress and anxiety due to uncertainty about how others will react. Partners, family members and friends are usually the main source of support; however, this is not always the case. Due to the stigma and discrimination surrounding HIV and AIDS, relationships may be impacted significantly (Serovich, Craft & Yoon, 2007).

Individuals need to weigh the advantages and disadvantages of disclosure and who they are willing to disclose to. People diagnosed with HIV/AIDS need to disclose in order to receive support. However, the risk of stigma and discrimination means that disclosure may be limited; for example, only telling one's close family.

A study conducted in Gauteng among HIV-positive women found that all of the participants kept their HIV status secret for at least two years after being diagnosed (Walker, Reid & Cornell, 2004, p. 102). This demonstrates the lengths individuals will go to in order to protect themselves from stigma and discrimination. However, this means that they bottle up their emotional pain.

Kulzer et al stress the importance of disclosure, noting that it has important benefits which include access to social support, building stronger relationships, improving treatment adherence and reducing the risk of spreading HIV (2012). However, the challenges and obstacles involved in disclosure (Kulzer et al, 2012, p. 2) may include stigmatization, violence and abuse, being treated differently and being isolated.

### **2.6.3 Stigma**

Walker, Reid and Cornell examine the negative household and community experiences that people living with HIV and AIDS may have. Disclosure may elicit a hostile response from family members. Experiences may include being isolated, being told to use separate cutlery and crockery, being relieved of household chores, feeling rejected, and interactions with other family members being restricted (2004).



Makoe et al cite The Insideout Research Report which observed that, “HIV-infected participants who experienced supportive environments, such as support of families, religious faith groups, non-governmental organizations such as an AIDS support group, AIDS training, and counseling centers, had success in overcoming internal stigma” (2007, p. 7). This demonstrates the importance of a supportive environment, both within the family and the community.

“Stigma, denial and fear of rejection continue to impede HIV testing, and along with limited access to care and treatment services, act as barriers to engaging in medical care for those who test HIV positive” (Kulzer et al, 2012, p. 1). The researcher has observed that some clinics in KwaZulu-Natal have a separate section marked for HIV and AIDS care. Anecdotal evidence suggests that people have reservations about visiting these clinics for check-ups or treatment, as community members are aware that if one goes to that section, they are living with AIDS. People are also afraid to test for HIV and AIDS, and are in denial that they might be HIV-positive.

#### **2.6.4 Rape and AIDS**

Rape and sexual violence are important issues when conducting research on HIV and AIDS. Bezuidenhout (2004, p. 153) defines rape as “sexual intercourse without the consent of one of the parties, who is usually a female.” HIV/AIDS can be one of the consequences of rape.

The ‘HIV/AIDS virgin cure’ myth is described by Meel as follows: “the HIV/AIDS Virgin cure, sometimes known as the ‘virgin cleansing myth,’ is the belief that having sex with a virgin will cure and/or prevent a person from developing AIDS” (2003, p. 86). Meel presents the case of a nine year old girl who was a

victim of this myth. Her uncle, who was living with HIV/AIDS, sexually assaulted her. According to Meel, this myth is most prevalent in the former Transkei community in the Eastern Cape, where this incident occurred. The researcher wonders about the relevance of this latter statement today, given the current numerous reports of rape of children and babies.

In a patriarchal society, women and children are vulnerable and often oppressed, making them more vulnerable to sexual abuse and rape and therefore more at risk of contracting HIV and AIDS. "Women and girls' relative lack of power over their bodies and their sexual lives, which is supported and reinforced by their social and economic inequality makes them more vulnerable in contracting and living with HIV/AIDS" (Human Rights Watch, as quoted in Hinga, Kubai, Mwaura & Ayanga, 2008, p. 3). "Many women and girls face the threat of violence and abuse from their intimate male partners on a daily basis and many face additional abuse when they refuse sex or demand safer sex" (Ndinga-Muvumba & Pharoah, 2008, p. 67).

Bezuidenhout identifies two phases experienced by female rape victims: disorganisation and reorganisation. The disorganisation phase includes the physical pain after the rape as well as stress and emotional pain (Bezuidenhout, 2004, p. 160). "In the phase of reorganisation, the victim tries to resolve feelings of guilt and fears that were generated by the trauma of the assault, and to rebuild a safe physical, emotional and social environment in which to function" (Burgess & Holmstrom as quoted in Bezuidenhout, 2004, p. 160). Apart from these effects, the victim may also contract STDs as well as HIV/AIDS, and may fall pregnant.

Ndinga-Muvumba and Pharoah note that accurate rape statistics are not available for South Africa as many cases go unreported. However, South Africa

has the highest number of reported rape cases in the world (2008, p. 48). This has implications for HIV and AIDS prevalence.

## **2.7 MEZZO SYSTEMS**

### **2.7.1 Family**

Defining the family in the context of HIV and AIDS is not easy. In this context, the definition may include blood relationships or a common household (Bor, Miller & Goldman, 2004). Pequegnat and Szapocznik state that due to AIDS, families have crossed the nuclear family boundary and now include extended family members, foster parents, friends and partners as well as non-blood relations (2000, p. 4).

The current study found that many participants viewed those who support and accept them as family. Extended family members (aunts, grandmothers etc, whether biological or distant) and even friends form families in this era of HIV and AIDS. However, for the purposes of this study, the researcher defined families as those who were related through blood or marriage so as not to skew the results when analysing family support. Brincks, Feaster and Mitrani concluded that their study, discussed earlier, was limited by the fact that their definition of family was too broad and included partners and friends (2010, p. 527). They found that this might have biased their results. The present study sought to avoid such bias.

“HIV and AIDS is a disease that affects the entire family system. Despite the growing burden of this disease on family systems, families in South Africa

remain remarkably resilient in determining existential ways to cope with HIV and AIDS” (Iwelunmor et al, 2006, p. 3). Families form a major support structure for individuals living with HIV and AIDS; indeed, it is remarkable to observe how, even with very limited resources, families can step up to the plate and unite to support one another.

“There are also issues of the family in relation to its social environment, such as social stigma if extended family, friends, and neighbours find out about the HIV status; relationship between family of origin, on one hand, and family of choice and friends, on the other; and relationship between the various aspects of family and the health care system” (Pequegnat & Szapocznik, 2000, p. 15). This demonstrates the extent of the difficulties families may face in dealing with HIV and AIDS. How well they cope may depend on the nature of their relationships with other family members, friends, and the broader community.

Davey, Foster, Milton and Duncan criticise intervention models for constantly focusing on individual needs and interventions, instead of looking at the family as a whole; they note that “families live with HIV” (2009, p. 40).

### **2.7.2 Family Support**

Bor, Miller and Goldman stress the benefits of family support, observing that, “studies of social support and emotional well-being have demonstrated that people with AIDS report fewer feelings of depression and helplessness if they have close friends or relatives to talk to about emotional and illness-related problems”. Interestingly, mothers and close friends have been found to be the most supportive (2004, p. 194). The literature as well as anecdotal evidence from the researcher’s practical experience shows that family support is crucial in order for individuals living with HIV/AIDS to feel positive about life and decide to

live it to the fullest. If individuals are stigmatised and discriminated against within their own families, the burden of living with HIV/AIDS is that much greater.

According to UNAIDS, “almost universally, families provide the bulk of care and support for persons living with HIV/AIDS” (as cited in Palattiyil & Chakrabarti, 2008, p. 881). Palattiyil and Chakrabarti examined the experiences, coping strategies and mental well-being of the caregivers of people living with HIV/AIDS in Kerala, India. A lack of resources made the task of caring for family members living with HIV and AIDS more difficult since “the success of the family’s coping efforts may depend on the resources available to the family” (Palattiyil & Chakrabarti, 2008, p. 884). The researcher believes that this is a global pattern. The current study was conducted in a rural community with few services and resources; where they exist, the community is unaware of them. A lack of resources can make supporting an individual living with HIV/AIDS more stressful, as basic needs are not able to be met. Problems such as poverty, unemployment and alcoholism can increase the burden of HIV and AIDS on individuals as well as their families.

“All therapeutic interventions with families coping with AIDS must begin with the concept of empowerment” (Boyd-Franklin, Steiner & Boland, 1995, p. 117). The authors view empowerment as giving families tools to complete interventions themselves, instead of helping, which is doing something *for* another person. It is important for people to gain mastery over their lives and to feel good about it. The researcher concurs with this viewpoint. Family members need to be empowered to support one another.

Rojano’s Community Family Therapy Model (2004) emphasises the importance of people taking responsibility for their own lives and being empowered, rather

than simply 'helped' (Rojano, 2004). However, Rojano observes that this would be easier in a world where there was equality and fairness; the realities of social oppression are evident. Therapists need to build their clients' capacity to assume mastery over their own lives, to take care of themselves (Rojano, 2004, p. 37) and then serve others. The researcher believes that it is important for families to serve as support systems to others and for them to empower their loved ones.

"When a person is in a 'social hollow,' with little social support and no leadership role, he or she may feel so disempowered and overwhelmed that he/she lacks the energy or motivation to take action" (Rojano, 2004, p. 37). This emphasises the importance and benefit of a solid support structure. Being supported and assuming a leadership role would assist individuals to feel motivated and encourage change. For example, people living with HIV and AIDS might be able to share their stories with the community, spreading awareness and reducing stigma while building their own confidence and self-esteem.

"Issues related to unresolved grief, shame, pain, anger, frustration, and hopelessness need to be deconstructed, proposing new paradigms that not only help reframe past and present realities but also promote forward movement" (Rojano, 2004, p. 32). The Community Family Therapy model encourages people to deal with past challenges and hurts by not letting them control one's future. As Rojano notes, while deconstructing such challenges is important, so is moving on with new ideas and feeling encouraged and empowered for the future.

Boyd-Franklin, Steiner and Boland also note that, "support for families through the bereavement period after the AIDS-related death of a child or another family

member is often lacking because of the stigma and secrecy surrounding AIDS” (1995, p. 191). While it is important for families to support those living with HIV/AIDS, it is also crucial that the same families receive support, whether in coping with a loved one living with HIV/AIDS or having to deal with grief at the loss of a loved one. This is where the community needs to step up and provide support to families. As Boyd-Franklin, Steiner and Boland state, however, stigma and discrimination often render it difficult for families to ask for help and to reveal why they need such assistance.

“Multiple problems create obstacles and challenges for families attempting to cope with AIDS, including: geographical distance, competing demands for family members’ time, energy, or other resources; lack of knowledge about how to be helpful, and a history of negative interactions” (Pequegnat & Szapocznik, 2000, p.15-16). Nuclear families are not very common in modern South Africa, and family members are often geographically dispersed, making supporting a loved one living with HIV/AIDS more difficult. At the same time, families are not equipped to cope with the effects of AIDS; Pequegnat and Szapocznik observe that supporting an individual or family demands time and energy. Other difficulties confronting families include complex medical management, the disruption of family roles and routines and concern about the family’s future (Pequegnat & Szapocznik, 2000, p.16). Palattiyil and Chakrabarti (2008, p. 881) state that supporting a family member living with HIV can place strain on a family’s physical, emotional and financial resources; and that family members often provide support with little or no help from the community. These are some of the multiple challenges and burdens faced by families caring for a person living with HIV/AIDS.

AVERT states that families are generally the primary caregivers when an individual falls ill, and that they are the primary source of support for people living with HIV and AIDS (n.d., p. 7). However, AVERT also notes that not all

family systems are supportive; individuals living with HIV and AIDS may find themselves discriminated against and stigmatised within their own home (n.d., p. 7). While many families support, love and understand their loved ones living with HIV/AIDS and it is crucial that such family members receive support, support within a family is not always realistic. As AVERT observes, individuals can be stigmatised in their own homes; as the home should be a place where they feel safe, this severely impacts their well-being.

Brincks, Feaster and Mitrani (2010, p. 517) state that “to date, many studies have focused on modelling the stress and coping process for the individual, isolated from the family.” Brincks, Feaster and Mitrani’s study sought to establish a cross-sectional stress and coping model for HIV-positive African-American mothers (n=214) and their family members (n=294) (2010, p. 517). One finding of this study was that individuals living with HIV and AIDS are not only affected by their own stressors and burdens but those of their families (p. 525). This confirms the need to include the family and community, working from a systems perspective.

### **2.7.3 Stress and Coping**

Stress is commonly seen in families attempting to cope with a family member’s HIV/AIDS diagnosis. Bor, Miller and Goldman (2004, p. 192) state that “stress is commonly seen in family members who may react to news of the diagnosis with disbelief, shock and confusion” and feelings of guilt, helplessness, hurt, anger and confusion.

“Given the scope and uncertainty of the challenges they face, families affected by AIDS need flexible coping skills that can be applied to a variety of



circumstances” (Pequegnat & Szapocznik, 2000 p. 214). This links to the concept of empowerment through the Community Family Therapy Model. Families need to be educated and empowered so that they can empower their family member living with HIV/AIDS, and be able to cope and manage effectively as a family.

Germain and Gitterman identify four main sources of support that are essential for protection and coping (2008, p. 65):

1. Instrumental (goods and services)
2. Emotional (nurturance, empathy and encouragement)
3. Informational (advice and feedback)
4. Appraisal (information relevant to self-evaluation)

It is important to note that only one type of support should not be privileged. All forms of support are important in the HIV and AIDS journey. As Germain and Gitterman note, meeting financial needs, being able to speak openly and have someone listen to you, being able to receive advice based on love, and evaluation and feedback are all important aspects of support.

#### **2.7.4 HIV and Poverty**

According to Walker, Reid and Cornell, “HIV/AIDS places an already economically vulnerable group at greater risk” for the following reasons (2004, p. 118):

- If the family breadwinner is living with HIV/AIDS, he or she may not be able to work any longer, or may die, leaving other family members to fend for themselves. Many individuals living with HIV/AIDS are adults in their productive years.

- The nutritious and healthy food required to boost the immune systems of those living with the virus is expensive.
- Funeral costs are high in South Africa and traditional burials can be expensive.
- When parents are ill or die, grandparents shoulder the burden of caring for their grandchildren.

“Given high levels of poverty, substance use, unemployment, and poor health care, at any given time, AIDS-related problems may not even be the most pressing for these families” (Smith, as cited in Pequegnat & Szapocznik, 2000 p. 18). While HIV and AIDS is rife in poverty-stricken communities, it may not be the only burden families carry; meeting basic needs may be the priority. Kasiram (2011, p. 3) states that “the effect of loss to HIV and AIDS is devastating to many sub Saharan countries that struggle with the twin injustices of poverty and prejudice.” This demonstrates the impact that compounding factors such as poverty and prejudice can have on an already devastating disease.

### **2.7.5 Stigma**

Social isolation can also result from the stigma around HIV and AIDS (Bor, Miller & Goldman, 2004, p. 191). Families affected by HIV and AIDS may build walls between themselves and others in the community as well as extended family members by choosing not to disclose their family member’s status (Bor, Miller & Goldman, 2004, p. 191). Ngcobo (2011) found that some participants chose to only disclose their status to a limited few within their family, while others disclosed to all family members as well as the broader community.

Families where one or more members are living with HIV and AIDS face discrimination and stigmatisation. Davey, Foster, Milton and Duncan found that, in Nigeria, when a family member is living with HIV/AIDS, the whole family is termed an “AIDS family” (2009, p. 40 as quoted by Alubo, Zwandor, Jolaemi & Omudu).

“Too often, many HIV-infected children and their families live in a ‘conspiracy of silence’ because of the stigma and shame associated with AIDS, as well as related issues and risk factors” (Boyd-Franklin, Steiner & Boland, 1995, p. 5). “One disturbing consequence of the ‘conspiracy of silence’ is that families may withdraw, become socially isolated, and become ‘emotionally cut off’ from their traditional support systems” (Boyd-Fanklin, Steiner & Boland, 1995, p .5). This conspiracy of silence prevents families from getting the support they need, as they fear stigma and discrimination.

## **2.8 MACRO SYSTEMS**

### **2.8.1 Stigma**

Stigma is a major problem within communities in South Africa. Due to the many myths surrounding HIV and AIDS, individuals living with HIV and AIDS are often discriminated against and ostracised. In a national survey conducted in 2002, 26% of the participants said that they would not share a meal with someone who was living with AIDS, 18% said that they would not share a room with them and 6% stated that they would not talk to someone with AIDS (HIV/AIDS in South African Townships, 2012).

South African women are vulnerable to infection and stigma as they are often oppressed, financially dependent on men and lack access to education (HIV/AIDS in South African Townships, 2012). While women may be diagnosed when visiting a clinic or hospital for pre-natal testing, men may avoid testing, thus labelling women “spreaders of the disease” (HIV/AIDS in South African Townships, 2012). This can result in abuse and abandonment. Ngcobo (2011) notes women’s susceptibility to being infected, as well as their vulnerability to being discriminated against. Walker, Reid and Cornell state that “in sub-Saharan Africa, 55% of HIV-positive adults are women. In South Africa twice as many women between the ages of 15 and 24 are HIV positive than men in the same age group” (2004, p. 22).

In terms of negative community experiences that people with HIV and AIDS may encounter, Walker, Reid and Cornell describe a study conducted in Mpophomeni and Alexandra where ‘community’ was not seen as an inclusive and supportive environment but rather as one of exclusion and discrimination (2004). Stigma has a significant impact on community-based services and volunteerism.

### **2.8.2 Community Support**

The same study cited by Walker, Reid and Cornell found that the main barriers to community-based support were stigma, fear of AIDS and beliefs about the causes of HIV (2004, p. 101). Community awareness and education are essential to dispel myths around HIV and AIDS and present a realistic view of the epidemic.

### 2.8.3 Services and Gaps in Services

The researcher also explored service delivery in the community.

Welz et al emphasised that, “The extremely high prevalence of HIV suggests an urgent need to allocate adequate resources for HIV prevention and treatment in rural areas” (2007, p. 1467). HIV and AIDS care should be a priority in communities and resources should be made available to provide such care.

*“Programs to assist children, families and communities have proliferated throughout the region as governments, foreign donors, local non-governmental organisations (NGOs) and community-based groups have responded to the plight of affected children... The general picture is one of pockets of local knowledge and experience, but a continued collective ignorance of what the real impacts of AIDS are on children and families, and what the appropriate responses should be in any given context” (Richter, Manegold & Pather, 2004, p. 6-7).*

Richter, Manegold and Pather refer to the role of external agencies in the community and state that, “concern has been growing around the role of external donors and external organisations, and the need to find ways to ensure that external forces support, rather than undermine, the emergence and sustainability of community based actions” (2004, p. 19). The researcher understands this to be closely linked to empowerment (described earlier in Rojano’s Community Family Therapy Model under family and community support); encouraging and maintaining community-based projects is far preferable to services provided by an external agency, where the service is simply given without the involvement of community members. It is problematic when external agencies enter a community and offer a service without exploring

the needs of the community. If community members are involved in planning and executing the support service or project, they will feel empowered, and the real needs of the community will be met, rather than the needs perceived by 'outsiders'.

Altman states that the AIDS epidemic has “produced an extraordinary amount of creativity, political activity and compassionate care at a grass roots level in virtually every country where there exists the possibility of community organising” (1994, p. 6). Communities have found innovative ways to provide services and resources in the face of a shortage of such resources. In this regard, Kanya (as quoted in Kasiram, 2001, p. 6) speaks about the importance of a “critical consciousness” in facing challenges with creativity on the individual, family and community level.

Altman speaks of the term 'community control' which is essentially the community having control, and managing the issues that affect them (1994, p. 9). This is closely linked to empowerment, where the community plays a role in the services that are available, and ensures that they are sustainable.

Furthermore, “The combined efforts of government, Non-governmental Organisations (NGOs), the private sector, churches and communities have not slowed down the rate of infection” (Walker, Reid & Cornell, 2004, p. 19). Although much has been achieved much also remains to be done to combat HIV and AIDS. There is a need for continued awareness and education.

“The scope and scale of the HIV/AIDS epidemic in sub-Saharan Africa is almost beyond belief. The statistics simply do not capture the human tragedy and the hugeness of the challenge facing the subcontinent. Effective intervention from

states, NGOs and civil society has thus become a matter of unprecedented urgency” (Walker, Reid & Cornell, 2004, p. 106).

Walker, Reid and Cornell note that in South Africa, people living with HIV do not have access to adequate health care facilities and welfare organisations and are struggling to cope (2004). They add that there is insufficient research documenting or analysing the effectiveness and impact of community-based services (2004, p. 120).

#### **2.8.4 Education and Awareness**

Myths and false beliefs about HIV and AIDS are prevalent, especially in townships around South Africa as many individuals have not received formal education (HIV/AIDS in South African Townships, 2012). HIV and AIDS is often thought of as a sexual disease, and individuals (mostly women) are labelled ‘easy’ when their diagnosis is made public. It is not taken into account that HIV and AIDS can be contracted through blood and mother to child transmission as well as unprotected sex. Such myths worsen stigma within communities.

“There is currently no law requiring AIDS education in South African schools, and government attempts to raise AIDS awareness have largely failed to reach South Africa’s underserved townships, where the quality of education is poor” (Kuhn, Steinberg & Mathews, as cited in HIV/AIDS in South African Townships, 2012).

Bennell, Hyde and Swainson (2002) stress the importance of educating children about HIV and AIDS from a young age. Kelly (2000, p. 9) states that prevention

is essential and education is a powerful weapon to combat HIV and AIDS. Treating HIV and AIDS and coping at a micro, mezzo and macro level is important, but as Kelly (2000) emphasises, prevention is better than treatment. Children in South Africa need to be taught about HIV and AIDS in an environment that is safe for them to listen and ask questions. AIDS needs to be spoken about so as to reduce stigma and increase awareness. As important as it is to educate children, the researcher believes adults also need to be educated so they can pass the information on to their families and create awareness. Education is a powerful tool that needs to be used effectively to promote an atmosphere of knowledge and change.

#### **2.8.5 Multiple Family Members Living with HIV/AIDS**

In the researcher's experience, more than one family member in a household is often infected with HIV. This increases the burden on families. Pequegnat and Szapocznik state that "coping with AIDS is exacerbated when more than one family member in a household, or even in the close extended family, is HIV infected, including children" (2000, p.18).

"Almost three quarters of 'AIDS-affected' households in South Africa are female-headed, a significant proportion of women are also battling AIDS-related illnesses themselves" (Ndinga-Muvumba & Pharoah, 2008, p. 69-70). As AIDS is rife within South African communities, it is common to find more than one person living with HIV/AIDS in a family. This increases the physical, financial, and emotional burden. However, it might be possible that this situation increases the levels of support, as one family member does not have to walk this journey alone.



## **2.9 CONCLUSION**

This chapter explored concepts and theory related to confronting HIV and AIDS as a family, using the lens of the systems theory. Concepts were divided into micro, mezzo and macro systems to simplify and organise the information. The chapter also illustrated the relevance of the theoretical frameworks that the researcher employed. The research gaps concerning family support were also discussed, therefore highlighting the relevance and significance of this study. The theoretical frameworks and literature review are important aspects of any research study in order to compare and contrast data, explore where the similarities and differences lie and provide a foundation to work from in progressing with the remainder of the study.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

This chapter presents the research methodology utilised for this study. Different aspects of the research methodology are discussed including the research approach, research design, sampling and sampling methods, data collection and data analysis methods. The chapter will also discuss how trustworthiness, validity and reliability of the study were maintained. It concludes with a discussion of ethical considerations and the limitations of the study.

#### **3.2 RESEARCH APPROACH**

This study was based on the qualitative research approach. Qualitative researchers are interested in understanding how others experience life and in interpreting the meaning attached to it (Alston & Bowles, 2003, p. 10). This approach was appropriate as the study sought to record the stories of individuals living with HIV and AIDS as well as their families.

While quantitative research plays a very important role in research in general, for the purposes of this study, there was a need to gain a holistic and in-depth view of the research topic without limiting the data received from the participants. The qualitative approach was also chosen as answers to the research questions in this study cannot be fixed; each participant's situation and experiences were different.

According to Alston and Bowles, qualitative research does not begin with a preconceived idea but is rather based on the patterns and themes that emerge from the participants' experiences and observations (2003). Rather than presenting the participants with a questionnaire or survey where they choose from a set of answers, qualitative research allows participants to present their own thoughts, feelings and experiences; themes and patterns then emerge.

Creswell (2007, p. 37) describes qualitative research as beginning "with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem." Qualitative research highlights the importance of the views, opinions, beliefs and experiences of individuals. It approaches research in a holistic manner, valuing the life stories that participants are willing to share.

### **3.3 RESEARCH DESIGN**

According to de Vaus (2001, p. 9), "the function of a research design is to ensure that the evidence obtained enables us to answer the initial question as unambiguously as possible." The research design used by the researcher throughout this study was a mixture of both exploratory and descriptive approaches.

Exploratory research is designed to "become familiar with a new phenomenon or to gain new insights into it" (Steinberg, 2004, p. 43). The researcher made use of this type of research design as there was a need to explore support systems from the perceptions of individuals living with HIV and AIDS, their families and the community. According to Babbie and Mouton (2001), exploratory studies are open, flexible and inductive as they search for new

insights into phenomena as well as generate new questions and ideas. The exploratory research design was the umbrella design for this study – with the descriptive research design narrowing it down and bringing it all together as discussed below.

As defined by Neuman as cited in De Vos et al (2005, p. 106), descriptive research is designed to present a picture “of the specific details of a situation, social setting or relationship, and focuses on ‘how’ and ‘why’ questions.” It leads to a more thorough and intense study in a field and topic of interest to gain deep description (De Vos et al, 2005 p. 106). According to Babbie and Mouton (2001), descriptive studies aim to describe phenomena. In this study, this was achieved by means of narrative type descriptions (the interviewing process) (Babbie & Mouton, 2001). The descriptive research design was employed to narrow down results from the exploratory component of this study by focusing on specifics. The study posed ‘how’ and ‘why’ questions to gain in-depth data and focus on the participants in a holistic manner.

Both these research designs tie in with the qualitative approach and helped provide a holistic view of participants’ perceptions and experiences.

### **3.4 SAMPLING AND SAMPLING METHODS**

Terre Blanche et al (2006, p. 133) state that, “the process of selecting cases to observe is called sampling.”

The sample for this study involved three data collection methods. The samples were as follows:

1. Twelve adults (above the age of 18) living with HIV/AIDS were interviewed.

2. Seven family members (above the age of 18) related to individuals living with HIV/AIDS, either by blood or marriage, were interviewed.
3. A once off focus group discussion of nine community members (above the age of 18) was held.

Convenient and purposive sampling was used to select the two groups of participants as well as the focus group members.

Purposive sampling “consists of purposely selected elements (people, cases, objects) because of their particular characteristics... such as people with a certain illness or social situation of interest” (Steinberg, 2004, p. 102). This type of sampling was utilised as there was a specific target group - participants who would be able to share their insights and experiences of coping with HIV/AIDS as a family.

Gravetter and Forzano (2011) describe convenient sampling as selecting participants who are available and willing to participate. This was relevant for this study.

The researcher gained entry to a day-care centre for physically and mentally disabled individuals in the community; she was able to use the premises to conduct the interviews. The researcher had a previous working relationship with the manager of the centre. This assisted her to gain entry to the community. The manager of the centre is a well-known and respected community leader who was able to help the researcher to select her sample.

### **3.4.1 Individuals living with HIV/AIDS**

The community leader has a good relationship with community members; she was thus able to identify twelve participants whom the researcher could interview, rendering the sampling procedure convenient. The community leader introduced the researcher, who described the purpose of the study to the participants and asked if they would be willing to be interviewed. The method was also purposive as the researcher connected with individuals who were willing to share their experiences through the community leader and the target group was therefore achieved.

### **3.4.2 Family members related to individuals living with HIV/AIDS**

The researcher also interviewed seven family members related (either by blood or marriage) to individuals living with HIV and AIDS. The researcher was able to gain a sample of individuals and their family members; however, in some cases the researcher was able to interview an individual living with HIV, but not the family member, or interview the family member and not the individual.

The researcher made use of purposive and convenient sampling for this group of participants. Again, it was purposive as she needed to meet the criteria for the defined sample. Snowball sampling was also utilised. According to De Vos et al, (2005, p. 203), “snowballing involves approaching a single case that is involved in the phenomenon to be investigated in order to gain information on other similar persons.” This was used in this study as participants could also recommend other families that they knew who were willing to be part of the study.

### **3.4.3 The Focus Group**

Litosseliti (2003, p. 1) defines focus groups as “small structured groups with selected participants, normally led by a moderator that are set up in order to gain an understanding of participants’ views, attitudes and experiences through group interaction.” The researcher conducted a single focus group discussion in order to gain an understanding of how community members perceive family support in the context of HIV/AIDS. The purpose was to gain an objective view of the perceptions of family support in the community, and to discuss factors such as stigma and myths in the community.

Focus group members were randomly selected by the manager of the centre, but were people who were directly or indirectly affected by HIV and AIDS. After being informed about the study and its purpose as well as the nature of their involvement, the participants signed informed consent forms. Group guidelines were drawn up by the researcher and group members, emphasising confidentiality, respect and openness.

## **3.5 DATA COLLECTION**

Data were collected from all three groups of participants using a semi-structured interview guide. This provided a structure and outline that ensured that the research questions were answered whilst at the same time offering flexibility to explore participants’ insights and opinions, and gain an in-depth and holistic view of the research topic.

Steinberg (2004, p. 107) listed the advantages and disadvantages of using interviews as a data collection method. The advantages include that the

researcher is able to control the process to gain the information that is needed, and issues are able to be addressed and questions and answers clarified; interviews also allow for flexibility. The researcher was thus able to observe the 'person-in-environment' as well as non-verbal communication (Steinberg, 2004, p. 107). The researcher felt that interviewing was the most appropriate data collection method for this study. It enabled the researcher to interact directly with the participants, be able to prompt responses and follow up on the answers given.

The disadvantages identified by Steinberg include the fact that the researcher's presence impacts the interviews and creates bias and that the researcher's personality affects the study (2004, p. 107). Conducting interviews can also be expensive and time consuming (Steinberg, 2004, p. 107). Despite these disadvantages, the researcher felt that the positives outweighed the negatives.

The interviews allowed the researcher to gain a holistic view of family support and listen to participants' stories and experiences. Instead of forcing people into categories that do not fit their experience (Steinberg, 2004, p. 109), the researcher was free to explore information with participants.

Interviews were conducted where the participants were most comfortable. This included the centre, where the researcher was based for the duration of the research, as well as participants' homes. The focus group discussion was facilitated at the centre. Individuals living with HIV/AIDS and family members were interviewed individually so as to maintain confidentiality and create an atmosphere of trust and openness. Informed consent forms were signed by all participants. The interviews and the focus group discussion were all recorded with the permission of the participants.



Use was made of two interpreters during the study. This was essential as this is a predominantly isiZulu speaking community. The researcher made every effort to ensure that this would interfere with the study as little as possible. The interpreters were informed of what would be expected of them before the interviews commenced and a contract was drawn up and signed. The interpreters were remunerated for their services. Confidentiality and accuracy of the translated information was emphasised. The researcher was aware that one translator for the entire duration of the study would have been best. However, the one interpreter had to relocate at short notice and the researcher had no choice but to find another interpreter. However both interpreters were trustworthy and had previous interviewing experience; they were aware of the absolute necessity of confidentiality. The manager of the centre translated the focus group discussion where necessary for the researcher. By using interpreters and taping the interviews, the researcher ensured that the findings were accurately portrayed.

### **3.6 DATA ANALYSIS**

According to Steinberg (2004, p. 120), the purpose of qualitative data analysis is “to understand, interpret and represent the meaning of what has been said.” “Analysis begins by developing clarity about the narrative itself – by understanding the words as said... and continues with some assessment of their greater meaning – the larger stories they tell” (Steinberg, 2004, p. 120). Data analysis is important in order to understand and explore what was said during interviews and ascribe meaning and themes to it.

Alston and Bolwes (2003, p. 204) state, that, qualitative data analysis “usually occurs simultaneously with the data collection phase, in a continuous, cyclical

process.” Analysis is done continuously throughout the research process, collecting the data, organising and finding meaning in it.

According to De Vos et al, data analysis is the process of “bringing order, structure and meaning to the mass of collected data” (2005, p. 333). The researcher decided to use Terre Blanche et al’s (2006) steps for data analysis as they are clear and concise. Terre Blanche et al emphasise that these steps are not fixed but are rather used as a guideline and to unpack the data. They are as follows:

- STEP 1: Familiarization and Immersion

Terre Blanche et al (2006, p. 323) state that it is important for researchers to immerse themselves in the data. This included reading the material repeatedly, making notes and brainstorming. It was important to familiarise oneself with the material.

- STEP 2: Inducing themes

According to Terre Blanche et al (2006, p. 323), inducing themes is a bottom-up approach. It is important to use the language of one’s participants to label themes and categories. Terre Blanche et al state that inducing themes is more than just summarising. It involved finding similarities and relationships, differences, functions and processes. They stress that researchers need to find a suitable number of themes – not too few and not too many. This was achieved by having a certain number of themes, each with sub-themes. While it was important to experiment with themes, the researcher did not lose the focus and direction of the study (Terre Blanche et al, 2006).

- STEP 3: Coding

This entails marking sections of the data that correlate to different themes (Terre Blanche et al, 2006, p. 324). The researcher chose to do this by marking sections of the text in different colours, relating to the different themes. Terre Blanche et al (2006) note that inducing themes and coding work alongside each another and also run into each other.

- STEP 4: Elaboration

Terre Blanche et al (2006, p. 326) state that elaboration involves exploring themes more closely to capture finer meaning that may have escaped during coding and inducing themes. The themes and data that the researcher used were revised in order to ensure that the analysis is thorough (Terre Blanche et al, 2006).

- STEP 5: Interpretation and Checking

This step involves compiling one's interpretation of one's topic and study. It was important to double check that the information fitted in the study and was necessary and objective (Terre Blanche et al, 2006, p. 326).

### **3.7 VALIDITY, RELIABILITY AND TRUSTWORTHINESS**

#### **3.7.1 Validity**

The validity of a study refers to "the extent to which an empirical measure accurately reflects the concept it is intended to measure" (De Vos et al, 2005, p. 160). Gravetter and Forzano (2011) note that this means asking the question: Did the study answer the research questions that it intended to? Honesty and

accuracy are important factors in any research study and it is important to be aware of the validity of the study. The researcher made every effort to ensure that this study was valid, by recording and transcribing correct data and immersing herself in the data in order to check that what she identified as themes and categories accurately represented the views of the participants. The semi-structured interview guide provided a framework for answering the research questions. Data were recorded and transcribed as accurately as possible, and the categorisation of the data into themes and generating results was based on this. Therefore, the researcher is confident that this study has high validity.

### **3.7.2 Reliability**

Reliability refers to “the stability or consistency of the measurement” (Gravetter & Forzano, 2011, p. 82). The researcher ensured that this study was valid and reliable by constantly integrating theory with the study. The research was consistent and the data analysis covered emerging themes from all interviews. McBurney (2000, p. 169) notes that to achieve validity, the researcher needs to make sure that the conclusion or results of the study are true and correct.

### **3.7.3 Trustworthiness**

Qualitative research aspires to trustworthiness, as reliability and validity are generally terms associated with quantitative research.

The trustworthiness of the data was ensured, by hiring a person to interpret and translate for the researcher. The data was also recorded so that it could be translated with no time pressures. According to Lincoln and Guba, (1985, p.

288-331), “recorded materials provide a kind of benchmark against which later data analyses and interpretations could be tested for adequacy.” The interpreters were informed of the nature of the study, as well as its sensitive and confidential nature. Trustworthiness was also ensured by the interpreters repeating and summarising the said information in order to ensure that each participant agreed with what had been recorded. This allowed for errors of fact to be corrected immediately, opportunities for the participants to add to what had been said and for them to confirm that the data had been captured correctly (Lincoln & Guba, 1985, p. 288-331)

According to Babbie and Mouton (2001, p. 276) trustworthiness is concerned with a basic issue: “how can an inquirer persuade his or her audiences (including him or herself) that the findings of an inquiry are worth paying attention to or worth taking account of?”

Trustworthiness will be discussed under the following headings: credibility, dependability, transferability and conformability.

#### a) Credibility

In order to achieve credibility, one needs to ask the questions: “does it ring true” and “is there compatibility between the constructed realities that exist in the minds of the respondents and those that are attributed to them?” (Babbie & Mouton, 2001, p. 277)

According to Babbie and Mouton (2001, p. 277), credibility can be achieved in a number of ways. Prolonged engagement in the area of study is one way. The researcher was able to ensure such prolonged engagement with the community as she had worked there previously and had made contacts. People that she

had worked with previously were familiar with her. Another method suggested by Babbie and Mouton to achieve credibility is triangulation, which they define as to “collect information about different events and relationships through different points of view.” The researcher was able to achieve triangulation by interviewing different sources about family support in the community: individuals living with HIV/AIDS, family members related to someone living with HIV/AIDS and a once-off focus group discussion to gain an understanding of how the community perceives family support. Through the use of triangulation, this study maintained its credibility as multiple sources were studied to explore family support.

Babbie and Mouton add that referential adequacy is also important to maintain credibility. This was achieved in this study by taping the interviews, and using field notes as well as an interpreter.

Engelbrecht (lecture slides) describes credibility as carrying out an analysis in such a way that the findings will be credible and having the analysis approved by the constructors of the themes of the study. The researcher understands credibility as being able to trust that what has been analysed is accurate and that the data is true and correct. Credibility was ensured in this study by hiring translators who interpreted and translated the interviews for the researcher. By discussing the importance of accurate translations and by taping the interviews in order to retain the information as raw data in case there was a need to go back to it, the researcher ensured that all the information analysed was true and correct.

#### b) Dependability

Babbie and Mouton define dependability as follows: “an inquiry must also be able to provide its audience with evidence that if it were to be repeated with the

same or similar respondents (subjects) in the same (or a similar) context, its findings would be similar” (2001).

#### c) Confirmability

Confirmability is “the degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher (2001, p. 278). This includes the use of raw data. The researcher utilised a voice recorder to record the interviews as well as field notes, and ensured that the raw data was written up on the day of the interview. The interpretation was as accurate as possible.

#### d) Transferability

Babbie and Mouton state that transferability refers to “the extent to which the findings can be applied in other contexts or with other respondents” (2001, p. 277). This was made possible by densely describing the research process, sample and results.

### **3.8 ETHICAL CONSIDERATIONS**

The researcher understood how important ethics are in the Social Work profession, as well as in conducting research. She made every effort to ensure that this study was ethical in every respect. The research study was granted ethical clearance by the University of KwaZulu-Natal’s Ethics Committee.

The researcher was extremely aware of ethical considerations when conducting this research study as the target group was vulnerable to stigma, discrimination and trauma. The participants who volunteered to take part in the study did so of

their own free will, were aware of what this study entailed and were made aware that they could withdraw from the study at any time. The researcher also made plans to counsel and refer the participants – individuals living with HIV/AIDS as well as their families – if need be at any point in the study. Painful issues that emerged during the study were addressed by the researcher as a social worker but could also have been referred to another social worker in the area for follow-up, although there was no need for referrals during the study. Confidentiality was of the utmost importance.

Alston and Bowles identify the following five ethical criteria that are important for research (2003, p. 21):

1. Autonomy/self-determination (includes informed consent and confidentiality)
2. Non-maleficence
3. Beneficence
4. Justice
5. Positive contribution to knowledge

With regard to autonomy and self-determination, it was made clear that participating in the study was voluntary and that the participants were free to decline to answer questions and to withdraw from the study at any time. The purpose of the study was explained in depth and informed consent forms were given to all participants to read and sign. Included in the consent form was the purpose of the study, how the researcher planned to conduct it, with whom and the importance of confidentiality and how it was going to be maintained throughout the study.

Non-maleficence is extremely important in any research study. The researcher ensured that no harm was done to the participants. This was achieved by being



aware of the risks from the beginning as well as doing as much as possible to prevent harm. One of the ways the researcher ensured this was to counsel participants when the telling of their stories became traumatic. Referring them to community social workers was also an option but, as noted earlier, there was no need for this.

In terms of beneficence, the researcher made sure that the participants were aware of the purpose and relevance of this study. The participants were conscious of the fact that the study aimed to increase awareness around HIV/AIDS and family support.

Justice tied in with beneficence, ensuring that the purposes of the study were just (Alston & Bowles, 2003, p. 21).

Making a positive contribution was important in order to ensure that the study was worthwhile. According to Alston and Bowles (2003, p. 22), the data must be collected carefully and the correct research design, collection and analysis needs to be utilised. Results and limitations need to be reported honestly and credit needs to be given to other authors that contributed to the study (Alston & Bowles, 2003, p. 22). To the best of her ability, the researcher ensured that all the information reflected in this study was accurate, and was honest about the risks and limitations of the study.

### **3.9 LIMITATIONS OF THE STUDY**

- As the researcher could not understand or speak the participants first language, isiZulu, there was a need for an interpreter/translator. This

may have hampered the research process as data was passed through another source to the researcher. The interpreters were 'trained' in what to expect during data collection. Although the interpreters made every effort to translate what was said during the interviews word for word, some data may have been lost.

- Families may have been hesitant to be completely open with the researcher for fear of exposing their own discrimination; hence answering some questions in the way they thought was 'right', rather than speaking about their reality. The researcher ensured that all participants were aware of the value of the study and guaranteed confidentiality and anonymity in order to promote trust and openness. The focus group discussion was also held to address this limitation to understand community members' perspectives on family support, and promote objectivity.
- Another limitation was that the majority of participants were black South African women; therefore the research may have been biased to this race group and gender.

### **3.10 CONCLUSION**

This chapter presented the research methodology and how it was practically carried out during the study. The researcher adopted a qualitative research approach and convenient and purposive sampling methods. Data collection took the form of interviews with two groups of participants as well as a focus group discussion. Terre Blanche et al's (2006) steps were used to analyse the data. The validity, reliability and trustworthiness of the study were discussed as well as ethical considerations. Finally, the limitations of the study were highlighted.

## CHAPTER 4

### RESULTS AND DISCUSSION

#### 4.1 INTRODUCTION

This chapter presents and analyses the data collected for the study using the steps identified by Terre Blanche et al (2006). After data immersion, the researcher was able to generate themes which are discussed, highlighting similarities and differences with the relevant literature.

As noted earlier, twelve individuals living with HIV/AIDS were interviewed about their experiences of HIV/AIDS and their perceptions of family and community support. In addition, seven family members of individuals living with HIV/AIDS were interviewed on their experiences, thoughts and feelings as well as how they gave support to their loved ones, and received support from the community. To ensure that community members were included in the study, a focus group discussion was conducted to compare individual and family members' perceptions with those of the broader community, building on sample and methodology triangulation as discussed by Terre Blanche et al (2006, p. 287):

*“Triangulation entails collecting material in as many different ways and from as many diverse sources as possible. This can help researchers to ‘home in’ on a better understanding of a phenomenon by approaching it from several different angles.”*

In this study, various data sources and research instruments were used to gain a comprehensive picture of the topic at hand.

The researcher combined all the data from the three sample groups into the same themes and sub-themes in order to maintain continuity; different perspectives were discussed in the different themes. The amount of content within the themes differed depending on the data that was collected from the participants as well as how relevant the specific theme was to the overall research questions. Pseudonyms were used for all participants (in the interviews and the focus group) to protect their identity and preserve anonymity. The following table overleaf provides basic demographic information on the individuals living with HIV/AIDS who were interviewed.

**Table 1: Sample Details of Participants living with HIV and AIDS**

	<b>*Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Employment Status</b>	<b>Year of HIV diagnosis</b>	<b>Current medication</b>	<b>Family members living in household</b>
1	Annie	Female	25	Unemployed	2011	TB medication	Brother & mother
2	Ntokozo	Female	52	Unemployed	2012	Diabetes	Husband
3	Naledi	Female	54	Self employed	2004	ARVs, high BP, diabetes, arthritis medication	Daughter & grandchildren
4	Mpho	Female	36	Unemployed	1994	ARVs	2 children & boyfriend
5	Thembeka	Female	50	Employed	1988	ARVs	2 children
6	Bongi	Female	59	Unemployed	2012	ARVs	1 child & 1 grandchild
7	Mary	Female	23	Unemployed	2012	ARVs	Mother, sister & boyfriend
8	Zanele	Female	32	Self employed	2007	ARVs	Daughter (5 years) and older sister
9	Mrs Radebe	Female	53	Unemployed	2012	ARVs	1 daughter and 3 grandchildren
10	Mrs Ncube	Female	52	Unemployed	2000	ARVs	2 children and 2 grandchildren
11	Pretty	Female	41	Unemployed	2004	ARVs	Mother, 2 children and her sister's child
12	Lungi	Female	26	Unemployed	2008	None	Lives with brother (28) and her child (8)

\*Pseudonyms are used to protect the identity of all participants

As the table above shows, the participants living with HIV/AIDS were all black, female adults between the ages of 23 and 59. The year of HIV diagnosis ranged from 1988 to 2012. The majority of these participants were on ARV medication at the time of the interview. Only one of the participants interviewed was formally employed while two participants were self-employed and generated income from making or selling items. The majority (N= 9 participants) were unemployed. The number of family members living in each household differed across households, and families were often not typically structured as a nuclear family. This suggests that perhaps due to HIV and AIDS, families have crossed the boundary of being nuclear families and now include extended family members, foster parents, friends and partners as well as non-blood relations (Pequegnat & Szapocznic, 2000, p. 4). It is also likely that the extended family system, which is traditional in South Africa, was not replaced by the nuclear family system, as it served all family members better. For the purposes of this study, the researcher limited the study to family members who were related either by blood or marriage to individuals living with HIV/AIDS.

The following table presents basic demographic information on family members related to individuals living with HIV and AIDS. Less demographic information was collected from this group of participants as some of the details collected from participants mentioned in Table 1 were not relevant to this group of participants or to the study.

**Table 2: Sample Details of Family members of individuals living with HIV and AIDS**

	<b>*Participant</b>	<b>Gender</b>	<b>Relationship to family member who is living with HIV/AIDS</b>
1	Joyce	Female	Mother
2	Mr Zuma	Female	Husband
3	Sarah	Female	Daughter
4	Fikisile	Female	Sister
5	Mrs Zwane	Female	Mother
6	Bertha	Female	Cousin
7	Lindiwe	Female	Step Mother

\*Pseudonyms are used to protect the identity of all participants

Similar to the participants described in Table 1, the participants who were willing to be interviewed were females with the exception of one male. Females are generally more willing to speak out and share their experience of sensitive issues, while males may be more hesitant. Clearly this was the case with these participants. While some of these family members spoke of their experiences of supporting their loved ones it was not possible to interview family members of all the participants living with HIV and AIDS noted in Table 1.

The following table presents basic demographic information on the members of the focus group. Limited information was required, as the aim was to gather information from community members regardless of their experience of HIV and AIDS.

**Table 3:** Sample Details of members who participated in the focus group discussion

	<b>*Participant</b>	<b>Gender</b>	<b>Age</b>
1	Rosemary	Female	33
2	Alice	Female	31
3	Phili	Female	26
4	Samantha	Female	30
5	Patricia	Female	42
6	Nozipho	Female	51
7	Chrisy	Female	20
8	Zama	Female	48
9	Thando	Female	Unwilling to disclose

All these participants were female, although male community members were asked to join the discussion. The community members' age ranged from 20 to 51, which allowed for a range of experiences and opinions.

The following section of the chapter discusses the themes that emerged from the data collected through interviews with individuals living with HIV/AIDS, family members whose loved one was living with HIV/AIDS and narratives from the focus group discussion.

The following themes were identified:

1. Disclosure of an HIV status
  - a) Family's response following disclosure of an HIV status
  - b) Disclosure to the community
2. Relationship changes from pre-diagnosis to post-diagnosis



3. General awareness of HIV and AIDS
4. Family and community support
  - a) Emotional support
  - b) Physical support
  - c) Financial support
5. Coping with stigma and discrimination from family and community
6. Fears and goals of individuals living with HIV and AIDS
7. Advice to the broader community
8. Services
  - a) Services that provide support to those infected and affected by HIV and AIDS
  - b) Service needs

#### **4.2 DISCLOSURE OF AN HIV STATUS**

The responses from individuals living with HIV/AIDS as well as family members on disclosure of an HIV status are presented here. Perceptions and thoughts from the focus group are also described.

Disclosure was an important theme to explore as being aware of one's status may influence the level of family and community support. This theme is broken down into family members' reactions and response following disclosure of an HIV status as well as disclosing to the broader community. Disclosure to families and communities can be linked to the Systems Theory. Kirst-Ashman and Hull (2006) note that, that the Systems Theory emphasises interactions between people and their environments. Disclosure prompts these interactions, as it entails communicating one's status and trusting that the outcome will be favourable.

#### **4.2.1 Family's response following disclosure of an HIV status**

Most participants in this study had disclosed their status to at least one family member. However, the time that they waited between being diagnosed with HIV/AIDS and disclosing their status to their family varied. The longest that any participant took to disclose her status to her family was 10 years and the shortest was the same day that they were diagnosed. There were different reasons for being tested for HIV and AIDS in the first place as well as choosing when to disclose their status.

Serovich, Craft and Yoon observed that HIV disclosure is a sensitive issue which can cause stress and anxiety due to uncertainty of how others will react (2007, p. 970). Such anxiety was evident in some participants' choice to withhold their status from their family and friends and take on the burden of keeping their status to themselves rather than risk being treated in a negative way as a result of their disclosure. Some participants were anxious, but found that when they disclosed, they did not have anything to worry about as their families were supportive. Others were not anxious about disclosure as they knew that their families would be supportive.

Family reactions and feelings also varied in terms of disclosure. The majority of individuals living with HIV/AIDS mentioned that their family members were accepting of their diagnosis. It was interesting to note that a few of the family members' were living with HIV/AIDS as well, so the experience was not a new one for them. As noted in chapter 2, Pequegnat and Szapocznik speak of multiple family members being HIV positive. Another related finding was that of females with the illness. As noted by Ndinga-Muvumba and Pharoah, "almost three quarters of 'AIDS-affected' households in South Africa are female-headed, a significant proportion of women are also battling AIDS-related illnesses themselves" (2008, p. 69-70). Annie's mother, Joyce said:

*“I wasn’t very scared when Annie told me she was HIV positive. I had HIV too and was on ARVs.”*

Other participants reported feeling supported by their families, even if they were the only one in their family living with HIV/AIDS. Mrs Radebe said that when she disclosed to her family:

*“...They supported me and helped me.”*

Although some family members were supportive and encouraging following disclosure, many did not experience this, citing active discrimination as noted by Ntokozo:

*“Some of the people in my husband’s family were not so accepting of me. When I was sick, they would treat me differently. They would stay away from me because of their wrong ideas about AIDS.”*

Mrs Dlamini shared this sentiment:

*“They don’t love me anymore now that I have HIV.”*

This finding is understood using the risk and resilience model. According to Greene (2007, p. 44), risk is “a concept that examines the probability that a person who has experienced a critical life event will encounter future difficulties. *Risk factors* may be internal biological conditions, such as low-birth-weight, or external environmental factors, such as poverty.” Being diagnosed with HIV is a critical life event that places the person at risk of future challenges. Having no family support places an individual who is already at risk, at even greater risk. AVERT (n.d. p. 7) notes that not all families are supportive, and individuals may find themselves being discriminated against and stigmatised within their own home, as outlined in some of the above quotations.

Family members recalled that they experienced different emotions on hearing a family member disclose their status. These included shock, hurt, blame and fear. Stress is common in families attempting to cope with a diagnosis of HIV and AIDS among them, as well as supporting the individual. Bor, Miller and Goldman (2004, p. 192) state that “stress is commonly seen in family members who may react to news of the diagnosis with disbelief, shock and confusion” and with feelings of guilt, helplessness, hurt, anger and confusion. The following are examples of narratives from individuals living with HIV/AIDS about their family’s responses and emotions when disclosing their status to them.

*“My mother cried when I told her I had HIV. She was scared that I was going to die.”* – Mpho

*“My mother looked for someone to blame. It was hard for her to accept.”* – Pretty

*“My mother was so shocked.”* – Zanele

However, there were also instances when family members were not surprised to be told about an HIV diagnosis. Bongi describes her daughter’s reaction to being told of her HIV status:

*“My daughter did not have a problem with it. She was supportive.”*

Typical of the complexity of the human experience, there is another aspect to this theme, that is, non-disclosure or limited disclosure – choosing to disclose to certain individuals.

One participant did not disclose her status to any of her family members, mainly for fear of her brother finding out. She was worried about his reaction and how he would treat her. Unlike Ntokozo, who, as noted above, felt discriminated

against by her family when she disclosed, Lungi chose not to disclose out of fear of discrimination and ostracism. Lungi disclosed her status to two families in the community who she trusted but otherwise:

*“...No-one else knows as they won’t take it well.”*

Lungi mentioned the negative way that her brother spoke about people living with HIV and said that he even ignored and isolated his best friend when he found out he was HIV positive.

Thembeke kept her HIV status a secret for ten years. She was scared of disclosing her status in 1988 when AIDS was a relatively unknown disease and stigma was rife. Thembeke feared that disclosing her status would only have negative consequences for herself and the people around her:

*“If I told anyone, they would have shouted at me.”*

Lungi and Thembeke both chose to keep their status a secret from others – either from specific family members or from everyone they knew. Similarly, a study conducted in Gauteng among HIV-positive women found that all the participants kept their status a secret for at least two years (Walker, Reid & Cornell, 2004, p. 102), demonstrating the need to protect themselves from possible stigma and discrimination.

The focus group discussion enabled the researcher to gain community perspectives on this issue. Focus group members were in two minds about disclosure. The main opinion in the group was that disclosing one’s HIV status to one’s families is important – as long as the family can be trusted. Patricia explained:

*“It is important to tell your family... you can’t just stay with that thing and not tell anyone...”*

However, she felt that if an individual is not close to their family, they should rather keep their status to themselves:

*“But then there is this thing that the sister might have issues and then she’s going to tell the neighbours... this one is HIV positive...”* – Patricia.

Thando (from the group) shared similar views when it came to disclosing to one’s family, saying that:

*“The time I test positive, it will be very hard for me to tell anybody because the family that I am staying with, they have this thing of saying, ‘I can’t stay with someone who has got HIV,’ so that is when I decided to keep quiet you know?”*

The focus group agreed that the issue of disclosure was a personal one and depended on the individual and their specific situation. Samantha summarised this by stating that:

*“...Sometimes it is right, but sometimes it is wrong to talk to the family.”*

Disclosure to the family can affect the amount of support that an individual living with HIV/AIDS receives. To summarise the findings under this theme:

- Some individuals felt supported by their families when they disclosed their status, despite some initial reactions of hurt, anger and fear.
- Other individuals didn’t feel at all supported when they disclosed their status to their families. Even today, they did not feel supported by their loved ones.

- Some individuals chose to disclose to only a few members of their family in order to protect themselves from possible hurt and discrimination. In most instances, these few family members were supportive.
- Others chose not to disclose their status to anyone in their families, as they did not want to risk being rejected. This meant that they were not able to be supported in the way that they would need to be, as their families did not know about their status.

#### **4.2.2 Disclosure to the community**

Families are affected by HIV and AIDS and may build walls between themselves and others in the community as well as extended family members by choosing not to disclose their family member's status (Bor, Miller & Goldman, 2004, p. 191). This was also generally established in the present study.

The amount of disclosure to the community varied from one participant to the next. Some participants like Ntokozo and Thembeke were very open about their status and would disclose to anyone in the community. Ntokozo believed that talking about HIV and AIDS would educate community members and create awareness, thereby lessening the stigma and myths that surround it.

*"It is a common disease and everyone needs to know about it... it is important to open up and talk and not hide so that people can start supporting one another."*

Thembeke emphasised the need to be open with the community by stating that:

*"Everyone knows I am HIV positive. I am a survivor and have had the virus for many years."*

Other participants such as Annie and Mpho were wary of and selective about disclosing their status to the broader community. Mpho only disclosed to her boyfriend and a few close friends. Annie mentioned that people in the community did not know she was HIV positive, and she is worried about them finding out for fear of stigma.

*“If they find out I am HIV positive, they will think I am ‘easy’.”*

Most of the participants in the focus group discussion were not certain that disclosing one's HIV status to the broader community was a good idea. Patricia stated that:

*“... to tell the person from outside of the family, it's just that... you never know.”*

One barrier to doing so is lack of trust. According to Zama:

*“The greatest problem is to tell others that if we had a fight, I can go up the street and tell everyone and shout and say that you are HIV positive. Yet I told you because I trust you. That is why I said that is a lack of trust... You can't trust everybody.”*

No member of the focus group felt that individuals who have been diagnosed with HIV should disclose to their communities. It was interesting to note however, that during the individual interviews, a couple of individuals stated that they had disclosed to their community and were open about their status, with positive results.



#### 4.3 RELATIONSHIP CHANGES FROM PRE-DIAGNOSIS TO POST-DIAGNOSIS

Serovich, Craft and Yoon (2007, p. 970) note that while family, partners and friends should ideally be supportive, due to stigma and discrimination, this is not always the case with relationships being negatively impacted. The narratives that follow illustrate the varied effects of the illness on relationships.

Most participants (individuals living with HIV/AIDS as well as family members) reported that their relationship with their loved one/s did not change significantly from before diagnosis to after. Mpho stated that her relationship with her mother became even closer after she was diagnosed with HIV, possibly assisting in creating resilience. However, some participants spoke about a negative change in their relationships with family members which impacted the level of support that they received. In this regard, Mrs Radebe commented:

*“My family were shocked.... Now it isn’t easy to talk to them. They won’t eat the food I cook... They laugh at people with HIV.”*

Mrs Radebe’s experience relates to Walker, Reid and Cornell’s (2004) statement that experiences may include being isolated, being told to use separate cutlery and crockery, being relieved of all household chores, feeling rejected, and interactions with other family members being restricted. Mrs Ncube also noted a change in her relationship with her sisters from pre-diagnosis to post-diagnosis, as follows:

*“They don’t love me anymore now that I have HIV... after the HIV diagnosis things just got worse. My brother who stayed with me started using a different toilet when he found out and then moved out... My sister didn’t speak to me...”*

#### 4.4 GENERAL AWARENESS OF HIV AND AIDS

Myths and false beliefs around HIV and AIDS persist, especially in townships around South Africa as many individuals have no formal education (HIV/AIDS in South African Townships, 2012). HIV and AIDS is often thought of as a sexual disease, and individuals (mostly women) are labelled 'easy' when their diagnosis becomes known. It is not taken into account that HIV and AIDS can also be contracted through blood and mother-to-child transmission. These misconceptions around HIV and AIDS increase stigma within communities.

It was established that most participants and their families learnt more about HIV and AIDS after they or their loved ones were diagnosed. Annie knew that she must not spread the virus by having multiple sexual partners. Instead she only had sexual intercourse with her baby's father, saying:

*"...at the beginning we were not using condoms but now that I know I am HIV positive, we use protection."*

The study also aimed to gain an understanding of the degree to which individuals living with HIV and AIDS and their families were educated about the virus, in order to establish whether such awareness impacted the level of support. If a family was not educated about HIV and AIDS and believed the myths surrounding it, they might stigmatise their loved one living with HIV/AIDS for fear of contracting it. Thus the researcher believes that education and awareness for families supporting a loved one living with the disease is vital in order for support to be maintained and myths surrounding HIV and AIDS to be dispelled.

The majority of the family members interviewed believed that it is possible for someone who is living with HIV and AIDS to live a normal life. Joyce thought that it was different living a life with HIV stating that:

*“Sometimes these people will get sicker and have colds, headaches and become sore more easily.”*

Some family members thought it was possible to live a normal life with HIV/AIDS as they were also HIV positive and had personally experienced this. Fikisile reported that:

*“I know that it is possible to live a normal life because I have been living with HIV myself since 2003...”*

Some participants such as Thembeke and Bongi did not know much about HIV and AIDS until after their diagnosis.

*“I didn’t know nothing. I heard about AIDS in the paper and on the news. That was it. I learnt a lot when I got AIDS.” – Thembeke.*

Bongi reported that she did not know much before she was diagnosed with HIV except that it was important to get tested regularly which she did not do.

*“I have learnt a lot from the HIV classes now...”*

Awareness of HIV and AIDS differed within the focus group. Thando spoke about how HIV can affect anybody:

*“HIV is not a racist. It can affect anybody... most people are thinking that it’s only black people who are HIV positive...”*

However, Phili told the group that:

*“I don’t need to know more about AIDS, I am HIV negative and I know how to protect myself.”*

#### **4.5 FAMILY AND COMMUNITY SUPPORT**

Family support differed from one family to the next. Some individuals living with HIV and AIDS reported that they received little or no family support while others felt they received a lot of support in all spheres. Generally, family members reported that they provided support. Bor, Miller and Goldman (2004. p. 194) stress the benefits of family support and state that people living with AIDS “report fewer feelings of depression and helplessness if they have close friends or relatives to talk to about emotional and illness-related problems”. Mothers and close friends have been found to be the most supportive. Linking family support to the risk and resilience theory, Greene (2007) suggests that focusing on family strengths has replaced the focus on problems within the family. Support within a family is a strength which encourages resilience.

Palattiyil and Chakrabarti maintain that as important as family support is, without available resources, the family’s coping efforts may not be very successful (2008, p. 884). It is important to reiterate that the research described in this dissertation was conducted in a rural community where resources were limited and poverty and unemployment were rife.

The category of family support ties in closely with the risk and resilience theory. Individuals living with HIV and AIDS who experienced good family and community support had more resilience in their HIV and AIDS journey. However, some individuals living with HIV and AIDS showed resilience despite a lack of family support as they received support from other sources.

The following discussion focuses on support from the individual and the family member's perspective. The types of support discussed are emotional, physical and financial. While many of the examples refer to the positive aspects of support, a few participants cited experiences of limited or no support. Keeping one's status secret can also mean that support is limited to the people that do know. Lungi described her experience of not being supported.

*"I didn't get any support from my family when I found out I was HIV positive because none of them knew. I have to pretend that I don't have HIV. It is hard."*

Mrs Dlamini related to Lungi's experience of not being supported; although she had disclosed to her family, they chose not to support her.

*"I have been living this life and need to accept it. It is too late for my family to support me now. There are many ways they could help me but they choose not to."*

This narrative shows that support was not always dependent on disclosure.

Members of the focus group believed that nowadays, there is more support from families and the community in general than previously. Patricia clarified:

*"It is better now because we do have people that go and visit people at home and there are support groups. Families also take care."*

Sarah provided an example of support or non-support in a different form.

*"My mother having HIV doesn't affect me. I don't talk to her about her HIV. My mom is a normal person. She still looks after her family."*

Although Sarah showed care for her mother, she viewed her as normal. Since she saw her mother as healthy, there was no reason for additional support.

Patricia, a member of the focus group, introduced another aspect; a family member's willingness to support, but the individual living with HIV/AIDS not accepting the support.

*"... We do have those families who support for those living with HIV and AIDS. But then you got that person who's infected who doesn't bother... By the time he is supposed to go drink his medicine, maybe he's at the tavern. They (family) have to go and grab him. We do have those people who are HIV positive and don't accept the support. They are not ashamed.... They don't care anymore...."*

The three different forms of support highlighted in this study are discussed below. Although the researcher has tried to place these forms of support into the three categories, there is overlap. Nonetheless the categories are important in order to identify the challenges relating to each. This ties in with the systems theory as micro, mezzo and macro elements will constantly overlap and interact with one another.

#### **4.5.1 Emotional Support**

This section discusses the general findings on how families in the community provide emotional support to their loved ones living with HIV and AIDS. While some participants felt that they received emotional support, others felt that, due to the stigma and discrimination they had experienced, this was an aspect of support that was incomplete.

Annie described the emotional support she receives from her mother.

*"... (my mother) she talks to me and counsels me. I know she is here for me."*

Joyce, Annie's mother, stated that:

*“Annie took care of me when I was told I have AIDS and when I am sick. So I am going to take care of her too.”*

Ntokozo said:

*“My family encouraged me when I was down in a pit and felt hopeless. When I was sick, I became close with them. My husband is strong for me. He hasn’t left my side. My family is close together.”*

However, there were additional emotions that complicated the picture of support as per the systems theory where overlap is evident. An example of this was Pretty who said:

*“My mother did support me... but she saw AIDS as a death sentence and said things to me that hurt me.”*

While Pretty may have felt supported by her mother, she did not feel that she had received the emotional support that she needed. This demonstrates the compounding factors that the systems theory also describes.

#### **4.5.2 Physical support**

The participants recounted different experiences of physical support. It is also interesting to note that some even cited feeling physically supported by children in the family.

This again raises the question of the relationship between more than one person in a household living with HIV and AIDS and support for individuals. If there is more than one member living with HIV/AIDS in a household, the support might be more effective as the family member would be able to

empathise, rather than sympathise, knowing how best to support their loved one. An example of this correlation is Joyce, who stated that:

*“We remind each other to take our ARVs”*

Participants provided the following examples of physical support:

*“When I got sick, my family took care of me. They accepted me and my HIV and they talk to me about being healthy. My mother and husband even buy me healthy food...” -Ntokozo*

Naledi provided an example of both physical and emotional support:

*“My family... cook meals and run my bath for me even when I am being difficult.”*

Some family members are supportive from a young age. Sarah recalled that she was still young when her mother became ill and could no longer work: *“...We would have to stay home to look after her.”*

Another narrative that describes the support of younger family members was that of Mrs Ncube:

*“My children tell me to take my pills. Even my little one says, ‘Mom, it’s time to take your pills now.’ They are very supportive even though they are young.”*

### **Financial support**

According to Palattiyil and Chakrabarti (2008, p. 884), “the success of the family’s coping efforts may depend on the resources available to the family.” A lack of financial or other resources may make the task of caring for family members who are living with HIV and AIDS more difficult.



Many of the participants mentioned that they were financially burdened – whether they were being supported financially by their families or not. Apart from feeling financially supported and being happy with that, two elements emerged during the study. The first was not feeling financially supported at all. The other was being financially supported but feeling that they were a burden on their families, making it difficult for them to be empowered and independent; or that the financial support they received was not sufficient. As important as other aspects of support are, financial support enables people to meet their basic needs in order to survive.

The following is an example where a participant was financially supported, but felt that what was provided was not enough for her family's needs.

*“...this is not enough and we can't afford to buy food that's good for us.” - Joyce*

Ntokozo's narrative described feeling supported by her family in other aspects, but not financially:

*“...my problem is money... my sister is unemployed and cannot help in this way.”*

Some participants like Zanele felt financially supported within their home:

*“Before my husband died he supported me because he had a job. Now me and my family have started a tuckshop from our home and we also hire out tents and chairs for people in the community for when they have a function.”*

A few participants felt disempowered by their family members' financial support. Mrs Radebe became emotional, saying:

*“I feel like I can’t provide for my own family. I don’t have my own money. My daughter gives me money for looking after her children... but I don’t like to rely on my children for money... but I have no choice.”*

Mrs Zwane said that it is not easy for her children to support her financially:

*“My children have their own families, their own families and need their money. It’s not fair to expect them to support me.”*

Mary felt that she wasn’t able to be independent because she needed the help of her family:

*“...but I try not to ask for money all the time.”*

This raises the question of whether too much support can create dependency and disempowerment. Rojano’s Community Family Therapy Model (2004) stresses the importance of empowerment and helping people gain a sense of mastery over their lives. These participants’ narratives suggest that a sense of disempowerment was mainly felt with regard to financial support. It is clear that being able to earn and control their own money would mean a lot to individuals living with HIV and AIDS. Even though some families willingly supported their loved ones living with HIV and AIDS, some still felt shame and guilt as well as frustration for having to rely on their families in this way.

All members of the focus group agreed that financial support was probably the most difficult type of support to provide to individuals living with HIV and AIDS. Thando mentioned that:

*“...a lot of people are unemployed here... you can also find that if a family is getting a grant, that one grant is helping the whole family to live.”*

It was important to gauge the focus group members' perspectives on family support. Support was seen as important, but people are not always aware of the challenges involved in supporting an individual living with HIV/AIDS. Rosemary mentioned that:

*"It is difficult to support a person with AIDS."*

Patricia expanded on this by saying that:

*"It depends on the person... if they are willing to welcome you to support him or her. Some people are very much interested in getting support from others but some don't want support, they say I would rather die..."* - Patricia

Members of the focus group provided examples of family support in their community around HIV and AIDS:

- *"A friend of mine was staying with her boys... The way they were supporting her, you know when it comes time to take your tablets, instead of telling their mother straight away that you need to take your tablets, the youngest boy used to go outside and then he going to shout 'look there!', and then the mother going to remember that now the time to take the tablets... without anybody noticing."* – Thando
- *"Another relative of mine, her sister used to say in terms of reminding her, 'you said you going to call Anastasia at 8 o'clock, now call her.' Now she is going to remember its 8 o'clock now, now it's time to take my tablets... it's a good support."* – Thando

Members of the focus group also provided examples of individuals living with HIV/AIDS not being supported by their families:

- *"Sometimes people end up dying because they don't get family support. There were these land claims, they were R54 000 per person. So most of the people*

*used to take the money and come stay their own life, leaving their families. When it comes to that stage when the person is sick and they want to go back to their family, they will say 'oh you spent all your R54 000 so there is no support we can give you now'.*" – Samantha

- *"There was a lady... her sister gave her a lot of clothing and one day she (her sister) said to her, 'I didn't send you to get this HIV thing and now I want my clothes back...' and even if she went to the toilet, they used to say to her she must take the chloride and the JIK and clean it thoroughly... what I can say is those people who aren't getting the proper support, they don't live longer. That lady passed away..."* – Thando
- *"Sometimes other people locked the HIV person without even giving her a sip of porridge."* - Zama

The support received from families overlaps with the responses on disclosure. In the systems theory, nothing exists in discrete compartments; rather, the elements constantly overlap and interact.

These examples of non-support also tie in with some of the individual responses citing non-support by families and stigma and discrimination in the home. Mrs Ncube said:

*"They don't love me anymore now that I have HIV... after the HIV diagnosis things just got worse. My brother who stayed with me started using a different toilet when he found out... My sister didn't speak to me... When my other HIV positive sister goes to visit my other sister, they make her sleep in the dining room on a towel on the floor..."*

#### 4.6 COPING WITH STIGMA AND DISCRIMINATION FROM FAMILY AND COMMUNITY

Participants coped with the stigma experienced from family members and the community in different ways. It is important to note that not all participants experienced such stigma and discrimination.

Where stigma was rife in the community, this is what was said:

*“There is a lot of name calling and talking bad about people who have HIV in our community. When the community find out that a person is HIV positive, they call them a bad person with no future.” – Annie*

*“The stigma from the community is painful because people will say bad things about AIDS. I don’t know if they are talking about other people with AIDS or if they are talking about me and Annie...” – Joyce*

*“Stigma is carried by people who have not been tested for HIV themselves; they do not understand that HIV is in the blood, not on fingers. So these people will not eat in your home if they know you are positive.” - Naledi*

It was interesting to note that most participants felt that the stigma in the community was not as bad as it was previously.

*“There isn’t a big stigma anymore. Many people have the virus now, maybe over half of the community.” – Fikisile*

Thembeke experienced stigma a lot more in 1988 when she was first diagnosed. *“Now people know that if you are positive, you are okay. You are not dying. Some of them still gossip about it but people are educated now. Before, people wouldn’t even touch a cell phone of someone who had HIV because they thought they would get the virus then, even using the same spoon...”*

Zanele's description of stigma provides insight into how things have changed in the community:

*"HIV was something to be ashamed of, seen as a death sentence. Now things have changed and I don't care who I tell. Things are better in the community... People accept HIV and see it just like having flu."*

Mrs Ncube shared this sentiment by stating that *"In the past, the stigma was bad in the community. In the streets, people would curse you and swear you. They would say to me: 'why are you coming here from Joburg with your HIV?' People thought you were useless and there was no point in being alive if you had HIV. Now the stigma is a lot better and people even say that having HIV is better than having TB."*

In line with Walker, Reid and Cornell (2004), this study found that the extent of stigma experienced within participants' households also differed.

*"Sometimes my sister uses my HIV against me in fights and bring it up which hurts me."* – Mary

*"My sister is negative about HIV and says means things to me. It is hard to speak to my sister because I feel ashamed of being HIV positive... My sisters won't eat the food that I cook... They are mean to people who have HIV and laugh at them."* – Mrs Radebe

*"My brother speaks badly about people who have HIV. He even ignored his best friend when he found out that he had HIV and pretended he wasn't even there anymore."* – Lungi

Thando from the focus group shared a personal experience of stigma when she was diagnosed with TB:

*“I was once attacked by TB... my (HIV) test was negative but TB was positive. And I lost a lot of weight, I nearly die... whenever I walk on the street, people used to point at me and say, ‘you know, she’s dying – HIV’. And I just pretend as if I didn’t hear anything.”*

#### **4.7 FEARS AND GOALS OF INDIVIDUALS LIVING WITH HIV AND AIDS**

The researcher considered it important to gain some understanding of individuals’ future goals and their perspectives on living a healthy life; this also ties in with the concept of resilience in the risk and resilience theory. The researcher observed that having goals increased resilience and empowered people to have hope for their future. Likewise, a lack of family support could prevent individuals from achieving their goals.

The goals identified by the participants included the following:

*“I want to build my house and make it big for my family. We are all living in one room now. Then I will know that if I leave this world, my family will be okay. I pray to God for strength to stay until my last born finishes school... then I can lie down in peace.”* – Thembeke

*“I want to change how people see AIDS so people won’t be scared of us.”* - Mary

*“I want to upgrade my matric so I can get into paramedics.”* – Zanele

*“I want to have my own hairdressing business and live in my own home one day.”* – Lungi

As important as it is to consider goals as part of resilience in family support, it is also necessary to explore how individual and family members’ fears may affect

‘risk,’ the corollary to resilience within the risk and resilience theory. It was found that no matter how positive a participant was about living a healthy life with the virus, they also suffered from fears. It was interesting to note that participants were not afraid of dying, but rather of external factors. Some fears related to how the community would perceive them. The majority of participants were able to describe one of their fears without hesitation. This demonstrates the emotional trauma that can occur in an individual who is living with HIV and AIDS. The following are examples of the fears that participants described.

*“Some people say that when the virus increases, people can become crazy. This is one of my fears that this will happen to me. I am scared of me dying and the virus winning.”* – Ntokozo

*“I fear my children getting sick... I also fear getting raped because here people think that if you have sex with an old person, you will be cured.”* – Mrs Ncube

*“I am scared that my appearance will change and this is a problem because people will see that I have HIV.”* – Pretty

*“I am worried about my brother finding out... I don’t know what would happen...”*  
- Lungi

#### **4.8 ADVICE TO THE BROADER COMMUNITY**

It was important to capture advice that the participants would give their community to enhance the support they receive, on living positively and on eliminating stigma within the community. The researcher identified resilience in these narratives, as discussed by Greene (2007). Participants knew what they would want their communities to know, if they had a chance to tell them. Many of these statements stemmed from personal experience. Linked to the gaps in services that will be discussed shortly, one aspect that emerged was that there



was a need for individuals living with HIV and AIDS and their loved ones to have a platform on which they could share their stories with the community.

It was interesting to note the similarities across the responses from the different sample groups, confirming the importance of the above.

The participants' advice was categorised into four themes; one or two quotations are used as an example for that theme.

- Importance of testing and taking medication

*“Get tested early and get treatment and support before things get bad.”* –

Mary

- Importance of practicing safe sex

*“Condomise and have one partner.”* – Mpho

- Importance of a positive attitude

*“When you have HIV it is not the end of the road.”* – Thembeke

*“Just because you are HIV positive, it’s not the end of life. Do the right things for your life.”* – Lungi

- The hardships of being HIV positive

*“You don’t know just how hard it is being HIV positive when you are negative.”* – Pretty

*“I speak to young women and warn them about AIDS. I talk to them about protecting themselves and not having sex... I tell them that they are like oranges. Boys like you when you’re healthy and juicy, but when you have been bitten into and are old and used and have HIV, they will just leave you.” - Mrs Radebe*

#### **4.9 SERVICES**

It was important to explore the existing services that are available in the community to assist individuals living with HIV/AIDS and their families, as well as the gaps in services. This section explores these factors. Services dedicated to assisting individuals living with HIV/AIDS and their families could enhance resilience at all the levels pertaining to the systems theory at individual, family, and community level.

Silberberg and Walsh, as quoted in Greene (2007, p. 30) state that the risk and resilience theory has moved the focus from solely on families, to viewing community resources as also enhancing resilience. It was for this reason that the risk and resilience theory was used in conjunction with the systems theory which focuses “on the dynamics among and interactions of people in their environment” which views all systems as interrelated and interactional (Kirst-Ashman, 2003, p. 17). The researcher linked this with the participants’ narratives – where they felt there were gaps in services, as well as where there were services available that assist and promote resilience.

#### **4.9.1 Services available in the community to support individuals living with HIV/AIDS and their families**

Welz et al (2007) emphasised the importance of providing resources and services to meet the needs of individuals. High HIV prevalence creates an urgent need to allocate resources to HIV prevention and treatment. This was emphasised by participants who stated that support services should be available in the community.

Some participants mentioned that there were services available, but these were either limited or there was insufficient awareness about them in the community. This was a concern as community members could be making use of services that are there for them, but due to lack of awareness, they are missing out.

Joyce (Annie's mother) told the researcher that there is a clinic in the community that assists in the field of HIV and AIDS as well as:

*"...volunteers who do home visits when people living with AIDS become very sick... (they) clean the house, bath the patient and look after them."*

Naledi's daughter, Sarah, stated that services for people living with HIV/AIDS and their families include Ithembeni and Howick Hospice which provide food parcels.

Mpho mentioned that although there is a support group at the clinic for individuals living with HIV and AIDS, the distance prevents her from attending:

*"It is very far to travel so I don't attend."*

Thembeke, who is living with HIV, works for a mission for HIV and AIDS that assists people in the community. The only places she is aware of that facilitate support for people living with HIV/AIDS and their families is this mission and the Place of Hope. These organisations provide:

*“food parcels and transport money, counselling and support groups.”*

Bongi who is also living with HIV/AIDS mentioned that:

*“Services in our community include a car coming around to hand out food parcels. I don’t know what organisation they are from or where they are based. There are no other services here.”*

It is evident from this narrative as well as others that the services that do exist in the community are not well known. Participants know that there are people who assist those living with HIV and their families, but they do not know who they are affiliated to or where they are based.

There are also gaps in services and a need for new services and resource centres within the community.

#### **4.9.2 Service Needs**

Some participants suggested that there were no services available to them in the community, or at least none that they knew of. Fikisile stated that:

*“There are no services here for us...”*

Nellie, Ntokozo and Naledi agreed.

Many of the participants identified gaps in services in their community. Some of the services that participants mentioned do actually exist in the community but due to a lack of awareness, participants did not know of their existence.

Altman states that the AIDS epidemic has “produced an extraordinary amount of creativity, political activity and compassionate care at a grass roots level in virtually every country where there exists the possibility of community organising” (1994, p. 6). Where there are gaps in services and resources, communities need to adopt innovative and creative responses. Participants from all groups were creative and suggested services. These services are grouped together hereafter.

a) The first need was education and support groups

Myths and false beliefs about HIV and AIDS still exist today. This could result from a lack of education and awareness about the disease. For example, Mrs Ncube fears that she will be raped as there is a myth that if you have sex with an old person, you will be cured of HIV.

Annie emphasised the importance of education in the community:

*“People need better education so that they can learn more about AIDS and be accepting of people who are living with AIDS.”*

Joyce stated that:

*“If there was more education and knowledge about HIV and AIDS, it would make things better. Maybe people wouldn’t be so scared to come out with their status then.”*

Sarah mentioned that a priority for individuals living with HIV/AIDS and their families is:

*“...to educate people about HIV and AIDS. It is about educating people who have AIDS but also educating people who do not have AIDS.”*

Thembeke agreed but added that even with education and awareness there will be community members who are not interested:

*“...even though AIDS is killing, but they still do not want to learn... only some people would come and listen to talks. Maybe education needs to happen in support groups.”*

Bongi concurred with Thembeke:

*“There isn’t a lot of education here – people don’t understand HIV and AIDS. Some people pretend that HIV doesn’t exist or that they don’t have it, and they don’t educate themselves. Support groups need to deal with this.”*

b) A need for social workers

Annie’s mother, Joyce, emphasised the need for social workers in the community, noting that they are needed

*“...to educate, to counsel and to encourage and motivate people.”*

This could correlate to the other service needs including facilitating support groups and creating awareness.

c) A need for food parcels

Participants identified food parcels as a need in their community, and healthy food was emphasised. One participant stated that there is an organisation that supplies food parcels, but the workers only give the food parcels to their friends.

According to Joyce:

*“people living with HIV and their families should be given healthy food parcels.”*

Fikisile agreed:

*“decent food should be given out to people with AIDS.”*

d) A need for a ‘drop-in’ centre

This need was identified by a couple of participants in various forms. A drop-in centre would require the assistance of several professionals. The researcher believes that this service would assist community members in that education and follow up would be part of the plan. This is not simply a ‘give and go’ practice.

Ntokozo was passionate about the need for such a centre:

*“There is a need for a community centre and clinic in the community that could take care of sick HIV positive people as some are treated so badly by their families. A place where they could feel safe, get the right medication and healthy food as some people with AIDS are very thin and don’t have money to eat.”*

Thembeke spoke of some people being very sick and

*“needing that special care... When going to the clinic or the hospital, they just give you a note and then discharge you. They do not go to your house for follow up. The drop in centre would have beds, a doctor, a nurse, a social worker... Making sure they take their pills until they are better and then doing home visits.”*

It is interesting to note that this need was identified by another group of participants in a different study. In the related study, this concept was termed “a one-stop centre”. Individuals living with HIV and AIDS and their families stated that this would “greatly help reduce costs to them and thereby promote greater treatment adherence” with the goal being to create a “safe, central environment” (ICEEPS Conference Program, 2013). Raniga’s point of view coincided with this, as discussed by Kasiram (2011) where she states that a one-stop support service centre would ensure that people are able to access services and resources in one visit – saving time and money. So this is clearly not a new concept that was introduced in this study; however the repetition of the one-stop centre in different studies, emphasises the need for such a service.

e) Counselling

Naledi stated that there is a need for individuals living with HIV and AIDS and their families to receive counselling. This could link with the point about having more social workers present in the community.

*“Spiritual counselling to help them cope with what is happening and to encourage them to rely on God, and to prepare them for death and what happens afterwards... Physical counselling to tell them what they need to do to stay healthy and live better lives.”*

f) Platform to share stories

Linked to education, participants’ identified the need to be able to share their stories with the community. As noted previously, participants identified what they would share with the community if they had the chance to.

*“People need to be able to share their stories and this also educates people on what it is really like to live with HIV and AIDS. Forums and organisations can be used for this.” – Sarah*



#### **4.10 CONCLUSION**

This chapter portrayed the themes that emerged during the study using the narratives of the participants – individuals living with HIV/AIDS, family members related to an individual who is living with HIV/AIDS and focus group participants. Similarities and differences between the interviews were discussed with a view to establishing how family and community support was experienced and the factors influencing such support.

## **CHAPTER 5**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

This chapter presents a summary of the research findings, the conclusions that stemmed from the findings and the researcher's recommendations. Recommendations are important as they can assist with further studies related to the topic as well as guide practice. Questions and thoughts that arose during the course of this study that were not directly related to the study topic could be explored in the future and are therefore included under further research.

This study demonstrated the obvious need for family and community support – both from the individual and family perspective as well as from the community's point of view. The expressed needs could be addressed at the practical level by means of the recommendations provided later in this chapter. The researcher hopes that this study is as meaningful and insightful to its readers as it was to her.

The study was guided throughout by the aims and objectives set out in the first chapter. It was necessary to gather information about these factors in order to ascertain how they influenced the support that was provided and received by individuals living with HIV/AIDS and their families. The researcher has listed the prominent themes from the study and explained briefly how each correlated with the main topic and in so doing, fulfilled the aims and objectives of the study.

It was interesting to note that there was a constant overlap of information between the various themes, which is clearly linked to the systems theory. For example, the forms of support (one of the themes) that an individual living with HIV and AIDS was receiving from their family also depended on when they chose to disclose to their families or not (another theme), and the subsequent reaction to disclosure.

The aim of this study was to explore how an HIV/AIDS diagnosis in a family affects the family as a whole and to determine the role of the family as a major support system.

The reader is reminded of the objectives of the study:

- To explore the family's understanding, perceptions, attitudes and beliefs about HIV/AIDS and to understand if there have been any changes in these since learning of the diagnosis.
- To explore the support system and the resilience of the family in dealing with HIV/AIDS – both support to the individual living with HIV/AIDS as well as the support they are getting as a family.
- To understand how the individual living with HIV/AIDS perceives the support they are getting from their family and community.
- To determine the challenges experienced regarding support in the midst of an HIV diagnosis.
- To explore available or needed services in the community relating to HIV and AIDS that could aid support.

The researcher employed an exploratory and descriptive qualitative research design.

Three data collection procedures were followed:

- a) Twelve interviews were conducted with individuals living with HIV/AIDS
- b) Seven interviews were conducted with family members of individuals living with HIV and AIDS
- c) A once-off focus group discussion was held, consisting of nine community members.

The above data collection methods were used in conjunction with a semi-structured interview schedule. Triangulation was achieved in an attempt to collect as much data from different perspectives as possible – ensuring that the results were objective and reliable.

The conclusions that emerged from the study are discussed under the following themes:

- a. Disclosure of HIV status to a family and community and relationship changes from pre to post diagnosis.
- b. General awareness of HIV and AIDS
- c. Family support – emotional, physical and financial
- d. Coping with stigma and discrimination from families and the community
- e. Fears, goals and living a healthy life
- f. Advice to the broader community
- g. Services that provide support to those infected and affected by HIV and AIDS.

Secondly, recommendations that emerged from the general findings are presented in conjunction with the levels of the systems theory – micro, mezzo and macro.

Finally, the researcher presents ideas for further research in this field. The Social Work profession encourages those in practice to constantly learn and grow through research. This study recommends further research to increase and update knowledge and practice on an issue that presents major challenges in South Africa.

## **5.2 SUMMARY AND CONCLUSIONS THAT EMERGED FROM THE DATA ANALYSIS**

### **5.2.1 Disclosure of HIV status to a family and community and relationship changes from pre to post diagnosis**

This theme was important to establish whether the family's response following disclosure impacted the type and amount of support they were willing to provide. This information was also gathered to ascertain if the support that was provided would have still been provided without disclosure. Positive reactions leading to the support of a loved one seemed to increase the resilience of the individual living with HIV and AIDS and the family as a whole (risk and resilience theory and interactions of systems as per systems theory).

The subject of disclosure was broken down into two categories, disclosing to the family and disclosing to the community. The results generally showed that disclosing to the community was less common than disclosing to one's family, but there were varied responses as follows:

- Some participants living with HIV and AIDS were open about their status to both their family and to the community, with good outcomes.
- Other participants living with HIV and AIDS were open about their status to both their family and to the community, but did not receive as much support.
- A few individuals living with HIV/AIDS disclosed only to their family, with the community being unaware.
- Still other individuals living with HIV/AIDS disclosed to a few members of the community, but decided against disclosing to their families for fear of possible stigma and discrimination from their loved ones.
- Some participants chose not to disclose their status to either their family or the community, and are living with HIV in secret.

As the results show, disclosure was a very personal experience and each individual living with HIV and AIDS chose to approach it in a different manner.

Most of the participants who disclosed to their families and community did feel supported, although it was established that there were some individuals who would not have decided to disclose their status had they been able to foresee what the reactions and outcome of this would be.

It is clear from the findings that disclosure of one's status and family and community support are linked.

The findings raise a recurrent question: is the risk of disclosing one's HIV status to family and the community in order to potentially gain needed support worth it?

It was clear that most participants' relationship with their family members did not change drastically from pre to post diagnosis on disclosure. Family members experienced various emotions such as fear, guilt, hurt and anger, but most were able to support their loved one. In some instances, relationships with the family strengthened, but for others it grew worse after disclosure.

### **5.2.2 General Awareness of HIV and AIDS**

The researcher sought to ascertain whether the level of knowledge around HIV and AIDS correlated with family support. It was established that being more educated helped provide resilience against myths and discrimination as a whole.

Participants stated that they became more aware about HIV and AIDS when they or their loved ones were diagnosed, suggesting that knowledge was not there to begin with, but was sought upon a positive diagnosis. It was also established that when more than one family member in a household was living with HIV/AIDS, there was more awareness of the virus.

Furthermore, the researcher observed that many participants viewed being diagnosed with HIV and AIDS as not as 'scary' as it used to be, indicating the normalizing of this illness as a regular life event. Such normalizing may have dire consequences for poor preventative action, if HIV/AIDS is viewed as a 'certainty' of living.

The findings suggest that, if people were more educated about the facts and were able to dispel the myths around the virus, both the home and community environments would be more supportive, and stigma and discrimination would be reduced.

### **5.2.3 Family Support – Emotional, Physical and Financial**

This theme was central to the study – for participants to be able to describe the forms of support received from their families, as well as where they felt there were gaps in support. It was essential to gather the perspectives of both the individuals living with HIV/AIDS and their families. The risk and resilience theory underscored the results summarised here.

The three main forms of support that emerged from the narratives were emotional, physical and financial support. The results differed from one participant to another. The main findings concerning the different forms of support were:

- Some participants felt supported in all spheres.
- Other participants stated that they received one or two forms of support, but at the same time felt that they were being discriminated against and stigmatised, despite the apparent support.
- Financial support was the main challenge for individuals and family members living with HIV and AIDS. This is linked to the high levels of poverty and unemployment in this community.
- In some instances, individuals were overwhelmed by the support received; this served to disempower them.
- On the other hand, some individuals living with HIV and AIDS did not feel supported at all by their family members and/or the community. This included individuals who had disclosed their status with negative results



and individuals who had chosen not to reveal their status, thereby eliminating the risk of stigma along with their chances of support. This aspect links with the previously discussed aspect of the relationship between disclosure and support.

With financial support being scarce and distressing, the question arises: would individuals living with HIV and AIDS feel more secure and empowered if they were able to obtain jobs? This issue emerged as an indirect consequence of the interviews and requires further exploration.

#### **5.2.4 Coping with Stigma and Discrimination from Families and the Community**

Stigma and discrimination clearly play a role in the receipt of family and community support. It was found that despite a family being 'supportive,' the persistence of the myths surrounding HIV and AIDS meant that the individual living with HIV and AIDS would be stigmatised and discriminated against due to the family and community not knowing the facts about the epidemic. This suggests the need for education and awareness on HIV and AIDS.

Participants differed on the extent of the stigma that was occurring in various households and in the community. It is important to note that the majority of participants stated that there is far less stigma now than previously. This could be due to a number of factors including the increasing prevalence of HIV and AIDS and more awareness of the disease. Stigma in the community could result in individuals living with HIV and AIDS and their families not accessing support services that are available in the community as was expressed by a few study participants.

It was clear from this study that participants who were living with HIV and AIDS and who were experiencing stigma were more vulnerable and at risk of not receiving the support that they needed. The researcher observed that this had either made it more difficult for these individuals to ask for support because of their expectation of a negative response, or because family members would practice discrimination by not providing the support even if it was requested.

#### **5.2.5 Fears and goals**

This linked strongly with resilience as per the resilience theory. Fears linked with risk often included fears about the way the participants were or could be treated by their family and the community, as well as the effects of AIDS. Goals linked with resilience, as this encouraged the participants to look to the future and focus on what they would like to achieve. It was evident from the study that participants who felt more supported by their families were able to focus on their life goals. Participants who had not disclosed their status reported fear of their family members or the community finding out.

All participants were able to share their fears and goals, and their perceptions of living a healthy life.

It was interesting to note that many participants who felt supported by their families included in their goals the desire to help others. This suggests that when individuals living with HIV/AIDS feel supported, they are able to reach out and think about how they can help the broader community. In contrast, individuals who did not feel supported by their families, reported goals which focused on themselves, rather than helping others.

### **5.2.6 Advice to the Broader Community**

Results in this regard varied, but most reflected resilience. The main themes that emerged were not giving up in the fight against HIV and AIDS, and protecting oneself against the virus. Advice to the broader community also tied in with the need for those infected and affected by HIV and AIDS to share their stories. This stresses the need to create a platform in the community where stories can be shared in an open and safe environment (see recommendations pertaining to this). It was interesting to note that most participants had advice to offer and would have liked to receive such advice prior to or after their own diagnosis.

### **5.2.7 Services that provide support to those infected and affected by HIV and AIDS**

In summarising the findings regarding the services available to individuals living with HIV/AIDS and their families, it was evident that services were available in this community. However, not a single participant stated that the existing services were sufficient. Another finding was that although some services existed in the field of HIV and AIDS, not all community members were aware of them, suggesting poor advertising of these services.

From the narratives of individual interviews as well as those from the focus group, it was apparent that while there were still gaps in services in this rural

community, the lack of awareness about the existing services hampered positive living.

Participants expressed the need for education and support groups, social workers, counselling, food parcels, a drop-in centre and a platform for individuals living with HIV/AIDS and their families to share their stories with the community.

One of the ways in which individuals living with HIV and AIDS felt supported by their families was having their loved ones access services in the community with them. Some family members reported accompanying their loved ones to clinic visits to demonstrate to them that they are not alone in their journey with HIV and AIDS, but face it as part of a family.

### **5.3 CONCLUSION**

Following on from the conclusions that arose from the findings, it is evident that being supported by one's family created resilience in many ways. The element of support affected the stigma experienced, types of support offered, fears and goals, willingness to disclose and experience of services available in the community. The experience of not being supported resulted in aspects of risk – for example, being more vulnerable to stigma and discrimination. Therefore the importance of family support in the midst of a HIV diagnosis is vital in order to face the HIV and AIDS journey with resilience, and to feel supported at a micro, mezzo and macro levels.

## **5.4 RECOMMENDATIONS**

The recommendations offered here are generated from the narratives of the participants. In keeping with the study topic, all the recommendations are based on factors that could increase family and community support in the area of HIV and AIDS. These recommendations are categorised under the various levels in the systems theory. In keeping with this model, recommendations overlap over more than one level, and interactions between the different systems levels are evident.

### **5.4.1 Micro Systems**

Recommendations under this heading dealt mainly with individuals, as per the systems theory. These include how individuals may be able to gain or receive the support they require in living with HIV and AIDS.

One factor that emerged from the narratives was that individuals living with HIV and AIDS need to accept the support offered by both their families and the community. On the other hand, they and their families need to be empowered to support one another. This suggests the need for education at both individual and family level to demonstrate how support can be sustainable within a family.

Some participants reported feeling discriminated against within their own homes after disclosure of their status. On-going family therapy, social work and other professional intervention could assist. Although pre and post HIV testing counselling is growing in South Africa, this should be made compulsory. Counselling could include the issue of disclosing one's status, and how to handle the situation if the outcome is negative. Social workers could also visit

homes to engage with the whole family. Professionals need to make themselves available at the grassroots level in order to walk alongside individuals living with HIV/AIDS and their families.

#### **5.4.2 Mezzo Systems**

Recommendations from the mezzo level related to this study included aspects of family support.

Family counselling is important, although this does not occur due to the shortage of professionals and social workers' heavy workloads. The researcher recommends that professionals enter the community to train lay counsellors - community members who are trusted and can take this role seriously, ensuring that confidentiality is protected. This will directly assist those infected and affected by HIV and AIDS and also empower community members.

The participants also noted the need for awareness of existing and further support groups. Such groups create a sense of unity and togetherness among individuals living with HIV and AIDS. It is important to realise that they are not alone in this journey and that the challenges and difficulties confronting them are not unique. The researcher believes that there is a definite need for support groups which could be extended to family members. It appeared that some family members felt overwhelmed by the task of supporting and caring for a loved one living with HIV/AIDS. It would be helpful to come together and share ideas on providing support.

### 5.4.3 Macro Systems

Kirst-Ashman (2003) notes that macro systems deal with the community at large. Recommendations in this regard are based on what services the community can provide. Following from the narratives, the following recommendations are made:

HIV and AIDS awareness days should be held where professionals and community members will participate. For example:

1. A dietician to talk about healthy eating (but being realistic as many people living with HIV/AIDS and their families cannot afford to spend much money on healthy food). Food hampers can be given out as examples of healthy eating (to all attendees or to selected people who participate and contribute to the discussion).
2. A social worker to talk about grants – how to apply for one (including child grants, disability grants, old age grants, etc.).
3. A medical doctor to talk about medication, side effects, etc.
4. A pastor or spiritual leader to talk about the spiritual side of living with HIV and AIDS.
5. A social worker or psychologist to talk about being able to support one another emotionally and talking to children about HIV and AIDS.
6. A person from the South African Police Service to talk about the effects of stigma around HIV/AIDS that the police have witnessed.
7. Community members to share their stories about living with HIV/AIDS – to show others that they are not alone in this journey.

In the event of community members not attending these awareness days for fear of being discriminated against and stigmatised, other options need to be considered such as education in schools. This would create a safe platform for awareness as individuals would not be singled out as attending an HIV/AIDS awareness day. The participants who suggested that there was a need for a platform for them to share their stories could also speak at schools about their experiences. Starting HIV and AIDS education at a young age (such as hearing first hand from an individual living with HIV/AIDS as opposed to learning about AIDS in a textbook or from a teacher who has not experienced the effects personally), might result in an increase in awareness.

Another way to share stories and give and receive support is through electronic services - many people, including those who are poor, have cell phones which affords an opportunity for relatively cheap and anonymous communication.

Following from the participants' narratives on gaps in services, the researcher recommends that the community creates platforms where different organisations can create awareness of the services they offer. This could include groups that offer counselling, food parcels, home visits, and social work services and so on. Some services are available in this community and community members should be making use of them. Platforms can be created at awareness days and even at schools where children would not be singled out for going to an awareness day about HIV and AIDS.

The need for food parcels was raised by many participants. The researcher recommends that alongside healthy food parcels, community members be taught how to grow their own vegetable gardens and sustain them. This would be more empowering than handing over food parcels. There is an organisation that visits communities, plants gardens for residents and educates them on



sustaining their garden. All that is required is a piece of land the size of a door. This organization could be invited on a regular basis (e.g. quarterly) to inspire gardening.

## 5.5 FURTHER RESEARCH

This research study explored factors influencing the support provided to individuals living with HIV and AIDS and their families. The following aspects need to be further explored:

- Disempowerment as a result of too much support. The researcher observed that some participants felt disempowered and would have liked to achieve things on their own. The question is how much support is sufficient and when does it get to the point of being too much?
- It would be interesting to study whether the way that an individual became infected with HIV, affected the type and amount of support received from the family.
- The study participants were overwhelmingly female. It would be interesting to analyse support among men, and how they handle caring for someone living with HIV and AIDS.
- While many study participants stated that the stigma in the community is not as bad as it was previously, many community members and even a few participants chose not to disclose their status for fear of stigma and rejection. There is a need to further explore and study the correlation between disclosure of one's status and being stigmatised because of it. This could include an investigation of whether stigma on the part of family members or the community has a worse effect on an individual living with HIV and AIDS.
- It would be interesting to gather narratives from individuals in the community who are known to stigmatise and discriminate against

individuals living with HIV and AIDS. Are these individuals HIV positive themselves and trying to hide their status, or are they individuals who do not want to be tested?

## **5.6 CONCLUDING REMARKS**

The researcher is confident that the research topic ‘Understanding family support: a study in rural KwaZulu-Natal’ has been holistically covered. The research topic has been analysed and discussed in correlation with the systems theory and the risk and resilience theory that underpinned the entire study. The aims and objectives of the study have been achieved by:

- Examining the family’s understanding of HIV/AIDS and support, and the impact of an HIV diagnosis on family relationships and support.
- Exploring elements of both risk and resilience and how these impact family and community support.
- Exploring individuals’ perceptions of how their family and community are or are not supporting them
- Understanding what services are available in the community and how they can promote and enhance individual and family support.

This study has enriched the researcher both in terms of the selected theoretical frameworks and the narratives of all participants. Theory is a necessary part of all research, but it is the interactions with, and in-depth narratives of the participants that provided a realistic view of support within families affected by HIV and AIDS. The resilience observed in many participants’ narratives – in the midst of support or lack thereof – was inspiring. The positive attitude of the participants and their zest for life was encouraging and reminded the researcher of priorities and purpose in life. As noted throughout this study, support begins

with disclosure. In conclusion, Lindiwe (a participant) reminds us that AIDS does not exist in isolation, and neither does support:

*“It is important for people to tell their families... if someone is affected, the whole house is affected. The whole family is affected and they need to help.”*

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## APPENDICES

### APPENDIX A

#### INFORMED CONSENT FORM FOR INDIVIDUALS LIVING WITH HIV/AIDS AND FAMILY MEMBERS

Dear Participants

##### **RE: RESEARCH STUDY CONSENT FORM**

My name is Kim Beattie and I am a registered social worker who qualified from the University of Johannesburg with an Honours degree in Social Work. I am currently completing my Masters degree with the University of Kwazulu Natal. Should you need to get hold of me, my contact number is 074 166 1617.

My Supervisor is Professor M. Kasiram (PhD in Social Work) from the Department of Social Work at Howard College, UKZN. She can be contacted on 031 260 7443.

My research topic is "Facing HIV and AIDS: Understanding Family Support in a Rural KwaZulu-Natal Community". By the end of the study, I hope to get an understanding of how an HIV/AIDS affects a family as a whole and to explore how the family can play a role in being a support for the individual affected with HIV/AIDS.

My objectives for the study are:

- To see what families think and feel about HIV/AIDS and to understand whether there have been changes in this since learning about the diagnosis of an individual in the family.
- To understand the role the family plays in supporting (and getting support) and how they are dealing with HIV/AIDS.
- To understand how the individual living with HIV/AIDS see their family's feelings towards them.
- To understand what challenges families face in coping with HIV/AIDS and how they are coping.

The reason why I chose to do this particular study is because I have a passion in working in the field of HIV/AIDS. I have met people living with HIV/AIDS who have inspired me with their strength and courage. I would like to see how families are coping with family members who are living with HIV/AIDS; how they are supporting them as well as how they are being supported.

Should you agree to participate in this study, it will mean being interviewed by me with the help of a translator. I will be talking to you about the topic and asking you some questions but at the same time, I want to hear your story. You do not have to answer any questions that you do not feel comfortable in answering. Interviews should not be more than two hours each. The nature of the questions will be slightly different for the two groups of people I would like to interview. These are:

- a) Individuals living with HIV/AIDS (10 adults over the age of 18)
- b) Families who have a family member living with HIV/AIDS (10 family members, related to individuals living with HIV/AIDS: either by blood or marriage)

Participating in this study will help me gain information that will be valuable in understanding HIV/AIDS from the family's perspective as well as from the individual's perspective. There is always a need for more research to be done in the area of HIV/AIDS. People who read the research may learn things that they never knew, therefore increasing awareness in certain areas around HIV/AIDS. This is a chance for you to tell your story and be heard, to share your opinions, thoughts and ideas. I would love you to be a part in this study. I will try my best to make the interview at a time and place that is convenient for you.

I will be taking notes during the interviews and may be taping some interviews should you agree to this. However, in the write up of my research, names will be changed to protect your identity. All material will be locked away and destroyed after five years. Confidentiality is taken seriously and this will be maintained throughout the whole process.

It is your decision to participate in this study and should you decide to withdraw from the study at any time, please be assured that you are free to do this. You are also not obliged to participate in this study should you choose not to and your decision will be respected.

Should you wish to get information on your rights as a participant, please contact Ms. Phumelele Ximba, Research Office, UKZN, on 031 260 3587.

#### **DECLARATION:**

I \_\_\_\_\_ (full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participate in the research project.

I understand that I am free to withdraw from this study at any time, should I so desire.

SIGNATURE OF PARTICPANT

DATE

\_\_\_\_\_

\_\_\_\_\_

## APPENDIX B

### INFORMED CONSENT FORM FOR FOCUS GROUP MEMBERS

Dear Participants

#### **RE: RESEARCH STUDY CONSENT FORM**

My name is Kim Beattie and I am a registered social worker who qualified from the University of Johannesburg with an Honours degree in Social Work. I am currently completing my Masters degree with the University of Kwazulu Natal. Should you need to get hold of me, my contact number is 074 166 1617.

My Supervisor is Professor M. Kasiram (PhD in Social Work) from the Department of Social Work at Howard College, UKZN. She can be contacted on 031 260 7443.

My research topic is "Facing HIV/AIDS as a Family: a Study in Rural Kwazulu Natal". By the end of the study, I hope to get an understanding of how an HIV/AIDS affects a family as a whole and to explore how the family can play a role in being a support for the individual affected with HIV/AIDS.

My objectives for the study are:

- To see what families think and feel about HIV/AIDS and to understand whether there have been changes in this since learning about the diagnosis of an individual in the family.
- To understand the role the family plays in supporting (and getting support) and how they are dealing with HIV/AIDS.
- To understand how the individual living with HIV/AIDS see their family's feelings towards them.
- To understand what challenges families face in coping with HIV/AIDS and how they are coping.

The reason why I chose to do this particular study is because I have a passion in working in the field of HIV/AIDS. I have met people living with HIV/AIDS who have inspired me with their strength and courage. I would like to see how families are coping with family members who are living with HIV/AIDS; how they are supporting them as well as how they are being supported.

I am interviewing individuals living with HIV/AIDS as well as family members who are related to an individual living with HIV/AIDS to gain an understanding of family support. During this study, I realised there was a need to facilitate a focus group meeting to gain an understanding of how community members perceive family support. This focus group will be a once off meeting, consisting of 8 members of the community. I will be asking some leading questions, based on

the information I have gained from individual interviews, and hope to generate discussion around this. I want to hear your experiences, your stories and your opinions and views about the topic. This will help me in gaining a holistic view of my topic and adding to my existing data. I appreciate your willingness to be involved and participate. This group meeting should not last longer than 2 hours. Please feel free to talk in English or Zulu. There will be an interpreter available to translate questions and your answers for me.

Participating in this study will help me gain information that will be valuable in understanding HIV/AIDS regarding family support from the community's perspective. There is always a need for more research to be done in the area of HIV/AIDS. People who read the research may learn things that they never knew, therefore increasing awareness in certain areas around HIV/AIDS. This is a chance for you to tell your story and be heard, to share your opinions, thoughts and ideas. I would love you to be a part in this study.

I will be taking notes during the focus group meeting and will be recording the group session should all participants agree to this. However, in the write up of my research, names will be changed to protect confidentiality. All material will be locked away and destroyed after five years. Confidentiality is taken seriously and this will be maintained throughout the whole process.

It is your decision to participate in this study and should you decide to withdraw from the study at any time, please be assured that you are free to do this. You are also not obliged to participate in this study should you choose not to and your decision will be respected.

Should you wish to get information on your rights as a participant, please contact Ms. Phumelele Ximba, Research Office, UKZN, on 031 260 3587.

#### **DECLARATION:**

I \_\_\_\_\_ (full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participate in the research project.

I understand that I am free to withdraw from this study at any time, should I so desire.

SIGNATURE OF PARTICPANT

DATE

\_\_\_\_\_

\_\_\_\_\_

## APPENDIX C

### INTERVIEW SCHEDULE: INDIVIDUALS LIVING WITH HIV/AIDS

Name:

Age:

Gender:

Employment status:

Members in the household:

Date of diagnosis:

CD4 count (then and now):

Reason for testing:

Medication:

The questions below were used as a guide as a semi structured interview schedule was used.

1. How did you feel when you first found out you were HIV positive?
2. How did your family respond when you disclosed your status?
3. What support (if any) did you get from your family?
4. Did your relationship with your family change from how it was before you disclosed to after, if so in what ways?
5. Strengths and challenges seen in your family's support?
6. What services are offered to people infected and affected by HIV and AIDS in this community? What services is there a need for?
7. Experience of stigma in the community and in the household?
8. Fears, goals and living a healthy life.
9. Any advice to the broader community?



## **APPENDIX D**

### **INTERVIEW SCHEDULE: FAMILY MEMBER OF AN INDIVIDUAL LIVING WITH HIV/AIDS**

Name:

Age:

Gender:

Relationship to family member who is living with HIV/AIDS:

The questions below were used as a guide as a semi structured interview schedule was used.

1. Do you think it is possible for someone living with HIV/AIDS to live a “normal” life? How so?
2. When and how did you find out your loved one was HIV positive?
3. How did you feel and what was your reaction?
4. How was your relationship with your loved one before they told you of their diagnosis?
5. In what ways has your relationship changed towards your loved one since learning of their diagnosis?
6. What is your deepest worry about supporting your loved one?
7. How do you support your loved one emotionally, physically, financially etc?
8. How do you deal with the stigma in the community that affects you and your loved one?
9. How open are you with the community about your loved one’s diagnosis?
10. What challenges do you face in supporting your loved one?
11. What could be done in the community to help you get support and give support?

## APPENDIX E

### INTERVIEW SCHEDULE: FOCUS GROUP DISCUSSION

Name:

Age:

Gender:

The questions below were used as a guide as a semi structured interview schedule was used.

(The researcher will introduce her study and go through the consent forms with participants before they sign them. The researcher will also explain the importance of having this once-off focus group meeting to add to data collected from individual and family member interviews and to gain the community perception around family support)

1. How big a problem do you think HIV and AIDS is in your community?
2. Do you think it is important for people to tell their friends and family when they find out they are HIV positive and would you do the same?
3. In what ways do you think your community is becoming more open and accepting of HIV and AIDS? – or more stigmatising and discriminating?
4. How does your community treat people living with HIV and AIDS?
5. What are the chances for people living with HIV and AIDS to live a “normal” life?
6. What support is there for people living with HIV and AIDS within their families?
7. In my study so far, I have heard that many families do support their family members living with HIV/AIDS. Do you think this is true?
8. Do you think it is easy to support a loved one living with AIDS? Why or why not?
9. What type of support do you think families find most difficult to give to their loved ones living with HIV/AIDS? Financial (why?) Emotional (why?) Spiritual (why?) Physical (why?)
10. Tell me about the stigma around HIV and AIDS in this community.
  - Do you think this affects the support that families give to their members living with HIV and AIDS?
11. What do you think hampers or stops family support?
12. What could be done to increase family support and community support?
13. Examples seen in the community of support vs non-support?
14. What services and resources are available in this community to support individuals living with HIV/AIDS and their families?
  - Where do you see a need for services? Where are the gaps? What could be done?

## **APPENDIX F**

### **ETHICAL CLEARANCE**

22 March 2013

**Professor Steven Collings (Chair)**

**c/o Ms. P Zimba**

**Humanities & Social Sciences Research Ethics Committee**

**Westville Campus**

Dear Mr Collings

**Protocol reference number: HSS/0989/012M**

**Project Title: Facing HIV and AIDS: Understanding family support among communities in Rural KwaZulu-Natal**

Your letter dated 15 November 2012 was received and has reference. Please see the following in response to the conditions set out for approval.

1. The location for the study was changed as the researcher was unable to gain a sample from the clinic as stipulated in the original proposal. The study is now being conducted in a selected day-care centre for physically disabled persons. The identifying details of the Centre however, will not be disclosed within the report to preserve anonymity.
2. This is not applicable any longer as the location of the study has changed. However, the researcher will get a confidentiality agreement signed by the manager of the day-care centre who helps the researcher to gain her sample as she is a well-known community leader. The premises of the day-care centre are also used for the purpose of interviews.

3. Consent forms have been updated to indicate that the all participants need to be 18 years or older to be included in the study. Please see typing in bold on attached letter.
4. Timeframes have been reworked accordingly as follows:

<b>Final draft of Chapter 2</b>	29 March 2013
First draft of Chapter 3	12 April 2013
<b>Final draft of Chapter 3</b>	26 April 2013
First draft of Chapter 4	10 May 2013
<b>Final draft of Chapter 4</b>	24 May 2013
First draft of Chapter 5	7 June 2013
<b>Final draft of Chapter 5</b>	21 June 2013

Yours faithfully,

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Ms Kim Beattie

Masters Research Student

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Professor Madhu Kasiram

Supervisor