The Experience of Disclosure in Fathers diagnosed as HIV Positive

by

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Submitted in partial fulfilment of the requirements for the degree

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April 2008

Abstract

The goal of the research was to investigate how fathers diagnosed HIV positive experienced disclosure. Gaining an understanding of the issues that fathers' face regarding their decision whether or not to disclose their status, as well as to whom they decide to disclose their status, will contribute to an understanding of the complexities of disclosure. This information could then be used to set up strategies to assist fathers in dealing with HIV and issues regarding disclosure.

This research was undertaken from a phenomenological position, using an interpretive framework. Because the research was qualitative in nature, with the primary objective to understand an individual's personal and subjective experience, the sample size was restricted to four participants. This provided the opportunity to conduct in-depth interviews. The sampling criteria used to identify participants was the following; fathers, living with their 'families', who were residents of Diepsloot, diagnosed HIV positive and with a conversational level of English equivalent to Grade 10.

The unique stories of each research participant were systematically presented to illustrate the collection, analysis and synthesis of the data. The phenomenological method of data analysis is ultimately aimed at developing a composite description of the meanings and essences of the fathers' experiences of disclosure.

The main finding of the research was that disclosure of an HIV positive status appears to be an extremely difficult experience. With disclosure comes both relief and a sense of shame and loss of face, which for some of the fathers interviewed, seems to undermine an already fragmented sense of self. For they, like all men, aspire to earn and enjoy respect - from their partners, children, parents, peers and community. However, all the fathers in this research project had the courage to disclose their HIV positive status to others and directly to the researcher. In so doing, they not only earned the researcher's respect, but were availing themselves of a unique opportunity to talk about something very personal and significant in their lives. It is hoped that their positive experiences of disclosure will encourage others in South Africa to do the same.

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CHAPTER 1

INTRODUCTION

1.1 BACKGROUND

The Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) are global phenomena. However, the epidemic is not the same all over the world. Whiteside and Sunter (2000) highlight that most people infected with HIV – an estimated 95% – live in the developing world. They predict that:

> "the infection rate will continue to rise in countries where poverty, poor health systems, lack of education, inequality and limited resources for prevention and care, fuel the spread of the virus" (Whiteside & Sunter, 2000, p 38).

South Africa reportedly has the most severe HIV/AIDS epidemic in the world (AIDS Foundation South Africa, 2006). The UNAIDS 2006 Report on the global AIDS pandemic estimates that in 2005, approximately 5.5 million people were HIV positive and that there were 320,000.00 AIDS-related deaths in South Africa – more than 800 people every day (UNAIDS/WHO, 2006).

Although the situation is severe, great progress has been made in the last few years with the rollout of free anti-retroviral drugs and an ongoing media campaign to educate the public. Also noteworthy is the work that has been done by numerous Non-Government Organizations (NGOs) to stem the tide.

I became involved in HIV/AIDS counselling through the Bryanston Methodist Church in February 2005, when I joined a weekly support group for people diagnosed HIV positive. The group met in Diepsloot, a semi-informal settlement north of Johannesburg, and was attended by approximately 15 women. The women were greatly strengthened by the disclosure of their HIV positive status within the group and the normalisation of their experiences. They were also empowered to live healthy and productive lives.

My second exposure to people living with HIV occurred during 2006 when I worked as a Masters student at Serithi, a project for pregnant woman recently diagnosed with HIV, at Kalafong Hospital in Atteridgeville, Pretoria West. Again I witnessed the empowerment of women through their ability to disclose their HIV status in a safe environment, by gaining greater knowledge about HIV/AIDS and benefiting from the support of others in a similar predicament.

A dominant theme that emerged from both groups was the difficulty women experienced in disclosing their HIV status to their partners, husbands and fathers. There was a real sense that men were unapproachable concerning the subject of HIV and AIDS, despite the possibility that in many cases, these men may have infected the women concerned.

The women also indicated that their partners were reluctant to go for HIV-testing and would possibly not disclose their status. Another theme that emerged was thus that while women had a tendency to test, seek support, and discuss the challenges of living with HIV, men seemingly did not. This is supported by research indicating a fear among men to test, as their HIV positive status may be disclosed through testing and result in discrimination (Pembrey, 2007).

An article in *The Star* newspaper entitled: "A place for men to talk about HIV" refers to research highlighting a serious lack of programmes catering for men living with HIV (Maphumulo, 2005, p.7). This may confirm that men are more in denial about the HIV pandemic or else suggest that men have other strategies to assist them in dealing with HIV.

I became increasingly interested in conducting research among men diagnosed HIV positive and living in settlements like Diepsloot, in order to better understand their experiences of HIV and disclosure. I chose to research fathers as opposed to men, because fathers are defined in terms of relationships and role fulfilment within a family. In an HIV context it is important to know how disclosure of a father's HIV positive status will impact his role within the family and community.

Diepsloot is the location for the research I undertook due to my established connections within the community. It is also a rapidly expanding semi-informal settlement which is representative of many similar settlements around towns and cities throughout South Africa. Diepsloot has an estimated population of 150, 000.00 (O'Reilly, 2006). It comprises high-density shack dwellings as well as recently completed low-cost houses. The social ills that residents face include high rates of unemployment, poverty, crime and violence. Basic amenities such as running water and electricity are in short supply. There are also a limited number of health clinics and social service facilities. These are all risk factors that make such communities more susceptible to the impact of HIV/AIDS (AIDS Foundation South Africa, 2006).

1.2 RESEARCH QUESTION

The research aimed to answer the following question: "How do fathers diagnosed HIV positive deal with disclosure of their HIV-status to their partners, family, friends, work place and local community? And how does disclosure impact upon their lives?"

1.3 GOALS OF RESEARCH

The goal of the research was to investigate how fathers diagnosed HIV positive experienced disclosure. Gaining an understanding of the issues that fathers' face regarding their decision whether or not to disclose their status, as well as to whom they decide to disclose their status, will contribute to an understanding of the complexities of disclosure. This information could then be used to set up strategies to assist fathers in dealing with HIV and issues regarding disclosure.

1.4 RESEARCHER ASSUMPTIONS

In conducting the research, a number of assumptions were made. These included the following:

- The researcher would have a significant impact on the research process, due to the socio-economic and cultural differences that exist between himself and the research participants.
- The research participants would be forthcoming and share their own experiences.
- The questions formulated by the researcher would elicit sufficient data for further analysis.
- The data analysis would reveal information that could be considered valid and reliable, which would facilitate greater knowledge and understanding.

1.5 DEFINITION OF TERMS

1.5.1 Experience:

The research was undertaken from a phenomenological perspective which places value and importance on the unique and subjective descriptions of the research participants, as they related their experience of HIV disclosure. Through an analysis of the phenomenological data, the meaning and essence of their experiences of HIV disclosure were highlighted and better understood.

1.5.2 Disclosure:

Disclosure is the revelation of personal information. In this study it refers to the disclosure of one's HIV positive status.

1.5.3 Fathers:

Fathers in this study were males who have biologically fathered children, whether or not they have fulfilled their roles and responsibilities as fathers on a daily basis in the context of a family.

1.5.4 Diagnosed:

Diagnosed is a medical term which is used to indicate that a scientific investigation has been undertaken to prove, and supported by physical evidence, that a certain condition does or does not exist, in this case HIV.

1.5.5 HIV Positive:

HIV positive means positively tested for the Human Immunodeficiency Virus.

1.6 RESEARCH PARADIGM

The research was undertaken from a phenomenological position, using an interpretive framework. This approach was well suited to the research question as the aim was to better understand the unique experiences that fathers diagnosed with HIV have regarding disclosure.

1.7 RESEARCH PROCESS

The literature review identified a gap in the body of knowledge relating to the research topic. Research participants who met the required criteria were identified and contacted. Once they had signed the informed consent letters, they were individually interviewed in order to gain the phenomenological data on disclosure. This was then transcribed and analysed according to a prescribed procedure, which resulted in the findings presented in this report, with reference to the literature review and research question.

1.8 STRUCTURE

Chapter One is the introductory chapter to the research report and provides a background to the research, the research question, and the goals of the research and the structure of the report.

Chapter Two is the literature review, which firstly provides an overview of the current body of knowledge that informs the research, and secondly identifies any gaps in existing knowledge, which may be addressed by the research.

Chapter Three is the research inquiry, which describes the theoretical framework and methodology used to conduct the research. It covers the research context, participants, material and ethics.

Chapter Four presents the research findings based upon the analysis of the phenomenological data gathered from the research participants.

Chapter Five is the conclusion, which summarises the research and discusses the findings in relation to the literature review and the research question. It also considers the limitations of the study and recommendations.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The literature review is a means of identifying, justifying and positioning a research topic within the current body of knowledge (Henning, van Rensburg & Smit, 2004). Through related research and the theories that underpin them, new insights along with a greater complexity of understanding of the research topic, can be developed.

In this chapter an overview of the existing literature on HIV, disclosure and fathers is given as a background to the current research.

2.2 HIV AND AIDS

A great deal of literature has been produced on HIV/AIDS over the past 20 years, since the discovery of the virus in 1981. HIV stands for the Human Immunodeficiency Virus, a virus that is specifically designed to attack and replicate through the human immune system, via CD4, cells which protect the body from infection (Whiteside & Sunter, 2000). Once HIV enters the body it is a matter of time before the viral load increases and an individual's CD4 count declines from a healthy level of 1 200 cells per micro-litre of blood, to below 200 (Whiteside & Sunter, 2000). It is at this stage that an infected person will very likely experience an increasing number of opportunistic infections that commonly include influenza, pneumonia and tuberculosis. It is also at this stage that a patient would be classified as having AIDS. AIDS stands for Acquired Immunodeficiency Syndrome.

Whiteside and Sunter (2000) point out that HIV is relatively difficult to transmit, as the virus has to enter the body in sufficient quantities for infection to take place. In other words it must pass through the skin or mucous membranes and enter the bloodstream.

The main modes of transmission, in order of importance, are:

- Unsafe sex
- Mother to child transmission (MTCT)
- Intravenous drug use from infected needles
- Blood transfusions
- Contact with open bleeding wounds

In South Africa HIV is primarily transmitted through heterosexual sex. It is therefore the sexually active population, between the ages of 15 and 49, that is predominantly affected (Desmond & Desmond, 2004). The majority of this age group are parents who will eventually succumb to the disease, creating an ever growing number of orphaned children and child-headed households. How parents cope with living with HIV and issues of disclosure have significant consequences for both the wellbeing of their children and the containment of the disease.

2.2.1 Prevention and Treatment of HIV/AIDS

Currently there is no known cure for HIV/AIDS as the virus cannot be eliminated from the body, once infected. However, a number of medicines, called Antiretrovirals or ARVs, are now able to significantly delay the onset of full-blown AIDS and death. ARVs help contain the reproductive process of the virus, enabling one's immune system to recover (Gennrich, 2004).

The South African government was at first reluctant to make ARVs freely available through the public health sector. Gennrich (2004, p. 34) writes that this may have been due to a number of factors, including the following:

- Distribution of ARVs was contrary to the government's economic policy of increasing privatisation and reducing the budget allocation.
- Acknowledgement of the challenging task to deliver ARVs nationally.
- Recognition that once begun, there would be no turning back.

- The government being somewhat caught up in a neurosis of denial that gripped the country.

As the scale of the pandemic increased, the government realised the need to act more decisively. On 19 November 2003, the plan for comprehensive care and treatment of people living with HIV and AIDS was launched in South Africa (Gennrich, 2004). This included the provision of free antiretroviral treatment to those who could not afford them. The plan also involved an increased education programme to encourage voluntary counselling and testing (VCT), as well as improving prevention efforts.

> Gennrich (2004, p. 35) writes, "It is hoped that the offer of really comprehensive and effective treatment will encourage increasing numbers to come forward for testing, which in turn is likely to reduce the new infection rate as people will be counselled about the need to protect those around them from becoming infected, as well as slowing down the death rate".

Whilst voluntary counselling and testing for HIV should be promoted as the first important step, without disclosure little benefit can be realised (Norman, Chopra & Kadiyala, 2005).

2.3 DISCLOSURE

2.3.1 What is disclosure?

The definition of disclosure is "the action of making something known, or a thing, especially a secret, that is made known" (Oxford Advanced Learner's Dictionary, 1995, p. 329). Disclosure is the ability to share deeply personal information with another person or group of people. Issues of trust, safety and confidentiality are critical.

Thom (2003) refers to HIV/AIDS as "The Silent Killer" spreading insidiously like a cancer, because no one wants to talk about it. A comment by Johannes, a 28 year-old South African, known to his friends as "Ghetto" and who featured in a documentary about living with HIV sums it up by saying:

"The most difficult part of this disease for a person is to be quiet. If you could try to talk more about this AIDS. It's almost like cancer, but people talk about that. Why can't they talk about this? I think more people are dying very early because this thing is killing them inside, alone. They don't speak out" (Gibbs, 2000).

According to Norman et al. (2005) an individual's experience of the disease is largely informed by the decision of whether or not, how and to whom to disclose their status.

2.3.2 Costs of HIV Disclosure

The literature indicates a strong case for increased levels of disclosure around HIV/AIDS, but acknowledges that it is a high risk decision (Zea, Reisen, Poppen, Bianchi & Echeverry, 2005). Paxton (2002) writes about disclosure being a very stressful experience as the discloser exposes him or herself to the perceived and sometimes real stigma of friends, family and community. Stigma is a significant factor that restricts people living with HIV from disclosing their status. Skinner and Mfecane (2004, p.157) point out that "fear of discrimination limits the possibility of disclosure even to potential important sources of support such as family and friends." The stigma of living with HIV is well described in prevailing literature (Akani & Erhabor, 2006).

The threat of violence, particularly for women, has been identified as a reason not to disclose by Vetten and Bhana (2006). However, males also fear for their personal safety as reports of social ostracism, abandonment and even murder due to disclosure of HIV status reveal (Taylor & Malan, 2006). Pembrey (2007) notes that South African men show a particular concern for being stigmatised and discriminated against for being HIV positive, as this may impact upon their ability to find employment and provide for themselves and their families. Akani and Erhabor (2006) confirms that barriers to HIV serostatus disclosure include fear of abandonment, stigmatisation, victimisation, and the possibility of confidants telling others, as well as fears of accusations of infidelity.

Campbell, Foulis, Maimane and Sibiya (2005) refer to stigmatisation as politically orchestrated to maintain the status quo, undermining the voices of marginalised groups such as young people, women and the poor. They state:

> "various forms of stigma are united by the way in which they serve to support systems of social inequality and social difference and to reinforce the interests of powerful social actors seeking to legitimize their dominant status" (Campbell et al., 2005, p. 808).

2.3.3 Benefits of Disclosure

Whilst there are many social factors at work to create a hostile environment for disclosure to take place, the benefits of disclosure are significant. These are discussed below:

1. Psychological Wellbeing

Despite the high risks associated with HIV disclosure, there is a potentially higher price to be paid for non-disclosure. It is widely known and understood that suppressing thoughts or emotions about difficult experiences can negatively impact a person's health and lead to stress-related problems (Paxton, 2002). As one HIV participant in a study said: "When you haven't disclosed, you are always worried." (Norman et al., 2005, p. 5).

The knowledge of one's HIV status is burdensome and research indicates that the experience of disclosure represents a lifting of this burden (Norman et al., 2005). Paxton (2002) supports this notion, referring to the paradox of 'coming out' and facing a perceived stigma only to find the experience to be psychological liberating. Zea et al. (2005) researched the patterns of HIV disclosure among gay and bisexual men and the consequent costs and benefits in terms of mental health and wellbeing. They found that disclosure elicited increased social support, leading to improved mental health.

2. Economic and Social Support

Serovich (2001) sees disclosure as the gateway to education, healthcare and social support, which results in improved physical health. In South Africa, this would

include home-based care and HIV specific social grants. In a study of two distinct communities, one in a peri-urban setting and another in a rural setting in South Africa, Norman et al. (2005) found that disclosing to loved ones and professionals generally meant increased access to both material and emotional support. This research indicates that whilst loved ones usually take time to come to terms with the news, many express concern and a willingness to help. This study also found family members to be the most supportive, both materially and emotionally. However, in these communities, neighbours also bolstered family resources or filled the chasm left by deceased family members, an encouraging sign of ubuntu (Norman et al., 2005).

Norman et al. (2005) found that another positive spin-off of disclosure is that people who are taking medication don't have to do so surreptitiously. Family support has also been shown to increase adherence to the complex medical regimes required (Norman et al., 2005). From a medical service delivery point of view, the creation of an enabling environment for disclosure of HIV status is essential, and a necessary prerequisite to acquiring economic and social support (Serovich, 2001).

3.   Activism and Destigmatisation.

Research indicates that through the process of disclosure and the support gained, people feel empowered to assume positive leadership roles and become more active in the fight against HIV (Norman et al., 2005). They describe how HIV disclosure presents people with an opportunity to educate others and challenge stigmatisation within their social network and community. Disclosure to family members is nearly always combined with an attempt at education regarding HIV to alleviate stigma and increase understanding of their own condition (Norman et al., 2005).

Medley, Garcia-Moreno, McGill and Maman (2004) reviewing research on women disclosing their HIV positive status, found generally positive outcomes from disclosure. They indicate that perceived stigma is invariably greater than actual or experienced stigma. Researchers have also found that those in contact with people living with HIV showed a more tolerant attitude towards the disease and those infected (Takai, Wondkhomthong, Akabayashi, Kai, Ohi & Naka, 1998).

Campbell et al. (2005) believe that local communities need to engage in more critical thinking about why stigma exists and how it is socially maintained, in order to challenge it at its core. They write that:

> "community participation has a key role to play in promoting forms of critical consciousness that both expose and challenge the unequal social relations drawn on and sustained by stigma" (Campbell et al., 2005, p. 814).

Paxton (2002) believes that public disclosure can also be a powerful tool in reducing stigma, breaking the silence and helping individuals overcome fear and prejudice. Clearly, it involves courageous leadership, as was demonstrated in 2000 when Justice Edwin Cameron, a prominent South African judge, publicised his HIV positive status (Pembrey, 2007). The response from the public was largely positive.

> "Disclosure as a means to eradicate stigma as well as to increase resistance is thus a powerful tool in protecting the next generation from similar experiences of discrimination and vulnerability" (Norman et al., 2005).

4.   Reducing the spread of HIV.

Van Niekerk (2005, p.703) supports the need for transparency: "People living with HIV and AIDS should be able to live openly and experience compassion and support within their communities." Van Niekerk's view is that the more people are able to disclose their status, the more personalised the risk and experience of HIV/AIDS will become, with efforts to reduce the spread of the disease being more effective.

There is growing evidence that disclosure of HIV status is an essential behavioural change that will reduce the incidence of HIV (Norman et al., 2005). Knowing someone with HIV is also positively associated with increased condom use and negatively with multiple partners and casual sex partners (Ijumba, Gamieldien, Meyer & Morroni, 2004).

2.3.4 Negotiating Disclosure

Disclosure of one's HIV positive status is a complex issue. Norman et al. (2005) describe a temporal stage, between non-disclosure and full or public disclosure, during which time a person manages their HIV disclosure. This is usually a period of struggle before disclosure to those nearest and dearest, and can sometimes take up to two years. This management of HIV disclosure involves people expending great deals of energy to avoid detection (Clark, Lindler, Armistead & Austin, 2003).

Appreciating the difficulties individuals have in deciding when, to whom, and how to disclose their status, Serovich (2000, p. 367) formulated six stages of disclosure:

- Make a disclosure list of all people considered for possible disclosure.
- Evaluate the nature of each relationship for levels of satisfaction.
- Assess the recipient's unique circumstances to determine the appropriateness of disclosure.
- Assess the recipient's HIV knowledge and possible reactions.
- Question motive for disclosure to each person.
- Make a decision and pick a suitable time and place for disclosure to occur.

Serovich (2000) points out that disclosure is not a once-off event but rather an ongoing process that unfolds over the life of the infected person. This highlights that there is a time and place for everything and that disclosure is a very personal decision based on many complex factors.

During the management of a person's HIV positive disclosure, 'tactics' are applied to maintain relationships, while at the same time feeling out the impact an HIV positive disclosure would have on various relationships (Norman et al., 2005). Norman et al. (2005) indicate that the strategies used to manage and counteract the fear of discrimination versus the need to disclose need to be better understood. One of the primary tactics employed is to assess how an intimate partner may react to the disclosure.

The fear of losing a valued relationship makes HIV disclosure a very real way to test levels of commitment (Derlega, Winstead, Greene, Serovich & Elwood, 2004). An interesting tactic described in the literature is to facilitate alternative ways for a partner to find out, rather than through direct disclosure (Norman et al., 2005).

2.3.5 Factors Influencing Disclosure

A number of theories have been developed to explain why and when people disclose their HIV positive status. One of the main theories, called the Disease Progression Theory, contends that it is the disease's progression that triggers disclosure (Kalichman, 1995). Its premise is that as the disease progresses from HIV to AIDS it becomes harder for people with HIV to hide their status. As physical symptoms and visits to the hospital increase, so the need for additional resources necessitates disclosure (Kalichman, 1995). This theory was developed prior to the advances in anti-retroviral medication now available, when disease progression was more consistent and predictable. Ironically, the more uncertain the course and prognosis of the disease has become, the more difficult it is to predict disclosure patterns.

Another theory, developed by Serovich (2001) is known as the Consequence Theory. This theory postulates a relationship between disease progression and disclosure based upon the perceived consequences of disclosure. It proposes that as the disease progresses, so do the pressures to evaluate the consequences of disclosure. If the rewards for disclosing outweigh the associated costs then disclosure will take place. Hence, Consequence Theory says that disclosure is based upon a careful analysis of the positive and negative consequences associated with the event (Serovich, 2001). According to Norman et al. (2005) the decision to disclose hinges upon an individual's own perceptions and the local context of HIV/AIDS. Where individuals are able to enhance their current circumstances, they are more likely to disclose.

2.3.6 Patterns of Disclosure

It does appear from the research that men are still dragging their heels when it comes to disclosure. Akani & Erhabor (2006) found that females are significantly more likely to disclose (60%) than males (40%). As mentioned previously, this could well

be explained by men's greater fear of stigmatisation and discrimination on socio-economic grounds.

The target audience for disclosure has also been researched. Kalichman, DiMarco, Austin, Luke and DiFonzo (2003) investigated patterns of disclosure to family and friends of men and women living with HIV. They found that friends were disclosed to more than family members, with fathers and brothers disclosed to the least. Hence, men are perceived as being less supportive. It may be argued that context has great relevance as this study was conducted in a Western society. Visser, Neufeld, de Villiers and Forsyth (in press) found that African women rarely disclose outside their immediate family, except where formal support groups are available.

Bor, du Plessis and Russell (2004) refer to a 'self-defined' family, which is not necessarily the biological family members, but those seen as a person's primary social support system. This could explain why HIV support groups are so important and effective in helping people living with HIV.

2.3.7 Conclusions

Material and emotional support is only accessible if people are willing and able to disclose their HIV positive status. The challenge is therefore to create a climate within families, communities and institutions in South Africa where people feel safe and encouraged to self-disclose. The aim of this research project was to understand how fathers diagnosed HIV positive experienced disclosure, what informed their decisions to disclose, what barriers they encountered and what response they had following their disclosure.

2.4 DISCLOSURE OF FATHERS

2.4.1 What is a Father?

The Oxford Advanced Learner's Dictionary (1995, p.515) describes a father as "a male parent, the progenitor or originator". As such a father can be viewed as biologically related to a child through procreation. Anthropologist, Godelier (2004) says that the fathering role is what distinguishes human society from our closest biological relatives, chimpanzees, who appear to be unaware of their 'father' connection.

With the steady rise in divorce rates worldwide and the associated decline in the traditional marriage, Richter (2006) refers to a change occurring in the way men's roles in the family and the care of children are perceived.

> "Men are now more likely than ever to live separately from their children and to father outside marriage. Many men experience fatherhood as a sequence of relationships with children, some biologically theirs and some the children of spouses and partners" (Bachrach & Sonenstein, 1998, p. 1, cited in Richter (2006)).

The context of fathering has changed, requiring men to fulfil the role of father in many non-traditional settings. Tamis-LeMonda and Cabrera (1999, p.3) state the following;

> "New types of fathers are being acknowledged – in step, recombined and cohabiting families. All of these family types call for men – even those not biologically related – to increase their involvement in the lives of children."

As the number of female-headed households increases throughout the world, there has been a significant shift in focus to the wellbeing of children, and how the role of a father critically impacts upon the healthy development of children as human and social capital (Richter, 2006). There is a growing body of evidence that supports the important role that fathers play in the healthy development of children. Some studies even suggest that it is the father's involvement and responsiveness to the emotional

needs of his children that has the greatest long-term impact on a child's development (Grossman, Pollack & Golding, 1988). The recently introduced Children's Act (2005) is aimed at encouraging the active participation of fathers in the lives of their children, whatever the circumstances.

Richter (2006) confirms that research on fathering has moved from a simple family structure approach towards a focus on the quality of the relationships within the family. This includes how the father behaves, what the parent relationship is like, and how the father and child interact. The Fatherhood Project currently being undertaken by the Human Sciences Research Council of South Africa "aims to recognise, encourage and support men's care and protection of children" (HSRC, 2005). The move comes at a time when a negative picture of men in South Africa has been painted, given many stories of neglect, violence and abuse that emerge through the media.

2.4.2 The Importance of a Father/Child Relationship

"The child is father to the man" is the title of a poem by Gerard Manly Hopkins (1918). This short, but profound sentence succinctly encapsulates the power of role modelling. The social learning theory of Bandura (1977) supports the significance of observing and modelling the behaviours of others as a means of achieving mastery over one's life circumstances. Bandura (1977, p. 22) stated;

> "Learning would be exceedingly laborious, not to mention hazardous, if people had to rely solely on the effects of their own actions to inform them what to do. Fortunately, most human behaviour is learned observationally through modelling: from observing others one forms an idea of how new behaviours are performed, and on later occasions this coded information serves as a guide for action."

The role of a father undoubtedly looms large in the life of a child. Simpson (2005) who investigated the relationship between Zambian fathers and sons, from the grown sons' points of view found that the father's example was always in the son's mind, even though he might question his father's conduct. Simpson (2005, p. 571) concurs

with Hopkins, the poet, when he writes that "childhood experiences were undoubtedly central to the making of men as engendered beings."

Erikson (1980, p.103) in his stages of human development refers to 'generativity' as an adults' natural desire to have and nurture children. He saw it as fundamental to making the world a better place for the next generation. From this perspective, a father's involvement in the care of children is not only important for the children, but is also an important aspect of a father's personal growth (Richter, 2006). Richter (2006) cites Marsiglio and Day (1997) who ran an outreach programme for low-income fathers, which demonstrated that assisting a group of fathers to get more involved with their children was a strong incentive for the men to develop themselves and become more involved in their community.

The challenge is therefore to find ways and means of increasing men's exposure to their children, because through connecting with children more, men's development and sense of wellbeing is enhanced, and can be the catalyst for a more considerate and nurturing individual (Richter, 2006).

> "We need to recognise that fathers and men in families represent one of the most important – yet in many cases untapped – resources for children's wellbeing. Children in difficult circumstances, including poverty and economic stress may depend even more on good parenting, including good fathering, than those in more comfortable circumstances" (Richter, 2006, p. 64).

Whilst such a paradigm shift is sorely needed, attention must also be given to the economic, political and structural forces that inform gender identity, often seriously limiting the choices young people can make about their identities and future (Simpson, 2005).

2.4.3 Unique Challenges in South Africa

The role of men as fathers in South Africa has been brought under the spotlight, due in part to the massive HIV/AIDS pandemic affecting this country. Research shows that men have played a major role in spreading HIV and they therefore need to be

involved in efforts to stem the tide of HIV and AIDS (Gennrich, 2004). A number of systemic factors are thought to be responsible for this.

1. Migrant Labour System

The migrant labour system, which predominantly involves men moving away from home to find work, has been in existence for over 100 years (Gennrich, 2004). This has resulted in family dislocations, changing sexual relations, lack of father role models and an increase in illegitimate births. The breakdown in traditional family structures, which provided protection to women and children, has exposed the more vulnerable members of society to the possibility of abuse and coercion (Gennrich, 2004).

One of Simpson's (2005, p. 572) research participants who grew up with an absent father commented: "We just used to see my father in chapters." Many men who have grown up without a father nearby express feelings of bitterness. Experiences of abandonment, physical vulnerability and lack of provisions are at the root of this bitterness. In South Africa, approximately 60% of children do not live with their fathers (Simpson, 2005). This absence and neglect of fathers in the lives of their children presents significant challenges. However, as Cabrera, Tamis-LeMonda, Bradley, Hofferth and Lamb (2000) point out that it would be unwise to overlook the significant contribution that non-resident, non-custodial, low-income and unemployed fathers make to the lives of their children. To do so would be to further alienate an already marginalised section of society.

2. Gender Inequality

According to Lesejane (2006), many African men, despite living in a modern age, are still rooted in a traditional African cultural value system. Under this system, patriarchy is considered the norm, with the role of the father as head and final arbiter in the family. Such a system might well be regarded as sexist by modern-day standards, as women are subjugated by men. However, these traditional structures were significantly disrupted with the arrival of colonialism, apartheid and westernization, but their influence still remains (Lesejane, 2006).

Lesejane (2006) says the current problem is that 'African patriarchy' has been misinterpreted and applied in coercive and destructive ways. He refers to "a new patriarchy of male dominance without obligations and reciprocity," in which authority is not balanced with responsibility (Lesejane, 2006, p.179). He argues that without the traditional systems in place to support, channel and challenge men's behaviour, their abuse of power has been somewhat inevitable, although not condonable. He believes that there is much that is of value in the African cultural system which could help 21st century African men to fulfil their responsibilities.

> "The image of a father as a patriarch, somebody who cares for, nurtures, leads, guides, and is a role model in the family and community, can be restored. To overcome attendant distortions and abuses, it is proposed that such a restoration process should be in harmony with the core values of equality, respect, human dignity and freedom such as those enshrined in the South African constitution" (Lesejane, 2006, p. 179).

3. Unemployment and Poverty

High rates of unemployment (25.5% in March 2007) have been contributing factors in undermining the concept of marital and family stability (Labour Force Survey September, 2007). The psychological impact of poverty is enormous. Research highlights the association between the inability to feed one's children and parental depression (Wilson, 2006). Wilson (2006, p.30) quotes an unemployed father who speaks for all fathers facing economic hardship saying: "It's just like these hands of mine have been cut off and I am useless."

Denis and Ntsimane (2006) write that among the poor, the institution of marriage has ceased to be the dominant regulator of relations between men and women. According to Gennrich (2004) the relatively high cost of 'ilobola', the bride price, has meant that many men simply cannot afford to purchase a bride and are choosing casual relationships over traditional marriage. As a result marriage rates are falling and family units are increasingly unsettled (Denis & Ntsimane, 2006). Most children are raised by their mothers or grandmothers and are often unaware of who their real fathers are, having never met or having had no contact with them.

2.4.4 The Father/Son Relationship

Simpson (2005) indicates that the father/son relationship in an African context is often characterised by distance. This distance is both physical and emotional and is based upon the level of respect that is demanded by the African elder. For many fathers and sons this distance is regrettable as it prevents any form of intimacy or opportunity to learn more about each other (Simpson, 2005). Simpson (2005) refers to a real sense of envy expressed by African men for the relative closeness they perceive between white fathers and their children. One research participant commented; "You Europeans really love your children!" (Simpson, 2005, p. 573).

Simpson (2005) also found that silence and violent outbursts characterised the perceived behaviour of fathers. Many respondents were to draw upon this model in managing their own roles as husbands and fathers. Whether a father figure is present or absent, research indicates that African boys are often raised in a culture of violence (Simpson, 2005). The dominant discourse, which says males must be tough and unemotional, has created a scenario in which open communication based upon trust and care is hard to come by. Clearly, for some men, their childhood and adolescent experiences of manhood provide significant stumbling blocks to becoming active role models in the fight against HIV/AIDS.

2.4.5 The Impact of HIV on Masculinity/Fatherhood

Simpson (2005) posits that the spread of the HIV/AIDS pandemic in Africa is driven, to a large extent by the expression of a dominant and sexually aggressive masculinity. Whilst this may appear to be a deeply rooted and intractable problem, Simpson (2005, p. 569) states that a "recognition that masculinities are historically, socially and economically constructed, and that gender is a process, offers the potential for change." He argues that if men are to be included in the war against HIV/AIDS, a change in perceptions of masculinity, gender and sexuality needs to take place.

The role of men in South African families in the era of HIV/AIDS has been examined by Montgomery, Hosegood, Busza and Timaeus (2006). They point out that the

dominant discourse that confines men's roles to that of breadwinner and provider fails to acknowledge the many other roles that men fulfil within the family. They conclude:

> "While it is important, therefore, to highlight the overlooked existence of men's positive involvement in household management and care in the era of AIDS, what will prove crucial in future is identification of approaches that might help men redefine their masculinity to encompass a wider social role, and to gain acceptance for it." (Montgomery et al., 2005, p.2418).

Lynch (2008) in a study of men living with HIV found that being diagnosed HIV positive challenged the normative constructions of masculinity, which are seen as traditionally hegemonic, invulnerable and unemotional. The experience of HIV resulted in a transformed masculinity, to one of greater dependence, vulnerability and emotionality. Lynch (2008) describes how the norm of having multiple sexual partners is rejected by many men diagnosed HIV positive. Hence, being diagnosed HIV positive confounds the dominant discourse of masculinity and therefore has the potential to be a positive life-transforming experience.

2.4.6 Conclusion

The literature review confirms that fathers play a significant role in modelling behaviours to other family members. The way that fathers diagnosed with HIV deal with their condition has a direct impact on many people's lives. The appropriate disclosure of one's HIV status can help to contain the condition through education and understanding of risk factors. Advantages of disclosure by fathers include the following:

- It enables medical intervention and treatment so that fathers can support their families for a longer time.
- It can initiate counselling and support for the family members.
- It facilitates greater knowledge about the condition and how to cope with it within the family.
- It facilitates family planning regarding financial and social support.

- ▪ It can protect the sexual partner through safe sex methods and prevent re-infection when both partners are HIV positive.
- ▪ It can enhance safe behaviour amongst children if parents can openly talk about HIV in the household.

Failure to disclose one's HIV positive status frustrates the containment of HIV/AIDS. Many HIV positive people have chosen not to disclose their status to avoid rejection by family members and stigmatization by others. Much research has been done concerning issues of disclosure among women, but very few studies have considered disclosure by men infected with HIV in Africa. Norman et al. (2005) write that describing, analysing and understanding the internal dialogue taking place prior to disclosure, and the event itself, is critical to designing effective interventions that will facilitate disclosure. They point out that most of the studies regarding disclosure have taken place in developed countries, with few in sub-Saharan Africa.

Understanding more regarding how fathers diagnosed HIV positive, and living in an informal settlement, experience disclosure of their status to those around them, will add to this growing body of knowledge. The research inquiry itself is now considered.

CHAPTER 3

RESEARCH INQUIRY

3.1 INTRODUCTION

This chapter describes the theoretical framework of the research inquiry, which includes the underlying theories, concepts, and processes that delineate the essentials of the research design. The chapter also includes an explanation of the methodology adopted and procedures followed to prepare and conduct the research inquiry.

3.2 THEORETICAL FRAMEWORK

Henning, van Rensburg and Smit (2004, p. 12) points out that research can never be carried out in a "theoretical vacuum". As human beings we are always in the process of interpreting our world and forming ideas about the way things are connected. These ideas or 'theories' help to explain the way things are. As such, theories are human constructions that help us to make sense of our world, guide our behaviour and bring about a level of predictability (Henning et al., 2004).

In the realm of scientific research, the quest for knowledge and understanding requires that certain criteria be met, in order for it to be considered 'good' science. Social scientists, in adhering to these principles, generally agree that research should be empirical, systematic, disciplined and self-critical (Puttergill, 2000). However, the debate amongst research practitioners continues around the nature of reality, what is knowledge, and how further knowledge can best be acquired. These are philosophical issues that lie at the heart of research inquiry, and respectively refer to a researcher's ontology, epistemology and methodology.

A researcher's ontology is what he or she thinks is reality regarding any subject matter. Thus, a person's ontology is based upon assumptions that are rarely consciously evaluated or scrutinised. According to Puttergill (2000) it is these

ontological assumptions that will determine the type of questions a researcher seeks to answer. It is therefore important that researchers consider their own worldview and the assumptions that underpin them. Epistemology comes from the Greek word for knowledge, and means 'how we come to know' (Puttergill, 2000, p. 20). Walliman (2005) writes that a researcher's epistemology or theoretical perspective should be made explicit at the start of the research, in order for the associated assumptions to be understood by the reader. Methodology is also about how we come to know, but in a far more practical sense. It is about the methods used to gain further knowledge. A researcher's ontology, epistemology and methodology are all inextricably linked and need to be explicated.

3.3 PHENOMENOLOGY

This research was undertaken from a phenomenological position, using an interpretive framework. Meyer, Moore and Viljoen (1997) point out that phenomenology has its roots in the philosophical thinking of Edmund Husserl (1859–1938), who identified the importance of an individual's subjective world of perception. He emphasised that people intentionally engage with their environment in order to "attach personal meaning to the things they experience" (Meyer et al., 1997, p.364). As such, individuals' lived experiences of the world are unique, with the challenge being to comprehend the experiences of others as accurately as possible. Phenomenology is a philosophical approach, a "tool" which when used correctly, can greatly enhance research and praxis in the human sciences (Bradfield, 2007, p. 2).

Phenomenology considers the issues of truth and reality and questions the long-held western view that an objective reality exists that can be observed and measured scientifically (Spinelli, 1989). It challenges the assumptions that have given rise to a modernist epistemology and its associated positivist framework, with its claims of accuracy. Husserl believed strongly that science, as it was then, with all its knowledge and presuppositions, was in no position to "comprehend and narrate the human and lived experience of being-in-the-world" (Bradfield, 2007, p. 3).

The conclusion of phenomenological thinking is:

> "that true reality is, and will forever remain, both unknown and unknowable to us. Instead, that which we term reality, that is, that which is experienced by us as being reality, is inextricably linked to our mental processes in general, and, in particular, to our in-built, innate capacity to construct meaning" (Spinelli, 1989, p.2).

The concept of an absolute universal truth was also rejected in favour of a multi-verse of local or indigenous realities. It was Immanuel Kant (1724-1804) who first distinguished between things as they actually are, independent of sensations and knowledge, which he termed "nuomena" and things as they are experienced, which he termed "phenomena" (Meyer et al., 1997). It is therefore people's experiences of the world - the "phenomena" – that should not be ignored, but rather critically examined and better understood.

In rejecting a positivist framework as inadequate, a new paradigm of scientific research emerged in the mid- 20th century, aimed at capturing more of people's lived experiences, in order to better understand and interpret their meanings (Henning et al., 2004). The interpretive framework argues that knowledge is not only constructed by observable phenomena, but also by people's descriptions of events, experiences and self-understanding. A key assumption of phenomenology is "the notion that human experience can best be explored by describing the immediate and lived world in which that experience takes place" (Bradfield, 2007, p. 2). Descriptive narratives and the information they contain are therefore given priority.

The aim of the phenomenological method is to grasp the pure essence of a lived experience. In focussing on the descriptions or narratives, the process of phenomenological reduction, quite simply reduces outside interference and influence. It ensures that the essences of the experience are not lost or overly contaminated by the inevitable subjectivity and pre-suppositions of the researcher or observer. Spinelli (1989) recommends that three unique rules be kept in mind during the analysis of phenomenological data to enhance the stability and trustworthiness of the interpretation:

3.3.1   The Rule of Epoche:

This rule challenges the listener or researcher to set aside all biases, preconditioned thoughts and prejudices to "focus on the primary data of the experience" (Spinelli, 1989, p. 17). This receptivity to the experience facilitates a more accurate interpretation of the actual experience and may be referred to as "bracketing" (Spinelli, 1989, p. 17). While it is virtually impossible to bracket all previous learning and bias from the interpretation of experiences, the very act of recognising our tendencies towards meaning attachment reduces its impact on the process of apprehension.

3.3.2   The Rule of Description:

Spinelli (1989, p.17) writes that the next challenge is to "describe, not explain the experience." Like the rule of Epoche, the rule of Description, requires that we not limit or mitigate our experience by immediately trying to explain it using a theory or hypothesis. Rather, by concretely trying to describe the experience, the subjective variables that constitute the experience, are highlighted. This was part of Husserl's move towards empiricism, where the description of any experience was considered prima facia evidence of the experience – "the more rational repository of truth" (Bradfield, 2007, p. 3).

3.3.3   The Rule of Horizonalisation:

The rule of horizonalisation urges that the listener or researcher avoid placing the items of the description into any hierarchical order of significance (Spinelli, 1989). To treat each unit of the description with equal worth means the risk of losing a piece of the overall puzzle of experience is reduced. The argument for horizonalisation is that "through avoiding assumptions of hierarchy, the examiner of experience is better able to describe that experience, with less prejudice, and greater subtlety" (Bradfield, 2007, p. 4).

3.3.4　The Role of Intuition:

Following on from the three rules and critical to phenomenology's return to the essence of experience is "the notion of intuition within the inter-subjective analytical space" (Bradfield, 2007, p. 3). By rigorously applying the 'reductionist' rules of epoche, description and horizonalisation, the researcher is better able to utilise their intuitive skills to apprehend the essence of experience. Bradfield (2007, p. 4), in stating that the essence of experience is intuited before it is perceived, writes the following:

> "Grasping the phenomenon as a pure essence within its immediate lived world permits a method of being-with the individual, and narrating that individual's experience, without embellishing upon the essence." (Bradfield, 2007, p. 4)

Uncertainty, as opposed to certainty, is a key principle of both the phenomenological and interpretive paradigms (Henning et al., 2004). This approach was well suited to the research question as the aim was to better understand the unique lived experiences that fathers diagnosed with HIV have regarding disclosure.

3.4 RESEARCH DESIGN

Van Eeden and Terre Blanche (2000) describe the two broad fields of scientific research as being quantitative and qualitative. The difference between the two paradigms "lies in the quest for understanding and for in-depth inquiry" (Henning et al., 2004, p.3). Henning et al. (2004) point out that a qualitative study aims for depth rather than quantity of understanding and is usually limited to a theme of inquiry.

While quantitative research focuses on statistical data involving numbers, qualitative research is interested in "meaning, experience and understanding" (Van Eeden & Terre Blanche, 2000, p.134). They point out the importance of establishing relationships of trust and empathy with the research participants in qualitative research. According to Henning et al. (2004), within qualitative research there are as many as 30 design types. This study is phenomenological and interpretive.

3.4.1 Selection of Participants

Because the research was qualitative in nature, with the primary objective to understand an individual's personal and subjective experience, the sample size was restricted to four participants. This provided the opportunity to conduct in-depth interviews. The sampling criteria used to identify participants was the following; fathers, living with their 'families', who were residents of Diepsloot, diagnosed HIV positive and with a conversational level of English equivalent to Grade 10. The language specification ensured that the researcher could remain an active participant in the research process. This would not have been the case if translations from an African language were required.

Participants were selected using convenience sampling. Van Rensburg (2000) describes convenience sampling as the process of selecting participants who can most easily be accessed, until the required sample size is met. The researcher chose this means of sample selection because some of the participants were already known to him, while others were referred by HOPE Worldwide, an International faith-based organisation who are involved in community-based HIV/AIDS care, support and prevention efforts in Diepsloot and elsewhere (HOPE Worldwide, 2005). A disadvantage of this method of sampling is that those selected may not be representative of the broader population. This is addressed in the limitations of the research in the final chapter.

The researcher also worked collaboratively with Mr Silver Malele, a resident of Diepsloot and a trained community health worker, who has a long-standing relationship within the Diepsloot community. Between Silver, HOPE Worldwide and the researcher's existing contacts, a number of suitable participants were identified. All of the participants had cell phones which assisted in the organization of suitable meeting arrangements. All of the participants contacted were willing and able to participate in the research. In order to motivate their participation and acknowledge their contribution to the research, all participants were offered the incentive of a food-parcel.

3.4.2 Data Collection

The researcher conducted two individual interviews with each co-researcher, Diepsloot fathers diagnosed with HIV. Moustakas (1994) refers to the research participants as "co-researchers" because their consent and involvement in the research project is critical. Most of the interviews took place at the HOPE Worldwide offices in Diepsloot. One interview took place at a co-researcher's place of employment, and two interviews took place at co-researchers' homes. Confidentiality was maintained at all times.

The interviews were semi-structured, in that a number of open-ended questions relating to the specific phenomenon of disclosure were asked. While the research questions were focused on the experience of disclosure, they were also formulated to give the fathers both the space and time to share in an unhindered way. The following questions formed part of the interview schedule:

- When did you find out you are HIV positive? Can you please tell me about that?

- What were your feelings at the time? What did you think? What did you do?

- Did you tell anyone about your status? Can you tell me more about that?

- How do you feel about disclosing your status to other people?

- How have you dealt with the disclosure of your status within your family?

- Has disclosing your status been helpful or harmful and if so how?

- From your own experience, do you think people diagnosed with HIV should be more open about their status?

- How has disclosing your status to others changed your relationships?

- What is it like being a father in this time of HIV/AIDS?

- What do you think a father's role is with regards HIV/AIDS?

- Is there anything else you would like to say about your experience of living with HIV?

Two one-hour interviews were contracted with each father, to ensure sufficient time to cover all the questions and responses. During this time the participants were invited to consider and discuss the issues they had encountered and/or anticipated since learning that they were HIV positive. Their experiences were recorded on a voice recorder and then transcribed for analysis. Through the listening and transcribing process the researcher was able to get progressively closer to the participants' experiences in preparation for the data analysis.

3.4.3 Data Analysis

For this study Moustakis' (1994, p. 120) modification of the van Kaam method of analysis of phenomenological data was used. The following procedure was followed for the entire transcription of each co-researcher:

1. List every expression that relates to the experience of disclosure. This is known as 'horizonalization', and means to treat each expression with equal importance.

2. Test each expression for two requirements:
   a. Is there a moment of the experience within the expression that is both necessary and sufficient to understand the phenomenon under investigation?
   b. Can the moment be abstracted and labelled? If yes, then this becomes a horizon of the experience.

   Expressions that do not meet these two requirements are eliminated, along with overlapping, repetitive and vague expressions. The remaining horizons are the unchanging constituents of the experience.

3. Cluster these horizons or unchanging constituents of the experience of disclosure into core themes.

4. Check the horizons and their accompanying themes against the entire record of the co-researcher, for two key criteria:

    a.   Are they expressed explicitly in the transcription?

    b.   Are they compatible with the transcription if not explicitly expressed?

If not explicit or compatible then they are not considered relevant to the co-researcher's experience and are eliminated.

5. Using the relevant and validated horizons and themes, an **Individual Textural Description** of the experience of disclosure is constructed. This includes verbatim examples from the interview.

6. Construct for each co-researcher an **Individual Structural Description** of the experience based on the Individual Textural Description and Imaginative Variation. Imaginative Variation is the researcher's own ideas to explain how the co-researcher's experience of the phenomenon came to be what it is.

7. Construct a **Textural-Structural Description** of the meanings and essences of the experience of disclosure for each individual, including the horizons and themes.

8. From the Individual Textural-Structural Descriptions, develop a **Composite Description** of the meanings and essences of the experience, representing the group as a whole.

3.4.4 Reliability and Validity

It is widely acknowledged that social science, unlike the natural sciences, is not an exact, clear cut science. There is often a great deal of uncertainty and ambiguity that requires interpretation and explanation, hence the development of qualitative research methods. However, reliability and validity of data remain important criteria in qualitative as well as quantitative research. Plummer (1995) writes that the challenge is to inspect how the data came to be produced, taking account of the interviewee, the interviewer and the social setting. These may be referred to as the three domains of inspection.

Considering domain one, Plummer (1995, p. 56) refers to 'demand characteristics' in which interviewees attempt to work out what interviewers expect of them, and then act accordingly. The research validity may to some extent be compromised by such a process. Issues of confidentiality, rapport and trust would hopefully mitigate such biases.

Domain two has to do with researcher bias, based upon the unexplored assumptions and prejudices of the researcher that inform the direction and outcome of the study (Plummer, 1995). A rigorous process of personal reflection, researcher accountability and peer review would help to reduce the impact of this domain. In the concluding chapter the researcher acknowledges his own bias, as a middle-class, white, English speaking male, as a potential shortcoming of the research.

Finally, domain three refers to the interaction in its totality, including the physical setting, prior interaction, verbal and non-verbal communication (Plummer, 1995). Whilst bias can not be eradicated, the challenge is to create a context in which authentic and congruent communication can take place. The researcher can only rely on his acquired experience, knowledge and skills to facilitate this process.

To increase the validity of the interpretation of data and research findings, a colleague of the researcher critically evaluated the data analysis and conclusions. This was done to make sure that the researcher's interpretation was in keeping with what the client said. This colleague also signed a confidentiality agreement and the names of the research participants were anonymous.

To avoid any sense of exploitation on the part of the research participants and in order to facilitate closure of the research project, a feedback meeting to discuss the findings of the research was arranged and conducted with each father. This also enhanced the validity of the data. Bradfield (2007, p. 6) refers to a "mutual validation process", in which the researcher checks whether his or her intuitions are accurate in terms of the interviewee's own experiences.

3.5 ETHICAL CONSIDERATIONS

Before participating in the research, the fathers were informed about what the study entailed, what was expected of them, and were then asked to sign the informed consent form. Given that they were all over the age of 18 years, they qualified to sign their own consent. The names of the fathers who participated in the research will remain confidential. Because conversations around HIV/AIDS are thought-provoking and inevitably laden with emotional content, follow-up counselling sessions were offered to all research participants, but were not utilized.

In the next chapter the findings of the analysis of phenomenological data are presented.

CHAPTER 4

RESEARCH FINDINGS

4.1 INTRODUCTION

This chapter presents the process of analysis of the phenomenological data and research findings. Each research participant is presented systematically, starting with a demographic description, which includes their age, marital status, children, living circumstance, employment history, current state of health and an explanation of how the researcher became acquainted with them. Pseudonyms are used to identify the participants.

All the steps in the van Kaam method of analysis, are shown for each research participant, which illustrates the collection, analysis and synthesis of the data (Moustakis, 1994). The method is ultimately aimed at developing a composite description of the meanings and essences of the fathers' experiences of disclosure, which is presented at the end of the chapter.

4.2 PROCESS OF DATA ANALYSIS

4.2.1 Phenomenological Reduction

Through the process of phenomenological reduction described previously, the entire transcript for each co-researcher was transformed into an **individualised textural description**. These descriptions consist of the unchanging horizons and themes of the experience of disclosure (See table 1). Moustakis (1994. p.95) describes a horizon as the "condition of the phenomenon that gives it a distinctive character". The horizons from the transcript, along with their textural qualities, were identified in order to better understand the experience of disclosure. They include verbatim examples from the original transcripts, and represent the first step in phenomenological data analysis.

Table 1: Example of Boswell's horizons and themes of disclosure.

Does it contain a moment of disclosure?	Can I label it?
I felt something bad had happened to me.	Struggle
But I didn't put that in my mind. I just said that HIV can happen to anyone and if it happens to me I have to accept it.	Negotiation
Trying to deny it is going to damage me psychologically, it is going to damage my relationship with other people.	Negotiation
When she told me I didn't fight her, I didn't say anything silly. I didn't say anything actually.	Silence
We had to sit down and talk about it, because we'd been told that your life is over. But we didn't believe that.	Togetherness
I just had to bring it and we just had to look at it together.	Togetherness
No they didn't believe me. They just thought I was joking.	Disbelief
I just told him because I guess I wanted him to look after the kids.	Planning
Yes because at that particular time people didn't understand HIV. I didn't believe I would live more that 5/6 years. So it was a very difficult time.	Uncertainty
So I said it takes time for HIV to kill a person and I told him that I can get TB or any other disease and it can kill me.	Educating
Maybe they'll talk behind our backs.	Stigma
But the environment, their attitude towards us didn't change.	Acceptance
No we can speak about it.	Openness
Sometimes some people don't like speaking about it.	Consideration
We don't want to burden other people.	Consideration
At first it was difficult.	Struggle
Because I have accepted my situation, and I don't want people to talk behind my back, I want them to know the truth, what is happening to me now.	Self-acceptance
There's nothing we don't talk about with them.	Openness
It brought us closer, especially me and my wife and my children.	Relationship
We talk more and are very open with each other.	Openness

4.2.2 Individual Structural Descriptions

The next step in the analysis of phenomenological data is to construct an individualised structural description of the experience for each co-researcher, based upon the individual textural description and imaginative variation (See table 2). Moustakis (1994, p. 98) writes that the main objective of imaginative variation is to describe "the essential structures of a phenomenon." It is here that the researcher's own creative ideas, to explain how the co-researcher's experience of the phenomenon came to be, are utilised. The process of imaginative variation is directed towards meaning making, and as a result relies heavily upon intuition to "integrate structures into essences" (Moustakis, 1994, p. 98).

Moustakis (1994, p. 99) refers to the universal structures which exist for all textural descriptions, these being the "structures of time, space, bodily concerns, materiality, causality, relation to self, or relation to others". It is these structures which the researcher uses as lenses through which to consider the essences and meanings of the experience of a phenomenon (See table 3).

4.2.3 Synthesis of Meanings and Essences

Moustakis (1994, p. 100) sees the last step in the phenomenological research process as "the intuitive integration of the fundamental textural and structural descriptions into a unified statement of the essences of the experience of the phenomenon as a whole". Essence, according to Husserl and cited by Moustakis (1994) is a defining quality, which makes something fundamentality what it is, without which it could not be.

Moustakis (1994, p. 100) points out that the essences of any experience are in fact infinite, but that "the fundamental textural-structural synthesis represents the essences at a particular time and place from the vantage point of an individual researcher following an exhaustive imaginative and reflective study of the phenomenon". The essences of the experience of disclosure for the research participants as a whole are presented in the conclusion at the end of this chapter.

Table 2: Example of Step 2, moving from individual textural description to an individual structural description.

Boswell			
Texts (Examples)	Possible structural meanings underlying textural meaning	Underlying themes/contexts related to experience of disclosure	Structures that precipitate thoughts/feelings
Reaction to Diagnosis			
My wife found out she was HIV+ when pregnant with our first child in 1998	Reflecting back	In the beginning	Time – Past event
When she told me I didn't fight her, I didn't say anything silly.	I love and accept my wife unconditionally	Unconditional love	Relation to other – acceptance.
I didn't say anything actually.	Overwhelming news	Self-control	Relation to self – who am I?
I went to the clinic to have a test.	I took action	Responsibility	Causality – VCT
When I got my results, I just had to bring the letter home and we just had to look at it together.	We are one flesh	Unity of marriage	Relation to other – unity in marriage
We had to sit down and talk about it, because we'd been told that your life is over. But we didn't believe that.	We are a team	United we stand	Relation to other – communication and solidarity
Disclosure to Others			
I have only disclosed to certain people, my wife and a few members of my family.	I am a private man	Family closeness	Relation to other – privacy
At first it was difficult to disclose.	I struggled with it	Inner conflict	Relation to self – inner turmoil
It's a very traumatic experience, just before disclosing because you really don't know how people are going to react so you have those fears.	I was frightened	Uncertainty	Relation to self – fear
But after, it's much better because people take you as you are.	From anxiety to relief	Acclaiming	Time – past and present
To close friends and family it wasn't that traumatic afterwards, just before.	Perception worse than reality	Acceptance	Relation to others – acceptance
I disclosed to my brother who was more like a friend because we can talk about anything	No barriers	Comforting	Relation to other – brotherly bond
He didn't believe me.	Incredulity	Denial	Causality – denial
He just thought I was joking because I wasn't sick	Too much to accept	Humour	Materiality – humour
So I said it takes time for HIV to kill a person and I told him that I can get TB or any other disease and it can kill me.	How the virus operates	Illness	Bodily concerns – disease progression

Table 3: Example of the third step, using the universal structures as lenses through which to view the essences and meanings of disclosure.

Boswell			
Texts (Examples)	**Possible structural meanings underlying textural meaning**	**Underlying themes/contexts related to experience of disclosure**	**Structures that precipitate thoughts/feelings**
Time			
My wife found out she was HIV+ when pregnant with our first child in 1998.	Reflecting back	In the beginning	Time—Past event
You see at that particular time in 1998, people didn't understand HIV.	How things were	Knowledge at the time	Time—past
I didn't believe I would live more than 5/6 years.	Limited lifespan	Mortality	Time—projected future
But after, it's much better because people take you as you are.	From anxiety to relief	Advancing	Time—past and present
So if it's 8 O'clock and I don't see the time, they'll come and say it's time to take your medicine.	They keep track of the time	Time is important and precious	Time—present
When I go to an interview, they ask me questions.	Past experiences	Disempowerment	Time-past
I can talk about anything today.	Where I am at now	Courage	Time—present
Relation to others			
When she told me I didn't fight her, I didn't say anything silly.	I love and accept my wife unconditionally	Unconditional love	Relation to other—acceptance.
When I got my results, I just had to bring the letter home and we just had to look at it together.	We are one flesh	Unity of marriage	Relation to other—unity in marriage
We had to sit down and talk about it, because we'd been told that your life is over. But we didn't believe that.	We are a team	United we stand	Relation to other—communication and solidarity
I have only disclosed to certain people, my wife and a few members of my family.	I am a private man	Family closeness	Relation to other—privacy
I disclosed to my brother who was more like a friend, because we can talk about anything.	No barriers	Comforting	Relation to other—brotherly bond
I told him because I guess I wanted him to look after the kids.	Concern for children's future	Planning for future	Relation to other—protecting his children
To close friends and family it wasn't that traumatic afterwards, just before.	Perception worse than reality	Acceptance	Relation to others—acceptance

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4.3 PRESENTATION OF BOSWELL

4.3.1 Boswell's Demographics:

Boswell is 37 years' old, married and lives with his wife and two children, a son of eight and a daughter of six. They live in a shack in Diepsloot and have been residents of Diepsloot for ten years. They are from Zimbabwe originally.

Boswell was employed up until 2006, when he became ill with Tuberculosis. He lost his job as a result of a prolonged illness and has been unemployed ever since. He is on ARV medication. The researcher met Boswell through an HIV support group held at a clinic in Diepsloot.

4.3.2 Boswell's Individual Textural Description:

Theme – Acceptance and Resignation
"My wife found out she was HIV+ when pregnant with our first child in 1998. When she told me, I didn't fight with her, I didn't say anything silly. I didn't say anything actually. I went to the clinic to have a test."

Theme – Shared Experience
"When I got my results, I just brought the letter home and we looked at it together. We sat down and talked about it, because we'd been told that one's life is over. But we didn't believe that."

Theme – Passive Acceptance
"I felt something bad had happened to me. But I didn't keep that in my mind. I just said that HIV can happen to anyone and if it happens to me then I have to accept it. Trying to deny it is going to damage me psychologically and it's going to damage my relationship with other people."

Theme – Discretionary Disclosure
"I have only disclosed to certain people, my wife and a few members of my family. At first it was difficult to disclose. It's a very traumatic experience, just before

disclosing, because you really don't know how people are going to react so you have those fears. But afterwards, it's much better because people take you as you are. To close friends and family it wasn't that traumatic afterwards, just before."

Theme – Educating Others

"I disclosed to my brother who was more like a friend, because we could talk about anything. At first he didn't believe me. He just thought I was joking, because I wasn't sick. So I explained to him, it takes time for HIV to kill a person. I told him that I can get TB or any other disease and it can kill me."

Theme – Concern for Children

"I told him because I guess I wanted him to look after the kids. You see at that particular time in 1998, people didn't understand HIV. I didn't believe I would live more than 5/6 years. So it was a very difficult time."

Theme – Protective Concern for the Future

"I also told my other brothers because they are not Christians like me. Those kinds of people you have to tell so that they know exactly what is going on and don't trouble anyone. Otherwise, if it happens that I become sick and die, they'll start accusing my wife of bewitching me, or accuse someone else of bewitching me. So the people need to know to make life more manageable."

Theme – Trust and Emotional Support

"I have also disclosed to members of my church. Not the whole congregation, but to those who are responsible for the congregation – the elders. There's no need for me to hide anything from them. I trust them, they trust me – we are like brothers. They have been a great support, because anytime when we're feeling psychologically broken, we can call them and talk. They guide us and give us strength. It makes me feel very strong, very strong."

Theme – Fighting HIV Together

"Being HIV+ has brought me closer to others, especially my wife and children. We talk more and are very open with each other. There's nothing we don't talk about to the kids. My children know about HIV. So if it's 8 O'clock and I don't see the time,

they'll come and say "daddy, it's time to take your medicine!" This releases a lot of pressure, because life becomes more normal."

Theme – Buffer of Support

"Considering people's reactions to our disclosure, some people easily accept you. Generally the environment and people's attitudes towards us haven't changed. For now, the people I am close to, they know and accept it."

Theme – Discrimination by Potential Employers

"Some people really don't know or understand. When I go to an interview, they ask me questions. So I tell them I didn't leave my previous job, I just got sick. Then they start to say "are you okay now, are you well now?" And it just ends like that. It makes me feel bad, but now I'm just not interested. I just don't want to know what other people say, what other people think."

Theme - Benefits of Disclosure

"From my experience, telling others makes me feel less burdened, especially telling those who are closest to me. It helps a lot, it helps a lot. Because I have accepted my situation, and I don't want people talking behind my back, I talk directly with people. I want them to know the truth, what is happening to me now. Sometimes people don't like speaking about it, and of course, we don't want to burden other people."

Theme - Impact of Disclosure

"HIV has changed my life a lot. You know people must judge you for what you are, not what they don't know. I can talk about anything today. And when I talk about it to other people, when I disclose my status, other people might think twice about the risks. I think I am handling it quite well. Sometimes it feels as if I get relief and strength from talking about it. You see it's a reality, it's here, which means that if you don't talk about it, it becomes like slow poison."

4.3.3 Boswell's Individual Structural Description:

Boswell reflects back in time to how things were when he first found out he was HIV positive. He considers his limited knowledge at the time about HIV and his sense of

mortality and imminent death. He contrasts the anxiety before disclosure to the relief after disclosure. Time has become a precious commodity. He keeps track of time to manage his medication. He reflects on past experiences of prejudice and discrimination, arriving at a present experience of inner peace and a hopeful sense of the future.

Boswell considers the unity of his marriage and how he and his wife have managed the journey with HIV. He is a family man, deeply concerned about his wife and children's wellbeing. He believes in honesty and openness with his children who are well informed on the subject of HIV. His actions of disclosure to others reflect this concern. Whilst being a private man he knows the value of friendship and has disclosed his status to those he trusts and respects. He is encouraged by the love and support he has received which makes him and his family stronger.

Boswell is a man of self control. His faith in God guides his every word and deed. He believes that we live in a fallen world and that we are all subject to sin and death. He accepts his status as part of life and has found inner peace. He faces his own fear and inner struggles with disclosure, knowing that he cannot always be in control of the outcome. However, he has found that life can still go on and be a positive experience.

Boswell sees disclosure as the responsible thing to do. It is good for others to know, and it is good for him. He wants to make sure his family are treated properly when he dies. He feels that his load is lighter because he has disclosed and believes others should do the same. He is however disappointed at how some people respond to those living with HIV, but he chooses not to let that get him down.

4.3.4 The Essences of Disclosure for Boswell:

For Boswell the essence of disclosure is **obedience**. Boswell is a man of deep faith and conviction who is guided in his behaviour by God. Living righteously - knowing and doing what is right - is how Boswell operates. He finds great strength and encouragement from his values, values he shares with his wife and children.

The second essence of disclosure for Boswell is **responsibility**, or the ability to respond. Boswell exercised his own personal freedom in how he responded to his wife's disclosure and how he chose to handle his disclosure to her. Because Boswell sees the unity of marriage and the family as critical, openness and faithful living have helped his family to manage living with HIV and normalised the experience.

Another essence of disclosure is **discretion**. The inner struggle Boswell experiences prior to disclosure means that he has confided in those he trusts, people who have a similar belief system in his church, as well as family members who might not be Christians. The uncertainty of people's reactions still challenges him as he faces the decision whether or not to disclose to others.

Added to the essence of discretion that originates in the inner struggle prior to disclosure is the **relief** or **congruence** that follows disclosure. Boswell contrasts the two very vividly in his transcript, with disclosure opening the way for normalization and support from others. Disclosure opens the door to sharing the experience, letting the poison of secrecy out.

The final essence of disclosure for Boswell is **honesty** or **transparency**. Rather than having people talk behind his back, he wants to deal with others directly, in order to answer any questions they may have about HIV and shed light on a difficult subject.

4.4 PRESENTATION OF DESMOND

4.4.1 Desmond's Demographics:

Desmond is 38 years old and lives with his girlfriend in a shack in Diepsloot. He has two sons, aged 18 and five, who stay with their mother in Krugersdorp. Desmond appears to have limited contact with his children. He has lived in Diepsloot since 2001.

Desmond is unemployed but does voluntary work for an HIV/AIDS home-based care organization in the community. He is studying to become a male nurse and has been

on ARVs since his diagnosis in January 2006. Desmond was referred to the researcher by HOPE Worldwide, where he attended an HIV support group.

4.4.2 Desmond's Individual Textural Description:

Theme – Powerlessness and Hopelessness
"I found out I was HIV+ in January 2006. To be told that you're HIV+ changes your life. You put yourself down. You think many things and behave like a mad person. You don't care for yourself, you don't bath, you just exist. You say, "I'm going to die." And so I said "there's nothing I can do. If I'm going to be worried, there's nothing I can do." Maybe you can take poison, something like that."

Theme – Gradual Acceptance
"I said "no, not now, because I've suffered too much with TB so I don't care about anything now. I must go for it." And then they were always telling me "when you are HIV+ there's no problem, you can live many, many years." And so I just came slowly, slowly and I said "okay, if you say so, it's alright. We can keep on going."

Theme – Discretionary Disclosure
"The first person I disclosed to was my sister. It's important to say something to your family, but it's not easy. I told her "you know what, you must go to the clinic for counselling, because when you live like this, sleeping around, not using condoms, you're going to get sick like me. You see, I behaved like you, I didn't use condoms and now, you see that bottle there, every morning and every night I take medication. I'm HIV positive". I said to her "I am only trusting you. You are the only one I am choosing to tell." So even one day, when she's cross with me, she won't tell anyone."

Theme - Dissonance
"It was a good decision to tell her my status, but you know, when you say something to someone, whether your family or your friend, afterwards you don't feel good. You just feel sad. I thought, why must I tell my sister about my status? I was worried that she might tell someone. It's not easy. It's like when you've got a bucket of water, and the bucket falls down and all the water spills out. That water is gone. It's like that.

The words are coming out, but they're not coming back. But now I think if she wants to tell somebody, it's up to her, it's not up to me. There's nothing I can do."

Theme – Concern for Future

"I told my sister, one of my family, so that she could say something when I'm dead. She can say, "This man was HIV+. I'm the only one who knew this secret, so that I could pass a message on to others." You see when you don't tell anyone, they may say that it was poison that killed this man, and then spend money to find out. Our nation is bad because they trust sangomas - they walk around and waste money. That's why I thought it was better to say something to another person, this time my pastor."

Theme –Discretionary Disclosure

"After a particular sermon on the topic of people living with HIV and AIDS, I approached my minister and said, "I'm very happy you say that because I am one of those people who are HIV+." His response was supportive and he kept on counselling me."

Theme – Emotional Support

"My relationships are different since disclosure. If my sister hasn't seen me for a few days she gets worried. Sometimes she sends me a sms to say "Where are you? Why aren't you calling me? You must come and talk." Her concern makes me feel very happy. And when I am with my sister or the pastor there's no problem. I feel fine. I don't think, I told you something I shouldn't have. Everything with them is just normal."

Theme - Managing Disclosure

"But it's not easy to go straight to the point. You must take time to assess the situation, find out what is going on. You need to know what's in their mind, what they think. And when you tell someone you're HIV+, you mustn't just say it. First, you must use an example, before you tell someone of your status."

Theme – Fear of Burdening Others

"With my family, they actually don't know what is going on. There's an important saying in life, which is "don't trust a friend, even your family". Trust no one. I haven't told my older son because he has a very weak heart, and I don't want to burden him. If I told him my status I am sure he would worry. And then there at school, he's just going to think about HIV and that his daddy is going to die. This will make him more sick."

Theme – Planning for Disclosure

"When I go home to Krugersdorp, I will have a chance to sit down with him and share some things. But before I tell him my status I will educate him about HIV and AIDS. I will ask him questions to test what he's thinking. Then I can say, "Okay Sipho, if you went to the clinic and the doctor said you're HIV+, what would you do?" If he says, "I can do this and that and that", then I know what he's thinking, and that he might accept the disclosure. Then I can say, "Do you still remember when I was very sick and on TB treatment? Well my TB treatment is finished. Now what are you going to say when I tell you I'm HIV+?""

Theme - Vicarious Learning

"There's this guy near my place, he's HIV+. The problem is that he just talks about his status like he doesn't care what other people think. He talks to everybody. And now he's like a mad person, he's not well, because you can't do that. It's not good. When you do that, at the end of the day you sit down alone with your status. Then your only option is to take poison and go to heaven, because everyone in the world knows your status. It's like when you wear a t-shirt that says "I'm HIV+!" It's not a good idea."

Theme -Uncertainty

"Currently I am living with my girlfriend, but I don't know what's best in terms of telling her my status. If I say to her "you know I'm HIV+", at least I must know how she is going to respond, so that she will not leave me, but stay with me forever. But the problem is that no one wants to live with a person who has HIV. I know she's waiting for me to tell her. I sometimes think that when I tell her I'm HIV+, she's not going to say anything because she already reminds me to take my medicine. She has

said to me that even if I'm HIV+, she's going to stay with me. She says we're going to get married. I think the best thing is to tell her straight away. My idea is to tell her. Before marriage I will say to her, "If you marry me you must know I'm HIV+". Otherwise if I wait and only tell her afterwards, I'm abusing her and that's not good."

Theme - Stigma and Shame

"But why, when you are HIV+ must you hide yourself? To me it doesn't make sense. We can tell each other we have a fever, but this thing is not like that. This thing is terrible."

Theme - Activism

"That's why when I walk around I try to tell people about HIV and AIDS. There by the clinic they know me, and maybe next month there'll be visitors there. They want me to come say something to each and everyone who attends the clinic. I have been called to many places to share with people about TB and HIV and I am free, but not to talk about myself. So now I say to the pastor, "Every time you talk about HIV like that, the world may change because someone who didn't know their status can go to the doctor, know his status and then keep going."

Theme - Victory

"Even me, I was drinking and smoking and sleeping around before. When I went for the first test, they said my friend, your CD4 count is 28. You're going to die now. I said, "Okay, I'm going for it". Now I'm living. Now I'm strong. It's much better. Everything is going up, even my weight. I was 30 – 35 kilograms, just skin and bone, because it was two things, TB and HIV. These things were fighting in my body. Big challenges like Kaiser Chiefs and Pirates."

Theme - Transformation

"But God is great. You say you're going to die, but you can live until you are old. I am a church man now, and I'm encouraging my family to go to church. Everyday, early in the morning, maybe 6 O'clock I go to church, before doing anything. My life is just normal. I don't feel like the virus is in my body. No, I don't care about that, I care about life."

4.4.3 Desmond's Individual Structural Description:

Desmond reflects back on his condition, two years ago when he was so sick and weak with TB. He can see how his life has changed and how different he was then to now. Where before he used to drink, smoke and sleep around, he is now a church man who encourages others to look after themselves and go to church. He appreciates life and is very grateful for a second chance.

Desmond has generally kept his status to himself. He disclosed to his sister out of concern for her wellbeing and hoped she would benefit from his experience. He also disclosed because he wanted at least one person to know the truth. At the same time he struggled with the loss of control that comes with disclosure.

Desmond still struggles with the concept of disclosure. He believes that people first need to be assessed as to their knowledge and attitude before being told. He would rather avoid disclosure than deal with it, due to the uncertainty of people's behaviour and the possibility of discrimination. He finds it difficult to disclose to his girlfriend because he fears her rejection.

Desmond sees the threat of public disclosure as real and relates it to a death experience. He is frustrated by the stigma that exists around HIV, which restricts his freedom to be open and authentic. However, he does talk about HIV and TB in public where people may assume his status, but he does not directly disclose. He has learnt to live within the restrictions of such a society, by managing his status very carefully. Desmond is street wise and a survivor.

4.4.4 The Essences of Disclosure for Desmond:

For Desmond the first essence of disclosure is **caution**. Desmond is very concerned about other people knowing his status, so his perception of stigma is high. The fact that he still hasn't disclosed to his live-in partner confirms this.

The second essence of disclosure flows from the first and is **hiding status**. People need to be assessed for what they know and think about HIV, before disclosure. As

Desmond says, 'you can't just come straight to the point'. This aligns with his first essence of caution.

The third essence of disclosure for Desmond is **transformation**. Desmond was very sick, but with the help of ARVs and support from others, he has fought his way back to health and strength. He is very purposeful and enthusiastic about the opportunities that lie ahead. Desmond has been encouraged by those he has disclosed to. He has left his past behind and redefined himself in a new role as a covert activist, a care giver to others suffering with AIDS and a 'churchman'.

4.5 PRESENTATION OF IZAAK

4.5.1 Izaak's Demographics:

Izaak is 47 years' old and lives on his own. He has a son of 23 and a daughter of 18. His son lives in the Eastern Cape and his daughter lives in Boksburg. He has very limited contact with his children. He was a resident of Diepsloot until a few months ago when he moved to a government-provided house in a nearby community.

Izaak is not on ARVs, but takes vitamin supplements to boost his immune system. He was a painter, but has been unemployed for some time. Izaak was referred to the researcher by HOPE Worldwide, where he attends an HIV support group.

4.5.2 Isaak's Individual Textural Description:

Theme – Acceptance and Resignation
"When my girlfriend became ill in 1997, she was tested and disclosed her status to me. I did accept it, you understand. I didn't say anything. I didn't worry. It's a sickness you see. You can forget about where it comes from. They say promiscuity and things like that. I never took it like that. I didn't reject her. Then they told me I'm HIV infected. I did accept it. I said there's nothing I can do because it's in my blood and I can't change it. I made friends with the one who was found infected. I didn't

think it was her sleeping around. I did accept it. I can't point fingers at someone. Maybe it was me, I don't know, but I just took it as any disease."

Theme – Regret at Lack of Information

"The problem was that me and my girlfriend we didn't have enough information on how to manage living with HIV. I was just doing the usual. Then I became part of a support group in 2003, when my girlfriend passed away. You see at the time I was so stressed I was getting sick. I joined weekly classes and got information. Then I was well and I did accept it. I didn't worry anymore. I'm still in the support group."

Theme – Fear of Rejection

"Sometimes it's difficult to disclose. Before you disclose your status, you must first give education. The first person I disclosed to was a good friend of mine. He knew my girlfriend was HIV+ when she passed away. Before I disclosed to him I thought about it for a long time. It was painful for me to speak to him, because in my mind I just thought he may reject me. I was also wondering how long he would take to accept it. But as I told him he did accept it. He never rejected me. He is still my friend till today. There was no change in the relationship."

Theme – Discretionary Disclosure

"I never told everybody. If you tell somebody, then you tell everybody. You must know that when you tell this person, he's not just going to go and tell everybody. Yes, not everybody you know, you can tell. My experience is that whenever you've got something important to say, it is better to find someone who is reliable, and who will keep every thing confidential. Also, when you've got this virus, before you tell somebody, you must know whether they're going to accept it or not. First you must have information and the person you are going to disclose to must have an understanding about this illness."

Theme - Disclosure to a Pastor

"You see I'm a Christian now. I only told my pastor, no one else in the congregation knows. At church during prayers, you get a piece of paper and you write something that you want prayer for, your expectations if you like. Then after a time he took out that letter of mine and came to me and we prayed together. There was no one else at

that time. I told him because I believe he is a man of God, so he can keep that thing a secret."

Theme – Emotional Support

"Telling my friend and the pastor made me stronger, because I know there are people on my side who won't tell other people, you understand. When you need help they can give you help. If there's something you don't understand, you can sit down and check with that person. I feel closer to them. When I see the pastor he never points fingers at me. No. He even comes to my house and sits down."

Theme – Planning for Disclosure

"As for now my parents are not here. I have never been home because I have that burden I cannot go and tell them. You see some people in the homelands, they know nothing about this illness, no education. So before I tell them anything, I must educate them. If I said to them, father, mother, I'm like this, they'll have a heart attack. But now that I have information, everything, it would be easy to just sit down with them and prepare them. I think maybe next year I have to go and tell them, this is the sickness and it's like this."

Theme - Stigma and Activism

"It is better if you know about something to let other people get the information, because then they can look after themselves. But the problem is that people don't want to listen to be educated. They are scared to get information about this illness, because of death. They say it kills so they reject us."

4.5.3   Izaak's Individual Structural Description:

Izaak reflects back to when he was first diagnosed with HIV. He indicates that his survival for so many years has been due to the knowledge and support he has gained from being in a support group since 2003. He cites education as being critical in dealing with HIV, and mourns the loss of his girlfriend due to insufficient information

In terms of disclosure to others, Izaak sees himself as a role model of accepting behaviour, as he didn't discriminate against his girlfriend when she told him. He

sticks with his belief that HIV should be treated like any disease, immaterial of where it comes from. He has found disclosure to be a necessary, but nerve racking experience. He still feels the anxiety of an uncertain situation, but is thankful for the support he got from a friend. He believes that one has to be very careful who to disclose to. For example his mother and father would need to be prepared with information before a disclosure, because they live in a rural community.

Izaak is a loner who keeps mainly to himself. He does however attend church and a support group for people living with HIV. He decided to trust his pastor with the news because he was sure he would not tell anyone else. He is grateful for the support he has got from people, and feels closer to those he has disclosed to.

Izaak is concerned that people's fear of the subject, never mind the disease, prevents them from getting all the information they need to manage their lives in an HIV infected society. He feels quite de-motivated and disappointed by this reality.

4.5.4 The Essences of Disclosure for Izaak:

For Izaak, the first essence of disclosure is **unconditional acceptance** - acceptance that HIV exists and is a disease of the body no matter where it comes from or how it is contracted.

The second essence of disclosure is **discretion**. Izaak sees confidentiality as a critical prerequisite for disclosure which facilitates the management of disclosure.

The third essence of disclosure is **privacy**. Whilst Izaak believes that people should have the opportunity to discuss their HIV status with others, it remains a private and sensitive issue for him.

The fourth essence of disclosure for Izaak is **frustration**, which he expresses regarding people's attitudes towards the disease and by proxy, those infected. There's a sense of him feeling like a leper, whom others would view with deep mistrust and caution, were he to raise the subject of HIV/AIDS.

4.6 PRESENTATION OF MICHAEL

4.6.1 Michael's Demographics:

Michael is 34 years' old, traditionally married, and lives with his wife and two children, a son of eight and a daughter of six. Michael is a Zulu and a resident of Diepsloot.

Michael is employed as a builder. He is not taking any medication. Michael was referred to the researcher by HOPE Worldwide, but Michael has never attended an HIV support group.

4.6.2 Michael's Individual Textural Description:

Theme - Hopelessness

"About four years ago, I was suffering with a bad chest and went to the hospital for a check-up. After they did a blood test, I was found to be HIV+. Aish, it was painful. I didn't think I could live for even one year from that time. I didn't want to do anything because I thought my time is over. I was surrendered, which means I was giving up my life, because my experience was that you can't live long if you have this disease."

Theme – Fear and Secrecy

"I was very scared when I got home and felt that everything had changed. But I just kept it a secret for a long time. You see my problem was that I have got children. If I didn't have children I would be in the street or in the park, staying there now, because I didn't want to do anything."

Theme – Guilt and Denial

"It took me a long time to talk about it. I didn't disclose to my wife. I was scared to tell her my status, but encouraged her to get tested. She went and when she came back she told me she was HIV+. I felt guilty in my body. I went to the clinic and tested for a second time because I was a little bit driven now because she told me to go. I didn't tell her that I was tested before. I was still pretending about it and didn't know what she was going to say."

Theme – Fear of Blame and Rejection

"I didn't tell her the first day when I came home from the clinic. It took time again to speak about it, because I didn't know what's going to happen when I tell her. My thought was that if I tell her, she may say that I am the one who gave her the virus and leave maybe."

Theme - Indirect Disclosure

"So she was asking, didn't you go for the results? No I didn't. You know it's like in our tradition things like sexual disease, aish, it's difficult to speak with your wife on things like that. It was when we were asleep, because she asked me all the time. I didn't just tell her. This time I gave her the letter with the results. I told her that I didn't understand what it said. She looked at the letter and said, "You're HIV positive". I said to her, "No, I don't know how to see if it's HIV or not, because I don't know how they write these things". It was better to give my wife the results than to say it myself."

Theme - Masculinity

"She cried for the first time and she was very worried what were we going to do for the children, because it was the end of the road. For days she was crying and I tried to support her. It was like as a man, if you see a snake come in the house, you make yourself brave in front of the children even though you are scared. That is what I was doing. Trying to be brave, but knowing in my heart I am scared."

Theme - Relationship Changes

"I have never disclosed to anyone else. Just me and my wife, she is the only one that knows. For us, knowing our status is good because now even though I am sick or she's sick, we can take care of each other, more than before. The only thing that's changed is that I am not fucking around these days because when they counselled me, they told me to use a condom and I decided I must stay with my wife only."

Theme – Concern for Children

"To tell my children is difficult. It would be too much for them. It would be too much for them. If you talk about this, you talk about dying, even to them, so they'll think I could die tomorrow which is not a good thing. I think if I tell the kids, aish, it will

change them too much. There are some other people I would like to tell, like my mother has to know about this, but it's difficult."

Theme – Stigma and Shame

"It's difficult because people in the townships, once they know that you are HIV+, they don't talk to you like a normal person. Especially we people who are poor. We are not educated to know much about this thing. When someone has got this disease they don't treat them like a normal person. They try by all means to keep away from you, or otherwise they will be pointing every time, even friends. When you are HIV+ they take it like a sin or something, which is not true."

Theme - Gossip

"When your neighbour knows, everyone knows what is happening in your life. You have to hide from people because everything has changed and you can't be happy with this. It's too much talking and some people when they talk they don't give you power. They let you down and you think that if people are saying you're dying so quickly, of course I will be dying so quickly."

Theme - Coping

"There is no way I can manage this disease, because I sometimes think about it and it hurts me. Then in the meantime something else comes in my mind and I forget about thinking about the disease. But it is not cured in my heart because tomorrow I must think about it again. I think it is easier to speak about HIV to somebody you don't know or aren't going to see everyday. I have never been in a support group, because of my job – I must work."

4.6.3   Michael's Individual Structural Description:

Michael reflects back to his original diagnosis and the shock of it. He describes the news as if it were a death sentence, his life shortened to just a year or two at most, in his understanding of the disease. Now four years later, he is grateful that he is still alive and able to carry on with things.

Michael considers his own guilt for possibly infecting his wife and how he was unable to disclose his status to her for fear of rejection. He shares how he engaged in a process of deception and denial until his wife eventually read the letter from the hospital and learnt of his status. He tried to be brave and pretend everything would be alright. He acknowledges the importance of his children in his life, without which he might not have held himself together.

Michael reflects on what he has learnt about himself. How he realised the need for more responsible behaviour with regard to condom use and being faithful to his wife. He also considers that HIV has brought him and his wife closer together.

With regards to disclosure to others, Michael is unwilling to trust others with the news. He feels his children are too young to understand and that other people, especially those where he lives, are likely to gossip and make matters worse. He would like to disclose to his mother, but is not sure how to go about it.

Michael sees HIV as a problem that has to be faced alone as he doesn't have the time to join a support group. He can see the merit in telling people you don't know or wouldn't ordinarily see. However, work and providing for his family are his main priorities.

4.6.4 The Essences of Disclosure for Michael:

The first essence of disclosure for Michael is **fear**. For Michael, his fear of death and the stigma associated with being HIV positive, nearly drove him to abandon his family, work and life itself.

The second essence of disclosure is **denial**. Michael is so overwhelmed with the condition and his guilt that his only recourse is to live in denial of his HIV positive status, keeping it a secret from his family, friends and community.

The third essence of disclosure is **incongruence**. The fear and denial that Michael experiences creates a sense of incongruence, which was partially eased with his disclosure to his wife.

The fourth essence of disclosure is **closeness**. Michael describes that he and his wife are closer because of disclosure, and yet a distance remains between himself and all those he has been unable to disclose to.

4.7 CONCLUSION

The final synthesis was of all the co-researcher's textural and structural descriptions of disclosure into a composite textural-structural description of disclosure. According to the researcher's interpretation of the phenomenological data, the essences of disclosure for the group as a whole were as follows:

Disclosure of a father's HIV positive status is a harbinger of truth and pain. It gives birth to an experience of suffering that is handled variously, depending on the circumstances, and characteristics and convictions of the giver and receiver of the disclosure. It is faith-questioning and fear-provoking, a reality check and a call to assess what is important in life. It is to encounter one's own mortality.

Disclosure introduces an uncertain future, an exposure to what others might say, think or do. It is not knowing who, what, how much and when to tell someone. It is a tension between keeping things to one self, and surrendering one's self to others. It is relief at another's acceptance, and disappointment at another's lack of understanding.

Disclosure is managing other peoples' attitudes, beliefs and behaviours. It is about assessing what people's responses might be and providing information to prepare the way for disclosure. Of finding like-minded people who can be trusted and depended upon for support. It is about normalizing the experience of living with HIV so that life can continue.

Disclosure is about opening a space for vulnerability and intimacy, which is particularly difficult for men. It is about being authentic and congruent, and allowing others to be likewise. It is about imparting knowledge which can inform and protect others, especially sexual partners and children.

Disclosure for a father is about challenging the stereotypical role model of the self-sufficient, distant and silent patriarch. It is about reformulating the role of a husband, father and son through personal reflection and responsibility.

Disclosure is a personal journey. It is doing what is right for each affected individual, family and community. It is facing fear directly and finding the courage to speak out, or remain silent. Disclosure is ultimately a choice.

In the fifth and final chapter, a summary of the research, its implications and applications are considered.

CHAPTER 5

DISCUSSION AND CONCLUSION

5.1 INTRODUCTION

In the final and concluding chapter, the researcher will summarise the research and present the findings on the experiences of disclosure in fathers diagnosed HIV positive, in relation to the existing research presented in the literature review. The relevance of the research to society, psychology, other fields of study, and to the researcher himself will be explored. The researcher will also critique his own methods and procedures, including limitations within the study. Recommendations for further research will be made and finally, a personal reflection of the research experience will be given.

5.2 SUMMARY OF RESEARCH

In chapter one, the researcher introduced the research topic and described how he became involved with people living with HIV. The researcher explained that because it was mainly women who made use of support group structures, men living and dealing with HIV were very under-represented. He therefore became interested in the possibility of researching men, and specifically fathers diagnosed HIV positive, to better understand their experiences of HIV and disclosure.

In chapter two, the researcher presented some of the relevant existing research on HIV/AIDS, and the subjects of disclosure and fathering. A brief overview of the nature and challenges presented by the HIV pandemic in South Africa was given. This was followed by an extensive literature review on the subject of disclosure, which considered the cost and benefits of disclosure, the factors influencing disclosure and the impact of disclosure. Two disclosure theories were presented. The final part of chapter two focussed on the fathering role, particularly as it relates to an African context. The challenges of fathering in South Africa were explored, with a look at the historical impediments to a fathers' role fulfilment.

In chapter three, the researcher explained the theoretical framework for the research project, which was phenomenological and interpretive. He also outlined the research design being adopted and considered why a qualitative approach was suitable to the current study. The research process was covered systematically to include selection of participants, data collection and data analysis. The van Kaam method of phenomenological data analysis was outlined.

Chapter four elucidated the textures and structures of the research findings. Each research participant was comprehensively presented to demonstrate the methodology used to analyse the data, and to allow the reader to engage with each father's unique story. The synthesis of the meanings and essences of disclosure for the group as a whole were presented in the conclusion of chapter four.

5.3 DISCUSSION OF FINDINGS

The literature review indicated a lack of research regarding black father's experiences of disclosure of their HIV positive status in sub-Saharan Africa. Therefore this research was directed at answering the following questions;

- How do fathers, diagnosed HIV positive, experience disclosure to their partners, family, friends, work colleagues and members of the community?
- How does disclosure impact upon their lives and roles within the family and community?

The costs and benefits of disclosure were evaluated in the literature review. All the father's interviewed described disclosure as an anxiety promoting and difficult experience. The uncertainty of another's response created a feeling of not being in control, of being subject to others, and hence vulnerable. Fear of the unknown was the dominant emotion being expressed prior to disclosure. Prior research indicates that one of the benefits of disclosure is increased emotional and material support. Once disclosure had taken place to those considered trustworthy, the father's expressed feelings of relief, as well as dissonance. It therefore appears that disclosure was a

bitter, sweet experience, in that they were sharing bad news, but at the same time becoming less burdened by it.

Regarding the impact of disclosure upon their relationships, all the fathers indicated that disclosure had made their relationships closer and more significant. This was perceived as a positive outcome of the disclosure, in contrast to the anxiety experienced prior to disclosure. However, the fear of stigma and discrimination, also highlighted in the literature review, was very much a controlling factor in their decisions whether or not to disclose.

The management of one's HIV status in terms of disclosure is said to be an ongoing process. This was apparent in the research findings, with each participant being at a different stage on the continuum between non-disclosure and full-public disclosure. Boswell may be considered the most advanced, whilst Michael was the least, having only disclosed to his wife. Desmond and Izaak appeared to be moderately cautious, having both disclosed to two significant others, as well as support group members. An explanation for this phenomenon may be the strong motivation in all human beings to be known and understood by at least one other person. Added to this, the extent of disclosure was quite limited to a few carefully selected individuals, mainly within the family and church.

The value of support groups in helping people manage their HIV/AIDS status was confirmed in the study. Access to HIV/AIDS related information and the psychological benefits of a support group appear to be critical factors in facilitating disclosure. This may explain why Boswell, Desmond and Izaak, who have all been in HIV support groups, are more positive about disclosure and its benefits, than Michael, who has not.

The roles within the families do appear to have shifted as a result of the fathers' disclosures. Boswell and Michael are the only participants who live in a conventional family context, that being father, mother and children. However, their roles and how they fulfil them appear to be quite divergent, with Michael being more of the traditional, distant African patriarch, whilst Boswell is a more contemporary and engaging African family man. In Boswell's family, there appears to be a strong sense

of cohesion and mutual support as the family adjusts to the challenges of living with HIV. For Michael, his disclosure to his wife appears to have shifted their roles to becoming more mutually caring and mindful of one another's conditions. It would appear that disclosure has brought both men closer to their families and affirmed their significance as husbands and fathers.

In contrast, both Desmond and Izaak are examples of the absent father described in the literature. Due to the physical and emotional distance that separates many families in South Africa, these fathers have relatively little contact and psychological investment in the lives of their children, hence their non-disclosure to them. However, the permission they have given themselves to be somewhat dependent and reliant on others for support, appears to have helped them to cope. Both these fathers indicated a desire to disclose their status to their families in the near future.

Regarding the impact being HIV positive has had on the fathers' masculine identities and associated behaviours, the study confirms findings in the literature review. All the fathers interviewed indicated that disclosure had brought them closer to others, increasing levels of intimacy. Desmond and Michael clearly demonstrated a change in attitude and behaviour, from high risk behaviours like multiple sexual partners, unprotected sex, drinking and smoking, to greater personal responsibility, control and discipline.

5.4 FUTURE STUDIES

Given the significance of the emotional and material support obtained as a result of disclosure, the researcher would recommend further studies on how African men feel about formal support groups, and what suitable alternatives might be. It is the researcher's belief that creative solutions that facilitate the provision of support groups for men, is essential.

Another factor to emerge from the research was that three out of the four fathers chose to disclose their status to their pastors. It would appear that there may be a strong link between the availability of a perceived neutral and trustworthy male figure, such as a

pastor, and increased levels of disclosure by men. This could however be influenced by the sampling procedure, with the participants being recruited via church organizations. Further research is recommended.

5.5 LIMITATIONS OF RESEARCH

A possible limitation of the study was that three of the four selected fathers have been part of an HIV support group at some time. Because support groups do influence people's experiences, ideas and coping strategies, the sample may not have been a typical one for father's diagnosed HIV positive. In defence of this approach, only fathers who knew and had disclosed their status could have been approached to participate in the research. Also, given the qualitative nature of the research, the objective was more to understand the fathers' unique experiences, than to generalise findings to the wider population.

The researcher acknowledges that his own expectations, experiences and unique worldview may have biased the outcome of the research. For example, the type of questions listed on the interview schedule dictated to a large degree the type of answers given, which then narrowed the research to what the researcher thought was pertinent. The researcher therefore accepts the inevitable limitations of subjectivity and 'meaning making' in the research, but believes that an awareness of this reality enhanced the end product.

5.6 SOCIAL AND PROFESSIONAL IMPLICATIONS

The research indicates that the fathers generally found it extremely difficult to disclose to their partners, never mind their children. They were more likely to disclose in circumstances where the relationships were strong and supportive. Therefore a key intervention would be to work with couples in areas like communication skills and conflict resolution in order to facilitate healthier, happier relationships where honesty has a place.

Following on from this a major factor influencing the degree to which the fathers disclosed their status was the perceived level of support available. If they anticipated getting support, they were more likely to disclose. Research participants who belonged to support groups appeared to be more confident and better equipped to manage disclosure. Hence the importance of providing support group structures for men living with HIV.

It is recommended that more time be invested in the post-test counselling sessions with men, to deal with their particular concerns about disclosure to family members and others, and to discuss the availability of confidential support structures within the community. However, the level of confidentiality and privacy realistically available to anyone living in an informal settlement such as Diepsloot remains low.

As a means of coping, a number of the fathers found solace in the church and organised religion, disclosing their status to their pastors in the process. It would appear that the church represents a safe haven, an environment where confidentiality and trust is anticipated. As mentioned previously, NGO's such as church organizations will continue to play a fundamental role at a grassroots level in supporting people infected and affected by HIV/AIDS in South Africa

5.7 PERSONAL REFLECTION ON RESEARCH

First of all, it has been a great privilege to conduct this research with the four fathers represented in this study. Without their willingness to come forward and share their experiences, this project could not have taken place.

Personally, I have found the research to be a significant undertaking – like completing a very large and complex jigsaw. But with the final convergence of the disparate pieces into a clearer picture, there comes a great sense of satisfaction. I have also learnt that research is like chipping away at a gigantic iceberg. What is seen on the surface is just a small portion of what lies below. This makes research a humbling experience. On reflection I would have liked to do more, read more, discover more, but just as an artist has to finally put down the brush and say 'It is done', so do I.

On a professional level, I believe the phenomenological approach has challenged me to become a more thorough psychologist, in searching for the meanings and essences of experience, as I engage with my clients. The research has also taught me the importance of ethical considerations that protect the human rights and well-being of both the researcher and the researched.

5.8 CONCLUSION

For the fathers, disclosure of an HIV positive status appears to be an extremely difficult experience. With disclosure comes both relief and a sense of shame and loss of face, which for some of the fathers interviewed, seems to undermine an already fragmented sense of self. For they, like all men, aspire to earn and enjoy respect - from their partners, children, parents, peers and community. However, all the fathers in this research project had the courage to disclose their HIV positive status to others and directly to the researcher. In so doing, they not only earned the researcher's respect, but were availing themselves of a unique opportunity to talk about something very personal and significant in their lives. It is hoped that their positive experiences of disclosure will encourage others in South Africa to do the same.

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