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The Lived Experiences of HIV-positive Mothers

by

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A research project submitted in partial fulfilment of the requirements for the degree of MA by Coursework and Research Report in the field of Community Based Counselling Psychology in the Faculty of Humanities, University of the Witwatersrand, Johannesburg,

September, 2011.

DECLARATION

I declare that this research report is my own, unaided work. It has not been submitted before for any other degree or examination at this, or any other, university**.**

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Sacha Tarryn Street

8 September, 2011

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ABSTRACT

The AIDS pandemic has posed a major challenge to traditional motherhood. The dual challenges of being both a patient and a caregiver mean that there are many women who are facing unique physical and psychological difficulties. This study aims to explore the lived experiences of HIV-positive mothers and to gain an insight into the impact that the diagnosis of HIV had on the lives of the research participants. The study was exploratory and, thus, a qualitative research design was adopted. Semi-structured, individual interviews were conducted with eight HIV-positive mothers living in a government funded HIV care centre in Johannesburg, South Africa. A thematic content analysis method was utilised to derive themes relating to the subjective experience of mothering subsequent to the HIV-positive diagnosis. The results indicated that motherhood, for many HIV-positive mothers, was a fairly ambivalent experience characterised by a pervasive sense of loss and closely allied to various emotional and psychological challenges. Shared mothering, a lack of independence and strong institutional influences all contributed to the way in which the participants experienced motherhood and how they perceived themselves. The fears of future illness and death were prominent concerns which further fuelled the ambivalent nature of HIV-positive motherhood. Stigmatisation and rejection on the part of friends and family resulted in the participants' experiencing a deep and pervasive sense of loss. This, in turn, was experienced as a strong assault on both their egos and their sense of self. Various psychological and emotional challenges, as a result of a general lack of social support and a combination of contextual stressors, were, therefore, particularly common experiences before arriving at the care centre. However, the mothers all reported that they had received invaluable emotional, social and instrumental support from the care centre. HIV care centres offer a place of refuge and protection from ostracism within the community context. Although the mothers manifested a yearning for their pre-diagnosis sense of independence and general functioning,

nevertheless, despite the tensions inherent in being a HIV-positive mother, it was found that care centres play an insulatory role and help to act a buffer against the various challenges associated with living with HIV.

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CHAPTER 1: INTRODUCTION AND RATIONALE

When HIV-positive women are not vaginas waiting to infect men, they are uteruses, waiting to infect foetuses (Patton, 1993, p. 175).

The field of health psychology has long been interested in the role that psychological factors play in physical illness. Both HIV and AIDS constitute major public health challenges which have been of concern for South African health professionals since it is estimated that approximately 67% of people living with HIV in the world are from Sub-Saharan Africa (UNAIDS Report, 2009). While it would appear that there is an abundance of research worldwide on the onset, course and morbidity of HIV and AIDS, there is limited research in Sub-Saharan Africa on the psychological and emotional consequences of living with the diagnosis. With an estimated 29.1% of pregnant mothers in South Africa being HIV-positive South African women are, clearly, particularly vulnerable (Department of Health, 2007) and there is a serious need for research which focuses on the psychological wellbeing of HIV-positive mothers in South Africa. The dual challenge of being both a patient and a caregiver means that many women are confronting unique physical and psychological difficulties.

Motherhood is a crucial part of this study because, theoretically, both socially and personally, motherhood is often constructed as a function rather than as an experience. In particular, the focus of past research on mothering has usually been the child receiving mothering rather than on the mother herself (Long, 2009). In other words, women's experiences of motherhood and their feelings about being mothers have rarely been explored and are often found tucked away in studies on children (Phoenix & Woolett, 1991). Feminist researchers have aimed to document experiences that have been forgotten, ridiculed and devalued over the years and, in addition, they have tried to collect alternate voices on motherhood (Kruger, 2006). Accordingly, feminist research has proved beneficial because,

not only has it provided a platform for women's voices to be heard, but it has also problematised aspects of women's lives which had previously been taken for granted (Van Doorene, 2009).

For many HIV-positive women mothering is particularly difficult within the South African context because of the array of challenges which characterise life in South Africa. In addition, black women in South Africa have been disempowered in a number of ways. Firstly, they have been racially disempowered through the country's turbulent political history of discrimination (Arnfred, 2003). However, despite the fact that South Africa is no longer bound by this policy, the effects of apartheid have meant that there is still extreme inequality and poverty in the country and this means, in turn, that black women are still further marginalised (Walker, 1990). The reality that there are various social constructions and popularised myths which construct women who contract HIV as "prostitutes" or "promiscuous" individuals who deserve such a disease implies that being an HIV-positive mother is particularly challenging (Gilman, 1988). Past research has, therefore, often been guilty of portraying HIV-positive women in both a negative and a judgemental light and, in addition, a significant amount of research has focused on the potential harm that HIV-positive women may cause to their unborn children.

The experience of motherhood is not only an extremely personal event in life, but it is also an event which is marked by complex and shifting social and political constructions. This study, in examining the lived experiences of motherhood, entailed research into what it is like to be a mother on a day to day basis. In addition, the study focused on the way in which HIV-positive women make sense of the daily challenges and setbacks involved in their child rearing.

It is hoped that research into the lived experiences of motherhood from the perspective of institutionalised, HIV-positive women will, firstly, result in insights into what

it is like to be such a woman, secondly, insights into the nature and quality of the care accorded to these women and, lastly, that it will reveal what yet needs to be done if the emotional and psychological needs of HIV-positive mothers are to be met.

1.1 Research Aims

This study aims to explore the experiences of HIV-positive mothers as conceptualised by such women who are living in a government funded, HIV care centre. In addition, the study aims to find out more about the impact that the diagnosis of HIV had on the lives of the participants, both as women and as mothers. The objective of the study is, thus, to contribute not only to theory, but to engender insights into the experiences of HIV-positive mothers living in HIV and AIDS care facilities in South Africa. In keeping with these aims, a qualitative approach was adopted during which a wealth of information was gathered through the use of semi-structured interviews. This information was then analysed using thematic content analysis. To this end the following research questions guided the study.

1.2 Research Questions

1. How do the participants experience "motherhood"?
2. What impact has the diagnosis of HIV had on the lives of the participants, both as both women and as mothers?

1.3 Rationale

In 2009, the United Nations report on AIDS revealed that, of the 33 million people infected with HIV worldwide, 22.4 million (67%) were living in sub-Saharan Africa (UNAIDS, 2009). South Africa has the highest number of HIV infected people worldwide with a current infection rate of 5.7 million (UNAIDS, 2008). However, of even greater concern than these statistics is the ongoing, disproportionate impact of HIV on both women and girls. Research has revealed that women comprise nearly 61% of the total number of

people living with HIV in sub-Saharan Africa (UNAIDS, 2008), with women under the age of 30 being the most vulnerable (UNAIDS, 2008). In addition, women under the age of 30 are usually of child bearing age and, thus, the babies born to these mothers are often at an extremely high risk of infection through mother-to-child transmission. In an interesting systematic study conducted Brandt (2009) reviewed published quantitative research on the mental health of HIV-infected adults in Africa, and it was found that, of the 23 studies reviewed, only eight of these studies had focused specifically on women's issues while just over a third of the studies that involved both men and women failed to report some form of gendered analysis. The article also points out that research conducted in Africa (and elsewhere) has suggested that the mental health needs of HIV-infected men and women differ in terms of quantity and/or quality and, thus, it is extremely important that new studies focusing on women's issues be carried out (Brandt, 2009).

Despite the abundance of research on HIV and AIDS, the mental health correlates of HIV and AIDS remain largely unacknowledged and also under-researched in sub-Saharan Africa. While various other countries have realised both that mental health care is an integral component in the continuum of care for those individuals living with HIV/AIDS and that mental health care has been associated with improved quality of life and overall wellbeing (Shacham, Basta & Reece, 2008; Kalichman, 1998, Nilsson-Schonnesson, 2001), South Africa has been slow to address the HIV mental health nexus and, thus, services and interventions geared at addressing this significant health burden are also lacking. In addition, research has revealed the existence of several links between HIV and mental health, including higher levels of mental illness among people living with HIV or AIDS (PLHIV) (Brandt, 2009). However, the evidence base is largely from the developed world (Baingana, Thomas, & Comblain, 2005) and research from the developing countries remains limited (Collins,

Holman, Freeman, & Patel, 2006). Clearly, it is vital that research aimed at addressing this gap in developing countries such as South Africa be conducted.

Research into the mental health challenges confronting individuals with HIV has revealed that these individuals are often forced to cope with a combination of psychological challenges caused by multiple losses, fears and anxieties, feelings of shame, self-blame and social stigmatisation (Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002). More specifically, an HIV diagnosis may mean the loss of health, friends, employment, financial independence, physical intimacy, and the support of family members (Dansky, 1994; Friedland, Renwick, & McColl, 1996). Individuals may obsess over symptoms and temporary illnesses, fearing that death may be imminent (Holtby, 1999). In addition, HIV-infected individuals not only worry about their own futures, but also about how their children will cope once their parent(s) have died (Mellins, Ehrhardt, Rapkin, & Havens, 2000; Kaleeba & Ray, 2002). The latter is just one of many concerns that affect the psychological wellbeing of HIV-positive parents.

While there are various studies that have focused on the psychological distress of HIV-positive women (Murphy *et al*., 2002), little work has been done on assessing the psychological wellbeing of infected mothers. The experience of South African mothers has been largely influenced by the country's unique, sociopolitical history which was characterised by extreme inequality (Walker, 1995). This has resulted in constructions and conditions of motherhood which differ along racial lines in South Africa (Arnfred, 2003). Discussions will focus primarily on black women both because they represent the majority of women in South Africa and also because this research will focus on the experiences of black, HIV-positive mothers.

Research into HIV-positive motherhood has tended to be characterised by both thin and negative descriptions (Long, 2009). According to Squire (1993), HIV-positive mothers

are described either as unidimensional victims, or else they are portrayed as hazardous sources of infection in public policy, through medical discourse and in popular culture. Several studies have focused primarily on antiretroviral treatment (ARVs) and, thus, these studies construct HIV-positive mothers only in relation to the potential harm they may cause their babies (Long, 2009). There have been very few studies conducted which focus on the HIV-positive mother as a subject in her own right and which look at multifaceted accounts of the experience of mothering within the context of HIV (Long, 2009). Despite the fact that motherhood and chronic illness have each, separately, been important topics of inquiry in health-related research, there have been relatively few studies conducted which have been specifically directed at examining motherhood within the context of maternal, chronic illness, (Radtke & Van Mens-Verhulst, 2001; Thorne, 1990) and even fewer studies which have examined motherhood within the context of HIV.

Since the introduction of combination ARV therapy in 2003, the percentage of HIV-positive mothers who pass on the virus onto their newborn babies in KwaZulu-Natal has dropped by nearly two-thirds (Irin, 2009). A study carried out in 2005 found that, on the Nevirapine-only regimen, one in five HIV-positive mothers were still transmitting the virus to their infants (Irin, 2009).This implies that it has not been possible to erase the rapid spread of infection over the last ten years and that the number of children living with HIV is still extremely high. It is also a known, obvious reality that HIV-positive infants and children require intensive medical care and, very often, because they have faced rejection from their partners and families and have been cast out of their communities, single mothers do not have sufficient funds at their disposal for these high medical costs. This lack of social and financial support has forced many such mothers to seek help from specific NGOs and HIV care centres. Nevertheless, there has been relatively little research conducted on the experience of motherhood when living in HIV care centres.

Overall, the extremely high HIV infection rate among women of child-bearing age together with a lack of focus on the mental health correlates of HIV in South Africa and, more specifically, on the experiences of HIV-positive mothers, there is an urgent need for research which focuses on the in-depth and lived experiences of HIV-positive mothers. This research study will, therefore, aim to capture the intricacy of the experience of HIV motherhood.

CHAPTER 2: LITERATURE REVIEW

This chapter will introduce the concept of motherhood within the context of HIV. It will also provide an overview of both the relevant literature documenting the experiences of HIV-positive women, the themes relating to mothering in general as well as the specific challenges of mothering while, simultaneously, being HIV-positive.

2.1 Constructing Motherhood

Motherhood is, possibly, the most profound life transition a women experiences. Whether her point of departure is biological or not, mothering is a voyage that forever marks a woman's private and cultural existence (O'Barr, Pope, & Wyer, 1990). The experience of motherhood is, thus, not only an extremely personal event in a woman's life, but it is also an experience which is characterised by complex and shifting social and political constructions. Phoenix and Woollett (1991) have written extensively about the way in which mothering is a socially prescribed phenomenon. They also argue that psychology has been instrumental in constructing the ways in which motherhood is perceived and maintained. In addition, they suggest that various social and psychological constructions of "normal mothers" (with normal being synonymous with good and ideal) run counter to the reality of motherhood (Phoenix & Woollett, 1991, p. 13). Generally, it would appear that, when mothers are the focus of research, it is those mothers who are perceived to be deviant, rather than those mothers who are assumed to be "normal". Phoenix and Woollett (1991, p. 15) also discuss, in detail, the fact that "there are psychological studies of depressed mothers, single mothers, employed mothers, working class mothers, and mothers in their teenage years".

In her elaboration on the distinction between the "good" and the "bad" mother, Woodward (1997) argues that motherhood is constructed within a moral context with idealised representations of the Madonna − the self-sacrificing mother figure − representing

Eurocentric attitudes towards women. Woodward goes on to assert that "the perfect mother is a mother and a virgin and is idealised as asexual. In contrast, the "bad" mother is the opposite of the "good" mother who is self-sacrificing and self-effacing" (Woodward 1997). In a similar vein, feminist writers argue that the dominant perception of "good" motherhood is defined within a child-centred society as maternal sacrifice with the needs and rights of children being placed frequently before those of women (Richardson, 1993; Burman, 1994). The idealised view of the "good" mother is that of someone who willingly gives her time and energy to "meet the child's needs for nurturance and stimulation" (Richardson, 1993, p. 40). The problem with such idealisation is that it sets an impossible standard against which women are expected to measure themselves (Long, 2006).

Woolett and Phoenix further suggest that, when a woman becomes a mother, she usually finds that the everyday tasks of mothering are far removed from the ideal as she imagined and that, instead, the everyday tasks are socially devalued and relegated to individual households (Phoenix & Woolett, 1991). This, in turn, often leads to maternal ambivalence (simultaneous, contradictory feelings of love and hate towards the child) which then results in feelings of maternal guilt (Parker, 1995). This coexistence of love and hate is a product of motherhood and, hence, this experience is viewed as a normal and inherent aspect of motherhood.

In addition, motherhood is perceived to be both central to the identity of women and as an all-consuming identity. In terms of a white, middle-class mother this generally means that she is obliged to view intensive mothering − she is the sole carer of the child − as part of her job (Hays, 1996). On the other hand, mothers who do not practise intensive mothering or who are not part of a nuclear family are often looked down on for raising children in "broken homes" and, thus, raising children who may grow up to create problems for society. Hays (1996) further argues that these notions about "intensive mothering", in terms of which the

mother is primarily responsible for the process of childrearing (which is child-centred, expert-guided, emotionally absorbing, and financially expensive) stem from an economic system which is based on competitive individualism. Consequently, mothers who deviate from this norm and who are poor, working class, single and black are likely to be viewed as more "problematic" (Phoenix & Woollett, 1991, p. 19).

Within this context, deconstructing the notions of motherhood becomes an important task for critical psychologists and theorists. This deconstruction involves a rejection of unitary truths, highlighting, instead, that constructions of motherhood take part in, and reproduce, power relations (Long, 2009). In order to gain a deeper understanding of this, a feminist lens will be utilised.

2.2 Deconstructing Motherhood

A feminist lens was applied in this study in order to understand the theoretical field of motherhood. Feminism explores, among other things, the way in which motherhood as an institution has been named by the authoritative voice, not of women, but of a patriarchal culture. Feminist writers believe that, through the exercise of moral, social, legal and economic powers, the male paradigms of normative gender behaviour are continually being reinscribed (O'Barr *et al.*, 1990).

However, feminism extends further than mere theoretical study and it endeavours both to challenge and to change the subordination of women to men in all domains. In general, however, a common focus in feminist research is to give a voice to those women who have been silenced, to address the lives and experiences of women in their own terms and to create theory which is grounded in the actual experience and language of women (Kitzinger, 2004). Feminism has, indeed, accomplished much as it has progressed over time. Not only have male oriented and male-influenced interpretative frameworks been challenged, but the white Western feminist worldview has also been heavily challenged (Olesen, 1998).

In addition, black feminism has been instrumental in addressing the shortcomings of previous research conducted into motherhood. Black feminist theorising places African American women at the centre of its analyses (Collins, 1986; King, 1988). By grounding their theorising in the cultural experiences of African American women, many black feminists argue that experience is crucial to the black women's ways of knowing and being in the world. It may, therefore, be suggested that it is only by capturing the cultural experiences of African American women that it becomes possible to conduct a grounded analysis of the lives of these women (Brewer, 1994). Various female scholars of colour have tried to document the different historical experiences of communities of colour and, thus, also the differing cultural contexts and material conditions in terms of which mothering has been carried out. As a result of varying historical experiences, these communities of colour have constructed mothering in ways that diverge from the dominant model (Glenn, 1994).

An examination of the way in which mothering takes place among black women in both Africa and beyond, renders it evident that it is not possible to analyse motherhood in isolation from its context (Daniels, 2004). In her article "Shifting the centre: Race, class and feminist theorizing about motherhood", Collins notes that much of feminist writing has failed to recognise the diversity in mothering and has, instead, projected the concerns of white, middle-class women as universal (Collins, 1986). For example, if one focuses on mothers from a white, middle-class background, one assumes that all mothers and their children enjoy a degree of economic security and that women have the luxury of perceiving themselves as individuals in search of personal autonomy, instead of as members of communities struggling for survival. Accordingly, if one focuses on the experiences of women of colour, very different concerns emerge. For example, such mothers are often concerned with working for the physical survival of both their children and the community and, thus, they tend to focus on self-definition and on trying to construct individual and racial identities (Glenn, 1994). In

order to understand fully the other concerns of black mothers, it is essential that the role that history has played in affecting entire populations not be forgotten. In addition, in order to understand the constructions of motherhood in South Africa, one needs to take into account the country's unique and dynamic cultural history (Long, 2009).

2.3 Motherhood in South Africa

There has been very little research conducted on South African motherhood and, particularly, in relation to the maternal experience (Kruger, 2006). The few studies which do exist focus on the perspectives of contemporary South African mothers who are usually white, middle-class women (Long, 2009). These studies focus mainly on the concept of motherhood as a selfless, natural and idealistic notion, although this construction is also resisted and overturned by actual mothers (Daniels, 2004; Lesch & Kruger, 2005).

Daniels (2004, p. 1) argues that the general trend in South African research has been to portray black mothers, particularly poor mothers, as helpless victims "with little or no control over their lives; as objects to be bartered for by men; to be invested similarly to property". Nevertheless, historical studies on the centrality of motherhood in terms of the political development of South Africa contest this view and, when reviewing the literature it becomes evident that black mothers are represented in one of two ways − either as the strong, resilient mother or else the demoralised and oppressed mother in terms of race and gender (Long, 2009).

Most of the historical studies of motherhood in South Africa have focused on the time period from colonialism onwards but it is, nevertheless, important to note that prior constructions of motherhood are still relevant for many black women today. These include the value accorded to fertility and the relative power that motherhood offers to women (Walker, 1995). However, African conceptions of motherhood have been strongly influenced by colonialism, urbanisation and Westernisation. Historical analyses have also shown that,

from the mid-twentieth century, the Christian notions of motherhood became dominant (Walker, 1991) but, since then, these Christian notions have merged with African formulations (Walker, 1990, as cited in Long, 2009). The dominant discourse was centred on Euro-Christian and Victorian notions of "the Good Mother" as the emotional centre of the family with motherhood as the ultimate destiny of women and the source of their deepest fulfilment. However, as it moved out from its centre, this construct became infused with significant elements from indigenous formulations and was, thus, reshaped and rearticulated (Long, 2009).

During the apartheid era constructions of motherhood combined both Western and traditional formulations, with motherhood being idealised on both sides of the apartheid struggle (Long, 2009). Afrikaners revered the concept of the Volksmoeder (mother of the nation) and they believed mothers should not only to be dependent on and supportive of their men (Brink, 1990), but also that they should be responsible for producing and maintaining the Afrikaner culture (Du Toit, 2003). On the other hand, during the apartheid era, African women were often organised politically around their identities as mothers (Walker, 1991). In the fight against apartheid mothers were perceived as playing a central role as custodians of both the culture and of future leaders. It has been suggested that, even though motherhood was essential to the political project for both white and black women, the way in which they were portrayed differed slightly with white women being portrayed as more passive and home centred, while black women had a stronger and more active voice (Walker, 1995, as cited in Long, 2009).

Apartheid had a significant effect on both the family structures and dynamics of black families, as the movement of black people was closely monitored through the complex systems of pass laws, homelands and the migrant labour system (Long, 2009). In addition, the traditional family structure was undermined as many men were forced to leave their families

and seek work in urban areas (Duncan & Rock, 1997). This meant that female-headed households became the norm in both urban and rural areas (Pick & Obermeyer, 1996) and, thus, black mothers often had to shoulder the daily duties and responsibilities. In addition, during the apartheid era, the Nationalist government implemented family planning programmes which were directed specifically at the black population and which were aimed at limiting fertility (Long, 2009).

Despite the fact that South Africa is no longer bound by racial inequality, the effects of the apartheid era have meant that extreme inequality and poverty still exist and, thus, women are still marginalised in various ways. Women with HIV, for example, typically experience multiple psychosocial stressors and stigmas, including racism, poverty, current or previous drug use, relationships with violent or coercive partners, and various health risks associated with poor nutrition, physical and sexual abuse, and marginal living conditions (Gallego, 1998, as cited in Tangenberg, 2000). In addition, their social power is extremely limited with most of them lacking the education and resources associated with privileged, epistemological positions (Tangenberg, 2000).

South Africa's political history has, therefore, played a fundamental role in shaping the constructions of motherhood both between and within the racial groups. When looking at the constructions of motherhood among black South Africans today it is interesting to note that, despite the changes in history and the increasing diversity, African motherhood continues to remain both a central and a defining identity. In his article on women in South Africa, Walker (1982) notes that the terms "mother" and "woman" are frequently regarded as interchangeable and that the word "mother" is a compliment often paid to black women. It is evident from the above literature that motherhood among black South Africans has been heavily influenced and shaped by both history and culture. Ideologies originating in both

Western and African contexts have collectively constructed motherhood and continue to make motherhood an idealised part of life (Long, 2009, p. 80).

2.4 The HIV-positive Mother

There has been very little research or social commentary on HIV-positive motherhood, with those studies that have been conducted often portraying such women in a negative light and constructing mothers only in relation to the harm they may potentially cause their babies (Long, 2009). Various theorists have commented on the problematic ways in which HIV-positive mothers are referred to both in academic literature and the public realm. Zivi (1998), for example, suggests that, when mothers are mentioned in HIV studies, they are usually demonised and portrayed as the culprits in the perinatal transmission of HIV. In addition, Zivi (1998) adds that these studies, whether intentionally or not, often describe these mothers as irresponsible, irrational and uncaring. Patton (1993, p. 175) goes so far as to suggest that, when HIV-positive women are "not vaginas waiting to infect men, they are uteruses, waiting to infect fetuses". It is, thus, evident that HIV-positive women are largely portrayed in public policy, through medical discourse and in popular culture, as either unidirectional victims or as hazardous sources of infection, and seldom simply as women with their own thoughts and feelings (Squire, 1993).

Long (2009, p. 82) notes that HIV-positive mothers are usually portrayed in one of two ways − either they "are characterised by the idealisation of their status as mothers (and concomitant denial of the emotional pain involved in being HIV positive) or by denigration through the identification of deficit". What is apparent from the literature above is that the experiences of HIV-positive mothers are not being foregrounded and that, very often, research fails to take the HIV-positive mother as a subject in her own right. It is, therefore, problematic that, while the research does offers descriptors, it often leaves one with little

sense of what the experience of being an HIV-positive mother must be like (Long, 2009, p. 83).

It becomes evident historically how these negative constructions have come into existence. For example, the increase in the number of HIV-infected women in the early 1990s naturally meant an increase in the number of babies born with HIV. According to a UNICEF report, approximately 70,000 babies are born with HIV every year in South Africa (UNICEF, 2009). This significantly high number of infected children resulted in mother-to-child transmission being construed as a national crisis in South Africa (Avert, 2009) and the South African government has attempted to address this problem by introducing various policies, including mandatory testing. Mandatory testing is a term commonly used to describe HIV testing as a precondition for either receiving a service or being granted a privilege (Avert, 2009).

Although the actions taken by the South African government, as well as various other social action campaigns, have had relatively positive results, there have also been inevitable secondary effects which have contributed to the negative constructions of HIV-positive women. Firstly, as the government became preoccupied with mother-to-child transmission the focus shifted from the women to their unborn babies. Accordingly, the needs of the infant became paramount and were placed ahead of the mother's rights to autonomy. Much of the research on women living with HIV has focused on the issue of reproduction, with the emphasis on either the foetus or the infant (Hankins, 1995). This naturally meant that there was a subordination of women's interests and women's bodies.

Secondly, women with HIV were constructed as bad mothers for allowing themselves to fall pregnant and infect their innocent, unborn children. Barolsky (2003, p. 38) comments that women are often blamed for "bringing the disease into the home". The good mother or bad mother dichotomy that is, thus, created is particularly problematic as it ignores various

social and historical contexts which contribute to the decisions many women take. For example, black women in South Africa have been disempowered in a number of ways. Firstly, they have been racially disempowered as a result of the country's turbulent racial history and, even though South Africa is no longer bound by racial inequality, the effects of apartheid have meant that there is still extreme inequality and poverty in the country. This, in turn, means that such women are further marginalised.

In addition, women are also not included in the AIDS discourse as they are often viewed as conduits of the disease. The characterisation of HIV infection as a sexually transmitted disease has attracted to it the stigma associated with other sexually transmitted diseases, including notions of indiscriminate "promiscuity", "pollution", and "uncleanliness" (Gilman, 1988). Accordingly, women living with HIV have often been positioned as either a source or a potential source of infection and likened to prostitutes (Waldby, Kippax, & Crawford, 1991; Batten, 1992; Goldin, 1994).

Long describes the HIV-positive mother as a mother with a contradictory identity as the denigrated, abject and feared identity of being HIV-positive as well as the idealised identity of motherhood with all its associations of purity and goodness, are positioned together (Long, 2006). It is evident that both identities hold complex and competing personal, as well as social, meanings, with motherhood and HIV invoking powerful discursive positions (Long, 2006). Both motherhood and HIV are created in a moment of intimate sexual contact, but both exist uneasily with sexuality. Motherhood, paradoxically, is associated with chastity rather than with sexuality (Kristeva, 1983; Warner, 1976). Whether justified or not, HIV has, thus, becomes a metaphor for aberrant sexuality (Sontag, 1988).

An HIV diagnosis when pregnant means entering into these two contradictory identities which, independently, encompass complex meanings of life and death, and which collide in the same moment in time (Long, 2006). In addition, uncertainty as to whether the

mother will transmit HIV to the unborn child provides fertile and perilous soil for fantasy (Long, 2006). HIV-positive motherhood is, thus, located within a collision of opposites and, contained in the same individual, are profound contradictions of creativity and destruction, life and death, self and baby. For new mothers, the obligation and enjoyment of maternal care occupies the present, but awareness of the future, with all its uncertainties, is never far away. This ambiguity is complicated by the social images of HIV-positive motherhood (Long, 2006).

The issue of motherhood is contradictory in its own right, bringing expectations of virtue and purity of experience but evoking the opposites of idealisation and denigration, power and powerlessness, and creativity and destructiveness, with "good" motherhood always on the brink of failure (Long, 2006). These contradictions of motherhood become solidified around the potential of the mother to damage her child and they have become hyperbolised in the popular and scientific imagination around death, guilt and abnormality. Various theorists have noted that motherhood for HIV-positive women entails, "love, toil, and trouble" (Brush, 1996, p. 92). These "mother troubles" (Hanigsberg & Ruddick, 1999) are, however, exacerbated when they involve the resolution of the contradictions posed by both HIV infection and motherhood.

2.5 The Quality of Life of Individuals Living with HIV

HIV infection influences an individual's quality of life on a physical, social and emotional level. Initially, the term "quality of life" (QoL) referred not only to the "the absence of infirmity and disease, but also to a state of physical, mental and social well-being" (WHO Chronicles 1947). QoL is generally perceived as multidimensional with the most prominent domains being General (physical) Health, Psychological Wellbeing, Social Relationships and Environment (Jansen van Rensburg, 2009).

There are many factors which may lead to reduced levels of QoL or life satisfaction among persons living with HIV. These include multiple AIDS-related losses and bereavements, the need to make significant changes in sexual behaviour, relationship and social support disruption, exposure to discrimination and prejudice, and limited employment opportunities (Heckman *et al.*, 1997). One author described the quality of life of PLHIV as a complex constellation of disease, poverty, stigma, discrimination, and lack of treatment (Kovacevic, Phaladze, Human, Dlamini, Hulela, Hadebe, *et al*., 2005). However, when focusing on HIV, it is important to take into account the way in which it affects not only the individual person, but also his/her family, community, and country. The physical, psychological and social effects of the HIV diagnosis will be investigated in greater detail below in order to determine how such a diagnosis may influence the QoL of the individual concerned.

Physical impact

South Africa introduced ARVs into the public health sector in 2003 (Ruud, Srinivas, & Toverud, 2010). As a result, people living with HIV may now expect to live longer and, while they continue to pursue the normal activities of daily living, their health-related quality of life is expected to improve (Peltzer & Phaswana-Mafuya, 2008). In South Africa there have been numerous studies which have investigated the health-related quality of life (HRQoL) of PLHIV in both rural and urban settings in the country. Jelsma, Maclean, Hughes, Tinise, and Darder (2005) investigated the HRQoL of individuals receiving highly active retro-viral therapy (HAART) in Cape Town and found that, even in a resource-poor urban environment, the HRQoL was greatly improved by HAART, while the potential side effects of the ARV drugs appeared to have a negligible impact on the wellbeing of the subjects.

However, despite the fact that persons infected with HIV may report a myriad of physical symptoms that indicate disease progression, the consequences of these physical changes are very often expressed on a more psychological and social level. For example, a recent study conducted by Chandra, Ghandi, Satishchandra, Kamat, Desai, Ravi, *et al*. (2006) found significant associations between low CD4 cell counts and the psychological and social relationship domains among HIV patients in South India. For the purposes of this study, subsequent sections will focus on the psychological and social domains of quality of life.

Psychological impact

Mental health concerns are also important psychosocial factors that may affect individual's QoL (Aranda-Naranjo, 2004). The various HIV-related threats may evoke not only psychological issues such as a sense of persecution, loss and mourning, loss of control, and despair versus hope, but also existential concerns in respect of the meaning of life, death anxiety, existential death anxiety and awareness, existential isolation and existential responsibility (Nilsson Schonnesson & Ross, 1999). All these stressors represent potential threats to the individual's psychological wellbeing and quality of life. Research suggests that PLHIV in Africa experience more mental health problems than either non-HIV-infected individuals or the general population. In addition, HIV-infected adults are more likely to experience depression, post traumatic stress disorder (PTSD), anxiety, psychosis, alcohol abuse and a generally poor quality of life (Sebit, Chandiwana, Latif, Gomo, Acuda, Makoni, *et al.*, 2000; Jelsma *et al*., 2005; Shisana, Rehie, Simbayi, Parker, Zuma, Bhana, *et al*., 2005; Adewuya, Afolabi, Ola, Ogundele, Ajibare, & Oladipo 2007). Despite improvements in physical health after three months on ART, PLHIV in the urban areas of South Africa also continue to report a poorer quality of life than a matched community sample (Jelsma *et al.,* 2005). Among HIV-infected women greater anxiety, greater overall morbidity and a poorer

self-perceived quality of life were reported among those women who were pregnant (Mfusi & Mahabeer, 2000; Bernatsky, Souza, & De Jong, 2007).

Being an HIV-positive women and being pregnant with a child who may or may not also be infected, is an extremely stressful experience (Lazarus, Struthers, & Violari, 2009). Besides worrying about the health and future of their unborn child, many mothers may only find out about their own HIV diagnosis at the same time as their pregnancy is confirmed and they then have to cope with the feelings of shock, anxiety, fear, and guilt about their own diagnosis (Stevens & Doerr, 1997). In addition, many HIV-infected mothers are young, single parents who live in poor housing, are experiencing financial difficulties, and may have limited social support as they may be carrying an immense burden of caring for children and also, sometimes for other family members, who themselves may be infected with HIV (Hackl, Somlai, Kelly, & Kalichman, 1997). Research indicates that HIV-positive women often have low self-esteem, feel stigmatised by their HIV status, and are at high risk for depression (Jones, Beach & Forehand, 2001; Miles, Burchinal, Holditch-Davis, Wasilewski, & Christian, 1997; Miles *et al*. 2003).

Depression is one of the most prevalent psychiatric conditions seen in HIV-positive individuals with the lifetime prevalence of major depression among people living with HIV varying from 22 to 45% (Penzac, Reddy, & Grimsley, 2002). Several studies have reported rates of clinical disorder or depressive symptoms above the levels expected for non-HIV-infected populations. Depressive symptoms are also prevalent, with most studies reporting over 30% and as high as 64% (Mfusi & Mahabeer, 2000; Sebit *et al*., 2003; Kaharuza, Bunnell, Moss, Purcell, Bikaako-Kajura, Wamai, *et al*., 2006; Rochat, Richter, Doll, Buthelezi, Tomkins, & Stein , 2006; Simbayi, Kalichman, Strebel, Cloete, Henda, & Mqeketo, 2007; Stangl, Wamai, Mermin, Awor, & Bunnell, 2007). In one of the few large-scale longitudinal studies conducted with an HIV-infected population in Africa, Antelman,

Kaaya, Wei, Mbwambo, Msamanga, Fawzi, *et al*. (2007) found that more than half of the HIV-positive pregnant women surveyed in Tanzania had been depressed either at some point during their pregnancies or during the first year following the birth of their child. Women are particularly vulnerable to depression since they are faced with the specific burdens of living with HIV. They often feel isolated and experience shame, stigma, anxiety and feelings of ambivalence and, in addition, they are often challenged in their roles as caregivers, mothers and wives (Chung & Magraw, 1992).

In a study conducted by Mello, Aluisio, and Malbergier (2010), a high prevalence of lifetime and current major depression in women living with HIV was found. Most women in the study had already experienced a major depressive episode with this episode tending to appear after the HIV serodiagnosis, while 22.4% only of the women who had experienced depression in the past having had their episode of depression before the diagnosis of HIV infection. This result may suggest that the first depressive episode was unleashed by the difficulties both of being diagnosed with HIV and with living with this disease. When compared to their seronegative counterparts, it is possible that the increased prevalence of depression in women living with HIV is the result of a combination of the stress factors with which they have to cope. These stress factors include not only the fear of death but also episodes of stigma and discrimination in family and social interactions, having to act as caregivers for sick partners or other family members and experiencing the adverse effects from ART (Ferrando *et al*. 1999; Kaplan *et al.,* 1997, as cited in Mello *et al*., 2010).

Suicide is the most serious complication of depression and anxiety. Studies have found that between 1.9 and 4.6% of persons in the United States admit to having attempted suicide (Kessler, Borges & Walters, 1999; Kuo, Gallo & Tien, 2001), although similar statistics for South Africa are not available. A number of other risk factors common among persons with HIV (lack of employment, financial difficulties, substance use, physical and

sexual abuse, and social isolation) have been shown to predict suicidality (Brady, Gallagher, Berger & Vega, 2002; Cooperman & Simoni, 2003; Roy, 2003), with numerous studies indicating that this population is at an increased risk of suicidal thoughts and behaviour (Cote, Biggar & Dannenberg, 1992; McKegney & O'Dowd, 1992). However, there are also studies that suggest that HIV-positive individuals are not at a higher risk for suicidal ideation than their seronegative counterparts (Perry, Jacobsberg, Fishman, Weiler, Gold & Frances, 1990; Schneider, Taylor, Kemeny & Hammen, 1991).

However, the stage of the disease may also play a role in an increased risk of suicide and thoughts of death. Although thoughts of death and suicidal ideation may occur independent of one another, it may be expected that both would increase with as the disease advances, as many of the potential etiological factors are exacerbated by declining health (Braunstein, 2004). Bellini and Bruschi (1996) found increased suicidal ideation during the period of testing in both HIV seropositive and seronegative persons. They also found that HIV seropositive persons are particularly susceptible to suicidal ideation during the first three months following diagnosis. In the era prior to the advent of HAART, a diagnosis of HIV-positive meant the very real possibility of degeneration to a vegetative state and, ultimately, death. It is common for individuals afflicted with serious and fatal diseases to experience increased thoughts of death, unrelated to suicidal ideation (Robertson, Parsons, Van der Horst & Hall, 2006). In historical clinical interviews, subjects in a study conducted by Robertson *et al*. (2006) very often reported experiencing thoughts of death immediately after testing HIV positive. This clearly happens at a time when the individual is severely threatened and in psychological shock and this, in turn, may overwhelm the available coping resources. These early thoughts of death may reflect anxieties related to thoughts of a painful death, afterlife concerns, or a realisation that one's hopes and dreams will not be fulfilled (Robertson *et al.*, 2006).

It is both widely known and accepted that depression is most commonly linked to anxiety. Studies have demonstrated that mood and anxiety disorders are more prevalent in persons with HIV than in the general population (Kemppainen, Holzemer, Nokes, Sanzero, Corless, Bunch, *et al*., 2003). However, the prevalence rates for anxiety vary widely with regard to the population studied, the stage of the HIV disease, and the time which has elapsed since diagnosis. Among a recently diagnosed population of HIV-infected adults in Nigeria, Adewuya *et al*. (2007) reported that 34% of the individuals had manifested some form of anxiety disorder. Other reports of high levels of anxiety-related symptoms or specific anxiety disorders, such as panic disorder or generalised anxiety disorder, ranged from 19 to 37% (Mfusi & Mahabeer, 2000; Sebit *et al*, 2003; Shisana *et al*., 2005).

Some studies have attempted to identify risk factors as regards the development of HIV-related anxiety. Dew *et al* (1997) found that persons with a prior history of an anxiety disorder before their diagnosis of HIV are at higher risk for a recurrence of anxiety related symptoms. Inadequate partner support and a coping style characterised by low feelings of mastery or control over life events also increase the risk for the development of HIV-related anxiety (Kemppainen *et al*., 2003). Kemppainen Van Servellen, Sarna, Nyamathi, Padilla, Brecht, *et al.* (1998) measured levels of anxiety and depression and found that 72.7% of the participants in their study scored high on the anxiety scales. In addition, increased anxiety was associated with adherence to the HIV/AIDS medical regimen and disruptions in physical status. In a related study, Kaplan, Marks, and Mertens (1997) found that nearly 40% of a multiethnic sample of 53 women from a large mid-western city in America reported clinically significant levels of anxiety, with 6% of the sample demonstrating extreme levels of anxiety. It is widely agreed that anxiety is one of the most prevalent symptoms in HIV/AIDS.

Death anxiety is also a common form of anxiety present in HIV-positive persons. Death anxiety may be viewed as a state of distress accompanied by either an encounter with

death or the prospect of death (Neimeyer, Stewart, & Anderson, 2005). Although past research has provided evidence for the existence of death anxiety in the HIV population it has also demonstrated frequent contradictions in the severity of the death anxiety at different stages of the illness (Catania, Turner, Choi, & Coates, 1992; Hayslip, Luhr, & Beyerlein, 1991; Hintze, Templer, Cappelletty, & Frederick, 1993). Death-related anxiety may involve apprehension of the dying process and fear of the afterlife, as well as the effects on loved ones.

Franks, Templer, Cappelletty, and Kauffman (1990) studied males with AIDS and found greater death anxiety among person with AIDS as compared to the HIV-negative controls. Catania *et al*. (1992) also reported that HIV-positive symptomatic men exhibited significantly higher levels of death anxiety than both asymptomatic and HIV-negative participants. Despite the fact that there are a limited number of studies which have been conducted on death anxiety among HIV-positive individuals, the literature does indicate that HIV is similar to other long-term illnesses in that evoke death anxiety at various stages of the disease.

One particular area that elicits anxiety among HIV-positive women is the diagnosis of their children. Establishing the HIV status of babies born to HIV-positive mothers is a complicated process because the antibody tests for HIV yield reliable results only once the baby has lost the maternal antibodies at approximately twelve months of age (Lazarus *et al*., 2009). The highly sensitive and specific polymerase chain reaction (PCR) tests directly for viral DNA and allows diagnosis at 4 to 6 weeks after birth, thus facilitating improved management of the baby's health. This test is now part of standard HIV care in South Africa (Department of Health, 2005).

However, the period immediately before and after early diagnosis of the baby's HIV status and the weeks waiting for the results of the tests have been found to be extremely

stressful for HIV-positive mothers (Lazarus *et al*., 2009). One study found that, during this waiting period, the mothers manifested an extreme preoccupation with infection, with this preoccupation being related to the uncertainty that the mothers had to endure before they knew whether their babies were infected or not (Long, 2009). As regards these uncertainties, Long (2009) found that the women in her study often became obsessed and had a compulsion to examine their baby's body for signs of infection.

The importance of seeking medical attention for one's baby at the merest hint of a problem was also seen as important as this tended to lead to a hypervigilance emerging in the mother. Some mothers also experienced difficulties in being consoled by medical opinion while many who found out about the initial status of their child were only temporarily appeased (Long, 2009). Women are often told that there is a small possibility that their babies will test falsely negative and, therefore, for some women then there is a slight chance that their fears will be confirmed and that their babies will, in fact, turn out positive at a later date (Long, 2006).

Disclosure is another particular concern which is often related to the psychological and emotional quality of life of HIV-positive women. Disclosure demands careful consideration because of its potential for adverse social consequences including rejection, abandonment, and even physical assault (Bharat, 1996; Rothenberg & Paskey, 1995). For example, Gielen, O'Campo, Faden and Eke (1997) found that one in five women who disclose their HIV-status experience negative reactions that, ultimately, result in loss of social support. HIV-serostatus disclosure decisions depend on the barriers and needs associated with specific types of relationships. It has been found, for example, that people living with HIV demonstrate a greater inclination to disclose their HIV-status to friends rather than to their families. For many people, disclosure decisions must balance the need for social support specific to coping with HIV against the potential loss of what may otherwise be generally

supportive relationships. For example, Kimberly and Serovich (1996) did not find an association between the disclosure of HIV-status and the support received from family members which suggests that support may be gained, lost, or unchanged with decisions to disclose or not to disclose. HIV-status disclosure decisions may, therefore, be a source of conflict and stress and it is clear that such decisions merit careful consideration.

Women with HIV often experience immense difficulty in telling others that they are infected and they may not disclose their status to anyone (Gebrekristos, Abdool Karim, & Lurie, 2003; Olley, Seedat, & Stein, 2004). At present, because of the efforts worldwide to decrease perinatal HIV transmission, increasing numbers of women are being tested during pregnancy and this may have unique implications regarding disclosure (Dabis, Fransen, Saba, Lepage, Leroy, & Cartoux, 2000). A woman who finds out while pregnant that she is HIV positive has a relatively short period of time before the birth of her child in which to cope with her diagnosis. However, hiding her diagnosis may put her child at risk of HIV infection if, fearing exposure, she feels unable to take her ARV prophylaxis or to choose a safe method of feeding her baby (Makin *et al*., 2008). A number of studies have documented that rates of disclosure are generally low, although these results vary substantially in respect of different populations. Studies conducted in South Africa have also reported low rates of disclosure (Kuhn, Mathews, Fransman, Dikweni, & Hussey, 1999; Sigxashe, Baggaley, & Mathews, 2001). For example, 36% only of a South African rural sample of 55 women had disclosed their status five months after diagnosis (Sethosa & Petlzer, 2005).

Previous research has identified the many complexities that impact on disclosure to partners with barriers to disclosure including factors such as fear of accusations of infidelity, abandonment, rejection, discrimination, and violence (Sigxashe *et al.*, 2001; Medley *et al.*, 2004; Maman, Mbwambo, Hogan, Kilonzo, & Sweat, 2001) and, most of all, fear of loss of economic support from a partner (Medley, Garcia-Moreno, McGill, & Maman, 2004).

Women in longstanding relationships and those reporting trust and love as part of their relationships are more likely to disclose than women in relationships of shorter duration or women who have had multiple sexual partners (Sigxashe *et al.*, 2001; Antelman *et al*., 2007). In a study conducted in Tanzania, both fear on the part of the women of their partners' reactions and communication in decision making were important factors affecting disclosure. It is easier for a woman to disclose her status to her partner if he has also tested or if there has been prior discussion on testing (Maman *et al.*, 2001).

The stigma associated with HIV disease also affects disclosure. In a study involving both men and women, stigma and fear of discrimination were the main reasons for nondisclosure (Chandra, Deepthivarma, & Manjula, 2003). In some African communities people are reported to be more fearful of the social consequences of AIDS than of the disease itself (Biswalo & Lie, 1994). It is interesting to note, however, that African research shows that, while fears of disclosure are legitimate, the consequences are often less severe than anticipated. Medley *et al.*'s (2004) review of disclosure found that, while 4 to 28% of women reported negative consequences to disclosure, including blame, violence, abandonment and stigma, many respondents reported positive outcomes such as kindness, understanding and acceptance after disclosure. In a South African study, 12% of disclosures only had resulted in less kindness; 70% in no change in the relationship and 19% in an increase in kindness (Kuhn *et al*., 1999). The adverse effects as a result of disclosure included violence on the part of their sexual partners (13%), loss of a partner (9%) and eviction from home (3%). However, for pregnant women in South Africa, voluntary disclosure ultimately resulted in a supportive, constructive response (74.2%), even after initial upset, anger or rejection on the part of some partners (27%) (Varga, Sherman, & Jones, 2006). Clearly, it is essential for women to weigh the likelihood of an expected negative reaction against the possibility of a positive outcome when considering to whom to disclose.

Among the many challenges faced by mothers living with HIV is the decision about whether and how to disclose their HIV serostatus to their children. In studies exploring the impact of HIV and AIDS on the ability of mothers to raise their children, the disclosure of serostatus emerged as one of the mothers' main concerns (Donenberg & Pao, 2005; Faithfull, 1997; Moneyham, Seals, Demi, Sowell, Cohen, & Guillory, 1996). This decision about disclosure may result in high levels of tension and stress for parents (Marks *et al*, 1992).

These concerns may be exacerbated among parents of younger children as a result of the fact that these parents face additional worries, such as whether the child is old enough to understand, or if he/she will be able to keep the information confidential. The latter is of special concern amongst mothers living with HIV and who have children of school going age (Pilowsky, Wissow, & Hutton, 2000). Many parents choose not to tell their young children about their HIV-positive status, either because are worried about whether their children will be able to handle the news (Black, 1993), or because they must also weigh the benefits of disclosure against the risk that sharing the information may render the family vulnerable as a result of the child's disclosure to others (Murphy, Steers, & Dello Stritto, 2001).

Faithfull (1997) mentions that one of most severe anxieties for HIV mothers stems from this issue of disclosing their status to their children and, thereby, perhaps introducing discrimination into their lives. In addition, mothers worried how this may affect their relationships with their children as well as how it will affect their children's social interactions with others (Faithfull, 1997). Mothers are also often concerned about exacerbating their existing guilt and self-reproach through the child's brutal awareness of the mother's impending death. However, studies have also demonstrated that harm may result from not disclosing to children (Forsyth, Damour, Nagler, & Adnopoz, 1996). Children may intuitively know something is wrong by reading signals such as their mothers going to the doctor, taking medicine or losing weight. Theoretically, this may cause anxiety and confusion

(Murphy *et al*., 2001). However, parents who defer disclosure also run other risks including the possibility that the decision may be taken from them should someone else discloses their HIV status, that their children may guess the secret; or that they may inadvertently reveal it in a moment of stress, thus depriving them of the opportunity to plan their disclosure.

Nevertheless, not disclosing may take both a physical and a psychological toll on mothers. Mothers living with HIV report that they do not take their medications at times because they are afraid their children will observe them and suspect that something is wrong. Furthermore, mothers who have not disclosed often schedule medical appointments only when their children are in school and they are also more likely to miss medical appointments (Hackl *et al*, 1997; Mellins *et al*., 2000; Murphy *et al*., 2001). Clinicians often advise mothers to disclose because it is thought that both parents and children may benefit (Armistead & Forehand, 1995; Zayas & Romano, 1994). In addition, disclosure may provide time for the child to grieve, social support for the child and an opportunity to clarify any misconceptions that the child may have regarding HIV (Doll & Dillon, 1997; Zayas & Romano, 1994).

Open discussions about illness and anticipated loss have been shown in some studies to lead to more fulfilling family relationships (Brown & Powell-Cope, 1993) and it is thought that a child's misconceptions about his/her mother's health will likely persist if such discussions do not occur (Siegel & Gorey, 1994).

Stigma is yet another psychological effect of an HIV diagnosis. HIV/AIDS-related stigma may be damaging to an individual's quality of life and may also have broader consequences from a public health perspective (Mann & Tarantola, 1996). HIV or AIDS related stigma most often manifests in prejudice, discounting, discrediting, and discrimination directed at both those individuals who are perceived to have either AIDS or HIV and also the people and communities with which they are associated (Herek, Capitanio, & Widaman, 2002).

There have been a few studies conducted which have empirically explored the relationship between quality of life and perceived HIV stigma over time in persons living with HIV infection in Sub-Saharan Africa with some studies directly exploring the link between HIV stigma and QoL. Neely-Smith (2003) reported that both the oppression of women in a patriarchal society and HIV-associated stigmas had resulted in decreased QoL and a shortened life span of Bahamian women. In a study conducted by Greeff, Uys, Wantland, Makoae, Chirwa, Dlamini, *et al.* (2009), which examined perceived HIV stigma and life satisfaction among persons living with the HIV infection in five African countries, it was found that, as the reports of stigma increased, life satisfaction scores decreased. This finding, thus, provides evidence that perceived HIV stigma has a significantly negative and constant impact upon the life satisfaction and QoL of people living with the HIV infection.

The discrimination which exists against women in various societies often means that attitudes towards those who become infected are often less accommodating as compared to the attitudes towards men in the same situation. HIV-positive women are often blamed for infecting their husbands and unborn children and are described in stigmatising terms such as "vectors", "diseased" and "prostitutes" (terms that are rarely used when describing infected men) (UN/WHO, 2000). In Africa, various human rights violations have been reported as having been perpetrated on HIV-positive women. These include sexual abuse and coercion, discrimination in terms of access to health information, discrimination in property inheritance, rape and labour exploitation (Human Rights Watch, 2003b).

However, although still prevalent in the Republic of South Africa, it would appear that AIDS stigmas appear to be declining somewhat (Simbayi *et al*., 2007) with the national HIV/AIDS household survey conducted in South Africa in 2005 finding that endorsements of AIDS stigmatising beliefs had declined from the previous household survey reported in 2003 (Shisana *et al*., 2005). Nevertheless, studies have found that people living in Cape Town,

South Africa, frequently endorse AIDS stigmatising beliefs (Deacon, Stephney, & Prosalendis, 2004; Kalichman *et al*., 2005). For example, 43% of people surveyed in local townships and neighbourhoods stated that people living with HIV should not be allowed to work with children, while 41% felt that people with HIV should expect to have restrictions placed on their freedom (Kalichman *et al*., 2005). Accordingly, Simbayi *et al*. (2007) conducted a study aimed at finding out whether these findings in respect of men and women living with HIV in Cape Town were, indeed, true. They found that discrimination experiences were both common and internalised and that AIDS stigmas were prevalent among people living with HIV/AIDS in Cape Town. Nearly one in four of the participants in this study had never discussed their HIV status with a friend while one in three indicated that they had been treated differently by both friends and family once they had tested HIV positive. In view of the fact most participants in this study had been diagnosed with HIV infection for less than three years only (Simbayi *et al*., 2007), it seems feasible to state that discrimination practices still persist in present day South Africa.

Social impact

Social support is a multifaceted concept with several dimensions, namely, emotional, informational, and instrumental support. Emotional support has been defined as the providing of esteem and affiliation to others (Norbeck, Lindsey, & Carrieri, 1983), while instrumental support comprises financial or housing assistance (Gielen, McDonnell, Wu, O'Campo, & Faden, 2001). Informational support, on the other hand, has been defined as the giving of advice and information on social, health, or employment matters (Turner, Hays, & Coates, 1993). In a study on the quality of life in persons with HIV infection, Wachtel, Piette, Mor, Stein, Fleishman and Carpenter (1992) found that HIV-positive women scored worse than men in the areas of role and social functioning and in mental health.

Researchers have noted an association between social relationships and health. According to Berkman, Glass, Brissette, and Seeman (2000), it is widely recognised that both social relationships and affiliation exercise powerful effects on physical and mental health and on wellbeing. Furthermore, research suggests that socially isolated or socially marginalised individuals are less healthy psychologically and physically, and are more likely to die prematurely from illnesses (House, Landis, & Umberson, 1988). Accordingly, an understanding of the impact of social networks on health status, health behaviours, and health decision may contribute to the development of effective interventions aimed at preventing poor health outcomes.

As regards to the support offered to people living with HIV, it has been indicated that there is a lack of support for people living with HIV in South Africa (Russell & Schneider, 2000). While there is generally support provided to the patients before and shortly after the HIV test in the form of counselling it would, however, appear that there is minimal ongoing support in the form of follow-up counselling and other types of support such as support groups or practical support (Pienaar, 2004).

In view of the fact that a HIV and AIDS diagnosis represents a major life crisis, support after the diagnosis is vitally important. In a study conducted by Coetzee and Spangenberg (2003), the participants stressed the fact that becoming aware of one's HIV status without the possibility of follow-up care and support causes depression, despair, and death. According to Russell and Schneider (2000), there are not enough support programs available in South Africa for people who have been diagnosed HIV-positive and also guidelines and standards in terms of the existing programs are lacking.

A lack of social support has been positively associated with physical illness, psychological distress, and mortality in a variety of populations (Berkman & Syme, 1979; Broadhead, Kaplan, James, Wagner, Schoenbach, Grimson, *et al.*, 1983). Conversely, support

from significant others has been shown to buffer the impact of a wide variety of stressors (Cohen & Wills, 1985). In addition, the presence of social support has been correlated with both a reduction in maternal drug use (Giblin, Poland, & Ager, 1990) and also with improved birth outcomes in pregnant women from impoverished backgrounds (Norbeck & Anderson, 1989). Accordingly, an HIV-seropositive woman's social support network may promote healthy behaviours and help reduce the delay in seeking care.

For those women who are at risk for HIV infection, social support interventions have proved to be helpful in coping with environmental stressors such as homelessness, substance abuse recovery, and poverty (Freudenberg, Lee, & Germain, 1994; Hobfoll, Jackson, Lavin, Britton, & Shephard, 1994; Nyamathi & Stein, 1997). In addition, supportive interactions for women living with HIV infection have addressed stressors such as social isolation, stigma, and disclosure (Chung & Magraw, 1992).

Children are very often an important source of social support for HIV-infected women (Andrews, Williams, & Neil, 1993; Barroso, 1997). Findings from a study on impoverished HIV-positive women found that their self-identified needs included involvement and supportive interactions between the fathers and their children as well as support from family and friends (Bunting, Bevier, & Baker, 1999). Based on findings from relevant literature, it is evident that positive social interactions are beneficial to both HIV-infected women and their families.

The way in which those infected with HIV perceive and experience relational challenges is of key importance in respect of the social support of HIV patients. Research indicates that the quality of partner relationships may have particularly profound implications for the emotional adjustment and health status of those infected with HIV (Fox, 2010) with studies indicating that those individuals who are more satisfied with their social support are less likely to show signs of psychological distress (Schmitz & Crystal, 2000) and depression

(Hays, Turner, & Coates, 1992), and that perceived low social support and unsupportive interactions may be related to increased levels of anxiety and depression (Song & Ingram, 2002).

The way in which HIV infection impacts on partner relationships and whether partner relationships are experienced as either "supportive" or "stressful" may have potentially significant consequences for the health and life span of those living with HIV. In addition, the impact of chronic illness on a partner relationship is also influenced by the nature of the illness and several unique aspects of HIV infection suggest that it may present particular challenges. Couples may be required to confront the stigma associated with HIV infection – a stigma which, as a result of its principal modes of transmission, its association with stigmatised groups, and its transmittable nature, is commonly perceived to be significantly greater than the stigma associated with many other chronic illnesses (Green & Sobo, 2000; Van Devanter, Thacker, Bass, & Arnold, 1999). In addition, disclosure of one's HIV status to a partner may involve revealing past history or activities associated with infection that may, otherwise, have remained concealed while the issue of disclosure of an HIV-positive status to a new partner is often a fraught issue (Green & Sobo, 2000).

As an infectious disease, there is also the potential for HIV to be transferred, thus raising particular issues for sexual relations. In cases in which the risk of infection was either known or unknown, to one or both individuals, couples may also have to confront the psychological impact of one partner's having infected the other. The impact of HIV infection on women's relational experiences is a key issue. Psychologists have long argued that social and partner relationships are of particular importance for women in terms of both their identity and their sense of self (Gilligan, 1993; Miller, 1976). Miller (1976) suggests that relationships are central to women's self identity and goes on to state that "women stay with, build on and develop in a context of attachment and affiliation with others" and that a

“woman’s sense of self becomes very much organized around being able to make, and then to maintain, affiliations and friendships” The perceived stigma accompanying an HIV-positive identity and women’s responses to this stigma often mean that women are left struggling with the dilemma of how to manage their HIV-positive identity to “keep safe” whilst, at the same time, maintaining their need for affiliation and connection with others .

Kalichman, Rompa, and Cage (2000) proposed that HIV-infected men and women in relationships reported significantly less symptoms of somatic distress than those without partners because partner relationship may buffer and, thus, offer some protection from the emotional distress of living with HIV by providing both tangible and emotional social support (Kalichman *et al*., 2000). However, their study suggests that the picture is more complex, and that the benefits provided by a partner relationship may not necessarily be in the form of tangible or emotional support but, rather, that it may be that the relationships are providing a protective function at a more fundamentally psychological level by offering a defence against feelings of isolation and otherness. In addition, the study suggests that partner relationships may also influence the way in which a women’s illness identity relates to other aspects of her identity. The latter is illustrated by the “sense of normality” in terms of which the women describe their partner relationships as compared to the dominance of the HIV-positive identity when relationships are either threatened or ended. However, the study also indicates that whether or not an infected partner has disclosed his/her positive status in a sero-discordant relationship may have an important impact on whether or not the partner relationship offers psychological protection, and whether or not the woman feels defined by her HIV-positive diagnosis (Kalichman *et al*, 2000).

Another social aspect that has been found to play a role in the quality of life of HIV-positive persons is the presence or absence of spirituality and religion. Research has documented the importance of spirituality − defined broadly as prayer, meditation, faith in

God and drawing strength from one's beliefs − on the psychological health of HIV-positive individuals (Mamana, Cathcart, Burkhardt, Ombac, & Behets, 2009). Research has also shown that people living with HIV who report a greater engagement in spiritual activities report lower emotional distress (Phillips & Sowell, 2000), less depression (Simoni & Ortiz, 2003), greater optimism (Biggar, Forehand, Devine, Brody, Armistead, & Morse., 1999), and better psychological adaptation (Simoni, 2002).

In one study conducted in the United States, the researchers found that spirituality was strongly and positively associated with the feeling that life had improved (Braxton, Lang, Sales, Wingood, & DiClemente, 2007). Those individuals who report an increase in spirituality after the HIV diagnosis have also been shown, after controlling for other factors, to have a significantly greater preservation of CD4 cells, as well as a significantly better control of viral load (Ironson, Stuetzle, & Fletcher, 2006). Somlai and Heckman. (2000) found that prayer, "strong beliefs in life after death", "believing that a higher power cares for them", the possibility of miracles and a belief that HIV is not a punishment from God were important supportive constructs for people living with HIV and AIDS. Doyal and Anderson (2005) have also pointed to the fact that women living with HIV and AIDS regularly turn to religion as a source of support and help in coping with difficulties.

2.6 HIV and its Effects on Mothering

The physical, psychological, and social influences of HIV as outlined above are particularly important as regards HIV-positive mothers. There has been considerable interest in the way in which a HIV-positive diagnosis may or may not compromise the ability to mother a child. Maternal role attainment is a psychological construct that was defined by Mercer (1985b; 1986a; 1995) as the process in terms of which a mother achieves competence in her role and also integrates mothering behaviours into her established role set so that she feels comfortable with her identity as a mother. Maternal role competence, on the other hand,

refers to the mother's skill, sensitivity, empathetic response and nurturing behaviour that all promote the infant's health and development (Mercer, 1995). For most mothers, the process of maternal role attainment begins during the prenatal period while the time frame for the integration of the maternal role is three to ten months after the birth of the infant (Mercer, 1986a, 1985b).

Current knowledge illustrates that those factors affecting maternal role attainment include a mother's characteristics (e.g. health, self esteem, depression, maturity, attitudes, pregnancy, birth experience, and role conflict); the child's characteristics (e.g. temperament, ability to give cues, appearance characteristics, and health), and environmental conditions (e.g. social support, family functioning, stress, mother father relationship) (Koniak-Griffin, 1993; Meighan, 2001). These variables may be investigated in order to ascertain their influence on maternal role attainment by either strength or relative form. In addition, some variables may interact either to facilitate or to hinder the process of maternal role attainment.

Psychological theorists have investigated several factors influencing maternal role attainment in HIV-positive mothers (Pakdewong, 2006). Those factors which have been found to correlate with maternal role attainment in HIV-positive mothers include the three maternal characteristics of depression, self esteem, and health status; infant health status and the two environmental conditions of social support and stigma (Pakdewong, 2006).

In the context of HIV infection, evidence suggests that mothers with HIV work towards self-preservation as a mother in order to protect their children from both the illness and HIV stigma (Sandelowski & Barroso, 2003c). Overall, previous findings show that HIV-positive mothers place a high value on both their children and their maternal role despite the fact that the HIV disease threatens their own health and psychosocial condition (Salayakanon, 1997; Jiarapaet 2000). Conversely, it has also been found that some HIV-positive mothers struggle with maternal attachment − a component of maternal role attainment. Accordingly,

those factors that are related to the context of mothers with HIV infection and which are also relevant to the factors previously identified as affecting maternal role attainment, therefore, merit further investigation and should be borne in mind when looking at the experiences of HIV-positive mothers.

To summarise, this chapter reviewed the literature regarding motherhood in the context of both HIV and the HIV-positive women's experiences of motherhood. The chapter also identified various social, psychological and emotional HIV related challenges and discussed the interaction between these challenges and the ability to mother in the face of such an illness. Accordingly, the chapter has provided both a context in which to understand what HIV-positive motherhood entails as well as insights into HIV-positive women's experiences of the mothering process.

CHAPTER 3: RESEARCH METHODS

3.1 Research Approach

In view of the fact that interpretations of experiences were central to this study in order to understand the meanings which the participants ascribed to motherhood within the context of HIV, the study adopted an interpretive paradigm. More specifically, an interpretive phenomenological approach was used as such an approach acknowledges that a person's life is shaped by social experiences and individual subjectivity (Fossey, Harvey, McDermott, & Davidson, 2002).

An interpretative phenomenological analysis (IPA) is concerned with trying to understand both lived experience as well as the way in which the participants themselves make sense of these experiences. Accordingly, such an approach is principally concerned with the meanings which those experiences hold for the participants (Smith & Osborn, 2004). An approach may be described as phenomenological if it involves a detailed examination of the participant's world. In other words, it attempts to explore personal experience and is concerned with an individual's personal perception or account of an event as opposed to an attempt to produce an objective statement of the event itself (Smith & Osborn, 2008).

It is important to note that, while IPA involves trying to get close to the participant's personal world, it must be acknowledged that it is impossible to do this either directly or completely. Access to this world is dependent on the researcher's own conceptions which are, nevertheless, necessary in order to make sense of that other personal world through a process of interpretative activity (Smith & Osborn, 2004).

Accordingly, hermeneutics − the theory of interpretation – constitutes a second important theoretical current for IPA (Smith & Eatough, 2006). In IPA a two-stage interpretation process, or a double hermeneutic, is involved. While the participants are trying to make sense of their world, the researcher is trying to make sense of the participants as they

attempt to understand their own world. IPA is, therefore, intellectually connected to both hermeneutics and to theories of interpretation (Smith, Flowers, & Larkin, 2009).

In terms of this research study it was decided that, since IPA aims to find out about the way in which individuals are perceiving the particular situations they are facing and how they are making sense of both their personal and social world, IPA was a suitable approach (Smith & Dunworth, 2003). In view of the fact that the participants in this research were HIV-positive mothers who had experienced life both inside and outside of care centres, their reflections would provide a thorough understanding of the "lived experience" of mothers living with HIV. Accordingly, the use of a qualitative methodology within an interpretative paradigm helped to unpack areas relating to HIV and motherhood and, thus, enabled a more nuanced study.

3.2 Participant Selection

One of the obstacles to research endeavours is finding people who are both willing and able to tell their stories. Studies which are conducted using an interpretive, phenomenological lens are usually conducted on small sample sizes. The detailed case by case analysis of individual transcripts usually takes a significant amount of time while the aim of the study is to say something in detail about the perceptions and understandings of the particular group rather than to make more premature, general claims. Accordingly, IPA researchers usually try to find a fairly homogeneous sample. In addition, IPA researchers often used purposive sampling in an effort to find a closely defined group for whom the research question will be significant (Smith & Osborn, 2004).

The specific type of non-probability sampling that was used in this research is termed convenience sampling. Convenience sampling generally involves collecting data from the most convenient sample (Whitley, 2002). In this research study the sample comprised eight mothers who fulfilled the criteria of the study. These mothers were sourced from an HIV

children's home in Mondeor, Johannesburg. The home accommodates mothers and children who are both destitute and HIV-positive. In addition, the research focused on mothers between the ages of 18 and 30. The reason for this choice was because teenage mothers and elderly mothers often face fairly unique challenges which are specific to their developmental stages and this fell outside the scope of this study. The mothers chosen for this study were required to have their biological children staying with them at the home and the children had to be between the ages of 2 and 7. This latter age range was chosen as the experiences of motherhood vary according to the age of the child and, thus, the age limit imposed represented an effort to prevent too much variability. All participants also had to be relatively proficient in English and feel comfortable speaking in English. The choice of participants who were proficient in English may have limited the depth and richness of the data collected since many of the women came from socially disadvantaged backgrounds and did not speak English as their first language. It may, thus, have proved more beneficial to use a translator but, because the therapist working at the centre had confirmed that most of the women were able to speak English and also because using a translator may have compromised the issue of confidentiality, it was decided to conduct the interviews in English.

Lastly, only women on ARV's who had not been compromised by any HIV-related illnesses were allowed to participate. This precaution was intended to ensure a degree of homogeneity among the group. The therapist at the home had indicated that 80% of the mothers were healthy and responding well to the required ARV treatment.

3.3 Procedure

The HIV children's home had initially made contact with psychologists at Wits University and requested them to assist with a psychological intervention aimed at helping the HIV-positive mothers living at the home who were struggling with various psychological and emotional problems. The therapist and the medical director of the organisation had given

both written and verbal permission to conduct the study to the psychologists and they also indicated that they were happy with Psychology masters students coming in to conduct the research before an intervention was designed. As soon as ethics clearance had been obtained from the university (see Appendix A), the participants were approached.

Once the participants had been identified, the researcher arranged to go to the HIV care centre to address the ladies and to provide a full explanation of the study. The researcher also answered any questions posed by the potential participants. The participants were then given a copy of the Participant Information Sheet (see Appendix B), the Participant Consent Form (see Appendix C) and the Consent to Audio Record and use Direct Quotes (see Appendix D). These documents provided the participants with all the information needed to make an informed decision about whether or not to participate. Once consent had been given, the researcher contacted the participants and arranged a suitable time at which to conduct the interviews.

3.4 Instrument

In view of the fact that researchers operating within an interpretative phenomenological framework wish to analyse in detail the way in which participants both perceive and make sense of the events which are happening to them, a flexible data collection instrument is needed (Smith, Flowers, & Larkin, 2009). While it is possible to obtain data suitable for IPA analysis in a number of ways, the most suitable way in which to collect data for an IPA study and the way in which most IPA studies have been conducted is through the semi-structured interview (Smith & Dunworth, 2003).

The semi-structured interview may also be described as the “general interview guide” approach (Patton, 2002) in terms of which the issues to be included in the interview are covered in the order that best fits the interaction between interviewer and interviewee. In other words, the semi-structured interview is a tool that provides both structure and

flexibility, especially as regards the facilitation of probing which, in turn, enables the interviewer to elicit meaningful information.

In addition, this form of interviewing allows the researcher and participant to engage in a dialogue whereby the initial questions may be modified in the light of the participant's responses and the investigator is able to probe interesting and important areas which may arise (Smith & Eatough, 2006). Accordingly, while the interview questions in this study were standard, in order to ensure understanding on the part of each participant and to maximise the opportunity for unexpected material to emerge, it was necessary to be flexible in terms of the way in which the questions were adapted and framed.

An interview template was developed based on the literature review and structured around the research questions (Please see Appendix F). The interview focused on the lived experiences of HIV-positive mothers. One question, for example, focused on some of the difficulties that participants had experienced in being a mother with HIV. Although the interview contained certain questions and probes, these were relatively open-ended since it was hoped that the questions would serve to open up new avenues of questioning which could, in turn, be pursued as far as possible within the interview structure. As a result of the flexible nature of qualitative interviews, the subjects were given space to shape the interview to a certain extent (Bogdan & Biklen, 2003).

3.5 Data Analysis

On completion of the data collection, the tape recorded interviews were transcribed and then compiled into a corpus of transcriptions that formed the raw data for analysis. The transcribed interviews were analysed using the thematic content analysis method of Braun and Clarke (2006). According to Braun and Clarke (2006), this thematic content analysis method is a suitable method for identifying, analysing and reporting patterns (themes) within data. Such an analysis is concerned with the systematic coding of the data gathered during the

data collection phase and it results in core themes which are present within the data being identified. According to Braun and Clarke (2006), a theme encapsulates significant aspects of the data in relation to the research question and, in addition, it reflects some degree of shared meaning across the data gathered. In order to execute the data analysis process, the researcher took the role of the primary interpretative instrument by drawing on the subjective interpretations of the participants whilst, at the same time, considering the scientific principles guiding the systematic coding process. The thematic content analysis method was employed to analyse the entire body of transcripts with the expectation that the results yielded would comprise a description of the most salient themes and patterns emerging from the data.

The process of carrying out a thematic content analysis is laborious, with the analysis occurring over a number of phases. The steps in this data analysis process involved a number of phases as adapted from Braun and Clarke (2006). In order to familiarise herself with the data, the researcher transcribed the eight interviews herself, thus signalling the beginning of the data analysis process in terms of which she was able to become immersed in the data. The interviews were transcribed verbatim to enable the researcher to be able to use direct quotations as part of the writing up as well as for accuracy in identifying themes. The researcher read through the transcribed data several times while noting the initial ideas that had emerged from each of the texts. These initial ideas were, thus, influenced, to a certain extent, by the research questions posed as well as relevant literature in the field. The researcher made use of a deductive or top down approach (Braun & Clarke, 2006).

Subsequent to this phase, the researcher generated a coding system based on the repetition of patterns or themes that had emerged from the analysis of the data set by highlighting interesting features across the data set. Thus, a bottom-up approach was employed as the categories were derived from the data itself. For example, categories from the data included *discrimination on the part of family and friends, the loss of relationships*

and intimate partners, and *the loss of a good future*. In searching for themes within the data set, codes were collated and entered into a separate document as potential themes while data was gathered which was relevant to each theme. An initial thematic map was, thus, designed to show the main themes which had emerged, for instance, the above categories were condensed under the theme of "*the experience of multiple losses*". These themes were then reviewed by reading the collated extracts in order to assess their relevance to each theme. The themes were further refined through ongoing analysis in order to establish the final themes. These final themes were then given clear titles. Finally, the researcher selected some of the most vivid and compelling extracts which were used in the interpretation in relation to the research questions and the literature.

3.6 Issues of Self-reflexivity and Representation

In qualitative research, the researcher plays a key role in the research process. It is impossible for the researcher to be objective and "unobtrusive" and, therefore, it is imperative that the researcher be aware both of his/her position and his/her influence within the research setting. Thus, with regard to this study, the researcher acknowledges that the fact that she is a young, white, female student psychologist may have influenced the way in which the volunteer participants related to her and expressed themselves.

The fact that people tell the same story differently to different people (Reissman, 1993) means that, in interpreting interviews, it is incumbent on the researcher to acknowledge the way in which his/her role may have influenced the story being told. In addition, the researcher must also be aware of the fact that he/she is making interpretations about someone else's story. In other words, the researcher must acknowledge that "the anticipated response to the work inevitably shapes what gets included and excluded [from the analysis]" (Riessman, 1993, p. 13).

The researcher must also consider his/her own ideas, values, beliefs and expectations, and the impact that these factors may have on the analysis of the data. Accordingly, in this research study the researcher kept a journal in which she reflected on her own personal feelings during the process. This helped enable her to distinguish between what were her own and what were the respondent's thoughts and feelings. Since it was possible that the research could have elicited a variety of emotions in the researcher, the keeping of a journal ensured that, when feelings were aroused, she was able to check them on a ongoing basis.

The researcher, thus, approached the study with the intention of being open and explorative and she endeavoured to seek the real experiences of participants at all times. She also tried constantly to bear in mind the powerful impact that her own position may have had on both her interviewing approach and her subsequent interpretations.

3.7 Ethical Considerations

When working with human subjects it is crucial to consider any ethical issues which may arise during the course of the research process. In view of the fact that the researcher had been invited to conduct the research at the care centre by the psychotherapist working there, the study was considered as low risk, with minimal psychological consequences. The research domain consisted of examining the mothers' self-esteem, their child rearing practices and their everyday experiences of motherhood within the context of their HIV status. The researcher was extremely discrete about using HIV related terminology.

It is important to note that the mothers at the HIV care centre have access to weekly individual or group counselling sessions. All the participants would, thus, definitely have received some form of psychological intervention before taking part in the current research. There was, therefore, very little, if any, risk that the research would cause any severe emotional distress. Accordingly, because the response group had had prior access to therapy, the research was far more viable than it would have been using other HIV-positive mothers.

The researcher approached the HIV-positive mothers and asked them to participate in the study. She explained the purpose of the study and the method which was to be used. It was emphasised that participation was voluntary and that the participants were free to withdraw at any time, with no negative consequences. Despite the fact that the women are in institutional care, it must be emphasised that the potential participants were not coerced in any way into participating in the study. In additional, the participants were made aware that there would be no benefits from taking part in the study. The researcher also clarified that confidentiality was assured and that, even though quotes may be used and themes discussed, no identifying information would be used in the written report, and the raw content of the interviews would only ever be seen by herself and her supervisor. It was stated that the researcher would send feedback in the form of an executive summary to the institution.

All ethical and procedural information was contained in a consent form which the participants were asked to sign prior to participating. The participants were, presented with a form in which they gave their consent to the researcher to record all proceedings and to use quotations. These forms had to be signed before the interviews could begin. After the interviews had been concluded, the participants were again informed that, if they had any concerns as a result of what had happened during the research process, they would able to access therapy either individually or in a group context through the internal counselling resources at the HIV care centre.

In view of the face-to-face nature of the interviews and the fact that the researcher needed to access the names and contact details of the participants for practical reasons, it was not possible to guarantee anonymity. However, privacy was ensured, as the researcher did not request, record or use surnames, birthdates, or any other identifying information with the participants being referred to in the written report by letters which were assigned alphabetically. Confidentiality was ensured as the researcher and supervisor of the project

only had access to the data. After completion of the project, all the raw data was to be kept in password-protected files on the researcher's computer for a period of two years, after which it would be permanently deleted. The participants were not provided with feedback on an individual basis, but the institution was provided with an executive summary of the results of the study by e-mail. The participants were informed at the start of the study that the report would be available in the library at the University of the Witwatersrand, and that it would be accessible to anyone wishing to read it.

CHAPTER 4: RESULTS

This section presents the results which were derived from the thematic content analysis of the interview transcripts. The first research question related to the way in which the participants experienced motherhood. One theme emerged with regards to this question and the researcher termed this theme **the ambivalence of motherhood**. The second research question explored the impact that HIV had had on the participants' lives as both women and mothers. Two themes emerged directly with regards to this research question, namely, **the experience of multiple losses**, and **the psychological and emotional impact of having HIV**. These themes all contained various subthemes which will be discussed later in this chapter.

4.1 The Ambivalence of Motherhood

This study aimed to gain insights into the lived experiences of HIV-positive mothers. An important theme, thus, emerged relating to the way in which the participants experienced life as a mother. It became evident that all eight of the participants felt fairly ambivalent about this phase of life. In addition to the normal frustrations and stresses involved in raising a child, it was evident that the diagnosis of HIV had further intensified, and often exacerbated, these challenges.

Some mothers, for example, experience feelings of frustration when looking after either a baby or a young child. The participants in this study struggled particularly with trying to be "good mothers" and to devote all their time and effort to caring for their children. They also recounted feeling helpless when they were unable to console their child. These "everyday struggles" of motherhood often resulted in the participants' feeling exhausted, helpless and extremely frustrated.

> When the baby is sick or even not is not sick, when he cry and you give him a bottle and he doesn't want the bottle. You try to change him − still he is screaming, so that

> one is very tough, because I don't know what he wants... he's screaming. .. I get so upset and just start crying (Participant 4).

The addition of HIV-related concerns meant that these daily frustrations were often intensified. For example, the participants spoke about the difficulties they faced when they fell ill with an HIV related disease. Unlike the typical tiredness and frustration that a mother experiences when she is not well, many of the participants reported experiencing difficulty in taking care of their children when feeling extremely ill. Some women reported becoming sick often and, sometimes, very suddenly. This meant that these participants were not able, at times, to look after their children properly and this was experienced as extremely distressing to them.

> When you are positive you just get sick, just for a small thing, then you'll be sick, seriously sick. So, sometimes, I tell myself that I can be strong now − but when I'm sick, I'm weak, weak, weak. I can't even do many things for my children (Participant 1).

> I had a flu and they expected it to be a TB, only later to find out it was not a TB, it was a pneumonia, but, what was worse, was that I had to be away from my child for two weeks (Participant 8).

Another challenge with which mothers sometimes struggle is the loss of freedom and independence that may accompany motherhood. The "self sacrificing" nature of motherhood has been widely documented in literature and is something to which new mothers sometimes find difficult to adapt. Five participants in this study reported struggling to live up to this societal ideal and they expressed how difficult they found being selfless on a continual basis and focusing solely on their children.

> So hard, it is too hard, you know? Because you have to think that even if you have that money to buy sweets − you won't buy that sweet or chappies … you'll remember that, no, I've got a child … let me keep it for my son to make him happy. You know, you grow … there's something changing in your mind, you don't act like that young stage you were, you know? To be a mother is something really tough (Participant 5).

The participants all felt that being a HIV-positive woman living in an institution exacerbated the challenges of motherhood. In addition, they all spoke about the difficulty of living in an institution as this compromised their independence even further. Although the participants all reported feeling grateful to have had the opportunity come to the care centre and to have received financial, medical and emotional support, nevertheless, some of the participants referred both to the dependent position in which they had found themselves since coming to live in the care centre and to the fact that the staff focused so strongly on the children. Five of the eight participants reported that the children were the institution's primary concern and that this meant that the feelings and needs of the mothers were often marginalised. These women struggled particularly with this issue and also with the lack of freedom to raise their children in their own unique way.

Living under the control of the institution meant that there were rules for both children and adults − rules to which the mothers, in particular, needed to adhere − and also a hierarchy which was stratified in a very specific manner. This, in turn, meant that the mothers were not able to experience an independent type of motherhood as there were clearly defined rules stipulating how they were to mother their children. The participants admitted to feeling restricted and dependent as mothers and this, perhaps, was also what accounted for their experiencing motherhood in a fairly ambivalent manner. The ambivalence between instinctual mothering and intensive mothering was, therefore, clearly exacerbated by living in the care centre.

> … if I'm here − it's like you feel like a small baby, you are like a prisoner, you know, because the life which we are living here is not a is not a life for mothers like us … [it] is for children, this place, you know (Participant 5).

The participants reported several contradictions which are posed by HIV infection and motherhood. It was evident that HIV-positive motherhood is located within a collusion of opposites in terms of which the joy and excitement of being a mother is often overturned by an awareness of an uncertain and fearful future which is never far away. Mothers, in general, are concerned about the future development of their children and they want the best possible opportunities for them. Nevertheless, many of the participants in the study struggled intensely with fear and uncertainty when thinking about what the future might hold for themselves and for those whom they loved. This fear of death and dying was discussed by many of the participants and was described as being the most pronounced when the participants had first found out about their diagnoses and also when they became ill.

Seven of the eight participants had found out about their HIV status when they were pregnant and had been tested at a local clinic. While the mothers mentioned their fears of possible death at various times throughout the interviews, it was when they had first heard about their HIV status that they had been the most afraid of the possibility of dying. The participants all reported that they had not known much about HIV at that time and, therefore, they said they had not thought that they would be able to survive or live for much longer. All the participants spoke about being plagued by worries of their imminent and impending death when they had first been diagnosed.

> … when I was going to a clinic, then they said, you are HIV-positive … I was stressed; I thought I was going to die. (Participant 4).

The second instance in terms of which some of the participants reported feeling most fearful about the possibility of death was when they became ill. Ill health as a result of HIV related

infections was not only a painful reminder of previous encounters with illness but also a reminder about what may possibly happen to them in the future. The fear of becoming ill was, thus, a huge concern for some of the mothers who feared what would happen to them and to their children. The presence of even the slightest sign of illness was often a cause of both dread and extreme fear. Five participants, in particular, reported feeling extremely worried about what an illness would mean and whether it would signify the beginning of the end of their lives.

> Actually, when I'm coughing, I think, yo, is this the time that I'm going to pass away? I can't sleep, you know, when I have a cough − I can't because I think that when I sleep, at the morning, I will never wake up, you see (Participant 4).

Closely related to the fear of death and dying was a pervasive concern and uncertainty about what death would mean for their own children. Six participants expressed concerns about the children they would leave behind and how their children would cope once their mothers had died. They reported various concerns about their children's material and emotional needs if they were to die and whether the care accorded to their children would be adequate. The inability either to exercise any form of control over this or to plan ahead was also extremely difficult and distressing for the participants.

> Obviously, I was thinking that I was going to die and what about my kids? How are they going to survive when I'm not there? … I was just thinking that maybe they'll be brought up somewhere in a home … who is going to take care of my kids? … Like maybe if I die, where are they going to be? … How they going to cope and you know? (Participant 2).

Some of the participants spoke about a contract at the care centre which all mothers are obligated to sign. The contract stipulates that, should anything happen to their mothers, the organisation will endeavour to look after their children and to put them through school until

they are legally adult. Despite this stipulation, some of the participants were still extremely worried about the wellbeing of their children. In addition, they were concerned about the standard of care that their children would receive. Three mothers spoke about their concerns about whether other mothers who lived at the care centre would treat their children in a "good enough manner" once their mothers had died.

> Because sometimes you think the people you leave with your child, they are not treating them like you treat them, they are not treating them like you, like mina. I was thinking too much when I was hospitalised. I was thinking they are swearing to my children. People are not the same. When I'm with my child they can be treating them well, but when I'm not there they might not be treating them well (Participant 1).

Throughout the interviews, the issue motherhood was constantly discussed in terms of hope and despair. There were narratives related in which some women spoke about the future possibilities for which they hoped for themselves and their children. However, with all the mothers, there was always a constant awareness of the possibility of despair. Although the participants did not always consciously relate their experiences of motherhood to their HIV status, it was evident that the ambivalence that they highlighted was as a result of the presence of the disease. Throughout the interviews there were several occasions on which the participants' ambivalent feelings towards motherhood were overtly verbalised.

> I mean … I won't say it's good, I won't say it's bad 'cause I didn't see good, I didn't see bad. I should say it's stress, it's really stressful − ja, I should call it stress to be a HIV mother (Participant 5).

4.2 The Experience of Multiple Losses

For many of the participants the experience of being an HIV-positive mother had been characterised by a series of multiple losses. These losses had occurred in many areas of life and had affected the way in which the women experienced both life and themselves. Loss

was understood in one of two ways, namely, actual loss and symbolic loss. The first type refers to the actual loss of people who had chosen to abandon the participants after disclosure. The second type of loss was more a symbolic type of loss in terms of which the mothers had lost respect and a sense of emotional support from both friends and family.

The participants discussed their experiences when they had shared their HIV diagnoses with their loved ones. Six of the eight mothers had experienced severe forms of stigmatisation, including reactions of fear, shock and blame. In addition, irrational fears of casual transmission meant that some women had not only found themselves being isolated but sometimes even deserted by family members.

> Cherry on top becomes with the status … I've lost most of my friends − there's that minor group that seems to be understanding of my status … The rest, they just completely cut off the ties (Participant 8).

> I was staying with my aunty, then I just found out I am positive, then I told my aunty I am positive, then my aunty started to treat me ugly like I am going to going to infect her with my HIV, I don't know … since my aunty chased my sisters, they chased me away just because of this status (Participant 1).

The loss of respect and acceptance on the part of friends and family was perceived as an extremely distressing experience. The isolation and loss of support had resulted in many mothers feeling extremely alone and hopeless. In addition, the participants had found it difficult to accept that those closest to them were often the ones who offered the least support and understanding.

> And the relatives also didn't, my mom didn't, accept me, ever since I told her my status, she started acting funny ... they chased us out of the house (Participant 2).

> First thing to be judged, not to be judged by an outsider but to be judged by your family − people that you know that when you have a problem you can come talk. They become far away from you. You don't have a support system, you don't have nothing (Participant 8).

The participants cited several instances where they had felt significantly discredited and that an undesirable "differentness" had arisen between them and friends and family members with this usually occurring once they had disclosed their HIV status. In addition, disclosure had often led to various forms of HIV-related discrimination. Various participants reported being treated rather badly by loved ones who would refuse to eat food cooked by them, or refuse to share cutlery with them. It was evident that the mothers had been perceived as vehicles of disease who might infect others simply by being near to them. There was also evidence that many of the myths surrounding HIV still exist and these myths serve to devalue and "other" the HIV-positive individual. Many participants spoke about the negative manner in which others had treated them after disclosure and it was clear that the participants equated these behaviours with a lack of respect and acceptance.

> Yes, they were good people but, after they found out about my status, they just [said] 'uh you've got to eat the special food' … yo, it's not nice … they treated me differently … when it comes to my family, they didn't understand because they give you your separate things to use. You have to use your own spoon, … they put your toothbrush separate − it's not nice (Participant 7).

The experience of actual and symbolic loss was also discussed in terms of relationships with intimate partners. Four participants expressed their feelings about having to forgo past and future relationships with men as a result of their HIV-positive status. Three of the women spoke about the actual loss they had encountered when the fathers of their children had chosen to abandon them on hearing about their status while two of the women were more

focused on the sadness they were experiencing at the thought that they would never be able to have intimate relationships in the future.

Those participants whose partners had deserted them after they had disclosed their status were extremely frustrated and angry. They appeared to experience this abandonment as unfair and selfish and they voiced their anger at the fact that their partners had left them despite the fact that these partners probably had the same disease. There was a general feeling of hopelessness and despair with some of the women lamenting that even those men who are HIV-positive themselves, often do not want a relationship with HIV-positive mothers and choose to abandon them. Some women discussed this in greater detail and expressed their frustration in that they had remained faithful to their partners but had, nevertheless, been infected with a devastating illness in return. There was also a degree of anxiety about being left alone to raise a child as a single mother. One mother explained this when she said

> Uh it's very hard, it's very hard being a mother...a single parent, especially 'cause, um, most of the times when men find out that you are HIV-positive, they run away. They forget that they have the same sickness, the same thing that you have. (Participant 7).

There was some concern voiced about the loss of possible future relationships as a result of their own HIV status with the women expressing their pain and sadness at the prospect of not ever being able to have a “normal” and “healthy” relationship. One individual spoke about how difficult it was for her since men did not usually want to continue a relationship with her once she had disclosed her status. Some participants tried to rationalise this behaviour on the part of men by saying that many men are afraid of being infected with HIV and, also, that they place a high value on a woman’s fertility and potential for bearing children. The inability to provide a man with a “normal” sexual experience and a “normal” family may be difficult for some men to accept.

> You know, recently, I had a friend here [in] Diepkloof … It was worse … it was worse … Like, for instance, you get somebody who wants [to] date[you] and then you say 'let's be friends' and, as time goes on, he tells you his secrets and you tell him your secrets ... The next thing he disappears ... Later on when he calls you and tells you that 'I find somebody else because me, I'm scared because you have this thing ... So I can't date you. I need somebody who I can have a family with and have a life with' … But I told him that I can still have life, it doesn't mean it's the end of my life ... 'No, I can't have it with you because you have this virus' … it's not nice (Participant 8).

Numerous examples of discrimination and stigmatisation were mentioned during the interviews. When discussing her experiences as a HIV-positive mother, one participant recalled the sadness and loss she had experienced at not being able to breastfeed her child. It was also evident that, besides being angry, she was more concerned about how others would react towards her if they found out she was not breastfeeding as a result of being HIV-positive. She reported having to hide the baby formula and lie to her relatives about why she was unable to breastfeed because she feared they would reject her and discriminate against her.

> I hated it because I couldn't breastfeed my kids … . Because I had to hide them, in Eastern Cape, if you give your baby the formula, they know you are HIV-positive so I had to take an empty tin of the other milk … so they think I am feeding my baby this milk before … I knew that if they found out I was HIV-positive, maybe I'll lose everything, my friends and everything (Participant 6).

The fear of losing the respect and acceptance of both family and members of the community proved to be a fairly significant issue for the participants as all of them were able to recall various instances of HIV-related discrimination.

4.3 The Psychological and Emotional Impact of Having HIV

This study aimed to provide insights into the impact of HIV on mothering. Accordingly, an important theme emerged which related to the psychological and emotional experiences of HIV-positive mothers. The participants expressed various psychological challenges which they had had to confront as a result of their diagnoses. Together with existing contextual stressors, many of the mothers struggled with feelings of depression, anxiety, guilt and self reproach with some of them also experiencing difficulties in managing their emotions.

Six of the mothers recalled a time in which they had felt depressed. However, it is not clear whether these were appropriate feelings in the context of their lives at the time or whether they were true incidences of major depression. Limited resources and the focus on their diagnoses meant that the only medical assistance that was sought was for HIV related concerns and not for their psychological and emotional concerns. The feelings of depression had occurred in the months following their diagnoses.

Although it is not possible to state categorically that it was the HIV diagnosis that had caused the participants' depression it is, nevertheless, possible that these feelings of depression were unleashed by the difficulties of living with the disease. In addition, these individuals were particularly vulnerable to depression since they were facing specific burdens as a result of living with HIV. They reported being isolated, experiencing shame, stigma, and anxiety and feeling overwhelmed by the challenges they were facing in their roles as caregivers, mothers and, sometimes, wives. Other contextual stressors were also mentioned with a particular focus on financial difficulties. Almost all the participants had been living in temporary shelters when they had first found out about their status and they had often had to look after young children as well as managing their pregnancies and their own health related challenges.

The feelings of depression had occurred most often when they had first discovered that they were HIV-positive. It was also at this stage that some participants had contemplated committing suicide.

> When I found out I was HIV I, just, I just feel like, cause since my aunty chased my sisters, they chased me away just because of this status. And I even wanted to kill myself by that time cos I didn't know much [about] HIV (Participant 1).

> I was giving up with my life, really, I didn't want to lie, I was giving up with my life ... I was like − what am I living for because I've already got it? (Participant 5).

Although some of the participants had merely thought about committing suicide, two participants recounted that they had actually attempted suicide. These participants reported experiencing intense hopelessness and pain and recalled how they had viewed death as the best way out of the hurt and pain. It was clearly difficult for these women to speak about this time in their lives although they admitted that they had not felt bad about ending their own lives as well as the lives of their unborn children. This extreme and pervasive hopelessness meant that their thoughts and judgment had often been extremely clouded.

> It was painful and I even wanted to kill myself. I ended up in Johannesburg hospital ... I think another person said it's not good for pregnant women to drink poison so, I was thinking, I would do it to die and abort my child, but it was late...It was because I was thinking that everyone [in my family] don't even wanted to see me. They are chasing me just because I am positive, so I was thinking that what is the use for me to live? I don't have anyone to turn to (Participant 1).

> The the only problem was that I wanted to kill myself. I was thinking of suicide at that time. Not eating, crying all the time. I was blaming myself so badly... [So] I drank Jik [in] 2007, 27 June... I just took the Jik and drank the whole bottle and I just want[ed]

to die right [then] ... When you want to kill yourself you don't feel anything, you just want to make everything easy, you think it's an easy way to die (Participant 6).

During the initial months after finding out about their diagnoses almost all participants reported feeling extremely anxious. However, the degree of anxiety felt by the mothers at the time of the interview varied. Anxiety was perceived as unpleasant feelings that the participants had experienced and which were typically associated with uneasiness, apprehension, fear, and worry. There were many situations from both their past and current lives which evoked these feelings in the participants and which they felt impacted on their daily functioning as mothers. Three primary issues evoked anxiety. Firstly, pregnancy was a period of uncertainty with regard to the HIV status of the unborn child. Secondly, there was anxiety about the possible future infection of their HIV negative children and, thirdly, some participants were extremely anxious about disclosing their own HIV-positive status at some time in the future to their own HIV-positive and HIV-negative children.

Some of the mothers reported feeling extremely anxious and stressed during pregnancy and, more specifically, at the time of their children's birth. The uncertainty of not knowing whether they had passed the virus onto their child during childbirth was very challenging. In addition, having to wait, not only for the initial test result at birth, but the subsequent results every few months, meant that they had struggled to enjoy the experience of both pregnancy and the first few months of motherhood. Feelings of doubt and disbelief even after doctors had given the results were typical with the participants fearing that the test results were either wrong or that the virus had not yet been picked up in the young infant.

I was worried that, maybe, my baby will be positive too...Firstly, when you delivered your baby, they'll tell [you] that, even if they test the baby for the first time, sometimes they can't see that she or he is positive. So you have to test him like three times so that you can know really that he is negative. So, when they tested him, like

> for the first time, even though [I was relieved], I was still worried that, maybe, on the second time he will be positive. I was still worried but they tested him and he was also negative. Then I told myself that, *eish,* for the last time let's hope he's still negative (Participant 1).

Four participants reported their ongoing worry and anxiety about making sure that they protect their HIV negative children from future infection with severe anxiety being reported about watching one's child and checking to ensure that the child is protected from both the HIV infected mother as well from other HIV-positive children living at the care centre. Some of the mothers feared that their HIV negative children may accidently contract HIV from an accident on the playground or when in the house. This immense fear has caused some of the participants to become obsessed about watching their children's every move and, subsequently, to some of the mothers becoming obsessed with cleanliness. One participant spoke at length about washing her hands as often as possible and using Dettol to ensure that everything that her child used would always be clean.

> I is scared with HIV fear, you see. I have already two kids in the negative, HIV negative, so I[am] scared [for] them to get HIV from me or other children or their brothers. (Participant 3).

> Yo, I was worried and I was careful that, even if I was touching something, even if I touch something, I have to wash my hands too much, I was using Dettol too much … I was making sure that everything I am using for my baby is clean, clean, clean (Participant 1).

Even though all the participants were aware of the ways in which HIV is transmitted, nevertheless, some of them struggled to share facecloths or towels with their children with even normal maternal tasks, such as feeding and bathing one's child, often becoming sources

of anxiety as the mothers feared that they may "somehow" infect their children accidently. However, the majority of these behaviours had evidently taken place before the mothers had arrived at the care centre although other behaviours continued to persist even after the mothers had received specific psycho-education about the spreading of HIV.

> I couldn't even trust myself and when I was eating something, you know − sometimes the children weren't eating something they wanted, so when I give my child I will just feel, like maybe, I've infected her with HIV or, when they are playing or when she fall down, when she comes to me, I can't, and I'm even scared to touch her cos I'll think maybe, mina, I have got sores then I'll infect her. Eish I was not comfortable actually, especially when it comes to blood (Participant 1).

Disclosure to children was one of the most anxiety provoking prospects highlighted in the interviews. All their children were between the ages of two and seven and there were several concerns voiced about how the children would react to the news and that they would respond with anger and confusion. There was a general fear that telling a child of about the HIV status of the mother would burden the child and that disclosure would result in an unfavourable response in terms of which the child would experience the same guilt and anxiety as his/her mother. Some participants were struggling with ways in which to negotiate this tension as they wanted to ensure that their children would have a normal and carefree childhood.

> I do have worries − the other thing is that I still have to explain to my child ...Right now he does not understand, he is still growing up and he is just a child, there is still a lot of things, lots of question... Because I am going to have to be able to explain...You know, when you raise a child being HIV-positive you cannot always say because you are a mother you can just throw him a bone and say it... Yes, how is he going to react? Is he still going to be the same? You never know ... my concern is that it affects him in a way and I have to tell him that I am like this ... I don't know how he is going to

> accept it or how he is going to react towards me? I am worried of how I am going to tell him one day that his mother is positive. It's hard … For my child to be worried that his mother is HIV-positive and that he will have to worry now about me and that it might disturb him at school or varsity one day, or whatever. So, it's a lot of things to worry about (Participant 8).

Another emotional difficulty involved the tremendous sense of guilt and self reproach that some of the women admitted to experiencing. Four of the participants expressed feeling initially guilt ridden after finding out their status, while others admitted to still struggling with these feelings on a daily basis. These participants discussed how they blamed themselves, God as well as their partners who had infected them. Self reproach was the most common emotion with the participants also reporting feelings of extreme frustration and regret. One participant spoke about how she often wished she had listened to her parents and had not dated young men as a teenager. There was some concern that it was, perhaps, her fault for being disobedient and that she had, therefore, deserved to have contracted HIV. Other participants blamed themselves for not going for an HIV test soon enough as they felt that this may have prevented the progression of the illness as well as ensuring they would have taken the relevant medication to prevent mother to child transmission. These participants were evidently struggling with several difficult questions to which there are no answers to them and this further exacerbated their ongoing distress and frustration.

> I do blame myself ... Why do I have this HIV? Why [did] the person who [gave it to] me, why didn't he tell me? Why didn't he just, maybe, see it? ... Why did my baby have [to be HIV] positive? (Participant 4).

Mothers who had HIV-positive children reported experiencing extreme feelings of guilt about the infection of their children. One participant, in particular, feared that one day her son may blame her and eventually reject her for not having protected him and being tested sooner than

she had been tested. She was struggling to let go of this guilt and believed that she was primarily responsible for the diminished quality of life that he would have as he grows up.

> He's going to grow up and ask me, why am I taking this? And I will start to explain ... He will say, 'Mommy why you didn't protect me? ... why you didn't protect me from this virus?' You know then, what I am scared of, what if he [is] going to hate me or is he still going to love me as he loves me now? You know, most of the kids, when they found out that [it] is their mother's fault, they start to leave their mothers. 'I am dying because of you'. [He may say]. You know, I am scared that I am going to lose him, so me, I am still stressed. You have to ask, when you are sitting here, you ask, sometimes I just sit and look at him play and I say 'My son, I am praying [to] God that you must grow up'... but I fear he will blame [me] for this, he will blame [me], definitely (Participant 5).

Three of the participants reported being overwhelmed by emotions at times. These women spoke about the challenge involved in controlling their anger and how this anger had emerged only after they had found out about their HIV diagnoses. The immense pressures involved in being an HIV-positive mother and having to deal with their own problems as well as with their children meant that they often experienced great difficulty in controlling their anger. One participant was concerned about how her uncontrolled anger was affecting her child since she sometimes resorted to beating the child when she was not able to control her feelings. Nevertheless, it did appear that the rules in the care centre did help the participants at such times and also the staff and other mothers helped by intervening and assisting these mothers to manage their emotions in a more socially appropriate manner.

> … when I'm angry, I can't control my anger sometimes. Sometimes even when the child do [a] small thing ... I can't even hold myself, I just, I beat her, like bad sometimes. Even in this house they say "... you need to control your anger with your

> child.' But I've noticed that ... they are speaking the truth and I've got anger when beating the child (Participant 1).

In addition to religion and spirituality, social support appears to represent the primary means for helping the mothers to cope with their situation with the need for social support being very apparent. There was a clear message communicated that being able to talk and have someone with whom to share one's fears and thoughts was vitally important in helping these mothers to cope. Nevertheless, the women shared how this was quite difficult as not many people were open and willing to accept them and provide them with the support and advice they so desperately needed. While most participants spoke about a general lack of social support from those in the outside world, they all mentioned the support they had received at the care centre. The staff members and the other mothers living at the centre were clearly seen as an invaluable source of support and strength. In addition, there appeared to be a general understanding in the care centre that it was incumbent on the mothers to look out for all the children, even if the children were not one's own biological children. In addition to their own children most mothers at the home are given one or two orphans to look after. Also, when the mothers are unwell or unable to take care of their children for a period of time, the other mothers step in and help to look after the children. This takes immense pressure off the participants who usually experience considerable distress when they fall ill.

> Yes, here it's better, 'cause other moms, they can help you, they know [how to] help me with the child. We help each other with children ... The other mother will come and help me if she's feeling sick −I'll go there and help bath her child, feed her child, you know (Participant 7).

One participant explained the support she feels from other mothers in an interesting way. She maintained that, since they have all been through similar trials and experiences with HIV, there is a bond which makes it easier to open up and speak to one another. She expressed that

feeling valued as a person and not being perceived as either different or ill, was the most comforting thing for her

> Because I don't see them different to me and me different from them. I see that our problems are not the same but, the thing is, we have a problem with our families and our lives are mostly the same in some ways. Like, I have a family that won't take me if they knew that I'm HIV-positive... You keep your stories and you know that you are here because you are HIV-positive and that makes us the same because we are here and we are HIV-positive, all of us... they don't discriminate [towards] me because I am HIV-positive, they don't look me as that [sick] person (Participant 6).

At the care centre the mothers are offered weekly individual and group counselling sessions with a social worker and a counsellor. Five participants spoke about the support they had received in attending therapy and that the therapy had helped them to look at the pain and traumas from the past and had assisted them in living meaningful lives. These therapy sessions were regarded as being valuable in helping the mothers to feel heard while, for some, it was the very first time that they had been able to speak about their lives and their pain.

> Uh, I don't want to kill myself, maybe it's because of the therapy. Heather is my therapist so, maybe, it's because she helped me with it (Participant 6).

> It helped me a lot 'cause I got counselling and, uh, the upliftment when you come with your problems to Nkosi's Haven, there [is] upliftment. The counsellings that you get and, uh, the other thing, your interests, your interests as a mother, what do you want to do. A sense of direction that, ok, I'm here then, at least now, I want to be able to stand up on my feet and they will do this for me (Participant 8).

The social support that the participants received at the care centre was perceived by the mothers as being of immense value with their the relief they felt at being able to live in a place in which they are neither judged nor discriminated against and where they are able to speak freely about HIV and how it is affecting them. Some spoke about the sense of freedom they experienced in being able to do this and how being accepted and valued has lifted a large weight off them.

> Where I used to stay, when we always talk about HIV, you know, some people doesn't like that, so here, you talk free, just because you are all like that, you see. I just talk free (Participant 4).

It was interesting to note the degree of emphasis which the participants placed on finances. For example, when asked about how they managed to get through challenging times, they often related general coping and wellbeing to the presence or lack of financial resources. The lowest times in their lives had encompassed a general lack of finances and this had placed a immense burden on them. All the women reported that prior to coming to the care centre, they had struggled to provide for their families and, without an income from either the father of their children or from their families, many had been unable to provide shelter, food, clothes, nappies, toiletries and basic schooling opportunities for their children. This, in turn, had created immense pressure for the participants who also spoke about the need for medical supplies needed when one is HIV-positive. In other words, not being able to buy the required healthy food for themselves and their children and often not being able to get to hospitals for medicine meant that they had struggled to cope. The participants articulated that coming to the care centre had helped them to cope in numerous ways but the provision of material and financial resources was found to be most relevant. The participants discussed the absolute relief of finding assistance in their time of greatest need. When Participant 2 was asked

whether she thought her life would have been different if she had not come to the care centre, she responded with the following.

> I'm not sure, but what I know is, it was, maybe going to be different since I was not working, everything is money − for kids to go to crèche is money. So, here, they can go to crèche. Most of the things they get. I think it made a difference 'cause, before I came here, I was desperate, I didn't have anywhere to go. My kids did not have a shelter to sleep or food to eat (Participant 2).

Two participants spoke about their religion and about how their faith in God had assisted them to cope with being a mother with HIV. They reported that believing in God and engaging in spiritual acts, such as prayer, fasting, and reading encouraging scriptures, had helped them to find comfort. These mothers explained how knowing that God was with them had helped to ease their fears about their uncertain futures and had helped to give them the strength to accept what had happened to them. It was evident that these individuals found comfort in knowing that, regardless of what happens to either them or their children, they would not be alone or find themselves in a hopeless situation. Accordingly, their beliefs clearly helped them to manage the difficult emotional and psychological distress brought on by having HIV as a mother.

> And we believed in prayer also, so we know that God is there... 'cause when I started my year here, I was scared, and I stay for a long time without praying and I prayed, and they always say, like maybe, when you starting the year when you fall sick [you should pray]. I prayed and I felt different (Participant 2).

CHAPTER 5: DISCUSSION AND CONCLUSIONS

5.1 Discussion

The challenges experienced by HIV-positive mothers living in a HIV care centre appear to be more complex than may be commonly thought. In addition, the challenges inherent in living with HIV, coupled with the contextual difficulties of being a poor, HIV-positive woman living in a government funded institution, often mean that the experience of motherhood is clouded in ambivalence.

Parker (1995) wrote about the concept of maternal ambivalence and how the co-existence of love and hate is an inherent product of motherhood. The participants in this study all admitted to experiencing such ambivalent feelings towards motherhood and they expressed their difficulties in managing the "normal" struggles of raising young children. However the participants in this study felt that this ambivalence is further exacerbated by the presence of HIV. These findings indicate that, in addition to the struggles of motherhood as cited by Parker (1995), the added pressures of having HIV and dealing with the problems of being both a patient and a care giver, increase the ambivalence and often lead to an inability truly to enjoy motherhood. There appeared to be a tension between enjoying this time in their lives (supposed to be "special" and "idealistic") and the stark reality of the many responsibilities and frustrations that often accompany being both a caregiver and a patient.

In terms of motherhood , Richardson (1993) and Burman (1994) both expressed ideas on both intensive mothering and the way in which "good motherhood" is defined in a child centred society as maternal sacrifice and involves the needs and rights of the child frequently being placed ahead of those of the mothers. In the literature review it was mentioned that many mothers struggle particularly with the loss of freedom and independence that often accompanies motherhood. In this study the participants also struggled with the demands of intensive mothering but these struggles were intensified by their coming to stay at the care

centre where the main focus is on the interests and wellbeing of the children. In addition to the "common loss of independence and "self sacrificing" nature of motherhood, the participants felt that their independence was further compromised by the fact that the focus in the centre is on providing the best possible life for one's child. Accordingly, the needs of the mothers were regarded as secondary. It is, therefore, possible that the participants were experiencing rather ambivalent feelings about motherhood as they were unable to experience an independent form of motherhood and felt even more marginalised. Living under the rules of a care centre means that not, only are they restricted from mothering in their own unique ways, but they are often forced to give up even more of their own needs and desires. This dependent type of motherhood may have had a negative impact on some of the participants' sense of self as the divide between instinctual mothering and intensive mothering was even more pronounced in the situation.

Long (2009) wrote about the contradictory nature of HIV-positive motherhood. The findings of this study confirmed this paradox of motherhood as motherhood was located within a collusion of opposites in terms of which the joy and excitement of being a mother was often overturned by an awareness of an uncertain and fearful future. Fear of the future and, particularly, fears relating to future illness and death were highlighted by the participants as primary concerns. Neimeyer *et al*. (2005) indicated that death related anxiety may involve apprehension about both the process of dying and pain, doubts or fear of the afterlife, as well as the effects on loved ones. Past research has provided evidence for the existence of death anxiety in the HIV population (Braunstein, 2004). Studies by Franks *et al*. (1990) and Catania *et al*. (1992) reported that HIV-positive symptomatic men exhibited significantly higher levels of death anxiety than both asymptomatic and HIV-negative participants. The findings in this study are similar to these findings, although this cohort in this study comprised single, South African, HIV-positive women. This death anxiety was reported by the participants as at

its most intense after they had found out about their status although it was also pervasive when the participants became sick with HIV related illnesses. These fears were accompanied by fears of the effects that death may have on their children and loved ones. Even though the mothers in this study were aware that, in the event of their deaths, the care centre would continue to look after their children, some of the participants were not consoled by this and they continued to worry about the wellbeing of their children. It is possible that either the participants, because of their lack of education, did not understand the contract that they had signed or, perhaps, there were genuine concerns about the adequacy of the care that the other mothers would provide. It is suggested that, if such extreme death anxiety existed within this cohort of individuals living in a care centre which offers both present and future economic and emotional support, other HIV-positive mothers, who live independently, may experience more intense forms of death anxiety as regards the wellbeing of their children since, in such cases, there is often no definite caregiver to look after the children in the event of death.

Their familiarity with various types of loss was an additional finding in connection with the participants' experience of HIV-positive motherhood. After disclosure, instances of stigmatisation and discrimination, for example, were common in this study with a special focus on the abandonment that some participants had experienced on the part of family and friends. These findings are in stark contrast to the findings from a study conducted by Medley *et al*. (2004). In their cohort of participants, it was found that the respondents reported positive outcomes such as kindness, understanding and acceptance after disclosure. The findings in the current study also differ as compared to the findings of South African studies conducted by Kuhn *et al*. (1999) and Varga *et al*. (2006) who found that voluntary disclosure by HIV-positive women ultimately resulted in both a supportive and constructive response. The participants in this study also reported a second form of loss that had often occurred after

disclosure, namely, a general loss of respect and value which, in turn, had led to the participants' being treated quite differently by others around them.

These findings concur with those of a study by Simbayi *et al.* (2007) who also found that discriminatory experiences were common among South Africans in Cape Town. The participants in Simbayi *et al.*'s study reported being treated with less respect once they had tested HIV-positive. The high levels of stigma and isolation found in the present study illustrate that, even after many years of HIV and AIDS campaigns, there are still severe forms of stigma and a general lack of social support for those diagnosed with HIV. This may be as a result of the stigmatising beliefs that many South Africans still hold while it may also indicate that HIV and AIDS related myths are endemic to many communities. Nevertheless, it is clear that, even although much has been done to change the attitudes of communities towards people with HIV, there are many who still view HIV-positive women as sources, or potential, sources of infection.

The findings in the present study also reveal the way that HIV-positive women are often viewed as conduits of disease by others. This was also expressed by Long (2009) who noted that HIV-positive women are largely portrayed as hazardous sources of infection. It is also possible that the reason for this belief is the fact that that many South Africans live in poverty and come from low socio economic backgrounds. A consequent lack of education may mean that individuals may be ignorant of the facts about HIV and how it spreads and, thus, they fear contamination by those infected.

This study also revealed the sadness that some mothers felt about the loss of past and intimate relationships with the participants grieving about past relationships in which they had been abandoned by their partners after disclosure. There was also a considerable amount of anger as many of the participants had contracted HIV from their partners who had then chosen to leave them. These findings may indicate that a fairly chauvinistic attitude persists

within some South African communities as, very often, the women are abandoned while their HIV-positive partners are able to move on with no dire consequences and start new social relationships with other women.

The sadness of the possible future loss of intimate relationships that some women expressed is explained by Kalichman *et al*. (2000) who wrote about the benefits which relationships offer to HIV-positive women. It was suggested that relationships provide a protective function at a psychological level by offering a defence against feelings of isolation and otherness (Kalichman *et al*., 2000). In the present study it was clear that the women felt that a relationship would help them to feel a "sense of normality" when compared to the dominance of the HIV-positive identity they had had when relationships had been threatened or had ended.

In the literature review pertaining to the psychological and emotional challenges of HIV-positive patients, studies by Jelsma *et al*. (2005), Shisana *et al*., (2005) and Adewuya *et al*. (2007) suggested that people living with HIV in Africa experience more mental health problems than either non-HIV-infected individuals or the general population. The participants in this study also indicated the various psychological and emotional challenges they were forced to confront as a result of their diagnoses.

Many of the mothers struggled with self reported feelings of depression, anxiety, and feelings of guilt while had difficulties in managing their emotions. Although some of the participants were still struggling with these issues, the symptoms and experiences of distress had occurred primarily before arrival at the HIV care centre. In the cohort of participants in this study, it is also important to take into account the contextual factors which may have influenced both the presence and the degree of distress. For example, all the participants were single mothers who had been living in poverty prior to their staying in shelter facilities. The HIV diagnosis, together with the lack of social support and the combination of contextual

stressors highlighted above, may have played a role in the development of the participants' psychopathology. In addition, the fact that many of symptoms had occurred prior to coming to the care centre and that the symptoms had been the most severe at this stage, indicates the potential positive and beneficial role that such care centres may play in the lives of HIV-positive women.

Mello *et al*. (2010) maintain that it would appear that depression is the most common mental health problems encountered in African, HIV-positive patients. More specifically, the study of Mello *et al*. (2010) found that most HIV-positive women had already experienced a major depressive episode in the past and that this episode had tended to appear after the HIV serodiagnosis.

In the present study, although it is not known whether any of the women had had an actual episode of major depression, feelings of depression were also reported to have manifested soon after the HIV diagnosis. This result also agrees with the findings of various South African studies to the effect that depressive symptoms are prevalent among HIV-positive women with most studies reporting a prevalence of over 30% and even as high as 64% (Mfusi & Mahabeer, 2000; Sebit *et al*., 2000; Kaharuza *et al*., 2006; Rochat *et al*., 2006; Simbayi *et al*., 2007; Stangl *et al*., 2007). This prevalence of depressive feelings is to be expected as a result of the combination of stress factors with which HIV-positive women have to cope. In addition, not only did some individuals in the present study manifest a fear of death but it is also possible that the episodes of stigma and discrimination in both family and social interactions, as well as having to having to act as caregivers while sometimes battling with their own illnesses, played a role in the development of depressive symptoms.

It is also important to examine what these depressive symptoms may mean for the HIV mother and her child. It is known, for example, that a mother's depressive mood may have an adverse effect on the maternal infant relationship and that mothers who suffer with

depression may interact less with their children and struggle to perform various parenting tasks. In light of these findings above future research on the way in which HIV related depression affects the experience of motherhood is clearly important.

Bellini and Bruschi (1996) found an increased suicidal ideation in the period of testing in both HIV seropositive and seronegative persons. They also found that HIV seropositive persons are particularly susceptible to suicidal ideation during the first three months following diagnosis. The findings of this study concur with these results as many of the participants reported a suicidal ideation soon after finding out about their diagnoses with some even making an actual attempt to end their lives. It is possible that the immense feelings of hopelessness and depression occurred at that particular time because the mothers were feeling severely threatened and in a state of psychological shock. This, in turn, may have overwhelmed the available coping resources and, thus, thoughts of suicide had arisen. It is also possible that the depressive and suicidal feelings in this cohort of HIV-positive mothers were as a result of the fact that they had experienced severe isolation, episodes of shame, stigma, anxiety and feelings of ambivalence. In addition, as single parents, they may have been severely challenged by their multiple roles as caregivers and mothers.

According to this cohort of HIV-positive mothers, anxiety was a common reality that had been most prevalent during the period of waiting to find out the HIV status of one's child. Secondly, the mothers with HIV negative children experienced intense forms of anxiety about their own possible illnesses as well as those of their children. Lazarus *et al*. (2009) highlighted the fact that the period immediately before and after early diagnosis of the babies' HIV status, as well as the weeks waiting for the babies' test, are extremely stressful for HIV-positive mothers. The participants in the present study agreed with this finding and indicated that these periods had, indeed, been severely distressing and anxiety provoking, particularly in view of their fears about the possibility of an unfavourable result. It is possible

that this cohort of participants also struggled particularly during this time with severe anxiety as they were mostly uneducated and, thus, had little knowledge about both HIV and AIDS. The immense fear of infection and mistrust in medical opinion also points to a potential lack of education as they may not have been aware of how nevirapine works. Alternatively, however, since, in reality, it is a complicated process to establish the HIV status of a child as the virus may only be picked up at 12 months of age, their anxiety may have been warranted and, even, expected.

This finding concurs with a study conducted by Long (2009) which found that mothers found it difficult to be consoled by medical opinion and that some women, who found out about the initial negative status of their child, were only temporarily appeased. Although the women in the present study appeared to have a basic understanding of HIV, their knowledge about HIV transmission and testing seemed rather tenuous and easily disrupted by incorrect or poorly conveyed information. Accordingly, the resultant misconceptions and confusion had the potential to diminish their confidence in health workers and, thus, to increase their levels of stress. It is possible that this lack of confidence in the test results occurred because the women had been informed that there was a slight possibility that their babies would test falsely negative and perhaps, for some women, there was, thus, a small chance that their fears would be confirmed and that their babies would, in fact, turn out positive at a later date.

For those participants with HIV negative children, there was always a fear of possible future infection. This meant that some of the mothers became increasingly anxious about watching and checking their children to ensure that they were safe from infection. The study conducted by Long (2009) found similar concerns in terms of which the women in her study often became obsessed and had a compulsion to examine constantly their baby's body for signs of infection. Accordingly, the mothers would anxiously search their babies in a

common process to check whether there was anything wrong with them. These mothers also regarded it as extremely important to go the doctor and to be proactive about protecting their own bodies. This study also revealed how important the mothers felt it was to seek medical attention for one's baby at the slightest sign of illness although this may be as a result of the fact that, for most HIV negative mothers, despite the fact that sickness is not a pleasant occurrence in one's life, it is usually seen as a relatively normal part of life. Accordingly, for the HIV-positive mothers in this study, even a mild illness signalled extreme fear and distress at what it may mean for themselves and for those around them. Also, in view of the reality of living in a HIV care centre, relatively normal behaviours such as playing in the playground, could became quite stressful events because the mothers worried that an accident may occur that could possibly lead to a new infection.

Besides their preoccupation with watching the interactions of their children, certain participants spoke about their obsession with cleanliness to ensure that the spread of infection would be limited. These mothers tried to "protect" their children but it is important to note that, prior to coming to the care centre, there had been a general lack of knowledge of HIV and its transmission and this added to these fears. In addition, the mothers became anxious when feeding and bathing their children out of fear that they may "accidently" infect their children. It is, thus, critical that concepts around transmission and various related anxieties be dealt with among HIV-positive mothers as it is possible that even moderate levels of anxiety may impact negatively on their relationships with their children. In the study conducted by Long (2009), it was found that, when babies tested negative, some women were able to relax in their caring for their babies and were able to shift HIV out of the centre stage in the mother-infant relationships. Long, further, found that an HIV negative diagnosis often allowed a playfulness to emerge in relations to the baby's body and within the mother-infant relationship with this being totally different to the serious vigilance and anxiety described

before diagnosis (Long, 2009) .This finding points to the need for psychological counselling and services in order to address the fears of HIV-positive mothers. In addition, it is suggested that, if there is constant vigilance and anxiety around simple motherly tasks, it may be that the mother-child interaction will be influenced in a negative manner and that attachment may be compromised.

Donenberg and Pao (2005) indicate that the decision relating to maternal disclosure may result in high levels of tension and stress for parents. The participants in this study agreed with this finding and were hugely concerned with the way in which their children would react to disclosure. Studies by Black (1993) and Faithfull (1997) found that many parents choose not to tell their young children about their HIV-positive status because of their concern that the children will not be able to handle the news. A similarly overwhelming fear emerged in this study. There were also concerns that telling a child about one's maternal status might burden the child and that this may result in an unfavourable response in terms of which the child would end up experiencing the same feelings of guilt and anxiety as his/her mother.

However, a study by Forsyth *et al*. (1996) found that harm may result from not disclosing to children. Thus, in view of the numerous other studies and clinicians mentioned in the literature review writing about the potential negative consequences that may result from withholding such information from a child, it is suggested that therapists working with HIV-positive mothers explore possible options of how to address this difficult topic and, perhaps, that they give practical advice about how to approach maternal disclosure in a manner that makes sense to the individual. The participants in this study mentioned that they had discussed disclosure with their therapist but that it was still of major concern for them.

An additional finding related to the participants' experiences of HIV motherhood was the need for social support since becoming HIV-positive. A clear message emerged that being

able to talk and to have someone to share one's fears and thoughts with was vitally important in enabling the participants to cope. The women shared how, in reality, this was actually fairly difficult as not many people outside of the care centre were open and willing to accept them and to provide them with the support and advice they so desperately needed.

This finding concurs with the findings of Bunting, Bevier and Baker (1999) in a study on impoverished HIV-positive women. These findings reveal the general lack of social support for HIV-positive women living in South Africa although, since the participants had come from all over the country, it is possible that this lack of social support may be as a result of possible stigmatising beliefs and the HIV and AIDS myths that are endemic to many rural and urban communities.

Although participants had experienced a general lack of social support from those in the "outside world", it is important to note that they highlighted a network of social support within the care centre itself and that this network was perceived as extremely beneficial in coping with daily challenges. Staff members and the other mothers living at the centre were identified as sources of invaluable support and strength. In addition, the freedom to talk freely about one's status and not to have to worry about being judged or seen as an "other" was regarded as very important by the participants. It is also possible that the shared nature of mothering in the home may mean that there is both emotional support from other women and constant assistance should one become ill with an HIV-related illness. Berkman, Glass, Brissette, and Seeman (2000) found that social relationships and affiliation have powerful effects on physical and mental health and wellbeing.

A few of the participants mentioned the emotional support gained from attending counselling sessions with the therapist at the care centre as being beneficial in helping to cope with the past and present stressors involved in being an HIV-positive mother. However, this exposure to long term therapy is extremely unique in the South African context and it

highlights a particular strength of government funded HIV and AIDS care centres such as the one in the study, namely, that these care centres are able to provide a place of safety and restoration to marginalised and, sometimes, very distressed HIV-positive women.

It was pointed out in the literature review that, according to Pienaar (2004), there is, generally, support for the patients immediately before and shortly after the HIV test in the form of counselling, but that there is minimal continuation in the form of follow-up counselling and other types of support such as support groups or practical support. It is, therefore, suggested that, since HIV and AIDS represents a major life crisis in an individual's life, support, especially after an HIV diagnosis, be regarded as of vital importance. This is, perhaps, something that the South African public health sector should look into. In a study conducted by Coetzee and Spangenberg (2003), the participants stressed that knowing one's HIV status without the possibility of follow-up care and support causes depression, despair, and even death. When reviewing the various forms of distress mentioned by the participants in this study, it seems imperative that the provision of psychological services that offer emotional support to HIV patients become more of a priority in the public health sector.

As noted in the literature review social support incorporates the dimension of instrumental support. Instrumental support comprises financial or housing assistance (Gielen, McDonnell, Wu, O'Campo, & Faden, 2001). The participants in this study reported that, before coming to the care centre, they had been living in abject poverty and had been unable to provide food, clothing or shelter for their families. Financial or instrumental support was perceived as vitally important in terms of the coping abilities of the participants as the presence or absence of financial support is related to how well individuals are able to cope with challenging times.

The participants indicated that the support from the care centre in the form of providing basic supplies for their family had helped to ease the distress of these mothers who

were, in general, unemployed and lacking any form of financial resources. In addition, the participants admitted that the lack of financial resources had added to their feelings of desperation and hopelessness. This is, thus, an important finding which points to the essential role that financial support may play in the quality of life of HIV-positive women in South Africa. Since these women are, generally, single mothers who have experienced a loss of social support as a result of stigmatisation and discrimination, it is essential that financial support be considered as a way of helping these marginalised individuals to cope better with the difficulties of HIV-positive motherhood.

Lastly, Doyal and Anderson (2005) point to the fact that women living with HIV/AIDS often turn to religion as a source of support and help in coping with difficulties. This study confirms these findings. It was evident that some of the participants felt that having God in their life had helped to ease the stressors of HIV-positive motherhood and that it had provided them with a degree of relief. The findings of this study also concur with the findings of research conducted by Phillips and Sowell (2000) and Simoni (2002) to the effect that people living with HIV who report greater engagement in spiritual activities also report lower emotional distress and better psychological adaptation (Simoni, 2002).

5.2 Concluding Comments

It would appear that the various encounters and challenges experienced by HIV-positive mothers living in a HIV Care centre are of a far more complex nature than is indicated in general psychological literature. Although it has already been said that motherhood for HIV-positive women entails “love, toil, and trouble” (Brush, 1996,p.23), for the participants in this study, these “mother troubles” have proved to immensely challenging as they have involved resolving the contradictions posed both by HIV infection and motherhood whilste simultaneously living in a HIV Care centre. It is, therefore, extremely meaningful that this study located the experiences of HIV-positive mothers within this

particular context as it would appear that the care centre has had a significant impact on the experiences of the mothers, both positively and negatively.

For many HIV-positive mothers motherhood appears to be a fairly ambivalent experience which is characterised, in turn, by a pervasive sense of loss and also closely related to various emotional and psychological challenges. It is evident that HIV-positive women living in institutional care are forced to confront various challenges with shared mothering, a lack of independence and strong institutional influences all affecting the way in which the participants in this study experienced motherhood and how they perceived themselves.

The contradictory nature of HIV-positive motherhood adds to this ambivalence as the fear of the future and, particularly, fears of future illness and death all contribute to the difficulties of motherhood. Despite the guaranteed emotional and financial security offered to the mothers and their children by the care centre, the participants in this study were all still experiencing a level of insecurity as regards the future.

A deep sense of loss was prevalent among the participants. The stigmatisation and rejection by friends and family based on their HIV diagnosis had been extremely distressing for the participants. This may have given the message to the mothers that they were not only bad mothers, but, also bad women. The immense stigma and loss of relationships may also have been linked to the emotional upheaval that many of the mothers had endured and still continued to endure. The rejection was experienced as a strong assault on the participants' egos and their sense of self .The high levels of stigma and isolation which emerged in the present study reveals that there are still severe forms of stigma and a general lack of social support for those diagnosed with HIV and living in South African communities.

Although a general lack of social support had been experienced in the "outside world", nevertheless, the participants highlighted a network of social support within the care

centre with staff members and other mothers being perceived as offering immense support in coping with daily challenges. The emotional support gained from attending counselling with the therapist at the care centre was also found to be invaluable in helping the participants to cope with the past and present stressors of being an HIV-positive mother. It is, thus, suggested that long term psychological services that offer emotional support to HIV-positive mothers living independently become more of a priority in the public health sector in South Africa. In addition to the care and support offered by the care centre, the instrumental support was also found to be vital in helping these marginalised individuals to cope better with the difficulties of HIV-positive motherhood.

The ambiguity inherent in the participants' responses regarding their experiences of motherhood makes it difficult to draw broad conclusions as several factors had influenced their experiences. However, in view of all the challenges involved in being an HIV-positive mother in South Africa, together with the stigma and discrimination experienced on the part of friends and family, it was suggested that HIV care centres offer a place of refuge and protection against the real world.

Although the mothers in the study all appeared to yearn for their pre-diagnosis sense of independence and level of general functioning, nevertheless, post diagnosis, in view of the tensions inherent in being an HIV-positive mother, it would appear that care centres play an insulatory role and help to act a buffer against the various challenges related to living with HIV. However, living in a care centre does not take away the ambivalence and paradox of being an HIV-positive mother and the various stresses, although somewhat alleviated, did still to exist for the participants and, thus, long-term support and psychotherapy is needed for such mothers. The findings of this study reveal that the experience of motherhood, from the perspective of institutionalised HIV-positive women in South Africa, is more complex than previously thought.

5.3 Limitations of the Study

It is important to take into account the limitations of the study in evaluating the results of the research and opportunities for improvement are apparent. Firstly, a limited number of participants were interviewed. This study was based on eight interviews and, although a rich corpus of data emerged, it would be an advantage to interview a larger number of participants in order to increase the generalisability of the findings. Furthermore, it may be useful to include a wider selection of care centres and, thus, make it possible to compare findings across institutions in order to ascertain whether all care centres offer similar forms of assistance.

Generalisablity is essential when conducting research and, therefore, it may have been useful also to have interviewed mothers living independently in urban Johannesburg as it is likely that they may have had quite a totally different experience living without the medical, psychological and financial resources that the care centre provides. In addition, it may have been useful to have used participants from various race categories and mothers of different ages.

Since the researcher is also the primary interpretative instrument and the process of thematic analysis is highly subjective, it must be understood that the researcher's own ideological frameworks will, inevitably, emerge in the research material and this may also constitute a limitation.

5.4 Implications for Future Research

Despite the above limitations, this study provides valuable information which has implications for future research into the experiences of HIV-positive mothers. While a qualitative research design does not focus primarily on the generalisability of research results, it is, nevertheless, important in that it stimulates the way in which we think about and approach subject matter.

Research into the lived experiences of HIV-positive mothers is scarce in South Africa. Accordingly, this study has been able to delineate the way in which these individuals experience motherhood while simultaneously experiencing the various psychological and social challenges that are associated with being HIV positive. The coping mechanisms employed by HIV-positive mothers as well as maladaptive coping mechanisms were briefly touched upon and could be interrogated in greater detail in future research.

In view of the fact that demographic variables were not included in this study, further research examining the impact of certain variables such as educational background, age, mothering experience, the circumstances that led the individual to a care centre and the social economic status of participants is suggested. The impact that these variables have on the experiences of HIV-positive mothers would be both valuable and interesting to research.

This research may also stimulate further areas of research into steps that may be taken both to preserve and to promote the psychological wellbeing of HIV-positive mothers who are living independently. In view of the fact that the participants in this study were living in a government funded care centre which catered for many of their basic needs, it would be useful to conduct further research on HIV-positive mothers living independently in both rural and urban parts of South Africa in order to ascertain whether their experiences differ in any way from the experiences of the participants of this study.

Since this study identified several psychological and emotional challenges confronting HIV-positive mothers, it is suggested that more psychological services that go beyond the usual pre and post test counselling, be made available in the public health sector. Individual counselling and support groups for HIV-positive mothers would, hopefully, provide these individuals with more ongoing support to enable them to cope with the many challenges involved in being both a patient and a care giver.

The research raised interesting ideas in respect of institutional care for HIV-positive patients. While both positive and negative elements were highlighted, nevertheless, ambivalent feelings about living in a care centre did become apparent. Future research could, perhaps, focus on the long term efficacy of care centres for HIV-positive mothers.

This study was able only to make qualitative comments on the lived experiences of HIV-positive mothers. In future research, a mixed methods design which looks more closely at, for example, the psychological impact of HIV may be employed in order to increase the reliability and validity of the research study and, thus, facilitate the more effective deduction of both comparisons and conclusions.

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APPENDICES

Appendix A: Permission to conduct research

Appendix B: Participant information sheet

Appendix C: Participant consent form

Appendix D: Recording consent form

Appendix E: Use of direct quotation consent form

Appendix F: Semi-structured interview guide

Appendix A

Permission to conduct research

Faculty of Humanities - Postgraduate

Private Bag 3, Wits 2050, South Africa • **Tel:** +27 11 717 4007 • **Fax:** +27 11 717 4037

Student Number: 0502563D

Ms S T Street
P O Box 782137
SANDTON
2146

11 May 2010

Dear Ms Street

APPROVAL OF PROPOSAL FOR THE DEGREE OF MASTER OF ARTS IN COMMUNITY-BASED COUNSELLING PSYCHOLOGY

I am pleased to be able to advise you that the readers of the Graduate Studies Committee have approved your proposal entitled "*The Lived Experiences of HIV positive Mothers*" and you have now been admitted to full candidature. I confirm that Dr. V Jithoo has been appointed as your supervisor in the Department of Psychology.

The research report is normally submitted to the Faculty Office by 15 February, if you have started the beginning of the year, and for mid-year the deadline is 15 August. All students are required to RE-REGISTER at the beginning of each year.

You are required to submit 2 bound copies and 2 1 CD in pdf (Adobe) format of your research report to the Faculty Office. The 2 bound copies go to the examiners and are retained by them and the 2 corrected unbound copies are eventually sent to Archives and to the Library.

Please note that should you miss the deadline of 15 February or 15 August you will be required to submit an application for extension of time and register for the research report extension. Any candidate who misses the deadline of 15 February will be charged fees for the research report extension.

Kindly keep us informed of any changes of address during the year.

Note: All MA and PhD candidates who intend graduating shortly must meet your ETD requirements at least 6 weeks after your supervisor has received the examiners reports. **A student must remain registered at the Faculty Office until graduation.**

Yours sincerely

V N Mnguni
Virginia Mnguni
Postgraduate Division
Faculty of Humanities
Private Bag X3
Wits, 2050
Tel: +27 11 717 4007

Appendix B

Participant information sheet

SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

UNIVERSITY OF THE WITWATERSRAND

Private Bag 3, WITS, 2050

Tel: (011) 717 4500 Fax: (011) 717 4559

Hello.

My name is Sacha Street. I am studying a Masters degree in Community-based Counselling Psychology at the University of the Witwatersrand. I would like your permission to conduct research as part of my degree. I am interested in finding out about your experiences and thoughts of motherhood and looking at what difficulties, if any, you face while living at the care centre.

If you decide to take part in my study, I will need 1-1 ½ hours of your time to ask you a few questions. This interview will also be recorded if you agree. I will come and see you at Nkosi's Haven at a time that is convenient for you. Taking part in my study is voluntary and you may stop the interview at any time with no negative consequences. You will not receive any benefits or money for your participation. You may also choose not to answer any questions that you do not want to. There are no right or wrong answers in this study – what I am interested in are your own experiences and views.

I will conduct interviews face to face, and even though I will know your name, I will not use your own name or any other information which might identify you. The information collected will not be seen by anyone except for myself and my supervisor. After the report is finished, data will be either destroyed, or kept in password-protected files for future research, which only I will have access to. General feedback will be given in the form of a letter to Nkosi's Haven, but the finished research project will be available in the library of the University of the Witwatersrand. You will be able to access it there at anytime. If you would like more feedback, please contact me by e-mail or phone, and I will provide it to you with pleasure.

I would like to invite you to participate in this study. If you choose to participate in the study, please sign the attached consent form and give it back to me. This study is low risk, but if for any reason you feel upset or sad afterwards, you will be able to go for counselling with Heather Snyman at the centre.

If you have any questions, please contact the researcher or supervisor.

Counselling Service

- Therapist at Nkosi's Haven: Heather Snyman

If you have any additional questions or concerns, please feel free to contact me or my supervisor.

Kind regards

Ms Sacha Street

(Masters student)

Tel: 0724656092

Email: sacha.t.street@gmail.com

Dr V Jithoo

(Research supervisor)

Tel: 011 717 4523

Email: Vinitha.jithoo@wits.ac.za

Appendix C

Participant consent form

SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

UNIVERSITY OF THE WITWATERSRAND

Private Bag 3, WITS, 2050

Tel: (011) 717 4500 Fax: (011) 717 4559

I have read and understood the purpose of this research.

I, _____, a resident at _____ (name of institution) hereby consent to participate in Sacha Street's study on the lived experiences of HIV-positive mothers, which comprises taking part in a 1-1½ hour interview with the researcher. I will allow the researcher to quote me directly in her written project, on the condition that:

- I remain completely anonymous to everyone but the researcher and supervisor.
- The data remains confidential.
- My personal details remain confidential.
- If the data is kept, it is not seen by anyone except the researcher; otherwise, it is destroyed.
- I may withdraw from the study at any time.
- I may refuse to answer any questions.

I understand the risks involved, and that I will not receive direct benefits from participation. I undertake this willingly and knowingly.

Signed: _____

Date: _____

Appendix D

Recording consent form

SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

UNIVERSITY OF THE WITWATERSRAND

Private Bag 3, WITS, 2050

Tel: (011) 717 4500 Fax: (011) 717 4559

I have read and understood the purpose of this research.

I, _____, a resident at _____ (name of institution) hereby give my consent to the researcher to record the interview in MP3 format, on the condition that:

- The data remains confidential.
- If the data is kept, it is not accessed by anyone except the researcher and her supervisor; otherwise, it is destroyed.
- My identity is protected.

I understand the risks involved, and undertake this willingly and knowingly.

Signed: _____

Date: _____

Appendix E

Use of direct quotations consent form

SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

UNIVERSITY OF THE WITWATERSRAND



Private Bag 3, WITS, 2050

Tel: (011) 717 4500 Fax: (011) 717 4559

I have read and understood the purpose of this research.

I, _____, a resident at _____ (name of institution) hereby give my consent to the researcher to use direct quotations from the interview in her final write up, on the condition that:

- The data remains confidential.
- If the data is kept, it is not accessed by anyone except the researcher and her supervisor; otherwise, it is destroyed.
- My identity is protected.

I understand the risks involved, and undertake this willingly and knowingly.

Signed: _____

Date: _____

Appendix F

Semi-structured Interview Guide

SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

UNIVERSITY OF THE WITWATERSRAND



Private Bag 3, WITS, 2050

Tel: (011) 717 4500 Fax: (011) 717 4559

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1. What does it mean to be a mother?

2. How did you learn about motherhood?

3. If you were not living in this care centre, would you have been different with your child? In what ways would you have been different?

4. How has your HIV status influenced your ideas about being a mother?

5. In your opinion, what are some of the difficulties you experience being a mother diagnosed with HIV?

Prompt: What are some of the physical, emotional and social difficulties you have experienced?