

**THE EMOTIONAL EXPERIENCES OF HIV-POSITIVE MARRIED
WOMEN WANTING TO BEAR CHILDREN: AN EXPLORATORY
STUDY**

BY

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DECLARATION

I, declare that the dissertation hereby submitted to the University of Limpopo, for the degree of MSC Clinical Psychology has not previously been submitted by me for a degree at this or any other University; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

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DEDICATION

Dedicated: to my Lord and Saver, Redeemer, Rock, Shepherd and Shield.

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ABSTRACT

Recent literature on childbearing and HIV has indicated a plethora of evidence suggesting that many women living with HIV continue to desire children, become pregnant and give birth after knowing their HIV status. This desire to have children has been associated with the availability of HAART and PMTC interventions and its improvement in the quality of life for HIV-positive women.

This study aimed at exploring the emotional experiences of HIV-positive married women wanting to bear children. A qualitative research design was used to explore the above mentioned aim. Through the use of semi-structured interviews a sample of 12 HIV-positive married women were purposefully selected. The participants were chosen from Tshepang clinic at Dr. George Mukhari Hospital situated in the township of Ga-Rankuwa using a purposive sampling design. Semi-structured interviews using interview guide were conducted to explore their unique and subjective emotional experiences of being HIV, married and in need of a child. The process of data analysis in the current study was guided by phenomenological approach in order to allow the inherent meaning of the data to emerge without being distorted.

The findings of these study revealed that the experiences surrounding HIV positive diagnosis, marriage and childbearing proves to be associated with overwhelming emotional experiences for women in the current study. Most of the participants in this study viewed motherhood as a unique, subjective and a personal fulfilment for all women irrespective of their HIV status. Participants felt that children stabilise a marriage by giving it meaning. A decision to conceive for some participants is influenced by pressure as a result of their marital, social and situational context.

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CHAPTER 1

INTRODUCTION

1.1 Orientation of the study

In the era of rampant HIV infection, an obligatory public health aim is to reduce transmission and prevent the emergence of new HIV/Aids infection. However, a number of HIV positive women has increased, especially women who are of reproductive age (13-44 years) (Mantell, Smit, & Stein, 2009).

Researchers have been studying the interaction between HIV and female reproductive health, especially as antiretroviral medications allow HIV positive women to live a longer, healthier life. Life has been prolonged by expanded access to free treatment with antiretroviral therapy (ARV) drugs and better care in the public sector (Mantell *et al.*, 2009). HAART was introduced within the last decade in Africa (2001 in Lesotho, 2002 in Botswana and Nigeria, 2003 in Swaziland and Uganda, 2004 in South Africa and Zambia) (Mantell *et al.*, 2009). Issues of sexuality and fertility are now prominently thrust into the arena of care for HIV infected persons.

In terms of literature reviewed, most of the above countries have also developed *HIV and AIDS Charter of Rights*. In Swaziland a charter was drawn up in 2004 as part of a young positive women's dialogue. The charter declares that HIV positive women have the same rights as other women but also need access to HIV specific information and services (Bell, Mthembu & Sullivan, 2007). Reproductive rights called for, in the charter to include the right to decide whether and when to conceive without being judged, to decide on the number and spacing of children, to abortion or sterilisation on demand (without requiring the

consent of another person), to keep the baby, to education on labour, delivery and breastfeeding, to quality antenatal care, regardless of social, economic or political status, to family planning information and decision-making over type and use of contraception, to access HIV and sexually transmitted infection (STI) preventative methods such as microbicides when they become available, to safe delivery how and where women want, to assisted conception or artificial insemination, to feed the baby the way women want and to have accurate information about feeding options to be able to make informed decisions and to prevent mother-to-child transmission of HIV (Bell *et al.*, 2007).

Another charter that takes account of issues for both men and women living with HIV/Aids on a national level is the *Nambia HIV/AIDS Charter of Rights*, drafted in 2000 by the AIDS Law Unit Legal Assistance Centre with the support of the United States Embassy, Windhoek and the Ford Foundation (Bell *et al.*, 2007). It states that people living with HIV/Aids are entitled to autonomy in decisions regarding marriage and reproductive health, including in decision-making on matters of family planning, and the right to take appropriate precautionary measures to prevent transmission of HIV (Bell *et al.*, 2007). It calls for appropriate counselling and information regarding transmission of HIV to be available to persons living with HIV/Aids who wish to exercise the right to marry and/or start a family (Bell *et al.*, 2007).

Advanced research and treatment on HIV/Aids antiretroviral therapy (ART) has restored health and fertility in people living with the virus and drastically reduced mother-to-child transmission (MTCT) of HIV (Homsy *et al.*, 2009). As major efforts are under way to expand access to this life-saving treatment in sub-Saharan Africa, thousands of men and women on ART are resuming a socially productive and sexually active lives involving protected and

unprotected sex with or without a desire for children (Homsy *et al.*, 2009). While most research has focused primarily on providing prophylaxis against and care for opportunistic infections and delivery of antiretroviral treatment (ART) less attention has been given to provision of appropriate reproductive health services for HIV positive women and men (Cooper, Harries, Myer, Orner & Bracken, 2007). As there is also a strong personal desire to experience biological parenthood among HIV positive men and women, which are influenced by social values that encourages childbearing. This indicates that a substantial proportion of HIV positive women continue to desire to bear children despite their positive status.

1.2 Motivation of the study

This study originated out of a brainstorming session between the researcher and the supervisor. It was with interest from brainstorming about this topic that the researcher decided to embark on literature review on HIV and childbearing. In the process of literature review the researcher discovered that enormous focus is placed on access to prevention of parent-to-child transmission (PPTCT) and antiretroviral therapy (ART). There were further indications that the relationship between fertility and HIV/Aids has been largely clinical focusing on the ability of women living with HIV/Aids to conceive or their pregnancy outcomes (Kanniappan *et al.*, 2008). However, there is limited understanding of the emotional experiences of HIV-positive married women wanting to bear children. Given the recent scale-up of National AIDS Control Organisation's PPTCT/ART programme, it is crucial to understand the factors associated with shaping women's fertility desires and intentions and the obstacles they face in making informed choices about childbearing.

Research has also shown that there was also strongly perceived community disapproval associated with HIV and reproduction. The prejudice in society has also often been reflected

and reproduced by health care providers (Bell, Mthembu & Sullivan, 2008). Yet on the other hand a strong desire to experience parenthood, mediated by prevailing social and cultural norms that encourage childbearing in society were reported. Motherhood has been found to be an important component of married women's identity and important for women's social status (Cooper, *et al.*, 2007). Family, husbands' and societal expectations for childbearing are important influences on women's reproductive intentions. Hence, it is important to view motherhood and HIV beyond the biomedical interpretation of disease and explore the meaning and value that motherhood has for communities; so that socially acceptable alternatives to motherhood can be provided (Farlane, 2009).

1.3 Aim of the study

This study aims to explore the emotional experiences of HIV-positive married women wanting to bear children. As more than 80% of all women living with HIV/Aids and their partners are in their reproductive years, many will continue to want children after learning their positive status, whether to start a family or to have more children (Delvaux & Nostlinger, 2007).

Literature has revealed that giving birth and having children play a significant role for the social and the personal identity of women and men in most, if not all cultures especially in cases of marriage. Attention will be given in exploring women's beliefs about society's; parents, partners, relatives, friends' and health care workers, perceptions and influence to their reproductive aspirations and intentions. The aforesaid explore influential factors involved in the process of making reproductive decisions.

1.4 Overview of the methodology

In exploring the emotional experiences of HIV-positive married women wanting to bear children a qualitative research design was chosen in order to explore the women's unique and personal experiences to HIV/Aids, marriage and childbearing. Whitehead (2007) showed that qualitative research is a broad term used to describe research that is focused primarily on human experiences through exploring attitudes, beliefs, values and experiences. The collected data was analysed using the following five stages of framework analysis approach outlined by Pope, Ziebland and Mays (2000).

1.5 Chapter overview

This study will be structured as follows:

Chapter 2 will entail literature review regarding the experiences of HIV-positive married women with childbearing needs, intentions and desires. **Chapter 3** will describe the research methodology (research design and process) used in this study. **Chapter 4** will entail a detailed presentation of the results. **Chapter 5** will focus on the integration and discussion of the results with the literature reviewed from chapter 2. Furthermore there will be a presentation of the strength, limitations, conclusions and recommendations of the study.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter reviews the journey of HIV/Aids and pregnancy with a focus at the developments made by ARTs, PMTCT and HAART. Attention will be paid to marriage as a factor to childbearing by reviewing findings from studies done in other places. Social and cultural factors associated with childbearing in HIV/Aids infected married women of childbearing age will be highlighted by specifically focusing in the African context where this study was conducted. Then later attention will be paid to dilemmas faced by HIV/Aids infected women with regard to healthcare providers in meeting their reproductive intentions and desires.

2.2 HIV: An evolving journey

Despite the advancements being made in behavioural and medical research from 1994 HIV/Aids was the leading cause of death among Americans between the ages of 25 and 44 years of age (Mayer & Pizer, 2009). However, developments were discovered which gave hope that early treatment of pregnant women with the drug zidovudine (AZT) could reduce or prevent all mother-to-child transmission of HIV (Connor *et al.*, 1994; Mayer & Pizer, 2009). According to Homsy *et al.* (2009) recent cross-sectional surveys and qualitative studies have shown that women on antiretroviral therapy (ART) in sub-Saharan Africa resume their love and sexual life once their health is restored and want to have children.

By the end of 2007 there was almost 3,000,000 HIV infected persons receiving ART in resource limited settings. According to Myer *et al.* (2010) the global roll-out of ARTs has

contributed to a greater awareness of issues related to fertility and childbearing among HIV/Aids infected women and men, particularly in sub-Saharan Africa where a large proportion of HIV/Aids infected persons are women in their reproductive years. A study on the impact of antiretroviral therapy on the incidence of pregnancy among HIV/Aids infected women was conducted in Sub-Saharan Africa. The findings from this study showed a high overall incidence of pregnancy (more than seven pregnancies per 100 woman years of observation) and a significant association between the use of ART and increased incidence of pregnancy (Myer *et al.*, 2010).

In a study conducted in rural Uganda on women receiving ARTs it was shown that sexual activity and the incidence of pregnancy significantly increased over follow-up, yet more than 93% of the women repeatedly expressed not wanting or not planning to have more children and said the same was true for more than 75% of their partners (Homsy *et al.*, 2009). Cooper *et al.* (2005) revealed that women and men on ARTs overwhelmingly experienced positive effects on their health and some felt that being on ARTs would alter their attitudes towards childbearing.

Then in 1995 highly active antiretroviral therapy (HAART) was introduced with the first protease inhibitor, saquinavir. HAART is a treatment for human immunodeficiency virus (HIV) infection that uses a combination of several antiretroviral drugs (Karim & Karim 2010). The goals of HAART are to suppress HIV replication to a level sufficient to prevent the development of drug-resistant mutations, to prevent the progression of HIV disease, and to reconstitute the immune system (Friedland & Williams, 1999; Mayer & Pizer, 2009). Patients begin to feel better and, when the virus is not detectable, they feel that unprotected sex is safe behaviour. Several studies revealed that optimism about HAART effectiveness

might be contributing to relaxed attitudes towards safer sex practices and increased sexual risk-taking by some HIV/Aids infected positive persons (Mayer & Pizer, 2009).

The advent of HAART and its increased uptake both in developed and developing world was bound to be an impact both on fertility and reproductive plans of HIV/Aids infected people. Studies that have been conducted in other areas so far indicated a positive impact of HAART on fertility (Ndlovu, 2009). An investigation was conducted on the relationship between HIV infection and childbearing before and after the availability of highly active antiretroviral therapy among HIV-positive and HIV-negative women (Sharma *et al.*, 2006; Ndlovu, 2009). The findings showed that among HIV/Aids infected women the HAART era live birth rate was 150% higher than in the pre-HAART era versus a 5% increase among HIV uninfected women in the same period.

In addition the developments made on the prevention of mother-to-child transmission since the first description of AIDS in children in 1980 have also indicated a possible link between HIV and childbearing (Oleske *et al.*, 1983; Cowan *et al.*, 1984; Mayer & Pizer, 2009). Remarkable progress has been made in the years since then in the prevention of mother-to-child transmission (PMTCT), leading to extremely low rates of infection in well-resourced countries, one of the major advance in HIV prevention (Homsy *et al.*, 2009). It is in the light of this breakthrough that some women felt that the availability of pre-natal transmission prevention (PMTCT) would influence them in favour of having children. However, a number of women felt that this would not influence them, if their own health remained compromised (Cooper *et al.*, 2005).

Then a question of whether HIV/Aids infected mothers should exclusively breastfeed their babies or combine breastfeeding with other formula and foods has been extensively debated in recent years (van Dyk, 2008). Initially researchers indicated that one of the major factors contributing to the very low rates of vertical transmission in well-resourced settings has been the avoidance of breastfeeding (Sansom *et al.*, 2007 Mayer *et al.*, 2009). However, this approach is much more difficult in less-resourced countries, where the more significant risks of replacement feeding have to be balanced against the risk of HIV transmission (Wilfert & Fowler, 2007; Mayer *et al.*, 2009). Recent evidence shows that exclusive breastfeeding or exclusive feeding with milk-alternatives, rather than mixed feeding, is effective in reducing mother-to-child transmission of HIV (ICW, 2008).

It is also suggested that the issue of bottle feeding should be handled very sensitively in Africa. Since mothers usually breastfeed in public, they are often stigmatised as being HIV positive when they do not breastfeed their babies (van Dyk, 2008). The recent developments to the issue of PMTCT through breastfeeding have decreased the dilemma which most HIV positive women were faced with in the past. In addition to the developments of ART and HAART which have recently influenced childbearing decisions among HIV-positive individuals.

2.2.1 The current status and statistics of HIV among women of childbearing age

In sub-Saharan Africa, women of childbearing age comprise 61% of people living with HIV/Aids, accounting for over 12 million women. In many regions, the HIV/Aids incidence is increasing most dramatically among young women aged 18 to 30 years, which coincides with their peak reproductive years (Kaida *et al.*, 2011). Globally, a plethora of evidence

indicates that many women living with HIV/Aids continue to desire to bear children, become pregnant and give birth after knowing their HIV status (Kaida *et al.*).

In a more recent Brazilian study, nearly 60% of non-sterilised HIV infected women desired to have a child (Nobrega *et al.*, 2007). In the United States, 29% of almost 35 000, and in a small study in Switzerland, 48% of 46 HIV positive women desired a child (Nobrega *et al.*, 2007). A study in Malawi showed that the desire for more children in HIV infected women was 15.1%, whereas a study of HIV positive women receiving ARTs in South Africa revealed the desire to have more children to be 29% (Heys, Kipp, Jhangri, Alibhi & Rubaale, 2009). Nobrega *et al.* (2007) indicated that the availability of therapy and the improvement in the quality of life may be associated with the woman's desire to have a child.

South Africa's HIV/Aids epidemic has had a devastating effect on children in a number of ways. There was an estimated 280,000 under 15s living with HIV in 2007, a figure that almost doubled since 2001 (Karim & Karim, 2010). It was also shown that HIV prevalence is 28% among pregnant women aged 20 to 24 and 38% of those aged 25 to 29 (SA Ante-natal Care HIV/Syphilis Report, 2008; Farlane, 2009).

Research findings have also shown that the HI virus affects or potentially affects, all the dimensions; of women's health, pregnancy, childbirth, breastfeeding, use of contraception and diagnosis and treatment of sexually transmitted infections (STIs) (Phaweni *et al.*, 2010). The transmission of the HI virus is predominantly heterosexually between couples, with mother-to-child transmission being the other main infection route. The national transmission rate of HIV from mother to child is approximately 11% (Karim & Karim, 2010). In most instances the virus was transmitted from the child's mother.

Underwood *et al.* (2007) showed that it is vital for health communicators to understand how an HIV positive status and high prevalence, regardless of one's status, influence fertility-related decisions so as to more fully address the public's reproductive health concerns especially within a context where cultural practices of marriage put women in a vulnerable position.

2.3 Marriage, HIV and Childbearing

2.3.1 Defining marriage

Marriage more than any other relationship, holds the hope for permanence although it is statistically less permanent now than it has ever been in our society, marriage is still pretty much "for keeps" (Lamanna & Reidmann, 1988). The marriage contract remains the one legal contract between two persons that cannot be broken without permission of society or the state. Many religions also urge permanence in marriage (Lamanna & Reidmann, 1988). In support of the above statement it was reported that religious ceremonies often attempt to reinforce traditional conceptions of marital obligations, conceptions which stress the value of keeping families intact (Booth, Johnson, Branaman & Sica, 1995; Lipman, 1997). Religious ceremonies often include public vows which express a commitment to stay together "until death do us apart", or "so long as we shall both live" (Lipman).

The expectations for permanence are also seen in both civil and traditional ceremonies. Within civil ceremonies marriages are concluded by an official after mutual agreement between the parties but could only be dissolved by the highest court (Lipman, 1997). The expectation of permanence is also seen in traditional ceremonies where two families come together for the payment of lobola after a mutual agreement between two parties (Dlamini,

1987; Lipman, 1997). Lamanna and Reidmann (1988) revealed that economic security and responsible childbearing required marriages to be permanent, although less so than in the past. Today even intimate marriages are usually held together by more than mutual affection, and that is why marriages remain more permanent than other intimate relationships. If there were no legal contract, marriage would be no different from living together.

Kulczycki (2008) showed that marriage implies that two individuals come together to form a couple, and they intend to stay married because they see life in a similar way, consequently, they are likely to seek consensus on matters of mutual importance. More broadly, statistical non-independence in dyads may be due to compositional, partner, mutual influence and fate effects, all of which are observed within marriage (Kulczycki, 2008).

Within the South African context traditionally, payment of the bride price (lobola) by the groom is a demonstration that he had come of age and has the means and capability to support himself and his wife (Wendo, 2004). Acceptance of the bride price signifies the families' support and blessing of the union. Payment and acceptance of the bride price, whatever the currency used, seals the traditional marriage ceremony and authenticates the union between the man and woman (Wendo).

The institution of marriage is the core of South African culture, around which the entire social structure revolves. In its most basic function marriage is directed at producing children, through marriage the human needs for sexual expression, physical intimacy, psychological comfort, and social partnership are satisfied and contained (Afolyan, 2004; Molelekeng, 2009).

2.3.2 Childbearing in marriage

Each culture group has prescriptions on the circumstances under which pregnancy may take place and who may legitimately engage in childbearing (Browner & Sargent, 1996; cited by Maithya, 2006). In most cultures marriage in one form or another often paves the way for childbearing and rearing, to the extent that it is often regarded as the universal legitimate setting for this event (Olenja & Kimani, 1998; Maithya, 2006). For example, many societies still frown upon motherhood outside marriage. But with so many cases of premarital pregnancies today, this may be the ideal rather than the real situation, even in those societies which traditionally stigmatized premarital pregnancy (Maithya, 2006).

Families also attach important social value to married kin having children and marriage without children was perceived to taint the family reputation (Cooper *et al.*, 2007). Hence married women and those anticipating marriage felt they would encounter and need to conform to family expectations to produce children. A recently married woman professed: “Before I got married I was not thinking about having a child [now] I do want to have at least one child because it is a disgrace not to have a child there” (Cooper *et al.*, 2007, p. 278).

In a study conducted in Cape Town, South Africa on reproductive intentions and choices among HIV infected individuals the findings suggested that married women, in particular, reported strong family pressure to reproduce (Cooper *et al.*, 2005). This was more so if they had not yet disclosed their status. For some of these women and a few single ones, the pressure was from the partners to have children (Cooper *et al.*, 2005). One woman stated that if she did not bring children into a marriage, her child from a previous relationship would be stigmatised (Cooper *et al.*, 2005). Women seemed more influenced by family attitudes than

men though some men felt that their masculinity was tied to their ability to reproduce and maintain a family. (Cooper *et al.*). From both personal and social factors, one can deduce that factors that influence decision-making are unique to most individuals (Cooper *et al.*).

These findings were supported by another study where the reproductive choices of HIV positive married women were associated with pressure of marriage and childbearing. Nduna (28 April 2008 conference presentation; cited in Farlane (2009) showed the influence the family has on married women in a discussion with older women in the Eastern Cape Province, South Africa. Women said there was no reason for a married woman not to have children in the marriage. One woman asserted that she gave birth to her son; therefore her daughter-in-law should also give birth to her own sons. In the light of these norms around the meaning of marriage for a woman, it may be difficult to exercise autonomous decision-making in this matter because it is not treated as private (Farlane, 2009, p. 27).

There are also countervailing community pressures that exist when a person's HIV positive status is known. Both women and men perceived that communities disapproved of reproduction in these circumstances (Mantell *et al.*, 2009). The complexity faced by HIV positive men and women is further escalated by the bias and negative attitudes of some health care providers resulting in HIV positive women choosing not to discuss their fertility intentions with them (Mantell *et al.*).

Regardless of these concerns, many HIV positive women still elect to have children after receiving an HIV diagnosis for various personal, cultural and economic reasons. In most places in Africa, a common expectation of marriage is that the couple will have children (Heys *et al.*, 2009). This is especially an important expectation in Uganda as children become

members of the paternal clan (Heys *et al.*). Women are often valued for their ability to bear children and a high social good is placed on fertility. Because of this value and these expectations, women and couples may continue childbearing even when they are HIV infected or destitute in order to avoid social stigma and isolation (Heys *et al.*).

It is therefore clear that across most of Africa and many other parts of the developing world the majority of women do not use 'modern' means of contraception, or indeed any means (Blanc & Way, 1998; Baylies, 2001). This amounts to a substantial unmet need for effective fertility control. Many women similarly have a limited ability to protect themselves from HIV, not least within marriage, and especially during its early years when families are being built (Baylies, 2001). On the other hand women who become pregnant when they are aware of their HIV status may be exercising a choice.

2.3.3 HIV and Marriage

As the HIV/Aids epidemic spreads to the general population a large and increasing proportion of HIV transmissions occur within marriage (Bongaarts, 1996). According to Anglewicz, van Assche, Clark and Mkandawire (2010) discordant couples (i.e. couples where only one partner is infected with the HI virus) represent the majority of HIV infected couples in sub-Saharan Africa. A large proportion of new HIV infections in this region occurs within discordant couples in long-term stable partnerships. Among married couples an individual's perceived and an actual risk of being infected with the HI virus is closely intertwined with his or her spouse's.

Okwun and Siraj, (2010) for all married individuals the institution of marriage is however, not without its problems as unfulfilled expectations and hope in marriage often give rise to

maladjustments. Therefore within the context of HIV positive married couples unless the couples concerned face the reality of any given situation, conflicts might abound in such relationships as a result of childbearing dilemmas. However, it is often inevitable that individuals involved in marriage will experience conflict puts it “conflict is seen as a situation whereby a husband and wife desire goals which may be perceived as attainable by one but not by both” (Justin, 2004; Okwun & Siraj, 2010, p. 237). In such situations, the characteristic of the family reflects incompatibility, interactive struggle and interference. To buttress this, it was postulated that conflict is associated with; anger, criticism and struggles, adversity, tension, battle, fight, trouble, challenge, pressure and warfare. The above researchers’ perceptions on the institution of marriage affect all individuals within marriages whether infected or affected with HIV (Gangle & Carine, 1992; Okwun & Siraj, 2010).

Rispel *et al.* (2011) supported the above findings from a research conducted on sexual relations and childbearing decisions of HIV discordant couples as most respondents reported experiences of tension in the relationship. He further stated that tension arose because of fear of infecting the negative partner, real or perceived infidelity and problems experienced from consistent condom use (Rispel *et al.*). In some instances tensions in the relationship arose because of the reluctance by one partner to use condoms, either because that partner wanted to have a child or felt that condoms interfered with intimacy and love-making. Couples also alluded to the conflict between the desire to have children and preventing HIV transmission (Rispel *et al.*).

Anglewics and Clark (2009) revealed that as a result of the widespread risk of HIV infection within marriage, condom use within marriage is an important strategy in preventing the spread of HIV/Aids. Despite this, condom use does not appear to be a widely-accepted

strategy to prevent HIV infection. While survey data throughout sub-Saharan Africa indicates that individuals are well aware of the threat of HIV infection and know that condoms can prevent HIV infection, many prefer not to use condoms with a spouse (Chimbiri, 2007; Watkins, 2004; Anglewics & Clark, 2009).

From the above information it is clear that HIV positive married couples whether sero-discordant or concordant couples face emotional challenges with their marriages. Not only is their HIV status an impact on their daily lives there is an addition of decision making to condom use, childbearing decisions and meeting the expectation placed on them by their marital status. Hence, Rispel *et al.* (2011) showed that there is a need to understand; complex personal, interpersonal, medical and health care factors of HIV positive married couples in order to assist them in meeting their reproductive needs.

2.3.4 HIV and Pregnancy

Numerous behavioural and contextual factors interact in a complex way to determine intended and unintended reproductive outcomes among women living with HIV. Age, marital, educational, and socio-economic status, cultural and religious beliefs, sexual behaviour as well as family size and losses, and access to family planning services are documented predictors of pregnancy (Homsy *et al.*, 2009).

In sub-Saharan Africa where HIV prevalence is highest, these factors may be considerably influenced by the traditional roles of women, the socio-cultural importance of motherhood, and a woman's partner's desire for children independent of her own (Homsy *et al.*, 2009). The added risk of Mother-to Child-Transmission (MTCT) of HIV through breastfeeding and reduced capacity for timely diagnosis and treatment of infants infected with HIV compounds

the complexity of the choices that couples or women living with HIV must make in relation to childbearing (Homsy *et al.*).

It is therefore indicated from the literature reviewed that HIV positive women are faced with complex factors on the decision of whether or not to have children. They further have additional consideration, largely negative, to take into account when deciding whether or not to have children. These include the possibility of passing HIV from mother to child and the likelihood that one or both parents could die prior to the child reaching adulthood (Heys, Kipp, Jhangri, Alibhai & Rubaale, 2009).

Women who are infected with the HI virus may be less fertile and may be more likely to experience adverse maternal outcomes as it is stated that generally these women are more likely to have; poor pregnancy outcomes; miscarriages, stillbirths and low birth weight infants, than HIV negative women (Markson *et al.*, 2001; Ross *et al.*, 2004; Mukasa, 2007). Therefore making a decision to fall pregnant or bear a child while being HIV positive it is never an easy decision to make.

2.3.5 Childbearing after HIV-diagnosis

Literature reviewed from studies conducted previously initially revealed that pregnancy rates among HIV positive women were low. It was also shown that pregnancy rates in the US after HIV diagnosis were at 18% to 40% (Chenet *et al.*, 2001; Mukasa, 2007). Another study conducted described a 24 % pregnancy prevalence rate after HIV diagnosis, in a French cohort of HIV positive women (Vincenzi *et al.*, Mukasa, 2007). These relatively low pregnancy prevalence rates after HIV diagnosis in developed countries are associated with an

increase in pregnancy avoidance behaviour e.g. reduced sexual activity, increased contraceptive use and high abortion rates (Mukasa).

However, recent literature reviewed has shown a shift from the initial low pregnancy rates and this is supported by studies conducted which indicate that since the development of reduced HIV infection through HAART, ARVs and PMTCT more women have chose to bear their own children. Kaida *et al.* (2011) supported the above statement as he stated that expanding access to highly active antiretroviral therapy (HAART) is changing the landscape of childbearing decision making of people living with HIV.

Studies from Europe and North America showed that HIV infected women frequently become pregnant and most HIV infected individuals have fertility desires that change over time (Myer *et al.*, 2010). Data are sparse from Africa however, where socio-economic and cultural imperatives have a substantial impact on female fertility desires among HIV infected women, possibly through increased hopes and planning for the future (Myer *et al.*).

A study conducted in Brazil showed that most HIV positive women of reproductive age desire to have children and is common in the Brazilian culture. The findings of this research revealed that the high proportion of women desiring a child (40%), even knowing their seropositive status, suggests; the complex interplay of disease, healthcare providers and social and cultural features that play an important role in this choice within Brazil (Nobrega *et al.*, 2007). The proportion of HIV positive women desiring a child was almost double than that found in another study carried out in Sao Paulo in south-eastern Brazil (21% of 148 women), one of the most developed regions in the country (Nobrega *et al.*).

2.3.6 Cultural/traditional significance of childbearing

Many traditional people consider it as extremely important to acquire personal immortality through their children. In traditional African thought, history does not move forward into the future, but backwards in time towards the *Zamani* (the Swahili word for the past) (Mbiti, 1969; van Dyk, 2008).

So long as they are alive in the memories of those who knew them, they are in a state of *personal immortality*. Mbiti explains this in the following way:

“Unless a person has close relatives to remember him when he has physically died, then he is nobody and simply vanishes out of human existence like a flame when it is extinguished”.

“Therefore it is a duty, religious and ontological, for everyone to get married; and if a man has no children or only daughters, he finds another wife so that through her, children (or sons) may be born who would survive him and keep him (with the other living-dead of the family) in personal immortality”.

(Mbiti, 1969, p. 26; van Dyk, 2008)

To be forgotten after one's death and to be cast out of the *Sasa* period into the spirit world of the *Zamani* is the worst possible punishment (van Dyk, 2008). Procreation is therefore one way of ensuring that a person's personal immortality is not destroyed. According to Mbiti a traditional woman might consider the failure to bear children a worse fate than committing genocide. She has not only become a dead end for the family's genealogical line: she has also failed to perpetuate her own self through her children. The following authors; Ujiji, Ekstrom, Ilako, Indalo and Rubenson (2010) stated that children ensure the continuity of the family lineage, confer a sense of continuity and inherit family land and wealth.

Some people from the Shona ethnic group in rural Zimbabwe believe that those who die childless cannot be accepted into the spirit world of the ancestors and they are doomed to wander the earth as evil, aggrieved or haunted spirits (Mutambirwa Scott & Mercer, 1994; van Dyk, 2008).

2.4 Factors associated with childbearing among HIV positive women.

Dyer, Abrahams, Mokoena and Van der Spuy (2004) showed that generally childlessness could have very negative effects on a relationship, including divorce and domestic violence. They revealed that a few men acknowledged that women were likely to suffer more under these negative experiences when compared to men (Dyer *et al.*). In support of their statement Ujiji et al. (2010) showed that childlessness and infertility have a stigma attached to them and often associated with profound negative social repercussions in African societies.

2.4.1 The significance of motherhood

Literature review suggests that for women in general as well as for HIV positive women motherhood it is important and an inherent part of their femininity (Cabral 1998; Hebling & Hardy, 2007). A qualitative study was carried out with 12 HIV positive women to describe their feelings about motherhood in Brazil which confirmed that motherhood was seen as an essential attribute of women and a reason for living. The testimonies from the research findings showed that for some HIV positive women, having a child in spite of HIV positive status allows them to “*come back to life*”. It further represents an opportunity to reclaim their social identity, which was put into question by the infection (Hebling & Hardy, 2007).

Becoming a mother, they can continue saying: “*I am a woman just like any other*” (Hebling & Hardy, 2007, p. 1098). Motherhood symbolizes life and represents a challenge to being a

woman (Knauth, 1999; Hebling & Hardy, 2007). Perceiving motherhood as a woman's right also helped to legitimate their desire to become mothers in spite of the risk of vertical transmission and possibility of orphanhood.

In a study conducted in Zimbabwe the findings correlated with those from Brazil as women described motherhood as a primary source of self-esteem and that an HIV infected woman may want to replace a child lost to AIDS (fhi, 2001). Pregnancy may provide hope for the future; a dying woman can console herself if she has healthy children who survive. The findings of this research further suggested that other HIV positive women may not be able to accept the seriousness of their diagnosis and denying it, become pregnant (fhi, 2001). Other HIV positive women may become pregnant to conceal their HIV status from relatives, especially in-laws.

2.4.2 Social expectations regarding childbearing in marriage

Children stabilise a marriage by giving it meaning. Children confer certain status to the mother and the father in the family, community and the society (Maithya, 2006). To be addressed as father or mother of so-and-so is a social status men and women look forward to. Therefore the symbolic nature of marriage is not complete without children (Maithya). Gipson and Hindin (2007) added another factor to Maithya's findings by stating that married women living with their in-laws felt that having children substantiated their position within their new households and communities.

Literature reviewed suggests that family formation was seen as 'natural' and 'necessary' part of marriage (Cooper *et al.*, 2007). One woman stated "I am going to get married and I will have to have a child, it is going to be a must". The other woman also stated that "When I am

married I will have to have a baby because...only my boyfriend and I...are aware that I am HIV positive and...People will ask why I am not becoming pregnant in marriage” (Cooper *et al.*, 2007, p. 278). Yet on the other hand, there is research findings where societies’ or communities’ view to childbearing is not in support of HIV positive women’s reproductive intentions in particular.

Myer, Morroni and Cooper (2006) showed that social contexts have a strong influence on fertility intentions and reproductive decision-making, particularly among HIV infected women and men. Research they conducted on community attitudes towards sexual activity and childbearing by HIV-positive people in South Africa indicated participants stating that HIV infected individuals should not be sexually active and others stated that HIV positive individuals should not have children (Myer *et al.*,).

Their findings were supported by another study conducted by Kanniappan *et al.* (2008) where the findings from exploring HIV positive women’s; desires, intentions and decision-making in attaining motherhood suggested that women changed their fertility intentions after disclosure and they were firm in decisions of not having a child. Unmarried women reported autonomy in their personal relationships in reproductive decision-making. One unmarried woman said: “*I would not give in to have a child just because I want to please him*” (Cooper *et al.*, 2007, p. 278). Available evidence shows a strong influence of sociocultural factors on people living with HIV, fertility decision-making beyond personal autonomy (Kanniappan *et al.*, 2008).

The intentions by HIV positive women are driven not only by an HIV diagnosis but by individual concerns as well as larger societal and cultural expectations (Gruskin, Mia,

Firestone, MacCarthy & Ferguson, 2008). For example, decisions around motherhood throw into sharp relief unequal power dynamics in personal relationships and cultural expectations about marriage (ICW, 2008). Secondly, women with HIV may be left balancing the possibility of not surviving long enough to raise their children, or of giving birth to HIV positive children who will require significant care with the potential of being stigmatized for not bearing children at all (Gruskin *et al.*, 2008).

2.5 Implications of the ‘desire to have children’ on an HIV-positive woman

2.5.1 HIV risk factors

Literature abounds on HIV risk factors from the impact of the virus on the immune system of an individual to mother-to-child transmission of the virus and many other aspects of it. In this context attention will be paid on HIV risk factors on discordant couples where one partner is HIV positive and the other is negative and to the transmission of the virus on their unborn children. The continued sexual activity of HIV positive people has significant implications for the sexual transmission of the virus and secondary prevention efforts (Kelly & Kalichman, 2002; Myer *et al.*, 2006). Childbearing among HIV positive women may lead to the vertical transmission of HIV and when this can be prevented, the care of future orphans may be of concern (Myer *et al.*, 2006).

Rispel *et al.* (2011) supported the above statement by stating that a key challenge for HIV discordant couples is minimizing the risk of HIV transmission to their negative partner(s) and to any children conceived. Then, Wilde (2008) reported that semen contains the male reproductive cell, the spermatozoa, and other cells including macrophages, lymphocytes, and neutrophils suspended in a fluid, the seminal plasma. HIV has been found to be present in the non-spermatozoa cells and as free virus in the seminal plasma (Wilde). He further stated that

the spermatozoa can also be infected with HIV, but whether the virus remains alive in these cells and therefore contributes to sexual transmission has still to be clarified. As the spermatozoa contribute only around 10% of the total volume of semen, even if these cells contain active HIV they contribute only a small part to the overall “risk” of sexual transmission by semen (Wilde).

The above HIV risk factor is mostly seen among HIV discordant couples who use a timed unprotected intercourse as a means to try and conceive. van Dyk (2008) explained this method where the couple has unprotected sex (that is, they do not use condoms) only during the fertility window (when the woman ovulates, 14 days before menstruation starts). He stated that this method is not risk-free as the negative partner can still be infected with HIV. Therefore this has led to increasing attention to and advocacy for the provision of reproductive assistance (such as sperm washing or in-vitro fertilisation (IVF) to reduce the risks of HIV transmission and to satisfy the desire for children with little or no risk (Rispel *et al.*, 2011). However, there is still a growing number of HIV positive women who still conceive naturally through timed unprotected intercourse thereby putting their health and that of the child at risk.

2.5.2 Financial implications of other conception methods

Myer *et al.* (2006) stated that other interventions, such as assisted reproductive technologies for HIV discordant couples, are not accessible in most parts of South Africa and other countries in sub-Saharan Africa where HIV is most prevalent but may represent an important option where available. Siegel and Schrimshaw (2001) reported that although these options can obviate the risks, it is unclear if this would be an affordable or acceptable procedure to most socio-economically disadvantaged women or couples.

Wilde (2008) showed that the alternative conception methods available for HIV discordant couples are as follows:

- **Timed ovulatory intercourse:**

Unprotected sexual intercourse is restricted to the time of ovulation which was discussed above with its own implications.

- **Artificial insemination of the female with washed sperm from her HIV-positive partner:**

This method involves direct conception in HIV Discordant Couples 3 injections of the sperm into the uterus after the sperm has been “washed” to remove seminal plasma and non-spermatozoal cells.

- ***In vitro* fertilization (IVF) with prepared sperm from the HIV positive partner:**

This method involves the removal of sperm from the seminal plasma and the collection of eggs from the female by a surgical procedure such as laparoscopy. The eggs are then fertilized in a test tube (*in vitro* fertilization). *In vitro* fertilisation is routinely indicated in couples with fertility problems and has been considered as an alternative to artificial insemination of the female with washed semen in discordant couples to further reduce the risk of HIV transmission. However, because of the invasive nature and costs of this procedure, it is usually restricted to HIV discordant couples who have co-existing infertility problems.

- **Artificial insemination of the female with sperm from an HIV negative male donor:**

This method totally eliminates the risk of HIV transmission to the female but is not acceptable to many couples. van Dyk (2008) supported this statement by indicating that to use donor sperm is often not an easy decision for discordant couples to make.

Van Dyk (2008) explained the abovementioned conception procedures, another method of conception through surrogate mothering. This is a process where a husband fathers a child with another woman by artificial insemination; the woman or surrogate mother carries the child to term, then turns the baby to the couple. The other option is through adoption and both of these procedures can become a problem especially when we refer back to the discussion made earlier on cultural/traditional significance of childbearing where value is highly placed on bearing one's own child.

In terms of literature review there is a growing attention given to the above methods of conception so as to minimise the risk of HIV transmission to HIV negative partners and unborn children. However, these methods can be problematic within the South African context where for example an adopted child will not be linked to the ancestors (van Dyk, 2008). He further indicated that if ancestors (and the honouring and continuation of their names) play an important role in the lives of the family, they may well be reluctant to introduce new ancestors, those of the orphaned child. In case of surrogate mothers van Dyk reported an emotional complex, involving jealousy on the part of the wife, possessiveness on the part of the surrogate mother and the couple's feelings that the child is not completely theirs.

In general there are challenges with almost all techniques used for conception away from the natural form of conception. This therefore indicates that it can never be easy with HIV positive married women to meet their reproductive needs without having to face the emotional implications of their decisions. Van Dyk (2008) revealed that there are cultural, ethical and religious concerns to consider and the other partner who is infected might be deprived from being the genetic father of the child. In addition HIV positive couples still have to deal with the financial implications of these procedures and decisions of whether to disclose their statuses in the process of trying to meet their reproductive needs.

2.5.3 Disclosure as a challenge

Pressures experienced by HIV positive women, it has been shown that the women who had disclosed their HIV status were more likely to be discouraged from bearing children (Farlane, 2009). Most of these women felt that the community would disapprove of them having children and this constitutes moral judgement on a highly personal issue. While on the other hand previous studies investigating fertility desires have shown that, like the general population, People Living with HIV (PLHIV) desire to have children despite the HIV status (Chama, Morupa & Gashau, 2007; Chen *et al.*, 2001; Nobrega *et al.*, 2007; Panozzo, Battegay, Friedl & Vernazza, 2003; Wesley, 2003; Phaweni *et al.*, 2010).

Literature suggests that for women living with HIV infection means living with the fear and the hurtful effects of stigmatization, including social rejection, discrimination, and even violence, in relations with children, partners, relatives, friends and acquaintances, employers and co-workers and health care providers (Sandelowski, Lambe & Barroso, 2004). The above effects of stigmatization can largely affect issues of disclosure among HIV positive women

and possibly contributing the risk taken to conceive despite one's status or conceal their status (Farlane, 2009).

Research has shown that planning for the future in couples with HIV is often complicated by the conflicting need to disclose the infection to extended family and/or friends in order to make appropriate plans and the desire to keep the information secret to protect the partner/family from stigma associated with HIV (van Deventer, Thacher, Bass & Arnold, 1999).

In a qualitative enquiry among 50 HIV positive women in the US indicated that experiences following disclosure included both positive (acceptance, understanding) and negative consequences (rejection, abandonment, verbal abuse, physical assault), reported by 75% and 25% of the sample respectively (Gielen, McDonnell, Burke & O'Campo, 2000). The researchers also showed that although women frequently report serious concerns about disclosing their HIV status, the weight of the evidence suggests that the vast majority of women do eventually disclose their status to partners, family members and friends (Gielen *et al.*).

The literature on the experiences and factors that influence disclosure of HIV seropositive status among women in many developed countries is quite extensive. However, in sub-Saharan African countries including South Africa where the prevalence of HIV remains high, there is scant evidence on the disclosure experiences of women (Iwelumor, Zungu & Airhihenbuwa, 2010).

A qualitative study conducted in two South Africa communities; Gugulethu and Mitchell's Plain in Cape Town explored whether motherhood plays a role in influencing decisions to conceal or reveal knowledge of seropositive status among women living with HIV/Aids (Iwelumor *et al.*). The findings of this study suggested that motherhood was important in shaping decisions regarding disclosure of HIV seropositive status in that there was an inherent belief that mothers would not "chase" their daughters away when they disclose their seropositive status and that they would provide "necessary support" for living with HIV (Iwelumor *et al.*).

On the other hand the findings indicated that the daughter's disclosure of HIV status to her mother sometimes acted to disrupt relationships between the two. It was also found that some mothers engaged in drinking after hearing the news, which was indicative of the responsibility and burden that they felt even when they were not supportive (Iwelumor *et al.*).

The challenges confronting heterosexual HIV infected couples are further emphasised, as other stresses and emotions experienced by couples were often increased by the stigma associated with HIV and the subsequent fear of disclosure (van Deventer *et al.*, 1999). Researchers showed that family stability was threatened by the secrecy surrounding HIV, and social support outside the family was frequently absent because of the reluctance to disclose an HIV diagnosis to friends and family (van Deventer *et al.*). This further leaves HIV positive women with the dilemma of cultural demands placed upon them by their societies.

2.5.4 Cultural factors influencing the desire to have children

Most studies describe the demographic, health-related, stigma-associated and psychosocial factors that influence fertility desires but only a few explore the cultural factors and gendered

dimensions that have an important impact on fertility desires and intentions especially in pronatal societies (Phalweni, Pelzer, Mlambo, Phaswana-Mafuya, 2010). Cultural factors highlight in different societies on decision-making of HIV positive married women on whether to conceive or not. Research indicated that people living with HIV do not make fertility decisions on their own and they feel a lot of stress because they not only have to consider the potential risks to themselves and future children but also meet their families' demands (Nattabi, Li, Thompson, Oranch & Earnest, 2009, Phaweni *et al.* 2010). Pervasive 'pronatalist' attitudes in sub-Saharan Africa place pressure on women to become pregnant, regardless of their HIV status (Mantell *et al.*, 2009).

Cultural factors in the study area also strongly dictate the importance of childbearing, which makes it difficult for couples to remain childless or with fewer children (Heys *et al.*, 2009). Whereby, available evidence indicates a strong influence of socio-cultural factors on HIV infected men and women's fertility decision making (Kanniappan *et al.*, 2008). Giving birth and having children play a significant role for the social and the personal identity of women and men in most if not all cultures. Research conducted in Zimbabwe indicated that "the desire of women to have children is rooted in a context of a need for both love and financial security, especially where women are economically vulnerable." Dr. Rayah Feldman explained that: "Marriage especially if *lobola* or bride-price has been paid by a man's family to a woman's family is based on an expectation of having children" (fhi, 2001, p. 1).

The impact of a women's HIV positive status is even more complicated by the role expectations placed on married women. Research has indicated that in many cultures, children define a woman's social identity and they guarantee her status in her community and in some instances also her very survival through financial support from the child's father

(Karim & Karim, 2010). Therefore their need to bear children can require consultation or involvement of health care providers considering their health status.

2.5.5 Communication with health care providers

The negative impact of HIV/Aids on fertility has been well documented even high rates of desire to have children have been documented (Sharma *et al.*, 2006; Ntozi, 2002; Zaba & Gregson, 1998; Ndlovu, 2009). The documentation of HIV/Aids on fertility has not excluded the views and perceptions held by the communities, cultural and social structures and/or individuals who are professionals within; the medical community, non-professionals, religious, political to an extent of lay persons within the community.

Health care providers; doctors, nurses, social workers, counsellors and others are regarded as part of the community have in their line of work influence childbearing decision-making among HIV positive women. Wilcher and Cates (2009) showed that all women regardless of HIV status have a right to make informed reproductive choices. However, because infected women may be more vulnerable to rights abuses than uninfected individuals, sexual and reproductive health and HIV linkages at policy, programme and service delivery levels are especially important to ensure their sexual and reproductive needs are met. In fact, the sexual and reproductive health needs and desires of women and men living with HIV are not significantly different from those who are not infected (Mantell *et al.*, 2009).

People living with HIV have the same human rights as those not infected with HIV. Yet, the right to parenting among HIV positive men and women remains neglected, especially safer conception, an issue seldom explicitly addressed in sexual and reproductive health policies (Mantell *et al.*, 2009). Current reproductive health guidelines, moreover, are not proactive in

supporting HIV positive people desiring children. These policies, frameworks and consultations are silent on the sexual and reproductive health needs of HIV infected men and HIV negative male partners of infected women, ignoring their rights and interests (Mantell, *et al.*).

This issue has generated much controversy as clinicians and ethicists have grappled with the question of how to respond to HIV positive women and their childbearing decisions. Nurses and other health care professionals regularly involved in the care of HIV positive women are concerned with how best to counsel these women regarding their reproductive decisions (McCreary *et al.*, 2003). Researchers have indicated that many health professionals and ethicists have felt that the consequences to the affected children and to the society as a whole dictate a more directive approach to HIV positive women wanting children (McCreary *et al.*, 2003). Therefore these professionals have intervened with directive counselling, advising HIV positive women to avoid or delay childbearing (Arras, 1990; Levine & Dubler, 1990; Kass & Faden, 1996; McCreary *et al.*, 2003).

While on the other hand other health professionals and ethicists contend that directing women to avoid or delay childbearing is an inappropriate impingement on their autonomy or right to self-determination (Faden *et al.*, 1996; McCreary *et al.*, 2003). It has been that from the evidence of the existing controversies that the Centers for Disease Control and Prevention (CDC) made recommendations for the reproductive counselling of HIV infected women in advising health care providers to be non-directive and supportive of any decisions regarding HIV positive women's reproductive options (McCreary *et al.*).

In a recent study conducted in Kenya on the decisions on motherhood among women on ARTs, a shift on the attitudes of health professionals with regard to counselling HIV positive women of childbearing has been identified. The women acknowledged being treated well and welcomed by the counsellors (Ujiji *et al.*, 2010). They expressed satisfaction with their providing information about childbearing when living with HIV. While on the other hand some women felt that health professionals were restricting them and expecting them to ask for permission to become pregnant (Ujiji *et al.*).

It is clear that there are still existing challenges faced by HIV positive women wanting to bear children and the attitudes of health professional might affect their decisions and impact them emotionally. Research has shown that HIV positive women and men have a right to form families but are sometimes discouraged or barred from doing so (Bell *et al.*, 2007). The desire to have children does not disappear because of one's HIV status; however, women and men do not often have access to appropriate information on their reproductive choices and can be pressured by family, health workers and communities to give up on the idea to having children (Bell *et al.*).

Yet on the other hand literature has suggested as stated earlier on the issue of HIV; as an evolving journey that there are HIV positive women who intended to have children as a result of diminished chances of PMTCT and the good health afforded by HAART and ART (Ndlovu, 2009). Though some HIV positive people are anti-conception; others are pro-conception while others are undecided. Literature has suggested that the decision-making to have children is in addition influenced by many other factors; marriage, social expectations and culture/traditional views on childbearing as there is an increase of HIV positive women deciding to bear children. Okwun and Siraj (2011) reported that despite the high prevalence

of HIV infected couples who are sero-discordant that does not change their family planning practices and fertility desires.

Therefore bias against HIV infected women and men having children may lead them to conceal their HIV status from family and friends as well as from healthcare providers (Mantell *et al.*, 2009). According to Mukasa (2007) childlessness may therefore be a result of, or the cause of exposure to HIV, making investigation into the reproductive desires of women all the more important.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents the research design and methodology applied to explore and describe the emotional experiences of married women faced with HIV positive status and wanting to bear children. The research method, data collection and data analysis are discussed in detail in the current chapter. Methodological issues will also be presented namely; credibility, transferability, dependability and confirmability.

3.2 Aim and objective of the study

The aim of the study was to explore the emotional experiences of HIV positive married women wanting to bear children. This study sought to explore the emotional experiences of these women on factors influencing their reproductive aspirations, intentions and decisions.

The objective of this study was to:

- To explore the emotional experience of being married and HIV positive while wanting to bear children.
- To explore factors affecting reproductive decisions and choices.

3.3 Research design

A good research-undertaking starts with the selection of the topic, problem or area of interest, as well as the research design (Creswell, 1994; Mason, 1996). This view is supported by Creswell (2009) as he defines research designs as plans and the procedures for research that plan the decisions from broad assumptions to detailed methods of data collection and analysis. Creswell (2009) further indicated that the overall decision involves which design should be used to study a topic. Informing this decision should be the worldview assumptions

the researcher brings to the study; procedures of inquiry (strategies); and specific methods of data collection, analysis, and interpretation. According to Creswell, the selection of a research design is also based on the nature of the research problem or issue being addressed, the researchers' personal experiences and the audiences for the study.

A research design can be from a quantitative or qualitative perspective. Qualitative research is a broad term used to describe research that is focused primarily on human experiences through exploring; attitudes, beliefs, values and experiences (Whitehead, 2007). Qualitative research is more in-depth and holistic than quantitative, generating rich material on which to base the findings of a piece of research (Polit & Beck, 2010).

Sandelowski (2000) asserts that qualitative studies are descriptive and present a comprehensive summary of an event in everyday terms of those events. This study will be conducted from a qualitative approach whereby the researcher seeks to understand the participants'; thoughts, feelings and behaviours and understand the issues from the viewpoints of the participants (Struwig & Stead, 2001). The data are therefore not presented in a static, reductionistic, decontextualised manner (Struwig & Stead, 2001). An approach which has been selected under qualitative strategies is phenomenological.

3.3.1 Phenomenological research approach

Phenomenological research is a strategy of inquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by participants (Creswell, 2009). "Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences" (Patton, 2002, p.104). "A phenomenological approach involves the researcher in intensive sampling of a small group and the detailed exploration of

particular life experiences over time” (Grbich, 2007, p.93). His statement speaks directly to the nature of the current study whereby a small sample group of HIV positive married women wanting to bear children is used in order to gain and explore the participants’ unique emotional experiences in making reproductive decisions.

In the process qualitative researchers try to present data with ‘open minds’ but realise that all data are ‘value laden’, therefore acknowledge that the researcher and the study are intimately connected and that the researcher cannot be completely objective (Struwig & Stead, 2001). It is imperative therefore that the role of the researcher will be highlighted in the following section.

3.3.2 Role of the researcher

The definition of “Qualitative research is interpretative research, with the inquirer typically involved in a sustained and intensive experience with participants” (Creswell, 2009, p.117). This introduces a range of strategic, ethical, and personal issues into the qualitative research process (Lock *et al.*, 2007; Creswell, 2009). His statement was supported by Davies (2007) as he reported that the specialist texts on qualitative methods lay great emphasis on the potentially prejudicial influence of the researcher’s self, both on the process of data collection and its analysis.

Researchers in qualitative research should have specific qualities “Good qualitative researchers will acknowledge the power of self, but they will also employ professional skills in order to gain access to the perspectives of those whom they are interviewing” (Davies, 2007, p.156). Hence, the inquirers explicitly identify reflexively; their biases, values and

personal background, such as; gender, history, culture and socioeconomic status that may shape their interpretations formed during a study (Creswell, 2009).

In the light of the above the researcher has to be cautious of what has been stated by the above researchers and must be kept in mind throughout the research process. mentioned that Another author stated that “in your work, you must be aware of yourself, but you must also do everything in your power to put yourself to one side and focus totally on the independent worlds of the people you are interviewing and observing” (Davies, 2007, p.157). Secondly, issues of ethical considerations are addressed in section 3.5.2 and the steps which will be followed for data analysis are stipulated in section 3.6 in an attempt to minimise bias. In the following section attention is paid to the research sample.

3.4. The research sample and sampling method

Polit and Beck (2010) illustrated that a sample is a portion of the population chosen to represent the entire population. The purpose of sampling is to obtain data from a smaller particular sample which in turn increases efficiency by allowing generalisations to be made about the population without having to examine every member (Polit & Beck, 2010). The sampling technique will affect the validity of the research therefore it should be undertaken with maximum rigour (Procter & Allan, 2007).

Struwig and Stead (2001) indicated that there are several alternatives of sampling techniques grouped into probability and non-probability sampling techniques that can be used for the purpose of research sampling. In probability sampling every element has a known probability of being included in the sample and in non-probability sampling, the probability of any particular member of the population being chosen is unknown (Struwig & Stead, 2001).

Therefore the selection of sampling technique depends on the nature of the study that the researcher is using.

In this study non-probability purposive sampling will be used. The researcher chose to use non-probability purposive sampling for the following reasons: Procter and Allan (2007) highlight that in qualitative research non-probability sampling is used to study the population of interest and to ascertain that the research sample is a rich source of data. While purposive sampling is predominantly used in qualitative research as it involves the researcher intentionally selecting who to include in the study on the basis that those selected can present the requisite data (Parahoo, 2006).

According to Parahoo (2006) preparation of a study deciding on the number and characteristics of participants is one of the most fundamental decisions. In qualitative studies, samples are typically small and based on information needs (Polit & Beck 2010). Whitehead and Annells (2007) suggest a common range in qualitative research is usually between eight and fifteen participants but this can vary. The small sample size is suitable because of the potentially detailed data that can be generated from each participant.

In this current study the researcher has purposefully chosen participants who are thought to be relevant to the research topic. Purposive sample of twelve HIV positive married women wanting to bear children will be selected.

The inclusion and exclusion criteria of participants are highlighted by the researcher. According to Haber (2006), the establishment of inclusion and exclusion criteria will increase the precision of the study and strength of evidence.

Inclusion criteria: This refers to specific characteristics or criteria that participants must possess to be included in the study. The characteristics that the participants required to meet included:

- Women who are HIV positive; married and want to bear children.
- The women are either married through customary or civil rites;
- Willingness to volunteer to participate in the study;
- The women ages ranged between 18 to 50 years, from all cultural backgrounds and socio-economic status;
- Fluency in Setswana, Sesotho and/or English.

Exclusion criteria: Participant characteristics or attributes that is not suitable for inclusion (Polit & Beck 2010).

- Women who are not married but want children;
- Women who want to adopt children;
- Women who are diagnosed with mental retardation or any psychiatric condition.

3.5 Data collection

Polit and Beck (2010) highlight the goal of data collection as a way to generate data that is of exceptional quality. Qualitative research relies on methods that permit researchers into the personal lives of the participants. To facilitate this process flexible and varied strategies are required (Parahoo, 2006). These data collection methods include; interviews, observations, focus groups and action research. Interviews are a common method of data collection in qualitative research; the individual questions must be clear to the respondent, free of suggestion and use correct grammar (Whittemore & Grey, 2006).

Face-to-face or one-on-one in person interview is useful when participants cannot be directly observed, participants can provide historical information and it also allows the researcher control over the line of questioning (Creswell, 2009). “On the other hand the limitations of this type of interview is that it provides indirect information filtered through the views of interviewees, provides information in a designated place rather than the natural field setting, researcher’s presence may bias responses and not all people are equally articulated and perceptive” (Creswell, 2009, p.179).

With the above understanding of the pros and cons of this method of data collection, the researcher has for the purpose of this study used one-on-one interviews with participants for approximately one hour long semi-structured interviews. In semi-structured interviews, predetermined questions are posed to each participant in a systematic and consistent manner but the participants are also given the opportunity to discuss issues beyond the questions’ confines (Struwig & Stead, 2001).

In the process of data collection the following interview process will be used by the researcher. The interview will start off with demographic information of participants as part of the semi-structured interview serving as an ice-breaker (Appendix A). The demographic information will be utilised to understanding each participants’ context and not for statistical purposes.

Then an interview guide (Appendix B) designed by the researcher will be used as a second phase. The aim of using an interview guide is to explore similar questions from all the participants for the purpose of this study.

Due to the nature and sensitivity of this study, data will be collected by the researcher who has been trained in client/person centred interviews and has served a one year practical experience in sharpening this skill. In addition to this the researcher has been trained in structure and un-structured interviews as part of the Masters programme.

The interviews will be conducted in one of the local languages (Setswana and Sesotho) and/or English as the researcher is proficient in these languages. The interviews will be recorded for later transcription and analysis.

To maintain confidentiality the interviews will be conducted in a private and quiet room away from distractions. Secondly, the collected data will be stored in a safe and secure place by the researcher until all the requirements for the current research and academic purposes are met, following which some of the tapes and transcripts will be archived for future follow up from the recommendations.

3.5.1 Research Setting

The study will be conducted at Tshepang clinic; Dr George Mukhari Hospital (DGMH), in Ga-Rankuwa Township (Gauteng Province). Dr. George Mukhari Hospital is a tertiary institution that has a clinic that focuses mainly on counselling and treatment for HIV/Aids infected individuals and a reproductive clinic for women with different needs and circumstances and it is for this reason that it has been chosen to conduct the research.

This clinic caters for women and men from; different townships, age group, and cultural, religious and educational level around Gauteng who come to collect their HIV treatment. The clinic has a follow up consultations on; Monday, Wednesday and Thursday for the collection

of medication. It is on the above specified days that the interviews will all be conducted within the hospital during official hours. A period of a week is perceived to be sufficient to collect data and four participants will be interviewed in a doctor's consultation room per day.

3.5.2. Ethical considerations

In the current study, approval to conduct the research was obtained from the SREC (School Research and Ethics Committee) and MREC (Medunsa Campus Research and Ethics Committee). Permission was requested from the Director of the Clinical Services at Dr George Mukhari Hospital as well as from the Sister-in-charge of the Tshepang clinic.

An informed consent will be obtained from the participants. The purpose and the objectives of the study will be explained to them. Patton (2002) mentioned that the interviewer often provides information about the research in advance of the interview and then again at the beginning of the interview. Statements of purpose should be simple, straightforward and understandable (Patton, 2002). Confidentiality will be guaranteed and maintained for the participant by keeping all the participants anonymous and pseudonyms will be used in the final report when discussing the findings. It will be explained that participation is voluntary and participants can withdraw at any time and that they will not be prejudiced with regard to their management and treatment.

3.6 Data analysis

Data analysis involves examining, sorting, categorising, evaluating, comparing, synthesizing and contemplating the coded data as well as reviewing the raw and recorded data (Neuman, 2000). It is also a method that enables the researcher to organise and bring meaning to large amounts of data (Struwig & Stead, 2001).

In this study data from the recordings will be transcribed verbatim. The interview transcripts will be typed verbatim and not rephrased to be grammatically correct. Struwig & Stead, (2001) stated that if raw data are summarised, they no longer become the original data and this becomes methodologically problematic. There are steps which will be followed in the analysis of data and are stipulated below.

3.6.1 Steps in analysis

Three research experts will follow five stages of data analysis in the framework analysis approach outlined by Pope, Ziebland and Mays (2000). The steps outlined are as follows:

i. **Familiarisation**

It is an immersion in the raw data (or typically a pragmatic selection from the data) by listening to tapes, reading transcripts, studying notes in order to list key ideas and recurrent themes.

ii. **Identifying a thematic framework**

This step involves identifying all the key issues, concepts, and themes by which the data can be examined and referenced. This was carried out by drawing in a priori issues and questions derived from the aims and objectives of the study as well as issues raised by the respondents themselves and views or experiences that recur in the data.

iii. **Indexing**

It involves applying the thematic framework or index systematically to all the data in textual form by annotating the transcripts with numerical codes from the index, usually supported by short text descriptions to elaborate the index heading.

iv. **Charting**

It is a step where data is rearranged according to the appropriate part of the thematic framework to which they relate, and forming charts. This assisted to develop topics into categories.

v. **Mapping and Interpretation**

In this step the charts will be used to define concepts, map the range and nature of phenomena, create typologies and find associations between themes with a view to providing explanations for the findings.

3.7 Bias

Any research strategy ultimately needs credibility to be used. “No credible research strategy advocates biased distortion of data to serve the researcher’s vested interests and prejudice” (Patton, 2002, p.51). Patton further opined that any credible research strategy requires that the investigator adopt a stance of neutrality with regard to the phenomenon under study. According to Creswell (2009) this self-reflection creates an open and honest narrative that will resonate well with readers. Good qualitative research contains comments by the researchers about how their interpretation of the findings according to Creswell is shaped by their background, such as their gender, culture, history and socioeconomic origin.

The nature of qualitative research implicates the researcher and participant’s involvement in the research process, with the researcher trying to understand and interpret the participant’s perspective (Struwig & Stead, 2001). This then does not exclude the researcher’s frame of reference and subjectivity becoming confounding factors. It is assumed that the researcher’s values and biases are an integral part of the research process and cannot be ignored (Struwig & Stead, 2001).

The researcher will try to control her bias by engaging three research experts who will be involved in analysing the recorded interviews for objectivity through following the steps outlined in framework analysis approach as a method of choice. In addition issues of ensuring trustworthiness and quality are highlighted below.

3.8 Ensuring trustworthiness and quality

Quantitative conventional terms, reliability and validity are conceptualised as trustworthiness and quality in qualitative paradigm (Golafshani, 2003). According to Holloway and Wheeler (2002) trustworthiness in qualitative research means methodological soundness and adequacy. The aim of trustworthiness is to support the argument that the research's findings are worth paying attention to (Lincoln & Guba, 1985). Shenton (2004) indicated that Guba proposed four criteria that he believes should be considered by qualitative researchers in pursuit of a trustworthy study, namely; credibility, transferability, dependability, and confirmability.

Credibility

According to Lincoln and Guba (1985) credibility is an evaluation of whether or not the research's findings represent a "credible" conceptual interpretation of the data drawn from the participants' original data. How congruent are findings with reality (Shenton, 2004) is a critical credibility question. Holloway and Wheeler (2002) reported that the research's findings should at least be compatible with the perceptions of the people under study. Shenton (2004, p.66-69) mentioned several possible ways to ensure credibility; the researcher can ensure credibility by:

- *"Tactics to help ensure honesty in participants when contributing data"*. In this way participants are given an opportunity to refuse to participate in the project so to ensure

that the data collection sessions involve only those who are genuinely willing to participate and prepared to offer data freely. The right to refusal under ethical considerations was detailed as to how it will be achieved in this research project.

- *“Background, qualifications and experience of the researcher”*. The credibility of the researcher is especially important in qualitative research as it is the person who is the major instrument of data collection and data analysis (Patton, 1987; Shenton, 2004). In this study, the researcher will collect data making use of her interviewing skills experience. The researcher is a student in Masters of Science in clinical psychology and has been trained in conducting interviews. She has a working practical experience as a clinical psychologist (internship) at Dr George Mukhari Hospital conducting psychotherapy where interviewing skills are utilised. Data will be analysed by a qualified clinical psychologist working at Dr George Mukhari hospital, this psychologist has experience in qualitative research.
- *“Examination of previous research findings”* to assess the degree to which the project results are congruent with those of past studies. The ability of the researcher to relate his/her findings to an existing body of knowledge are a key criterion for evaluating works of a qualitative inquiry (Silverman, 1985; Shenton, 2004). Chapter five (5) will present an integration of the research findings of this study with available literature on the emotional experiences of HIV positive married women wanting to bear children.

Transferability

Transferability is the degree to which the findings of the inquiry can be applied or transferred beyond the boundaries of the present project (Lincoln & Guba, 1985). According to Holloway and Wheeler (2002) findings from the study should be able to be transferred to similar situations or participants. The findings of this study should be relevant to other studies and researchers conducting research in a similar context will be able to apply certain concepts originally developed. Shenton (2004) reported that since findings of a qualitative enquiry are specific to a small number of a particular environment and individuals, it is impossible to demonstrate that the findings and conclusions are applicable to other situations and populations. Shenton (2004) argued that although each case may be unique, it is also an example within a broader group and, as a result, the prospect of transferability should not be immediately rejected. As a result of such arguments, suggest that it is the responsibility of the researcher to ensure that sufficient contextual information about the fieldwork site is provided to enable the reader to make such a transfer (Lincoln & Guba, 1985; Firestone & Shenton, 2004). Shenton (2004) emphasised that it should be questioned whether the notion of producing truly transferable results from a single study is a realistic aim or whether it disregards the importance of the context which forms such key factors in qualitative research.

Dependability

Dependability is an assessment of the quality of the integrated processes of data collection, data analysis, and theory generation (Lincoln & Guba, 1985). If the findings of a study are to be dependable, they should be consistent and accurate (Holloway & Wheeler, 2002). Shenton (2004) showed that in order to address the dependability issue more directly, the process within the study should be reported in detail, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results. Thus, the research design may be viewed

as a “prototype model”. In order to enable the reader of the research report to develop a thorough understanding of the methods and their effectiveness, the text should include the following:

- The research design and its implementation, describing what was planned and executed
- The operational detail of data gathering, addressing the minutiae of what was done in the field
- Reflective appraisal of the project, evaluating the effectiveness of the process of inquiry undertaken

To achieve dependability of this study it is divided into three sections namely; research methodology, discussing the methodology of the study and its approach and the reason for selecting the methodology; research design, discussing how the research study is to be implemented including the sampling process, method of data collection and data analysis; and research methods, discussing how the research was implemented and executed.

- **Ensuring trustworthiness and quality**

Ensuring trustworthiness and quality is a measure of how well the inquiry’s findings are supported by the data collected (Lincoln & Guba, 1985). Shenton (2004) reported that steps must be taken to help ensure as far as possible that the work’s findings are the result of the experiences and ideas of participants, rather than the characteristics and preferences of the researcher. The reader of the study findings should be able to follow the path the researcher has taken and the manner of arriving to the constructs, themes and interpretation (Holloway & Wheeler, 2002). Confirmability in this study will be achieved by authentically detailing the research process including steps followed in data analysis. Data will be analysed as detailed

in chapter four will present findings of the study systematically allowing the reader to follow as to how data was analysed. Furthermore, a detailed methodological description in this chapter enables the reader to determine how far the data and constructs emerging from it may be accepted (Shenton, 2004).

In order to ensure the quality of the study and reduce researcher bias, an independent psychologist will analyse data. This process might detect bias and inappropriate subjectivity.

Confirmability

The researcher ensured confirmability in this study as detailed in this section. To ensure more credibility of the study, the researcher did what is referred to as “peer scrutiny of the research project” (Shenton, 2004, p.67). In this regard, opportunities for scrutiny of the project by colleagues, peers and academics are welcomed and feedback offered to the researcher during the duration of the project is also welcomed. The fresh perspective that such individuals may be able to bring, may allow them to challenge assumptions made by the researcher, whose closeness to the project frequently inhibits her ability to view it with real detachment. After data was analysed by an independent clinical psychologist, the researcher presented the findings to another researcher who has experience in qualitative research. This researcher provided feedback regarding data collection, research findings and actual presentation of the findings. Chapter 4 has been updated taking into account these researcher comments and suggestions.

After completing writing the whole document, the researcher presented this document to another clinical psychologist student who is in the process of completing her research from a qualitative perspective. In addition, this researcher provided feedback regarding the emerging

themes and the logic of data presentation. Feedback provided was integrated in writing up this research project.

3.9 Research process

In carrying out what has been mentioned in this chapter of research methodology. The research process involved first the attainment of research approval from the SREC and MREC as indicated in a section of ethical considerations. In addition permission to conduct research was also attained from the Director of the Clinic Service at George Mukhari Hospital as well as the sister-in-charge of Tshepang clinic.

Following the above process the researcher was introduced to the clinic staff and the patients who were at the clinic on the days stipulated in the section of research setting. The introduction to the patient was done every morning as different patients came every day. A private doctors' consultation room was used to collect data. Though there were challenges where some staff members will disrupt the interview process by knocking or entering the interview room ignoring the do not disturb sign indicated outside.

An informed consent form was provided to all the participants who volunteered to participate in this study. Another requirement with regard to informed consent is that "the researcher must develop an informed consent form for participants to sign before they engage in the research" (Creswell, 2009, p.89). This form acknowledges that participants' rights will be protected during data collection (Creswell,). As part of the process of signing an informed consent form a guarantee of confidentiality was mentioned to the participants. Secondly, it was explained that they can withdraw at any time should they wish to do so in the process of data collection.

In terms of data collection indicated in section 3.5 the process was followed as outlined through the process of an interview guide. Patton (2002, p. 343) stated that “an interview guide lists the questions or issues that are to be explored in the course of an interview”. An interview guide is prepared to ensure that the same basic lines of inquiry are pursued with each person interviewed. In addition allowing for the process of data analysis mentioned in section 3.6 where the steps of analysis outlined through the use of framework analysis approach were followed for the presentation of the results.

3.10 Conclusion

In conclusion this chapter has provided an overview of the research design and methods. In addition the collection and analysis of data, ethical considerations and the reliability and validity of the study have been indicated. It is thereby in the next chapter a presentation of the results will be given.

CHAPTER 4

PRESENTATION OF RESULTS

4.1 Introduction

This chapter will focus on the presentation of the results from the conducted interviews. As indicated in chapter three the study is qualitative in nature using a phenomenological approach. In which the emotional experiences of HIV-positive married women wanting to bear children were explored. The analysis of data for the results was guided by, Pope, Ziebland and Mays' framework analysis approach (in chapter three).

The chapter will be presented as follows: A summary of demographic information's for all participants will be given (refer to Appendix A). Secondly, for the presentation of the results a table is being provided below indicating the four categories and their themes from the interview guide. Sub-themes and allocated alphabetical codes to sub-themes from the interviews are provided. The table will be followed by a summary of the results indicating number of participants who have given responses under the specified subthemes. All quotes from the interview are put in "italics".

4.2 Demographic information

The participants' age ranged from 19 to 42 years. Those who met the inclusion criteria and were willing to participate in the research were selected. All the participants were black females from different ethnic groups including one Zimbabwean woman. In this study, five participants were Setswana speaking, four were Sepedi speaking, two were Zulu and one participant was Shona speaking. The language preference in this study was; two participants

were interviewed in English and for the rest of the participants it was a combination of English and Setswana was used as a means of communication.

Regarding the type of marriage; ten participants were married according to customary law (lobola) two participants were in a civil marriage. Six of the participants; were unemployed, five employed and one was a student at the time of the interview. Most of these women relied on their husbands as a major source of financial support.

In the next section the coding process from these interviews is provided.

4.3 Coding of themes and subthemes

The table presented below will reflect the process of how the information from the interviews was coded.

Table 4.3.1 Categories, themes, sub-themes and alphabetical codes.

<u>CATEGORY I: JOURNEY OF</u>	
<u>DIAGNOSIS</u>	
THEMES	SUB-THEMES & CODING
1. Time of diagnosis	Diagnosis made while sick (DS)
	Diagnosis made while pregnant (DP)

<p>2. Husband's status</p>	<p>Husband positive (HP)</p> <p>Husband negative (HN)</p> <p>Status unknown (SU)</p>
<p>3. Impact on marriage</p>	<p>Impact positively (IP)</p> <p>Impact negatively (IN)</p> <p>Nothing changed (NI)</p>
<p><u>CATEGORY II: PERSONAL</u></p>	
<p><u>ASPIRATION & INTENTIONS ABOUT</u></p>	
<p><u>MOTHERHOOD</u></p>	
<p>THEMES</p>	<p>SUBTHEMES & CODING</p>
<p>1. Significance of motherhood</p>	<p>Motherhood as a means to nurture (MN)</p>

<p><u>CATEGORY III: IMPACT OF</u> <u>REPRODUCTIVE INTENTIONS AND</u> <u>DISCLOSURE</u> THEMES</p>	<p>Marriage as an influence (MI)</p> <p>Getting older (GO)</p> <p>In-laws want a child (IL)</p> <p>Child as an expansion to family (CE)</p> <p>No grandchildren & having girls only (SGG)</p> <p>Leaving a remembrance (LR)</p> <p>Pressure from family (PF)</p> <p>Need biological child (BC)</p> <p>Improve relationship (IR)</p> <p>SUBTHEMES & CODING</p>
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<p>1. Disclosure of status to family and in-laws</p>	<p>Disclosed to family (FK)</p> <p>Not disclosed to in-laws (ND)</p> <p>Disclosed to both family & in-laws (DI)</p> <p>Not disclosed to both family & in-laws (FI)</p> <p>Disclosed to closest family members (DC)</p>
<p>2. Spouse & families' feelings to the need for children</p>	<p>Family supportive (FS)</p> <p>Partner supportive (PS)</p>
<p>3. Health care providers' reaction to reproductive intentions</p>	<p>Not communicated (NC)</p> <p>Communicated intentions (CI)</p> <p>Fear of judgment (J)</p>

CATEGORY IV: JOURNEY OF

REPRODUCTIVE INTENTIONS

THEMES

1. Procedures undergone to try to conceive

2. Emotional journey

SUBTHEMES & CODING

Tried to conceive or still trying (**TT**)

Still Planning (**SP**)

Possible pregnancy (**PP**)

Partner refusing to test (**PRT**)

Partner refusing treatment (**PRM**)

Partner refusing condom use (**PRC**)

Participant needs information (**PNI**)

Avoidance (**AV**)

Coping difficulties (**CD**)

	Issues of denial (ID)
	Fear of loss (FL)
	Risk taking (RT)
	Self-educating on HIV (SE)
	Leaving the child through death (LC)
	Rape, violence (RV)
	Acceptance over time (A)
	Blame (B)
	Infidelity (I)
	Irritation (IR)
	Rejection (RJ)
	Stigma (S)
	Transmission to child (TC)

In the following section, a summary of the results reflecting the above table is provided below:

4.4 Summary of the results

CATEGORY I: JOURNEY OF DIAGNOSIS

Theme 1: Time of diagnosis

Sub-theme: Diagnosis made while sick

Eight of the participants [P2, P3, P4, P5, P6, P9, P11, and P12] reported that they were diagnosed with HIV while they were sick. One of the participants stated that: *“I was admitted when I was sick [DS] I tested and was told at the hospital that I’m HIV-positive”*. [P6]

Subtheme: Diagnosis made while pregnant

While four [P1, P7, P8 and P10] were diagnosed during pregnancy. One of these participants articulated that: *“Oww!!, I found out in 2007 I was pregnant [DP]. So I went to a clinic in Rosslyn, at that clinic they told us that every mother is forced to be tested. So I did agree, I tested I found out that I’m HIV-positive”*. [P7]

Theme 2: Husbands’ status

Sub-theme: Husband positive

Six participants [P1, P2, P4, P6, P10, and P11] stated that their husbands are HIV positive. This was with reference to one participant who mentioned that: *“he is also positive” [HP]*. [P2]

Sub-theme: Husband negative

Three participants [P3, P8, and P12] reported that their husbands are HIV negative. As one participant articulated that: *“He’s been checking but he has nothing”* [HN]. [P12]

Sub-theme: Status Unknown

Three of the participants [P5, P7, and P9] indicated that they do not know their husbands’ HIV status. With one participant stating that: *“My partner refuses to test but he is positive”* [SU] [P5].

Theme 3: Impact on marriage

Sub-theme: Impact positively

Three of the participants [P2, P3, and P5] reported that their HIV status has brought them close to their husbands as they support each other. One participant stated that: *“It made us to be close to each other”* [IP] [P2]

Sub-theme: Impact negatively

For five of the participants [P1, P4, P6, P7, and P9] their HIV status has impacted on their marriage significantly that there are issues of blame and denial. This became evident when one participant stated that: *“he had this thing of saying I’m the one who made him sick [B] and we fought now and then”* [IN]. [P1]

Sub-theme: Nothing Changed

Four participants [P8, P10, P11, and P12] stated that nothing has changed since their HIV diagnosis. One participant mentioned that: *“He was ok, he did not get worried [NI]. He is handling me well”*. [P12]

CATEGORY II: PERSONAL ASPIRATION AND INTENTIONS ABOUT MOTHERHOOD

Theme 1: Significance of motherhood

Sub-theme: Motherhood as a means to nurture

Three of the participants [P5, P8, and P11] revealed that motherhood signified an opportunity to nurture. This became evident when one participant stated that: *“It means a lot of things you become responsible like from being pregnant, you become responsible for the life growing inside of you, you nurture, you take care, have you see all those things to guide and do those things, to love unconditionally [MN, C]. [P8]*

Sub-theme: Impact of not being able to mother

Four of the participants [P3, P4, P6, and P9] expressed the impact of not being able to mother a child when asked about the significance of motherhood. One participant asserted that: *“It’s a big thing to me”. “When I see other girls having children and not having them is a big pain to me” [IM]. [P3]*

Theme 2: Feelings about being a mother

Under this theme a couple of feelings about being a mother were expressed by most participants. The following subthemes were identified:

Sub-theme: Belong

Two participants [P5 and P7] revealed that being a mother made them feel like they belong and they are like other women. *“Have seen how stressful it is sitting with people while they talk about their kids saying hey my child this and that while you don’t talk anything cause you do not have a child” [IM, BL]. [P5]*

Sub-theme: Content and care

One participant [P8] mentioned that being a mother will allow her to be able to care for the child. *“I can be able to take care of that child”*[C]. [P8]

Sub-theme: Happy

Two participants [P1 and P10] reported that they would feel happy to be mothers. One participant asserted that: *“I will be right. If it was possible I was going to pray to God that tomorrow I be pregnant I was going to be so happy with all my heart”* [H]. [P1]

Subtheme: Able to love

Five of the participants [P4, P5, P7, P8 and P12] stated that being a mother provided an opportunity to love. One participant mentioned that: *“I would like to have one so at least I know I have child who is mine so that I can be able to take care of that child and give her love”* [MN,L]. [P5]

Sub-theme: Being responsible

Four participants [P4, P6, P8, and P11] reported that being a mother elicits feelings of being responsible. This was evident from one participant who stated that: *“Eish! its life changing (pause, then eish!)”. It means a lot of things you become responsible like from being pregnant, you become responsible for the life growing inside of you, you nurture, you take care, have you see all those things to guide and do those things, to love unconditionally* [MN, C, R]. [P8]

Theme 3: Influences to childbearing

All the participants expressed different reasons and influences to childbearing decision which included the following subthemes:

Sub-theme: Partner wants a child

Five participants [P1, P6, P7, P9 and P10] reported that their partners want a child. With one participant expressing that: *“Yes, he has verbalised his need for a child” [PW]. [P10]*

Sub-theme: Partner childless

Two participants [P3 and P9] mentioned that their partners do not have biological children within or outside the marriage. *“He wants to spend the rest of his and my life being together so he does not have a child of his own in the world” [PC]. [P3]*

Sub-theme: Partner’s support

Three of the participants [P3, P4 and P7] reported that their partners’ support is influencing their need to bear them a child. This was evident from one of the participants who mentioned that: *“His handling my child well and handling me well and does not treat us harshly, he treats us well together when we need something he does it [PS]. Like now he works he is self-employed with this white man and sharing a firm together. He took his child and works with him and he is not his flesh and blood. [P4]*

Sub-theme: Build a future

Two of the participants [P2 and P7] expressed that bearing a child of their own allows them to build a future for themselves. One of the participants stated that: *“It is important because we both want to have a child for future [BF]. [P2]*

Subtheme: Duration of relationship

Only one participant [P4] stated that the duration of the relationship is an influence to her need to bear a child. As she asserted: *“My heart becomes painful because he is taking care of me and I’ve been staying with him for long [DR]. He started staying with me while my child did not have a year until now. Even now he is taking care of me and I wish that one day God can help us so that I can be able to bear him a child of his own”. [P4]*

Sub-theme: Marriage as an influence

Three of the participants [P4, P6 and P11] stated that the fact that they are married influences the decision to try and conceive a child. This was evident as one participant explained that: *“I don’t know maybe because when you get married that is one of the things unless a couple decide that they do not want a kid. But that you enter knowing that it has to be like that at some point”* [MI]. [P6]

Sub-theme: Getting older

Three participants [P1, P5 and P7] declared that they were not getting any younger and as years are moving they felt it is time for them to bear children. One of these participants articulated that: *“I can see that I’m taking care of myself and I see that years are moving”* [GO]. *So I don’t see what is stopping me from having a child”*. [P7]

Sub-theme: In-laws wants a child

Two participants [P1 and P2] reported that their in-laws wanted a child. This was evident as one participant expressed that: *“From his home they ask us when I we going to have a child? They confront my husband”* [IL]. [P2]

Sub-theme: Child as an expansion to family

Three participants [P8, P10 and P12] mentioned that they need more children so that they can expand the family. One of the participants stated that: *“Well it’s not fair that I have one (laughs). I would like to add myself [CE], laughs. Like I have always wanted to have two kids a boy and a girl so now I have a boy at least a girl.* [P8]

Sub-theme: No grandchildren and having girls only

Only one of the participants expressed that she wants a child because she is the only girl at home. With reference to one participant as she mentioned that: *“Reason why, to my mother we are three and I’m the only girl”* [SGG]. [P1]

Sub-theme: Leave a remembrance

One participant expressed that she would like to have something to be remembered by when she dies and having a child would serve that purpose. As she asserted: *“I had a first child but she died and now I need the second one so when I die my mother will be left with something”* [LR]. [P1]

Sub-theme: Pressure from family

One participant mentioned that she is being pressured by her family with regard to reproductive intentions. She expressed that: *“Ok, my mom was asking when I’m I going to consider pregnancy?”* [PF]. [P6]

Sub-theme: Biological child

One of the participants revealed that the fact that she does not have a child with her husband is influencing her childbearing intentions. She asserted that: *“I thought probably it’s that thing of people always thought a child within a marriage [MI] (pause) or maybe it’s a fact that one is not his biological child [BC] or I don’t know”*. [P6]

Sub-theme: Improve relationship

Another one mentioned that she hopes by having a child her marriage will be better. She stated that: *“I think that our relationship will be better [IR], He will handle me better maybe if I give him a child”*. [P9]

CATEGORY III: IMPACT ON REPRODUCTIVE INTENTIONS AND DISCLOSURE

Theme 1: Disclosure of status to family and in-laws

Under this theme some participants reported that they have disclosed to their families and in-laws. On the other hand others have only disclosed to their families but not to their in-laws.

Sub-theme: Disclosed to family

Five participants [P4, P5, P6, P8 and P12] reported that they have disclosed their status to their families only. With one participant stating that: *“They do not know, pause. I don’t want them to know my in-laws” [ND]. “My family it’s ok they are supportive” [FK]. [P5]*

Sub-theme: Not disclosed to in-laws

Six of the participants [P1, P4, P5, P7, P8 and P12] stated that they have disclosed to their families but not their in-laws. This was evident as one participant asserted that: *“At home they know but my husband’s family do not know”. “She is saying if only he can give me a grandchild and he cannot disclose to her that is our secret [ND]. [P4]*

Sub-theme: Disclosed to both family and in-laws

Two participants [P2 and P3] mentioned that they disclosed to their families and in-laws. This was evident from one participant who asserted that: *“They know from his family [FK, DI] and even at home and they support me and ask me about my appointments to the hospital”. [P2]*

Sub-theme: Not disclosed to both family and in-laws

Two of the participants [P9 and P11] reported that they have not disclosed to both their families and their in-laws. One participant stated that: *“No, only the two of us know” [ND, FD]. “We decide to keep between us because we drink treatment at eight together. [P11]*

Sub-theme: Disclosed to closest family members

Only one participant reported that she only disclosed to the closest family members from both her family and in-laws. She asserted that: *“Yes, I just tell my sister-in-law and my sister those are the only two people who know that I’m HIV-positive because my husband does not want people to know our secret so I just my sister and his sister who are closest to us [DC]. [P10]*

Theme 2: Spouse and families' feelings to the need for children

In terms of this theme only participants who have disclosed their HIV status to partners and families expressed their support concerning reproductive intentions.

Sub-theme: Family support

Six participants [P2, P3, P5, P6, P8 and P12] have expressed the families' support to their reproductive intentions. One participant mentioned that: *"They are feeling ok they are sharp [FS]. Every time they ask me how come I do not have a child even my mother asks me why I don't have a child while she is alive. [P3]*

Sub-theme: Partner's support

Seven of the participants [P1, P3, P4, P5, P6, P7 and P10] expressed their partners' support concerning their reproductive intentions. This was evident as one participant asserted that: *"He wants the child, too much" [PS]. "He was telling me this Monday while we were having sex saying let's make a child and I said no you cannot say you want a child while you're on top of me and expect that thing to happen immediately".[P7]*

Theme 3: Health care providers' reaction to reproductive intentions

Some of the participants reported that they have not communicated to health care providers while others have tried to communicate their intentions.

Sub-theme: Not communicated

Nine participants [P2, P3, P5, P6, P8, P9, P10, P11 and P12] mentioned that they have not communicated their reproductive intentions with health care providers. This was evident from one participant who stated that: *"I tried to go to a counsellor but she told me she is busy" [NC]. [P3]. Another participant mentioned that: "No, I was afraid maybe I'm still too sick and it won't be possible [J]. [P9]*

Sub-theme: Communicated Intentions

Three of the participants [P1, P4 and P7] reported that they have communicated their intentions with health care providers. One participant stated that: *“I spoke to a nurse [CI], like I was telling you I spoke to a nurse from Mmakau where I tested that’s where I explained and she said it’s not possible” [LI]. She said it’s not possible cause my virus load was low and my CD4 count is low. So it’s not possible that you might have a child. “She did not explain. “She left like that and that’s when she was finished”. [P4]*

Other reactions and emotions identified by participants:

Sub-theme: Fear of judgement

Four of the participants [P2, P5, P6, and P9] reported that they feared to be judged by the health care providers. This was evident from one participant who asserted that: *“I have heard a sister saying that people are getting pregnant but they are sick. I withdraw” [J]. [P2]*

Sub-theme: Feeling ashamed

One participant explained that she felt ashamed to communicate her reproductive intentions with health care providers. She expressed that: *“I have not asked them cause they will say she is sick but wants a child [FA]. I feel ashamed. [P9]*

Sub-theme: Advice against pregnancy

Two participants [P5 and P12] mentioned that they were advised against pregnancy by health care providers. One participant said: *“So the other one told me another thing they make me loose hope, I no longer have hopes because they told me I cannot have a child while my partner is negative and I’m positive” [AP]. [P5]*

Sub-theme: Limited information

Four of the participants [P4, P6, P7 and P12] reported that they were given limited information concerning their reproductive needs. This was evident from one participant who stated that: *“I spoke to a nurse [CI, LI], like I was telling you I spoke to a nurse from*

Mmakau where I tested that's where I explained and she said it's not possible". She said it's not possible cause my virus load was low and my CD4 count is low. So it's not possible that you might have a child. "She did not explain. She left like that and that's when she was finished". [P4]

CATEGORY IV: JOURNEY OF REPRODUCTIVE INTENTIONS

Most of the participants expressed different emotions when asked about their reproductive journey and intentions.

Theme 1: Processes undergone to try to conceive

Under this theme some participants reported that they are currently trying to conceive or have tried while HIV positive, others reported a possibility of being pregnancy at the time of the interview. There were some who are not yet intending to fall pregnant but wish to as they still require more information and direction.

Sub-theme: Tried to conceive or still trying

Two of the participants [P4 and P5] reported that they have tried to conceive recently. This was evident as one participant stated that: *"Eish! it's been difficult but now I feel that if she comes, she comes cause I genuinely need her" [TT]. "I am currently trying to fall pregnant. [P4]*

Sub-theme: Still planning

Eight of the participants [P2, P3, P6, P7, P8, P9, P11 and P12] reported that they have not yet tried to conceive. One participant stated that: *"No, I have not tried anything" [SP]. [P12]*

Sub-theme: Possible pregnancy

Two of the participants [P1 and P10] mentioned that they currently thinking that they are pregnant. This was evident from one participant who stated that: *“I think I’m pregnant but I’m not sure and will ask doctor”* [PP]. [P1]

Theme 2: The journey of reproductive intentions

Under this theme the following emotions were reported by participants:

Sub-theme: Partner refusing to test

One participant stated that her partner refuses to test for HIV. She mentioned that: *“The thing is men are cheeky if you tell him lets go to the clinic he refuses, when you say go and test he refuses”* [PRT]. [P4]

Sub-theme: Partner refusing treatment

One participant reported that her partner refuses to take treatment, *“he said we will live the way we are [A] but he does not want to take treatment only I take it* [PRM]. [P1]

Sub-theme: Partner refusing condom

One participant stated that her partner refuses to use condoms. This was evident as she asserted that: *sometimes he has this thing of refusing to use a condom* [PRC]. [P1]

Sub-theme: Participant need information

Five of the participants [P1, P2, P4, P5, P7 and P8] reported that they require more information to assist them with their reproductive needs and intentions. One participant mentioned that: *“When they say so but when its painful like me wanting a child they must explain to me that you can get a child but what is required is so and so”* [PNI]. [P4]

Sub-theme: Avoidance

Two participants [P6 and P9] stated that they try and avoid talking about their HIV status. For one participant is a way to cope and not be remained of the emotional strain over

reproductive needs. She mentioned that: *“I hate it that is why I say I prefer not talk about it as often as I want” [AV]. [P6]*. For another participant is a way of maintaining peace within the relationship as the husband is in denial. She asserted that: *“It has not affected it because he does not agree to anything so I decided that for as long as he does not agree let me leave him” [AV]. [P9]*

Sub-theme: Coping difficulties

Two participants [P4 and P6] reported difficulties of dealing with their HIV status and the expectations placed upon them as women. One participant stated: *“I hate it. Ok, some days are different like I will have this positive attitude knowing that this thing is just a visitor and I’m just a hosted”. Sometimes I would say God please I know sometimes it’s hard and would just cry and cry and you would hear your friends at work talking about sex and you think yours it’s a job a condom issue a blar issue, eish! and eii!. “For me it’s a constant torture [CD] so I haven’t gotten to a point where it’s fine so I chose to ignore what is happening, you see. It’s suppressed somewhere every time I think about it I just drive myself into this little corner which is not good for me. [P6]*

Sub-theme: Issues of denial

One participant mentioned that her partner is in denial about her status. This was evident as she asserted that: *“I told him when I came back from the clinic but he did not believe” [ID]. “Then I thought let me leave him”. [P9]*

Sub-theme: Fear of loss

Three participants [P1, P3, P7 and P11] reported that they have had an experience of losing a child as part of their reproductive journey but wish to try again. One participant stated that: *“I used to come for treatment every month but I lost the child [FL]. The child died inside of me. That was in 2007 and in 2006 still I was pregnant I got the child well but she came through her legs. [P7]*

Sub-theme: Risk taking

One participant mentioned that she is willing to take the risk in order to meet her reproductive needs. She asserted that: *“Hhhyyy!! I’m no longer in her issues because she only told me it’s not possible [LI] and at the support group I listen isn’t and many women are pregnant while they are positive others even have given birth and they are fine taking pills and coming for treatment” [RT]. [P4]*

Sub-theme: Self-educating on HIV

One participant was willing to educate herself. She explained that: *The myths which are there is not like they are facts but I took it upon myself to find out the facts of this thing [SE]. You see with that of when your both HIV-positive you do not need to use a condom what the point but when you engage yourself more and not being ignorant helps cause when you become ignorant you kill yourself. The more you know the better. [P6]*

Sub-theme: Leaving the child through due to death

One participant expressed her concern about dying and leaving a child behind. This was evident as she stated that: *“No we were talking about it but we did not finalise anything cause when we die who will take care of the child” [LC]. [P11]*

Sub-theme: Rape and violence

One participant mentioned having to go through another emotional trauma of expressing violence and rape while HIV positive and attempting to conceive. She stated that: *“In fact (pause) when we are staying there’s someone when my husband was out there’s robbers who came and took my things and after that they raped me” [RV]. “Then at that time I was afraid to go to the police because those people said if you go to the police we are watching you”. “Then after that I started to lose weight and lose appetite until the clinic referred me here”. [P10]*

Sub-theme: Acceptance over time

Three of the participants [P1, P7 and P9] reported that their partners and families had to learn to accept their HIV status. This was evident as one participant stated that: *“it came a time when he changed I do not know what made him change and he stopped talking the things he used to me and he said we will live the way we are [A]. [P1]*

Sub-theme: Blame

One of the participants mentioned that she had to deal with the blame placed on her by her partner. She stated that: *“he had this thing of saying I’m the one who made him sick [B]. [P1]*

Sub-theme: Infidelity

For one participant issues of infidelity emerged as a result of her HIV disclosure. This became evident as she asserted that: *“He went to another woman and stayed with another woman then he came back to me” [I]. [P4]*

Sub-theme: Irritation

One participant expressed her irritation towards having to hear people talking about HIV. This became evident as she asserted that: *“People who are not HIV-positive would start conversation about people who are positive and stuff like that just irritates me every time I hear it just tick me off” [Ir]. [P6]*

Sub-theme: Rejection

Two participants [P4 and P6] reported that they have been rejected due to their HIV status. One participant stated that: *“he did not fight until then but later he showed me that he is the man. He left me with sickness [RJ]. [P4]*

Sub-theme: Stigma

Two of the participants [P6 and P11] reported on it as one asserted that: *“You just have that thing of it’s one of the sickness which are dirty, eish!” “Once your there is like your beyond redemption [S]. I characterise it as that, so it’s eyi! Another thing for the fact that you would*

disclose and people would know and how often would it be that people will treat you the same cause with me none of my friends know, you know [J]. Chances might be I don't know".
[P6]

Sub-theme: Transmission to child

Two of the participants [P7 and P9] reported that they are afraid they will transmit the disease to their children. This was evident as one participant mentioned that: *"If I get pregnant will the child be clean or be like her mother?" [TC]. [P9]*

4.5 Conclusion

The results from the interviews have clearly showed that subjective emotional experiences of HIV-positive married women with childbearing wishes and intentions. For the majority of these women being HIV-positive has not stopped them from wanting to bear children though to some it is a wish that they have not yet actively pursued. The results revealed that their spouses know about their HIV status and their need to bear children. Unique factors associated with their wishes and/or intentions have been reported by these women.

In the following chapter an integration and discussion of the results will be presented and integrated with the literature.

CHAPTER 5

INTERPRETATION AND DISCUSSION OF RESULTS

5.1 Introduction

This chapter presents the discussion of the results from the interviews and integrating them with the literature reviewed in chapter two. The integration will include the direct quotes from the participants and coding system used in Chapter four (presentation of results) which will be in italic form. Then a presentation of the strengths, limitations and recommendations regarding further researcher will be highlighted.

5.2 Overview discussion of biographical descriptions

Homsy *et al.* (2009) indicated that; age, marital, educational, socio-economic status, cultural and religious beliefs, sexual behaviour as well as family size are documented predictors of childbearing needs among women. It is within the findings of this current study that the results confirmed various; personal, situational and cultural factors in addition to what are stated by the above researchers as predictors of childbearing needs and desires. It is significant to note that the documented predictors of pregnancy and childbearing needs among HIV-positive women does contribute to their emotional turmoil, stresses and dilemmas they experience on a daily basis.

The biographical description within this current study indicated that the participants' ages ranged from 19 to 42 years all in the union of mostly customary marriage and in need of children. The majority of the participants indicated living with their husbands' and relying on them for financial support. All these give context within which to view the results/findings of the current study. It contributes to the depth of understanding the emotional experiences of

each individual participant. Rispel *et al.* (2011) showed that there is a need to understand complex personal, interpersonal, medical and health care factors of HIV-positive married couples in order to assist them in meeting their reproductive needs which in turn are impacted by some of the aforementioned individual characteristics.

5.3 Discussion of the findings

CATEGORY I: Journey of diagnosis

Within this category the following main themes emerged: time of the diagnosis, husband's status and impact on marriage. These themes were indicated by the researcher as part of understanding the impact of the diagnosis on the participants' lives from the time they were diagnosed to the impact it had on their marriages.

The participants in the current study expressed that their HIV diagnosis was made either during pregnancy or as a result of illness. The findings revealed that these women involuntary tested for HIV. One participant expressed that: *"I got sick [DS]. I then went to test for TB and they transferred me to the hospital saying I do not have water. So that's when I found out that I'm HIV positive"* [P3]. It is significant to note that current literature reviewed suggest that the provision of voluntary counselling and testing (VCT) in countries with generalized or high burden epidemics has expanded dramatically in recent years (Cremin *et al.*, 2010). However, what is suggested by literature review seems to be in contradiction to the findings of the current study.

It can be hypothesised that individuals need to be encouraged more and more to utilize the services of voluntary HIV counselling and testing (VCT). According to van Dyk (2008), it is important to ensure that testing is encouraged and supported by effective counselling with

adequately trained counsellors, in user friendly venues and with guaranteed confidentiality. In addition this process will assist in facilitating normalisation and de-stigmatisation of HIV among individuals.

When participants were asked about their partners' status the following responses emerged. Others reported that their partners' were positive while others are negative and for some women they were not aware of their partners' HIV status. According to Anglewicz, Bignami-Van Assche, Clark & Mkandawire (2010) among married couples, an individual's perceived and actual risk of being HIV positive is closely intertwined with his or her spouse's. It is in the light of the current study that most of the participants reported that their partners' are also HIV-positive. This finding suggests that safer conception services are needed for HIV infected women and men who desire children (Mantell *et al.*, 2009).

For some of the participants their partners' tested HIV-negative. One participant asserted: ***“He does not have anything”. “His been checking but he has nothing [HN] [P12].*** This finding illustrates what Karim and Karim (2010, p.291) indicated in their book that: “our understanding of the underlying biological mechanisms of HIV transmission is incomplete”. “While it is clear that both semen and vaginal secretions are able to transmit infection, the relative importance of cell-associated and cell free viruses as the source of infectious virus is not known”. It has been shown that discordant couples (i.e. couples where only one partner is infected with HIV) represent the majority of HIV-infected couples in sub-Saharan Africa (Walque, 2007; Anglewicz *et al.*, 2010).

To some of the participants their partners' HIV status will remain a mystery and/or speculation. One participant expressed: ***“My partner refuses to test but he is positive” [SU]***

[P5]. It can be hypothesized from this finding that there are still challenges faced by some individuals with regard to issues of denial, fear and ignorance to HIV. Literature review suggested that HIV/Aids stigma is significantly associated with reluctance to accept HIV antibody testing (Kalichman & Lurie, 2010; Karim & Karim, 2010).

In probing further, participants were asked about the impact of their HIV status on their marriages the following experiences were shared by the participants. In few of the participants being diagnosed with HIV facilitated increasing levels of closeness, care and attachment into their marriages. Kulczycki (2008) confirmed the experiences of some of these women when he stated that marriage implies that two individuals come together to form a couple and they tend to stay married because they see life in as similar way, consequently, they are likely to seek consensus on matters of mutual importance. This is an indication that some couples are able to support each other in an attempt to create a peaceful and healthy marriage against the odds of their HIV status. One participant explained: ***“He supports me.”*** ***‘He does not judge me’ [IP] [P3].***

While on the other hand for most of the participants being HIV-positive has resulted in experiencing emotional turmoil and stress within their marriages. Okwun and Siraj (2010) concurred this finding as they stated that the institution of marriage is however not without its problems. He explained that unfulfilled expectations and hope in marriage often give rise to maladjustments and unless the couple concerned face the reality of any given situation, conflicts might abound in such relationships. ***“We fought now and then” [IN] [P1].***

The responses provided by these women on the journey of their diagnosis suggested a roller coaster experience and emotional turmoil. An account of their marriages changing as a result

of tension in their interaction with their partners indicated the difficulties they constantly experience and live with. Their responses were confirmed by Rispel *et al.* (2011) from research conducted on sexual relations and childbearing decisions of HIV-discordant couples as most respondents reported experiences of tension in the relationship. He further stated that tension arose because of fear of infecting the negative partner, real or perceived infidelity and problems experienced from consistent condom use (Rispel *et al.*).

Blaming within marriages emerged from some of the responses given by the participants. One participant reported being blamed for her HIV status by the partner. *“He had this thing of saying I’m the one who made him sick” [B] [P1]*. According to Okwun and Siraj (2010) it is common that women who had history of HIV-infection are often left with guilt, fears and unresolved grief, which affects their psychology, motivation and readiness for sex. While on the other hand some women felt their HIV status did not affect their marriages. *“He was ok, he did not get worried [NI]. He is handling me well” [P12]*. The findings of the current study has strongly suggested that the experiences surrounding HIV, marriage and childbearing are associated with overwhelming emotional experiences for women in childbearing age.

CATEGORY II: Personal aspiration and intentions about motherhood

This category had aimed at attaining the participants’ personal aspiration and intentions about motherhood. It further focused on understanding their subjective view and perceptions with regard to the importance of bearing a child. Three themes were indicated from this category being the significance of motherhood, feelings about being a mother and the influences to childbearing. A number of sub-themes emerged from the three themes (refer back to

presentation of results) and these subthemes will be discussed and integrated with literature below.

For most participants motherhood signifies the fulfilment of being a woman and belonging. They indicated that motherhood provides an opportunity to nurture and care. Their feelings to motherhood did not exclude the impact and pain of not being able to fulfil this role. One participant asserted that: ***“I would like to have one so at least I know I have child who is mine so that I can be able to take care of that child and give her love” [L] [P5]***. Women in general as well as for HIV-positive women motherhood is important and an inherent part of their femininity (Cabral, 1998; Hebling & Hardy, 2007).

For these participants motherhood provides an opportunity to care, belong; feeling content and fulfilled. In addition motherhood elicited feelings of love and being happy for the participants. The findings confirm that motherhood is a unique, subjective and a personal fulfilment for all women irrespective of their HIV status. One participant asserted, ***“It means a lot of things you become responsible like from being pregnant, you become responsible [R] for the life growing inside of you, you nurture [MN], you take care [C], have you see all those things to guide and do those things, to love unconditionally” [P8]***. According to Hebling and Hardy (2007), motherhood is seen as an essential attribute to women and a reason for living. On contrary it is significant to note that though motherhood is perceived as an important and inherent part of femininity. According to Cooper *et al.* (2005) a number of women felt that this would not influence them, if their own health remained compromised

The participants further expressed numerous behavioural and contextual factors contributing to their needs to bear children. To some participants the desire and need to bear a child is influenced by factors such as my partner wants a child. One participant asserted: “***He is handling me well the only thing is that he is crying for a child***” [PW] [P9]. It is significant to note that of all the influences given to childbearing in this study this subtheme was mostly highlighted by most participants. The findings of this study is confirmed by Cooper *et al.* (2007) as they indicated that family, husbands’ and societal expectations for childbearing are important influences on women’s reproductive intentions.

Ujiji *et al.* (2010) stated that childlessness and infertility have a stigma attached to them and often associated with profound negative social repercussions in African societies. His statement correlated with the experiences of some of the participants as they expressed that their childbearing intentions is a result of partners not having children within the marriage nor from previous relationships. Participants felt that when a marriage is childless usually the blame is placed on them. Children stabilise a marriage by giving it meaning. Children confer certain status to the mother and the father in the family, community and the society (Maithya, 2006).

Given the importance of childbearing in many societies and their own desire for children women often face a stark dilemma (Baylies, 2001). This includes additional considerations, largely negative to take into account when deciding whether or not to have children. These include the possibility of passing HIV from mother to child and the likelihood that one or both parents could die prior to the child reaching adulthood (Heys *et al.*, 2009). One participant expressed: “***I used to come for treatment every month but I lost the child*** [FL] [P7]. The findings of this research have revealed the challenges faced by these participants in

a process of making a decision to bear as they must deal with psychological and emotional issues associated with childbearing in addition to their HIV status.

Even with the reality of their HIV status and challenges for some participants bearing children is a way of building a future. In addition to the support they expressed they received from their partners. Literature review indicates that family formation is seen as ‘natural’ and ‘necessary’ part of marriage (Cooper *et al.*, 2007). One participant stated ***“I don’t know maybe because when you get married that is one of the things unless a couple decide that they do not want a kid” [MI]. “But that you enter knowing that it has to be like that at some point” [P6].*** For some participants the years within the marriage without conceiving a child was a concern and problematic. This suggests that marriage is an addition factor contributes to the emotional experiences of HIV-positive women holding this status.

A conference presentation revealed the influence family has on married women in a discussion with older women in the Eastern Cape Province, South Africa (Nduna, 2008; Farlane, 2009). Women said there was no reason for a married woman not to have children in the marriage. One woman asserted that she gave birth to her son; therefore her daughter-in-law should also give birth to her own sons. The above findings correlated with the experiences expressed by the participants in this current study as they reported constant pressure from their in-laws to bearing grandchildren for the paternal family. One participant expressed that: ***“From his home they ask us when are we going to have a child [IL]? They confront my husband” [P2].***

For some of these participants pressure to conceive did not only arise from their in-laws but also from their families. The participants’ experiences to families’ perception around

childbearing influences their reproductive intentions and needs. Cooper *et al.* (2005) indicated that for many woman and man, the pressure from family, partners and peers to have biological children to prove fertility or ability to reproduce can be overwhelming. Children were seen as an expansion to the family and as a means to leave a remembrance when the parent passes on. Heys *et al.* (2009), indicated a significant factor to childbearing decision in that women and couples may continue childbearing even when they are HIV-infected or destitute in order to avoid social stigma and isolation. In the light of this study it can be hypothesized that conception pressures experienced by some participants from both their families and in-laws is a result of avoiding social stigma and isolation.

In the light of these norms around the meaning of marriage for women, it may be difficult to exercise autonomous decision-making in this matter because it is not treated as private. Furthermore when one does not conform to the expectations of bearing children there are often verbal and non-verbal questions, irrespective of one's circumstances or choices (Farlane, 2009). It seems difficult if not impossible for some of these participants to escape the expectations placed upon them through marriage. The institution of marriage is the core of South African culture, around which the entire social structure revolves (Afolayan, 2004 Molelekeng, 2009). In its most basic function marriage is directed at producing children. In the light of these findings there are suggestions that some participants may find themselves deciding to bear a child irrespective of the measures of their HIV progression.

It is significant to note that for some of the participants a decision to bear a child with their HIV status is complicated by the awareness of the communities and/or individuals' attitudes who are not in support of childbearing among HIV-positive women. Myer *et al.*, (2006) indicated that some individuals felt HIV-infected people should not have children. Therefore

HIV-positive married women are faced with a dilemma of building a future in their marriages by having children and having to deal with the possibility of disapproval of their decision to childbearing by their community in cases of disclosure.

CATEGROY III: Impact on reproductive intentions and disclosure

Literature suggests that experiences following disclosure included both positive; acceptance, understanding and also negative consequences; rejection, abandonment, verbal abuse and physical assault (Gielen *et al.*, 2000). It was with these anticipated reactions that disclosure could be affected resulting in the risk taken by individuals to conceive despite one's status or conceal one's HIV status. In this category issues of disclosure ranged from some participants taking a decision not to disclose their HIV status to their families and in-laws while others disclosed to their families and/or in-laws.

Some of the participants had disclosed to their families only, while others had disclosed to both family and in-laws. For those who had disclosed to their families indicated not feeling comfortable in disclosing their HIV status to their in-laws and felt their families support is sufficient. ***“My family it's ok they are supportive” [FK] [P5]***. Iwelumor *et al.* (2010) showed that motherhood was important in shaping decisions regarding disclosure of HIV seropositive status in that there was an inherent belief that mothers would not “chase” their daughters away when they reveal their seropositive status and that they would provide “necessary support” for living with HIV.

In this study there were further indications from some of the participants where disclosure of their HIV status posed a threat to their relationships with their family members particularly their mothers. One participant expressed that: ***“They are those kind of people when they talk***

about people who are HIV they are not saying good things and you would know if they knew about you, you would not feel good” [J] [P9]. Daughter disclosure of HIV status to her mother sometimes was responsible for disrupting relationships between the two (Iwelumor *et al.*, 2010). Hence there were those participants who reported making a decision not to disclose not even to their own families.

The reasons for not disclosing to family members were the same for not disclosing to in-laws. Some of the participants who reported taking a decision not to disclose to their in-laws did so, so as to protect themselves as they are the ones who are infected with HIV. One participant expressed: *“They do not know. My partner said I should not disclose maybe because he knows them better than me” [ND] [P8].* Van Deventer *et al.* (1999) stated that planning for the future among couples with HIV is often complicated by the conflicting need to disclose the infection to extended family and/or friends in order to make appropriate plans and the desire to keep the information secret to protect the partner/family from stigma associated with HIV. On the contrary Miller and Rubin (2007) indicated that mutual obligation seemed to underlie disclosure to family and partners. In addition there is an awareness of family members’ reciprocal obligation to them which is evidenced by their strong disclosure motivations of seeking material support and preparing for the future. From the findings of this study it can be hypothesized that disclosure will depend on anticipated reaction one holds with significant others.

For those who had disclosed to both their families and in-laws felt that they would receive support and not be judged for their HIV status. Gielen *et al.* (2000) stated that although women frequently report serious concerns about disclosing their HIV status, the weight of the evidence suggests that the vast majority of women do eventually disclose their status to

partners, family members and friends. This is an indication that the decision to disclose one's HIV status to family will largely depend on the kind of relationship an individual has with her significant others.

The findings of this study suggested that when participants had overcome issues of disclosure and had expressed their reproductive intentions and decision to spouse and families they received support. One participant asserted that: ***“Yes, they know and want me to have child and their also supportive” [FS] [P5]***. This was in contradiction from Farlane (2009) who stated that women who had disclosed their HIV status were more likely to be discouraged from bearing children. Meyer *et al.* (2006) was also in support of this finding. It was also revealed from Myer's study that societies' or communities' view point of childbearing is not in support of HIV-positive women's reproductive intentions in particular. However, it is significant to note that the current study suggests a paradigm shift with regard to attitudes towards childbearing among HIV-positive women in individuals and families.

On the other hand when participants were asked about the health care providers' reaction to their reproductive intentions and need the following responses and reactions were identified. Some reported having communicated their intentions while most of the participants reported that they had not communicated their intentions to health care providers. According to Bruyn (2006), health care workers are regarded with great respect and expected to be responsive to community needs. When they fail to do this or when they act in ways that contradict their caring role community members are either unable to consciously identify this as a violation of their rights or are seldom able to assert their rights (for example, through direct communication with health care providers or by initiating a complaints procedure).

Those who have communicated their intention expressed not having received enough information and/or clear understandable information. One participant asserted that: “*I spoke to a nurse from Mmakau [CI] where I tested that’s where I explained and she said it’s not possible*” [P4]. Mantell *et al.* (2009) showed that current reproductive health guidelines are not proactive in supporting HIV-positive people desiring children. Their communication experiences with health care providers contribute to some of these participants choosing not to ever inquire or seek information about reproductive intentions from health care providers. They then choose to rely on the information they hear from friends and television which was the case from the findings of this study. Wilcher and Cates (2009) asserted that all women regardless of HIV status have a right to make informed reproductive choices.

Some of the participants reported that they were advised against bearing children without being given enough information by health care providers. “*Aaa!, it’s the same like we get different doctors like when you speak to a doctor and he will say, hey, don’t do that you will die*” [AP] [P5]. It is interesting to note that earlier research by McCreary *et al.* (2003) indicated that many health professionals and ethicists have felt that the consequences to the affected children and to the society as a whole dictate a more directive approach to HIV-positive women wanting children. The consequences of such a stance have in certain instances for instance in this study proven to deny individuals appropriate information. Therefore these professionals have intervened with directive counselling, advising HIV-positive women to avoid or delay childbearing (Arras, 1990; Levine & Dubler, 1996; Kass & Faden, 1996; McCreary *et al.*, 2003).

Ujiji *et al.* (2010) in a recent study showed that a paradigm shift was identified were women acknowledged being treated well and welcomed by counsellors. They expressed satisfaction

with the information they provided with on childbearing when living with HIV. It is however, significant to note that only one participant in this study had reported the experience stated above by (Ujiji *et al.*). For most of the participants approaching a health care provider for advice with regard to childbearing intentions or need was either threatening or impossible. This was confirmed by Ujiji *et al.* other findings where some women felt that health care professionals were restricting them and expecting them to ask for permission to become pregnant. It is also within the findings of this study that most HIV-positive women chose not to communicate their reproductive intentions with health care providers.

For those who had not communicated their intentions to health care providers expressed fearing judgement and feeling ashamed. ***“I have heard a sister saying that people are getting pregnant but they are sick. I withdraw” [J] [P2].*** Wilcher and Cates (2009) showed that infected women may be more vulnerable to rights abuses than uninfected individuals. Mantell *et al.* (2009) revealed that people living with HIV have the same human rights as those not infected with the HI virus. For as long as participants are experiencing or anticipating negative responses and attitudes by health care providers to their childbearing intentions and needs there is still a challenge in bridging the gap of providing relevant and appropriate information to HIV-positive individuals with reproductive needs. In addition health care providers play a significant role in informing HIV-positive women of safer or risky behaviour to childbearing decisions and intentions.

CATEGORY IV: Journey of reproductive intentions

Myer *et al.* (2006) stated that childbearing among HIV-positive women may lead to the vertically transmission of HIV and when this can be prevented, the care of future orphans may be of concern. Even with awareness of the complex state or situation these women find

themselves in the need to bear a child continues to be high. When participants were asked about the processes they have undergone to try to conceive the following responses emerged. Most of the participants reported that they are planning to fall pregnant though at the time of the interview they had not attempted anything. Two participants were already engaging in unprotected sex as an attempt to conceive and two were suspecting that they are pregnant.

For those participants who reported that they had not yet attempted to conceive they had a couple of concerns they were battling with. Some of the participants are faced with challenges of meeting their reproductive needs without infecting their uninfected partners while other participants feared infecting their children. One participant expressed that: ***“If I get pregnant will the child be clean or be like her mother” [TC] [P9]***. Rispel *et al.* (2011) stated that a key challenge for HIV-discordant couples is minimizing the risk of HIV transmission to their negative partner (s) and to any children conceived.

Though the participants expressed the above concerns none of them mentioned other forms of reproductive technologies or adoption as a future possibility. According to van Dyk (2008) there are cultural, ethical and religious concerns to consider with almost all techniques used for conception away from the natural form of conception. It could be hypothesized that van Dyk s’ view is associated with the participants need to bear their own children.

In the process of fulfilling the need to bear their own children some of the participants reported that they could be pregnant with an exception of one participant whom the possible pregnancy could be due to a condom burst during sex. One participant asserted that: ***“I didn’t see my period cause when we do sex the condom burst so I didn’t see my period so I think I’m pregnant” [PP] [P10]***. Those who are currently attempting to fall pregnant indicated

their desperation for a child resulting in disregarding the existing risks involved from their actions. Rispel *et al.* (2011) stated that there are growing numbers of HIV-positive women who still conceive naturally through timed unprotected intercourse thereby putting their health and that of the child at risk.

The journey of reproductive intentions and needs for the participants indicated an emotional and overwhelming experience. It is with the following responses, encounters and feelings that the following experiences were reported by participants. Partners; refusing to test, take medication and/or use condoms, coping difficulties, issues of denial, avoidance, blame, rejection, infidelity, irritation, stigma, rape and violence; fear of loss, leaving child through death, risk taking behaviour, acceptance over time, a need to self-educating themselves and get more information.

Most of the participants highlighted their emotional difficulties in relation to their partners. They further expressed constant overwhelming experiences as a result of partners refusing to test for HIV to determine their status or refusing to take medication if tested positive. One participant expressed that: *“The thing is men are cheeky if you tell him lets go to the clinic he refuses, when you say go and test he refuses” [PRT] [P4]*. This is in addition to experiences of partners’ denial and/or blaming the women for the situation they are faced with. Okwun and Siraj (2010) stated that it is common that women who had a history of HIV infection are often left with guilt, fears and unresolved grief which affect their psychological, motivation and readiness for sex.

In some instances tensions in the relationship arose because of the reluctance by one partner to use condoms, either because that partner wanted to have a child or felt that the condom

interfered with intimacy and love-making (Rispel *et al.*, 2011). This has been the experiences of some of the participants who felt the emotional pressure from their partners contributing to individuals experiencing coping difficulties, irritation, blame, infidelity, rejection and risk taking behaviour. One participant expressed experience of infidelity and rejection: ***“He left me with sickness and went to another woman and stayed with another woman then he came back to me” [I] [P4].***

On the other hand some of these women expressed concerns of losing their children after conception or transmit the infection to the child as some of them had lost children before as a result of conception during their HIV status. ***“So if I fall pregnant without consulting a doctor will the child come being negative”? [TC] [P7].*** According to Kanniappan *et al.* (2008), women’s decision of not having a child after diagnosis included anxiety about their own and their child’s health, fear or imminent early death and apprehensions about leaving children orphaned. Though there are concerns with regard to childbearing among these participants it was shown that HIV-infected women frequently become pregnant and most HIV-infected individuals have fertility desires that change over time (Myer *et al.*, 2010)

It is in the light and awareness of these challenges, issues and emotional experiences of these participants that there is a need to gain more information and to self-education was identified. In an attempt to conceive and/or met their reproductive needs which are becoming increasingly important with or without the assistance of health care providers. In addition the rise and accessibility of treatment in managing HIV has increased and further providing a reason to bearing a child. Kaida *et al.* (2011) stated that expanding access to highly active antiretroviral therapy (HAART) is changing the landscape of childbearing decision making for people living with HIV.

5.4 Summary of the discussion

The findings and the literature survey of this study, it appears that reproductive decision, intention, needs and desires of HIV positive married women is an emotional and stressful event for them. More so because their reproductive decisions is not always an autonomous decision but influenced by factors such as their marital status, cultural and social expectation and communities and societies' attitude and views on childbearing within the institution of marriage.

The participants experienced various difficulties as they were faced with the challenge to balance their need to bear children and the condition of their HIV status. The findings of this study have indicated various influential factors to childbearing intentions, decisions and needs with an emphasis to the influence of marriage. Furthermore there are expressions of personal struggle in approaching health care providers for a safe conception method. Most of the participants felt that their spouse and families support to their reproductive decision intentions and needs is sufficient in assisting them try and meet their reproductive decisions. In the following section, the strengths and limitations and recommendations of the current study will be discussed followed by conclusion.

5.5 Strengths and limitations of the study

Below are the strengths of this study:

- This study aimed at exploring the emotional experiences of HIV-positive married women wanting to bear children. It is in the process of exploring their emotional experiences that the richness and quality of the data was derived from the in-depth interviews.

- Through the participants 'unique and subjective experiences a link was made between HIV, childbearing and marriage contributing to the limited literature that exists in this area.
- The study was able to show a growing need for childbearing in HIV-positive married women irrespective of their age and culture within the South African context. It also highlighted the influences to their reproductive decisions and intentions which is something rarely documented by other research.
- A challenge was identified between the health care providers and the patients with regard to providing of appropriate, clear and understandable information. In addition the reluctance from the patients side to approach the health care providers with regard to their reproductive decisions and intentions.
- The study highlighted a growing need for interventions in assisting HIV-positive men and women in meeting and understanding their reproductive needs and not only on paper but actively through developing an empathic ear to their context.

Limitations experienced during the process of this study:

- Many of the participants were initially reluctant to verbalize their experiences because of fears of judgement regarding their need to want children despite being HIV positive. Secondly, some of them were concerned about the issue of confidentiality as they expressed past experiences of the clinic where confidentiality was not maintained.

- The results of this research may not be generalised to the whole population as a small sample of 12 participants was used. Further research with a larger representative sample may provide more generalizable results.
- In the process of data collection, the language used in conducting the interviews was mostly Setswana. The interviews were later translated into English and this could have led to the meaning of some words being lost.
- Some of the participants were not free during the interview as they were preoccupied by the context of a moving line to collect medication or see a doctor outside. This was reflected through their body language and/or posture, brief expressions and short answers to questions asked and/or expression of their encounters of their experiences.

5.6 Recommendations

In exploring the emotional experiences of HIV-positive married women wanting to bear children it became clear that the reproductive decisions and intentions of these women cannot continue to be ignored.

- Fertility choices for HIV-positive married women should be viewed from their personal, subjective and unique context. In the process of considering not only their physical condition of HIV status but also the cultural, social and religious expectations of their marital status.
- There is a need to explore reasons and influential factors to the existence of cultural, ethical and religious concerns to most of all techniques used for conception away from the natural form of conception in a South African context.

- Provision of accurate and specific factual information is an important primary goal for intervention programmes. In the process bridge the gap on these very rapid changes in our knowledge and understanding of the virus and the disease so that accurate and relevant information is provided to HIV-positive married women in the childbearing age.
- Assist lay-persons in bridging the gap between scientific literature, jargon and educational pamphlets. In the process assist the uneducated and those whom out of fear of judgment choose not to approach health care providers will depend upon the information they find on educational pamphlets and television.
- Create an independent counselling section and/or department for HIV-positive individuals where they will experience limited contact with their doctors. In order to minimize the anticipated breach of confidentiality and privacy from counsellors to doctors.
- The *HIV and AIDS Charter of Rights* developed by many countries should be pragmatic and implemented according to what is on paper.

5.7 Conclusion

The importance of having children is a human need and part of their existence. It is therefore clear that it cannot be underestimated and it seems that not even a life threatening condition will stop this. It was in the process of exploring the emotional experiences of HIV-positive married women wanting to bear children at Dr. George Mukhari Hospital that women expressed their experiences. The findings of this study have indicated a high need to pay

attention to reproductive decisions and intentions of HIV-positive women particularly those who are pressured by their marital status. It has been documented that an HIV positive status does not deny the need to bear a child among women.

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