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**REPRODUCTIVE DECISIONS AMONG
COUPLES WITH HIV/AIDS IN ZIMBABWE**
A DESCRIPTIVE QUALITATIVE STUDY OF A
SAMPLE FROM BULAWAYO

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ABSTRACT

Men and women of reproductive age are the largest group infected with the human immunodeficiency virus (HIV) in Zimbabwe. Over 70% of the reported HIV/AIDS cases in Zimbabwe are among the 20-29 year age group. The purpose of this exploratory study was to explore and describe the impact of being HIV positive on the reproductive and sexual choices or decisions made by HIV positive couples given that in Zimbabwean society it is generally expected that couples, especially married ones, should reproduce. The study explored the context of decision making, the content of decisions made, the process of making those decisions as well as the actors involved in the decision making process. In pursuance of the purpose of the study, the socio-cultural context which determines the value framework within which HIV positive couples live and make their decisions was explored as was the economic as well as the medical context. The study also examined the role of health professionals and the family on the reproductive decisions made by HIV positive couples. The gender based power dynamics within the relationships of the positive couples was also given due attention. Having explored these factors the study found that being HIV positive has both direct and indirect effects on the reproductive and sexual lives of HIV positive couples as well as on the decisions that they make.

Several approaches were used to explore the impact of being HIV positive on reproductive decision making and how reproductive decisions and sexual choices were made by HIV positive couples within the context of the Zimbabwean patriarchal society. In analysing and interpreting the data, the etic approach as well as the constructivist and hermeneutic epistemologies were used. In describing and analysing the decision making process the study adopted a three dimensional framework that focussed on the context, content and process of decision making.

An analysis of data from the fifteen couples that were interviewed revealed four main positions regarding child bearing among HIV positive couples. Some individuals and/or couples were against child bearing by HIV positive

people, some desired to have a child or children but had no intention of doing so, others expressed an intention to have a child or children in the near future while others expressed neither desire nor intention to have a child or children but were not against childbearing by HIV positive couples. The findings also revealed three prevailing discourses on the issue of childbearing by HIV positive people among health professionals. These were the pro-children, the conditional pro-choice as well as the pro-rights discourses.

The process by which HIV positive couples made reproductive decisions is described as occurring in a number of stages which are not necessarily linear in progression. These are the conception of the idea, initial discussion and decision making between partners, searching for information, and weighing the risks and benefits of childbearing. In this study men and women expressed different concerns and attitudes on the issue of childbearing. Women showed more concern and worry about childbearing and were not as keen as men to have a child or children. On the other hand men showed a more positive attitude about childbearing. They seemed to be more prepared to take risks than their female counterparts. This difference between men and women regarding reproduction was explained from an evolutionary as well as from a behavioural change perspective.

This study found the following: i. that though being HIV positive had an impact on the reproductive and sexual choices made by HIV positive couples it was not the sole or main determinant of their reproductive decisions. Reproductive decisions were based on a myriad of psychosocial, medical, personal, economic as well as socio-cultural factors. ii. That the availability of HAART played a pivotal role in the decision to have a child among those who intend to have children. They pointed out that without it, regardless of the importance of children in their lives and all other factors, they would not have considered having a child or children. iii. The study found that among the respondents men do not dominate reproductive decision making. There is gender parity in so far as reproductive decision making among the couples under study is concerned. iv. Another finding was that health professionals do play an important role in the reproductive decision making process of HIV positive people as they act as informants and advisers. v. that reproductive decision making among the studied couples was a rational process. The study also found that stigma was still prevalent in the Zimbabwean society.

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University of Cape Town

CHAPTER ONE

INTRODUCTION AND STUDY BACKGROUND

1.0 INTRODUCTION

The advent of HIV/AIDS with its fatal prognosis and possibility of being transmitted not only horizontally but also vertically has had a significant impact on the reproductive and sexual lives of millions of infected people worldwide. In Zimbabwe the UNAIDS 2006 report on the global AIDS epidemic estimates that over 20.1% of the adult population (15-49) is living with HIV. With the total population of Zimbabwe estimated at 12.9 million, well over a million reproductively active people potentially have to make a difficult reproductive decision, that is, to have or not to have a child at all. Making this decision is made more difficult by the cultural value attached to children in Zimbabwean society as well as the stigma and discrimination faced by HIV positive people. This study explores the context in which reproductive and sexual decisions or choices are made by HIV positive couples as well as the content of those decisions. In the process it also examines the role and influence of different actors in the decisions made by HIV positive couples. This is important since to understand the decisions or choices made one has to understand the context in which such decisions are made as well as the role of different actors in the process. Thus the study explores the socio-cultural, medical, political as well as economic factors that impact on the decisions made by the study sample. The study also identifies and explores the role of the three main actors in the reproductive decision making process of HIV positive couples. These are the couple itself, family and friends as well as the health professionals/practitioners. The importance of this study lies in its exploration of reproductive challenges faced by a hard-to-reach group of Zimbabweans and how these challenges are linked to the socio-cultural and medical context they find themselves in. Since most of the respondents were from an Ndebele cultural background, the Ndebele culture was used as the main reference point in this study.

Before the field research was undertaken a number of assumptions and hypotheses were made regarding reproductive issues and decision making among HIV positive couples. One such assumption was that social norms and expectations

concerning child bearing in largely patriarchal Zimbabwean society would push HIV positive couples towards making socially acceptable reproductive decisions in order to maintain acceptance within the society. Child bearing is valued in Zimbabwean society especially among married couples and infertile couples are usually stigmatised. Couples usually face direct or indirect pressure to conceive from the family/society. Given such a cultural context, it was anticipated that despite the risks involved, HIV positive couples would try to conceive in order to conform to social expectations. The study findings on this, together with the stance taken by the society regarding reproduction among HIV positive people is discussed in depth in the thesis.

Another hypothesis that this study set out to investigate was that health professionals (HPs) play a vital role in the decision making of people with chronic illnesses. In Southern Africa, the role of health professionals in reproductive decision making among couples with HIV/AIDS has not been given wide coverage in the literature. There is little data on the attitudes and views of health professionals on child bearing among HIV positive people. In fact in most of the studies the HPs are silent. While investigating their role in decision making and how their attitudes and views on the issue of childbearing impact on HIV positive couples this study also gives voice to health professionals. Based on previous studies dealing with HPs and their patients, a number of perspectives regarding reproduction among HIV positive people were expected from HPs. Given the prognosis of HIV/AIDS and the possibility of vertical transmission, it was assumed that some HPs would take a pro-children perspective that is essentially against reproduction. Others were expected to adopt a conditional pro-choice perspective that imposes conditions on HIV positive people concerning reproduction. It was anticipated that some would adopt a pro-rights perspective which views reproduction among HIV positive people as a fundamental right and a personal choice of the infected person(s). With the positive impacts of HAART and the negative demographic, social and economic impacts of population decline that may be brought about by large numbers of HIV positive people not reproducing, some HPs were expected to advocate a pro-reproduction perspective. This study thus explores the perspectives of HPs regarding reproduction among HIV positive people as well as how these perspectives influence the information and advice given to HIV positive couples concerning reproduction. The study

argues that reproductive decisions of HIV infected heterosexual couples are not merely a medical issue but also a socio-political issue intertwined with complex gender, economic and cultural factors in which HPs play a significant role.

It is important at this early juncture to clarify an important aspect of this study. This qualitative study focuses on a small sample of HIV positive people; those who have disclosed their positive status at least to their sexual partners. Since the study focuses on those who have disclosed, it was not possible to aim to produce a representative study of all HIV positive couples, for there abound HIV positive individuals who, due to personal, social and perhaps economic constraints do not find it possible, advantageous or worthwhile to disclose their sero status even to their sexual partners. This exploratory and descriptive study attempts to give a glimpse into the reproductive world of those who have been able to disclose their positive status to their sexual partners. The study focuses on them because they at least have confronted or will be confronting reproductive decisions with the full knowledge of their HIV status. It is significant therefore to note that the phrase “HIV positive couples” will be used in the study to refer to those couples who have disclosed their status to each other. The findings discussed in this thesis have thus to be understood in the context of this study sample.

This study therefore discusses reproductive and sexual issues among HIV positive couples focussing on the forces that impact their reproductive and sexual lives. Important issues discussed in this thesis include the importance of children to HIV positive couples, the impact of HIV/AIDS on their reproductive plans and intentions, the role of gender in decision making, the impact of HAART on their reproductive lives and choices as well as the role played by HPs in their reproductive and sexual lives.

1.1 Significance of the Study

An exploration of the context and content of reproductive decisions made by HIV positive couples is relevant at broadly two levels – at the level of policy making as well as in addressing a number of knowledge gaps that exist in the literature on HIV/AIDS.

It is of essence to note that this study was undertaken against the backdrop of a high infection rate and death rate from AIDS and HIV related causes in Zimbabwe and in an era where evidence based practice had come to the fore. The high prevalence of HIV within the reproductive population means a greater number of couples have to grapple with the ultimate reproductive decision – to have or not to have a child. Though being HIV positive is not the only factor which determines a couple's reproductive choice or decision, it may play a critical role in decision making. Since HIV prevalence among the reproductively active age group remains high, what reproductive decisions do these women and men make regarding present and future reproductive and sexual health issues? By attempting to answer this question and others this study avails information that may be used for current or prospective planning by policy makers or for evidence based programming by NGOs and other private organisations involved in social and health issues.

In Southern Africa the reproductive concerns of HIV positive couples have not received much attention even though a high percentage of reproductively active adults are infected. A description of decision making among HIV positive couples provides a window through which we may begin to understand their concerns and needs in the area of reproductive and sexual health and why they make particular choices with regard to having children. Since the beginning of the epidemic the concern has been to control the spread of HIV and this concern has been extended to attempts at controlling the reproductive and sexual lives of HIV infected people. In a bid to safeguard both the health of the infected and the un-infected little attention has been paid to the sexual and reproductive needs of the infected. If sensitive and effective health interventions in this area are to be made it is important to understand these issues from the perspective of the affected and infected. To this end, this study explores the reproductive issues and challenges that face these couples. Though more in depth studies incorporating both urban and rural populations of infected people are needed to make more relevant and informed recommendations to inform policy on this important issue, this study offers important observations and opens new trajectories that other studies may pursue.

This study also addresses some knowledge gaps and inadequacies in the current literature on HIV/AIDS. Most studies on reproduction, decision making and

gender in Sub-Saharan Africa have concluded that men dominate both the public and private domain and that women have limited control over reproduction. However most of these studies have focussed entirely on women and as a result the role and influence of the male partner and other actors in decision making has been evaluated from the perspective of women. Since actors in any decision making environment tend to have their biases and certain perceptions of others which are not necessarily grounded in reality, to base conclusions about the role of each actor on reproductive decision making mainly on the views, perceptions and attitudes of a single actor is rather flawed and may produce biased results. The level of unreliability of findings is further exacerbated by the usual lack of communication on reproductive and sexual issues between partners which may lead to suppositions on what the other partner's attitude is towards these issues. Reliance on the testimony of one partner may also obscure the tensions and power struggles in decision making. This study addresses this weakness by considering the views of both partners as well as those of other actors such as health professionals in the decision making process. As noted earlier another gap in the literature which this study addresses concerns the lack of voice from health professionals regarding their views on the decisions made by patients with HIV/AIDS.

1.2 Study Background

In Zimbabwe, HIV has not only become a critical public health issue, but also an important political, security as well as economic problem with 1 in every 4 people estimated to be HIV positive at the time this research was done in 2005 (UNAIDS, 2004). A UNAIDS 2004 report estimated that by the end of 2003, 24.6% of the adult population (15-49 years) had HIV/AIDS, while over 15% of the entire population was infected. The report also estimated that there were over 900 000 HIV orphans in Zimbabwe by the end of 2003 (UNAIDS, 2004). This not only has economic repercussions but also far reaching social implications as it puts pressure on the already fragile social support systems which have been weakened by the volatile political and economic situation over the past decade.

The continued high level of infection rates despite protracted HIV/AIDS awareness campaigns in the country can be linked to the social construction of HIV/AIDS and the stigma associated with HIV/AIDS. Despite the high level of

knowledge among the populace about HIV (UNAIDS, 2004), high risk sexual behaviour is still common and the stigmatisation of those with the virus remains high. This indicates the strong influence of moral values in people's lives (Rugamela, 2004) which may be helping to sustain the risk denial syndrome. Stigma, that is, any condition, attribute, trait or behaviour that symbolically marks the bearer as socially or culturally unacceptable (Goffman, 1963), not only affects people with HIV/AIDS but also has far reaching consequences for the entire population. It can be argued that stigmatisation of people with HIV/AIDS in the society contributed and continues to contribute to the spread of HIV within the population. Fear of discrimination and rejection by the society or loved ones and the fear of loss of economic means may breed a culture of silence, denial and secrecy among those infected. This may help fuel the epidemic as it makes infected people reluctant to change their lifestyles, to take preventive strategies or to disclose their status. Despite protracted campaigns against stigma related to HIV/AIDS in Zimbabwe, stigmatisation is still very much alive in the society not least in health institutions and among health professionals (Tarwireyi & Majoko, 2003).

Over the past decade, reproductive health among HIV positive heterosexual couples has emerged as a challenge both to health officials and politicians. The infection of people of reproductive age not only impacts negatively on the country's health delivery system but also on its economy as there is a massive loss of human capital. Since reproductive health is socially constructed in a macro context, including kinship and family systems, it is important for this study to incorporate the WHO's definition of reproductive health. The 1999 WHO definition shifted focus from the macro concern with rapid population growth in the Third World, especially Sub-Saharan Africa, to individual rights in sexuality and reproduction. Reproductive health came to be defined as;

The promotion of safe and responsible sexual behaviour, particularly during adolescence; family planning; prevention of maternal and newborn deaths and disabilities; and prevention and management of unsafe abortion and reproductive tract infections, including those which are sexually transmitted; of harmful practices such as female genital mutilation; and of violence related to sexuality and reproduction (WHO, 1999)

In the patriarchal setting where men typically dominate social and economic relations, gender relations are expected to play an important role in influencing

reproductive behaviours and decisions. Gender in this study was not used to refer specifically to the situation of women but rather to culturally constructed social relations between men and women that have resulted in gender inequalities. As Hawkes & Hart (2000) note, whereas sex refers to biological differences between men and women; gender refers to culturally determined notions of masculinity and femininity which differ from culture to culture. Though a number of studies have been undertaken on the influence of gender on reproductive decision making in Zimbabwe (Grieser et al., 2001; Feldman & Maposhere, 2003), little attention has so far been paid to the role of gender power relations in decision making among couples with HIV/AIDS. In the analysis of how gender influences the decision making process among those infected with HIV/AIDS this study will define the concept of gender based power relationships as the ability of one partner to act independently, to dominate decision making, to engage in behaviour against the other partners' wishes, or to control a partner's actions (Pulerwitz et al., 2000).

HIV positive couples, whether discordant or concordant face difficult reproductive decisions especially in Zimbabwe where HAART is only available to about three percent of the people who need it (UNAIDS/WHO, 2005). Thus, though the risk of transmission from mother to child is low due to the use of nevirapine and azidothymidine (AZT), HIV positive people have to consider their health and future since they are not assured that they will get HAART when they need it.

The study is set against the backdrop of a potentially volatile political situation, economic meltdown, deteriorating social and health services and weakened social safety nets. There is also a high prevalence of HIV especially in the reproductive age group. The study is set in a cultural setting which accords high value to the roles of motherhood and fatherhood and has set values and norms on sexual conduct. This study presents findings on how HIV positive people deal with reproductive and sexual issues under such socio-economic and cultural conditions.

1.4 Chapter Layout

The thesis is organised into eight chapters. Chapter one comprises the study introduction as well as the background. Chapter two presents a critical analysis of the literature relevant to this study while chapter three focuses on the methodology used in this research. The study findings are presented in three chapters. Chapter four is a presentation of the findings regarding reproductive and sexual issues

among HIV positive couples. Chapter five presents the perspective of the HPs regarding reproduction among people with HIV while chapter six presents findings on the patterns and process of reproductive decision making by HIV positive couples. Chapter seven is a general discussion and analysis of the findings and chapter eight concludes the thesis.

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CHAPTER TWO

HIV/AIDS AND REPRODUCTION: A CRITICAL REVIEW

2.0 Introduction

This chapter critically reviews the literature on HIV/AIDS and its influence on reproduction. The chapter will present and discuss the literature on the effects of the epidemic on reproductive decision making and factors influencing the decisions of HIV positive couples. It has to be noted that decision making in relation to reproduction tends to be an emotionally laden and multifaceted process which is not only a determinant of couples. It is a sphere where a number of actors play a significant role in the Zimbabwean society today. These include the wider family who usually have an input in the decision making process either directly or indirectly and the health professionals who have a direct effect on reproductive decisions of couples either through contraceptive use/family planning advice or through putting a cap on the number of children a couple can have due to medical reasons. Apart from these sources of influence, the couple also has to contend with a number of socio-cultural and economic factors in its decision making.

HIV positive couples occupy a special but nonetheless precarious position in the web of decision making. Special in the sense that they are usually not regarded as “normal” couples, precarious since they may face stigmatisation, discrimination and censure both from the community and the medical fraternity. Thus their decision making process is rather complex and bears with it personal imprints, medical, emotional, moral and ethical issues. For HIV/AIDS infected couples in this study, the critical decision to make was whether or not to conceive after they discovered their HIV status and if so, when. They also had to make decisions regarding sexual behaviour as well as contraception.

Decisions at different stages of their lives are influenced by a multiplicity of factors, not least the social factor. The manner in which the society conceptualises HIV/AIDS may have a significant role in shaping the reproductive decisions of HIV positive couples. As Goffman (1963) argues, the bearer of a stigmatised condition may seek its management through concealment and behaving like the “normals”, in order to be accepted within the community. This may be a conscious

and sometimes unconscious behaviour of bearers of stigmatised conditions like HIV.

2.1 HIV/AIDS and its effects on reproduction

The AIDS epidemic which has hit Southern Africa with such devastating force affects a variety of reproductive decisions among infected people. These include the desire to have children, whether or not to become pregnant, when to use contraception and which type and decisions on whether to continue or try to terminate a pregnancy. It is important to note that infected couples exist within a social structure bound by cultural norms, ethics and morals and they may be influenced by these. The manner in which these social factors and being HIV positive affects the reproductive decisions of couples living with HIV is the subject of the following subsections.

2.1.1 The desire to have children

Findings from studies in the U.S. have shown that knowledge of HIV serostatus was not necessarily associated with the desire or intention to become pregnant. A significant proportion of HIV infected adults still desire or intend to have children. Chen and colleagues (2001) used U.S. nationally representative data to examine the desires of HIV-positive men and women. They found that 28% of HIV-positive men and 29% HIV-positive women desired and expected to have children in the future, and that women who expected to have children were most likely to be black, with no children, and with a partner with confirmed positive HIV status (Chen et al., 2001). However, they also found the percentage of HIV-positive women desiring children sometime in the future was 36% less than the percentage of women in the U.S. population who desired children in the future.

In a qualitative study conducted in New York City, Siegel & Schrimshaw (2001) interviewed 51 women with HIV and found that all of them were primarily concerned with the possibility of having an HIV-infected child, but they expressed considerable interest in or desire to have a child. In a cross-sectional study of 45 African American women with HIV, 17 (37.8%) reported positive motivation to have children even though they had HIV (Sowell et al., 1999). In Scotland, 12 (30.7%) of 39 respondents in a cohort of HIV-positive men and women reported having conceived, having tried to conceive, or intended to conceive since

diagnosis, and 17(43.5%) of them had not had any children since diagnosis (Green, 1994). In a study of condom use and family planning in people living with HIV in Zimbabwe, Meursing and Sibindi (1995) indicated that a considerable number of HIV positive women expressed a strong desire to have a child. In a later study Feldman and Maposhere (2003) reported that the desire to have a child was prominent in those women who had no living child, especially those who were under 25 years of age.

Though an HIV positive status does not seem to affect the desire of the infected couples, it does impact on their ability to have children. As these studies and others quoted in the next sub section indicate, HIV positive women tend to have a lower fertility rate compared to the rates among the general population or HIV negative women. This is partly because of their personal concerns about their status as well as the impact of the condition on their health. Ill health tends to impact negatively on fertility.

2.1.2 The incidence of pregnancy after HIV diagnosis

Studies have indicated that some HIV-infected women became pregnant after learning their HIV positive status. A U.S. study of 403 HIV-infected women showed that the incidence of subsequent pregnancy, defined as HIV-infected women who became pregnant after knowing their HIV positive status, was 6.3% for each person-year of follow-up (Bedimo et al., 1998). Another U.S. study reported 55 (23.1%) of 238 HIV-infected women had become pregnant since diagnosis (Kline et al., 1995). In a South Eastern Italy study, one of the few HIV-infected couple studies, 76 pregnancies in 76 women (33.7%) of a cohort of 225 sexually active women with HIV infection were reported during a follow-up period of 39 months (Greco et al., 1999). In an Australian study of 294 women with HIV infection, 58 (23%) of 246 women of childbearing age became pregnant after HIV diagnosis (Thackway et al., 1997). In a study of 59 HIV positive women in Zimbabwe, the incidence of falling pregnant after diagnosis was 30.3 %, with 18 women having fallen pregnant since diagnosis. The study further indicated that of the 18 women who had fallen pregnant, 38.8% had done so intentionally with the remainder having unplanned pregnancies (Feldman & Maposhere, 2003). The weakness of most of these studies is that they do not indicate whether the recorded pregnancies were intentional or accidental.

Findings from a number of studies showed that pregnancy rates were not significantly different between HIV positive and negative women. A study of 203 female IV drug users enrolled in a longitudinal study in New York City showed that there was no significant difference in pregnancy rate, 11.6% pregnancies per person-year for HIV-positive women and 10.3% pregnancies per person-year for HIV-negative women (Selwyn et al., 1989). In a study that followed 108 HIV-positive women and 98 HIV-negative women for 1.5 years, no significant difference was found in the numbers of live births between the two groups (Sunderland et al., 1992). A study of 71 HIV discordant couples in the U.S. found that women in couples with HIV had pregnancy rates similar to those of women of reproductive age in the general population (Van Devanter et al., 1998).

Contrary to the studies above Thackway et al. (1997) found the average general fertility rate for HIV positive women was 53% lower than the average general fertility rate for Australian women during the same period. However, comparisons between HIV-infected and uninfected women could be misleading if the two groups differ in ways that relate to fertility irrespective of HIV status. To avoid this problem, some investigators compared pregnancy rates among the same women before and after HIV diagnosis and reported a decline of pregnancy rates after HIV diagnosis. In a cohort of French HIV-infected women of childbearing age, the pregnancy rate decreased significantly after the diagnosis of HIV infection, from 20.4% to 7.9% per person-year (De Vincenzi et al., 1997). A large cohort study of 503 women with HIV in the United Kingdom found a decline of 44% in the age-adjusted live-birth rate from 10.2% per person-year before HIV diagnosis to 5.7% after diagnosis (Stephenson & Griffioen, 1996).

Studies carried out in Sub-Saharan Africa indicate that HIV/AIDS has a negative impact on fertility (Gray et al, 1998; Zaba & Gregson, 1998; Glynn et al, 2000). Gray et al, (1998) indicate that in a study of Ugandan HIV positive and HIV negative women of reproductive age (15-49) the incidence rate of recognised pregnancy during the prospective follow-up study was lower in HIV-1-positive than in HIV-1-negative women (23.5 vs 30.1 per 100 woman-years). Though HIV/AIDS lowers fertility among those who are positive, it seems that the world over, a considerable number of HIV positive couples continues with child bearing after infection. This may indicate the universality of the value of motherhood and fatherhood.

The results from the above studies indicate that there is a higher percentage of HIV positive people who desire to have children compared to those who intend or who have had children post diagnosis. This indicates that though these people have a desire to have children, there are constraints to their desires. These constraints may be socio-cultural, economic or medical. Thus being HIV positive does seem to change the decision making terrain of infected couples.

2.1.3 **The optimism of having a healthy child**

Concerns for the possibility of perinatal transmission of HIV and expectations about the neonate's HIV serostatus are crucial factors in couples' reproductive decisions. Studies from both the developed and developing world indicate that HIV positive women have stated their perception of the mother-to-child HIV transmission rate was greater than 50% which deterred their willingness to take risks to have children (Grieser et al., 2001; Selwyn et al., 1989; Williams, 1990). However, 36%-76% HIV positive women expected their babies would be free from HIV infection (Murphy et al., 1998; Sowell & Misener, 1997).

HIV positive women appear to have their own ways of interpreting the risk of perinatal transmission, which is different from the biomedical explanation of vertical transmission. For instance, HIV positive women who used drugs believed that the chance of vertical transmission was 100% when both parents were infected and only 50% if the mother alone was infected (Pivnick, 1994). One study conducted in Zimbabwe reported that people believed healthy children are indications of the health of the parents, thus, if a child survives to age five, the parents continue to have children (Grieser et al., 2001). In some studies, HIV positive women believe that God will intervene in determining the outcome of their pregnancy (Hutchison & Kurth, 1991; Siegel & Schrimshaw, 2001; Sowell & Misener, 1997).

HIV-infected women who were young and asymptomatic strongly believed that there were low risks to the child if a woman was healthy and took care of herself during pregnancy (Johnstone et al., 1990; Siegel & Schrimshaw, 2001; Sowell & Misener, 1997). This belief was strongest among women who had witnessed other HIV positive mothers who had given birth to a healthy baby or whose baby had seroconverted (Siegel & Schrimshaw, 2001). The recent finding that the risk of vertical transmission could be substantially reduced through a regimen of antiviral

medication was viewed by the women as an encouragement and they felt it was no longer inappropriate to consider pregnancy (Feldman & Maposhere, 2003; Siegel & Schrimshaw, 2001; Vitiello & Smeltzer, 1999). Thus most HIV positive women who intentionally become pregnant do so in the hope that their child will be born in a healthy HIV negative state.

2,2 The medically associated factors in decision making

2.2.1 HAART and Reproduction

The advent of HAART has led many scholars to predict an inevitable change in the perception of family planning and fertility among HIV positive people (Thornton et al., 2004; Panozzo et al, 2003; Sauer, 2003). In recent years, major strides in the development of effective drug regimens to counter the inexorable march of the HI- virus have been made. The result has been that people with HIV can now live longer, healthier lives, unpunctuated by frequent opportunistic infections. Studies, albeit mostly in the developed world, indicate that HAART can effectively control viral replication and reduce the risk of vertical as well as horizontal transmission considerably (Semprini & Simona, 2004; Thornton et al. 2004). Advances in HAART, combined with specific obstetrical procedures have enabled those HIV positive people who want children, to have them with a very low risk of transmitting the virus to their infants. With better health due to HAART, they stand a better chance of seeing their offspring mature. Thus the prediction in the change of perception on fertility is not misplaced.

It is notable that most studies of reproductive choice among people with HIV largely antedate HAART. A few studies have been carried out to evaluate the impact of HAART on reproduction and pregnancy trends. However, in the studies that have been carried out, the indication is that HAART has a positive impact on pregnancy trends and fertility. In a study carried out in the USA, Stewart et al. (2004) found that sero-positive women who conceived were more likely to continue their pregnancies after HAART than before. Blair et al. (2004) in a study of trends in pregnancy rates among women with HIV pre and post HAART in the US, indicate that higher pregnancy rates were observed for women prescribed HAART than women prescribed other regimens of antiretroviral regimens. The available evidence thus indicates that the availability of HAART does play a role in reproductive related decisions.

2.2.2 Health Professionals and decision making

Though the Zimbabwe National Aids Policy (1999) upholds the basic and reproductive rights of HIV positive people, there seems to be an unofficial policy in the medical fraternity that people with HIV/AIDS should be strongly discouraged from having a child or not be permitted to reproduce. In a survey of HIV positive women in 2001, 86% indicated that they felt the society expected HIV positive women not to reproduce (Feldman & Maposhere, 2003). It has to be taken into cognizance that although health professionals are expected to be professional in their discharge of duty they are also part of the society. They are influenced by its social and moral values as well as its prejudices like any other member. Thus their views and fears about HIV/AIDS may mirror and sometimes negatively influence those of the society. Although HIV is one of many conditions which can be passed from mother to child, it has been singled out for moral censure and coercive policies within a social climate of public opinions all over the world (Levine & Dubler, 1990; Semprini & Simona, 2004).

The evolution of reproductive health policy in the United States provides a good example of how policy influences reproductive decisions among people with HIV/AIDS. The initial recommendation for preventing perinatal transmission of HIV, announced by the United States Public Health Service (USPHS) in 1985, advised that women at risk should seek HIV antibody testing and should postpone pregnancy if they or their sexual partners were known to be HIV positive (CDC, 1985). In July 1995, the USPHS revised the recommendation and proposed that healthcare providers counsel all pregnant women about HIV prevention and encourage testing for HIV, and for the first time formally recommended initiating zidovudine (AZT) therapy to reduce the risk for perinatal transmission of the human immunodeficiency virus type 1 (HIV-1) (CDC, 1995).

Until 1998, pregnancy was regarded as a reason to defer standard therapy. Since then, more combination drug regimens that maximally suppress viral replication have been recommended. Health providers are encouraged to offer antiretroviral therapy to HIV-1-infected women during pregnancy to reduce perinatal transmission. The therapy is accompanied by a discussion of the known and unknown short- and long-term benefits and risks of such therapy for infected

women and their infant (CDC, 1998; 2000). However, some HIV positive women in the U.S. still face obstacles in accessing clinical care. One survey found that women with HIV have limited access to reproductive health services that provide gynaecologic, contraceptive and pregnancy-related care to women known to be infected with HIV (Williams et al., 1996). Data show that many HIV positive women found health care professionals were not willing to discuss reproductive options with them, encouraged them to terminate pregnancies, and reported that they learned about AZT or other options from magazines, television talk shows, and friends instead of from health care providers (Green, 1994; Sowell & Misener, 1997).

In Zimbabwe, a number of studies have indicated that health professionals actively encouraged HIV positive women to use contraceptive methods in order to prevent further pregnancies and counseled them against any repeat pregnancies. In a number of studies pregnant women have faced difficulties in health care centers, have not received adequate care or information and sometimes health officials have refused to help deliver them due to fear of HIV infection. It emerged that HIV positive women usually do not receive adequate information concerning their reproductive health and that of their child. Most women in the studies were discouraged from having a repeat pregnancy as a result of their previous experience at the hands of health professionals, some went to the extent of not disclosing their HIV condition to health practitioners for fear of victimization, yet others chose to deliver at home (Grieser et al., 2001; Meursing & Sibindi, 1995; Feldman & Maposhere, 2003; Bassett & Mhloyi, 1991). It is assumed that this behavior by health professionals was predicated on the fear of HIV infection due to lack of adequate knowledge about the virus as well as lack of preventive materials.

2.2.3 **Contraceptive use**

Contraception is an important factor that influences pregnancy rates but few studies have so far examined the contraceptive behaviors of sexually active HIV positive couples. Few studies have reported the contraceptive choices of HIV positive women. What has been reported is that there are high repeat pregnancy rates, low rates of consistent condom use, greater likelihood of voluntary sterilization, and high discontinuation rates of hormonal contraceptives (CDC,

1996; Diaz, Schable & Chu, 1995; Galavotti & Schnell, 1994; Wilson et al., 1999, Meursing & Sibindi, 1995; Dodoo, 1998). It is however not clear from the studies why these responses are so. Whether they are a reflection of unmet reproductive needs or a result of pressure from a partner or a deliberate choice is not clear. Though most of these studies isolate the important determinants and barriers to contraceptive use by women, a major gap is that the direct voice of men, who are said to be a stumbling block to contraceptive use and sexual health of women, is missing. With the shift in emphasis and direction of reproductive health programs since the ICPD (International Conference on Population and Development) in 1994, it is increasingly becoming evident that to understand the dynamics of reproductive processes it is best to collect data from both partners. It is not surprising however that people with HIV who desire or intend to get pregnant do not consistently use contraception. In a survey of HIV positive women carried out in Zimbabwe it was found that practicing safer sex after diagnosis and the use of contraceptives was inconsistent. Though 87% of the women interviewed indicated that they used contraceptives to prevent pregnancy and 75% also used condoms to prevent further sexually transmitted infection (STI) and re-infection, the use of contraceptive methods was irregular (Feldman & Maposhere, 2003). The use of condoms to safeguard one's health and that of the partner was found to vary greatly among the women surveyed. Variation was dependent mainly on age, relationship, number of surviving children and experiences of pregnancy (ibid).

A number of studies have also commented on the importance of gender based power relations in determining contraceptive use in Sub-Saharan Africa. Caldwell (1987) and Drennan (1998) have advanced the argument that men and their relatives dominate reproduction and decide on matters of family size in Africa. It has also been argued that women in Zimbabwe not only lack access to appropriate contraceptives especially in rural areas but that they also lack control over contraception and sex (Meursing & Sibindi, 1995; Feldman & Maposhere, 2003).

On condom use, Meursing & Sibindi (1995) have indicated that the resistance of men to use condoms in marriage in Zimbabwe remains a major barrier to HIV prevention. This study and others on this subject have not included the views of both sexes in their analysis of contraceptive use among those infected with HIV.

The role of health practitioners in influencing HIV positive women and men to use condoms and other contraceptives has also not been given much attention. Are infected women being encouraged to use contraception to prevent future pregnancies and how is this done? These are some of the concerns not addressed by these studies which this study addresses.

2.3 Socio-cultural factors

Individuals approach decision-making processes from a social, cultural, interpersonal, and medical context. The literature demonstrates that HIV status is not the sole determinant of reproductive decisions among people with HIV infection; rather, reproductive decisions are based on personal, medical and socio-cultural factors. This section reviews how the socio-cultural context may influence reproductive decisions among people with HIV/AIDS.

2.3.1 Motherhood and Fatherhood

Motherhood or fatherhood is a greatly valued status in the Ndebele society. A marriage without a child is regarded as incomplete and couples will do anything to have a child (Nyathi 2001, Ndlovu et al. 1995). Given the fact that most HIV positive couples do not divulge their status to the society or to their families, they are expected to reproduce like any other couple whether they are willing to or not. A number of studies from Africa and the developed world have indicated that due to these social expectations, HIV positive women do not feel that they can choose freely to become pregnant or feel comfortable continuing an existing pregnancy (Hutchinson, 1999; 2000; Pivnick, 1994; Sowell & Misener, 1997; Sowell et al., 1999; Van Devanter et al., 1998; Vitiello & Smeltzer, 1999; Williams, 1990; Feldman & Maposhere, 2003).

An HIV positive person's personal view of what pregnancy or a child means to them can influence their feelings and decisions regarding family planning. These views initially may have been shaped through cultural and spiritual development and integrated into the self by psychological factors and personal experience (Williams, Watkins & Risby, 1996). In African society, cultural norms and values emphasize motherhood/fatherhood as valued roles that represent not only maturity but responsibility. Pregnancy symbolizes an internalization of commitment and connection with a partner, family and extended community (Bradley-Springer,

1994). But different cultures place varying degrees of importance on reproduction and motherhood. In Ndebele culture, the inability to have children for the father's clan is a disgrace and may lead to divorce. However, not only are women expected to reproduce, they should also reproduce healthy, unblemished children and raise them successfully according to social standards. The concept of motherhood embodies all this and HIV positive people may find themselves in an unenviable position of trying to strike a balance between social values and expectations, their personal needs and the implications of an HIV positive status on their lives.

Women occupy a unique position in the AIDS epidemic because not only are they at risk of infection from the same sources as are men, they can also be the source of the virus for the fetus. Most literature about women and HIV focuses on the risk of maternal-prenatal transmission, ignoring the fact that women are individuals living in societies that have social-cultural expectations for women. Women with HIV who decide to initiate or continue a pregnancy are seen as selfish, irresponsible, immoral, cruel or uncaring (Bradley-Springer, 1994; Ingram & Hutchinson, 2000; Sowell & Misener, 1997; Williams et al., 1996; Feldman & Maposhere, 2003). The social expectation of women and the archetype ideal of motherhood force HIV positive women into a double bind situation in which society expects women to be mothers, yet at the same time, it negatively judges HIV positive women who choose to become pregnant (Ingram & Hutchinson, 2000; Feldman & Maposhere, 2003).

Although society holds negative attitudes toward HIV positive people, some qualitative research findings from both the North and South vividly portray the childbearing experience and the importance of motherhood among HIV positive women. Being a mother was viewed as a joy, a means of enhancing self-esteem, an identity of a complete woman, a means of a new chance, and a means of rebirth (Hutchison & Kurth, 1991; Ingram & Hutchinson, 1999; 2000; Siegel & Schrimshaw, 2001; Sowell & Misener, 1997; Feldman & Maposhere, 2003; Meursing & Sibindi, 1995). Children were described as a reason to continue living, a source of emotional and psychological support, a love both given and received and a meaning of new life (Hutchison & Kurth, 1991; Ingram & Hutchinson, 1999; 2000; Pivnick, 1994; Sowell & Misener, 1997; Williams et al., 1996; Grieser et al., 2001). Some women chose to have children in order to

strengthen their existing or new relationships and to gain acceptance by the in-laws (Meursing & Sibindi, 1995). Motherhood or fatherhood seem to be a greatly valued role that HIV positive people are willing to take risks to attain, especially those who have no surviving children.

2.3.2 Men in reproductive decision making

Until recently the role of male partners in reproductive decisions has not been given much attention (ICPD, 1994). Most studies have concentrated on women while giving scant attention to the role played by their partners in decision making (Williams et al, 1996; Wilson et al, 1999; Sowell et al, 1999; Wesley et al, 2000, Feldman & Maposhere, 2003). It may be the women who become pregnant and who may transmit HIV to their unborn babies, but their male partners may also play a role, sometimes a significant one, in making the decision on whether to have a child or not, and on whether to use contraception and which one. However, few studies of reproductive decisions among people with HIV/AIDS have included both partners. One study of HIV discordant heterosexual couples indicated that many HIV negative partners expressed a strong desire to have some part of the partner after death and saw having a child together as a way to fulfill this desire (Van Devanter et al., 1998). However, this study did not shed much light on the context and process of decision making.

As pointed out above most studies tend to evaluate the role and influence of the male partner and other actors in decision making from the perspective of women. Examples of such studies include that done in Zimbabwe by Feldman & Maposhere (2003). Actors in any decision making environment tend to have their biases and certain perceptions of others which are not necessarily grounded on reality (Schneider, 2002; Lewis, 2006). Thus, to base conclusions about the role of each actor on reproductive decision making mainly on the views, perceptions and attitudes of a single actor may produce biased results since that actor is more likely to highlight their side of the story. The level of unreliability or bias of findings is further exacerbated by the usual lack of communication on reproductive and sexual issues between partners which may lead to suppositions on what the other partner's attitude is towards these issues. A study on 'Fertility and child death in Zimbabwe' carried out in 1999 (unpublished – see Grieser et.al. 2001) found that a considerable number of couples did not discuss sexual and

reproductive issues. Another study done in KwaZulu-Natal (Maharaj & Cleland, 2005) also found that a substantial number of couples had never discussed the issue of contraceptive use. In an environment where communication between partners is not very high, the reliance on information from one partner whether male or female, may obscure important issues such as the power dynamics involved in decision making.

Among the few studies that incorporate both partners, most concluded that men often have greater influence in decision making than women (Grieser et.al., 2001; Gage, 1998). One study by Maharaj & Cleland (2005) contradicted this general view of reproductive decision making by couples. The study found that contrary to generally held views, among the Zulu, the wife's own desire to avoid future child bearing was the strongest predictor of contraceptive use. Thus instead of the husband, it was the wife who had greater influence in deciding whether to use or not to use contraception. Since women do not exist in isolation but in a socio-cultural context, in order to understand the choices or decisions that they 'make', it is imperative to include their partners in the equation as well as to explore the systems of power that govern such relationships. This study will look at how power is used to influence decisions not only by the individuals within a relationship but also by other actors like the family and health professionals.

In most societies, especially in Africa, where there is still a strong hold of patriarchy and tradition men are generally regarded as formidable barriers to women's decision making about reproduction and contraceptive use (Greene 2000; Toubia, 1995) yet most studies on reproduction do not give them voice. It is generally accepted as conventional wisdom that women have no control or power over the means of reproduction in Zimbabwe and other male dominated societies (Duffy, 2005; Feldman & Maposhere, 2003; Meursing & Sibindi, 1995). It is argued that in Sub-Saharan Africa, male dominance is spread over both the public and private domain making it "virtually impossible for a woman to move, act, or think freely" (Toubia, 1995). Machera (2004) argued that women lack 'bedroom power' and Caldwell (1987) said 'women have no voice'. In spite of the overwhelming evidence of the dominance of men in reproductive issues in patriarchal African societies, including the Zimbabwean society, for the purposes of this study it will be assumed that power in reproduction is a contested area

where both men and women play an active role. This assumption is based on the fact that “it is nearly always women who bear the physical and emotional costs of child bearing and who have to assume prime responsibility for preventing and/or delaying pregnancy” (Maharaj & Cleland, 2005). As such, using the reproductive decision making process of HIV positive couples studied this study explores the role played by each partner in the decision making process.

2.3.3 Family and social influences on reproductive choices

The meanings of childbearing are not static; rather they evolve over time and are influenced by historical, socio-cultural and political environmental changes. Traditional norms among the patriarchal societies of Zimbabwe from which the study sample was drawn define reproduction as a matter of family: it is not a matter in which an individual can make unilateral decisions, and the family is construed not in terms of husband and wife but in a wider patri- and matrimonial sense (Ndlovu et al., 1995). Selfhood is defined in the context of a wider society and not on individuation. As p'Bitek (1973) put it, in the African society, no individual is born free; everyone is born with responsibilities and is owed responsibilities by the society s/he is born into. The society expects every social member to discharge their duties to the best of their ability. Reproduction among the Ndebele is viewed as the social duty of every married man and woman (Nyathi, 2001). It is these social philosophical underpinnings that put married couples under pressure to conceive and reproduce. A child solemnizes the marriage and is the fulfillment of the parents' obligations to society.

In contrast to Western culture, most Zimbabwean societies are built on the philosophical tenet in which the socio political philosophy of group dependency is emphasized. The emphasis on community and family as the organizing social structure exerts fundamental pressures on the individual to subordinate rather than advance personal needs (Bradshaw, 1994). The family among the Ndebele people (who formed the bulk of the study respondents), it is argued, plays an important role in influencing reproductive decisions (Msimang, 1991). Pressure is exerted on married couples to have children. In a study of HIV positive women Meursing & Sibindi (1995) report that, a number of young women who had no surviving children intentionally became pregnant in a bid to strengthen their relationship with their husbands as well as their in-laws. These women pointed out that

children stabilized and ensured the survival of their marriages or relationships.

A strong preference for male children is well documented in Ndebele culture (Ndlovu et al., 1995; Nyathi, 2001; Krige, 1977). This is no surprise as it reflects the patriarchal nature of the society. Power and inheritance is transmitted patrilineally among the Ndebele hence the desirability of a son in every family. The importance of a son is linked primarily to the need to continue the father's clan into the next generation and secondarily as an insurance against old age (Nyathi, 2001; Krige, 1977). It is however important to note that society and culture are not static. They are in a process of constant flux and movement with values, traditions and norms changing over time. The question then is how much power or control do traditions have on couples in the present context? When making reproductive decisions do people follow what they say their culture expects; do they honour their traditional norms? The study deals with these issues as it grapples with the issue of the role of culture in decision making among HIV positive couples today.

2.3.4 Socio-political impacts on reproductive health

As a result of political and socio-economic changes, there have been corresponding changes in reproductive policies in Zimbabwe. Prior to independence, not much attention was paid to contraceptive and reproductive issues relating to the majority Black population in the country. With independence in 1980, focus was turned on the improvement of the masses through education and the improvement and provision of health care facilities. With the advice and the support of the World Health Organization and Western governments, the Zimbabwean government also focused its attention on the reduction of the country's high fertility rate. In accord with the neo-Malthusian philosophy dominant in the West at the time, high population growth was viewed as an antithesis to development. Thus the Zimbabwe government was persuaded to control the number of new births as the best way to improve economic development (West, 1994).

In the 1980's there was a massive campaign to promote family planning among the Zimbabwean population. There were free contraception services for females and males of childbearing age especially the contraceptive pill and the condom.

These were made available without a prescription and could be obtained easily from pharmacies, urban and rural clinics and hospitals as well as from Village Health Workers (VHW's). These methods were recommended by the World Health Organisation and the Health Ministry as the best and economically viable way to avoid unwanted pregnancies as well as the best tool for the state to control over population (WHO, 1985; Ministry of Health, 1986). The result was a massive reduction in fertility rates from 6 total births per woman in 1980 to 3.2 total births per woman in 2002 (UNAIDS, 2002; Grieser et al., 2001; Maposhere & Feldman 2003). According to statistics related to women's health from the WHO in 1997, 53.5% of married women had used contraception and nearly 100% of adults knew at least one method of contraception. Owing to the government's vigorous family planning program, the birth rate which was as high as 50 per 1,000 in 1981 has now declined to 24.59 per 1,000, with a population growth rate of 0.7 % in 2001 (CSO, 2002). As a result of this success Zimbabwe has been promoted as a model of one of the most successful family planning programs in Sub-Saharan Africa (West, 1994).

The ideology behind the national family-planning program was not based on the concept of women's rights or freedom of choice. On the contrary, it was mandated to gain control over population size (West, 1994). The wave of women's rights groups which sprouted after independence in Zimbabwe led to the push for women's rights based upon Western concepts of individual rights. Nevertheless, Zimbabwean women's bodies and their sexuality are still constrained by traditional expectations for women. For example, the desired number and occurrence of additional children is significantly related to women's perceptions of their in-laws' preferences for boys (Grieser et al, 2001; Meursing & Sibindi, 1995). The social expectation that a woman should have a son is evidence that the Ndebele traditional world view is deeply embedded in reproductive attitudes. Under this philosophical view, a woman is accountable to men all her life: to her father as a child, then after marriage to her husband, and in old age to her son. Thus, although Ndebele women have different options for contraception, their reproductive choices about childbearing, desired family size, and contraceptive use still seem to be controlled by others, particularly by husbands, family, medical authorities, and the government. How and to what extent this is real and how it has changed among couples with HIV/AIDS is discussed in the study findings.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

The following chapter outlines the epistemological and methodological framework for this study. It also outlines the data collection methods used, describes the data analysis strategies, as well as the characteristics of the respondents and gives the socio-economic background to the study.

3.1 Epistemological framework

The concern of this study was to find out what happens in the area of reproductive decision making among the HIV positive couples and how this happens. Its aim was to describe the factors that impact on decision making among this social group taking into cognisance the context under which such decisions take place. Making reproductive decisions or choices is a complex issue which not only has to be understood from a personal subjective level but also from a socio-cultural level since the value framework within which an individual decision maker usually operates is socially constructed. Decision making is usually an interaction of personal interpretation or meaning making and socially constructed meaning. Decisions or choices are made within a framework which incorporates both personal and social values.

To understand the complex and rather subjective phenomenon of reproductive decision making and to interpret it as objectively as possible, this study adopted an eclectic approach. That is a synthesis of different perspectives which makes the description and analysis of the complex process of decision making understandable both from an insider and outsider perspective. In analysing and interpreting the data, the etic approach as well as the constructivist and hermeneutic epistemologies were used. Both the emic and etic approaches were used in the study since to me “obtaining something of the understanding of an insider *was* only the first step” to understanding reproductive decisions among people with HIV/AIDS (Wax, 1971). As a cultural insider the researcher sought to obtain an understanding of reproductive issues among people with HIV/AIDS and then describe these to and for the outsiders. In doing this it was important to

assume a mental position from which one would be able to perceive and analyse the relationships, systems and patterns of which an inextricably involved insider is not likely to be consciously aware (Wax, 1971). Thus in interpreting and analysing the data the researcher had to try and stand outside his culture in a bid to give an objective view of what was happening inside.

The insider-outsider position is sometimes seen as an epistemological principle centred on the issue of access; which can take two forms. One is a 'monopolistic access' (Merton, 1972), in which the researcher possesses exclusive knowledge of the community and its members, and the other is where the researcher has privileged access, in which he or she has a claim to the hidden knowledge of the group that an outsider as a 'professional stranger' who is detached from the commitments of the group under study would be unable to access (Agar, 1996). Though in this study the researcher can not lay claim to the "hidden knowledge of the (HIV positive) group", as a cultural insider he can lay claim to an intimate knowledge of the society and its culture, morality and norms. This intimate knowledge offers insights that are at times difficult or impossible to access by an outsider. The values of shared socio-cultural experience, cultural interpretation, and deeper understanding and clarity of thought, are closely tied together and inform one another in a variety of ways. As an insider the researcher was in a position to interpret socio-cultural aspects accurately and also had a greater understanding of what respondents meant by what they said. As a result of a shared cultural and linguistic background with the respondents the researcher was able to create rapport relatively free from tensions and thus gather more in depth and relevant qualitative information. Though the researcher was not an insider to the HIV positive group, as a cultural insider he was able to understand and interpret socio-cultural concepts and nuances as well as the worldview of the respondents that might have been lost to an outsider.

The aim of emic description, according to Harris (1997), is to produce a view of the world that the participants accept as real, meaningful or appropriate. To produce such descriptions the research had to elicit the subjective understandings of reproductive issues among HIV positive people from the HPs and people with HIV/AIDS. Taking an insider's perspective meant that reproductive decision making had to be understood in terms of the respondent's own interpretation of reality and understanding of the situation. Such an approach was suited to this

study as the study sought to describe and reconstruct the reproductive world of HIV positive couples from their own understanding of it, focussing on discourses and lines of reasoning that underlie their reproductive decisions. The researcher attempted to get as close as possible to what really goes on in the process of reproductive decision making and thus capture and analyse the lived experiences of decision making among those who are HIV positive. This was only possible because the researcher could assume both the mantle of a cultural and linguistic insider as well as that of an outsider as a scientific investigator.

A constructivist perspective was used in describing and analysing how social constructions impact on the behaviour and actions regarding sex and reproduction among couples with HIV/AIDS. Using a constructivist philosophy I argue that the socio-cultural and economic 'reality' that impacts on people's views, attitudes and ultimately their decisions is socially constructed. People create 'reality' as much as this constructed reality/knowledge creates or shapes people's behaviour and actions. Constructivism, as Shadish (1995) notes, refers to constructing knowledge about reality and not constructing reality itself. This however does not mean that the socially constructed reality is not perceived and experienced as real by the people who constructed or construct it. What is perceived or defined by people as real is real in its consequences (Thomas & Thomas, 1928 in Patton, 2002). It is this constructed knowledge about reality, shaped as it is by cultural and linguistic elements, that influences people's views in one way or another. Through a constructivist approach the study sought to explore and interpret realities about reproduction constructed by HIV positive people and HPs as well as the implications of these constructions for their lives and their interactions with others (Patton, 2002).

The way people understand and interpret 'reality' is dependent on the way in which culture, in its dynamism, has shaped them. As Crotty (1998) notes "...social constructionism emphasises the hold our culture has on us: it shapes the way in which we see things (even in the way in which we feel things!) and gives us quite a definite view of the world". However the hold that culture has on us is not absolute and it does not mean that every individual will behave similarly in a similar environment. In the real world people may react quite differently to the same stimuli. The constructivist perspective argues that "all tenable statements

about existence depend on a worldview and no world view is uniquely determined by empirical or sense data about the world” (Patton, 2002). This means two people may have different perceptions or interpretations of the same reality depending on their standpoint. Taking the current study as an example, it can be projected that different actors in the reproductive decision making process of HIV positive people will inevitably have different expectations and perceptions on the issue of reproduction. The views of HPs on reproduction were to a large extent incompatible with those of HIV positive people but both views were experienced as valid. The study attempted to capture these different views through in-depth interviews with both HIV positive people and HPs. The implications of these different and sometimes conflicting views on the issue of reproduction were then analysed using the methodological model described below (see figure 1 below).

In analysing the interview data which forms the basis of this study I also used a hermeneutic approach. Hermeneutics posits that what something means depends on the cultural context in which it was originally created as well as the cultural context within which it is subsequently interpreted (Patton, 2002). The conditions under which a human act occurred may determine its meaning as much as the standpoint of the researcher may determine his/her interpretation of the data. Thus it was important in the study to be self aware and reflexive. The hermeneutic approach implies that the reproductive and sexual life of HIV positive people and the role of others in it have to be understood within the social, cultural, economic, political and medical context in which it occurs. As an insider who knew and understood the culture and language of the respondents I was in a position to interpret accurately what the respondents said and meant.

In analysing and examining the sexual and reproductive issues raised by both HIV positive people and HPs and the relationship of these two groups, etic approaches described above were adopted. By adopting an etic approach one is able to stand far enough from a particular phenomenon to see and understand emerging or existent patterns. It also enables one to describe the subjective reality of the respondents in an ‘objective’ manner by relating subjective experiences and views to relevant social theories and concepts. Being aware that pure subjectivity can undermine credibility, validity and reliability and that complete objectivity is impossible (Patton, 2002), this study sought balance in order to understand and

depict the reproductive world of the HIV positive couples authentically in all its complexity while being self-analytical and politically aware.

Decision making is an important aspect of this study. The study attempted to describe how couples make decisions regarding reproductive issues in so far as they make those decisions. Decisions, it has to be noted, are made within a social context. As Plous (1993) argues, there is no such thing as context free decision making. But how does an individual or, in this case, a couple arrive at a particular decision and how can the decision they make be explained? Is the choice to become pregnant and bring to birth a child an irrational choice (Benett, 2003) or is it a rational process where all the available information is taken into account and weighed carefully before a decision is made? Are HIV positive couple's in this study active processors of information from the outside world and do they use the knowledge at their disposal to consciously consider their constraints and weigh options available to them in their current context? A response to these questions is attempted in chapter six of this study.

This study also engages a number of theories and models in trying to explain the decision making patterns observed in the study sample. These include the evolutionary theory and the behavioural change models. The evolutionary theory posits that naturally men and women adopt different strategies of reproduction to maximise their reproductive success (fitness) and that women have always been significantly involved in the reproductive process than currently assumed as a result of their greater parental investment in the offspring (Campbell, 2002; Barash, 1979). The health belief model challenges this theory by arguing that the likelihood of a person adopting a given health related behaviour is a function of that individuals' perception of a threat to their personal health. Thus people tend to change their behaviour only if their health is under threat. The usefulness of these theories in explaining the reproductive behaviour and choices of HIV positive couples is evaluated later in the study.

3.2 Methodological framework

In describing and discussing the context and content of reproductive decision making among the study sample the study uses an analytical model adopted from policy analysis and adapted to this study (see figure 1 below).

According to this model to better understand the process of decision making it is important to understand the context of decision making, the content of decisions made and the process of making these decisions as well as the role of different actors in the process. This model also posits that power is an underlying factor in decision making. This study not only describes the context and content of reproductive decisions made by the study sample but in the process of doing that it explores the relative influence or power exercised by different actors (i.e. the couple itself, family, and health professionals) on decisions that pertain to reproduction (reproduction in this context encompasses contraceptive use, child bearing and sex). As a result of the role and impact of different actors in decision making the underlying thread in the discussion will be who exercises what kind of power in decision making and how they exercise that power. As such the study will explore how power over ideas, knowledge and information may be used to shape the views and attitudes of couples or individuals with regard to contraceptive use, sex and child bearing. Power in the context of this study will be used in a number of different but related senses. This includes power as the ability to achieve an outcome – to prevail. This power *to* can be contrasted with power *over* – which primarily describes a relationship between parties. Power can also be seen as a subtle ability to shape someone's views, beliefs and attitudes (Lukes, 1974). Thus power can generally be conceived 'as the ability of one partner to act independently, to dominate decision making, to engage in behaviour against the other partners' wishes, or to control a partner's actions' through overt or covert means (Pulerwitz et.al., 2000).

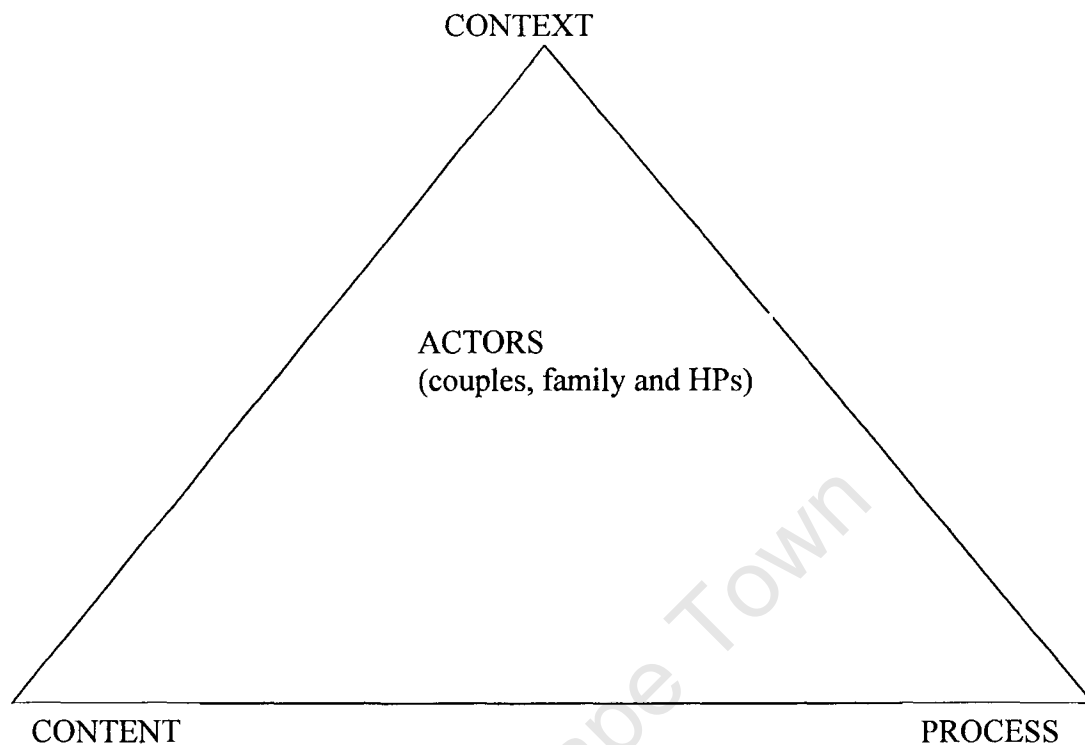


FIGURE 1. A framework for reproductive decision making analysis

The thesis proceeds by firstly exploring the contextual environment in which the study sample lives. It then discusses the content of their decisions and how these are affected by the contextual factors. Within the description and discussion of context and content is encapsulated the role of different actors in the decision making process. Thus in discussing decision making among the study sample the study engages the complex set of interrelationships that encompass context, content, actors and power. From the discussion of study findings it is notable that actors are influenced by the socio-cultural, economic, political as well as the medical context in which they live and operate. The context is also subject to the influences of culture, politics and other factors while the process of decision making itself is affected by different actors and the power they possess. Thus to make sense of the content of decisions made it is important to understand the complex interaction of content, context, process and the role of actors in it. No one element in this set (context, content, process) can be fully understood independent of others. Thus in exploring the context and content of reproductive decision

making among the HIV positive sample this study makes use of the above framework (figure 1) to better understand the process of decision making.

3.3 Research setting

The study was conducted in the city of Bulawayo, which is the second largest city in Zimbabwe. This was in a bid to narrow down the research setting to a manageable area and also reduce the problem of social differentiation which can be presented by incorporating a rural setting. Because of its position as an industrial hub and a major city in Matabeleland, cultural diversity is inevitable in Bulawayo as people of different cultural backgrounds converge there mainly for economic reasons. However most respondents were from a Ndebele cultural background and as a result the Ndebele culture is used as the main reference point in the thesis.

Since couples' reproductive decisions might be expressed and or discussed in a variety of places, the data for this study was collected in different settings as determined by field circumstances. These settings included opportunistic infections clinics and participants' homes.

3.4 Data collection methods

One method of data collection, the in-depth interview, was used in the field. Two main groups of people were interviewed in the research and these are the HIV positive couples and the HPs. HIV positive couples were interviewed to explore how being HIV affects their reproductive decision making process and to find out other factors that might affect their reproductive decisions. The health practitioners were interviewed in order to assess their role in and impact on the reproductive sphere of couples living with HIV /AIDS. Due to the nature of reproductive decision making and the medical condition of HIV positive people it was assumed that a sizeable number of actors would play a role in the decision making process of HIV positive couples. Actors expected to play a role in the reproductive lives of the HIV positive people included traditional birth attendants, traditional healers, church leaders, health professionals, family members and friends. However, as the study evolved it emerged that only health professionals and family members played an influential role in the reproductive lives of the study respondents. This may have been due to the atypical nature of the study

sample and its close relationship with the opportunistic infections clinic or the health sector. Thus based on the interviews with the HIV positive couples only health professionals were interviewed as other actors did not seem to play any important role in their decision making.

As this was a qualitative study the in-depth interview method was chosen as it facilitates the study of issues in depth and detail as well as in context. As (Patton 2002) notes, open ended questions and probes yield in-depth responses about people's experiences, perceptions, opinions, feelings, and knowledge. The depth interview is also suitable when dealing with sensitive issues like childbearing, one's sexual behaviour and health. These issues are usually political and tied up with personal and gendered identities such that a structured method may not be the best way of capturing the subjective views of both HIV positive people and health practitioners. Moreover an open interview accommodates the emergence of unanticipated issues and allows the researcher to explore them as well as allowing the observation and noting of non-verbal communication which may be critical in the research.

Two data collection strategies were used in this research. These are the depth interview and examination of related documentation. For HIV positive couples two interviews were conducted, that is one interview per partner. A single interview was also conducted with health practitioners. It was the intention of the researcher to interview people of different socio-economic background to obtain rich and diverse information. However, given the secrecy and stigma associated with HIV/AIDS in Zimbabwe this proved to be a big challenge. As a result I was unable to find willing respondents from those who can afford to procure ARV's on their own as well as afford private health care.

3.5 Data collection procedure and problems faced

The researcher faced a number of challenges in the field, one of them being forced to change the method of recruiting respondents. The initial targeted number of HIV positive respondents for the study was 30. However only 18 couples were recruited and of these only 15 were actually interviewed. It proved to be a difficult task to find willing respondents and maybe as a researcher I had underestimated the grip that HIV/AIDS associated stigma still has on Zimbabwean society. The

difficulties faced by the researcher in the field left him with no illusions about the persistence of stigma in Zimbabwean society. Shame and fear of HIV/AIDS still continue to fuel stigma in Zimbabwe. A study conducted by DFID in 2006, well after my field study, indicated that there were still high levels of stigma and discrimination in Zimbabwe with most stigma indicators well over 50%. In fact over 82 % of the respondents indicated that people with HIV/AIDS should be ashamed of themselves and that they would be ashamed of themselves if they had HIV/AIDS (DFID, 2006). This indicates that cultural and moral values still have a vice grip on people's lives. Because HIV is transmitted through sex – much of it of the sort that is itself morally, religiously, legally and culturally stigmatised - it has become surrounded by taboo, secrecy and moral judgement. As a result of the stigma attached to HIV and the possible negative consequences of disclosure most couples are unwilling to disclose their status to each other let alone talk to researchers. Also, with hindsight, the eligibility criterion that required couple's to be heterosexual and to have disclosed their status to each other was perhaps too strict. In an environment where stigma and discrimination is still high there were not many HIV positive couples in Bulawayo who met the stipulated qualifying requirements or who were willing to take the risk of exposing themselves by talking to a researcher. Thus the failure to get the targeted number of respondents forced the researcher to make do with those who could be found.

During fieldwork it became apparent that HIV positive people in Zimbabwe are still a rather 'closed community or group' and by that is meant that it is not easy for someone classed as an outsider, i.e. an HIV negative person, to easily get access to the group. This may be a result of the stigma, discrimination and shame associated with HIV/AIDS. The main method of recruitment that had been proposed was advertising the study by distributing leaflets with details of the study and eligibility criteria required through support groups, voluntary counselling and testing centres and opportunistic infections clinics. The researcher visited a number of support groups where leaflets and talks about the study were given. Some of these support groups were facilitated by the Population Services International/Zimbabwe, some by the MSF while others were facilitated by the HIV positive people themselves and permission was granted before they were visited. This method however had a very low success rate. Only two couples were recruited this way with only one successfully completing the study. The other

couple was excluded as the husband could not be interviewed due to his work commitments as a long distance driver. The failure of this recruitment method can be attributed to the fact that the researcher was regarded as an outsider to the 'group'.

The possible lack of success with one recruitment method had been anticipated by the researcher during the planning stage. From an insider perspective it is generally assumed that a common culture between interviewers and interviewees can provide a fertile ground for gaining access, nurturing rapport, asking meaningful questions and reaching empathetic and deeper understanding of issues being explored (Labaree, 2002). While this was the case in this research after gaining access to the 'group', cultural homogeneity did not provide the researcher with automatic access to this 'closed group' of people. Though I was culturally an insider I was still regarded as an outsider by the HIV positive people mainly because of my HIV negative status and my position as a researcher. Having failed to get through to the HIV positive couples within their 'closed group', I sought help from those who had been working with the group and had gained their trust. The MSF office in Bulawayo played an important role as the entry point through which I accessed willing respondents. The office seconded one of their HIV positive peer counsellors to act as my field assistant for the duration of my field research and help me find willing respondents. As an 'insider' the field assistant helped me to re-administer the recruitment flyer (Appendix F) in support group meetings and at the OI clinics. After administering the recruitment flyer prospective respondents who qualified to enter the study and were willing to do so were asked either to inform me or my field assistant. An appointment was then scheduled with those who were willing to participate in the study. Having a field assistant who had a background similar to that of the study sample helped a lot in recruiting respondents. As a result of his HIV positive status the field assistant shared his stigmatised condition with the respondents and was accepted by the 'group' as one of our 'own kind' as much as he regarded himself as part of the 'group'. His trust and acceptability by the 'group' was also enhanced by the fact that he worked closely with the HIV positive people as a peer counsellor at the Mpilo opportunistic infections clinic.

Snowball sampling was also used in recruiting respondents. Snowballing was used in this study as it offered better chances of accessing hard to reach and stigmatised groups like HIV positive people. Usually in a 'closed group' a link exists between the initial sample and others in the same target population, allowing a series of referrals to be made within a circle of acquaintance (Berg, 1988). The initial couples who came forward after administering the recruitment flyer were asked after the completion of the interviews if they knew another couple/s that will be willing to participate in the study. In this way the researcher moved from one couple to the next and managed to access most of the respondents in this study that would otherwise have been missed if some other method had been used. The main problem with this method was however the production of a somewhat homogeneous and atypical sample which was not representative of all HIV positive couples in Bulawayo since referrals were dependent on the social networks of the respondents first accessed. Due to the selection bias which produced a particular group of respondents with close inter-relationships the results of this study are not generalisable. However, though claims to generality can not be made from this sample the results reveal a number of important issues and suggest a number of inferences that can be made about HIV positive couples in relation to reproduction.

Once it became clear that only a particular sample of HIV positive couples could be interviewed, i.e. those who attended the OI clinics and support groups, the researcher made a conscious decision to interview only health professionals who dealt mainly with this specialised group. This was in a bid to enhance the value and replicability of the study. It is important to point out that I also worked closely with one of the MSF project officers at the Mpilo OI clinic who helped a lot in organising interviews with the health professionals and sourcing other relevant official data and statistics.

3.6 Sample characteristics

3.6.1 Couples with HIV

A sample of 30 couples was initially targeted but only eighteen couples willing to participate in the study were found. Of these, three couples were eventually left out of the study. In two of these cases the husbands worked out of town and I subsequently failed to organise a successful appointment with the couples. In one

of the cases the wife became seriously ill and the interview had to be cancelled. As a result only fifteen couples eventually took part in the study. An eligibility criterion was used in the recruitment of eligible candidates. The following characteristics were used to define eligibility for the study; i. The couple had to be of opposite sex in an intimate relationship in which at least one partner is infected; ii. Female partners had to be between 20 and 49 years of age; iii. Both partners had to have disclosed their HIV status to each other; iv. They had to be confronting or have confronted reproductive decisions after learning of the HIV status; and v. They had to be able to communicate effectively either in Ndebele, Shona or English.

Of the fifteen couples interviewed only two were sero-discordant (Couple 2 and Couple 9) and in both cases male partners were negative. In terms of age the respondents ranged from 25 to 55 with the median age being 36.1. Four of the couples had children together, ten of the couples had children from their previous relationships but none together and only one couple (Couple 14) had no child either from a previous relationship or together. Among the ten couples there were two where the male partners had never fathered a child (Couple 1 and Couple 9) and only one where the female partner had never mothered a child (Couple 5). The number of children among these couples ranged between one and four. Most couples indicated a desire to have children but only two (Couple 12, Couple 5) indicated that they intended to have a child in the near future. Of these only Couple 12 (C12) had actively tried to conceive in the past. Couple 1 Male (C1M), Couple 4 Female (C4F), Couple 9 Male (C9M) and Couple 14 Male (C14M) also indicated that they intended to have children in the near future. In terms of socio-economic status most respondents had incomes that are below the poverty datum line of US\$1 a day and the men were more likely to be working than the women. Educationally, most respondents had some secondary school education. Most of the relationships were relatively young at no more than a year old and eighteen of the respondents were on ARVs. Demographic and reproductive information concerning the fifteen couples is given in Table 1 and Table 2 below.

This study represents a small and unique sample of HIV positive people in that only couples, and among them only a limited number of those who had disclosed their status to each other and were willing to participate in the study, were

selected. Thus the sample is not representative of HIV positive people in Bulawayo let alone in Zimbabwe. UNICEF (2005) estimated that the population of Zimbabwe stood at 12.9 million by the end of 2004. Of these people nearly 800 000 lived in the city of Bulawayo and 24.6% of the total population were living with HIV/AIDS (UNICEF, 2005). Using these figures it can be estimated that over 150 000 people lived with HIV/AIDS by the end of 2004 in Bulawayo. The atypical nature of the respondents also has to be noted. Its effects on the findings and implications will be discussed at various points in this study. Snowball sampling led to the inclusion of people with mainly similar attributes since most people had come to know each other through support groups and opportunistic infections clinics. Some of the respondents interviewed in this study were involved in HIV/AIDS activism and work, with some being peer counsellors in Opportunistic Infections (OI) clinics (Table 1). Most were on ARVs and some on the waiting list and most had gone through intensive counselling and education through support groups organised by the OI clinics, NGO's and people living with HIV/AIDS themselves. Thus most of the respondents were exposed to information on HIV/AIDS. Apart from this those couples/individuals who intended and some who still desired to have children indicated that they searched for information regarding HIV and reproduction from a number of different sources including the internet. As a result of this pro activeness in seeking information some of the respondents displayed a high level of understanding of issues relating to their condition. As such these characteristics probably render the sample quite unrepresentative of the general HIV positive population of Bulawayo.

Regardless of the study limitations highlighted above, this study highlights important and significant issues in the area of reproductive decision making among HIV positive couples. The study sample is a group of Zimbabwean couples who are HIV positive and who have or are faced with the challenge of reproductive decision making – hence it is of value to see what effect their status has on them. Important lessons are drawn about how they perceive their status and make sense of it in relation to the pressure/desire to have children. The findings from this study indicate how this sub-set of Zimbabweans make reproductive decisions and how this is linked to what they know, the available medication and the views and pressure coming from HPs and the society.

Table 1 – Main Characteristics of the HIV positive sample

| | | Age | Relationship status | Level of education (years in educ) | No. of children | No. of pregnancies | Children in current relationship | HIV status: Year known | On ARVs? | Desires to have children | Intends to have children | employment |
|----|---|-----|----------------------------|---------------------------------------|-----------------|--------------------|----------------------------------|---------------------------|------------------|--------------------------|--------------------------|-----------------|
| C1 | F | 36 | Single; in a relationship | Secondary (11 yrs) | 1 | 1 | 0 | HIV positive: May 2004 | Yes: Nov.2004 | yes | no | Unemployed |
| | M | 33 | Single; in a relationship | Secondary (11 yrs) | 0 | NA | 0 | HIV positive Dec. 2004 | Yes: Feb.2005 | yes | yes | Self employed |
| C2 | F | 42 | married | tertiary | 1 | 2 | 0 | HIV positive 1986 | Yes | no | no | Peer counsellor |
| | M | 45 | married | Secondary (9 yrs) | 4 | NA | 0 | HIV negative | NA | no | no | Musician |
| C3 | F | 42 | married | Primary (7 yrs) | 3 | 3 | 2 | HIV positive 2004 | no | no | no | Unemployed |
| | M | 43 | married | Secondary (11 yrs) | 2 | NA | 2 | HIV positive: 2002 | No | No | no | Pensioner |
| C4 | F | 39 | Widowed; in a relationship | Secondary (11 yrs) | 3 | 3 | 0 | HIV positive Aug.2004 | no | yes | yes | Unemployed |
| | M | 40 | Widowed; in a relationship | Secondary (11 yrs) | 3 | NA | 0 | HIV positive Sept.2004 | No | no | no | Self employed |
| C5 | F | 26 | Single; in a relationship | tertiary (pending) | 0 | 1 | 0 | HIV positive 2003 | yes | yes | Yes | Unemployed |
| | M | 36 | married | Secondary (11 yrs) | 1 | NA | 0 | HIV positive 1996 | yes | yes | yes | Self employed |
| C6 | F | 43 | Widowed; in a relationship | Primary (7 yrs) | 4 | | 0 | HIV positive Mar. 2001 | Yes Aug.2004 | no | No | Self employed |
| | M | 38 | Widowed; in a relationship | Secondary (11 yrs) | 3 | NA | 0 | HIV positive 2001 | yes | no | no | Security guard |
| C7 | F | 36 | Widowed; in a relationship | Secondary | 2 | - | 0 | HIV positive | no | yes | no | Unemployed |

| | | | | | | | | | | | | |
|-----|---|----|-----------------------------|-----------------------|---|----|---|--------------------------|-----------------|-----|-----|---|
| | M | 42 | Widowed; in a relationship | (11 yrs) Secondary | 3 | NA | 0 | 2003 HIV positive | yes | yes | no | Security guard |
| C8 | F | 30 | married | (9 yrs) Secondary | 4 | 4 | 4 | 2001 HIV positive | Yes | no | No | Unemployed |
| | M | 36 | married | (11 yrs) Secondary | 4 | NA | 4 | 2002 HIV positive | 2004 yes | no | no | Self employed |
| C9 | F | 28 | Single; in a relationship | (11 yrs) Secondary | 1 | 1 | 0 | 2003 HIV positive | yes | yes | no | Unemployed |
| | M | 30 | Single; in a relationship | (10 yrs) Secondary | 0 | NA | 0 | 2000 HIV negative | NA | yes | yes | Factory worker |
| C10 | F | 43 | married | (11 yrs) Primary | 4 | 4 | 4 | HIV positive | yes | no | no | Community worker |
| | M | 48 | married | (7 yrs) Primary | 4 | NA | 4 | 2001 HIV positive | no | no | no | Tailor |
| C11 | F | 32 | Widowed; in a relationship | (7 yrs) Secondary | 3 | 5 | 0 | 2005 HIV positive | Yes | yes | no | Self employed |
| | M | 39 | Widowed; in a relationship | (11 yrs) Secondary | 4 | NA | 0 | 1999 HIV positive | 2004 Yes | yes | no | Self employed |
| C12 | F | 36 | Single; in a relationship | (9 yrs) Secondary | 1 | 1 | 0 | Aug.2004 HIV positive | Yes | yes | yes | Peer counsellor |
| | M | 38 | divorced; in a relationship | (11 yrs) Secondary | 3 | NA | 0 | Dec2002 HIV positive | Apr.2004 Yes | yes | yes | Security guard, part time peer counsellor |
| C13 | F | 34 | married | (11 yrs) Primary | 3 | - | 2 | 2003 HIV positive | May2004 yes | yes | No | unemployed |
| | M | 30 | married | (7 yrs) Secondary | 2 | NA | 2 | Jan.2004 HIV positive | Yes | yes | no | Security guard |
| | | | | (11 yrs) | | | | Oct.2003 | Jul.2004 | | | |

| | | | | | | | | | | | | |
|------|---|----|---------------------------|-----------------------|---|----|---|--------------------------|----|-----|-----|---------------|
| C 14 | F | 24 | Single; in a relationship | Secondary (11 yrs) | 0 | 0 | 0 | HIV positive Jan.2004 | no | yes | No | Self employed |
| | M | 29 | Single; in a relationship | Secondary (11 yrs) | 0 | NA | 0 | HIV positive Dec.2003 | no | yes | Yes | unemployed |
| C 15 | F | 35 | married | Primary (7 yrs) | 1 | 2 | 0 | HIV positive Feb.2005 | no | yes | no | Self employed |
| | M | 30 | married | Secondary (9 yrs) | 1 | NA | 0 | HIV positive Mar.2005 | no | yes | no | Self employed |

Table 2

Indications on MTCT risk, reproductive choices and reproductive attitudes of HPs from the perspective of HIV positive people

| | MTCT risk as seen by HIV positive people | | | | Reproductive plans of HIV positive people | | | | HPs and information given to HIV positive people as seen by HIV positive people | | |
|-----|--|-----|---------|----------|---|---------------------------------------|----------------------|--|---|----------------------|---------------------------|
| | high | low | average | On ARVs? | Against child bearing | Has desire but no intent to reproduce | Intends to reproduce | No desire, no intent to reproduce, not against child bearing | anti pregnancy information | balanced information | pro pregnancy information |
| C1F | | * | | yes | | * | | | * | | |
| C1M | | * | | yes | | | * | | * | | |
| C2F | * | | | yes | * | | | | * | | |
| C2M | | * | | NA | | | | * | * | | |
| C3F | | | * | no | | | | * | * | | |

| | | | | | | | | | | | |
|------|---|---|---|-----|---|---|---|---|---|---|---|
| C3M | | * | | no | | | * | | * | | |
| C4F | | * | | no | | | * | | * | | |
| C4M | * | | | no | * | | | | * | | |
| C5F | | * | | yes | | | * | | * | | |
| C5M | | * | | yes | | | * | | | * | |
| C6F | | * | | yes | | | | * | * | | |
| C6M | | * | | yes | | | | * | | * | |
| C7F | * | | | no | | * | | | * | | |
| C7M | | * | | yes | | * | | | | * | |
| C8F | * | | | yes | * | | | | * | | |
| C8M | * | | | yes | * | | | | * | | |
| C9F | | | * | yes | | * | | | - | - | - |
| C9M | | * | | NA | | | * | | | * | |
| C10F | * | | | yes | | | | * | * | | |
| C10M | * | | | no | | | | * | - | - | - |
| C11F | * | | | yes | * | | | | * | | |
| C11M | | * | | yes | | * | | | * | | |
| C12F | | * | | yes | | | * | | * | | |
| C12M | | * | | yes | | | * | | * | | |
| C13F | | | * | yes | | * | | | * | | |
| C13M | | * | | yes | | * | | | * | | |
| C14F | | | * | no | | * | | | * | | |
| C14M | | * | | no | | | * | | * | | |
| C15F | * | | | no | | * | | | * | | |
| C15M | | | * | no | | * | | | - | - | - |

3.6.2 Health Professionals

In this study 12 health practitioners out of a target of 15 were interviewed. A number of HPs especially doctors were reluctant to participate in the study since they felt there was nothing for them in it. Health practitioner interviewees were selected for their involvement in the care, treatment or counselling of HIV positive people. The defining characteristic for this sample was involvement with HIV positive people in the past two years. Using these characteristics six counsellors, four nurses and two doctors were interviewed. All of them were married and had children except one male nurse. More counsellors than any other group of HPs were selected because according to the interviews with HIV positive people, they seemed to interact with them more than the nurses or the doctors. The main characteristics of the sample are summarised in Table 3 below.

Table 3 Main characteristics of Health Practitioners

| Profession | Sex | Age | Years working with HIV positive people | Views on reproduction among HIV positive people |
|-------------------|------------|------------|---|--|
| Doctor | male | 47 | 3 | Pro-children |
| Doctor | male | 39 | 3 | Pro-children |
| Nurse | female | 33 | 2 | Conditional pro-choice |
| Nurse | female | 26 | 4 | Conditional pro-choice |
| Nurse | female | 29 | 2 | Conditional pro-choice |
| Nurse | male | 28 | 2 | Pro-children |
| Counsellor | male | 31 | 5 | Pro-children |
| Counsellor | male | 32 | 3 | Conditional pro-choice |
| Counsellor | male | 33 | 3 | Conditional pro-choice |
| Counsellor | male | 32 | 4 | Pro-rights |
| Counsellor | female | 36 | 5 | Conditional pro-choice |
| Counsellor | female | 34 | 2 | Pro-rights |
| | | | | |

3.7 Data analysis

An interpretative approach was used in data analysis since the objective of this study was to describe, explain and understand reproductive decisions among HIV positive people both from an insider's and outsider's perspective. This approach was also useful because as a researcher I entered the field with some preconceived hunches and assumptions of what to expect based on my readings of the literature on couples' reproductive decisions and experience from my culture. These hunches included the assumption that socio-cultural factors may push HIV positive couples who have not disclosed their status into being pro-natalist in order to avoid stigmatisation; that couples who already had children prior to diagnosis will be anti-natal and that men dominate reproductive decision making. These assumptions were evaluated, confirmed or disconfirmed using the interview data collected.

Taped interviews were transcribed in the original language. Transcribed interviews were then content analysed to identify patterns and themes concerning reproduction among HIV positive people. The strategies used in the data analysis were a systematic review and a thoughtful reading of interview data, coding, memo writing; categorizing and sorting for patterns and the construction of the story told. Through this, what is significant or the forces that underlie reproductive decision making were teased out and described to enhance our understanding of reproductive issues among HIV positive couples.

3.8 Ethical considerations

HIV/AIDS is a very sensitive area in which a researcher needs to tread with care, especially in the context of the Zimbabwean society where HIV/AIDS related secrecy, stigma and discrimination still abound. In trying to establish rapport with the respondents it is sometimes necessary to know their names. During the interviews I addressed the respondents by their names. However for confidentiality none of the respondents' names are used in the thesis. In protecting the respondents' identities in this research, respondents were asked to use pseudonyms when signing the consent form if they were uncomfortable using their real names. Most of the respondents were recruited at the Opportunistic Infections clinics and in support groups. With the assistance of an HIV positive field

assistant the purpose of the study was explained to potential participants and those willing to participate were asked to come forward.

Every participant was asked to sign a consent form (see appendix C). The consent form explained the purpose of the study and the rights of the participant. Further to this, before an interview I explained in detail the procedure and the purpose of the study. Permission to tape record the interview was sought from the participants and there was no instance in which it was refused. The participants were made aware of their right not to answer any question that they did not want to. It was also within their rights to discontinue the interview when they decided that they no longer wanted to carry on and they were informed of this. It was also made clear that there would not be any repercussions for discontinuing with the interview.

It has to be noted that this study was carried out mainly for academic purposes. It may or may not benefit the participants. It has to be noted also that the study involved minimal risk to participants. Throughout the research process I tried my best to conduct myself as professionally as I could and to be considerate and sensitive in order not to cause the respondents any discomfort or embarrassment.

3.9 Socio-economic background and context

This study was carried against the backdrop of ever deteriorating socio-economic conditions in Zimbabwe. Over the last decade or so, Zimbabwe has been gradually declining both socially and economically. Economic mismanagement, corruption, clientelist policies and the Structural Adjustment Programme (SAP) has seen the Zimbabwean economy nose dive from being one of the most promising economies in the late eighties with growth averaging around 4% a year, to one of the fastest shrinking economies in 2005 (Stoneman, 1992; IMF, 2005). According to the World Bank and the UNDP, Zimbabwe is the world's fastest shrinking economy, having declined by 10% annually between 2001 and 2004 (Reuters Foundation, 2005). It was estimated that with continued difficulties in agriculture, rising inflation, and foreign currency shortages particularly for fuel imports, the real gross domestic product (GDP) would contract by some seven percent in 2005 (IMF, 2005).

The continued slide of the local currency against all major currencies means that food prices are consequently rising faster than wages and other entitlements. The

people's entitlements are losing value everyday and the poor are simply being "priced out of the market" into destitution and extreme hunger. Poverty has more than doubled over a decade (1995-2005). The estimated proportion of the population living below the official poverty line has more than doubled since the mid-1990s due to decreasing real incomes and rising unemployment. According to the most recent Poverty Assessment Survey Study (PASS) conducted by the Ministry of Public Service, Labour and Social Welfare and the UNDP at the end of 2003, about 80 percent of the population is estimated to be living below the official poverty line (IMF, 2005). This effectively means that all the respondents who participated in this research lived well below the poverty datum line of US\$1 a day since most of them were either self employed in low income generating projects or were employed in low paying jobs. Generally, poverty has been on the increase in Zimbabwe since the economic meltdown began in the 1990's and this has had the effect of eroding people's safety nets and leaving them vulnerable to any crisis. Other major foreign exchange earners like tourism, tobacco and gold have been greatly crippled by the political and economic climate in Zimbabwe, which leaves the economy in dire straits and most of the workforce unemployed (Sunday Times, October 2005).

The economic situation in Zimbabwe as it stands is grave. The budget deficit is well over 30% of GDP. Government debt was around 60 % of GDP in 2005. Balance of payments deficit was over US\$600m due to deteriorating terms of trade. The tourism industry, which in its prime earned the country US\$400m/year, has virtually collapsed. The unemployment rate is over 70% and increasing with the manufacturing and mining industries being forced to downsize due to the un-conducive economic climate which is further worsened by a politically unpredictable government. Foreign investment continues to dwindle as the political and economic situation worsens. To date there is a high rate of capital flight, high inflation, high interest rates and an erratic power and fuel supply, all of which has led to a hostile business environment (The Financial Gazette, November 2005; IMF, 2005; Sunday Times, October 2005).

The meltdown in the economy has also had disastrous social consequences. One of the results of the economic decline has been that the government has been forced to reduce its expenditure on social security, charge health and school fees and

generally reduce its expenditure on health. The removal of social security at a time when economic screws are being tightened has left many vulnerable groups in the society tottering on the brink of dire poverty and destitution. The economic crisis has led to a sharp deterioration of the medical infrastructure and shortages of essential drugs and equipment, particularly in public hospitals (IMF, 2005). Budgetary cuts in the health budget have left hospitals with no medicines, equipment or with some equipment lying idle due to lack of foreign currency to purchase spare parts. Zimbabwe spent only 4% of its GDP on health care in 2004 while 10.8% went to debt servicing (ibid). UNICEF reported that the quality of health care services in Zimbabwe dropped by over 45% in the last decade (2004). The quality has since dropped further with the brain drain currently hitting the health sector. The high staff attrition, compounded by the lack of adequate resources to run health facilities, has greatly reduced the capacity of the sector to deliver services (IMF, 2005). This, combined with economic factors has increased people's vulnerability to curable diseases and has generally weakened the coping capacity of the health sector. The deteriorating economic situation with its attendant social impacts as well as the impact of the HIV/AIDS epidemic has led to a marked worsening of the quality of life with increased morbidity, mortality and orphan-headed households. Life expectancy at birth declined from its peak of 62 years in 1990 to the current 37 years for men and 34 for women (WHO, 2006).

The deteriorating economic conditions and their impact on the population, represents a serious constraint on reducing the incidence of HIV infection. The recent Zimbabwe Human Development Report (ZHDR) reveals that economic hardships expose poor people to high risk of HIV infection through risky sexual behaviour, including sex in exchange for cash, food, tillage and agricultural inputs, jobs and other basic necessities (IMF, 2005). There has also been a negative impact on education which has seen increased school dropout rates as well as a deteriorating standard of education due to staff attrition and the resulting increase in pupil/teacher ratios.

All of the respondents in the study have incomes that fall below the official poverty datum line. The Consumer Council of Zimbabwe in its monthly reports estimated that as of March 2005, a family of six needed at least Z\$34.9 million per month for basic necessities (AllAfrica.com, 2005). However, the bulk of the workers in Zimbabwe earned less than a third of this at that particular time. It was

assumed that the deteriorating socio-economic environment in the country as well as the economic status of the respondents would play a role in their reproductive decisions. The effect of the socio-economic factor on the reproductive decisions of HIV positive couples is considered further in chapter six which discusses how these couples made their reproductive decisions in so far as they made them.

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CHAPTER FOUR

STUDY FINDINGS

4.0 REPRODUCTIVE AND SEXUAL ISSUES AMONG HIV POSITIVE COUPLES

This chapter outlines the main findings of the study with regards to context and content of decision making among couples who are HIV positive. It focuses on issues such as reproductive health and sexual behaviour prior to and post diagnosis, the impact of being HIV positive on reproduction and the socio-cultural context in which the couples make their decisions. It also discusses at length the main actors in decision making; that is the couples. The impact of the family is also given attention.

4.1 History of reproductive and sexual behaviour prior to diagnosis

As indicated in Table 1 above, most of the relationships which are the subject of study are relatively new. They range between three month and five year old relationships. Only four couples among the eleven who were married prior to or at the time of diagnosis are still with the same partners they were married to. In seven cases where there was marriage at the time of diagnosis either the woman or man has since died and the remaining spouses are in new relationships. In four cases among the fifteen couples that were interviewed both male and female were single at the time of diagnosis though they were in relationships. The discussion of reproductive health and sexual behaviour below covers the time before diagnosis irrespective of the marital status of the respondents at that particular time.

4.1.1 History of pregnancy and abortion

Of the fifteen women who participated in the study fourteen indicated that they had a child or children with the number ranging from one to four. Most women carried all their pregnancies to full term with only three (C2F, C11F, C15F) indicating that they had had one or more miscarriages in their reproductive history. Only one woman reported that she had an abortion while still at school. Though abortion is illegal in Zimbabwe she felt that at that particular time it was in her best interests to terminate the pregnancy. According to the Education Act (1987)

no student is allowed to continue with her classes in a state of pregnancy.

Explaining why she chose to abort she said;

“I can say I was the best student (at school), even my headmistress thought it was the best decision. So at school they phoned my mother and she also thought it was the best thing to do” (C5F).

At the time of interview no woman had had a pregnancy after knowing her status. Of the three couples who indicated that they intended to have a child soon only one couple (C12) had actively tried to conceive but failed. They however later decided to postpone having the child until their CD4 count was high enough to warrant trying again.

4.1.2 Contraceptive use

Contraceptive awareness and use was high among the couples who were interviewed. Nearly all of the couples who were married and those who were not married but were sexually active used or had used a form of contraception prior to diagnosis. This concurs with the world health organisation (WHO) data on contraceptive use in Zimbabwe. According to its report contraceptive use in Zimbabwe is the highest in Sub-Saharan Africa with over 60% of sexually active women using some form of contraception (WHO, 2002.) Contraceptive awareness is also high with over 80% of adult women (above 14 years) aware of one or more family planning method (WHO, 2002). This observation supports the Zimbabwe Demographic and Health Survey of 1999 which indicated that the Total Fertility Rate in Zimbabwe had fallen to 4.0 births per woman compared to 6.0 births per woman in 1988 (CSO, 1999). This was a result of the efforts of the WHO and the government to control population growth in post independent Zimbabwe.

The most common method of contraception used by the majority of women who were interviewed was the oral pill. The other methods like the IUD (loop), Depo-Provera and the condom are not commonly used. This popularity of the pill may be due to the fact that it was the method which was promoted as the ideal method of family planning by the ministry of health and other WHO funded programs. It was also provided and continues to be provided freely in government run health centres and at a subsidised price in most pharmacies in the country. Though, like the pill, the condom was vigorously promoted both in the print and electronic media and provided free in government and private run health institutions it failed

to gain popularity among the populace as a method of family planning. Of the eleven couples who were married prior to or at the time of diagnosis only C10 used the condom for family planning purposes and this was because the other methods she had tried had not worked well for her. Even among those who were not married the condom was not a popular choice. It was used inconsistently and mainly for the purpose of preventing sexually transmitted infections since the concerned women used other forms of contraception to prevent pregnancy.

With regard to condom use there arises two scenarios among the respondents. On one hand, especially with regard to female respondents, the condom was used consistently for the first few occasions until stability and trust were established in the relationship. Thereafter the condom was discarded, which may indicate that like many people in committed relationships, these women may find intimacy in their relationship to be more important than protection against STI's or it may be due to their denial that their trusted partners may put them at risk of HIV. This tendency to discard the condom after people get used to each other was borne out by C1F when she said; "...we were madly in love for the rest of 2003 and we were condomising. But after six months we were not using anything"

Another scenario that emerged mainly among male respondents was the failure to use the condom with casual partners at all or at best an inconsistent use of the condom. This was mainly because they did not see themselves as at risk of contracting HIV. This may be linked to the construction of both condom use and HIV/AIDS in Zimbabwe which is discussed as part of the following subtopic.

4.1.3 Sexual behaviour

Most of those who were unmarried prior to diagnosis, both male and female, had had a number of sexual partners. Commenting on why he had a number of casual sexual relationships C1M said, "...as a man you will be telling yourself that you are enjoying yourself but I had a steady relationship... even then as a man you go around having 'small houses' (other sexual affairs)". This seems to have been a common trend among those who were not married. C4M, C5M, C6M, C12M and C14M all indicated that they had multiple partners prior to getting married. This trend of having casual affairs or engaging in serial monogamy was not limited to those unmarried or to men only. Among most of those who were married at the

time of diagnosis or prior, the men tended to have extra marital affairs. “I had a number of small houses for some time. I realised later that this is where one may get the disease”, confessed one married man (C3M). C13M also indicated that he had a number of casual relationships even after marriage.

In these casual relationships, condom use was mostly minimal and inconsistent. Even though all the respondents were aware of the existence of the condom and what its uses were, they did not take any serious heed to protect themselves. All those who were unmarried prior to diagnosis or those men who had extra marital affairs did not use the condom consistently. In the instances where they were used the primary purpose was not to prevent HIV infection per se. This comes out from the responses of C1M, C12M and C13M. Discussing inconsistent condom use

C1M said;

“...even using condoms I did use them sometimes but I did not use them mainly to prevent HIV. It’s like the thing I was preventing was pregnancy and other diseases like STD’s, that was the thing which was in my mind, not AIDS.”

Similar sentiments were expressed by C12M when he said, “What I feared was an STD only...it did not cross my mind that I could wear a condom thinking that this girl could give me HIV.”

In view of the sexual behaviour of the respondents prior to diagnosis, it can be said they were in a state of HIV/AIDS risk denial. This syndrome is noticeable in most of the respondents; they just did not see themselves as at risk of HIV infection. C1F said, “...but I did not think I could get HIV. No! not me, I was a clean somebody (not of loose morals)”. C5M said, “we used to think that these things (HIV) were only for prostitutes...”, while C5F had this to say; “...and you think it can’t happen to me, it happens to prostitutes”. To those people who knew or were aware of the causal relationship of HIV and AIDS, the issue was not ignorance but attitude. They developed an attitude that it could not happen to them. It seems the spectre of catching HIV was not taken seriously among those who were not married or who were having extra marital affairs prior to diagnosis. There was a general misconception among them that HIV or AIDS as they called it was a disease of a certain class of people and since they did not fall within that class they were safe. This attitude developed as a result of the moralisation of the disease. HIV/AIDS came to be associated with prostitutes, promiscuous and stupid people. It was such a conception that gave some of the respondents a false sense of

safety even though they indulged in risky sexual behaviour. This risk denial syndrome could have emerged as a result of the scare tactics adopted by early HIV/AIDS education campaigns, which in many ways led to the stigmatised social construction of both condom use and HIV/AIDS.

Writing in 1997 Wilton said, "I spend much of my time wondering, not why the advent of AIDS gave rise to panic, but why there is so *little* panic". In view of the early educational campaigns in Zimbabwe and elsewhere in the world I contend there was so little panic because people were not given the right information at the right time, there was so little panic because most people were falsely convinced they were safe in monogamous marriages or in one partner relationships and there was so little panic because of the othering of the disease and the politics of blame. Lack of commitment and political will by many governments meant that by the time they began to take the disease seriously it had already spread to epidemic levels (Usdin, 2003). Action against the disease came rather late with the government in Zimbabwe acknowledging that its actions against HIV/AIDS had been inadequate and limited in scope and effectiveness only in 1999 when it came up with a National AIDS policy (Garbus & Khumalo-Sakutukwa, 2003). This change of attitude towards the fight against HIV/AIDS has begun to bear fruit with the HIV sero prevalence rate among Zimbabwe's adult population declining from 24.6% in 2004 to 20.1% in 2006 (UNAIDS, 2006).

In Zimbabwe, as elsewhere in the world, early educational campaigns focused on AIDS (the last stage of the condition) and not on HIV which ultimately causes AIDS. This may be because the first thing to be scientifically known was the symptoms of the disease and not its cause. The first signs of the disease were noticed in 1981 in the USA and the disease came to be known as AIDS in 1982 (Kanabus & Fredriksson). The cause of AIDS was not isolated until 1983 and it was not officially known as HIV until 1986 (ibid). In the early years of the disease, especially in the media, the focus was on AIDS, its symptoms and the kind of people it infected (ibid; Usdin, 2003). The cause of the disease escaped attention. As a result of the delayed attention to the cause of the disease and how it was spread what became imbued into people's minds was AIDS (the disease) and its catastrophic consequences. HIV did not feature in most people's conception of AIDS (Kalipeni et al., 2004). The effect of this was that when the media and

educational campaigners began talking about HIV and AIDS most people were confused and some still are. To many, HIV and AIDS were and still are conceived as one and the same thing. To say one is HIV positive is similar to saying they have AIDS (ibid). This view may also be a result of the fact that most people in Zimbabwe only test for HIV when they are already sick. As this study will demonstrate the misconception that HIV is AIDS and that someone with AIDS can be easily isolated through his/her symptoms led and continues to lead to the infection of many. It also leads to failure to change risky behaviour that may lead to infection. This misunderstanding of HIV and its relationship with AIDS was not helped by the scare tactics used in the early HIV/AIDS campaigns.

In Zimbabwe the early campaigns focused on the grim prospects of having AIDS. An early billboard advert by the Ministry of Health showed a skeletal dying person with the epitaph "AIDS Kills" beneath it. In the two most popular magazines of the 1980's, the Parade and MOTO, around 80% of all the stories on HIV/AIDS led by the acronym 'AIDS' and in most stories HIV was not even mentioned (Parade, 1988-89; MOTO, 1987-89). The images used by the magazines to depict HIV/AIDS were scary and had moralistic undertones. In the Parade magazine beside every story on AIDS there was a scary sneering human skull with the acronym 'AIDS' above (see Appendix H). The MOTO (a Roman Catholic linked publication) used the image of a snake coiled around the heart which is pierced through by three forks (see Appendix G). Interpreted biblically this meant that AIDS was seen as a result of the sin of the flesh or more specifically the result of fornication. The snake represents evil or the devil and wherever the devil is depicted he always has his tool of choice – the fork, while the heart represents love/sex. Conceptualised this way, AIDS was seen as a punishment of those who indulge in the earthly sins of the flesh and thus people who were infected had got their just desserts.

This focus on AIDS and not HIV by the media and the campaigners against HIV/AIDS led to the misconception of the disease by the public which may have allowed it to spread easily among the population. As the study results reveal, people came to see **AIDS** as the main threat to their lives and not the Human Immuno-deficiency Virus (HIV). It was lost to many that AIDS was just the last stage of a long term condition caused by a virus. In their view what was spread

from one person to the other was AIDS, not the virus. Most were not aware of the HI virus, that it was this virus that led to AIDS or that it could be transmitted by seemingly healthy individuals (Kalipeni et al., 2004). Some extracts from the interviews I carried out will suffice to demonstrate this misconception. C2F said, “me, I did not know about HIV, I knew about AIDS...” C3M said, “I used to hear people just talking saying there is a new disease called HIV/AIDS, in fact they said AIDS, they did not say HIV”. On being told she was HIV positive C11F said,

“...and I said, HIV is one and the same thing as AIDS, isn't it? And she (counsellor) said “no, HIV is a virus which may lead to you developing AIDS after a number of years”.

In so far as informing and educating people on HIV/AIDS, the early educational campaigns and the media failed the public as there was a serious lack of accurate information and education. This lack of accurate and complete information led to the creation of AIDS myths and misconceptions which helped fuel the spread of the disease and heighten the stigma associated with the condition (Ashforth, 2001; Usdin, 2003). One myth that developed among the public was that seemingly healthy people did not have HIV (MOTO, April 1988; Kalipeni et al., 2004). This may have been the direct result of early adverts and media stories that portrayed someone with the disease as skeletal, severely emaciated, with wavy hair and rough skin and generally of poor health. This association of AIDS with emaciation and sickness led to the rise of the phenomenon that has come to be called ‘VAT’ (Visual Aids Test) in Zimbabwe.

This tendency to diagnose someone with HIV/AIDS by the naked eye, dangerous as it may be, is still prevalent in Zimbabwe. No one portrays this tendency more vividly than C12M when he describes his views on HIV/AIDS pre-diagnosis. He said;

“...what I feared was an STD only, when I looked at a girl and felt that no, she was not to be trusted, that is when I used a condom because I thought she may give me an STD but with HIV, it did not cross my mind that I could wear a condom thinking that this girl could give me HIV. No, that did not cross my mind. But I had that knowledge that there was AIDS because we knew AIDS but when I thought of someone with AIDS I saw someone who was in the throes of death. For me to get AIDS I had to have sex with that person; how could I surely have sex with someone whom I saw was dying? So I thought someone healthy looking could only give me an STD and not HIV, you see”.

Similar misconceptions were expressed by C13M, C1M and a number of other respondents. A number of respondents also indicated that they knew about AIDS long before they were diagnosed but they only came to understand the relationship between HIV and AIDS when they tested positive and were informed of the differences during counselling or in support group meetings. Examples are C11F (quoted above) and C4F who said, "I was not aware of the difference between HIV and AIDS until the counsellor explained it to me. I used to think HIV was AIDS". HIV/AIDS was not conceived in terms of viral or bacterial infection but was conceived only as a state of illness manifesting itself through emaciation, diarrhoea, wavy hair and other symptoms. The cause of AIDS did not cross many people's minds. To most of the respondents HIV was equal to AIDS.

The failure to understand the causal relationship between HIV and AIDS meant that most people did not see any need to use condoms for the prevention of HIV. In fact it did not make sense to them to use condoms to prevent AIDS because they could not visualise a normal person who could have sex with a visibly sick/dying person. This misconception of HIV/AIDS may have helped in its spread. It also had far reaching consequences in terms of behaviour change. The belief, that one could tell with the naked eye if a person had HIV/AIDS or not, gave those who indulged in risky behaviour a false sense of safety. As a result they did not see any reason to change their behaviour or to use any form of protection.

The scare tactics adopted by the media and the early HIV/AIDS campaigners to alert the public about the dangers of HIV/AIDS instead led to the moralisation of the disease and the driving of the epidemic underground. There seems to have been a belief among early campaigners that scare tactics would serve to jolt and spur the society into action against AIDS (Wilton, 1997; Naidoo & Wills, 1994). Though such scare tactics had been shown to be ineffective in health education (Naidoo & Wills, 1994), they gained ground in many countries around the world and they were based mainly on the individualistic approach to disease.

From the outset, awareness campaigns took on an epidemiological approach based on the KAP (Knowledge, Attitudes & Practice) model. The basic argument in this model is that, given all the information about the danger of HIV/AIDS and how it

can be prevented, the rational individual will choose to take preventive measures. This assumes that the sexual playing field is level, everyone in the field is equal and everyone has the liberty to make their own choice. The common denominator among the prevention strategies adopted from the early 1990s to the present is their focus on the individual. Sex in these strategies has been constructed as an individual and private matter beyond the sphere of socio-cultural and economic forces. The individual chooses when to have sex, with whom and with or without protection. This focus on the individual is epitomised by the “as easy as ABC (Abstain, Be faithful, Condomise)” prevention slogan which is the byword in most awareness campaigns in Zimbabwe.

The tone set by the HIV/AIDS Awareness campaign in Zimbabwe was that practising safe sex was the key to stopping HIV in its tracks. The individual was identified as the main player in the fight against the epidemic. Abstinence, faithfulness and condom use became the bywords in both the print and electronic media with messages such as “AIDS!!! Abstinence is survival” dominating the advertisements. The main aim of these KAP modelled strategies was to foster individual behavioural change, which, it was argued, would halt the spread of the epidemic. The emphasis in these early campaigns was on individual responsibility for health and they thus ignored the ‘complex interaction of social, cultural and biological forces’ in determining the nature of a disease. This individualist and rather victim blaming and moralistic approach to disease was based on the belief that “fear of disease will lead to a higher morality” and that “the way to control sexually transmitted disease is not through medical means but rather through moral rectitude. A disease such as AIDS is controlled by controlling individual conduct...” (Brandt, 1985)

As a result of such grounding, early campaigns targeted what were called ‘high risk groups’, which in the Zimbabwean context were prostitutes and those who patronised them. Consequently HIV/AIDS came to be associated with social deviants. It came to be seen as a disease of those who deviated from socially accepted or acceptable moral and sexual norms. Nearly all the respondents indicated that this was the impression they had about HIV/AIDS. C2F said, “...we used to hear that there is a new disease, but I really did not care about it because I heard that it’s gotten by prostitutes”. C2M said, “I saw it as a disease which could

be contracted by a person who likes women, who sleeps here and there with many women” while C10F indicated that it was a disease “found among people of loose morals”. C7F indicated that before she knew her status she used to look at those with HIV/AIDS negatively. “I used to look at them with a negative eye, that they were immoral people...”

This moralisation of the disease led those in monogamous and / or steady relationships to believe that they were safe from HIV/AIDS. As Feldman & Maposhere (2003) point out, those perceived to be at risk were frequently seen as other types of women (or men) who did not keep to the social and moral norms and values. This misconception that married women were safe from HIV/AIDS was aptly revealed by C11F. When she went for her initial HIV test she said she was very confident she would be negative.

“...when the counsellor asked me whether I was prepared for my results I said yes because I knew that my husband was the only person I had ever slept with. I had never had any other boyfriend. From school I went straight into marriage and became a housewife and never had any other men beside my husband. I was sure I was clean and I was very confident I would be negative” (C11F).

This notion that if one was faithful to her husband she would not get HIV/AIDS was also expressed by C13F when she said “I used to fear AIDS very much but I did not think I would get it. I thought I would not catch it because I was faithful to my husband”. The association of HIV/AIDS with prostitutes and immorality also led to the impression that hetero sex with any other person other than a prostitute was relatively safe. This may explain the risky sexual behaviour of a number of individuals discussed above particularly C1M, C12M and C13M.

The politics of blame and political inertia on the part of the Zimbabwean government also played a role in the stigmatised and negative construction of HIV/AIDS. As Usdin (2003) notes, the politics of blame characterised the early years of the disease with the North blaming the South and vice versa. In fact this came to be a classic case of chasing a rat from a burning hut while leaving the hut to burn. Gillman (1988) posits that humans generally have a tendency to disavow guilt. He said, “... the desire to locate the origin of a disease is the desire to be assured that we are not at fault, that we have been invaded from without, polluted

by some external agent". This blaming of each other led to xenophobia and scape-goating which has been widely documented (Usdin, 2003; Wilton, 1997).

Locally it led to a feeling among many that HIV/AIDS was a disease created by the whites or of the whites. C1F said, "...I read in another magazine that chimpanzees are the ones with HIV and I said 'what has that got to do with me?'" C6M said he heard that AIDS "was created by western scientists doing experiments on monkeys". C4M had this to say: "...I thought it's a disease of those who go overseas to Europe and have sex with whites, here in African countries it's not there". C12M said,

"...I said ah! these are things of the Whites, could I go and have sex with a white woman? Whites are the ones with AIDS, as for me where can I get it? And those people who travel overseas, they are the ones I thought could have AIDS".

This conceptualisation of HIV/AIDS meant that people did not see themselves as in immediate risk of contracting HIV and as such they did not take any necessary measures to protect themselves.

Such a construction of HIV/AIDS as has been outlined above does not appreciate the importance of condom use. Though people were afraid of HIV/AIDS, as the respondents pointed out, they just did not see themselves as vulnerable and how can a person who conceives his/her position as safe be expected to invest in further safety measures. The misconception of HIV/AIDS meant that most people did not use condoms for HIV prevention. Condoms predated HIV/AIDS by many years but they were not themselves conceived positively within the Zimbabwean society (Meursing & Sibindi, 1995). This negative view on condoms is not new. According to Ginsburg & Rapp (1995), condoms have always been associated with prostitution, philandering and lack of trust since their invention.

The view that condoms were a tool of the sexually immoral led to the view that they were inappropriate in marriage. Today, marriage as a monogamous institution survives mainly on trust and faith and as a condom is conceived as being used in liaisons where there is no trust, its role in the marriage institution is drastically limited. This dominant view of the condom makes it difficult to introduce it within a marriage or long term relationship. Suggesting its use may be construed negatively by one's partner. The fear of being perceived as having multiple partners and being unfaithful to a partner is a major obstacle to condom use in

marriages and other long term relationships (Mitchell & Stevens, 2004). The response by C6F when her husband suggested condom use in their marriage illustrates this point. C6F indicated that she refused to use a condom with her husband when he initially suggested it. She interpreted his suggestion as an accusation of unfaithfulness on her part. She said,

“I did not want to use the condom because I knew that people who used condoms were prostitutes so because I stayed at home (rural areas) I thought when he said we should use the condom it meant that he no longer loved me, that it was the end of my marriage.”

It seems as long as condoms or other barrier methods are associated with acts conceived as immoral in the society they will tend to be overlooked by both men and women in marriages or steady relationships.

This side stepping of condom use in steady relationships or marriages prior to diagnosis is evident in the study sample. A number of reasons for none or inconsistent condom use were proffered by respondents. C4M raised the point that “...condom use is not usually for people who are mutually in love”. This line of reasoning also ran through the reasoning of C5F, C6F, C6M and C7M. This means that when partners trust each other they usually do not concern themselves about their sexual history or condom use. Love and trust are seen as enough to warrant unprotected sex. This attitude to sex continues and needs to be tackled to reduce the risk of HIV infection. As far as these respondents were concerned condoms were used or to be used at one’s discretion with prostitutes or in casual relationships.

In some relationships condoms were used only at the beginning of the relationship but then discarded later on. This was the case with the relationships that C1F, C5F and C13M had. Narrating the nature of one of her sexual relationships C1F said “we stayed with XXX condomising, condomising but we ended up being used to each other and then we threw the condoms away, you see”. C13M had this to say,

“...I had some girls whom I ended up trusting too much and ended up telling myself that ah! this one is too beautiful and healthy, I can not wear a condom for her”.

It seems condoms may be used consistently at the beginning of some relationships but once people feel secure and comfortable in a relationship they discard them.

The condom seems to play a deeper role in some relationships than just protection against STI’s and pregnancy. Condoms are used in a way to protect oneself from ‘emotional hurt’. Perhaps if a condom is used in the early stages of a relationship

one would not feel 'cheap' and / or used when they are dumped early on in the relationship. Commenting on this sense of trust which develops in a relationship as time goes on C5F said,

“when you have sex with a man you will be telling yourself that you are in love, so you trust stupidly of course, but you will be trusting that person...and you think it can't happen to me (HIV), it happens to prostitutes”.

As has been argued above, this risk denial attitude may have been a result of the 'othering' and moralisation of the disease. This attitude towards HIV means that people in steady relationships usually did not / do not see the need to protect themselves even if they have sex with someone whose HIV status they do not know or indulge in other risky sexual behaviour. As a result they expose themselves to the risk of HIV infection without even recognising it. People in such relationships, where there is love and or trust, find it difficult to change their sexual behaviour as they see no immediate risk. Thus the risky sexual behaviour shown by respondents in this study may be explained through ignorance of some respondents and the risk denial attitude displayed by some.

4.2 Reproductive and sexual behaviour post diagnosis

The sexual behaviour of the respondents post diagnosis indicates a marked change from their pre diagnosis sexual behaviour. Where at one time there were a number of casual sexual relationships we have faithful one partner relationships, where there was inconsistent condom use there is disciplined and consistent condom use, where there was a disregard of reproductive health we have a high level of consciousness regarding health issues. Among the fifteen couples who were interviewed, there is only a single case where condom use seemed to have been a problem area (C4). All others did not report facing any problems with condom use in their relationships. It has to be noted that all the couples went through counselling where they were informed about the importance of condom use post diagnosis and that nearly all of them attended support groups where further education and discussion concerning reproductive and sexual issues took place. As a result of this, condom use came to be seen as “the most natural thing to do” with their current partners (C5F). In 14 of the investigated cases condom use in the relationship seems to have been a fairly smooth process. Even among those who were married the transition from non condom use to consistent condom use seems to not have been a problem.

Most of the couples use dual methods of contraception with the condom being used mainly as a preventive strategy against re-infection. “We are using it so we don’t keep on re-infecting each other, we don’t want to re-infect each other” said C5F. Asked what they use the condom for in their relationship C4F had this to say;

“so that we don’t increase each other’s viral load. The viral load he has and the viral load I have are different. His should always be his and mine should always be mine. If we meet (have sex) without a condom we can re-infect each other.”

The other six couples use the condom for the dual purposes of preventing pregnancy as well as re-infection. “we use condoms to prevent pregnancy, we also prevent re-infection, that’s it”, said C1M. Those couples (C1, 5, 6, 7, 9, 10) that use the condom as their sole contraceptive method expressed great confidence in the condom. They did not believe or were unaware that there was any risk of failure and that this could result in pregnancy or re-infection. Expressing this sentiment C5M said,

“Personally I don’t believe that a condom can just break, no, unless if you did not wear it properly or if your sexual act is that one which is aggressive. Ours is not like that, so I don’t see that kind of thing happening, no I don’t see it.”

C7F echoed a similar faith in the condom;

“The thing is that I have never seen a condom tear, it is difficult. And the female condom never gets torn, what can tear it? And as for the male condom you won’t be wearing it correctly. And if you are a woman who knows how to put on the condom on your man I don’t see that one (male condom) getting torn. As for me I trust the condom because I have never seen it getting torn”

This is the line of thinking among those couples who use the condom for both purposes of pregnancy and re-infection prevention.

With this evidence of consistent condom use among HIV positive couples studied, one is bound to seek the reasons behind this trend. What is noticeable among these couples is that most of them met after diagnosis when they already knew their status. What is more, most (11) met either in Opportunistic Infections (OI) clinics or in support groups. So when they met they were already well informed on issues pertaining to reproductive and general health. It is important to note that the main issues discussed in support groups pertain to living and coping with HIV. The main thing that is emphasised is prevention against re-infection as this can impact

negatively on the general health and medication of an HIV positive person. There is no other way to prevent this except the use of a condom and as such people in support groups always encourage each other to use the condom.

“We encourage each other that if we are having sex we should prevent, we should not do it without prevention because there are many diseases we may catch...and we will also be trying to prevent re-infection” (C6F). This view was expressed by most of the respondents.

Furthermore those who are now on ARVs went through extensive counselling at OI clinics where they were taught on the dangers of re-infection and how it may impact on their medication. Among those who were married at the time of diagnosis they got most of their sexual health information from testing centres where they went through post test counselling. It is notable that C2, C3 and C8 who were married went through this counselling as a couple. In these counselling sessions people are usually encouraged to use condoms to prevent new Sexually Transmitted Infections (STI's) and re-infection. At the OI clinics and in support groups HIV positive people are encouraged to always use condoms. An excerpt from the interview with C2F illuminates this point. Commenting on the emphasis put on condom use she said; “they teach us to always use protection, family planning plus condoms”. No wonder therefore that condom use is seen as a “natural thing to do” when it comes to sex. Thus it can be said this knowledge on how to live with HIV and the emphasis put on condom use played a role in influencing the couples to be consistent condom users.

The other reason that may have convinced most of these couples to consistently use condoms is the fear of sickness and or death. One can not help but notice a serious change about health concerns after these people were diagnosed with HIV. After discovering their status most of the couples took their reproductive health more seriously as compared to before diagnosis. This may be a result of suffering through sickness which most of them have undergone. As a result they have mortal fear of becoming sick again or even dying. So when they were informed that re-infection may set back their recovery process they were prepared to drastically change their views and attitudes towards condom use. Expressing her fear of re-infection C5F had this to say,

“I think I am more worried about re-infection than getting pregnant. I mean re-infection for us it means what? – you start getting genital herpes, you start getting flu, you start getting funny things again and we

don't want to go back to that... A-a-h, getting sick again, I don't want, I don't want!"

C7F buttressed this fear when she said;

"you know when you are living with someone who knows their status and your status, you prevent yourself equally because he also fears to die and you also fear to die".

The spectre of death and the actuality of going through the pain of sickness convinced many couples to use condoms consistently. Thus the 'actual' seems to have a greater impact on the people's behaviour than the 'possible'. The 'possible' is a matter of statistics, it may or may not happen but the 'actual' is real, it is the here and now and one has to deal with it one way or another, it can not just be ignored.

Another dimension to condom use introduced by C3F and C4F is that of a condom as a form of prescription. The way C3F presents the use of the condom in their relationship is reminiscent of the use of prescribed medication. She always prefixed any sentence on condom use with the phrase "it is said" (by the Health professionals). For example she said "**it is said** we should use this..." (emphasis mine). It seems to her, a condom is a doctor's or health practitioner's prescription which she has to follow in order to live. C4F also alludes to this feeling that condom use is something that is forced upon them both by the health staff and their condition. She feels that the condom is prescribed for them since they are positive.

"The thing is good if when you do it you do it voluntarily but as it is it is something that is crushing us, that is putting us into a corner, something that we have to do whether we like it or not".

Thus the condom has to be used even if people do not actually like using it in order to live.

Though most of the couples under study had no problem with issues relating to condom use after diagnosis it was not easy for all of them to make the transition. C4 did not find the transition from non condom use to consistent condom use easy at all. Even at the time of interview they were still facing some problems as the woman confessed that "even now we still have problems sometimes". It seems the major problem was with the man though the woman herself is not a firm advocate of condom use. Complaining about condom use she said "...you know that if you are not used to something it stresses you". The root of the problem for this couple

seems to have been the failure by the male partner to understand the logic behind condom use among couples who are both positive and in a steady relationship. When he tested positive in August 2004 he had been in this relationship for three years and all those years they had never used a condom. Even though he was advised to use a condom in his post test counselling he did not understand why he was supposed to begin using a condom now when both of them were positive. Narrating how he began to understand the essence of condom use he said;

“...we continued not using a condom. One day when we got to the OI I had to ask another (nursing) sister. I said but I don't get this sense that we should use a condom. Why, we are both positive, that means if we had not known our status we were still going to proceed not using condoms...why should we use the condom now when we are both positive?”

This particular case points to the need to move beyond mere information dissemination to ensuring that people understand the information they get. The male partner knew that he was supposed to use a condom but did not understand the reasoning behind it. He did not understand the underlying logic of condom use in a steady relationship as he went on to ask the nursing sister; “you mean if we were married I was supposed to use a condom on my wife?”. As far as he was concerned condom use was supposed to be limited to casual relationships or in cases where couples are sero-discordant. Condoms, in his view, are for cases where

“...there is no mutual love, it's just a case where you saw a girl with nice thighs and lusted after her, you want to taste her and then you pay her and have sex with her. So in such a situation you need to use a condom because you just want to relieve your sexual needs and go.”

It was only after he understood the notion of re-infection that he freely acceded to condom use. He said; “...then that is when they explained this whole thing of re-infection. You need to know because it is a matter of life and death. After this I now understand the importance of condom use”. Prior to this understanding he sometimes used the condom only because the Health Practitioners (HPs) had advised condom use.

Even though C4M now claims to use the condom consistently he confesses that it is not easy for him. Asked about how he took the issue of condom use after the sister had explained to him the issue of re-infection, he said;

“Ya-a-a, it was difficult. Yes it was difficult, because to change your sexual behaviour all of a sudden is not easy. We were people in love and

love making was part of that and all of a sudden you are told to change. Sudden changes are not easy that is why I had to go back again and try to get an explanation”.

This failure to understand the logic behind condom use among couples who are HIV positive partly stems from the social construction of condom use. The impression among the majority of people in Zimbabwean society is that condoms are used by prostitutes or promiscuous people (Feldman & Maposhere, 2003; Meursing & Sibindi, 1995). This seems to have been the belief of C4M and this may also have influenced his resistance to condom use. It is such views on condom use that led a number of respondents into engaging in risky sex prior to diagnosis. Being HIV positive has however drastically changed the sexual behaviours and practices of most couples who were studied as well as their views on reproductive health in particular and health in general. Most couples are now using one or more method of contraception with the condom being consistently used by nearly all the couples. This consistent use of the condom and concern about reproductive and sexual health does not mean, however, that these couples no longer desire or intend to have children.

4.3 Contextual factors and their impact on decision making

The following subsections consider some of the contextual factors that impact on reproductive decisions as identified by HIV positive couples under study

4.3.1 MTCT risk and reproductive decisions

This sub-section discusses the views of the respondents on the risk of infecting an unborn baby through pregnancy, the role of ARVs and nevirapine in mitigating this risk as well the effects of HIV on the reproductive desires and intentions of HIV positive people.

On the issue of the risk of MTCT there are two divergent views (high or low MTCT risk) amongst three distinct groups of people, i.e. those against child bearing, those who desire to have children and those who intend to have children. Those against child bearing are of the opinion that the risk of MTCT is high while others believe that it is low to medium and thus HIV positive people have a chance of having a negative child. It is noteworthy that most of those who see the risk as high no longer have any desire to have children whilst most of those who are of

the opinion that the risk is low or medium still desire to have children while some of them have an intention to have a child in the near future (see Table 2). It also has to be noted that of the high risk group five individuals are on ARVs while four are not and among the low risk group eleven are on ARVs while five are not. Based on these results it may be speculated that being on ARVs does not necessarily impact one's views on the risk of MTCT. However this is only an assumption, a more representative study is needed to establish the veracity of this relationship.

The High risk group

According to this group's perception, there is a high risk of a pregnant mother infecting her child with the virus. Judging by the cases he had seen so far where a positive mother has given birth to a negative child, C4M thinks the chances of having a negative child are very slim. He said, "...like I was saying the cases where the mother is positive but the child is negative, they are very rare..." C2F also had similar sentiments. She was of the view that ARVs do not have a mitigating effect but may in fact increase the risk to the child. According to her "antiretrovirals are quite strong drugs which can ruin the foetus". C7F and C8F also felt that the risk is rather too high even with the availability of nevirapine. C7F said though one is given "that pill" (nevirapine) "there is danger especially during labour, it (child) can get it (HIV) during labour. It may miss it during pregnancy but catch it during birth. It can just be luck for it to come out negative but a-a-ah, it is rare". C8F also expressed similar sentiments;

"...the risks – I can say to be pregnant when positive is very dangerous. Of course even if nevirapine is there such that you can go through the prevention of parent to child transmission programme the chances are that my child will be born positive".

It is notable that both these women have children that were born when they were already positive. C7F discovered her status after she gave birth to an HIV positive child while C8F discovered her status during pregnancy. She (C8F) went through the PPTCT programme and her child is negative. It can be argued that C7F conceived the risk of MTCT as high because of her experience of having an HIV positive child. As for C8F she attributed the negativity of her child to miracles. She is not fully convinced of the efficacy of nevirapine and ARVs. Like C2F she felt that instead of having mitigating effects, prophylactic drugs may make matters worse. Asked about the chances of having a negative child when you are positive

but on ARVs she had this to say; “imh, as for me I can say it makes matters worse to be on ARVs and then become pregnant. It may happen that I may give birth to an abnormal child”. The fears and concerns of these people with regard to in-utero effects of ARV’s may stem from the information they get from their HPs. In the study some HPs indicated that it was unwise for the people on HAART to get pregnant now as the effects of antiretroviral regimens on the foetus were not yet clear. This could have been interpreted as an indication that it was dangerous for HIV positive people to conceive.

Not only is this group concerned about the harm associated with antiretroviral drugs to the foetus in-utero, their concern also encompasses the welfare of the child after birth. Their argument pertains to the welfare and health of the child born of HIV positive parents. They are concerned that the child, who will be an ‘innocent victim’, will suffer the pain of sickness if born HIV positive and emotional and physical deprivation in the event that both her parents die early. On this, C4M said, “...obviously because of this disease you will leave those children. Who will you leave them for? So you should just look after those children you have now and stop troubling people”. Considering the risks which come with pregnancy both to the mother and child they argue that it is unreasonable for HIV positive couples to consider having a child. This view came out strongly from C2F, C4M and C8. C2F, like C8M thinks having children when one is HIV positive is irresponsible and borders on insanity,

“you know, honestly if you are taught, I mean all those counselling sessions that you got should really determine your decision if you make your decisions as a normal person. Being HIV positive does not mean you are mentally abnormal, you can think like everybody. After they waste their time going through those four counselling sessions you still get pregnant! Hayi a-ah! It will be as if you are mentally unstable”.

C4M also feels that HIV positive people should not consider reproduction until there is a guarantee of a drug that cures HIV. “There is no guarantee that we will get a drug that will completely eradicate this disease of HIV/AIDS, so in the meantime the only preventive methods; use condoms – no babies”, he said. The major concerns raised by this group are the perceived high risk of MTCT, the perceived adverse effects of ARVs on the foetus as well as the welfare of the child born to HIV positive parents. To this group, the advent of HAART was not be taken as an opportunity by HIV positive people to conceive. Though they realise

the positive impacts of HAART on the health of HIV positive people, themselves included, they argue that the drugs they are taking may have adverse effects on the foetus. Thus, it seems, among those who no longer desire any children or who have experiences of having positive children, the risk of mother to child transmission is conceived as too high. As such one should not contemplate having a child.

The low risk group

This group comprises mainly those people who still intend or desire to conceive and most of them are on ARVs though there are some who are not (Table 1). It is in this group that people who are proactive in gathering information relating to child bearing are found. They indicated that the risk of MTCT was low as a result of a number of possible medical and non medical interventions. C1M and C12F put the chances of having a negative child at 70%, C5M put them at 80% and C7M put them at 75%. Others put the risk of having a positive child at a low percentage. The factors that were emphasised in this group were the availability of nevirapine and ARVs. This group felt that the availability of prophylactic drugs had greatly lowered the risk of having positive babies and thus given those who want children a glimmer of hope. These people were confident that if one was on ARVs, had a high CD4 count and took nevirapine prior to delivery then their chances of having a negative child were quite high. C4F said,

“... looking at this pill, this nevirapine which you are given during pregnancy when you are HIV positive, which when you drink the child comes out negative, I don't see what can prevent us from having children if I am strong enough”.

Couple 5 also indicated their conviction that if all medical techniques and interventions available to them today were availed then they had a very high chance of having a negative child. Both of them also stressed the need to have a high CD4 count before one tried for a child. C5M put the safe CD4 count at which people can try for a child at between 800 cells/mcl and 1000 cells/mcl.

Commenting on her chances of having a negative child C5F said;

“...considering that I am on ARVs and he is also taking them, so that's forcing the virus to hide, right? So it's not in the blood anymore, it's in the other system, the lymphatic system...I am thinking my chances are good since I am on ARVs”.

She further said; “Actually it has helped (taking ARVs). I think that is what made me decide to have a child”. Her partner had this to say on the issue;

“so far from the information we have got there isn’t much of a risk if this whole process is done properly. The risk is there of course because they were saying there was an 80% chance to have an HIV negative child so there is still a 20% chance of having a positive child. It’s a small fraction though.”

The low risk group is characterised mainly by people who still desire to have children and those who intend to have children. What separates these two groups of people is that despite the fact that they both conceive MTCT risk as low, those who desire to have children still have doubts about the efficacy of prophylactic drugs. On the other hand those who intend to have children are convinced about their effectiveness not only in lowering MTCT risk but also in safeguarding their health now and in the future.

There are a high number of people in the study group who desire to conceive but because of their HIV positive status have no intention of doing so in the near future (see Table 2). A number of reasons for the need to have a child were raised by the respondents in this study. Among these were the desire for motherhood/fatherhood among those who have no children (C14F), family pressure among those who are married and have no children in that marriage (C15F) and the need to have a boy child (C13, C7M). These are discussed in the following sub-section.

Though a substantial number of the respondents expressed a desire to conceive, they cited their positive sero-status as the stumbling block. As C15F notes “...we told ourselves that since we are positive we should not have children. But the truth is that both of us want a child...” Being HIV positive was seen as the main problem by most of those who desire but do not intend to have children. As a result of their status there is a feeling among some of them that it will be improper to conceive. The dominant theme among this group is that of fear. There is fear of transmitting the virus to their child, there is fear of compromising their or their partner’s health as a result of re-infection and pregnancy, there is fear of negative response from the HPs and the community and there is fear of burdening the health system which is helping them. Their reproductive choices are dominated by the fear of one thing or the other related to their HIV positive status. A number of couples expressed fear of vertical transmission (C7, C15, C9F, C1F). Expressing this fear C14F said;

“I desire to have a child but not now...maybe when I have seen how these tablets (ARVs) work, how much they protect. Some are saying you can have a child- there is nevirapine but others are saying it's not 100% effective, some (children) can be positive some negative. I am afraid of having a positive child. ...if a drug that guarantees that my child will be negative is found then I will throw aside the condoms and rush to have one”.

Though this group sees the MTCT risk as mainly low to average there still exists that trepidation of being the unlucky one to have a positive child. To them that small percentage of risk is still significant. Another fear commonly expressed by this group is that of the negative impact of pregnancy on the mothers' health. These were some of the statements they made:

“I am concerned mainly about my immune system...” (C1F)

“I am concerned about the health of my partner...” (C7M)

“I feel afraid of getting pregnant since some say if an HIV positive person becomes pregnant that will be the end of them” (C13F).

According to the information they have, pregnancy is seen as a risk to their health as it lowers their CD4 cell count and the re-infection risk associated with it may lead to them getting drug resistant strains of the virus. To most couples in the study the only way of getting pregnant or having a child is through unprotected sexual intercourse as advanced technologies like in-vitro fertilisation (IVF) are beyond the reach of most couples hence the fear of re-infection. Another fear expressed is that of the medical system. A number of respondents, apart from those who do not desire to have children, indicated their concern about the possible negative treatment they may receive from health practitioners if they were to become pregnant. C15F indicated that she was instructed by the HPs in the hospital not to have another child ever. As such she felt that if she got pregnant again the HPs “will reproach” her. “They will say we told you not to have another child and you have become pregnant again! You will be troubling us, giving birth to your little things which will give us problems. Ah! they can treat me roughly!”, she said. Similar sentiments were echoed by C11F and C12F. Such expressions indicate the important role played by HPs in influencing the decisions of HIV positive people.

As a result of the advice from HPs and their perceived attitudes towards pregnancy, some respondents felt that by having a child they would burden the

health system as well as the social system that is taking care of them. Expressing this sentiment C11M said,

“...but the truth is that it is difficult to tell yourself that I am doing this (having a child) because I am afraid that I am putting 5kg more on top of those who are helping us (HPs) and burdening them worse. I would say I want a child, that one will say I want a child, that one also, how much trouble will we have added upon these people who are trying to help us”?

The emotional as well as the physical burden associated with taking care of an HIV positive and sick child was cited as another reason for not considering child bearing in the near future. C7F and C14F pointed out that they could not cope with the emotional guilt and pain of knowing that they may have given life with one hand but also taken it with the other. “The pain of seeing one’s child suffer illness, discrimination and stigma and know that you are the one who caused it is unpalatable”, said C7F. C14F said; “I love children a lot. I can not stand seeing them sick, what’s more if it is me who will have brought that sickness upon them?” C7F, who has an HIV positive child, also indicated that it was an economic and physical burden to care for a sick child when you are also unwell. She said,

“I wish to have a child but am afraid because it is not easy to have a positive child...you are always at the hospital and last week I had to go and talk to his teacher because other kids were taunting him about his status...so when I see this one who is unwell and think that maybe if I have others they will also be positive, it makes me afraid”.

C11M also pointed out that a positive child may add to their economic difficulties. He said, “...what if that child is not fully protected and becomes infected; we already have our (economic) difficulties and then we add another, how big a yoke will that be on us?”

Some in this group (C13F, C14F, C15) indicated that they did not have complete and reliable information on the effectiveness of HAART and how its use or that of nevirapine may play a role in reducing MTCT as well as ensuring that the health of the mother does not deteriorate after birth. They indicated that most of the information they have on the subject has been gathered from other HIV positive people and no reliable sources have been used. There was also concern among others that HAART and nevirapine “has had no child yet” (C11M). C11M and C15M indicated that as far as they were aware no child has been born to HIV positive parents on HAART. They were concerned that HAART is a relatively new form of therapy whose effectiveness and usefulness has not been proven. As a

result, though they desire to have children, they would wait until such a time that the effectiveness of this therapy in reproduction has been proven. Commenting on this C11M said;

“we are told that an HIV positive person can have a child if she takes the tablets (nevirapine) to protect the child so that it comes out okay, without being infected – but it is difficult to say let me try it because it’s not yet clear that here is a child who is a result of it...to say here is a child who is 10 years old, born of HIV positive parents...”.

To these individual’s the lack of evidence on the efficacy of HAART also plays an important role in their decision to withhold reproduction until it is clear to them that HAART is effective in reducing MTCT. Though people in this group are convinced of the effectiveness of HAART in halting their progression to AIDS they still have questions and fears in so far as its effectiveness in reproduction is concerned.

The responses of some, i.e. C14F and C15 above, indicate the existence of an information gap in their understanding of antiretroviral therapy and reproductive issues. There is thus a need to address this gap to enable HIV positive people to make their reproductive decisions from a well informed position. The reproductive choices of those who desire to have children but who do not intend to do so in the near future seem to be dominated by fears and uncertainties which include the fear of being labelled irresponsible or un-empathic, uncertainty over the efficacy of ARVs in mitigating the risk of MTCT as well as the fear and concern of emotional and physical burden of caring for an HIV positive child.

Remarks

What is evident from both the low and high risk groups is that among those who see the risk of MTCT as high, most no longer desire to have children or are against child bearing while among those who still have the desire or the intention of having children the risk is seen as low or medium. It also has to be noted that those who still have the intention to have children seem to be more informed on the issue of mother to child transmission than others. C1M, C5, C12, C14M and C9M took the initiative to research further on the issues of mother to child infection, re-infection, the impact of pregnancy on the health of the mother and their chances of having a negative child. Medical staff was approached to shed more light on these issues. This, however, is to be expected since these are people who intend to take the risk of trying for a child in the near future. They therefore

have to base their ultimate decision on reliable and relevant information. Though there are divergent views on the risk of mother to child infection, most couples indicated that they have fears and concerns about getting pregnant or having a child. The major concerns raised were worries about the health of the mother during pregnancy as well as after delivery and the health of the child and its welfare should the parents die while the child is still young.

Being HIV positive has also impacted on the reproductive intentions of many couples who still desire or intend to have children in the near future. The fear of re-infection and negative health implications associated with pregnancy when one is positive has persuaded many to alter their reproductive plans. Many couples indicated that they can not have their desired number of children as a result of being positive. C4F said she wanted to have a total of eight children but now will be content with having one or two more on top of the two she already has.

Responding to how being HIV positive has influenced her reproductive intentions C5F said;

“Now it has limited the number, I do not think I will be able to have three or four because pregnancy lowers your CD4 count any way so it’s a risk to get pregnant in the first place...so I can’t really say I will have more than one child, I will probably have one”.

Thus, though there are pregnancy fears among a number of couples, the perception of low risk of MTCT and the availability of prophylactic drugs has given those HIV positive couples who intend to have children a glimmer of hope that they may achieve their desire.

4.3.2 The Socio-Cultural context: its impact on reproductive decisions

This subsection discusses the respondents’ views on the importance of children in one’s life and how this may act as a push factor towards conception. It will also look at how the social perception of infertility impacts on the views of the respondents about having children. The HIV positive couples studied live in a culture that places high value on child bearing and where childlessness or infertility is despised and stigmatised. This section discusses the views of positive couples on child bearing in relation to the socio-cultural environment they live in.

The socio-cultural influences may not be obvious to the decision maker because of the nature in which they are learnt or internalised. One’s views and values are

shaped through cultural and spiritual development and integrated into the self by psychological factors and personal experience. Socialization plays a critical role in this (Williams, Watkins & Risby, 1996). Ousmane (1979) said, “man is culture”; that is humanity is a product as well as the creator of its way of life. Culture, according to Mazrui (1986) is a system of interrelated values active enough to influence and condition perception, judgement, communication, and behaviour in a given society. It is these values that shape society as much as society shapes them. Thus there is a symbiotic relationship between humanity and its culture. In many instances human beings are a product of their cultural values and principles and these are imparted to them mainly through socialisation. As Brody (1987) notes, one’s cultural belief system influences one’s social roles and relationships.

What comes out of the present study is that the values and ethics which children are socialized into have a life long effect and they do impact on their decisions later in life. Most of the respondents were socialized into the Ndebele culture where marriage and children are the mark of manhood and womanhood. From an early age, through the toys they play with, the games they play and the divisions of labour within the household, children are socialized into their roles and responsibilities as women and men (Ndlovu et.al, 1995; Msimang, 1991; Nyathi, 2001). As Nyathi (2001) notes, through socialisation “girls were introduced into the roles of women in society” and so were boys. In the life cycle getting married and having children is portrayed as the pinnacle of one’s development without which one will not be regarded a complete member of the society. That is why when describing the importance of marriage among the Zulus, a people whose social system is similar to the Ndebele, Krige (1977) said,

“the development of the Zulu (and this applies to the Ndebele) from childhood to manhood or womanhood is not, as among Europeans, one of gradual, almost imperceptible change, but consists rather of a series of clearly marked steps, each of which brings with it increased status and greater responsibilities.”

The influence of one’s culture reveals itself in the respondents’ views about the importance of children in one’s life and their views on infertility. The fact that when questioned about the importance of children, most of them always made reference to “esintwini” (our culture) reveals the impact that socialization has on one’s views and choices in life. It is important to point out that culture is dynamic as much as life is since it is nothing but a mirror of life as lived then and now. So

what the respondents may have referred to as 'isintu' (culture) may encompass some aspects of western cultural practices that have been incorporated into the Ndebele way of life. This should not be surprising since culture, unlike tradition, tends to incorporate both the past and the present. It is not frozen and can not be frozen into the past as long as the people who create that culture still live. It is this dynamism of culture that enables it to reinvent itself and remain relevant to society. Ndebele culture, through its interaction with the western culture has adopted from it certain practices that over time have come to be part and parcel of the Ndebele cultural fabric. It is not surprising therefore to hear C5F say, "...we should have good jobs but you should also have a husband, you should have a *white wedding* or at least he should pay lobolo and you should have children afterwards. That is how we were brought up". A white wedding is now seen as part of the institution of marriage among the Ndebele. Changes in the social, economic and political fabric of a society usually bring with them changes in the cultural fabric of that particular society.

The institution of marriage and the construction and definition of manhood and womanhood in Ndebele society also play an important role in pushing people towards conception. There are certain characteristics that define what being a man/woman is in Ndebele society and central to these characteristics is being able to reproduce – fertility. As Nyathi (2001) points out, "marriage as an institution, serves to bring into this world children. This is the procreational role of the institution". Those who qualify for the status of manhood and womanhood have social benefits that accrue to them. These include social respect and dignity. Failure to attain this status also brings with it a bag of demerits that include ridicule, lack of stature among others, and lack of social respect even by those younger than you. To a woman as much as to a man, childlessness is the greatest of all misfortunes (Krige, 1977). Emphasizing the importance of fatherhood in Ndebele society C1M said, "in our culture we know that a man is a man because of his children and wealth". Thus having a child is important as it determines one's social standing and qualifies one for the status of adulthood.

4.3.2.1 **Reasons for having children**

HIV positive people live in a social environment. As all social beings they are bound to be influenced by what other social beings do. In a social world, as Plous

(1993) argues, no decision can ever be said to be context free and no decision maker can claim that their decision is value free. In his theory on social comparison Festinger (in Plous 1993) argued that people evaluate their decisions by comparing themselves to others and that people are concerned about the opinions others have of them. He further argues that given a choice people have a tendency to compare themselves to those closer to them in opinions and abilities. To this may be added that they also tend to compare themselves to those closer to them in social status and many other factors. This social comparison factor seems to have played a role in influencing C4F, C5, C12, C9M and C14M in their decision to conceive. They compared themselves to other HIV positive couples who had conceived and had borne HIV negative children. This experience of witnessing other couples or other wo/men having children seems to play an important role in giving these couples and individuals the confidence to try for a child.

Couple 5 and Couple 12 pointed out that because other HIV positive couples had had HIV negative children this gave them confidence that the children they were planning to have may or will be HIV negative. C5F also alluded to the fact that she has a positive friend who is now pregnant and according to C5M this was pushing her into pressuring him to have a child now. Since her friend was pregnant she could not see why she could not try for a child as well. C5M said she was saying;

“...you see XXX is now pregnant, which means I can also have a child. I want a baby because I may end up dying without a baby, I should at least hold my own baby”.

C12F, who works as a peer counsellor at the Mpilo OI clinic, also justified her intention to conceive by pointing out that other HIV positive people had conceived HIV negative children even though they were in a worse health condition compared to her. She said,

“... I have seen a lot of children. Out of ten babies born of HIV positive women, you will find that maybe only three may be positive and that will have been caused by the fact that the child will not be sitting okay in her mothers womb and invasive methods of delivery are used, but otherwise if that has not happened most of them are born negative”.

This knowledge and experience gave her and her partner the confidence to try for a child. Thus there is a tendency among people to compare themselves to their friends and others who are in a similar position. Through social comparison and

witnessing others who had negative children while they are positive, these couples and individuals felt justified in their intentions of having children.

The respondents also discussed various reasons which make it important for them to have children. Among these is the importance attached to motherhood/fatherhood, strengthening one's relationship and children as a form of insurance.

Motherhood / Fatherhood

In Zimbabwean society, as is the case in other African cultures, motherhood and fatherhood are greatly valued roles (Krige, 1977; Msimang, 1991; Oyewumi, 2000; Nyathi, 2001). Women's and men's desire to have children is strong since they achieve social status through having children to survive them and perpetuate the lineage. As Oyewumi (2000) notes, "...the position as 'mother' is a position of power in African contexts with motherhood being the preferred and cherished self identity of many African women". In Ndebele society, cultural norms and values emphasize motherhood and fatherhood as valued roles that represent not only maturity but responsibility (Nyathi, 2001). Pregnancy symbolizes an internalisation of commitment and connection with a partner, family and the living dead (Bradley-Springer, 1994; Mbiti, 1977). Having a child is a rite of passage, where one passes from just being an adult to being a parent. It is a rite that every normal adult is expected to pass through if one is to be regarded as a complete being. That is why when this vital role does not happen measures are taken to rectify the situation (Nyathi, 2001). One's social status immediately changes as one attains the status of manhood or womanhood. More social respect as well as responsibility is accorded the new comer. All this is viewed as a positive and natural step in the development and growth of an individual by most Ndebele people and is expected from every member of the society (Nyathi, 2001; Ndlovu et al., 1995; Krige, 1977).

C1F points out that having a child is a source of pride in your mothering abilities. The fact that "the child is mine, it did not come from another person, I was not given the child" brings with it a sense of satisfaction and pride, she said. Stressing the point of self satisfaction and a sense of accomplishment and completeness which comes with having a child C5F said "I just want a child of my own, born of

me ...I still want to mother a child. I want to be a mother". Most of the respondents in the study mentioned the importance of being a mother or a father in the Ndebele social and cultural setting. Even those who had children before they got married (C10F, C9F), a socially inappropriate act, indicated their pride in having these children. C10F commenting about how she felt when she had her first child said, "I was very happy. I was still very young but it made me happy to have a child...I saw myself as complete". These women did not see their pregnancies as shameful disasters but rather as an affirmation of their womanhood. Motherhood and fatherhood seem to be defining moments in the lives of both men and women. Having a child is proof of one's manhood or womanhood. As C1M noted, "I must have a child to see that I am also a man, I am complete, normal". C4M also said, "what makes children important is that a child gives you confidence that at least you can reproduce". Because of the importance attached to motherhood and fatherhood HIV positive people are prepared to risk their health and lives to get a child. Being a mother/father was viewed as a joy, a means of enhancing self-esteem, as well as a way of becoming and being regarded as a complete woman/man. Walker (1995) notes that "an extremely high value is placed on children for and in themselves...so much that marriage is, in some contexts, quite irrelevant to the bearing of children". This seems to mirror the situation that those who intend or desire to have children find themselves in. All couples who desire or intend to have children are currently unmarried (see Table 1). However, none among them mentioned getting married as a prerequisite to having a child though they all stressed their need to have a child or children. It seems therefore that fertility – the capacity to bear children and assume the social identity of motherhood or fatherhood – continues to be very highly valued and to inform the choices of both men and women around childbearing.

Social status

As alluded to above, when people get married and have a child, their social status changes. They will have moved from one stage in the cycle of life to another and as such their status and responsibilities change accordingly (Bozongwana, 1983; Krige, 1977; Nyathi, 2001). They will no longer be regarded as youths but as adults and/or parents. The graduation into this stage in the life cycle comes with a bundle made of social dignity, respect and new responsibilities. Most of the respondents pointed out that having children endows one with social respect and

dignity among his/her peers. Answering a question on the importance of children in one's life C2M said, "you should have dignity among people, you see. You do not get that respect when you are just someone without a child. That is our culture and that is how I understand it". C5F and C1F also argued that being a parent enhances one's social standing. As such they aspired to get to that stage where they will no longer be called by their first name even by little children.

Commenting on why she needed a child so badly C5F said;

"I do not want to be called that girl until I die, no. I want to be called so and so's mother. You feel dignified. This girl! at 60 still being called this girl. No, I don't want. I want to be called so and sos' mother and I have already chosen the names".

The status that comes with being a parent plays a role in influencing the reproductive decisions of those couples who still desire or who intend to have children.

Children as a form of security and companionship

A number of respondents see children as a form of social and financial security later in life. Children are expected to support their parents financially and materially when they grow up as well as help them in their daily life activities as they grow up. Among those who are not well off and do not have the luxury of government social security systems as is the case with most of the respondents, children are valued for the security they may provide their parents in old age (Grieser et al. 2001; Cain, 1984). C4F said she intends to have two more kids in addition to the ones she already has because of the need for security in old age. She said; "when one grows old his children - the other will be bringing this while the other one will also bring that..." C7F, who was working at the time, said she was pressured into having her second child by her in-laws since they argued that "...money is not important, what's important is the child. Money will not look after you but a child would and he will also bury you". This hope or belief that one's child or children will take care of them as they grow old was also reiterated by C5F. As she is visually impaired she sees her own child as the best person to take care of her and also help her in her daily activities. She believes that her child will understand her position and predicament better than any other person.

While making reference to the role of children as helpers in the household C6F also brought in the dimension of children as comforters. She said; "I think a child is a comforter as well as a helper with daily household activities". Some

respondents also indicated that they may consider having children so that they may keep them company. C2M said;

“what can make us have one is that the ones we have are now grown up you see. They are no longer in our hands. Others are now married; others are doing whatever, so it is clear that now we are lonely. So being lonely sometimes may make people desire to have children”.

C3F also notes that children may keep one company in times of difficulty or when one is stressed. Even when one has had a fight with one’s husband one can get company from one’s children.

Children as marriage/relationship pillars

Children are seen as pillars without which a marriage can not stand. They are a rock on which a marriage is built. Krige (1977) noted that no marriage is considered complete before a child has been born. As C2M said, “...culturally we are unlike white people. In our culture it is said marriage is strengthened by having a child”. C7F concurred with C2M’s view when she said:

“it (the child) unites. He bonds us together, that is why I say he is like an adhesive. He strengthens our marriage because if I am at my in-laws, my mother-in-law won’t say, should I play with a doll? She will have something to play with”.

Family/clan name

A strong preference for male children is well documented in patriarchal societies (Ndlovu, et. al, 1995; Bozongwana, 1983; Krige, 1977). Commenting on the importance of having a boy child, C7F said, “it is really important because the fathers surname should not die”. C7M who has three girls said he still desires to have a child with the hope that per chance he may have a boy. His main concern is that among the children he has now there is none to carry on the family/clan name. In the Ndebele society it is the duty of every boy child to ensure that the clan name is carried on and does not die out. C7M commented about his desires this way;

“...I would wish to have one (child) and if God is willing I would wish to have a boy because there is no surname/clan name among these three...in our culture it is important to have a surname (boy child) because if there is a surname at home it means he will also remain increasing our clan/family. But if there is no surname our clan also stops there”

Similar concerns were also expressed by C13M, C12M who have no male children and C15M and C14M who have no children at all. The need for a boy child in a relationship or marriage may compel HIV positive couples to go on reproducing

until they get a boy. This will be in a bid to fulfil their social obligations as well as their personal desires.

The continuity factor is not limited to the continuity of the clan name alone. Even women felt that having children ensured the continuity of their name. The child as well as further offspring from the child will be identified as the descendents of so and so and their names will appear in that genealogy. C5F who has no child said,

“I want to continue. If I die now, I die and that’s it, you know what I mean. But if I have a child that child continues and the world will know that her mother was so and so you know that kind of thing – the lineage. I do not just die out”.

It seems that it is important to ensure that one’s name does not disappear into oblivion and this can only be done by having a child. Another important issue under the socio-cultural influences on reproduction is the perception of infertility in Ndebele society. The manner in which couples who have no children or who can not have children are viewed may play a significant role in influencing HIV positive couples in their decision making process.

4.3.3 The social perception of infertility/childlessness and its impact on reproductive decisions

The way infertility is perceived among the Ndebele and the Zimbabwean society in general points to the importance attached to having children. Infertility is painted in a negative light and the terms used to refer to infertile people border on insults. The women are usually referred to as “inyumba” (barren and useless thing) while an infertile man is referred to as an ox. Couples or individuals who do not conceive become victims of scorn and ridicule in the society. According to Krige (1977) “to a woman childlessness is the greatest of all misfortunes, for not only will she be taunted and giped at by her more fortunate sisters, but she may also be divorced on that account”. This is also equally applicable to infertile men. This negative perception of infertility emanates from the high value attached to children. As C6M noted;

“failure to have children in our culture is a source of ridicule, people laugh at you. It is difficult because you can have money, you can have everything but if you do not have a child people will laugh at you”.

Social respect is usually accorded to adults with children and indignity accompanies infertility (Nyathi, 2001; Krige, 1977). Commenting on how society views an infertile couple C1F said;

“their house is not accorded dignity. If you notice the men are called by their first name irrespective of their age...they do not have dignity. Even when important issues are being discussed you will hear people saying ‘ah, nx! How can you call so and so when he has not fathered a soul, what will he say when he does not have any children? As far as the society is concerned he is not a person”

A poor person with children is accorded a better social standing than a rich man without a child said C5F.

“I know a doctor who is divorced (has no children)...to most people she is not successful, she is just a doctor so what...my cousin is a lawyer but she is not married, so what. Until she becomes Mrs. Somebody with children as well as being a lawyer she is a nobody” (C5F).

Success in life is not measured only by what one has accomplished materially but also by whether one has children or not. Bozongwana (1983) posits that there are/were three important things to a Ndebele man; his beer, wealth and children. Children are the common denominator without which one can not be regarded as successful. Even though one has all the wealth but without children she/he will still be seen as an incomplete being among the Ndebele people.

Infertility among the Ndebele continues to be seen as a form disability. Disability in our society was seen and in some circles continues to be seen as a curse or a result of an avenging spirit (Krige, 1977; Gelfand, 1973). C5M sees the social perception of infertility in this manner;

“if you are infertile you are seen as a disabled person. When people say disabled, they are talking about that person who is really useless. Imagine yourself; you think you are okay, you are fit, a man but you are infertile, what kind of disabled person are you? You are worse!”

C7M further added to this when he described an infertile person as a useless receptacle. “If he is infertile they view him like—I don’t know- this jug is better because it is a water container, he is seen as something useless, something that has no use at all”.

Infertility is not a desirable condition and children are socialized accordingly. It is so undesirable that parents and the concerned individuals will do all in their power to promote conception (Krige, 1977; Ndlovu et al., 1995; Nyathi, 2001). Such

negative portrayal of infertility with the attendant insults heaped on the unfortunate ones may put pressure on HIV positive couples to procreate in a bid to escape the stigma attached to it. It may also force the family to pressurize couples to conceive or otherwise seek medical attention be it traditional or modern. C5F identified a case of her HIV positive friend who has been forced by family pressure to conceive. They had not disclosed their status to the husband's family and her in-laws were beginning to say unpleasant things and pressuring their son to divorce her. In the end they decided to conceive in order to placate the family. It seems that in pressurizing couples to conceive, the family will also be trying to dodge the negativity which comes with the associative stigma of infertility or childlessness.

The socio-cultural context seems to play an important role in decision making. Those who intend to have children in the near future emphasized the importance of children in one's life. Though they were aware of the health risks associated with pregnancy, this was overridden by the yearning for motherhood and fatherhood. The process of selective perception at play among the interviewed couples is interesting and points to the importance of the socio-cultural considerations when making reproductive decisions. People choose what is important to them according to the context they find themselves in. Those who already have children and no longer desire to have more emphasized biomedical and other factors in gauging the risk of pregnancy to an HIV positive person. Those who still desire and who intend to have children, though aware of the risks, emphasized the importance of having a child and the role of ARVs in ameliorating the risks associated with having a child when one is positive. Thus by planning to have children, HIV positive couples will not only fulfil personal needs but social expectations as well.

4.3.4 Family/Social pressure on HIV positive couples

The manner in which social pressure is applied to those who have disclosed their status to their families and those who have not disclosed seem to differ though both face some form of pressure or censure from the family and or society. Among those who have not disclosed their status the perception was that the family would exert pressure on them to conceive since they will be regarded as 'normals'. This pressure stems from the ingrained social expectations and the stigma associated

with infertility or childlessness. This may force HIV positive couples to conceive in order to conform to the social norm and be accepted in society. On this C1M said;

“I think social views (on infertility) may push HIV positive people towards conception...what makes HIV positive people to conceive is that they are also people, they want to be accepted by the society you see. That is the thing which I think many a time forces HIV positive people to have children. It is that thing that they want to be accepted in society”.

Also commenting on the possible effects of social attitudes on the reproductive decision making among HIV positive people C7M said;

“in other ways (social attitudes) may push them, especially the pressure coming from the family. They won't be making their own decision; they will be taking other people's decisions trying to placate the family who will be pushing for a child. So if you have not disclosed, you will be in great difficulty”.

A number of respondents pointed out that pressure to conceive is usually exerted on those couples who would not have disclosed their status to their families. This, however, does not mean that those who have disclosed do not face any kind of pressure. They also face what may be called 'reverse pressure'. While the undisclosed couple may find itself being pressured into conforming to the social norm, those who disclose find themselves being discouraged from the social norm of having children. As Rutenberg (2000) notes, there seems to be a widespread feeling among people in general, and even among the HIV positive people themselves, that HIV positive people should not reproduce. In their study, Feldman & Maposhere (2003) point out that the majority of HIV positive people felt the society was against reproduction by HIV positive people. People with HIV who decide to initiate a pregnancy are seen as selfish, irresponsible, immoral and cruel or uncaring, sometimes even by other HIV positive people (Bradley-Springer, 1994; Ingram & Hutchinson, 2000; Sowell & Misener, 1997; Williams et al., 1996).

C5F talked about this pressure not to conceive when she pointed out that the society and even family members do not expect HIV positive people to indulge in sexual activity. She had to conduct her affair secretly in fear of censure from her parents should they find out. She said;

“...they think she shouldn't be having sex. One, she is positive, two she is blind, so why bother. When I was sick my mother used to say 'when

you recover you should become a nun. The impression I got was that you should not have sex”

C12F also indicated that her parents, especially her mother, were against the idea of her having sexual relations. Thus some HIV positive people felt the family and the society placed some barriers in so far as their sexual and reproductive desires were concerned.

Most of the respondents were of the opinion that social attitudes towards procreation among those with HIV were negative. The society generally does not expect a child born to HIV positive parents to live (Grieser et al., 2001). C7M summed up the supposed feelings of many people in the society when he said, “...the seed is rotten and the product of such a seed will be of poor quality and it will not grow well”. It is also the feeling among social members that such people (HIV positive) should no longer engage in sexual activity since it is sex that brought them the disease in the first place (C5F as quoted above). C2F notes that people do not believe that a product of an HIV positive couple can survive, “people will say ‘this will die. In fact what were its parents doing when they knew they are HIV positive’? People talk you know”. C5F contends that society will question the mental stability of such a couple or individual. She said, “they will say I am mad”. The respondents felt that the society is against the notion of reproduction by people who have HIV. This stems from the verbal cues they get from some members of the society in general and also partly from the information and advice they get from health professionals. Generally this verbal and non-verbal information is construed as being opposed to reproduction among those who are positive. In a way, the social views on this issue are seen as upholding an unwritten edict that HIV positive people should not reproduce.

The dominant perception among HIV positive couples studied was that the society at large is against reproduction by those who already know their status. Thus there is bound to be negative portrayal of those who go against this perceived social reasoning. Among the respondents there were others, though in the minority, who believed that social perception of procreation among HIV positive couples was dependent on the understanding of HIV/AIDS that people have. These felt that those who understand HIV/AIDS and the advancements being made in the field of HIV/AIDS treatment are in a position to appreciate and support reproduction among HIV positive people. They were of the opinion that the negative social

attitudes towards reproduction by people with HIV/AIDS stem from the misunderstanding of the epidemiology of the condition which abounds among the general population. Responding to the question on social attitudes towards reproduction among those who know their positive status C2M said, “some do understand since we are being taught bit by bit. People understand that no these people (HIV positive) have a desire to have children...”

C7M also felt that if people understand the nature of HIV they will not be shocked if HIV positive couples conceived. Couple 1 felt that people’s attitudes may be negative at first but may change if that positive couple has a negative and healthy child. As a result of this perceived change of attitude, from a negative towards a positive one, HIV positive couples may be encouraged to conceive. C1M however feels that HIV positive people should be responsible enough to take all necessary medical steps to ensure that they produce a negative child. His concern is that if they produce a positive one, they may exacerbate the opposition that the society has to their reproductive rights. Commenting on the attitudes of society towards reproduction among those who find themselves positive but still go on to have children he said,

“people will bad mouth you at first but if those people (HIV positive) have been protected (against having a positive child), and they have children whom they bring up well then the society will learn a lesson that an HIV positive person is also a normal person, that is when they will accept that fact but as long as we HIV positive people just have children randomly, without proper medication, and those children die painfully due to HIV infection the society will continue having negative attitudes towards HIV positive people having children”.

Concluding remarks

This chapter has discussed important sexual and reproductive issues among HIV positive couples studied and the context in which they make their reproductive decisions. The study found that sexual behaviour and views on contraception changed drastically after being diagnosed HIV positive. The responses of most respondents regarding the importance of children in one’s life revealed that they were socialised into a cultural system where marriage goes hand in hand with having children. The respondents accepted that motherhood and fatherhood are coveted roles without which one is not complete. Though the respondents discussed a number of reasons for having children and other factors that may impact their decision making, they did not see these factors as overriding their

individual/couple choices and views. Thus their reproductive decisions are not solely determinants of socio-cultural and health forces upon which they have no control, they are a product of weighing these factors against their personal choices and choosing what is best for them in the given circumstances.

The following chapter discusses the role of health professionals in the reproductive lives of HIV positive people both from the perspective of the health practitioners and HIV positive people.

University of Cape Town

CHAPTER FIVE

STUDY FINDINGS

5.0 HEALTH PROFESSIONALS AND REPRODUCTIVE ISSUES AMONG HIV POSITIVE COUPLES

This chapter discusses the impact of HPs on the reproductive and sexual lives of HIV positive people as seen by HIV positive people themselves. It also gives voice to the HPs who are conspicuously silent in most of the studies on reproductive choices of chronically ill people. Their views and attitudes towards reproduction among HIV positive people are explored.

5.1 The role of health professionals in reproduction from the perspective of HIV positive couples

In this study the majority of respondents indicated that though they were given information on reproductive and sexual health issues, the health practitioners generally adopted an anti pregnancy stance. Among the respondents, the majority had not directly spoken to an HP regarding reproductive issues. Their views were based on information given in counselling, support groups and through observing the attitudes of HPs regarding reproduction. As a result of the information given and the manner in which it was given they felt the HPs were generally against reproduction among HIV positive people. Among those who had had direct one to one conversation with HPs the feeling was mixed. Some, (C12, C5F, C1M), felt that even though the HPs gave them the information they were seeking they did not take a neutral position with regard to reproduction among HIV positive people while others, (C5M, C9M, C7M, C6M), were of the opinion that HPs gave HIV positive people balanced, adequate and unprejudiced information regarding reproductive issues. They also felt that HPs took a neutral position when advising positive people on the issue of having children. These views are discussed in more detail below.

Though there was consensus that HPs are forthcoming with information needed by HIV positive people in their decision making with regards to reproductive issues the majority of respondents felt that HPs tied their hands in so far as making their own reproductive choices is concerned. The majority of the respondents, that is 26

out of 30, indicated that HPs actively discourage HIV positive people from conception. The respondents felt that HPs emphasised the negative aspects of pregnancy and having children when giving HIV positive people reproductive advice. Asked about what HPs encouraged them to do concerning reproduction some respondents responded this way;

“most of them say no you should not get pregnant. They tell us about that (merits and demerits of pregnancy) but they also say, ‘you see, if you are no longer condomising, what will you be doing’? You will be re-infecting each other and thus your life span will be reduced” (C1F).

“they told me that if you are HIV positive you should protect so that you do not have any other children because it is a disadvantage to have children since you can have an HIV positive child who may die or he may weaken you and you also die” (C7F).

“the advice that they give you is that do not get pregnant, it puts you in danger. Then they tell you that the danger is that it’s possible that during birth the child can die, or you die and the child remains” (C8M).

An excerpt from the interview with C5F further illustrates the view that HPs take a particular stance regarding reproduction among HIV positive people.

Interviewer: Looking at the information on reproductive health, what information do you get from doctors and nurses?

Respondent: Negative information, yeah. They do not encourage us.

Interviewer: What do they encourage you to do?

Respondent: Just stay like this. They do not encourage pregnancy when you know your status. It’s like they encourage mothers to test when they are pregnant. They do not encourage girls like me to get pregnant. As I said, last time the counsellor was totally down, down, down! (pointing to the ground emphasising that the counsellor was totally against it).

Interviewer: What can you say about that attitude, that way of looking at those things?

Respondent: I guess they are trying to be pragmatic, I mean they can’t give us false hope and I guess they do not want to see more sick children and a mother like me so I understand their position.

Most respondents think the HPs are against the idea of reproduction among HIV positive couples for the following reasons: the risks associated with pregnancy, the concern they have about the children that may be born positive or left by their parents at an early age and the fear by HPs that if HIV positive people are to make unfettered reproductive decisions and per chance have HIV positive children, the already overburdened medical resources will be overstretched. Thus, though there was wide acknowledgment that HPs gave HIV positive people some information regarding reproduction, the general feeling was that HIV positive people were consistently discouraged by HPs from having children.

There are a few respondents however who felt that HPs give HIV positive people the freedom to make their own choice. They point out that HPs only play an informative role and in that role they do not encourage an individual to take any particular route. C5M said HPs advised people to weigh the risks and benefits of having a child before they make their decision. He said;

“...if you are going to consider having a child when you are positive you have to weigh advantages against disadvantages and all that. So it’s up to you as an individual to decide what to do which is why it’s very important that you check your CD4 count and also your viral load...”

C6M was also of the view that HPs gave HIV positive people the opportunity to choose freely. Commenting on the advice they gave him he said,

“they told me that it’s up to me if I still want to reproduce. An HIV positive person has the rights to reproduce but before doing that he has to decide properly. There is a bag of disadvantages and a bag of advantages then you choose which bag is the best for you”.

However the general impression that HIV positive people have is that health practitioners are against the idea of them conceiving. They argue that that is why they are encouraged or sometimes instructed to use the condom consistently and to guard against pregnancy. Thus it seems HPs directly or indirectly (through perceived attitudes) play an important role in the reproductive decision making of HIV positive couples. People make decisions based on information and advice they are given by health professionals and also based on what they think health professionals expect from them. As a result of the perceived negative attitude of health practitioners towards reproduction some couples or individuals may feel discouraged or fearful of having children though they desire to. For example C15F indicated that she is apprehensive of becoming pregnant as she is afraid of negative treatment from the HPs. She said, “Ah! they will reproach me. They will say we told you not to have another child. They can treat me roughly”. Those who remained determined to carry through their decision to have a child based their decision on the information given to them by doctors and nurses as well as from their own research. They did not pay much heed to the negativity towards pregnancy among HIV positive people said to be displayed by HPs.

5.2 The health professionals speak

The above section looked at the role played by HPs in reproductive issues among HIV positive people from the view point of the HIV positive. It revealed that

according to the HIV positive couples studied HPs play a significant role, be it negative or positive, in their reproductive decision making process. This section intends to tell the other side of the story from the perspective of the HPs. The research revealed that people who feature most in the reproductive and sexual lives of HIV positive people are the HPs (nurses, doctors and counsellors). Counsellors seem however to play a greater role as they are the first port of call in Opportunistic Infections (OI) clinics, especially with regards to the ARV program. Most contacts are made with counsellors in the OI clinics and in support groups. As a result of this the HPs who were interviewed for this study are those from the OI clinics whom the HIV positive couples identified as playing a significant role in their reproductive and sexual lives.

This sub-section and others below look at the manner in which HPs view child bearing and reproductive health issues among people with HIV. They examine attitudes, views and mannerisms of HPs regarding reproduction as revealed by their speech acts. The HPs, especially those who have some training in counselling, claim that they do not advise but give complete and balanced information to HIV positive people in a manner and environment that allows them to choose freely without fear or implicit threats. It is claimed that people with HIV are given a platform to make their decisions without any interference physically or verbally from the HPs. The validity of these claims and assurances is evaluated below.

5.2.1 Information on reproductive issues given to HIV positive people in the clinics and support groups

This subtopic looks at the information that is generally given to HIV positive people who come to the OI's for their counselling sessions prior to ARV drug commencement, those who come for the treatment of opportunistic infections, those who attend their support group meetings at the clinics and those who counsellors and nurses meet in their support groups in the high density suburbs as part of their outreach program. It focuses not on any particular group of people but on the general populace of HIV infected people from the youths to the adults (age 14 – > 50years).

This study found that the majority of HPs interviewed generally gave people incomplete or biased information on reproduction. The information that people are given is not objective, complete or neutral. It fails to present fairly both sides of the story on HIV and pregnancy. The information given centres on pregnancy prevention and prevention of re-infection and as such the use of the condom and family planning are given precedence whenever the issue of reproduction is raised among people with HIV. The possibility of having children where and when it is talked about is usually presented as a dangerous possibility that people must try to avoid.

Responding to the question on what they tell people with HIV regarding reproduction HP respondents had this to say:

“we tell them there is re-infection when you have intercourse with an infected person so the first piece of information that we give them is the proper use of the condom and the reason why they should use the condom is if I am infected and we have unprotected sex I am exposed to re-infection and there is also the danger of impregnating thus putting the unborn baby at risk” (male counsellor)

“if you are having sex with an HIV positive person and you are also positive you are increasing the amount of the virus in your system. The use of the condom reduces the re-infection rate and apart from that it prevents pregnancy. If you get pregnant there are high chances of getting an HIV positive child. So we emphasise dual protection so that when the condom malfunctions you are covered” (nurse).

“what we tell them is that its not wise to be pregnant when one is HIV positive because- especially women, they will deteriorate fast once they get pregnant and also if the child is born positive she will have added a problem upon herself...so it will be wise to stay without a child” (nurse).

The nurse also added that “they are told that if you are more sexually active it is believed that you deteriorate fast. So they have to do it occasionally and not too often like everyday or every morning (laughs)”. Sexual activity has to be minimal so as to also reduce the chances of unsafe sex and risks of getting pregnant.

Another nurse added that women are told that “by any chance if one were to fall pregnant there are more negative implications that could happen to the mother and also to the child”.

One counsellor, inadvertently pointing out that they give clients information biased towards a particular form of action in spite of their professional requirements to be unbiased said;

“in our profession we hope to create a very conducive atmosphere for someone to be open, to express his or her own views without giving any

judgement. And if that person after the information we give decides to do **something contrary to the information that is provided** (emphasis mine) we do not judge that person.”

Doing something “contrary to the information that is provided” is going ahead and having a child, which is an indication that one was not using condoms or any form of family planning as recommended by the HPs.

Another counsellor also pointed out that they emphasised what he called ‘practical aspects’ when giving HIV positive people information on their future reproductive prospects. He said they emphasised the issue of re-infection and drug resistance if people do not use condoms and the negative repercussions this has not only for them but also for the OI clinics and others who are HIV positive. To put it in his own words;

“...these days in the times where people are taking ARVs we also address the possibility of drug resistance to the client and the implications of them not protecting themselves when they become resistant to drugs, they may share the drug resistant strain of the virus with their partners and what it then means is you end up having two or three people who are resistant to your first line drugs and what it means is you have to move them to your second line drugs and as I speak second line drugs depending on the combination you are talking of cost no less than Z\$2.5 million (June 2005) in this country which is really a challenge. So we want them to look at those aspects, the practical aspects, you can still go ahead, have your sex and enjoy it but when you become drug resistant it becomes not an issue for yourself alone but also becomes an issue for the clinic as well because what it means is we have to look for more expensive drugs to give you. And I normally joke with the clients you know. I normally use an example of a bus carrying 75 people and say when you become resistant because you have not been careful; you are like a person who is crossing the road when I am driving a 75 siter bus that is full. So what do I do, do I hit you and kill you alone or let the bus turnover and kill the 75 people...so these are the practical things we share with them”.

The practicalities that they are made to see are in a way meant to steer them from the path of unsafe sex and dissuade them from having children. The above quote also reveals the concern of the clinics about their budgetary constraints. They have to live within their means, so they have to avoid buying expensive second line drugs for a greater number of people. So HIV positive people are usually encouraged to be ‘sexually responsible’. That is to say they always have to use a condom and avoid pregnancy at all cost. Talking about the important topics they discuss with HIV positive people in their support groups one counsellor said “...there we try to discuss important topics like disclosure, importance of safe sex,

so we even do condom demonstrations for them”. The issue of having children is thus not seen as one of those important issues but that of avoiding conception is given prominence.

The manner in which the said objective information regarding reproduction is delivered reveals the subjective prejudices of most HPs interviewed. As a result, HIV positive people usually do not get balanced information from which to make informed and balanced decisions but get information tainted by the HPs personal and subjective prejudices. Since HPs are usually regarded as experts by HIV positive people their views and advice on reproduction are likely to have a significant effect in the decision making process of these people as indicated by the HIV positive couples interviewed in this study.

In discussing the information given to HIV positive people on reproductive issues, there was a tendency among HPs to omit information on ARVs. The information on how they can lower the incidence of MTCT and thus increase one’s chances of getting an HIV negative child was usually not given prominence. In their accounts of the reproductive information given to people ten of the twelve HPs interviewed were silent on the role of nevirapine and other ARVs in lowering the incidence of MTCT and how those who want children can take advantage of this. When probed on their silence on ARVs one counsellor quipped; “...people should not get pregnant because of the availability of ARVs”. True as this may be HIV positive people deserve to know all the possibilities available to them and it is the duty of HPs to avail that information to them. It appears that people were only given better information and advice on ARVs when they confronted the HPs with direct questions or when they became pregnant. As pointed out earlier, most of those who confronted HPs on this issue generally felt that though they were given some enlightening information, the attitude of the HPs towards their intention to conceive was generally negative.

5.2.2 HPs and HIV positive people who want to conceive

All of the counsellors and some nurses indicated that they had in the past months (before July 2005) been approached by an HIV positive individual or couple who wanted to have a child. The HPs agreed to discuss their experiences with these people. Most HPs empathised and some sympathised with them. Some pointed out

that these people could have a child provided they fulfilled certain conditions (conditional pro-choice stance). Some took a pro-rights stance. Others were of the view that though their need to have a child may be genuine it was not necessary to have a child considering their condition (pro-children stance). They felt the risks posed both to the mother and the child far outweighed the need to have a child.

Looking at the information that these children seekers were given, one can not help but notice that the information itself and the manner in which it was given was generally biased and meant to discourage child-bearing. Responding to a question on how he would deal with an HIV positive couple coming to him for advice on the issue of having a child, one counsellor responded this way;

“well, our most important area of discussion is; it is still possible to be pregnant and get a child when you are HIV positive but then our area of interest is what does it mean to be pregnant when you are HIV positive...it means whilst we had built your health so much with ARVs the stress and strain related to delivery and the psychological pressure related to nursing a child may actually be counter to what the ARVs are trying to achieve because stress is a very big problem in terms of the reduction of one’s CD4 cell count...the couple weighs whether it is worthy to have a child after all or it is better to conserve the health that they have”.

One counsellor relating her experience of dealing with a child seeking couple had this to say to the man,

“...let’s look at you as a husband, maybe you will benefit by exploring as you go back home whether really – do you really-really need a child? For what benefit? What will be the meaning to your health? Look at your wife as well – do you want her to fall pregnant, what could happen after that delivery?”

Giving people complete information on which to base their decisions does not entail emphasising negatives and being silent on the positives or just ignoring them as if they do not exist. Emphasising the negatives of having a child to those who had come forward for guidance, one counsellor said;

“...there is a lot that goes on when you are pregnant. You will find that you will end up having a lowered CD4 cell count which could lead to really quick progression to AIDS. Pregnancy lowers your immunity and you are then open to other infections, these other infections will also lower your CD4 cell count and increase the rate of progression to AIDS”.

A nurse commented;

“...if its going up (CD4 count) then you have to consider whether you want it to come down and then go up again. What are the chances that it

will go up again at the same rate at which it was going up or that it will ever go up again?”

Apart from the fact that the validity of this information can be disputed, the manner in which it is delivered makes it seem compulsory for HIV positive people to act upon it. It is as if some HPs are in a way trying to convince people with HIV to see reproductive issues from their medical perspective. Commenting on his reaction to a couple who informed him that they wanted to have a child a nurse at UBH said “...you feel pity for them, really it’s a young couple, they have no child, they really want to have a child but just because of this (HIV) they can’t”. Even before giving them any advice or information the counsellor had concluded that these people could not have a child because of their HIV status.

There is also a tendency among most HPs to over emphasise the risk to the child though they are aware that this risk is considerably reduced with the help of prophylactic drugs. The way the risk to the child and the mother is emphasised makes it loom larger in the minds of HIV positive people than it actually is.

It seems HPs do put themselves in positions of authority when dealing with HIV positive people. Instead of fostering a two way exchange of information with the HIV positive people they tend to dominate the exchange. Though most claimed to give HIV positive people balanced and unprejudiced information this actually is not so in practice as the study findings above demonstrate. HIV positive people are usually given a bundle of negatives and since the bundle of positives is usually missing, perhaps deliberately so, the scales tilt towards the negatives and point to non-conception – a desired result for most HPs who generally felt that this was the best option.

5.2.3 HPs and pregnancy among HIV positive women on treatment

This subsection looks at various responses displayed by HPs when they found that some of the women on treatment were pregnant. According to HPs this is becoming a regular occurrence in OI clinics. The Mpilo OI clinic statistics in the month of June and July 2005 indicated that they had five cases of pregnancy among women on treatment. Two views on the issue of having children while on treatment can be identified among HPs. There are those who are against it. The response of this group to pregnancy among women on treatment is usually anger, disappointment, dejection, a feeling of defeat and failure. The other group

comprises those who accept it. In this group there are those who, though they accept it, feel that these women should be given the go ahead by medical personnel. Then there are others who feel that HIV positive people should have the autonomy to make their decisions without interference from the HPs (pro-rights).

Those who are against HIV positive women on treatment getting pregnant had this to say;

“In fact a lot of people are discouraged and disappointed. You see it’s natural when- I mean especially when you get involved in the life of an individual and you start **instructing** [emphasis mine] that person to go and do this and this; if that person comes back and has not done what you told him to do, naturally you are more likely to be disappointed. Basically most medical practitioners are disappointed on the issue of these people. After they go through all those counselling sessions this person comes back pregnant!” (Doctor)

“It is disheartening, because as a health worker you are looking at the physical implications on this woman. We have seen many of them, I mean, after they deliver they struggle to survive...” (male nurse).

“It is difficult, like I said, for a moment you feel like you are defeated you know, you have not done anything for that client. You empowered them so much but there they are in front of you, they are pregnant again” (counsellor).

“I must admit that some patients I really get angry with them because some already knew they were HIV positive but they went on and got pregnant” (nurse).

There seems to be a view in this school of thought that the information given to HIV positives should make them arrive at what is seen as an ideal decision, that is, not to have a child. When people with HIV decide to get pregnant HPs are not happy with it. It is such an attitude that may discourage HIV positive people from consulting HPs on issues relating to their reproductive choices. Such attitudes also make some people see falling pregnant as an offence, a feeling and view revealed by HIV positive people in this study (C15F, C2F, C10F, C13F).

It also seems the clinics have taken it upon themselves to try and discourage women from exercising their right of having children. One counsellor commenting on the fact that it is not good or expected for those on treatment to fall pregnant as they will have been empowered with information said;

“...the number of women becoming pregnant within the ARV program has been increasing and to try and **control that** [emphasis mine] we ended up requesting others from the family planning program from the main hospital that...they should come and attend to women who want to use family planning methods... the reason being that regardless of the information that you give them...you find out that women still get pregnant.”

As a result of the continued rise in the number of women who became pregnant while on treatment the clinic tried to find ways of limiting the number of pregnancies within the treatment cohort without bothering much to find out and consider the reasons behind these pregnancies. The pregnancies were interpreted as a result of an unmet contraceptive need among people with HIV. Consequently family planning services are now provided in all the OI clinics in Bulawayo. However like most policies that are imposed from the top without consulting and involving the people affected, this move is likely to fail. The question then is; in such an environment, do HIV positive people have the freedom to choose? Such actions by the clinics confirm the assertion by some HIV positive people who were interviewed that HIV positive people are pushed into using family planning methods as a way of thwarting their plans to have children (C3F, C10F, C14F).

The other group of HPs falls into those who accept the pregnancies of HIV positive women on treatment though most insist that positive people should consult health professionals first. Here are some of their responses on how they felt about women who became pregnant while on treatment;

“...it is not for me to say they shouldn't have a child. If they have adequate information about the risk associated with pregnancy and they still decide they want to become pregnant they can go ahead and have a pregnancy...what we can simply do is to give advice and empower people to make decisions that they will blame themselves for tomorrow” (counsellor).

“me, I will simply assist that person so that they may access good services...I will give her information on how to join the PPTCT program and how she can keep accessing treatment as a pregnant mother and also how she can access services and how these services can help her. To me it is acceptable because it is something I usually encounter” (counsellor).

5.3 Prevailing discourses about child bearing among HIV positive people

The study found that there are three dominant discourses among HPs concerning reproduction among HIV positive couples or people. These are the conditional

pro-choice discourse, the pro-children as well as the pro-rights discourse. The study found that six of HPs interviewed took a conditional pro-choice stance, while four took a pro-children stance and only two took a pro-rights stance. The conditional pro-choice stance argues that HIV positive people may have children provided they satisfy certain conditions determined by the HPs. The pro-children stance is against HIV positive people having children at all. Its proponents argue that the risk to the child, despite the existence of ARVs remains too high to contemplate. Their major concern is the health and welfare of the child born to such parents.

Prevalent in the pro-choice and pro-children discourses is the view of HIV positive people as “abnormals” who do not have the same reproductive rights and freedom as “normals”. From the pro-children and the conditional pro-choice perspectives HIV is framed as a disability and like most people with disabilities HIV positive people find themselves in a position where their condition is viewed as a handicap. As Asch & Fire (1988) note, the attitudes and structural barriers of the non-disabled turn disabilities into handicaps. People with disabilities are usually assumed to be unfit for parenthood. Ferri & Gregg (1998) argue that the reasoning behind such a stereotype is the fear that people with disabilities will produce “defective” offspring. In the case of HIV positive people the fear seems to be that they will produce infected children and also that they will increase the number of orphans and child headed households in the society due to their early death. As a result people with HIV/AIDS find their right to reproduce being questioned and sometimes denied by both the medical fraternity and the society.

The pro-rights stance argues that like any ‘normals’, HIV positive people have the right to do what they want, when they want, in the matter of reproduction. The fact that they are positive does not make them any less human. This perspective does not frame HIV/AIDS as a disabling factor but rather a chronic but manageable condition. However the consideration of HIV positive people as ‘abnormals’ in the society in general and in the medical fraternity in particular means that HPs with such a liberal view are likely to be few. As a result their influence on the reproductive lives of people with HIV/AIDS is also likely to be limited.

5.3.1 **The conditional pro-choice stance**

The conditional pro-choice advocates indicated that they were not against HIV positive people having children as long as they made their decision on the basis of information and advice given to them by HPs. There are a number of conditions that these advocates see as necessary to be fulfilled before HIV positive people can decide to have children. It is important to note that these conditions are imposed by the HPs though on the other hand they claim to be neutral facilitators. The following are some of the conditions pointed out:

“they have to do that (decision making) on an informed basis...”

“I think people need information, the correct information and be allowed to make choices based on correct information...”

“people can have children as long as they are able to make sure that they make every effort to make sure that, that child does not become infected...”

“if they want to make a decision to get pregnant they have to consult a doctor who will advise them on how big the risk of getting pregnant is”

“they have to consult a medical person who will look at their CD4 cell counts, how they are clinically and what risk there is...”

“we also check the stage they are in...”

“I referred them to their private doctor so he may tell them whether they can have a child or not.”

It seems as far as these HPs are concerned HIV positive people have no entitlement to make decisions regarding pregnancy without first consulting them.

5.3.2 **The pro-children stance**

The proponents of this stance regard child bearing by people living with HIV as an unnecessary risk to the unborn child. Their concern is the wellbeing of the child more than anything else. As far as they are concerned it is not only irrational but also immoral for HIV positive people to have children. Immoral because there is a possibility of having a positive child and thus cause suffering to an “innocent soul” when this can be avoided by not having a child at all. Four of the HPs interviewed displayed pro-children sentiments. Here are some of their statements with regard to the issue:

“..this is a problem (having children). It will not only be a problem to them but also to the children. The painful thing is to see the children

when they get sick of AIDS...that is painful especially if you deal with children who are HIV positive which is what I do most of the time” (counsellor).

“I don’t think it is necessary (to have a child), it’s not necessary. I believe there can still be a happy marriage without children and perhaps my opinion is heavily influenced by my medical background. I wish I could come out of it and stand on neutral ground, but I do not think it’s necessary, they shouldn’t”.

“...both of you, you are ill now and the child will be ill as well and the child will be in and out of hospital now and again...or you have a child and five years down the line both of you die what will happen to the child and worse if the child is positive as well, even if its negative what happens to her and so forth” (nurse)

“I really feel pity especially for the children. They are very innocent but they are suffering” (nurse).

5.3.3 The pro-rights stance

What underlies this discourse is a human rights stance. Its advocates argued that it is the right of every human being to choose freely without fear or fetters. It is also everyone’s right to be given the correct and complete information regarding reproduction when they need it. They argued that;

“every human being has a right, has every right to decide what he wants concerning his health, family, just about everything. It should be his decision. As we have here at OI clinics there are people who choose not to take ARVs, that is the choice of the individual, it is his right...” (male counsellor)

Another counsellor argued that due to the number of adults infected with HIV in Zimbabwe and given the high chances of having a negative child people have the right to choose to reproduce freely. He said;

“it is very important, to me I think it is very important for HIV positive people to have children because even if I give you our statistics in Zimbabwe, it says 24.6% of the adult population are people living with HIV. That is a substantial number if you look at it. So considering the chances of these HIV positive people having negative children if they take the necessary drugs I think there is no reason for them not to have children. So I think being HIV positive should not ever be used to stop someone from having children”.

Concluding remarks

The above section has argued that the stance of most HPs in the area of reproduction among people with HIV is that of interested parties who instead of giving value free information, give value laden, authoritative advice. The

information given to HIV positive people generally emphasises safe sex and the risks involved in pregnancy while discounting the very low risk of having a positive child when one is on HAART. The risk of getting an HIV positive child is overemphasised though the HPs acknowledge the fact that there are high chances of getting a negative child if one is on drugs and takes nevirapine at the onset of labour. There seems to be a general tendency among the HPs to commit the error of omission when giving HIV positive people reproductive information. An analysis of conversations with HPs reveals four possible reasons for the negative attitude towards reproduction displayed by most HPs in this research. These are the principles of medical ethics, the clinic's criteria on ARV treatment, biomedically related reasons and to a certain extent the personal views of HPs on reproduction among HIV positive people.

The biomedical model of health is by its nature prescriptive and it views the HP as the authority in terms of HP-patient relationship (Wade & Halligan 2004). Modern medicine, argues Samson (1999), is based on a mechanistic, materialist view of the body and the HP, as the professional, exercises control over this body. This is the general view that the public has of HPs and such a relationship between HPs and patients has come to be seen as normal (Bologh, 1981). People normally do not talk back to the HPs, they just listen passively. As one nurse pointed out during the research,

“people generally have an impression that a nurse is someone who would just instruct you to do this and that. Now we have a challenge to change the whole process so that people can be able to approach us freely...”

Another reason that may be influencing most HPs to take an anti pregnancy stance in the OI clinic's is the criteria used by the clinic's on ARV treatment eligibility. The criteria used to choose those eligible for treatment states that for one to qualify for ARVs, they have to be practicing and continue to practice safe sex. However this criterion may be forcing people to lie in order to get treatment as noted by one counsellor in the UBH OI clinic. “Maybe most women who say ‘I am practising safe sex’ say so in order to access these drugs...” he said. Apart from this criterion the clinics seem to take a stance that discourages people from having children. For example the introduction of family planning clinics within all OI clinics with the aim of reducing the number of women who fell pregnant while

on treatment. This in itself may give the HPs the impression that they are expected to steer HIV positive people away from the idea of reproduction.

The anti-pregnancy stance taken by most HPs in this research may be based on a genuine concern for the health and well being of HIV positive people as well as for children born to them. Their (HPs) actions or non-actions may be justified on moral and professional grounds under the principles of justice, nonmaleficence and beneficence. The reasons behind the three prevalent discourses on child bearing among HIV positive couples identified above are discussed in more detail in chapter seven.

What this chapter has revealed therefore is that HPs play an important role in the decision making process of HIV positive people. The information they gave and their attitude towards reproduction as seen by HIV positive couples in this study played a significant role in determining their decisions on whether to have a child or not. It is also important to point out that some HIV positive people indicated that before they would decide to have a child the most important people they would consult are their doctors and counsellors for advice. Thus HPs were regarded by some couples as important agents in their reproductive decision making.

CHAPTER 6

STUDY FINDINGS

6.0 REPRODUCTIVE DECISION MAKING

Decision making in whatever context is a complex issue. Among the HIV positive couples studied it encompassed personal desires, medical, moral, ethical, economic and socio-cultural issues. As Plous (1993) argues, there is no such thing as context free decision making. The following discussion focuses on how the contraception use decision as well as the conception decision was made by HIV positive couples and the role of gender in decision making. It will also consider the problems they encountered and who if any dominated in making the decision. Thus the chapter describes and discusses the content of decisions made as well as the process of making those decisions.

6.1 Men in decision making

Among those who made decisions decision making was found to be a process where both partners were involved and in some cases women were more involved than men. Among all 'decision making' couples there was no case where decisions pertaining to reproductive issues post diagnosis can be said to have been dominated by men. However prior to knowing their status married couples indicated that there were some instances where men imposed or attempted to impose their decisions on their wives. These cases relate to C3, C8, C10 who were still married and C4 where both partner's were previously married. C4F indicated that her previous husband made the decision to have only two children and since he was the bread winner she felt her hands were tied though she desired a large family. She said,

“he said two were okay. Those are the ones he thought he would be able to support; he said it's not good to have children who would not be adequately provided for, who will end up stealing or something else”.

Though she raised her concern and told him about her desire to have a big family he was adamant that two were enough and he threatened that should she continue to have children against his wishes she would look after them herself. Narrating her story she said;

“I told him my wish, that for my sake let’s have five or six but my real desired number which I wanted was eight. But he said ‘no, please listen to me well, I am saying eight is too much, those two are enough. So what I am telling you is that if you become stubborn and go on having children that one who will have encouraged you to do so will help you look after those children’”.

The woman however points out that she would have had another child despite her husband’s protestation’s had he lived long enough. He however died a few years after the birth of their second child and there was no chance to prove whether the woman would have carried her intentions through. C8F presents a similar case of non-consultation by her husband when it came to matters of having children. She said “usually I used family planning you see, so it was common that when he wanted a child he would say ‘leave those things of yours’”. Asked on what if she did not want a child at that particular time she responded;

“you first of all ignore his demands but the atmosphere in the house wont be enjoyable at all when someone is pulling that way and another that way. What more you get the money from him so he will end up not giving you the money...so you end up not taking them. But no, I would not have gone beyond four children”

It is important to note that she desired four children and currently has four children – the exact number she desired and the one she said she would not have gone beyond. She insists that she would have not exceeded that number. Thus it seems she had four children not because the man demanded or commandeered her to have them but because she also wanted those children. Asked on what she would have done if the man had demanded to have more children she indicated that she would have resorted to ‘underhand tactics’ of using contraceptive methods secretly. These tactics to circumvent male demands on reproductive issues also come out in C4M’s story. He said they failed to arrive at an agreed position on the number of children to have with his wife. As a result he ended up dictating that those they had were enough and that they should have no more. However the woman had other ideas.

“she had another dream because we have girls only, so she said I would not stop having babies until I have got a boy. And I said no it doesn’t actually make any difference, a child is a child whether a boy or a girl... so I said no, this issue of boys no, no, no!” (C4M)

Having thus been blocked through dialogue she decided to carry her fight on through other means this time in the bedroom using the sexual language. “...she fell pregnant, I had actually forgotten we- - she had a Nor-plant, so she did not

want to tell me that it had expired because she had her own intention of getting pregnant...” Women may be forced into accepting some decisions but men do not always have the power to control women’s reproductive intentions as they have other ways of furthering or achieving their reproductive desires which men find difficult to control. Thus it can not always be argued, like Machera (2004) does, that women lack bedroom power, that they lack control over their own reproduction. As Greene & Biddlecom (2000) point out, men may not prevent women from covertly using or not using contraception.

6.2 Contraceptive use decision making

It was pointed out earlier that most of the relationships under study were relatively new and that most of the respondents met well after they knew about their status. They had undergone counselling and had been taught about issues of re-infection, MTCT and general health requirements if one is HIV positive. The importance of the condom in the sexual lives of HIV positive people had been impressed on the minds of many. As a result many couples reported that in so far as condom use in their sexual lives was concerned no conscious decision was made. Given their condition condom use was assumed to be the logical thing to do. Commenting on how they came to use a condom in their relationship C1F said, “you see, he is also someone who came with the full knowledge that if you are like this then you have to use a condom”. C5F said,

“no, we did not discuss it (condom use). We just assumed that it is the most natural thing to do since we both know our status and there is no way we want to go back because we have both been through the early stage (of AIDS), we do not want to go back there”.

This was the common trend among the respondents when it came to condom use. Condom use was seen as a normal thing which did not even merit discussion. There are only a few cases where couples agreed that they did talk about condom use. C2 and C4 had to discuss condom use in their relationships because they had gone for some time without using a condom when they were already positive. Furthermore when diagnosed they were already in those relationships and they were not using any condoms. In the case of C2 it took them about four years from the time the woman told her husband that she was positive to the time they began using the condom consistently. The use of a condom only came after the man had plucked up enough courage to go and test and he tested negative. It was then that

they talked about condom use and made the decision to use the condom from then onwards. The man said,

“...we sat down and had a close look at this thing and said if we continue doing this (sex without a condom) it will take us nowhere and perhaps we won't even be able to do what – to live for a long time. It is better we use this thing (condom) and protect ourselves so we may also be able to look after our children as they grow up”.

According to the couple this was a mutual decision. They did not encounter any problem. This seemed to have been a general trend among the couples. There are very few cases where one of the partners showed any resistance to condom use.

On the issue of family planning methods most men felt that it was up to the woman to use any family planning method or not. Some men said they had discussed the issue of dual protection with their partners but the general feeling was that it was up to the woman to make up her mind whether to use dual protection or the condom alone. A number of women also pointed out that their partners did encourage them to use dual protection.

6.3 Communication on reproductive and sexually related issues among couples with HIV/AIDS

Communication regarding reproductive and sexual issues was found to be lacking among some of the couples interviewed. The position of the other partner was either assumed or taken for granted. The issue of condom use discussed above is a case in point where the position of the other partner was usually taken for granted. The couples usually assumed that their positions on condom use were in tandem and hence did not merit any discussion. A similar attitude was observed on the issue of reproduction. While decisions had been made at the individual level they had not been communicated or discussed at the couple level. There were usually suppositions and assumptions on the expectations and intentions of the other part. For example in couple 15 both partners expressed a strong desire to have a child but they had not communicated this to each other as they both felt that as a result of their status they should not try for a child. Questioned on whether they had discussed their desire for a child C15F had this to say;

“no we have not talked about it because we told ourselves that since we are positive we should no longer have a child. But the truth is that we both want a child. That is where the problem is.”

Her partner said, “I do want to have a child but because of this (HIV) I do not think I can. I however have not discussed this with my wife”

Couple 7 also assumed that since they were HIV positive the sensible thing was not to have children without discussing this with each other. C7F said, “we have not discussed it, we still need to sit down and talk about it because you can not make a child alone, a child is something you have after talking to your partner”. However though her partner also indicated his desire to have a child he seemed also to rule out discussion on this issue as he seemed convinced that there was no possibility of having a negative child hence no need to discuss impossibilities. He said,

“the desire is there, the desire is really there, but if I look at the stage I am in I think that child will not have a healthy life because the seed (sperm) is rotten, it is rotten and something that comes out of it will be unhealthy and would not grow well”

Questioned on his partners’ views on the issue of having children he said; “I do not think she wants a child now, she can not say I want a child because she knows my status, she knows her status and she knows about life”.

Even among those couples who did not intend or desire to have any more children there were cases where partners did not express or communicate their positions vis a vis reproduction to each other. For example in couple 6 both partners do not want to have anymore children. Both indicated that they had not discussed this with each other. They just assumed that since they used the condom consistently and the woman also had a loop this communicated their intentions. While in the cases discussed above the couples had usually similar views or positions about the reproductive issues concerned even though they had not discussed them, in couple 4 it was found that the couples desires or intentions were incongruent and in most cases above the couple had not discussed these issues. Thus though they had both made decisions at the individual level there was still a need to communicate and discuss these decisions at the couple level. While C4F expressed her intentions to have at least two more children with her current partner, the concerned partner indicated that he did not intend to have any more children. An excerpt from my interview with C7F;

Interviewer: Eh!, your intention of having two more children with your partner once his health improves, have you discussed it with him?

Respondent: no, I have – I have not told him. But I have already made the decision that I will have the children.

Interviewer: what do you think he will say about this?

Respondent: I am not sure but I want to have children with him.

C7M however had a completely different view on the issue of child bearing. He said,

“I do not need any more kids. I already have two kids and I need to concentrate on bringing them up---I think because there is no total cure for HIV there is no guarantee that the child will be negative. So my view is use condoms, no babies”

While some couples discussed all issues related to their reproductive and sexual lives, i.e. C12 and C2, some couples discussed only some of the issues (C5, C1, C3) while others did not discuss or communicate about these issues at all (C7, C6). Thus in some couples there was lack of communication on important reproductive and sexual issues leading to assumptions and suppositions on the position or stand point of the other partner. Though in most cases in this study the couple's assumptions about each other were usually correct such a lack of communication on reproductive issues may possibly lead to conflict in relationships.

6.4 A description of the reproductive decision making process

To put the decision making process of HIV positive couples into context it is important to briefly look at reproductive decision making among the general population. Among HIV negative couple's decisions to have a child are not usually as involved and intense as is the case among HIV positive couples studied. As the results from this study and from an earlier study on fertility and child death in Zimbabwe indicate (see Grieser et al., 2001), in non-infected couples the decision to have a child might or might not be approached rationally or consciously. Among married and unmarried couples many if not most pregnancies “just happen” as it is an expectation that they should happen. The couple may decide to have a child but they do not set about having one deliberately at a specific moment as seems to be the case among HIV positive couples. Negative people, it seems, do not go to the same lengths as positive people in considering the decision to have or not to have a child. Unlike in negative couples (Grieser et al. 2001) among HIV positive couples information gathering, weighing of risks and benefits and the discussion about having a child or not seems to be a more intense process.

The lack of meticulous planning and consideration of risks and benefits of having a child seems to be a familiar trend among the negative couples. Grieser et al. (2001) in their analysis of reproductive decision making in Zimbabwe indicate that;

“...when asked about reasons to have children some of the older respondents had difficulties answering because it seems that they had never before questioned their desire for children. Adult life was taken to be synonymous with child bearing, and many respondents referred to the societal and marital expectations that contribute to the view of child bearing as a duty...”

Among many negative couples in Zimbabwe, except perhaps the well educated, it seems there is none of the conscious or rational approach to child bearing that is evident among the HIV positive couples who were studied. Child bearing seems to be an expected result of marriage or partnership. HIV positive couples usually weigh the potential risks and benefits of child bearing before they make a decision to have a child or not. Their decision making process also seems to be more involved in that both partners are seen to be involved in the discussion and they gather and process much more information before making a pregnancy decision.

Unlike HIV negative couples those who are positive are usually in no position to expect pregnancies “just to happen” or to be nonchalant about being pregnant. First, because of their ill health they have to consider the impact that pregnancy may have on their health and plan accordingly. They also have to guard against re-infection and its possible impact on their health hence they have to minimise unprotected sexual encounters. Unprotected sex has to coincide with the fertile period of the woman if pregnancy is the desired result. Thus having HIV introduces a different context in terms of reproductive decision making among couples with HIV. To them it becomes paramount to make rational and conscious decisions to have or not to have a child at a particular moment as this has implications for their overall health and well being.

Fifteen couples were studied and among them some were confronting, others had confronted reproductive decision making, and others had done neither (non decision makers) since knowing their HIV positive status. This section focuses on those couples and individuals who intended to have children and who had discussed their intentions as a couple. As such the discussion will centre on C1, C5, C9, C12 and C14. It will attempt to reconstruct the decision making process

from the time one partner conceived the idea to have a child up to the time they made a choice or decision as a couple. The process of decision making in this study will be characterised as occurring in a number of stages: from when the idea first enters into consciousness to discussion and decision making between partners to searching for information and to weighing the risks and benefits of having children. These stages by no means represent a linear progression of reasoning or action in the process of decision making. They do not necessarily occur one after the other. Any of the suggested stages may follow after the idea is first conceived and they may occur simultaneously. The attempt here is to describe what goes on from the time the idea of having a child enters one's consciousness to the time a decision is made.

It is not easy to determine exactly when the idea to have a child enters into one's mind but a number of factors that trigger the idea were identified in the study. These are different from individual to individual or couple to couple but they all seem to stem from the deep seated need to have a child or a child of a certain sex for those who already have a child or children. There are factors that may be said to offer fertile ground on which the seed to have a child is sown. These act as common denominators to all individuals who intend to have a child. They include the availability of HAART and the confidence they have in it, their newly found health and social comparison, i.e., the fact that others who are HIV positive and in a worse health state than them have negative children. These factors and the need to have a child are the wood with which to make a fire but the spark that sets the fire alight seems to differ from individual to individual or couple to couple.

For C1M the fear of dying without a child after recovering from a serious illness seems to have been the trigger. This fear was also detectable from C5F. She indicated that the information she received during counselling sessions made her decide to try for a child in the near future. This was her response when asked:

Interviewer: when did you decide that you will have a child?

Respondent: I decided- - when was it? I think 2004 when I used to go to counselling sessions and they'd tell us about it (possibility of having a child), so I thought okay – I'll just have one, just try for one.

She however pointed out that she had always wanted to have her own child and that her improved health as a result of ARV's had played a significant role in pushing her towards the idea of having a child. She said, "actually (the availability of ARV's) helped. I think that is what made me decide to have a child". In this

instance the availability of information on HAART, MTCT and reproduction through counselling acted as a trigger in the decision making process. However, for the male partner in C5 the trigger was different. The idea only came into his mind when his partner informed him about her need to have a child. Before she had raised the issue of having a child he had not thought about it and this may be because he already has a child. Describing how he came to decide to have a child with his partner he said; “A-a-h!, XXX wants a baby and she says she wants my baby you know and she is so beautiful I think I also want a baby with her, I would love to have a child with her...”.

For C12 the triggering factor to try for a child at that particular time in their life was similar and it was the need to eliminate negative family involvement in their relationship. At the time they decided that it was best to try for a child they were under immense pressure from the woman’s parents to end their relationship. Her parents did not approve of her sexual relationship with a man in her current state of health. She indicates that to them it was a worthless and dangerous endeavour in terms of health for her to have a male partner when she already was sick.

Commenting on this she said,

for them “...someone with HIV should not have sex. My mother, wherever I meet her, she always says ‘my child, never do it. When you have sex you will die quicker’. They say an HIV positive person should not have sex because that is believed to worsen the disease. Plus the old people believe that condoms are the ones that cause the disease”.

Due to this conceptualisation of HIV by her parents they had arguments and quarrels as they insisted that she ends her relationship. Her relationship with her parents became strained to such an extent that she broke all communication with them and went to stay with her partner against their will.

It was this family resistance to their relationship that triggered the idea of trying for a baby at that particular time. C12F said,

“there is a time last year (2004) in December when I missed my period for 3 months, I was happy because I thought I was pregnant because I want a child and I also saw it as a way of stopping my parents from interfering in my relationship because if I was pregnant and with a child they would give up and say let her stay”.

C12M also concurs that the family resistance to their relationship triggered the idea of having a child as a way of securing their relationship. So the reasoning behind their attempt to have a child was that if the woman became pregnant her parents will be forced to accept her relationship and as such leave them alone.

Thus though there are common factors in wanting a child what triggers the idea at a particular time differs from individual to individual or couple to couple. With the idea of having a child having been conceived, how then do couples or individuals proceed in fulfilling their quest?

6.4.1 Discussion and decisions between partners

With the idea having entered their consciousness the next step taken by most of those who conceived the idea was to discuss it with their partners. As indicated earlier, most couples in the study said decisions in their relationships are made through open discussion and communication with each other. C5F said that having conceived the idea she approached her partner and informed him about her desires. They discussed the issue, considered the obstacles on their way and conditions favouring their desire. Having considered their health, the implications of HAART on reproduction and their financial standing they agreed to have a child in the near future. They however decided to wait until their health and financial situation improved. Commenting on how they came to this decision and what issues they considered C5M said,

“...we have discussed this thing thoroughly and I have said no XXX your CD4 count, her CD4 was 44 by then while mine was 158, and I was saying with your CD4 at 44 now, at least for us to be able to have a child it should be around eight hundred to over a thousand. So we discussed it ...until we are satisfied that our CD4 cell count is alright we will not have a child because we have also enquired, talked to people in the field of medicine, trying to find out what the odds are, now we are quite aware of what we are supposed to do”.

While C5M emphasised their health concerns C5F focussed on the financial aspect. She pointed out that she intends to have a child in the near future but “I am waiting until I am financially stable”.

In their discussions the couples raised a number of key issues some of which are their concern about health, MTCT, the role of ARV's in reproduction, their parenting abilities and the issue of financial resources. Health concern is the main reason that made C1F, C9F and C14F decide not to accede to their partner's suggestions of having a child. C1F indicates that her partner did express his desire to have a child but she turned him down because of concern about her health. She said,

“ya-a; he talked about it but I do not see any way forward for now. You see this other partner will be safe but when I become pregnant my immune system will go down you see”.

She also indicates that they discussed the issue of child bearing and made a mutual decision. She said;

“we do not force each other, we discuss and agree...as long as we live together I think we must always try that whatever we do together should be agreed upon...so in most cases we discuss things, we have not had any difficulties so far, I know in life there are difficulties but we have not had any so far”.

Having discussed the issue based on the information that they had they decided as a couple that;

“...we will live as we are, we will live even without a kid...” (C1M). The male partner however indicated that he still intends to have a child and C1F did indicate that if her health situation changed she may consider having a child. She said, “I have the desire that maybe one child but here is HIV...in the future maybe and I will also be doing it for his sake because he has no child”.

In couple 9 the male partner’s intentions on the childbearing front have also been discussed but the female partner, despite her desire to have a child, has decided not to have one in the near future. Responding to the question of whether they had discussed the issue of having children as a couple she said,

“we were talking about it in this past month, he was saying he now wants a child. I told him that if he was serious we should go for counselling but I know he will not do that”.

She also said,

“...he says he wants to have a child with me but I can see that he is afraid. If he has a child with me he will become infected. So that means the child will have to come outside this relationship. It will have to be from outside this relationship because I also do not want him to say I am the one who infected him”.

The woman does not want to have a child because she does not want to shoulder the burden of blame and a guilty conscious should her currently HIV negative partner becomes infected.

In the case of C12 the initial decision was to have a child immediately so as to get rid of family interference in their relationship. However having had a false alarm (the woman missed her period for three months and thought she was pregnant) and with the family pressure having subsided over time, the couple decided to delay trying for a child. They still intend to have a child soon, “maybe early next year (2006)”, as indicated by C12F. It seems the consideration of their financial position convinced them to delay trying for a child by a year. C12F indicated that

they sat down and discussed their new position and decided to firstly try to be financially stable so that they would be able to care for their child. Narrating how they came to this new decision she said,

“we sat down and I told him that my friend, in the near future I would want a child but for now because of our condition which we know, let us first of all prepare for our child, so that if it happens that my health deteriorates after having the child you would have the resources to hire a maid to help you take care of the child, rather than having a child who will give us financial problems tomorrow.”

Among the couples where both or one partner intends to have a child, it seems the decisions that were made were a result of discussions and consultations. The discussion involved the consideration of factors that the couples regarded as critical in deciding whether to have or not to have a child. These included their readiness to be parents, their financial standing, and the impact of pregnancy on their health as well as the health risks to the child. The evaluation of these factors determined the standpoint of each individual during the negotiating stage. It can also be noted that the decision making process among the HIV positive couples was in no way dominated by men. Both sexes played a significant role in determining the path they would take with regard to sexual and conception issues.

6.4.2 Searching for information

Information gathering emerged as a continuous process from the time the one conceived the idea of having a child through to the decision making stage and beyond. Those who intended to have a child or children reported that they sought information about the effects of pregnancy on their health, the effectiveness of ARV's and nevirapine in reducing MTCT and their possible impact on their health as well as that of the child and also about the possible delivery options. The concern about the possible negative health impact of pregnancy on their health and the concern about the health of the child seem to have been the main factors among those who decided not to accede to their partners' desires to have a child, i.e. C14F, C9F and C1F. On the other hand the need to have a child and the optimism on the effectiveness of HAART and nevirapine seem to have been the main factors among those whose joint decision was to have a child in the near future, i.e. C5 and C12. The couples and individuals who intend to have children indicated that they gathered or searched for information mainly from the print and

electronic media, the pamphlets from health and OI clinics, counselling sessions, support groups as well as from HPs.

C5, C12 and C1M all said they had direct discussion with HPs on the issue of having children. They pointed out that they got worthwhile information from these discussions though most did indicate that the information they got was neither balanced nor unprejudiced. They had to take what they wanted from the information and discard what they did not want. The sample results indicate that men were more proactive in searching for information. This may be because in the cases of, C1, C9 and C14, the male partners did not have any surviving children while the women already had children except for C14F. Thus men may be motivated by their burning desire to have a child. Maybe by gathering more up to date information on HIV and reproduction they hoped to convince their largely reluctant and critical partners of the possibility of having negative children without undue risk to their health or that of the child.

It is important to note that when the reproductive decisions/choices were made they were based on the information available to the couple at that particular time and on their understanding of HIV and reproductive issues at that time. Since the situation in the frontline against HIV is continuously evolving the men may have felt that by continuously searching for more relevant and up to date information and learning more about HIV they may in the future be able to convince their partners to accede to their intentions of having children. It is notable that the women who did not accede to their partners' need to have a child indicated that they may change their minds in future depending on developments in the field of HIV/AIDS treatment. Thus decision making is not conceived as static but as a process in motion which responds to changing contexts.

6.4.3 Risk-benefit analysis

The process of reproductive decision making also entails the risk-benefit analysis of having children hence the justification by couples/individuals of why they decided for or against having children. To the two couples (C5 and C12) who decided to have a child in the near future the benefit of having a child outweighed the risks involved, while to the women who refused to have children the risks posed by pregnancy far outweighed the joy of having a child. Among the couples

who considered the issue of having children, it seems their decision involved the assessment of the following factors: their own psychosocial and economic readiness to have a child, the risk estimation to their health and the risk estimation of MTCT. In the case of C1, C9 and C14 while the men were psychologically ready to try for a child the women, it seems, were not. The women also felt the risk to their health was high and they were not willing to take any chances with the risk of vertical transmission as they were not ready to take care of an HIV positive child.

The possibility of perinatal transmission of HIV was a critical concern for the women in determining whether to have or not to have a child. C14F pointed out that she was afraid “to have a positive child” and that she was also concerned about her health. She said “...and I am also concerned about my health you see. It is said that if you give birth your health deteriorates and so on. That is what I do not want. I still want to live”. Similar sentiments were expressed by C1F and C9F which may point to the fact that they are not yet psychologically ready to have a child unlike C12F and C5F whose outlook on having a child is generally positive. The couple’s psychosocial readiness to have a child involved a number of considerations including their satisfaction with the number of children living with them (C12 also decided to have a child because none of their children lived with them), the stability of their health and their financial standing. C5 and C12 decided to delay having a child because of the consideration of some of these issues. They wanted to be in a better state of health (C5) as well as being financially stable (C5 and C12) in order to be able to discharge their parental duties effectively.

Study results indicate that in assessing risk women showed more concern than men. Women were more worried about the effects of pregnancy on their health, about MTCT as well as the possible effect of their positive status on the health and general welfare of a possible offspring. Men on the other hand seemed to be optimistic about the possibility of having a negative child as well as about the impact of pregnancy on the health of their partners. This may be because men in this study were more informed than their partners on the issue of HIV and reproduction as a result of their pro-activeness in searching for information. Their optimism may also stem from their intentions to have children. However, even after considering the possibility of having an HIV positive child, men seemed to

generally have a more positive outlook on the issue of reproduction than did women.

Concluding remarks

The process of reproductive decision making can be characterised as involving a number of stages which are not necessarily linear in progression. These include the conception of the idea, searching for information and encounters with HPs, risk-benefit analysis and discussion and finally making a decision. In making their decisions the couples also evaluated a number of factors some of which are the effects of pregnancy on their health, the impact and effectiveness of ARVs and nevirapine, perinatal transmission of HIV, the health of the child, their parenting abilities as well as the status of their finances.

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CHAPTER SEVEN

DISCUSSION OF STUDY FINDINGS

7.0 INTRODUCTION

This chapter discusses the main study findings and tries to unravel why particular decisions are made, why particular stand points are taken by certain actors in the decision making process and why particular patterns exist in the decision making process of HIV positive people. It examines the dynamics of power in decision making among the study sample and how powerful the HPs are in the decision making process of HIV positive couples. The chapter also assesses the impact that HAART has had on decision making among the couples. As pointed out in chapter three, it would not be wise to make generalisations and firm conclusions based on the findings of this study as the sample is small and homogenous. However, the value of this study lies in pointing out important reproductive issues among a 'hard- to- reach group' of Zimbabweans and in raising pertinent questions on these issues which could be further explored in future studies. This chapter discusses these important issues, making pertinent speculations based on the study findings.

7.1 **Who is who in Reproductive Decision Making? The politics of gender among HIV positive couples**

The gender imbalance in favour of men in the socio-econo-political setup of today's society need not be emphasised since it has been the subject of many studies and debates over the years (Baylies & Bujra, 1995; Wilton, 1997). This dominance of men over women, it has been argued, also extends to reproductive and sexual issues. Drennan (1998), Francis-Chizororo (1999) and Caldwell (1987) have characterised the power of men in reproductive issues as overarching. They argue that the men determine when and how many children to have. Bassett and Mhloyi (1991), see women in Zimbabwean society as generally having limited control to determine their own lives. This partly stems from the patriarchal nature of the society where men are the main decision makers.

Studies carried out between 1998 and 2001 in Zimbabwe do indicate that men seem to have a dominant role not only in household issues but also in issues pertaining to reproduction and sexuality (Grieser et al., 2001; Feldman &

Maposhere, 2003). In a study carried out in 1998-1999 in Matabeleland, of which I was part, (see Grieser et al., 2001), men and women concurred that men dominated reproductive decisions especially regarding how many children to have. The study also highlighted one issue which is usually conspicuous by its absence in gender literature, the covert strategies used by women to counter male dominance in reproductive issues. Women pointed out that they used traditional as well as modern forms of contraception secretly, or they sometimes claimed they were sick or on their monthly period to avoid pregnancy or sex. In the study of HIV positive couples women also did point out that they used these strategies and others to further their reproductive desires, if these conflicted with those of the male partner.

Gender power relations within the context of decision making among HIV positive couples have not been given much attention in the literature. Studies that look at reproductive decision making among HIV positive people focus mainly on women and how they make their pregnancy choices (Thornton et al., 2004; Chen et al., 2001; Kirshebaum et al., 2004; Mitchell et al., 2004; de Bruyn, 2002). The absence of male voices in decision making is intriguing considering that it is claimed they dominate this process. It seems gender relations among infected couples or people with HIV have been generally ignored or assumed to follow general social trends where men are said to dominate decision making (Feldman & Maposhere, 2003). Among the HIV positive couples studied men do not seem to dominate reproductive decision making. The HIV positive women seemed to have a stronger voice and to be more assertive in determining the nature of their sexual and reproductive engagement with their partners. In the study evidence of male domination in sexual and reproductive issues was not found after the partners had disclosed their status to each other. In the few occasions where men suggested non condom use, claiming among other reasons that they were not used to it, women stood their ground and refused sex. This was observed both in married and unmarried couples.

Among HIV positive couples women seemed to determine the nature of their sexual interaction with their partners. In C3, C13, and C15 (all married couples), women introduced the use of the condom in their relationships. In instances like

C14 and C15, where male partners did try to protest against condom use women stuck to the 'no condom no sex' policy. Commenting on this C14F said,

“no, we never did it that way (without a condom). We told ourselves that no condom no sex. So when he wanted to do it without a condom I would refuse. I would tell him that if you do not want go and look for other women outside, it's your life. I would tell him that it's his life”.

C15F indicated that she was ready to fight with her husband over the issue of condom use. She said,

“at the beginning he did not want to but he ended up agreeing because I ended up being harsh with him since I knew what they had said. They had told me at the hospital that when we were having sex we should use condoms. I would tell him that it is better to abstain if you do not want (to use condoms) or else look for others not me”.

Given the characterisation of women's lack of voice in marriage in the literature (Baylies & Bujra, 1995; Wilton, 1997; Grieser et al., 2001; Feldman & Maposhere, 2003) one would not expect such a bold stance from a married woman. However such assertiveness by women seemed to be a trend among the HIV positive couples who were studied. Couples who made decisions indicated that they consulted each other on reproductive as well as sexual decisions and that they made mutually agreed decisions. Thus contrary to other studies on gender power relations within relationships this study found that men do not always dominate decision making. However this has to be understood within the context of this study which as pointed out earlier is not based on a representative sample of the HIV positive population in Bulawayo.

HIV positive women in the study sample had reproductive decision making power in their relationships. This observed reproductive behaviour and decision making patterns between men and women under study may be explained from two perspectives: the evolutionary and the health belief or behavioural change perspectives.

Evolutionary theory is a “hotly debated theory which proposes to explain the evolution of behaviour” (Brand & Carter, 1992). From an evolutionary perspective it can be argued that naturally men and women adopt different strategies of reproduction to maximise their fitness and the biological differences between them may thus explain their behavioural differences regarding reproduction. On the basis of this theory it can be further argued that women have always been more

significantly involved in the reproductive decision making process than currently assumed in most studies as a result of their greater parental investment in the offspring. Trivers (1972) defined parental investment as any investment by a parent in an individual offspring that increases the offspring's chance of surviving at the cost of the parent's ability to invest in other offspring. Biologically and physically women invest more time and effort in any single offspring and as a result of this high cost of offspring they are limited in how many they can produce (Campbell, 2002; Barash, 1979). The costs of reproduction are greater in women than in men as it is the woman who produces the egg that sustains the zygote before implantation, she carries the pregnancy through and bears its risks and usually she carries the greater burden of caring for the child until it matures. Thus typically each child entails a greater investment of time, effort and energy for the mother than the father.

As a result of their larger parental investment it is understandable that women show more concern about reproduction than men. Their significant role in decisions concerning reproduction can thus be expected. The findings from this study seem to support the evolutionary view that women have more at stake in reproduction than men. Women in this study were assertive and choosy when it came to the issue of whether to have or not to have a child; a behaviour that is biologically expected from the parent who invests more in the offspring. With HIV parental investment and the biological costs of reproduction have significantly increased for HIV positive women. The process of conception poses more risks to their health as a result of re-infection as well as risks generally associated with pregnancy. There is also the possibility of caring for an HIV positive and perennially sick child with its attendant psychological effects as well as financial and physical commitment to a doomed reproductive cause. Thus the more visible voice of women among HIV positive couples is a reflection of this increased biological cost to women. To minimise these biological costs of reproduction and hence minimise their reproductive loss women had to be more assertive with regard to reproduction. The concern, worry and reluctance displayed by most HIV positive women towards reproduction have to be understood within the context of their increased parental investment in reproduction as a result of being HIV positive.

It can, on the other hand, be argued that the assertiveness shown by HIV positive women in decision making and their greater concern about reproduction than men is not an effect of biological or evolutionary mechanisms but a result of their state of health. Their state of health demands that they modify their behaviour if they are to survive. Thus women are more vocal in decision making because of the need to survive. The health belief model posits that the likelihood of a person adopting a given health related behaviour is a function of that individuals' perception of a threat to their personal health. This theory of behavioural change also offers plausible explanations for the observed behaviour change among HIV positive couples studied. According to this theory, individuals are more likely to change a given behaviour if they believe that such behaviour increases their risk for a certain condition and if they believe that this condition will form a serious threat to their health or well being. They are also more likely to make behavioural adjustments if they believe that behavioural change will reduce susceptibility to the condition or its severity and that the perceived benefits of changing behaviour outweigh potential negative effects (Rietmeijer, 2005).

Those who are negative and continue to indulge in risky sexual behaviour despite saturation advertising and all the information that is now available do not perceive the threat of HIV to their personal health as high mainly as a result of the risk denial syndrome. These people might still be at the pre-contemplation stage of behaviour change which Prochaska & DiClemente (1986) describe as a stage where changing behaviour has not been considered either because the person might not realise that change is possible or that it might be of interest to them. Many HIV negative people who still indulge in risky sexual behaviour do not consider change as of interest to them as they do not consider themselves vulnerable or in danger of HIV infection. Thus those already infected feel the need to adjust their behaviour more than those to whom infection is but a possibility because to them deterioration of health is a reality not a possibility and they know from their positive status that the threat of re-infection is as real and as likely as was the initial infection.

The reproductive and sexual advice and information that HIV positive people are given at OI clinics, and in their support groups, seem to invoke the reaction described by the health belief model. When their health and life is threatened

people react by taking the necessary steps to safeguard it. As discussed in chapter five, HIV positive people pointed out that HPs stressed the point of safe sex and most of the HPs concurred with this assessment. It was stressed that the condom had to be used anywhere, anytime and every time that HIV positive people had sex and as C14F quipped, 'the condom now rules the house'. No couple in the study indicated that they did not use the condom.

Thus it can be argued that HIV positive people were more willing to discard their socially constructed negative views about condoms as a tool for prostitutes and promiscuous people (Feldman & Maposhere, 2003; Usdin, 2003) and to embrace it because its non use would increase their risk of getting a higher viral load, different strains of the virus and ultimately developing drug resistant strains. This could impact negatively on their health ultimately leading to a quicker descent into AIDS and death. The conviction that adherence to safer sex would enable them to live longer enabled many couples to accept condom use even in marriage. Women asserted their demands in sexual encounters with their partners because they felt their life was at stake not only through re-infection but also through the risks of pregnancy. Addressing this felt threat to her life by becoming pregnant C14F said;

“Ah! me risking my own life? It's me and the child who are going to die and he will remain alive. He will be able to look for another woman but I will be dead...and me, I still want to live. Ha-a! to be alive, I really still want to live”.

It is not surprising therefore that people who still have such a passion for life will not indulge in risky behaviour that can endanger their health. It seems women's voices become more prominent among HIV positive couples because they feel it is their life that will be threatened if their sexual partners fail to understand their concerns; be they sexually or reproductively oriented. It may also be postulated that threatened by certain death through AIDS, men also feel obliged to discard certain norms and beliefs that go with masculinity and manhood in favour of behaviour and practices that will safeguard their health and life. Thus the benefit of changing behaviour by both sexes in the light of a life threatening disease outweighs potential negative effects of a premature death. It will seem that with the threat of death women have decided to be more vocal on issues of reproduction and sexuality while men seem to also have recognised the lack of wisdom of sticking to 'traditions' while sacrificing their health and lives.

Evolutionary theory explains the 'audible' voice and high visibility of women in reproductive issues among HIV positive couples in terms of increased parental investment and risk for the women while the health belief model explains it in terms of health needs. What is observable from the preceding discussion of reproductive issues and choices among couples with HIV is their determination to live, to survive. The ultimate question that arises then is: why do HIV positive people want to survive so much that they are willing to make drastic changes to their lifestyles? While the health belief model helps to explain why being healthy is correlated with feeling good and being sick is correlated with feeling poorly, it fails to account for the desire to survive shown by HIV positive people. On the other hand the evolutionary perspective seems to offer an answer as to why HIV positive people have such a determination to live or to reproduce.

The evolutionary theory argues that human behaviour is partly genetically influenced and that as a result humans tend to behave in a manner that promotes survival and reproductive success. This tendency, it is argued, is driven by the genes whose sole purpose is to successfully replicate and project as many copies of them self into the future as possible. For this to happen good healthy bodies are needed (Bharash, 1979; Campbell, 2002). Genes, as the building blocks of our bodies, not only provide a blue print for the body structure but also, so the theory argues, have a significant influence on human behaviour. Over time certain behaviours and traits that have been effective in the projection of genes into the future have been selected for and those less effective deselected. Thus from an evolutionary perspective the need to survive or to reproduce lies in the genetically influenced need to project oneself or one's genes successfully into the future. To replicate one's genes successfully or to make a worthwhile parental investment through bringing up one's own children, one needs to be alive hence the reproductive behaviours exhibited by HIV positive people. The reproductive choices and behaviours exhibited by the study sample emphasise survival either to take care of the already existent offspring or to reproduce. This behaviour is consistent with the theory's postulated innate drive to preserve life and to reproduce. This conscious or sometimes unconscious need to survive and reproduce and the behaviour that accompanies it shown by HIV positive couples is driven by the "whisperings" of the genes within their bodies (Bharash, 1979).

In spite of the scholarly controversy and debate that still surrounds this theory, it offers an explanation of the reproductive behaviour noticed among both the male and female respondents in this study as well as between those who want to have children and those who no longer desire to have children. As noted in the study those against child bearing or who no longer desire to have children already have surviving children. Their position and behaviour may be explained in terms of their need to live longer so as to safeguard their investment (bring up their children). The reproductive behaviour of those who still desire or intend to have children may be explained in terms of their need to project their genes into their offspring in order survive into the future. While those with children are already on the reproductive ladder and want to survive to safeguard their investment it can be argued that those without children are striving to get onto the reproductive ladder. According to evolutionary theory both have the same goal; to project themselves into the future through their offspring. And as noted above the prominence of women's voices among the respondents may also stem from this natural instinct to safeguard their parental investment and to project themselves into the future. Thus though there is still debate about the validity of this theory it seems to offer answers to the ultimate questions concerning the reproductive behaviour of HIV positive couples described in this study.

7.2 Health professionals and the politics of reproductive decision making among HIV positive couples

This sub-section attempts to evaluate the role of HPs in the reproductive lives of HIV positive couples in the study. Chapter five presented what HIV positive couples think of the role of HPs in their reproductive lives as well as what the HPs themselves construe as their role in the reproductive lives of positive people. This sub-section is an attempt at integrating views from both the HPs and the HIV positive people. This will be done to isolate why HPs seem to play such an important role in the reproductive decision making of HIV positive people and why the majority of HPs felt it was within their jurisdiction to play a role in the reproductive lives of HIV positive people.

There are few studies that have been undertaken to evaluate the role of health professionals in the reproductive sphere of HIV positive people yet they play such an important role. The few studies available have also tended to recruit HIV

positive people as respondents and left the health professionals out (Hopkins et al., 2004). As a result the direct voice of the HPs is missing in these studies. Their impact, which the studies indicate is strong, is only seen through the eyes of HIV positive people. The significance of HPs in these studies is thus presented as speculation and not fact. This study brings together the voices from both sides, and analyses the impact of HPs on reproductive decision making from both the view point of the affected and infected and from the viewpoint of the HPs themselves. It integrates views from both sides and concludes that health practitioners do indeed play a significant role in the reproductive decision making process of people with HIV/AIDS. This is mainly due to their 'traditionally' accepted position as authorities in the field of health and disease and the prescriptive nature of the biomedical model of health which is pervasive in the medical fraternity. As a result most patients tend to defer decision making to their HPs. However the study also found that the influence of HPs is not as strong among those with adequate information on HIV/AIDS as compared to those who have little information and/or education.

7.2.1 HIV positive people encounter health professionals

Most of the HIV positive people interviewed indicated that they experienced different treatment and attitudes from HPs in other clinics than what they experience at Opportunistic Infections clinics. The indication was that HPs in other clinics outside the OI clinics display discriminatory attitudes towards HIV positive people. In studies carried out in Zimbabwe (Tarwireyi & Majoko, 2003) and Nigeria recently (Reis et al., 2005), it was found that a considerable percentage of HPs still display discriminatory attitudes and practices toward HIV positive people. It is not surprising therefore to see such a high percentage of HIV positive people who claim to have experienced discrimination at the hands of health practitioners outside the OI clinics setup. All the respondents who attended the OI clinics indicated however that the treatment they got from the HPs there was in their judgement non-discriminatory and empathic.

Since the present discussion is on reproductive decision making it will concentrate on the HPs who play an important role in the reproductive lives of HIV positive people. As the respondents themselves pointed out these are usually the HPs at OI clinics. HIV positive people indicated that the HPs in these clinics treated them

like any normal patient without detectable discriminatory attitudes or practices as far as they were concerned. The majority however, were of the view that when it came to reproductive matters most of these HPs were against the idea of them having children. Most (23/30) of the respondents felt that HPs did not approve of them having children (see Table 2). It is interesting to note that HIV positive people did not construe this opposition as a form of discrimination or a denial of rights.

A substantial number of the HIV positive people interviewed indicated that they were counselled on the importance of safe sex, non pregnancy and the importance of dual protection. They indicated that emphasis was placed on the dangers of pregnancy both to the health of the mother and the child as well as on the danger of re-infection and drug resistance. The directive and prejudiced manner in which this information is delivered was discussed in chapter five above. It will suffice for the purposes of this discussion to note some actions which indicated to the HIV positive couples that most HPs were against child bearing. C11F relates an incident at the Mpilo OI clinic where all middle aged women were herded into the family planning clinic to discuss contraception. On this and the issue of pregnancy she said;

“Ah!, the issues of getting pregnant they do not encourage us. Now they have opened a family planning clinic for us at the OI. They come and look at you in the queue, they look at those of my age group (32 years) and say ‘you, you and you, go to that room there is family planning’. You will go there and talk to a nursing sister. So it is clear that this issue of pregnancy can be a problem to us especially if you are that person who is taking ARVs, it can put you in trouble, because they have opened a family planning clinic here. We did not have it but now we have it at. So what *mistake* can I make?”

Based on C11F’s comments and those of others (C13F, C15F) who had similar experiences it seems HIV positive women of reproductive age are compelled to use contraception. The attitude and practices of HPs and the information given to HIV positive people persuades and sometimes coerces them to form negative perceptions about pregnancy. C11F interpreted the action by HPs of forcing them to discuss contraception as meaning that if one got pregnant while on treatment she will get into trouble with the HPs. C15F indicated that she was afraid of getting pregnant again because the doctors had told her never to get pregnant again without explaining why. C13F noted that where previously one could hide behind

the fact that she had no access to family planning, now there was no room for mistakes, since the family planning services were now within the OI clinics where they are regularly treated. As a result of the attitudes and advice given to HIV positive people, some came to regard getting pregnant as a *mistake* and their desire for a child as misplaced.

Owing to the position they occupy as gatekeepers to medical information, HPs do play a significant role in influencing the decision making process of HIV positive people. An analysis of the interviews with health practitioners themselves revealed that most of what the HIV positive people said about their attitudes towards child bearing was true. All twelve health practitioners interviewed indicated that in the short period that HAART has been available (April 2004 – present) they had at least dealt with one case where an individual or couple indicated that they wanted to have a child. Upon analysis it became apparent that most HPs (10) were either pro-children (anti-child bearing) or conditionally pro-choice (leaning towards anti-child bearing) while only two were pro-rights. The pro-rights HPs supported the autonomy of the HIV positive to determine their reproductive and health decisions freely. The stance taken by the majority of HPs was consistently anti-pregnancy. This was in spite of the fact that they acknowledged that with the advent of HAART these risks were now minimal. It seems Bor et al. (1992) had a point when they wrote, “everyone has some prejudices and preconceived ideas about right and wrong. These may relate to a patient’s lifestyle or to the patient’s problem...some (counsellors) may never feel empathic towards people with certain problems”.

Given the high number of HPs who were against pregnancy among HIV positive people in the study one is bound to ask why this is so. The next sub-section discusses possible reasons behind this dominant discourse.

7.2.2 The anti pregnancy stance

Ever since the first case was discovered, HIV/AIDS has been conceived as a disease whose prognosis is fatal over a medium term. Those with the disease were not expected to live long. Since its infectivity and methods of spread were still debatable issues, reproduction among people with the disease was regarded as unwise (Thornton et al., 2004). The genesis of the disease itself as a fatal and

sexually transmitted infection with the ability to infect the foetus led to the medical community considering it as a serious barrier to reproduction (Thornton et al., 2004).

In the USA a number of medical and public health bodies advocated an anti pregnancy policy among HIV positive people. This policy became adopted by many countries in the world, though usually not formally so. In 1985, owing to the fatal prognoses of HIV and the risk of vertical as well as horizontal transmission the Centre for Disease Control and Prevention (CDC) in the USA recommended that HIV positive women should defer pregnancy (CDCP, 1985). This stance was followed in 1987 by the American College of Obstetrics and Gynaecology and in 1994 by the Ethics Committee of the American Society for Reproductive Medicine (Thornton et al., 2004). These advised health practitioners to encourage HIV positive people to consider not having children and to inform those already pregnant of termination options. This was not limited to the USA alone but it became in countries like Zimbabwe an informal policy in the medical fraternity. This was because in Zimbabwe no relevant policy was promulgated on this issue until 1999 when the National Policy on HIV/AIDS was introduced. As a result the advice usually given to couples and individuals was not to have children. This was due to both the fatal prognosis of the condition for the parent carrying the virus and the risk of horizontal transmission to the other partner and vertical transmission to the child if the woman was infected.

The stance against reproduction exhibited by the majority of HPs arose as a result of the prognosis of the disease in the early years. AIDS was conceived as a fatal disease that led to death within a few years of diagnosis. Therefore conception had to be discouraged since there was a significant chance (over 25%) of infecting the child or the child being orphaned. Given the stigma and shame associated with the disease there was a considerable chance that such a child would not get good care even in extended family settings existent in Zimbabwe. The proliferation of child headed households and street children bear witness to this (UNAIDS 1999-2004 reports). So HPs, it seems, had a duty to try and dissuade people from conception. There was also concern about the parenting abilities of such parents. The psycho-physical stress of taking care of a possibly infected child when one is also ill was seen as a barrier to effective parenting. There was concern that parents may be

unable to give the child the care that s/he needs owing to their deteriorating clinical or psychological condition (Bor et al., 1992). So the style adopted in counselling was meant to dissuade the HIV infected patient from having children.

Pregnancy was also associated with the rapid clinical deterioration of an HIV infected woman. Those considering pregnancy were urged to consider this carefully. Would they want to die prematurely just for the sake of having a child, was the question. As indicated above, in the early years of the disease HPs were advised to stress the need for safe sex and non conception. They had to try and prevent HIV positive people from conceiving by maintaining a firm line of advice against pregnancy. It is acknowledged today that the first role of the practitioner in this field is that of informing and counselling - detailing the implications of the disease for sex life and reproduction, as well as to promote 'safe sex' (Englert et al., 2001). However, this was not always the case and it also does not mean that all HPs embrace this role positively. Discussing how the issue of reproduction used to be tackled, Delvigne et al.(1990) indicate that when the need for a child arose during counselling it was important to remind patients to take account not only of the risk of transmission to the child but also of the difficulty of combining being a parent with the constraints of their illness. Their feelings; in relation to expressing their own needs in the face of the child's needs and the risk of the child becoming an orphan had also to be discussed (Kass, 1994). The projected aim of such a discussion was a situation in which, even though there was undeniably a desire for a child, the patients would decide to give up the idea due to their condition of having a chronic disease (Englert et al., 2001). Thus the health practitioner had to try to deter HIV infected couples from conceiving. This is the style of counselling that the majority of HPs who were interviewed in this study seem to use. As the results of the study indicate, most HPs made a conscious and sometimes an unconscious attempt to dissuade HIV positive couples from having a child or any more children.

Bor et al. (1992) bring in the issue of morality in the field of counselling. They point out that for some health workers it may be difficult to avoid disclosing their views about the morality of HIV-infected women having children. To some it may seem an immoral act for HIV positive people to consider having a child. This may be a result of the construction of the disease as a disabling condition by many

societies. As health practitioners are members of their societies some may have internalised this prejudice against positive people from their communities. This view of reproduction among couples with HIV/AIDS as an immoral act is expressed mainly by the pro-children HPs. In spite of the attempts by most HPs interviewed to dissuade HIV positive people from conceiving a sizable proportion (8/30) of the study sample indicated that they intended to have a child in the very near future. As Englert et al. (2001) pointed out, it is fortunate that most couples, provided they are fertile, do not need the doctor's authorisation to attempt unprotected intercourse. The impact of anti pregnancy counselling on the reproductive decision making process of HIV positive people should not be underestimated. As the study indicated, ten of the HIV positive respondents still desired to have a child or more children. However due to witnessed negative attitude of some HPs towards reproduction, as well as the information and advice they got from HPs, some are undecided, afraid and even confused about whether to follow their desires or heed the advice of health practitioners.

Some health practitioners interviewed take an anti-pregnancy stance because of their concern about re-infection and the development of drug resistant strains of the virus. They are concerned about the meaning of this for a resource constrained country like Zimbabwe where even first line ARVs are in short supply (The Herald, 2005). They argue that it will even be more expensive if these couples were to have positive children as there will be need for more resources to cater for these children in terms of ARVs. The situation can be further worsened if the children fail to respond to first line drugs or if the parents themselves develop resistant strains which will necessitate them being moved onto second or third line regimes which are more expensive. Thus different motivations ranging from historical, personal, medical and economic concerns influence the anti-pregnancy stance taken by the conditional pro-choice and pro-children HPs. It seems also that the clinics themselves follow an unwritten policy of discouraging procreation among the HIV positive people. This is indicated by their policy of extending HAART to only those who indicate that they practice safe sex. The introduction of family planning services within OI clinics and compelling all females of reproductive age to use contraception also reveals this anti-pregnancy stance.

Owing to these reasons and despite the ameliorating impact of HAART on MTCT and clinical deterioration of HIV positive patients, there remains among most health professionals a tendency to encourage HIV positive people not to conceive. It can be argued that HAART is a relatively new treatment method in Zimbabwe and as such HPs can not be expected to change from a pro-prevention and safe sex discourse and ideological stance to one that gives the patient power and the right to decide what s/he wants within a short period of time. It took five years from the inception of HAART in 1996 in the USA for the CDC to change its policy on reproduction among HIV positive people (Thornton et al., 2004). However whether the stance of HPs regarding this issue has changed is not clear since no studies were found discussing the issue.

It is also important to note that a number of studies have found no direct link between pregnancy and severe immunosuppression or opportunistic infections (Alliegro, et al., 1997; Saada et al., 2000). It also appears that there is no association between pregnancy and increased plasma HIV-1 RNA level (Burns et al., 1998). With the advent of HAART, the risk of vertical transmission has also been drastically reduced to between 1 and 2% (Cooper, 2002; Minkoff, 2003; Thornton et al., 2004). Given these developments, there is little justification to continue discouraging HIV positive people from child bearing. Though the interviewed health practitioners indicated that they were aware of developments in the field of HIV treatment, the majority are still generally against child bearing among HIV positive people.

Today, with access to HAART, the prognosis of HIV/AIDS has changed from a fatal to a chronic disease. The risk of MTCT has been greatly reduced and studies have shown that pregnancy is not directly linked to rapid clinical deterioration of an HIV positive patient. Notwithstanding this, the information and advice given to HIV positive people is generally against reproduction and HPs seem to play or attempt to play a dominant role in the reproductive and sexual decisions made by their patients. How can this be explained? The following subsection examines the relationship between HPs and patients from two different perspectives in a bid to explain how this relationship may influence the nature of information given to HIV positive people and the stance of most HPs regarding reproduction. The two perspectives are the Foucauldian perspective and the biomedical ethics

perspective. The formulation “Foucauldian perspective” is used here to refer to the critique of the biomedical model of health by Foucault and other scholars of the same persuasion.

The Foucauldian perspective argues that the dominance of HPs over the decision making process of their patients has been ingrained through the biomedical model of health which is by its nature prescriptive. It further argues that as experts in the medical and health field, HPs use their knowledge and expertise to dominate those without adequate medical related knowledge. As a result they exert unjustified influence over the decisions of their patients through directive advice and control of information. From the biomedical ethics perspective it can be argued that the dominant role which most HPs are seen to play may stem from a ‘genuine’ and rational concern for the health and well-being of their patients and justice for the unborn child which may be located in the moral and ethical rationalities of biomedical ethics. Until recently, HIV/AIDS has been a fatal disease and still is a potentially lethal and infectious condition. Thus the concern and involvement of HPs in the reproductive decision making process of HIV positive people as seen in this study may emanate from a rational logic to safeguard the health of HIV positive people and to discourage the conception of children who might suffer either as a result of being exposed to HIV or as a result of future health problems and possible death of their parents.

7.2.2.1 The Foucauldian perspective

This perspective argues that the dominant biomedical approach to health which imbues the HPs with authority over the bodies of their patients puts the patient in a position of weakness and the HP in a position of power. Over time, people have come to accept this unequal relationship between health practitioners and patients. In fact, most people both in the developed and developing world have been socialised to accept this relationship as normal. Fisher (1988), reporting on her study on the role of HPs in the medical decisions of their patients said; “...I saw physicians recommend treatments, and patients, usually unquestioningly, accept them”. Fairclough (1989) notes that consultations between HPs and HIV positive people embody ‘common sense’ assumptions which treat authority and hierarchy as natural – the doctor is in a position to determine how a health problem should be dealt with and the patient is not.

The relations between HPs and their patients and the power differences inherent in them have become socially acceptable and taken for granted. The dominant representations of the HP-patient relationship usually stress the naturalness and legitimacy of the authority of HPs. As Foucault argued, the success of power “is proportional to its ability to hide its own mechanisms ... its secrecy is indispensable to its operation” (cited in Wilton, 1997). The influence of HPs in the decision or non decision making of HIV positive couples studied exhibits these characteristics. It is largely shrouded in invisibility and as such remains unexamined and unquestioned by both the HPs and the HIV positive people. The interaction between HPs and HIV positive people are embedded in a social and political context in which HPs have medical knowledge and technical expertise that patients usually lack. Thus from the Foucauldian perspective it can be argued that by virtue of the authority vested in their professional role, HPs can and do control patients’ access to and understanding of medical related information (Samson, 1999). In the process they act as gatekeepers, providing options to some while denying them to others (Fisher, 1988).

This dominant influence on the reproductive decision making process of HIV positive couples may be exemplified from the study. It can be argued that pro-children and conditional pro-choice HPs felt that it is up to them as ‘experts’ to determine who can have a child and who can not and under what circumstances. One counsellor, commenting on the advice they give people who want to have children said; “at times you look at the person, at times because of the background information that we know about some of our clients, we have to advise them against having children”. As a result of the information they have about the social and health status of their patients some HPs felt justified to make decisions for their patients in the firm belief that that would be the best course of action for them. This relationship is played in a social world where the dominant position of the HP has been accepted as ‘common sense’ and where HPs are hardly questioned. The relationship has become an accepted norm and HPs usually expect patients to accept their recommendations. That is why when HIV positive people on treatment turn up pregnant at the OI clinics most HPs indicated that they were disappointed and dejected. They saw it as part of their duties to ensure that HIV positive people did not become pregnant.

Given the relation of knowledge and power, HIV positive people who lack access to information systems - print and electronic- either due to poverty or lack of adequate education find themselves in a much more compromised position. They have limited abilities to evaluate the recommendations made by the HPs regarding their desire to have children now and in future. This means they even become more dependent on their HPs to make 'appropriate' judgements for them. One pro rights counsellor noted this when he said, "there are (HIV positive) people who need a voice of authority from counsellors, to tell them do this and that but as a counsellor you should not do it". Yet another counsellor talked of the emotional dependence of HIV positive people on HPs as he noted that "these people will depend on you to make even the simplest decision you think they will be able to make themselves". This behaviour by HIV positive people stems mainly from the internalised view of the HPs as authorities who know what is best for their patients, a view which some HPs believe in as indicated by the above statement. The statement implies that there are some complicated decisions that HIV positive people should leave in the hands of the HPs and then there are some simple decisions which they have to make themselves. Ideologically, the counsellor who made the above statement sees HPs as having the right to make 'important' decisions for their patients. This view is so pervasive that HPs themselves "...believe that they are the appropriate ones to be making medical decisions" (Fisher, 1988).

The HPs usually recommended a course of action without consulting HIV positive people on such an important issue given the centrality of children in people's lives. Who said these people do not want to have children, and why are their views usually not sought? Thus as Zola (1981) notes, HPs tend to neglect aspects of patients' lives and experiences that transcend the biomedical milieu and treat departures from medical norms and expectations as irrational. HPs tell people what they think is best for them in the given circumstances without fully explaining to the patients the logic behind their recommendations and many a time HIV positive people fear to challenge them.

As noted above, the patient generally enters the HP-patient relationship from a position of weakness, both in terms of unfamiliar territory and lack of medical

knowledge and information. This position is further weakened by lack of education, where the patient can not read and/or understand information relating to her/his condition. Those with better education are in a better position as they may do research on their condition independently. This is what those who intend to have children did. For example C12M had previously decided not to try for a child because a nursing sister had told him that ARVs would have an adverse effect on the foetus. However, because he is better educated he took it upon himself to do his own research on the subject and not rely on the HP. He indicated that his research revealed that it was safer to have a child now since both he and his partner were on HAART. The ability to research and not rely solely on HPs seemed to be lacking among those with less education. C13F and C15 who only have primary education indicated that should they decide to have children, they would first get the approval of their HP. This indicates the importance of education and the availability and accessibility to relevant information in the decision making process of HIV positive couples. It is interesting to note that those with less education (7 years or less) had less information on HAART and MTCT and were more likely to identify HPs as the most important people in their reproductive decision making (C13F, C15). Those with better education (11 years or more), had better information and were more likely to challenge the putative power of the HPs. All those who intend to have children fall into this group. Thus education seems to be an important factor in decision making. Those with better education and better knowledge about their condition are in a better position to make independent decisions.

7.2.2.2 The biomedical ethics perspective

The above section has presented the nature and philosophical underpinnings of the Foucauldian view of the relation of knowledge and power in HP/patient interaction. From its perspective it has been argued that the dominance of HPs in the decision or non decision making of HIV positive couples described in the study is rooted in the nature of the knowledge and power relationship between HPs and patients which favours HPs. This section argues that the anti pregnancy stance taken by the majority of HPs and their attempt to influence the decisions of their patients may be justified on moral, ethical, rational, scientific and professional grounds. In many instances HPs may point out that they have better medical knowledge and as experts are better equipped to make or influence

medically critical decisions for their patients. Biomedical ethics has four major principles which act as guidelines in the relationship of HPs and their patients. These are beneficence, nonmaleficence, justice and respect for patients' autonomy.

Beneficence involves the health care provider's intention to promote health and well being (Williams et al, 2003). HPs are also responsible for ensuring prevention and removal of harm from patients. As Sauer (2003) notes, these duties are viewed as self-evident and are accepted as important goals of medicine. With regard to HIV/AIDS it may be argued that most HPs advise against conception because of the nature of HIV/AIDS infection. HIV/AIDS is an infectious and potentially fatal condition which if not well managed may have adverse effects on the health and well being of the patient. Thus, though there is availability of HAART, and HIV/AIDS is now a chronic disease there still is a need to manage the condition effectively. Patients need to strictly adhere to their drug regimen and schedule to minimise chances of developing drug resistant strains. In an environment where the compliance of the patients is not guaranteed, HPs may feel obliged to take the safest path – that of discouraging conception – for their sake as well as the patients'. The consideration and concern is not only for the health of the patient but also the child that may be born to such parents and possibly be infected. By emphasising the need for safe sex and non pregnancy, the HPs may be trying to impress upon their patients the need to take the disease, their behaviour and the reproductive decisions they make seriously. Most HPs in the study may be said to regard themselves as moral agents and since their action is for the good of both the patient and the unborn they may feel justified in advising HIV positive people against child bearing. To this may be added the concern about the increase of orphans and the burden that this as well as the development of drug resistant viruses may put on the fragile Zimbabwean economy and the country's medical resources.

Nonmaleficence focuses on the issue of needless harm or injury to the patient. Pregnancy may not only bring harm to the patient but also has the potential to harm the unborn child. Some HPs may feel it is immoral and unjust to expose the child to potential harm knowingly and hence they may feel professionally obliged to advice against pregnancy. The principle of justice pits the couple's right to

reproduce against the prospect of harm to the child. The issue then is whose right should prevail and who should determine this? HPs are also obliged to respect the autonomy of the patients to make their own decisions concerning issues relating to their health. The application of these principles is dependent on the moral agent (the HP). S/he is the one who determines which principle/s is best or which principle s/he will use to justify his/her action in the given circumstances. It has to be noted again that these principles are in conflict with each other and many a time it may be impossible to satisfy all of them. Deliberating with these principles, on the part of the moral agent means balancing and specifying them to a particular case (Mallia, 2003). In the study most HPs seem to have prioritised the principles of beneficence and justice in their reproductive advice to HIV positive people. As pointed above, HPs have to play a delicate balancing act in making these moral decisions. For example, beneficence and justice towards an unborn child has to be balanced against the wishes of a couple or individual to have a child (Mallia, 2003).

The decision to advise HIV positive couples against pregnancy also has to be undertaken against the backdrop of very low MTCT and health risks. With the advent of HAART the risks to the child as well as to the mother have been greatly reduced. They are actually lower compared to some other debilitating conditions. For example, the background risk of a significant congenital disease is 3%, which is greater than the perinatal HIV transmission rate of 2% for women on HAART (Williams et al, 2003). However the background risk of congenital anomaly is accepted routinely while that of HIV which is lower is not. Thus the use of these principles is dependent on the virtues of the moral agent as well as other extenuating circumstances. For example in the Zimbabwean case, the HPs may have to consider the cost of care should the child be infected and or the couple develops drug resistant strains of HIV. As such the decisions taken by the HPs have also to be understood from this moral and rational standpoint. Most of them regard it as best morally, rationally and professionally for HIV positive people not to conceive. As a result they generally give them reproductive information and advice that is biased against child bearing.

Remarks

What the two perspectives discussed above underline is the delicate and complex nature of the relationship between HPs and their patients. The discussion brought forth the ethical dilemma faced by HPs in so far as reproduction among HIV positive people is concerned. While HPs have moral and professional obligations to promote the health of their patients as well as that of the society, they also have to respect the autonomy and reproductive rights of their patients. Thus they have to perform a delicate balancing act. Regarding the Foucauldian perspective on the relationship between HPs and their patients as rather extreme and the biomedical ethics perspective as ignoring some important issues, this study argues that HPs should adopt what Patton (2002) has called empathic neutrality when it comes to reproduction among HIV positive people. Reproduction is usually regarded as a personal issue but among those with chronic diseases it becomes both a medical and personal concern. As such it becomes a difficult issue to address for the HPs as the reproductive desires of the patient may conflict with what is medically advisable.

While the study concedes that the HP usually does know more and better than the patient and that it is medically advisable for the patient to follow his/her advice, it also notes that the HP is bound by duty to offer unprejudiced, balanced and fair information and advice to the patient. The subjective and personal views and values of the HP should not interfere in the process. The study results suggest that the majority of HPs usually influence or try to influence the reproductive decisions of their patients by either omitting information critical to the decision making process or by deliberately giving patients directive advice. Though the influential role of the HPs may be justified on the principles of beneficence and nonmaleficence this study argues that it is unfair to HIV positive people for HPs to omit information that is critical to their decision making. There should be a balance between the principles of beneficence and autonomy.

It is important for HPs to adopt empathic neutrality when dealing with ethically problematic issues such as that of reproduction by chronically ill people. Patton (2002) sees empathic neutrality as “a middle ground between becoming too involved, which can cloud judgement, and remaining too distant,” which can reduce understanding on the part of the HP. When an HP becomes too involved in

the life of his/her patient he/she runs the risk of losing professional objectivity and infusing his/her subjective views in the advice and information he/she gives the patient. On the other hand, if the HP becomes too distant from the phenomena of decision making he/she risks becoming irrelevant and a disservice to the patient. Study results indicate that those HPs who indicated that they were personally against reproduction by HIV positive people were more likely than others to give biased and incomplete information and advice to HIV positive people. This however does not mean that HPs should not have a personal relationship with their patients. It means they have to try to balance medical needs with the patients' personal needs.

The study revealed that reproductive issues in this sample were generally not recognised by HPs as important or urgent patient needs. Distinct rationalities on this issue were observed between HPs and HIV positive people. To the majority of HPs in the study, controlling and treating HIV/AIDS was the dominant concern, while among those who still want to have children the desire to fulfil their needs remained important. This resulted in the inevitable clash of interests between HPs and HIV positive couples. Adopting the logic of empathic neutrality may go a long way in resolving this conflict of interests. Empathic neutrality entails being able to understand the position, feelings and experiences of the patient and being non-judgemental. Neutrality on the part of the HPs also entails giving the patient medically relevant advice and information in an unprejudiced and balanced manner. Thus patients have to understand the medical implications of their decisions and HPs have to understand the personal needs of their patients and respect their decisions in order to forge a mutually satisfying relationship.

Summary

The above discussion has tried to explain the stance taken by the majority of HPs regarding reproduction among HIV positive people from two standpoints. From the Foucauldian standpoint, it has been argued that owing to their position of power due to their knowledge and expertise in the field of medicine, HPs influence the reproductive decisions of their patients. From the biomedical ethics standpoint it has been argued that the influence of HPs is justifiable on moral and rational grounds.

Irrespective of the standpoint from which the position of most HPs on reproduction is viewed, what the study found is that they play an influential role in the reproductive lives and decision making process of HIV positive people. Though some HIV positive people, mostly the better educated, have been able to transcend the pervasive influence of HPs in their reproductive lives there are still many, especially among those who desire to have children, whose reproductive decisions have been largely influenced by health practitioners. This, however, is not to claim that HIV positive people no longer have the autonomy or right to make their decisions. They do have their rights, but they are sometimes afraid or hesitant to make medically related decisions independent of health professionals. This may be seen as a justifiable course of action on their part considering the knowledge and expertise of the HPs. However from another perspective it may be seen as a non-decision on their part. They are just following the decision or directive that has been made or given by the HP. For example C15F points out that she is afraid of becoming pregnant since HPs told her not to become pregnant again as she is HIV positive. The question then is who made the decision in this case? The patient was not given an option. She was told not to conceive again. Thus the decision was taken out of her hands. However it may be argued that though the patient is afraid of becoming pregnant as a result of the directive given to her, even if she desires to, the ultimate decision still rests with her. It is up to her to decide to try for a child or not to since the HPs have no way of stopping her from having sex. This case reflects the dilemma faced by some HIV positive couples, especially those with little education, who still desire to have children. If they try for a child and something goes wrong, i.e. the child becomes infected or they develop drug resistance, they risk an unpleasant reception from the HPs. On the other hand if they follow the HPs advice not to reproduce they risk forfeiting their chance of parenthood for ever. Thus such couples find themselves in an unenviable position where they are unsure of their stance hence the fear and hesitance that they display.

The above discussion also points to the importance of education and information in reproductive decision making. Those with better education were better able to make their reproductive decisions independent of the influence of HPs. It is the conclusion of this study therefore that irrespective of whether their role is conceived as negative or positive the HIV positive couples, HPs do play an

important role in the decision making process of HIV positive people as advisers and sources of information.

Another important finding from the study was the influence that HAART has had on the reproductive plans of HIV positive couples who still intend to have children. The following sub-section discusses how the advent of HAART has reshaped their views and plans on reproduction.

7.3 HAART and reproduction among HIV positive couples

This subsection discusses the impact of HAART on the reproductive decision making process of people with HIV/AIDS. In discussing this issue the influence of HIV on fertility and the importance of child bearing in Zimbabwean society and how it affects decision making are given brief attention.

The interesting issue which arises from the study is the centrality of HAART in the decision to have a child among those who intend to have one in the near future. Though social, personal, medical, economic and cultural factors were cited as important in desiring and deciding whether to have or not to have a child they were found to be overridden by the respondents' health concerns. All the respondents who intended to have children noted that they would not have considered having a child if there was no HAART and nevirapine. This reveals their confidence in HAART. However not all respondents shared the confidence of this group. From the results of the study three identifiable groups emerged with regard to the issue of HAART, MTCT, general health and reproduction. There are those who intend to have children as a result of diminished chances of MTCT and the good health afforded by HAART, another group encompasses those who desire to have children in the future but who are still not sure about the effectiveness of HAART and nevirapine in lowering the chances of MTCT and reducing the negative impact of pregnancy on their health and then there are those who though conceding the effectiveness of HAART in improving their health feel that the risk of MTCT is still high. They therefore argue against HIV positive people having children. The views of these groups were discussed in detail in chapter four. This section concentrates on those who intend to have children in the near future.

In Zimbabwe HAART was made available to the HIV/AIDS people who could not afford to procure it privately in April 2004 (The Herald, March 2004). It is interesting therefore to see the impact it is already having in the sphere of reproduction. The confidence that people with HIV/AIDS expressed in HAART in the study was not misplaced. In recent years major strides in the development of effective drug regimens to counter the inexorable march of the HI virus have been made. The result has been that people with HIV can now live longer, healthier lives unpunctuated by frequent opportunistic infections. Studies indicate that HAART can effectively control viral replication and reduce the risk of vertical as well as horizontal transmission considerably (Semprini & Simona, 2004; Thornton et al., 2004). Advances in HAART, combined with specific obstetrical procedures have enabled those HIV positive people who want children to have them with a very low risk of transmitting the virus to their infants. With better health due to HAART they stand a better chance of seeing their offspring mature. It is not surprising therefore to see a considerable percentage of HIV positive people who intend to have children given the efficacy of HAART and the fact that most of these people are still in their reproductive years and some have no children.

As noted in chapter two, most of the studies on the impact of HAART on decision making have been carried out in the developed world where the therapy has been available for years (Semprini & Simona, 2004; Thornton et al., 2004). This section examines the emerging scenario in Zimbabwe advancing the hypothesis that the improvement in health which is associated with the use of HAART may play a significant role in the reproductive decision making process of HIV positive people.

7.3.1 Child bearing: A dream come true?

The study found that eight people in the sample intended to have children in the near future. Some like C12, have tried for a child in the past year but failed and intend to have another attempt 'soon'. There are a number of factors that these couples and individuals cited as drivers behind their quest to have children, the most common one being the importance attached to motherhood/fatherhood as well as the need to have a child of a particular sex for some. C5F, C14M, C9M and C1M all want to have children because they currently do not have any and they feel it is an important milestone in life socially and personally for one to be a

parent. C4F and C5M point to the need to have another child as they had not had their desired number of children. The factors cited above are the ones which the respondents cited as the more immediate ones. Over and above these factors however, the availability of HAART and the impact it has had on their health seems to be the overriding factor in their quest to have children.

Most of the respondents who intend to have children are on HAART. However there are some who are not yet into the treatment program. These are C4F and C14M whose CD4 lymphocyte cell counts are still well above the threshold of ≤ 200 which is used as the commencement level for HAART at the OI clinics. C9M is HIV negative. All the respondents in this group indicated that the impact of HAART on their health or the observed impact of the therapy on others has played a pivotal role in their reproductive decision making. Commenting on their health since they commenced HAART between April and May 2004 C12M said,

“...we are now strong since we are on ARVs; we are strong, we can feel that we are now strong. You know, for me there came a time when I had told myself that I would no longer have sex due to sickness. But with ARVs, I felt that I needed somebody. That is nature; I can not run away from it”.

C5F had this testimony;

“I had all these opportunistic infections now and again but now I wonder where all that disappeared to. Even my face was no longer smooth. I have an oily skin; if I have a face wash after 10 minutes my skin will be oily but during those days when I had a face wash my face remained scaly as if I had dandruff on the face. I am light in complexion as you can see but during those days I would look at myself in the mirror and stare in disbelief. But since I began ARVs I am back to my normal self.”

Nearly all those on ARVs had similar stories of rising from their death beds to lead near normal healthy lives with some like C12M going back to work. C14M, who is not on therapy, also indicated that he has seen many people who have “unbelievably risen from death” as a result of HAART. With their health assured as a result of HAART the couples and individuals feel that they can take the chance and have a child. As C12 indicated, HAART has given them an assurance and hope that they can at least live a normal life, have children and raise them.

The advent of HAART seems to be significantly altering the landscape in reproductive decision making. Whereas couples had ‘only prayer to hold on to’, now they are almost certain of having an HIV negative child and this has

strengthened their resolve to have children. The impact of their good health due to HAART on their chances of having HIV negative children is not lost to HIV positive people. A number (C12, C5, C1) noted that as a direct result of HAART their CD4 cell count has gone up and their viral load is steadily declining. The link between this and MTCT was not lost either. All those who intend to have children were aware that as a result of a high CD4 cell count and diminished viral loads the chances of MTCT were significantly lowered. Though most of them put the chances of MTCT at between 5-30% when one is on HAART (actual risks are much lower at 1-2%), it remains an important point to them that these are relatively low percentages to such an extent that they are willing to take the risks.

Commenting on the low chances of MTCT when one is on HAART C5F said,

“...considering that I am on ARVs and he is also taking them, so that is forcing the virus to hide...so its not in the blood anymore, it is in the lymphatic system...I am thinking my chances are very good since I am on ARVs.” C12M added;

“if you are on ARVs there may come a time when they will tell you that your virus is undetectable, it will no longer be in the blood...so that shows that the chances for a child to get the virus are very slim, there are more chances for it to be born negative. That is what we are hoping for”.

The undetectability of the virus in the blood stream is inevitably associated with a low risk of vertical transmission. The significance of nevirapine in lowering MTCT risks was also pointed out. The respondents were confident that their being on HAART and with the availability of nevirapine placed them in a better position of having HIV negative children as compared to pregnant mothers not on HAART who are only given nevirapine as a single dose therapy. C12M who is a peer counsellor and works part time at the Mpilo OI clinic said;

“I have worked with nevirapine and people who use it. It really works...I have met many people who have negative children while they are positive who used nevirapine and they were not on ARVs. This shows that it is very effective.”

People who intended to have children in this study seemed to be very proactive in researching on their chances of having negative children. They researched further on issues of MTCT, re-infection, impact of pregnancy on the mother, dietary issues and their chances of having a negative child. They seemed well informed on the choices and chances that they have. In this sample Couple 12 used their association with OI clinics as peer counsellors as a stepping stone towards gathering relevant and appropriate information while C5F used her knowledge as a

former medical student to inform her decision. Others pointed out that they sourced information from both the print and the electronic media including the internet (C9M, C14M) and from people who work in the medical field. These people demonstrated resourcefulness in so far as information gathering was concerned which goes to demonstrate the importance of a child in their lives. Armed with what they regarded as appropriate and sound information they felt that having or trying for a child at that particular time was the right decision.

Talking of her impending intention to try again for a child C12F said "...I have since talked to another sister and she said 'you can have a child. Because you are on ARVs your CD4 cell count has gone up. If you become pregnant we will change your drug regimen'". She said 'look at these women who are not on ARVs who do have children. She can have a child and remain healthy for a long time, so it also depends on your lifestyle'." There is high optimism in this group about their chances of having an HIV negative child. This optimism is not based solely on their improved health as a result of HAART but also on the information they have on its efficacy and on other strategies that can be used in ensuring that the risks of vertical transmission are reduced both pre and post natal.

The respondents also cited a number of strategies that can be used to reduce MTCT apart from being on HAART and nevirapine. These included having unprotected sex only during the woman's fertile period and the practice of safe sex as soon as the woman becomes pregnant to reduce re-infection chances and the chances of infecting the foetus with drug resistant HIV strains (C1M, C12, C5M). There was mention of avoidance of contraindicated drugs in pregnancy. C12F and C5F indicated that there are certain drugs in triple therapy, like efavirenz, which are unsuitable for a pregnant mother as they may cause malformations of the foetus. Breastfeeding was also indicated as another way that the mother may infect her child and most indicated that it is best for the mother not to breastfeed. C5F and C12M indicated that given the risks of transmitting the virus to the child during birth they would opt for an elective C-section. As C5M indicated there is confidence in this group that if all the available strategies to minimize MTCT are taken into account, then the result will be an HIV negative child. He said;

"as long as this whole thing is done properly, I do not see any major risk. If you do not breastfeed, always use protection during pregnancy, take nevirapine if you are supposed to, go back for a caesar (caesarean) if

your immune is not strong; I do not see any risk of having a positive child”.

What is notable in this group is the centrality of HAART in their decision making. This points to the fact the being HIV positive plays an important role in reproductive decision making. The respondents in this group pointed out that had it not been for HAART they would not have considered having children in spite of all other factors they indicated as important in their decision making process. Though socio-cultural factors are seen as important in making a decision and are seen as behind their drive to have children now, they are not considered to be the overriding factors. All the respondents indicated that the presence of these factors will not have pushed them into having children in the absence of HAART thus pointing to the critical role played by being HIV positive in decision making.

Responding to how they would have approached the issue of conception in the absence of HAART, C12F said, “we were not going to consider it. It was going to remain a wish.” C5F added that being on antiretrovirals was what actually made her decide to have a child. “Actually it has helped. I think that is what made me decide to have a child”, she said. She further pointed out that without triple therapy she would not have considered having a child. Similar sentiments were expressed by others who further indicated that their experiences of seeing other HIV positive people having negative children as a result of nevirapine is what assured them that it is possible (C4F, C14M). Thus being on HAART, appropriate information and seeing living testimonies of people whose health has been transformed by HAART played a significant role in the decision by these couples and individuals to conceive.

7.3.2 HAART in the reproductive decision making process

Three important issues with regard to reproductive decision making emerged from the people who intend to have children. These relate to their being on HAART, their chosen mode of delivery should they conceive and their preferred mode of infant feeding. All these issues have an impact on their decision to conceive. As Sauer (2003) notes, though AIDS remains a serious disease which if not treated can lead to death, with appropriate medical intervention the disease usually revolves towards chronicity and patients generally enjoy years of good health. This view of the disease is beginning to take root among those who are on therapy

with most in the study reporting that they now conceive it just like any other debilitating or chronic disease like cancer or diabetes. The health that they have enjoyed since commencing therapy has made them see AIDS as a manageable disease whose progression can be successfully controlled through a cocktail of drugs, diet and safe sexual practices.

With such an outlook it is not surprising therefore to see a high percentage of people who intend to have children since they see themselves living longer and more productive lives. It is important to note that in the study all those interviewed were confident of the effectiveness of HAART in transforming their health. Those not on therapy pointed to examples of people they know who had AIDS but who since commencing therapy are now healthy. The general outlook on HAART among the interviewees was positive.

HIV positive people on therapy indicated that the increase in their CD4 cell count gave them the courage to conceive while those not yet on therapy pointed to their 'high' CD4 cell count, the availability of nevirapine as well as HAART to fall back on as a basis for their wanting to have a child now. It has been shown that CD4 cell count and HIV RNA levels are related to the likelihood of disease progression in the mother and also the risk of vertical transmission (Sullivan, 2003). A high CD4 cell count is associated with a lowered risk of vertical transmission while a low maternal CD4 count is similarly associated with higher transmission risk of HIV (Frenkel et al., 1997; O'Shea et al., 1998; Mayaux et al., 1995; Newell et al., 1996; Landesman et al., 1996; Maiques et al., 1999; Ioannidis et al., 2001). The optimism of people on HAART is therefore not misplaced. A number of observational studies have demonstrated low mother to child transmission in the setting of HAART (Cohan, 2003). The lowest transmission prevalence observed is among women with maximally suppressed virus at the time of delivery and, as Cohen (2003) notes; this is most likely to occur among women on HAART.

In a study in the USA the risk of transmission in women on HAART was 1.2% compared to 20% in women with no prenatal antiretroviral therapy (ibid, 2003). This means the couples and individuals in the present study stand a better chance of getting an HIV negative child than they gave themselves. Most of them

considered the chance of having an HIV negative child at between 70-95%. Recent studies have also shown that MTCT rates may be as low as 1-2% in women with HIV RNA levels of below 1000copies/mL regardless of mode of delivery (Minkoff, 2003; Cooper et al., 2002; Dorenbaum et al., 2002). HIV positive people with a low HIV RNA as a result of HAART thus have an over 98% chance of having an HIV negative child. Furthermore the effectiveness of nevirapine as a single drug therapy has also been noted in reducing MTCT to around 5% (Conway, 2005).

The other important issue arising from those who intend to have children is their chosen mode of delivery. C5F and C12F indicated that it was preferable to go for an elective C-section as this further reduces the risk of MTCT. The role of elective C-section in reducing MTCT has been well noted (Lancet, vol.353, 1999; NEJM, 1999, vol.340). However recent studies in the era of HAART have found no significant differences in transmission prevalence among women with vaginal deliveries (0.8%), elective C-section (0.8%) and non-elective C-section (1.1%) (Shapiro et al. 2002). Although some studies have found a potential protective role of elective C-section among women with HIV RNA levels greater than 1000copies/mL many study results point to the significant morbidity associated with caesarean delivery among HIV infected women (Semprini et al., 1995; Watts et al., 2000; Marcollet et al., 2002; Read, 2000). It is therefore important for those on HAART to consider this mode of delivery carefully with their GPs or HPs and the HPs have to play their role by giving up to date, appropriate and unprejudiced information so as to enable those who want to have children to make informed decisions.

A number of studies have demonstrated the role of breastfeeding in HIV transmission (Fawzi et al., 2002; John et al., 2001; Leroy et al., 1998; Willumsen et al., 2003; Meda et al., 1997). In a study carried out in Kenya it was found that breastfeeding increased the risk of transmission by as much as 16% (Nduati et al., 2000). In the study 44% of MTCT was attributable to breastfeeding. Even in the era of HAART it has been found that breastfeeding significantly increases the risk of MTCT (John et al., 2001; Dunn et al., 1992). Those who are against child bearing among people with HIV/AIDS raised an important issue, that of in-utero exposure of the foetus to ARVs and the possible adverse effects this can have on

it. This is still somewhat a grey area where research is still ongoing. There are drugs that are contraindicated in pregnancy as a result of their association with malformation. A number of studies have found no increase in any specific fetal abnormality, neonatal condition or low birth weight with currently recommended antiretroviral regimens. However there is mixed evidence regarding the association between combination antiretrovirals and premature delivery (AIDS, 2001; Tuomala et al; 2002; JAIDS, 2003). Notwithstanding this, the information that those who intend to have children seems to be generally sound. Given the information they have their hope and optimism of having HIV negative children is to be expected.

Studies in the USA where HAART has been available for years indicate that HIV positive women on HAART are more likely to choose to conceive than those who are not (Blair, et al., 2004). This is associated with improvements in health which are attributed to widespread use of HAART. This is seen as impacting on the decisions of HIV positive people as well as their sexual activity because of improved health. The availability of HAART makes it possible for HIV positive people to fulfil reproductive needs which they had before they discovered their sero status. HAART has given them hope, a new lease of life and as it reduces the risk of MTCT it will not be surprising to see more HIV positive people choosing to reproduce. As people feel the burden of being HIV positive lifted off them and as the disease ceases to be seen as a death sentence, many people may take advantage of their new found health and the low risk of MTCT afforded by HAART to reproduce.

Concluding remarks

Although the effects of HAART on fertility are not yet clear both in the developed world where HAART has been available for longer and in the developing world where it became available recently, the results of this study indicate that an improved immune system and good health led a sizeable portion (8/30) of the HIV positive sample to try for a child. From the results of the study it may be further hypothesised that as HAART becomes more accessible to a population which is mainly in its reproductive age, and as more information and evidence about its effectiveness filters into the infected population, more HIV positive people who desire to have children will opt for conception. What is suggested by the study is

that HAART has had a significant impact on the reproductive decisions of HIV positive people. It seems to have played a pivotal role among those who intend to have children. Where previously they only dreamed of having a child they can now make that dream a reality. It is significant to note that all those who intend to have children now do point out that in the absence of HAART they would not have considered having a child. HAART seems to have been the foundation upon which they have built their hope of having a negative child who they could bring up themselves.

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CHAPTER EIGHT

CONCLUSION

The study set out to investigate the context of reproductive decision making among HIV positive couples and how this impacted on their decisions or choices. The study also examined the content of decisions made and the process of making those decisions as well as exploring the role and impact of different actors in the decision making process. The thesis focussed on an understudied and 'closed group' of Zimbabwean couples; the HIV positive couples. In spite of the small study sample the study provides important insights into the reproductive behaviour of HIV positive couples, the meaning of being HIV positive and how this relates to child bearing, the role of different actors in their decision making as well as the social, medical and economic obstacles they face in their reproductive lives. The study sheds some light into the personal experiences of the HIV positive couples studied. It also offers a glimpse into how this group of Zimbabwean couples make reproductive decisions and how their decision making is linked to what they know, their personal desires, the available medication and the socio-econo-cultural context they live in.

The study discussed a number of social, cultural, economic, medical as well as personal factors that impact on the reproductive decisions made by HIV positive couples studied. These included among others the importance attached to children in the patriarchal Zimbabwean society, the availability of HAART, the availability of financial resources, and the influence of health professionals. The study also made a number of findings regarding reproductive related issues among HIV positive couples studied. Some of these are the impact that being HIV positive seems to have on their reproductive plans; that HAART plays an important role in reproductive decision making of those couples who intend to have children more than any other factor and that women seem to play a prominent role in decision making.

The importance of children among the Ndebele was one factor that was discussed. High value is attached to children in and for themselves and motherhood and fatherhood are revered roles which bring with them greater social status and dignity. Linked to this factor is the social view on infertility as well as the social

comparison factor. These are indirectly or directly influenced by the importance attached to children among the Ndebele. The importance of a boy child in the patriarchal family setting was also identified as an important motivating factor to conceive by both men and women. As argued and demonstrated in the study the boy child is a critical asset in a patrilineal setting and especially among those who are poor as the majority of the respondents are. The boy child is expected to assume the responsibility of taking care of his parents in old age and to carry on the family name and family leadership at his father's death. That is why a number of respondents in the study indicated that they desire to have more children because they do not have a boy child yet.

Another important factor raised by HIV positive people was the impact of HPs on their reproductive decision making process. The study found that HPs, regardless of their ideological standpoint, do play a significant role in the reproductive decisions of HIV positive couples be it negative or positive. This was pointed out by both the HIV positive couples and the HPs. HPs were usually regarded as experts and important sources of information and advice by most of the respondents. As the study results indicated, most of the HPs acted as gatekeepers to reproduction related information and medication dispensing information as they saw fit. The study found that there were basically three competing ideological positions among HPs; the pro-rights, the conditional pro-choice and the pro-children stance. The pro-rights HPs usually gave HIV positive people balanced and unprejudiced information on pregnancy and HIV. The conditional pro-choice and pro-children health professionals, who were the majority usually, gave biased and prejudiced information. Most of them were generally against child bearing by HIV positive people and the majority of HIV positive respondents also indicated that most of the information and advice they got from HPs was generally against child bearing. The study results indicate that some couples made decisions against child bearing based on the information they got from HPs while some made decisions to try for a child based also on information and advice from HPs. Thus HPs seem to have both positive and negative impacts on the reproductive decisions of the couples studied depending on their ideological standpoint.

What is evident from the discussion of the relationship between HPs and HIV positive people is the need for a set of guidelines to guide HPs on the reproductive

information and advice they give HIV positive people. Currently it seems the reproductive information given to the HIV positive people and couples depends on the personal views and attitudes of individual HPs. What this means is that there is no uniformity or consistency in the information given to HIV positive people. Given that around 20% of the Zimbabwean population is HIV positive (UNAIDS, 2004) there is need for clear guidelines from the ministry of health on the issue of reproduction among HIV positive people and the role of health professionals and other actors in it. The guidelines have to specify the ethical principles and stance that HPs should adopt when dealing with the issue of reproduction among HIV positive couples or individuals. Official guidelines on this issue would eliminate biases and prejudices discussed in this study and ensure uniformity, consistency and quality on the reproduction related information and advice given to HIV positive couples.

One of the important issues raised in this study was the high level of involvement of women in reproductive decision making among the study sample. The study found that neither men nor women dominated the reproductive decision making process. In fact it was found that women exercised more control and power over their sexuality and reproduction than previously assumed in most studies. The decision to use contraception and to choose the contraceptive method was usually left in the hands of women. The women were also able to assert their views and desires. This finding is contrary to the findings of most studies on reproductive decision making among couples in African patriarchal societies in general and in Zimbabwean society in particular (Feldman & Maposhere, 2003; Grieser et.al, 2001). The question that this finding raises then is: is this visibility and involvement of women in reproductive decision making limited to this atypical study sample or not? To adequately respond to this question a further study that involves a larger sample of both HIV negative and HIV positive couples needs to be undertaken. This study is thus limited to noting that among the study sample women played an important role in decision making among those couples who made reproductive related decisions and that there was generally gender parity in decision making.

It was found that among the HIV positive couples who wanted to reproduce reproduction or the decision to reproduce was a conscious and rational process

which was given intensive and extensive attention. This may be because of their ill state of health and the risks involved in reproduction if one is HIV positive. Using the knowledge and information at their disposal HIV positive couples consciously considered their constraints and weighed options available to them in their current context before making a decision.

The study found that women showed more concern or worry concerning reproduction than their counterparts. This may be because there is more at stake for women than it is for men in the area of reproduction. Women were more concerned about their health, the burden of nursing the child, and the stresses and pressures of pregnancy as well as the moral blame and psychosocial stress they may face should the child be positive. This greater parental investment may explain their more visible involvement in reproductive decision making and it is no wonder that less women intended to have children than men. Among the nine individuals who intended to have children in the near future only three were women. It seems women saw more risks in reproducing than men and as such it may be assumed that they got more involved in decision making to safeguard their interests.

Unity rather than conflict were found to dominate gender relations in so far as reproductive and sexual issues were concerned among the HIV positive couples. This may also have been due to the fact that both partners were HIV positive, aware of each other's status and the ramifications of sexual and reproductive involvement to their health and lives in general. The study also found that a considerable number of HIV positive people interviewed (19/30) still desired to have children. What seemed to drive this desire were unfulfilled personal needs in the reproductive area. This desire may also be linked to the socio-cultural context which places high value and status on children and child bearing. Socio-cultural pressure to procreate played an important role in sustaining the desire and intention to have children among the HIV positive respondents. However the study found that the couples' or individuals' decision to have or not to have a child now or in future hinged mainly on their view on HAART. The study found that those who were against childbearing were also mainly of the view that HAART and nevirapine would have a negative impact on the foetus. Most of those who were unsure about the efficacy of HAART in ameliorating vertical transmission

and the negative impact of pregnancy on the mother indicated that though they had a desire to have children they had no intention of doing so. On the other hand those who intended to have children pointed to their conviction on the efficacy of HAART. The most important factor in decision making among those who intended to have children was identified as the availability of HAART and its impact on MTCT and their health. Those who intended to have children indicated that the availability of HAART played a key role in their decision to conceive. HAART gave them hope of a longer life not punctuated by frequent opportunistic infections and therefore the chance to raise a child. It also reduced the risk of vertical transmission to acceptable levels as far as those who wanted to conceive were concerned. However, the different views on the efficacy and safeness of HAART expressed by HIV positive people in the study indicate the need for more up to date and in depth information on HAART and other prophylactic drugs to be made available to HIV positive people.

The study findings also pointed to the urgent need to tackle the existent risk denial syndrome and the popular belief on VAT (visual Aids testing). A sizeable number of respondents became infected as a result of the belief that one could tell using the naked eye if one had the disease/virus or not. Others became infected as a result of their denial that they were at risk. The risk denial syndrome persists regardless of saturation advertising, campaigning and education about HIV/AIDS. Some respondents had complete information on HIV/AIDS but still indulged in risky sexual behaviour in the belief that it could not happen to them. The failure to use the condom consistently in risky sexual encounters can be linked to these beliefs and attitudes whose genesis can be traced to the social construction of HIV/AIDS and condom use. Thus there is need to shift focus from the individual in the HIV/AIDS campaign messages to a socially inclusive approach so as to be able to effectively address the socially constructed myths, beliefs and attitudes on the subject of HIV/AIDS. The fact that such beliefs and attitudes still exist in an environment where over 70% of the adult population (UNAIDS, 2004) is aware of how HIV is transmitted, prevented and that healthy looking people can pass it on, indicates the urgency with which these attitudes and beliefs should be tackled. The study also found that the stigma and secrecy that usually surrounds HIV/AIDS is still strong in Zimbabwean society as evidenced by the failure of the researcher to recruit HIV positive respondents on his own. As a result of the stigma and secrecy

HIV positive people are reluctant to talk to 'outsiders' and the anti-childbearing stance taken by some of the HIV respondents may also be linked to the stigma associated with HIV/AIDS.

Reproductive decision making seems to be mediated by a complex set of medical, health, socio-economic and cultural factors as well as personal desires among HIV positive couples studied. The most important considerations in their decision making seem to be the impact that HIV and pregnancy may have on their health and possibly on the health of their children. This concern is mediated mainly by HPs who tend to monopolise legitimate and pertinent knowledge and information. The desire and importance of having children drives those individuals with the intention to have children towards researching more into the subject of HIV and childbearing. The confidence they had in HAART and other prophylactic drugs (nevirapine), especially regarding their impact on their health and on reducing the risk of vertical transmission made them confident to take the decision to conceive. The motivating factor in making a pro-conception or anti-conception decision seems to be the importance of children in these people's lives and the enabling factor among those who intend to have children was the availability and effectiveness of HAART.

The main observations and issues raised by this study relate to the following: the important role played by HPs in the reproductive decision making of HIV positive couples and the need for an official guideline on the ethical principles regarding reproductive information and advice given to HIV positive couples or individuals in order to minimise disparities in the information they are given as well as to safeguard their right to fair and balanced information. The prominent role played by women in reproductive decision making among the study sample was another important observation that this study made. In spite of the importance of the socio-cultural context in decision making it was not the overriding factor on the decision on whether to conceive or not. The availability of HAART was found to be the central factor among those who desired or intended to reproduce. Being HIV positive had a differential impact on the reproductive plans of the respondents depending on their personal circumstances and ideological standpoints. It was also found that among those couples who made decisions, the decision on whether to have or not to have a child followed a rational process which took into

consideration various options, making use of available information and knowledge. The study also noted that HIV/AIDS related stigma and secrecy was still prevalent in Zimbabwean society. Thus more still needs to be done on education to tackle stigma and dispel myths related to HIV/AIDS and condom use.

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APPENDICES

APPENDIX A

INTERVIEW GUIDE FOR THE HIV POSITIVE PARTNER

1. OPENING

Introductions

Thank you for your participation in this study. I am interested in hearing your views and experiences on reproductive issues and HIV/AIDS.

*Read the consent form to the interviewee and have it signed.

2, Establish rapport by asking the interviewees personal details, i.e, their name (*this not to be tape recorded or noted in the notebook*), when and where they were born, how many they are in their family, level of education, the occupation of their parents, their occupation and whether they have children or not.

3. Reproductive Health prior to diagnosis

i. Have you been pregnant before? If yes, how many times? What happened to each pregnancy? Have you had any miscarriage? If yes, when, how did it affect your reproductive intentions, was it before or after HIV diagnosis?

ii. When did you become aware of the existence of HIV/AIDS? How did you become aware of it, Can you tell me how it is transmitted, how it is not transmitted? How can it be prevented?

iii. At the time you became aware of the existence of HIV/AIDS were you in a relationship? If not did you have any relationship after learning about the existence of HIV? When was that? Did you discuss or talk about HIV with your partner? What made you talk/not talk about it? If discussed – what exactly did you discuss, how did you discuss it, and what did you agree on?

iv. Did you at this point take any preventive measures? – what measures did you take, did you agree with your partner to use this method – how did you agree on this – if you did not agree what may have caused the disagreement? If no preventive method used – what made you not take any action to protect your self or your partner (s)?

v. Tell me, how long have you been in your current relationship? Can you describe the nature of your relationship, i.e. casual etc...

vi. Prior to discovering your status, what was your desired number of children, how many boys how many girls and why? Had you discussed your desired number of children with your partner? If yes- tell me how you came to agree on that number. If no – probe for reasons. Do you desire/wish to have a child? Do you intend to have a child in the near future?

4, Stigma

i. When did you discover that you were HIV positive?

ii. How did you discover/get to know about your status?

iii. Tell me about the day you went for your tests. How were you feeling, can you recount to me what was going on in your mind during that time, how relaxed were you, if afraid- what were you afraid of – what was the cause of the fear? If relaxed probe further on why and on whether this changed after a positive diagnosis.

iv. What happened when you were told you were positive? How did you feel/react and what do you think made you feel/react that way? How did your counsellor/doctor handle the situation? Can you describe to me how the HP broke the news to you? How was the difference between HIV and AIDS explained to you? Were you satisfied with the way you were informed about your status? How is that? What were you told during counselling both prior to and after testing? What advice/information, if any, did the HP give you concerning contraception, pregnancy and reproductive health?

v. Tell me about your views on HIV/AIDS before you knew you were infected. Have those views changed in any way? What do you think of society's views on HIV/AIDS and infected people? What do you think is the cause of such views?

5. Disclosure

i. Who was the first person you disclosed to? What made you choose to disclose? Are there any particular reasons for disclosing to this person? How did the person react? How did you feel after disclosing? When and how did you break the news to your partner? What was their first/initial reaction? What do you think made them react the way they did? What happened after the initial reaction? Did you discuss your future and how you were to live with HIV? If yes how; if not what

are the reasons? Is your community aware of your HIV status? If not, what made you not disclose publicly? How has not disclosing been positive/negative in your life? If yes, how did the community respond to your disclosure and what made it respond that way? How has public disclosure impacted on your life? If an HIV positive person asked you for advice on disclosure, what would you advise them and what are the reasons for giving them such kind of advice?

ii. What difficulties did you face in disclosing? Did you have any fears; if yes what were they? What obstacles do you think HIV positive people face in dealing with disclosure? How can they be overcome?

6, Reproductive decision making

i. Tell me, which family planning methods are you aware of? Are you currently using any, if so which ones and why; if not why? Are you currently using condoms? If yes, what are they being used for, probe for whether they are being used as a contraceptive, re-infection prevention strategy or both. If **not**, probe whether lack of condom use is linked to desire for pregnancy or power dynamics within the relationship, i.e., who does not want to use the condom and what are their reasons. If **using the condom**; when did you begin using condoms in your relationship? Who made the decision to use condoms? How did you agree to use the condom? **Find out** if condom use was meant for personal/ partner protection or both.

ii. What are your plans for the future concerning child bearing? (Probe for the reasons for the chosen path). What effect, if any, does HIV have on your desire to have/not have (more) children? When did you decide to have/not have a child? Who did you involve in this decision? If child wanted; who can you say wanted the child more, you or your partner? What would you say was the main reason for wanting/not wanting to have this child?

iii. How important was/is it for you to have/not have (more) children? How important was/is it to your partner to have/not have (more) children? What are some of the reasons for the way you feel about this? **If had child after diagnosis**; how did having a child make you feel? What do you think made you feel that way? How important to you is it to be a mother/ father? What do you think makes it not/important? How has the community responded to your having this child? What may be the reasons behind such responses? If you were given a chance to do it again, would you decide to have this child? What can you say has been

good/bad about having this child? Assuming you lose your baby would you try for another one and why?

iv. Are you aware of any risks associated with pregnancy when you are HIV positive? Can you tell me those you know? From your point of view what are the benefits of having a child?

v. Are you currently on ARVs? Were you on ARVs before and during pregnancy? How did being on ARVs affect your decision to become pregnant? Would you have considered having a child if you weren't on ARVs? If no, what do you see as the benefits of ARVs?

vi. What do you think of the risk of MTCT? What is the likelihood of transmitting the virus to an unborn baby? What would you say of the likelihood if the mother was on ARVs? Where did you get this information concerning MTCT? If had child post-diagnosis; were you given any prophylactic drugs prior to delivery? If yes; what do you think of their effectiveness? How worried/concerned are you about the future of your child? What are you concerned about? Has the baby been tested for HIV? What is its status? If not yet tested, how worried are you about your babies HIV status and what makes you not/worried?

vii. During pregnancy how worried were you about your health/the health of your partner? How worried were about the health of the child? Why were you worried/not worried?

viii. Looking at your community or the society at large, how important is it to have a child? Why do you think it is so important/ not important? What does the society say is good about having a child? How is a childless couple viewed in society? Why is that so? In your view what impact do such social views have on couples reproductive decisions? How can you describe an ideal family in your society? **If the couple does not desire any further children probe accordingly-** would they change their stance if they were told that babies born to HIV positive couples had a 100% chance of being born HIV negative – try to find out what it is that makes them not desire any children and if they are aware of any modern methods of fertility treatment (is it the fact that they had already made a decision not to have any more children, is it the fear of having an HIV positive child, is it the fear of what the society and the Health Practitioners will say)? How did you come to that decision, what made you decide to take that route, what can you say are the main issues you considered before making that decision? Should you accidentally fall pregnant, what will you do and what will make you do that?

- ix. What are your views on HIV positive couples getting pregnant/having more kids? What makes you hold those views? In your view what are the chances of having an HIV negative child if both parents are HIV positive, what if only one parent is positive, what if the positive parent is a man and the women is negative, what if it is the other way round? What makes you say that?
- x. What do you think the society will say if a known HIV positive couple have a child, what about the Health Practitioners?
- xi. How do you make decisions in your relationship/household? Do you talk about contraceptive/ family planning issues with your partner; if no why? If yes; who initiates such discussions? How do you approach the issue and what do you discuss?
- xii. How did you decide which method of contraception to use? Who made the initiative, why and who made the final decision? What are your views about the position of women in decision making within the household/family?
- xiii. How did you decide whether to have or not have any more children? Who initiated the discussion? How did you come to the final decision? What can you say about the role of other family members in determining how many children a couple can have?

7. Encounter with Health Practitioners (HPs)

- i. From the time you discovered you were HIV positive, how often do you visit the HPs? What do you usually go there for? How far is your nearest health centre/surgery? How do you usually get there? How do you pay for health services and how affordable are they to you? Probe further.
- ii. Can you tell me how helpful these visits have been to you?
- iii. What information about reproductive health do you get from your HPs?
What information or advice concerning reproduction have you been given by HPs?
- iv. Can you tell me more about anything new you have learnt about HIV/reproduction during your visits?
- v. From your experience with HPs what can you say about their attitude/behaviour towards HIV positive people? Are you satisfied with the way you have been or are treated? Tell me more about it. What do you think makes HPs treat HIV positive people the way they do? How can you describe the relationship you have with health practitioners?

vi. What do you think are the views of HPs on HIV positive people getting pregnant? What could be the reasons behind such views? What is your opinion on such views? How justified are these views?

Support Groups/networks

i. Are you a member of any support group? If no, probe for reasons. If yes:

ii. Tell me when, how and what made you join and what kind of a support group it is? How often do you attend the meetings? Are you still a member of the support group; if **no** what made you leave? **If yes, ...**

iii. Take me through the day in a support group meeting; what is discussed? Tell me about your discussions concerning reproductive issues.

iv. How helpful has this support group been to you personally? How about as a couple?

v. How are you currently supporting yourself? How adequate are your financial resources? Who do you live with? What can you say are your family responsibilities? What is your relationship with your family? What kind of support are you giving or getting from them? What kind of support would you wish to get from them? What can you say about your friends? Are they aware of your status? Probe accordingly. What support are they giving you? What would you wish they did which they don't do? Do you talk to your family/friends about your concerns? Probe accordingly.

vi. Are you a member of any religious group? If yes; Is HIV discussed as an issue in your group? What are its views on HIV/AIDS? Probe accordingly. What kind of support can you say you have got from your

APPENDIX B

INTERVIEW GUIDE FOR THE HIV NEGATIVE PARTNER

1. OPENING

Introductions

Thank you for your participation in this study. I am interested in hearing your views and experiences on reproductive issues and HIV/AIDS.

*Read the consent form to the interviewee and have it signed.

2, Establish rapport by asking the interviewees personal details, i.e, their name (*this not to be tape recorded or noted in the notebook*), when and where they were born, how many they are in their family, level of education, the occupation of their parents, their occupation and whether they have children or not.

3, Reproductive Health prior to diagnosis

- i. When did you become aware of the existence of HIV/AIDS?
- ii. How did you become aware of it, Can you tell me how it is transmitted, how it is not transmitted? How can it be prevented?
- iii. From the time you knew about the existence of HIV did you discuss or talk about it with your partner/ friends? What made you talk/not talk about it? If discussed – what exactly did you discuss, how did you discuss it, what did you agree on?
- iv. Did you at this point take any preventive measures? – what measures did you take, did you agree with your partner to use this method – how did you agree on this – if did not agree what may have caused the disagreement? If no preventive method used – what made you not take any action to protect your self or your partner (s)?
- v. Tell me, how long have you been in your current relationship? Can you describe the nature of your relationship ,i.e. casual etc
- vii. Prior to discovering the status of your partner, what was your desired number of children, how many boys, how many girls and why? (*if they still have the partner they had before knowing their status*) Had you discussed your desired

number of children with your partner? If yes- tell me how you came to agree on that number. If no – probe for reasons

4. Stigma

- i. When did you discover that your partner was HIV positive?
- ii. How did you discover/get to know about it?
- iii. When did you go for your HIV tests – *was it before or after knowing the partner's status?* What made you go for the test? Tell me about the day you went for your tests. How were you feeling, can you recount to me what was going on in your mind during that time, how relaxed were you, if afraid- what were you afraid of – what was the cause of the fear? If relaxed probe further on why and on whether this changed after a negative diagnosis.
- iv. Can you recount to me the events of the day you went to collect your results. What happened when you were told you were negative? How did you feel and what do you think made you feel that way?
- v. How did your counsellor/doctor handle the situation? Can you describe to me how the HP broke the news to you? Were you satisfied with the way you were informed about your status? What advice/information did the HP give you?
- vi. Tell me about your views on HIV/AIDS before you knew you weren't infected. Have those views changed in any way? What do you think of society's views on HIV/AIDS and infected people? What do you think is the cause of such views?

5. Disclosure

- i. At what point in your relationship did your partner inform you of their status? Can you describe to me how s/he did it? What do you think made her/him disclose, and to you in particular? What was your first reaction? What do you think made you react the way you did? What happened after the initial reaction? Did you discuss your future and how you were to live with HIV? If yes how; if not what are the reasons?
- ii. What difficulties do you think HIV positive people face in disclosing their status? How can they be overcome?

6. Reproductive decision making

- i. Tell me, which family planning methods are you aware of? Are you currently using any, if so which ones and why; if not why?

ii. Tell me about your plans about having any children or in terms of reproduction? Find out if the couple still has the desire to have children- if so what is the driving factor, are they aware of the risks and benefits of pregnancy, what information do they have concerning this, how and where did they get the information, have they tried for a baby so far, were they successful, if yes has the baby been tested and what's its status, if no do they plan to continue trying. Is the couple aware of the existence of Antiretrovirals, are they using them, if yes, are they accessible; if no why? **If the couple does not desire any further children probe accordingly-** would they change their stance if they were told that babies born to HIV positive couples had a 100% chance of being born HIV negative – try to find out what it is that makes them not desire any children (is it the fact that they had already made a decision not to have any more children, is it the fear of having an HIV positive child, is it the fear of what the society and the Health Practitioners will say)?

iii. What are your views on HIV positive couples getting pregnant/having more kids? What makes you hold those views? In your view what are the chances of having an HIV negative child if both parents are HIV positive, what if only one parent is positive?

iv. What do you think the society will say if a known HIV positive couple have a child, what about the Health Practitioners?

v. How do you make decisions in your household? Do you talk about contraceptive/ family planning issues with your partner; if no why? If yes; who initiates such discussions? How do you approach the issue and what do you discuss?

vi. How did you decide which method of contraception to use? Who made the initiative, why and who made the final decision? What are your views about the position of women in decision making within the household/family?

vii. How did you decide whether to have or not have any more children? Who initiated the discussion? How did you come to the final decision? What can you say about the role of other family members in determining how many children you will have?

viii. Do you accompany your partner when s/he visits the HP/s? From your experience with HPs what can you say about their attitude/behaviour towards HIV positive people? What do you think makes HPs treat HIV positive people the way

they do? What do you think are the views of HPs on HIV positive people getting pregnant? How justified are these views?

7. Support Groups

- i. Are you a member of any support group? If no, probe for reasons. If yes:
- ii. Tell me when, how and why you joined. How often do you attend the meetings?
- iii. Take me through the day in a support group meeting. What is discussed? Tell me about your discussions concerning reproductive issues.
- iv. How helpful has this support group been to you personally? How about as a couple?

University of Cape Town

APPENDIX C

INTERVIEW GUIDE FOR HEALTH PRACTITIONERS

1. OPENING

Introduction.

Thank you for your participation in this study. I am interested in hearing your views and experiences on reproductive issues and HIV/AIDS.

*Read the consent form to the interviewee and have it signed.

2. Establish rapport by asking the interviewees personal details, i.e, their name (*this not to be tape recorded or noted in the notebook*), when and where they were born, how many they are in their family, level of education, the occupation of their parents, their occupation and whether they have children or not.

3. PERSONAL VIEWS ON HIV/AIDS

- i. HIV/AIDS has been around for some time now; tell me, what are your personal views on this epidemic? What do you think fuels it?
- ii. Despite high levels of awareness among the people the rates of infection are still very high, what may be causing this?
- iii. What can you say about the role of men in the spread of this epidemic? What about women? From your view point how can the spread of HIV be halted?
- iv. What do you think of people who get HIV infected? Do they deserve sympathy/support?

4. CONTACT WITH HIV POSITIVE PEOPLE

- i. Tell me about the first time you came into contact with an HIV positive person. When was it, in what context, how did you feel, what made you feel that way?
- ii. How often do you come into contact with HIV positive people?
- iii. Tell me about the risks involved in taking care/attending HIV positive people. In your view are these risks worth taking? From your point of view is it worthwhile taking care of HIV positive people? Why?
- iv. What kind of services do you provide for HIV positive people? Do you think they are adequate?

v. Have you ever cared/attended an HIV positive heterosexual couple? If yes can you relate your experience about caring/attending them?

5. REPRODUCTIVE HEALTH

i. Have you cared/attended an HIV positive pregnant woman before? If yes tell me about your experience. What advice concerning their pregnancy, health, MTCT and the child's health did you give them? Were they on ARVs? What combinations of ARVs are HIV positive people given and why? Is there any variation of drug combinations for those who are pregnant/ intend to be pregnant and those who don't? if yes; how do they differ and why?

ii. What are the risks associated with pregnancy if one is HIV positive?

iii. What was your advice concerning their future reproductive health? Why give them such advice?

iv. What are the chances of getting an HIV negative child if both parents are HIV positive, what if only one of them is HIV positive? Did you inform the patient of this? What was their reaction?

v. How would you react if an HIV positive couple informed you they planned on having a baby? Why would you react that way? What advice would you give such a couple and why? What do you think the community/society would say and why?

vi. In your view, should HIV positive people have reproductive rights? – probe accordingly.

vii. Do you have any care plans for HIV positive pregnant women? How did you design the plan and what were your considerations?

viii. Have you had a case where a woman has become pregnant after being told of her HIV status? If yes, how have you dealt with such cases? How did you feel about their becoming pregnant, what made you feel that way? What kind of support do you give to such women?

APPENDIX D

CONSENT FORM FOR COUPLES WITH HIV/AIDS

REPRODUCTIVE DECISIONS AMONG COUPLES WITH HIV/AIDS IN ZIMBABWE

RESEARCHER: VEZUNI NZINDLOVU

Statement

I am asking you to be in a research study. The purpose of this consent form is to give you information you will need to help you decide whether to be in the study or not. Please read it carefully. You may ask for clarification on anything in the form. When your questions have been satisfactorily answered you may decide if you want to be in the study or not. I will give you a copy of this form for your records, if you decide to participate in the study.

Purpose and study procedure

The main purpose of the study is to learn more about your reproductive behaviours and the process of reproductive decision making after you learnt of your or your partner's HIV positive status. I am undertaking this study as part of my PhD studies. I need your help in learning more about reproductive behaviour and how you make decisions as a couple. Your participation in this study will include one or two interviews with me. The interview may last for about an hour depending on how our conversation unfolds. As I am interested in learning from you I would like you to openly express your thoughts and feelings. I may ask you questions that you may consider personal or sensitive. If you feel like not answering them please feel free to do so.

Confidentiality

Be assured that no personal information will be divulged in the study report. No name or surname will ever be used in the study, thus no one who reads it will be able to identify you as one of the people I spoke with. **All personal information you share with me will be kept confidential.** Audio tapes of the interview.

which may contain personal information, will only be accessible to me and they will be destroyed after the study report has been completed.

Other information

You are free to tell me that you do not wish to participate in this study. It is also your choice to have the interview tape recorded or not.

Researcher:

Signature:

Date:

Participants Statement

This study has been fully explained to me. I volunteer to take part in this research. I have had a chance to ask questions and should I have any questions later, I will ask the researcher. I will receive a copy of this consent form.

-----I give permission for the interview to be taped.

-----I give the researcher permission to take notes during the interview.

Name/pseudo name:

Signature:

Date:

APPENDIX E

CONSENT FORM FOR HEALTH PRACTITIONERS

REPRODUCTIVE DECISIONS MAKING AMONG HIV/AIDS COUPLES IN ZIMBABWE

RESEARCHER: VEZUMUZI NDLOVU

Statement

I am asking you to be in a research study. The purpose of this consent form is to give you information you will need to help you decide whether to be in the study or not. Please read it carefully. You may ask for clarification on anything in the form. When your questions have been satisfactorily answered you may decide if you want to be in the study or not. I will give you a copy of this form for your records, if you decide to participate in the study.

Purpose and study procedure

The main purpose of the study is to learn more about the reproductive behaviours and the process of reproductive decision making among HIV positive couples. The study will also look closely at the role of health practitioners in reproductive decision making and it is in this capacity that this study seeks your participation. Your participation in this study will include one or two interviews with me. The interview may last for about an hour depending on how our conversation unfolds.

At any time during or after our conversation/my observation you can tell me that you do not wish to answer any question, you do not want me to tape record or take notes or that you do not wish to continue with the interview or with participating in the study altogether.

Confidentiality

Be assured that no personal information will be divulged in the study report. No name or surname will ever be used in the study, thus no one who reads it will be

able to identify you as one of the people I spoke with. **All personal information you share with me will be kept confidential.** Audio tapes of the interview, which may contain personal information, will only be accessible to me and they will be destroyed after the study report has been completed.

Other information

You are free to tell me that you do not wish to participate in this study. It is also your choice to have the interview tape recorded or not.

Researcher:

Signature:

Date:

Participants Statement

This study has been fully explained to me. I volunteer to take part in this research. I have had a chance to ask questions and should I have any questions later, I will ask the researcher. I will receive a copy of this consent form.

-----I give permission for the interview to be taped.

-----I give the researcher permission to take notes during the interview.

Name/pseudo name:

Signature:

Date:

APPENDIX F

RECRUITMENT FLYER

REPRODUCTIVE DECISIONS AMONG COUPLES WITH HIV /AIDS IN ZIMBABWE

RESEARCHER: VEZUMUZI NDELOVU

Statement

I am looking for HIV positive heterosexual couples to participate in a study about reproductive behaviour and decision making. The main purpose of the study is to learn more about your reproductive behaviours and the process of reproductive decision making after you learnt of your or your partner's HIV positive status. I am undertaking this study as part of my PhD studies. I need your help in learning more about reproductive behaviour and how you make decisions as a couple.

Eligibility Criteria

You are eligible for this study if you are HIV positive and are in an intimate relationship (not necessarily married) in which:

- At least one of you is infected with HIV
- You have disclosed your HIV status to each other
- You will be confronting or have confronted reproductive decisions after learning of your HIV status
- You are able to communicate in Ndebele, English or Shona

If you are interested in the study please inform your Health Practitioner or get in touch with me on the following number:

Tel:

Email: vezestha@yahoo.co.uk

PARADE'S SYMBOL FOR AIDS (TOP RIGHT CORNER)

NEWS FILE

Saving lives at the grassroots

By Peta Thornycroft

Mr Viri Chihata may be illiterate, and he does not know his age, nor when he arrived in Zimbabwe from Mozambique.

But he does know that when he sleeps with his youngest, second wife, he should use a condom. Because, he says, he has "some suspicion" that perhaps she has other partners.

He never uses a condom with his older, first wife.

Mr Chihata lives on a commercial farm village at Mvoshanga and both he and every other adult worker and resident there knows about AIDS, how it is caught, and how to prevent getting it.

The 100 percent AIDS awareness on this mixed farm, with a population in the village of about 620 is a result of three years of education by firstly the owner of the farm, Mr Peter Fraser-Mackenzie, and the efforts of the health worker Mrs Serena Damasoko. Both of them hand out condoms on request, at pay day, in the farm store, from her house in the village. In fact this community uses at least 2000 condoms a month, every month.

Mr Fraser-Mackenzie first became aware of AIDS when he attended a child spacing conference in Kenya. He represents the Commercial Farmers' Union at regular meetings of the family planning unit in Harare.

"In Kenya I met doctors from Uganda and heard about the results of AIDS testing on prostitutes there. I was quite horrified. I read whatever I could lay my hands on and gave my first talk on the disease in Harare in

December 1985."

At that stage he also found out he could obtain free condoms from the Ministry of Health and he started handing them out on pay day.

Mrs Damasoko was elected by the whole village the next year to become their health worker. She had no training but has the trust of the community. She went to Rollington for education in pre-natal health care in 1987 and learned more about this killer disease.

Mrs Damasoko has a clinic each morning, and has noticed that whereas previously there were at least 15 cases of venereal disease a month, the figure has dropped to about one — she puts this down to members of the village using condoms, and because they are being more careful about who they have sex with.

In addition the community is well served by a mobile clinic which visits once a month and there is a well-equipped clinic close by, and a hospital within 30 km of the farm.

In every community — and this one is no exception — there are mahures, and Mrs Damasoko estimates that about 15 women live by prostitution, and it is they who have been thoroughly educated into insisting that each man they sleep with — for about \$5 to \$10 a night — uses a condom.

"I give them condoms and I have told them to insist their partners use them. I have told them to send the man away if he refuses to use one. I have no way of knowing if they do, but they understand that AIDS can kill them if they don't."

Mr Fraser-Mackenzie pays Mrs Damasoko a salary himself, and says: "She is an essential human investment."

Each worker interviewed by *Parade* said they had learned about the disease from their employer. At first they found it difficult to comprehend that this frightening new fatal disease was unlike most sexually transmitted diseases which can be cured.

They admitted it took some time for the message to sink in, and while all are aware of it, not all are using condoms.

Mr Phineas Marimo from Zimbabwe who has had a reasonable education said he estimates only about 20 percent of the workers are using condoms whenever there is a risk of catching AIDS.

Mr Robson Marimo, his brother, with two wives said: "I have changed my life and remain with my wives now, because of AIDS."

Mrs Monica Kuvane originally from Mozambique and has been on the farm for longer than she remembers, says her husband takes condoms every month, and every month they get stuck up, but not on her. And she says she doesn't mind, she just hopes that he is sleeping with women at risk he always uses one. She is well aware of the risk of AIDS.

Mr Fraser-Mackenzie has tried as a concerned employer to do whatever he can to ensure that the risk of AIDS on his farm is kept to a minimum. But of course as the essential research is done in Zimbabwe about sexual transmission related to the spread of the disease, he is unable to make comparisons to learn more in his drive to halt the spread of AIDS.

Male workers on the farm say they believe some men have as many as eight different partners a month.

Also of course, as statistics which could help us estimate the extent of the disease are a secret there is no way, despite Mr Fraser-Mackenzie's tremendous personal effort to protect his workers, that he can do much more than he is about AIDS.

Parade understands that the Commercial Farmers' Union,



which employs 127 000 with a population of about 600 living on the farms (just the average family of six children) learned about the epidemic that is sweeping through Zimbabwe more than 10 years ago. But their efforts educate their workers have been difficult, particularly as the did not want to offend the Ministry of Health by taking too much about the disease. Their concern is understandable given cover up of the real statistics of the disease in official circles.

Mr Fraser-Mackenzie explains that by the end of this year he has realised just how serious the situation is, farmers will be taking the matter in hand themselves and will launch widespread education programmes.

If any of you reading *Parade*, live on commercial farms and are unclear of the causes of AIDS and how to prevent it, we suggest you visit your village health worker if you have one, and if not ask a workers committee to ask your employer who if he does not have the information himself will know how to find it.

A by-product of the awareness campaign on Fraser-Mackenzie's farm has been a noticeable drop in the birth rate. Mr Chihata has 18 children, he says while he loves all his children dearly, if he had his limit set again he would have limited to six of his family.

In a talk Mr Fraser-Mackenzie gave recently about AIDS in Harare he said:

"It must become fashionable to be informed, not to take risks. Zimbabwe fails with its infrastructure, then Africa fails with us."



Monica Kuvane - her husband uses condoms.



Viri Chihata uses condoms when he has to.



Serena Damasoko: concentrating on the prostitutes.



Peter Fraser-Mackenzie preventing AIDS on his farm.