

**AN EXPLORATION OF TIMING OF DISCLOSURE TO MALE PARTNERS  
BY HIV POSITIVE WOMEN ATTENDING A HEALTH CARE CENTRE  
IN LUSAKA, ZAMBIA.**

**MAXIMILLIAN M. BWEUPE**

A minithesis submitted in partial fulfilment of the requirement for the Degree of Masters in  
Public Health in the School of Public Health, University of the Western Cape, Bellville



Name of Supervisor: Ms. Nichola Schaay

February 2012

## **KEY WORDS**

- Prevention of Mother to Child Transmission of HIV (PMTCT)
- HIV Positive women
- Partners
- Baby
- Disclosure
- Timing
- Experiences
- Beliefs
- Benefits
- Couple relationship



## ABSTRACT

Disclosure of HIV positive status to male partners is well established as a key element in the success of prevention of mother to child transmission of HIV programmes, as it helps improve adherence to ARVs by the women within these programme. However, partner notification rates remain low in the urban areas of Lusaka, Zambia against a high HIV prevalence of 25%. The purpose of this study was to explore the *timing* of disclosure as part of the process of disclosure amongst women who were part of the PMTCT services at Kaulu health centre in Lusaka.

An exploratory descriptive study using qualitative research methods was conducted. 15 women, who were attending the Kaulu health centre PMTCT programme, were requested to participate in a semi-structured interview. The women, who were purposively selected with the aid of the health centre's PMTCT focal point nurse, had to have disclosed their HIV positive status to their partner, either before or during the course of their pregnancy or after delivery. To increase rigour, individual interviews were conducted with 5 health workers associated with the PMTCT programme so as to obtain their perspective and experiences on the issue of HIV disclosure amongst their PMTCT patients. Participation in the study was voluntary and all information obtained during the course of the interviews remained confidential and secure. Potential participants were each provided with an explanation of the purpose and process of the study and their informed written consent obtained before the researcher embarked on the interviews. Content analysis of the transcripts was done so as to develop coding categories and identify emerging themes.

Disclosure to male partners is an important step in PMTCT and facilitates adherence to HIV care for the family and should be done as early as possible after the woman receives her HIV test result, though there exists a range of alternative times when it can be done. The relationship existing between a couple is very important in determining the timing of when a woman chooses to disclose.

PMTCT services need to provide ongoing counselling for HIV positive women during pregnancy and after giving birth that supports, informs and equips them with the necessary skills to make an informed and timely decision about disclosure to a partner. In addition, the PMTCT service

providers need to be encouraged to implement couple counselling as a strategy to facilitate disclosure as well as establishment of a peer support network for HIV positive pregnant women.

The study findings will be used to contribute to health workers' capacity to support women manage the disclosure process to their male partners, thus helping to increase the disclosure rate and also contributing to improving the positive effect of the PMTCT services, in Lusaka, Zambia.



## DECLARATION

*I declare that 'An exploration of timing of disclosure to male partners by HIV positive women attending a health centre in Lusaka, Zambia' is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.*

UNIVERSITY of the  
WESTERN CAPE

Maximillian M. Bweupe

February 2012

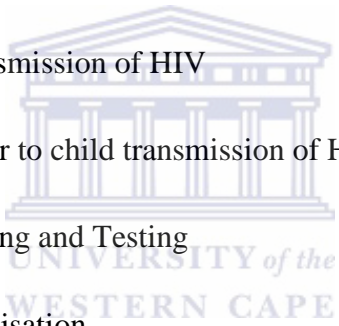
Signed\_



---

## LIST OF ACRONYMS

ANC	Antenatal care/clinic
ARVs	Antiretroviral drugs
CDC	Centres for disease control and prevention
HIV	Human Immunodeficiency Virus
KHC	Kaulu health centre
LDHMT	Lusaka district health management team
MCH	Maternal and child health
MTCT	Mother to child transmission of HIV
PMTCT	Prevention of mother to child transmission of HIV
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation



## CONTENTS LIST

Title Page	i
Keywords	ii
Abstract	iii
Declaration	v
List of Acronyms	vi
<b>CHAPTER 1: INTRODUCTION</b>	<b>1</b>
1.1 Background	1
1.2 Current Zambian guidelines on disclosure to male partners in the context of PMTCT	1
1.3 The study site in Lusaka district	3
1.4 Problem statement	4
1.5 Study purpose	4
<b>CHAPTER 2: LITERATURE REVIEW</b>	<b>6</b>
2.1 Positive benefits of disclosure to male partners by HIV positive pregnant women	6
2.2 Timing of disclosure to male partners by HIV positive pregnant women	6
2.3 The role of health workers in facilitating timely disclosure in the context of PMTCT	7
2.4 Role of the male partner and the relationship between a couple in facilitating timely disclosure	9
<b>CHAPTER 3: METHODOLOGY</b>	<b>11</b>
3.1 Aim of the study	11
3.2 Specific objectives	11
3.3 The study design	11
3.4 Sampling	12
3.5 Data collection methods	13
3.6 Validity and trustworthiness	15
3.7 Data entry and analysis	15
3.8 Ethical and legal considerations	16
<b>CHAPTER 4: RESULTS</b>	<b>18</b>
4.1 Introduction	18
4.2 Description of the respondents	18
4.3 Women's opinions and perceptions about disclosing HIV positive status to partners	23
4.4 Perceptions on the best time for disclosure	24

4.5	Motivation for the immediate disclosure of an HIV positive test result	27
4.6	The role of the couple's relationship in disclosure and its timing	29
4.7	Experienced benefits of early disclosure	31
4.8	Role of health workers in timing of disclosure	33
<b>CHAPTER 5: DISCUSSION</b>		<b>41</b>
5.1	Introduction	41
5.2	Importance of disclosure to male partners as a necessary step in MTCT and adherence to HIV care	41
5.3	Perceptions and experiences on the best timing of disclosure	42
5.4	Limitations of study	48
<b>CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS</b>		<b>49</b>
6.1	Recommendations	50
<b>REFERENCE LIST</b>		<b>52</b>
<b>APPENDICES</b>		
Appendix 1	<i>Informed Consent Form</i>	56
Appendix 2	<i>Participant Information Sheet (for Health Workers)</i>	58
Appendix 3	<i>Participation Information Sheet (for PMCTC Client)</i>	61
Appendix 4	<i>Guide for Interviews with Women (Participants)</i>	64
Appendix 5	<i>Guide for Interviews with Health Workers</i>	71



## **CHAPTER 1: INTRODUCTION**

### **1.1 Background**

The human immunodeficiency virus (HIV) epidemic continues to take a heavy toll on women and children worldwide, according to the World Health Organisation, with a reported 33.4 million individuals living with HIV in 2008, of whom 15.7 million were women and 2.1 million were children under 15 years of age (UNAIDS and WHO, 2009). Globally, HIV is the leading cause of death in women of reproductive age. Nearly all HIV infections in children are acquired from their mothers; the global HIV epidemic in children thus mirrors that of HIV in women (WHO, 2010). Southern Africa has the highest burden of HIV infection, contributing almost 80% to the global total of people living with HIV (WHO, 2006). In this region, almost 61% of adults living with HIV in 2007 were women (UNAIDS, 2007). The 2007 Zambian Demographic and Health Survey (ZDHS) estimates 1.2 million people living with HIV out of a population of 12.3million and HIV prevalence amongst pregnant women at 25% in urban areas and 12% in rural areas (Central Statistical Office, 2007).

Over the past 10 years there has been unprecedented political and community mobilization in response to the HIV pandemic, with new funding opportunities in resource constrained countries that have changed the paradigm of prevention of mother to child transmission of HIV (PMTCT) in these settings: by introducing the possibility of reducing MTCT to very low levels and achieving the virtual elimination of vertical transmission from mothers to infants (WHO, 2010). Wide implementation of the recent WHO guidelines on PMTCT has been projected by the WHO to reduce the risk of MTCT to less than 5% in breast-feeding populations from a background risk of 35% (WHO, 2010).

### **1.2 Current Zambian guidelines on disclosure to male partners in the context of PMTCT**

The current Zambian PMTCT guidelines '*2010 National Protocol Guidelines for Integrated Prevention of Mother-to-Child Transmission of HIV*' (Ministry of Health of Zambia, 2010) were adapted from the WHO 2010 PMTCT guidelines and state that disclosure of a newly diagnosed HIV positive pregnant woman's status to her sexual partner is an important public health goal.

Such disclosure, it is suggested, leads to increased opportunities for social support, improved adherence to necessary health care interventions, including taking ARVs, and planning for the future by the couple (Ministry of Health of Zambia, 2010). The Zambian guidelines further state that a counsellor or trusted friends and family members can be used to mediate the counselling process by providing a potentially effective and culturally sensitive approach to HIV disclosure (Ministry of Health of Zambia, 2010).

The Zambian guidelines outline the PMTCT schedule of visits to the health centre as follows: a minimum of 4 visits to the antenatal clinic; delivery within the health centre; and postnatal reviews at 6 hours, 6 days and 6 weeks after delivery. The woman attending PMTCT and her baby are thereafter reviewed at 6, 9, 12 and 18 months. At each of these visits, adherence to ARVs, HIV testing of the baby and HIV disclosure status to the partner ought to be checked - and if the latter has not as yet been done, it ought to be encouraged by the PMTCT service provider at each of these visits.

At present data on the rate of disclosure to male partners by HIV positive pregnant women attending PMTCT services in Zambia is not captured in the routine health management information system. Accurate, national information on disclosure is thus not readily available (Communication with the Monitoring and Evaluation Officer for the Zambian PMTCT programme, Ministry of Health, 2010).

However, a prospective cohort study done from 2001 to 2003 and conducted in two high volume Antenatal clinics (ANCs) servicing high density urban communities in Lusaka revealed that only 49.3% of HIV positive women – who had previously *not* disclosed their HIV status to their partners – had done so by the 6<sup>th</sup> months visit after delivery (Semrau et al., 2005). A non disclosing HIV positive pregnant woman may put her child at higher risk of HIV infection if, fearing exposure, she feels unable to take her antiretroviral prophylaxis or to choose a safe method to feed her baby (Makin, Forsyth, Visser, Sikkema, Neufeld & Jeffery, 2008). From the latter study, the authors concluded that providing support to women around disclosure should be an important component of any programme designed to prevent MTCT and that such support, that increases disclosure, could have a significant effect on reducing MTCT (Makin et al., 2008).

Reflectively, I am of the position that disclosure of HIV positive status by women who have

been a part of a PMTCT programme is beneficial. I also hold the view that by learning from the PMTCT clients for whom disclosure *has* been possible, we can begin to provide more informed and appropriate support for the PMTCT clients attending public health services in Zambia. This is particularly important given that Semrau et al. (2005) found that 51% of their HIV positive/ PMTCT clients in their Lusaka study found it difficult to disclose their status to their partners. The failure to disclose was significantly associated with not living with the partner or husband.

### **1.3 The study site in Lusaka district**

This study was conducted at Kaulu<sup>1</sup> health centre (KHC): a high volume PMTCT centre servicing a high density peri-urban community in Lusaka, with a catchment population of 57,278. It is one of 24 health centres managed under the local Lusaka urban district health management team (LDHMT), and was receiving support from the Centres for Disease Control and Prevention (CDC). In 2011 KHC attended to about 30 Antenatal Care/Clinic (ANC) patients per day, of whom approximately 25% were HIV positive. KHC is implementing the Zambian 2010 PMTCT guidelines and its PMTCT programme thus reflects the new emphasis placed on providing support to PMTCT clients around disclosure to their sexual partner at each of their scheduled visits.

ANC services are conducted in the facility every morning except during the weekends. All the antenatal attendees are gathered for group health education, which includes safe motherhood, birth preparedness and HIV counselling. HIV counselling encompasses information on modes of transmission of HIV, how HIV testing is done, and the meaning of an HIV positive or negative result. Additionally, women are informed about the interventions for HIV which are available, including PMTCT, CD4 testing, ARVs and partner counselling and testing. Routine ANC services are then provided on an individual basis. This includes weighing, abdominal examinations and the offering of blood tests such as haemoglobin assessment and HIV. Results are provided within 15 minutes for HIV as they are conducted with a rapid test, and post test counselling is routinely done. The antenatal attendee is then given a review date for their next visit where subsequent care will continue depending on her test results. In the post test counselling session, disclosure to the male partner is encouraged. In the years between 2005 and

---

<sup>1</sup> In order to protect confidentiality this pseudonym has been created for the clinic in which the study was conducted.

2010 HIV testing of women attending ANC at KHC had risen from about 50% to more than 95%, while the rates of disclosure to partners unfortunately remain at about 50% (Communication with PMTCT service providers at KHC, 2010).

#### **1.4 Problem statement**

While the proportion of women accepting the routine offer of HIV testing and counselling has increased almost two fold from 50% to 95% in the last 5 years, the proportion of HIV positive pregnant women who disclose to their partners whilst they are part of the PMTCT programme appears to have remained static at about 50%, in the period from their first ANC attendance to the baby reaching the age of 6 months. This means that about 50% of HIV positive pregnant women are still not disclosing to their partners and thus are unlikely to experience the beneficial outcomes of disclosure. Those that do not disclose might very well experience problems in negotiating safer sex, adhering to ARVs, and bringing their partners in to be tested for HIV. This may result in poorer health outcomes for the woman, her baby and her partner – specifically in relation to their needs in terms of HIV.

#### **1.5 Study purpose**

This study set out to explore how (and when) some women have successfully disclosed their HIV positive status to their partners. By describing their disclosure experiences, the support they needed and would like to have received, particularly in relation to the timing of disclosure, it was hoped that the results of the study could in turn be able to assist PMTCT service providers. Specifically, it was hoped that the findings of this study could assist the PMTCT service providers to provide their future clients with the additional support they would need to disclose their HIV positive status, at an appropriate time, to their sexual partner.

In the remainder of the mini thesis, the following aspects will be covered: the literature review in Chapter 2, which is a summary of all the policy documents, reports and journal articles reviewed on the topic under study. After the literature review, Chapter 3 outlines the aim and objectives of the study along with the study design and methodology used and the procedures for sampling, data collection and data analysis. In Chapter 4, the study results are presented along with the themes that emerged from the data. The results are discussed in relation to the literature

in Chapter 5 where comparisons are made with the findings of the literature review. Chapter 6, the final chapter, contains the conclusions of the study, its limitations and some final recommendations.



## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Positive benefits of disclosure to male partners by HIV positive pregnant women**

It has been shown by Varga, Sherman & Jones (2005) that a common obstacle to disclosure to partners is the PMTCT patients' fears of its consequences, including physical violence, rejection, blame and abandonment. Disclosure has also been described as being a highly stressful event for HIV-infected women (Siegal, Lekas & Schrimshaw, 2005). However, the beneficial outcomes of HIV positive status disclosure to sexual partners by pregnant women are revealed in a review of 9 studies conducted between 1990 and 2001 in sub-Saharan Africa and south east Asia, that reported on outcomes of HIV status disclosure to partners by women (Medley, Garcia-Moreno, McGill & Maman, 2004). Whilst the review did find that several studies mentioned that the fear of consequences such as abandonment, violence and discrimination was a major barrier to disclosure, the majority of the studies in fact reported positive outcomes related to disclosure - such as receiving kindness, understanding and acceptance from the partner (Medley et al, 2004). Further positive outcomes of HIV positive status disclosure that have been suggested by King et al. (2008), in their study conducted in Eastern Uganda among HIV infected women and men, include risk reduction behaviour, partner testing, increased care-seeking behaviour, anxiety relief and increased sexual communication and motivation to plan for the future. Medley et al. found that rates of disclosure across the reviewed studies varied widely: from 16.7% to 86%. The authors did recognize that the rates were impossible to compare directly due to the different time frames since diagnosis (2 weeks to 4 years), the measuring methods (cross-sectional and before-and-after) and the setting (ANC and stand-alone VCT centres) used in the different studies (Medley et al., 2004).

### **2.2 Timing of disclosure to male partners by HIV positive pregnant women**

Whilst barriers and facilitators to disclosure for HIV positive pregnant women have been documented in the literature, for example, by Makin et al. (2008), as well as the rates of disclosure, by Medley et al. (2004), very little information related to the *timing* at which PMTCT patients disclose their status to their partners has been explored or studied to date (Brou, et al., 2007). The timing of disclosure is a key part of the process, because part of the emotional benefit includes relief from sharing a burdensome secret, which a woman would otherwise have

to carry alone for some time (Siegal, Lekas & Schrimshaw, 2005). In terms of timing, a South African study, conducted among a cohort of women who had participated in a PMTCT programme, demonstrated that disclosure of their HIV positive status to their partners or family members is a process (rather than a 'once time' event) and did not have one inevitable outcome (Norman, Chopra & Kadiyala, 2007). The authors thus suggested that disclosure was a fluid process in which the respondents were actively involved in managing, including the calculation of the immediate benefits and risks of such an action (Norman et al., 2007). In addition, they also suggested that effective public policy could be fostered through an understanding of the issues that surrounded the disclosure of HIV infection and the environments that enabled disclosure at both the individual and community levels (Norman et al., 2007).

The view of disclosure as a process rather than an event that needs to be understood within a context was supported by the findings from another community based study that randomly sampled men and women in urban and rural South Africa, and similarly suggested that disclosure needed to be investigated longitudinally in time (Wong et al., 2009).

Of particular interest to this study was a study conducted in Abidjan by Brou et al. (2007) which followed up PMTCT clients for two years after their delivery, and explored with them *when* and *why* they disclosed their HIV positive status to their male partner. The authors identified that there appeared to be key moments during which the women had disclosed and these were: before delivery, upon resumption of sexual activity, and around the time for early weaning of babies (Brou et al., 2007). The authors concluded that in PMTCT programmes, specific psychosocial counselling and support should be provided to women during such 'key moments' of disclosure as this could contribute to improving women's adherence to the advice given to prevent postnatal and sexual HIV transmission (Brou et al., 2007).

### **2.3 The role of health workers in facilitating timely disclosure in the context of PMTCT**

Varga et al. (2006) conducted a qualitative study using a grounded theory approach with women in the PMTCT programme initially enrolled at a hospital in Johannesburg, and followed up through 12 months postpartum. The authors recommended that disclosure should be regarded as an important part of coping with HIV, and understanding the circumstances surrounding disclosure is critical in both the secondary prevention of HIV and the mitigation of its impact -

which is consistent with the other literature cited in this review.

Additionally, Varga et al. (2006) described the process of disclosure to a partner as being something that was done directly (for example, by telling the partner as soon as the HIV test result is known), or by proxy (for example, where clues are given as a means of disclosing either to the partner or to relatives). The authors concluded that for PMTCT programmes consideration ought to be given to assisting those living with HIV to disclose under conditions affording them maximum control over its timing, mode, and impact (Varga, Sherman & Jones, 2005).

This view was supported by Brou et al. (2007) who suggested that given that many African countries have implemented PMTCT programmes, women are often the first member of a partnership and/or sexual relationship to know their HIV status. And whilst the PMTCT protocol would then be to advise a woman to disclose her HIV test result to her partner and encourage him to then also have an HIV test, for many women, particularly those who are HIV positive, talking to their partner about HIV is hard because of possible negative outcomes. Thus, knowing more about when women disclose, and what makes them decide to do so, would enable service providers and PMTCT programme managers to support women during the difficult process of disclosure (Brou et al., 2007).

Along with obtaining a greater understanding of the issues associated with the timing of disclosure, there is a need amongst service providers, to also understand more about how to encourage male involvement in the PMTCT programme. Health workers in the PMTCT programme in Lusaka have expressed a need for training in being able to help women to not only disclose their status to their spouses but to also get the men involved in the programme (Communication with MCH Coordinator, Lusaka, June 2010). A similar concern was raised in the UK, in a briefing paper to the UK parliament by the International Community of Women Living with HIV and AIDS (ICW), in which they stated that badly designed services and indiscreet health workers may endanger women's rights to benefit from scientific progress in HIV treatment (International Community of Women Living with HIV/AIDS (ICW), 2008).



## **2.4 Role of the male partner and the relationship between a couple in facilitating timely disclosure**

From the service providers point of review, a recent study done in 10 antenatal clinics in 4 districts in Uganda, that routinely offered HIV testing for pregnant women, the PMTCT counsellors cited the most common challenge to PMTCT programmes as being the low rates of HIV serostatus disclosure to partners among antenatal clients (Medley & Kennedy, 2010). The researchers in the Uganda study found that service providers told women who were afraid to disclose their HIV status to bring their partners to the clinic, where both members of the couple would receive counselling and disclosure would be facilitated. However, few women were able to convince their partners to come to the clinic, and less than 10% of women were counselled and tested with their partner (Medley & Kennedy, 2010). Unfortunately, non-disclosure of HIV positive status by the pregnant woman to the father of the baby was associated with later initiation of ARVs for the woman, and usually at a more advanced HIV disease stage, according to the results of a study that included all HIV infected women delivering in France between 2005 and 2007 (Jasseron et al., 2010).

Auspiciously, a study conducted in Ethiopia among women and men attending HIV services at a university hospital in 2007 showed that 90% of participants had disclosed to their current partner and only 5% reported any negative reaction from the partner (Deribe, Woldemichael, Wondafrash, Haile & Ambebir, 2008). The authors in this study concluded that programmatic and counselling efforts should focus on mutual disclosure of HIV test results for optimal benefits. This study therefore suggests a useful role that promoting couples counselling can play in facilitating timely disclosure of HIV positive status.

In a similar university hospital setting, a more recent study that focused entirely on HIV positive pregnant women in Nigeria revealed that 97% had disclosed their status, 90% of them to their husbands, and the partners' reactions were supportive and understanding in all the cases. However, being single and having low educational status significantly increased the likelihood of non-disclosure (Igwegbe & Ugboaja, 2010).

Encouragingly, a prospective study conducted in the Midwestern USA on HIV positive women attending an AIDS Trials Unit between 2001 and 2004 showed that cases of regret after

disclosing to sexual partners were low at 8.6% of respondents, and the authors pointed out that disclosing one's serostatus eliminated hiding complicated adherence rituals required for treatment of HIV (Serovich, McDowell & Grafsky, 2008). These results imply that while at the time of disclosing a woman would undergo stress, ultimately disclosure is liberating.

In conclusion, Norman et al. (2007), assert that describing and analyzing the decision making process before disclosure of HIV infection, as well as the event itself within the wider socio-political context, is an essential step in designing effective interventions that will facilitate an increase in the rate of disclosure.

### Summary of the literature

Disclosure to partners by PMTCT patients is hampered by fear of negative consequences shows that which makes it a highly stressful event. The literature however shows that in the greater majority of cases, HIV-infected women actually experience positive outcomes related to disclosure while non-disclosure is related to poorer HIV care outcomes. While the rates, barriers and facilitators to disclosure have been well documented, very little information in the literature was found related to the *timing* at which PMTCT patients disclose their status to their partner. The literature reviewed considered the timing of disclosure as a key part of the process, which needed to be investigated longitudinally as there appeared to be key moments during which women disclosed. PMTCT programmes should innovatively assist women to disclose under conditions affording them maximum control over its timing, mode, and impact. Cases of regret after disclosing to sexual partners were low implying that while at the time of disclosing a woman would undergo stress, ultimately timely disclosure is liberating and is a worthy subject of more research.

## CHAPTER 3:            **METHODOLOGY**

### **3.1     Aim of the study**

The **aim** of this study was to identify and describe the experiences, specifically in relation to the *timing* of disclosure by PMTCT clients attending KHC in Lusaka for whom disclosure *has* been possible. In gathering these insights together it is hoped that the PMTCT programme will then be able to improve the support it offers to its future PMTCT clients as it encourages them to disclose their HIV status to their partners.

### **3.2     Specific objectives**

The **objectives** of the study were:

1. To explore with PMTCT clients attending KHC in Lusaka, who had disclosed their HIV positive status to their male partner, their experiences of the disclosure process – and particularly the decisions they had made around the *timing* of their disclosure.
2. To explore with these PMTCT clients how they believed the PMTCT programme could provide clients in the future with the necessary support to facilitate such disclosure.
3. To develop a set of recommendations that could contribute to the provision of more effective and on-going support for PMTCT clients attending the KHC in relation to the disclosure of their HIV positive status to their partner.

### **3.3     The study design**

This was an exploratory, descriptive study that used qualitative research methods. Given that the study aimed to explore the experiences, and specifically the timing and strategies used, by women participating in a PMTCT programme in disclosing their HIV positive status to their male sexual partners, a qualitative methodology was considered most suitable. As Pope and Mays (1995) suggest, qualitative research designs are best suited to research that aims to explore health behaviours and peoples' beliefs and also how people experience phenomena. The motivation for this study design was that the issue that was being explored is a highly personal experience, potentially perceived in a unique way by each respondent. As noted in the literature

review, disclosure of HIV positive status to partners by women attending PMTCT services can be a highly stressing personal experience, and the design suited to bring out this was by using the design utilised in the present study.

### **3.4 Sampling**

The study population was defined as all HIV positive women who knew their status and had disclosed their status to their partners, in the catchment area of KHC. In addition, these women needed to be attending the PMTCT service at KHC at the time of the study: either as part of ANC or had been attending PMTCT and had delivered and were now continuing to attend the clinic for growth monitoring and health promotion services for their baby.

Sampling was done purposively to include 10 women in the PMTCT programme who were attending ANC and 5 who had delivered. These numbers were chosen after the researcher consulted with the KHC manager who advised that these were the proportions of PMTCT clients that were normally seen at the centre. The initial plan had been to include in the study sample women whose babies were being attended to at the age of 9 months when they were routinely reviewed for HIV retesting and monitoring of infant feeding practices. This however was not possible to do as no respondents fitting this criterion - and who were willing to take part in the study - were identified. In the end, 11 pregnant women and 4 women who had given birth were included in the study. Within the sample of 15 the researcher attempted to obtain a range of experiences and circumstances (for example, in terms of age, length of relationship with partner, whether married or not, and whether this was a first child or not).

In terms of establishing the sample the PMTCT focal point nurse was requested to identify women who had disclosed their HIV status to their partners and who were scheduled to attend the KHC for the 3 types of PMTCT consultations within a given time period (either as part of ANC; had delivered and were now continuing to attend the clinic for growth monitoring and health promotion services for their baby; or had come for a review visit for ARVs). The PMTCT focal point nurse was asked by the researcher to introduce and explain the purpose of, and the processes involved in, participating in the study to PMTCT patients that were eligible to participate in the study. For those that expressed a willingness to participate in the study, a

separate appointment was set up with these clients with the researcher. Clients were approached sequentially as they came for their appointments during the study period. The PMTCT focal point nurse did not experience any woman who met the selection criteria, and declined to participate in the study.

In addition to the above, 5 health workers associated with the PMTCT programme at the KHC were requested to participate in the study so as to obtain their perceptive and experiences on the issue of HIV disclosure amongst the women attending PMTCT services. These were the ANC PMTCT focal point nurse, 2 PMTCT service providers (who are both nurses) and 2 lay (community) PMTCT counsellors attached to the health centre. The lay counsellors were community members nominated from the community and trained by the health centre to help in counselling women on PMTCT at both the health centre and within the community. The 5 health workers included in the study comprised the full complement of technical staff in the PMTCT services ( the only other associated staff were 2 cleaners and a guard)

### **3.5 Data collection methods**

The data collection method used was in-depth, individual interviews with both the 15 PMTCT patients and the 5 health care workers.

In terms of process, once the PMTCT focal point nurse had identified the appropriate women, the researcher met with each at the KHC at a time that was convenient for them. After the purpose and procedures of the study had been re-introduced to them by the researcher (see Appendix 3 [*Participant Information Sheet for Clients*]) and they had been given information about the consent procedure – and if they voluntarily consented to participate in the interview (see Appendix 1 [*Informed Consent Form*]), the researcher proceeded with the interview. None of the women presented to the researcher by the focal point nurse declined to be interviewed after going through the purpose and procedures of the study. All the women were interviewed using a semi structured interviewed guide (see Appendix 4 [*Guide for Interviews with Women Participants* ]) that included background demographic information such as age, marital status, number of previous pregnancies, number of living children and educational level attained. The women were then asked about the timing of when they disclosed their HIV status to their partners and their reasons for disclosing at that time. The women were additionally requested to

narrate in detail the disclosure process – including describing the strategy they used to inform their partner – so as to ensure that rich data was obtained. In addition, interviewees were also asked to suggest how they thought the PMTCT programme could best assist other women to disclose their HIV status to their partners.

Interviews were conducted in a separate room in the facility to ensure privacy and confidentiality and each lasted about 40 minutes to 1 hour. The interviews were conducted in the language each woman was most comfortable with, namely, English, Nyanja or Bemba. The researcher is fluent in all 3 of these languages and therefore did not need any translation. After seeking permission from the interviewee, and if she was in agreement, the interview was tape recorded and later transcribed. The researcher would then inform the interviewee that he might need to meet her at a later date if any further clarification was needed. The researcher personally conducted the interviews, recording transcription and translation.

The purpose and procedures of the study were individually introduced to the 5 PMTCT health workers by the researcher (see Appendix 2 [*Participant Information Sheet for Health Workers*]). They were each interviewed using a semi-structured interview guide, focussing on their perceptions of what proportion of the women attending PMTCT services at the health centre were able to disclose their status to their partners and *when* they generally disclosed their HIV status to their partners; what support they provided to the women in terms of HIV disclosure, and what key challenges they faced in providing such support (see Appendix 5 [*Guide for Interviews with Health Workers*]). Interviews for key informants were conducted in English and lasted between 30 – 60 minutes, after obtaining signed consent (see Appendix 1 [*Informed Consent Form*]). Permission to tape record and later transcribe these interviews was sought from them. In reflection, while the sampling was intended to provide responses from women with a variety of experiences, the respondents were largely women in stable marriages. This was noted, but unfortunately on this variable, the duration of the study period and the resources available to the researcher could not allow for the purposive search for women meeting the inclusion criteria, but selected for their relationship status, or having disclosed more than a week or longer after getting tested or HIV. This limitation may have implications on the results because the women included in this sample appear to be in a stable relationship, which has a positive impact on the ease of disclosure to the partner. This is an opportunity that future research would do well to

systematically investigate.

### **3.6 Validity and trustworthiness**

Validity within this study was sought by conducting interviews with both women attending the PMTCT programme and health workers working within the PMTCT programme. Obtaining information from two sources enabled the researcher to corroborate the information gathered from both perspectives. Such a process is referred to as *triangulation* and is regarded as a validity procedure where convergence can be sought by using different sources of information (Creswell & Miller, 2000). The eligibility criteria were strictly followed, and the interview guides were adhered to in order to maintain uniformity of the questions posed to all the participants. The data gathered in this study was also be considered in relation to what has been found through a review of the literature related to HIV disclosure in the context of PMTCT programmes in similar socio-economic contexts.

The researcher endeavoured to maintain reflexivity by maintaining a detailed journal, showing the chronology of events, as well as a narrative of his thoughts and observations during the study. This journal was used to facilitate an audit trail, as to when major decisions during the research were made, and for what reasons. The journal also assisted in checking the researcher's personal beliefs that might have encroached on the findings of the study. As Creswell & Miller (2000) have suggested: a qualitative researcher needs to be reflective, and disclose what they bring to the narrative. The researcher sought the reactions of the PMTCT health workers to the findings that emerged in order to help refine explanations, and potentially validate the findings, although the appropriateness of this as a validation method has been questioned by some commentators on qualitative research (Barbour, 2001). The researcher also maintained a thick, rich description of the setting, participants and the themes that arose during the analysis as a means of establishing credibility.

### **3.7 Data entry and analysis**

Analysis was conducted concurrently with the collection of data - which essentially comprised the interview transcripts. This sequential analysis has the advantage of allowing the researcher to go back and refine questions, develop hypothesis and pursue emerging avenues of enquiry

further (Pope, Ziebland & Mays, 2000). From this data, the researcher began eliciting recurring themes on the actual experiences and perceived processes and strategies that had been used and the timing of HIV disclosure to partners by women in the context of PMTCT – and the practices and concerns of health workers who were providing HIV disclosure support to the women.

The information obtained from the health workers assisted in developing the context, refining explanations and the collaboration of findings. The interviews with health workers were used to identify themes, to form categories into which they fitted, and assist in bringing meaning to the participants' responses which in turn formed the basis for thematic analysis. This procedure is supported in the literature, as it allows for the preservation of the data in its contextual form, which can then be indexed to develop analytical categories and theoretical explanations (Pope, Ziebland & Mays, 2000). The analysis report was prepared in the form of a summary of the main themes, and was analysed further in relation to the profile of the individual participants, with additional reference to the researcher's review of the literature relevant to the issue under investigation.

### **3.8 Ethical and legal considerations**

Authority to conduct the study was obtained from the Zambian Ministry of Health, Directorate of Public Health and Research, the District Director of Health for Lusaka and the manager of KHC. The Senate Research Committee of the University of the Western Cape provided ethical approval for the study on 21<sup>st</sup> February 2011.

Participation in the study was purely on an informed and voluntarily basis. Potential participants were each provided with a verbal explanation of the purpose and process of the study. This explanation was accompanied by a written information sheet that each potential participant was given (Appendix 2 & Appendix 3). Their consent was then sought and a consent form (Appendix 1) was then made available for them to sign if they were willing to participate in the research study. Given the nature of the research, it was unlikely that participants perceived the research as threatening. All interviewees were informed that if they decided not to participate, it would in no way jeopardize their access to health care (for the HIV positive women) or their position and responsibilities within the PMTCT programme (for health workers) for the key informants. It was anticipated that the research would cause no harm to the research participants.



However a trained counsellor from the clinic was available in case any of the participants required emotional support or counselling as a result of their participation in the research interview.



## CHAPTER 4: RESULTS

### 4.1 Introduction

This chapter presents the results from the interviews with the 15 HIV positive female participants, all of whom were part of the PMTCT programme, and the 5 health workers at KHC. The results describe the perceptions and opinions of the respondents on the timing of an HIV positive status disclosure to male partners by pregnant women. The results reveal the HIV positive respondents' suggestions around the preferred time of disclosure to male partners, the motivations for early disclosure, the perceived disadvantages of late disclosure and their reflections, in hindsight, about their own disclosure experiences. In order to facilitate early disclosure the results also highlight the support that women suggest they would need from health workers in this regard. Additionally, the results bring out suggestions that would help health workers and the clinic management enhance their ability to help women time their disclosure in a manner that would benefit their baby, themselves, and their male partner.

### 4.2 Description of the respondents

The selection of the participants was based on women attending the KHC who had been tested and found to be HIV positive during a pregnancy, and had disclosed their HIV positive status to their male partners. The background information of the women who participated in the interview is shown in the table below:

Characteristic	Category	Number of women (n=15)
Age	< 15years	0
	15 – 24 years	5
	25 – 34 years	7
	35 – 44 years	3
	> 45 years	0

<b>Education</b>	None	1
	Primary	5
	Secondary	7
	College/ University	2
<b>Marital status</b>	Never married	0
	Married	14
	Divorced or separated	0
	Widowed	0
	Staying Together	0
	Has a boyfriend but do not stay together	1
<b>Duration of Marriage<sup>2</sup></b>	0-4 years	1
	5-8 years	3
	9-12 years	2
	>12 years	2
<b>Parity</b>	0	3

<sup>2</sup> Duration of marriage was not recorded for 7 of the 15 women, and 1 of the women was unmarried but had a boyfriend.

	1 child	2
	2 children	2
	3 children	6
	>3 children	2
<b>Stage of pregnancy</b>	1 - 3 months	2
	4 - 6 months	7
	7 - 9 months	2
	Already given birth	4
<b>Age of baby if given birth</b>	0 - 6 days	0
	7days - 6 weeks	2
	7weeks - 6 months	2
	7months - 12 months	0
	12months +	0
<b>Number of ANC visits</b>	1 visit	2
	2 visits	3
	3visits	6
	4 visits	4

During the 20 days allocated to data collection in the study period, 15 women participated, whose age range was from 20 to 37 years of age. There were no women who fitted the criteria and were aged below 15 years or above 45 years, during this period.

The majority of the women were married (14 out of 15) for a duration ranging between less than 1 year to 20 years. One woman reported being engaged and was staying with her partner's relatives while she looked for her own house. None of the study participants were divorced, separated, widowed, had never married or were staying together. This may be consistent with the view that women are likely to disclose if they are in a stable relationship as suggested by Igwegbe & Ugboaja (2010).

Ten out of the 15 women were pregnant, 3 of them being in their first pregnancy, while 4 had already given birth (with their children ranging from 1 week to 6 months of age). This afforded the study a chance to obtain experiences and perceptions from HIV positive women across a wider spectrum: covering early pregnancy, having recently given birth and bringing up a child born from a pregnancy in which the woman had known she was HIV positive. All the women who had given birth had attended ANC 4 times. This is consistent with the WHO recommendation for limiting ANC attendance to 4 visits and the stated aim of the Zambian PMTCT Protocol Guidelines to fit PMTCT services within this schedule to avoid burdening HIV positive pregnant women with extra visits to the health centre (Ministry of Health of Zambia, 2010).

Four of the women had known their HIV positive status prior to the current or last pregnancy (and an additional woman who had been informed in a previous pregnancy that she was HIV positive but had declined to accept the HIV test results as true at that time). This perhaps reflects the recognition of the continuing sexual and reproductive lives of women who have been diagnosed with HIV: a subject of advocacy that a woman's right to continued sexual and reproductive health should be independent of her HIV status (International Community of Women Living with HIV/AIDS (ICW), 2008). No further enquiry was made by the researcher as to whether the pregnancies (after knowing their HIV positive status) were intended or not as this was out of the scope of the present study. Five of the respondents reported having had a child

who died at an age of less than 1 year. Again, an in-depth enquiry into the causes of these deaths was not made as it was beyond the scope of this study.

All the respondents had only attended ANC at KHC during the current pregnancy - or the last pregnancy for those that had already given birth. All the respondents had been tested for HIV on their 1<sup>st</sup> ANC visit and told their HIV positive status. This may reflect a tendency by HIV positive pregnant women to continue with ANC at the same health centre; therefore an opportunity to receive both pregnancy and HIV care in a facility without having to start explaining their situation at subsequent visits or to familiarise themselves with how services are offered.

Five health workers providing PMTCT services at KHC were also interviewed as part of the study – as key informants. This included the ANC PMTCT focal point nurse, 2 PMTCT nurse service providers and 2 lay (community) PMTCT counsellors. The nurses' role is to provide group health education to ANC attendees, HIV individual and couple post test counselling, testing, dispensing of ARVs and following up of mothers and babies to facilitate maximal benefit from PMTCT interventions. When mothers bring their male partners to the clinic either for couple counselling or for partner testing, they are usually attended to by the nurse. Two of the nurses had been working in the PMTCT programme in KHC for 5 years, whilst the third one interviewed had been working there for almost 2 years.

The nurses are supported by lay counsellors who are attached to the health centre and whose role is to conduct individual and couple pre-test and post-test counselling for HIV within the maternal and child health department (MCH). The 2 lay counsellors at the health centre who were interviewed have been involved with the centre's PMTCT program for slightly over 1 year since being seconded from an NGO.

The data that follows is from the 15 respondents and, where appropriate, data was included from the key informants' interviews in order to give context to the experiences of the 15 HIV positive respondents.

### 4.3 Women's opinions and perceptions about disclosing HIV positive status to partners

To establish the context, health workers were requested to highlight the current practice at KHC in relation to disclosure:

*In terms of HIV result disclosure, when we see women in the ANC, and they are tested for HIV, during post test counselling, we ask them whom they are going to tell the result to. Women usually say they will tell the partner, and we also tell them that they need to tell the partner, because that is the person they are most closely involved with, and in the immediate term, and even in the long term, it is him who will be involved in the care of the baby, including supporting the woman in her choice of the infant feeding options, so we actually encourage them to tell the male partner.*

*(Health worker no.2)*

In order to gain some perspective, the health workers were asked about what they felt was the proportion of HIV positive pregnant women who disclosed to their partners. The health workers suggested that in their experience between 3 and 5 (out of every 10) HIV positive pregnant woman reportedly disclose their status to their partner:

*I can say, maybe 3 out of 10, or maybe 5 out of 10 tell the partner that they are HIV positive.*

*(Health Worker no.1)*

*I would say it is fifty-fifty... I would say about 50%*

*(Health worker no.2)*

This proportion is consistent with the findings by Semrau et al. (2005) in Lusaka, Zambia.

All 15 women interviewed stated that it was very important for a woman to disclose her HIV positive status to their partner as soon as she knew her results:

*Yes, so that he also knows. And then when he knows, he also needs to go, so that he knows how his HIV status is. So that he also gets help and he knows how his status is.*

*(Respondent no.1)*

*When a pregnant woman learns that she is HIV positive...exactly she must tell her partner. When I was tested and found to be positive, I was told to be using protection. Now when you don't tell your partner, how will you use protection? You kill yourself. So you have to inform your partner, so that you even find a solution. How are we going to conduct things, how am I going to protect you (the partner), the baby, and myself.*

*(Respondent no.2)*

*Now, if I don't tell him, and he wants...the way we have been living, and then I tell him that no, we have to use condoms, he will ask me, why?*

*(Respondent no. 2)*

Whilst the majority of the women felt it was appropriate to give prior notice that they were going to be tested for HIV at the ANC, 2 of the 15 women dissented about informing partners, as they felt that male partners would just discourage them from testing, or would question their motivation:

*I don't have to tell him. You know men are on the side of saying...let's wait, why you have to do it now. Its better you just know, and then you go and tell him.*

*(Respondent no.2)*

All the respondents stated that they were aware that HIV testing would be performed routinely at the ANC.

#### **4.4 Perceptions on the best time for disclosure**

Health workers had experienced a range of times when women disclose to their partners:

*In my experience, in terms of timing of disclosure to partners, some women disclose as soon as they know their results, especially if you (the health workers) encourage them to go and tell their husbands... Some women will wait, because she has not emotionally prepared herself to tell the husband. Some will not disclose their results, because... they feel that the husband will leave (abandon) them.*

*(Health worker no.1)*



*And the other part (apart from immediately) where they disclose much is after delivery, they have tested, and then the baby is withdrawn from all exposures, to being exposed to the HIV, and they know that baby is HIV free, and then they will tell the partner...that I am HIV positive, the baby is HIV negative, I did this and this...this is the time of disclosure. So these are the times and reasons for disclosure at those particular times, because they are much appropriate for them because, (counting on fingers) (1.) They avoid re-infections, because they know this will increase their exposure, and then (2.) Also when they know that the baby is now HIV free, this man won't be very upset with me, because at least I have managed to do something... I managed to prevent the baby from being infected....which someone (partner) can say ah! At least you did the best... than when the baby becomes HIV positive (is infected) that's when the challenge now comes in.*

*(Health worker no.2)*

The term 'immediate disclosure' was used in this study to describe the period of time where an HIV positive pregnant woman disclosed her test results to her male partner on the *same day* she learnt of her test results – *and up to and including a week* after she received her test results. The idea of extending the time frame of 'immediate disclosure' to beyond that same day for a week after the event came about because some of the women respondents described how, even though they felt that their disclosure could be described as 'immediate', they often needed a little more time to assess their partner's mood before disclosing the news to him. This delay, from returning home and telling him the HIV test result immediately, sometimes necessitated waiting a few days:

*What is better, is (to) tell him when you are still pregnant, right there and then when you are told your results...you should not let even a month pass (with emphasis)! Like me, I let 4 days pass, I was just looking for a way to enter (into the issue)...because it is better from there you both know the way forward...considering that us we have been found with HIV, what are we going to be doing, are we going to be having unprotected sex, or what are the options....for having other children. You have to give him about two days before you tell him and to compose yourself.*

*(Respondent no.9)*

*Okay, you don't just go and start shouting, or if he is in a bad mood from work. Its better you wait, even some days, Then he is okay... you tell him. But not waiting until more time (than that) has passed.*

*(Respondent no.6)*

*So I remember a week passed, I remember it was a Saturday, I can never forget, and/so he was off duty. So I told him, Daddy, there is an issue we have to discuss, from the clinic. So he told me to say what it was. I asked him that won't you get annoyed, or maybe you will make me pack up and go. He said no, and I told him my blood was found not to be fine...so do they want me to go also? I said, yes, they allow going together, so that you (we) both know your (our HIV) status together...so they asked him... you did not beat her, he said... no, because even if she told me that her tests were negative on the day she came to the clinic, the questions she kept asking me over the next days about HIV between me and her were rather puzzling, until she finally told me... So with me I didn't waste time I told him my results just when I knew them.*

*(Respondent no.9)*

All but one of the respondents disclosed either on the same day she was told she was HIV positive, or within a few days. The majority of the women identified the period soon after being tested during the pregnancy as the opportune time to disclose to male partners:

*The worst time to tell your husband that you have HIV, is when you don't tell him that you have been found with HIV...when you keep it to yourself (carrying it as a burden on your back) , you start taking ARVs without saying anything and you even have the baby born... and then he finds out (that you have known you are HIV positive for a long time), he will not understand... he will believe you have had HIV for a long time, and you had your own bad reasons for not telling him*

*(Respondent no.1)*

*When timing the disclosure, the earlier the better, and the easier. ..because if you decide to tell him later, maybe some months, ...like...us women we have got different types of blood...maybe you develop some different kind of diseases...before you have expressed*

*yourself to your partner that you are like this....so it is better you tell him early, so that when you develop something like a rash, he also has that experience that maybe it is the CD4 count which has gone down and you need to start your treatment.*

*(Respondent no.3)*

*It becomes more difficult to disclose the more time you allow passing...and the burden is heavier on you as a woman. The burden is heavier you are just wasting time, and the viruses meanwhile are increasing, and maybe you even begin getting sick. When you delay in disclosing your status, and tell your partner after months have passed, or you have given birth, it will appear to your partner that you did not take the issue with the seriousness it deserves, and he will just ask you why you are bringing such topics again*

*(Respondent no.4)*

The respondent who had not disclosed immediately stated that she had not accepted the HIV test results and when she had a miscarriage a month after the test she felt no imperative to disclose. She did however disclose her HIV positive status during a subsequent pregnancy - within days of undergoing another HIV test during antenatal care.

When the health workers experience is added to the context, the findings parallel the findings by Brou et al. (2007) who described 3 peak times of disclosure starting from just before delivery; the time of weaning the baby, and resumption of sexual activity. In the end, it is difficult to find a single particular reason why each woman chooses a particular time to disclose. One health worker may have given clarity to the situation when she said:

*I am not too sure why women choose certain times to disclose as against other timing. It may have to do with emotional acceptance/preparedness.*

*(Health worker no.1)*

#### **4.5 Motivation for the immediate disclosure of an HIV positive test result**

##### **4.5.1 A liberating experience**

It appeared that disclosure was perceived and experienced as a liberating experience. Most respondents felt any delay in disclosure was an unnecessary burden for the woman to be carrying alone: *Even me (as a pregnant HIV positive woman)...will (feel) free. Because if I don't tell him, something will keep haunting me...that I am hiding something very big.*

*(Respondent no. 7)*

*The worst time to tell your husband that you have HIV...is when you don't tell him that you have been found with HIV...when you keep it to yourself...carrying it as a burden on your back.*

*(Respondent no.1)*

*For us women, it is a good opportunity when you are pregnant, you are tested, and you find you are positive, to share the information at that time with your husband, because it is always worse if he goes and finds out somewhere else, or at another time, that he is HIV positive, when with you, you have known for a long time. That is when marriages end just like that,*

UNIVERSITY of the  
WESTERN CAPE

*(Respondent no.1)*

#### 4.5.2 A sense of responsibility towards others

Respondents noted that the woman is usually the first person to know that she is HIV positive, through getting tested at the antenatal visits. Some respondents felt that their prime responsibility was to protect their baby from being infected with HIV:

*When I have told him (the result), then (it) becomes more easy for me to take ARVs, and we can use condoms, which means I am protecting the baby from HIV. When I don't say (disclose)...it is a problem even to take the ARVs, and maybe then the baby will be sick.*

*(Respondent no.4)*

Immediate disclosure facilitated the initiation of HIV care for the couple, and was felt by the women to be part of their responsibility:

*For the two of us, with me when I know my results, and I tell him, it means he can be tested also and if we have to start drinking (taking) the ARVs, then we can start because we both know. Not... you just go on without telling your friend*

*(Respondent no.4)*

Interestingly, another motivation that emerged from the interviews was the possibility of being able to give birth to an HIV negative baby even if one was HIV positive. Some respondents were aware, through their continued engagement with the PMTCT programme, that HIV positive couples had given birth to HIV negative babies: :

*What is more, even me I have seen mothers here, who are positive, and the baby is now big, and is negative. Even me it can happen.*

*(Respondent no.2)*

#### 4.5.3. Early disclosure as an imperative

A significant theme emerging from the interviews was that about half the respondents felt that a woman who was diagnosed HIV positive during pregnancy had an important obligation to immediately disclose to her male partner because it simply ‘had to be done’. This was relayed as a sense of duty and that delaying disclosure was equated to “killing your partner”. Such bold imagery was used because, as one of the respondents suggested, knowing your status as a woman you were then able to access treatment and if your partner remained ignorant of this, and possibly his own HIV positive status, he would not then be able to access the equivalent treatment. One respondent even went so far as to suggest that immediate disclosure had to be done despite a possible adverse or negative outcome from the partner:

*Even for those men who have a bad temper, who are always annoyed...the temper will come down eventually...they need to be told the results by the wife, instead of silently killing him because ...even if he gets annoyed, he will be annoyed for one day or two days, but in the end he will realize that...this disease has come, it is there...it is among us.*

*(Respondent no.2)*

#### **4.6 The role of the couple’s relationship in disclosure and its timing**

Despite the feeling amongst most respondents that there was a moral imperative to disclose to one's partner, it was suggested by some respondents that the likelihood of disclosure to a partner also depended on the *type* of relationship that exists between a couple. A third of respondents felt that a poor relationship with a lot of misunderstanding and a prior history of fighting leaned itself to non disclosure or a delayed disclosure.:

*And also, the person that he is...will also determine whether the woman will find it easy to disclose or not. There are men, who...everything you say is wrong. Everything you say doesn't make sense...he is never in the wrong (according to him). You are always the one who is in the wrong, so such a person, it is difficult to tell them anything... a person who cannot look inside themselves, even when they are wrong, it is very difficult to deal with such a person, whereas the other person who can sit and reason, with you at such a time, it is easier to deal with such a person.*

(Respondent no.1)

Another response refers to alleged lack of faithfulness:

*If she can't say, then she knows. She knows she has been jumpy, and now, if he is negative, it will end, she knows it's the end.*

(Respondent no.4)

*Some men are just difficult...he is always against everything. Even a small thing you are always fighting. Now how do (can) you tell him? Your ears don't know any peace (you have never experienced peace/ you are always in turmoil). Its better you just stay (without disclosing).*

(Respondent no. 11)

The view that immediate disclosure was essential was thus tempered by a woman's understanding of the type of relationship that existed between her and her partner and what would be best in terms of timing:

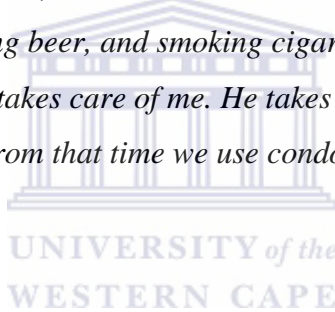
*No, I don't have to tell him just because I have to. It's me who knows how we live, and it's up to me who knows my friend and how we stay. I have to wait until ...the way I know him that he will understand.*

(Respondent no.3)

#### 4.7 Experienced benefits of early disclosure

All the respondents reported beneficial outcomes of early disclosure. Reported benefits included assistance with adherence to ARVs by being reminded at the time they were due to take them, and the dates for their subsequent visit to the clinic. Thirteen of the 15 women reported, as a result of their disclosure, improved health practices by their partner including that they then got tested for HIV, and in two cases, the male partners having quit drinking and smoking. Some of the benefits as reported by the women were as follows:

*The benefit I have found in choosing to tell him at that particular time is that since that time he has stopped drinking beer, and in the house, there is peace now...he has taken it well, and I even came with him, and he was also tested. Since we knew our results, as I said, he has stopped drinking beer, and smoking cigarettes, and he never made me suffer. He looks after me well and takes care of me. He takes care of me in that we protect each other, by using condoms. From that time we use condoms.*



(Respondent no.1)

*As I said, with me I told him as soon as I got the result. The timing I choose tell him, the benefit I have had is that I don't have the burden of hiding (my status/the services / medicines I am getting). Even when I came for review, I told him that my CD4 count has been found low, so I have to start treatment. His response was to say that he needs to get his CD4 result quickly also, so that if need be, he can start the treatment also.*

(Respondent no.7)

*Actually I phoned him, from just the antenatal classes, I told him (the result) over the phone. So he said...No, we will come and talk at home so when we reached home, again we talked...it has actually benefited me a lot because, you know, my husband was never keen to go for a test, but when I told him my status, and told him he also needs to go and get tested, he agreed and he has done it.*

(Respondent no.13)

*The benefit for me...even when I forget to take my medication, with the time –keeping, he reminds me. He is always on time, and he has now even set my phone, without me knowing. Every day at 21: 15 it rings. Generally he has taken it very well, even though he is dilly-dallying with testing for HIV. I am breastfeeding the baby, and he is the one who actually gives the baby the Nevirapine (ARV for prophylaxis). So looking back, the time I chose to tell him was the best and that is the way I would do it again if I had to do it all over.*

(Respondent no.14)

*My partner, he was hard to convince, so I kept telling him that even when you have some fever, some headache, it is better you know what is causing it...when you get tested, you will be given the right medicine, and you will even stop thinking too much. This would improve your health. Last week, with prayers... you(have to) put him into your prayers, I came from church and then he just told me that tomorrow, escort me to the clinic so that I get tested...I thanked God, that to lift this man just from this house to go and get tested, for him to know what is health is like, it has taken so much. That is when we came to the clinic and he was found to be positive.*

(Respondent no.5)

*And when I told him, he just sat very quietly...and then he said, okay, then tomorrow, I also need to go and be tested...He was not upset/annoyed...he can't be upset...unless it had been me who had been being naughty (ku samvela), but he knew it was him. If it had been me, maybe I would have been looking for a roundabout way of telling him/ lying to him that because of this and this we need to go to the clinic so that we are tested... but I knew it was him who had put me into trouble so I just told him. After I told him the result, we still stay well. He never made me suffer or abused me. Just 3 months after I told him, he began getting sick. He was checked for TB at the clinic, they didn't find it. He didn't improve for another month, and when we were referred to UTH (University Teaching Hospital), they told us that he had TB, and he needed to be treated for that, and not only the ARVs. He was actually admitted into hospital for a month. So how we stay...we just*



*stay well ...maybe in future that is when things will change (for the worse), but for now we are staying well.*

*(Respondent no.11)*

In reflecting on the timing of disclosure they chose, 14 of the 15 women stated that in hindsight they felt they chose correctly by immediately disclosing. The one respondent who disclosed her status in a subsequent pregnancy regretted not having done it immediately when she learnt she was HIV positive when she had a prior pregnant . The following quote illustrates how one of the respondents described the benefits of disclosure and how it introduced a positive element into her relationship:

*To me, the time I choose to tell him, that is, as soon as possible after knowing my result, was the best time...The way I have seen it between me and my partner, I see that our love has grown, more than before. This is after I told him my result, and he also tested for HIV. I see that our love has progressed more, than the way we used to stay before...because he is more considerate...he is different from the way he was earlier. Even earlier he used to make me happy, but then after that again he upsets me, but now he is more considerate (laughs).*

*(Respondent no. 12)*

#### **4.8 Role of health workers in timing of disclosure**

Almost all the respondents felt that health workers had a role to play in assisting HIV positive clients with the process of disclosure.

##### **4.8.1. Providing counselling that encourages immediate disclosure**

The women felt that counselling for HIV testing of pregnant women at the first ANC visit needs to include the encouragement of an immediate disclosure, and information about re-infection, getting the partner to test, and taking of ARVs consistently, with the support of the partner. In addition, respondents suggested they could play a mentoring role in relation to other women like themselves:

*The health workers, they help us, they do everything. It's only ourselves as women who do ourselves a disfavoured by refusing to immediately going to disclose...maybe us fellow women should talk to other women about telling their partners.*

*(Respondent no.3)*

The health workers reported that they do emphasize to women the need to disclose their HIV positive status to their partners so as to avoid re-infections. They felt that the first step to avoid re-infections is by immediately disclosing which allows, amongst other things, for the couple to practice safer sex through the use of condoms:

*The women understand, especially for re-infections...you explain, and they understand. It helps them know that they have to discuss with the husband.*

*(Health Worker no.3)*

Innovatively, health workers at KHC have set up a system where pregnant women that test HIV positive and express misgivings about their ability to go and disclose their results, are encouraged to invite their partners to the clinic and then undergo couple HIV counselling and testing. The results are then given to the couple, with the woman pretending to take an HIV test for the first time as well. The health workers felt that the benefits of facilitating timely disclosure by using couples counselling and testing far outweighed the extra cost and effort in repeating an HIV test for a pregnant woman who already knew her status from a previous test.

Further, the respondents felt that the PMTCT clinic is the best place for partners to also be tested for HIV and to commence treatment if found eligible:

*It would be advantageous for partners to be accessing all their HIV services here, together at this clinic, and especially in MCH, because the workers here already know the background to our story, rather than to go and start explaining to someone else again.*

*(Respondent no.8)*

#### 4.8.2 Specific support from health workers to women on timing the disclosure

Interestingly, when the women were asked a direct question about the *specific support* health workers can provide to a woman to *time* her disclosure, the majority were cautious, and it appeared women preferred to **own** a major role in determining the **timing** part of the disclosure process. As in the earlier results shown, women agreed about the need for disclosure, its benefits, and they described being given adequate information, followed up, couple counselled with their partners and “being made strong” as the support they would expect:

*Concerning who should help a woman with the timing of disclosure...I think it is only up to the woman, like for me, if I fail or feel I can't manage to tell my partner, it is for me to say the words... to take it out and tell the nurses, or the doctors who give me medicine, that with me, it is difficult to disclose, my man is difficult, I want you to help me...I will tell them the words to go and say.*

(Respondent no. 5)

*Well health workers to help with the timing... because some women cannot disclose to their partners. And some men, even when they know that they are the ones who brought the problem, they will seek to blame the woman...so the health workers should give the counselling, and information about re-infections, so that women tell their husbands early.*

(Respondent no.12)

*I think the health centre can help by making follow-ups. Like, I know my results. You need to get contact numbers, phone, continue counselling, because it is not an easy issue...it is not everyone who can just go home and say...let me tell him. And also, women need to be trained by the health workers, how they should talk to their partners, because sometimes you might say...quite okay, I am innocent...am not part of this, he is the one who gave me... then you just go and start shouting at him. That is bad. So the best is counselling should be effective, with follow-ups even the following day and afterward. Women need to be sensitized as to how they should address issues to their partners.*

(Respondent no.7)

*Pregnant HIV positive women need to be encouraged by the health workers here just after they test them that you need to go and disclose you results to your partner. She*

*needs to be strengthened just there to go and tell as soon as possible and even bring the partner...it makes things easier.*

*(Respondent no.8)*

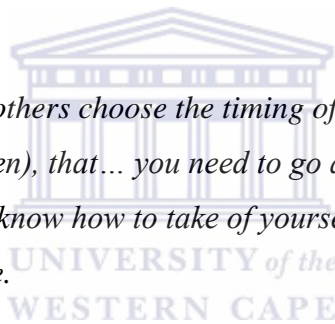
*The way health workers at the centre can help women time with the disclosure and the time to disclose...what is good here is that just the time we come for antenatal, when a woman is fearing to go and tell her partner...it is better she tells him that they come together and they are tested together and told the result.*

*(Respondent no.13)*

*The people who work at the health centre, they make us strong, which is the best way of helping and supporting disclosure.*

*(Respondent no.4)*

*Health workers can help mothers choose the timing of disclosing their HIV positive results, by telling (the women), that... you need to go and share your results with you husbands...so that you can know how to take of yourselves and you heath, as a couple and as a family/in the house.*



One respondent went further and stated that:

*There is not much which helps a woman decide that this is the right time to disclose my HIV positive results*

*(Respondent no.1)*

Another respondent who agreed about the important supportive and informative role that health workers could provide in relation to disclosure, had this to say in relation particularly to *choosing the timing* of disclosure:

*Some of these things are between two people. An outsider can't know. Even them (health workers) they have to let **me** decide.*

*(Respondent no.15)*

From the health workers perspective, they had identified some roles that they can play in relation to timing, and they also identified the limitations in what they could offer. Giving an outline of the current practice, a health worker revealed that:

*The discussions on disclosure actually start even in the pre-test counselling, we tell them that when they get the result, they need to share with their partners ( the results), and now, even during the next visits, we are encouraging male involvement after the first booking visit, so that they come together with their partners...in my experience, in terms of timing of disclosure to partners, some women disclose as soon as they know their results, especially if you ( the health workers) encourage them to go and tell their husbands.*

*(Health worker no.1)*

One health worker mentioned the on-going availability of health workers to support disclosure at any time period, and felt that this support could be improved upon:

*For the information and help that women need at the time of disclosure, what I can say is that they depend on us, because they (Partners) know that these are the most reliable people. So even when disclosing at home becomes a challenge, especially where a woman feels that issues of divorce are concerned,( at the time of disclosure,) when the woman feels that this man has to understand, they depend on us, so you need to have competent people who can help resolve any issues, so that in relation to the HIV (disclosure), whatever issues are going to arise...to make the partner understand..., during the course of the pregnancy or after, for them to know that help is still available and I think we don't go an extra mile to do that, it is just a matter of talking to them*

*(Health worker no.3)*

*The way we can improve support to HIV positive pregnant women around the timing of disclosure, is more time...I think if we had more staff, so that we can engage more time on one on one counselling, it would be easier...more time and more personnel ... so that say, you dedicate this hour to PMTCT, maybe with only two couples...or only two*

women...not the way we do it...we do not have enough time...it becomes difficulty to pay particular attention to each woman's individual needs (about the disclosure).

(Health worker no.1)

#### 4.8.3 Additional support needed by health workers to support immediate disclosure

Nurses felt that the best support they would like to get is an increase in the number of staff, including nurses and lay (psychosocial) counsellors, because of the increased workload as PMTCT services have expanded, as well as the need for more training:

*We are seeing many more women being tested for HIV, and sometimes you don't have enough time...you can't help a woman disclose because you are so busy. We need (more) nurses. It can be easier if people came here when they already know their results with their husbands.*

(Health worker no.2)

*I think, nurses, doctors should be trained in psychosocial counselling, to help women during the timing of disclosure, because you should be able to read your client's mood and mind and within the health centre, I think the psychosocial counsellors are best placed to support a woman when she decides that today, I am going to disclose to my partner.*

(Health worker no.1)

Lay counsellors expressed their desire to be given more roles, and to be trained in more skills:

*All the counselling, and all that, I know that...but the nurses are busy, and when the women have to wait for the nurse to get blood for testing for HIV related tests like liver, kidney functions and even CD4, then wait for the results and get more counselling. Time finishes. If I am trained and allowed to do all the tests and then refer the women for ARVs, it's less time, and can give us time to discuss disclosure and all that. We can even do that in our township.*

(Health Worker no.5)

Lay counsellors described their current roles as:

*My role as a lay counsellor in PMTCT is giving group health educational talk, involving minor things involving antenatal, and then PMTCT as the major part of it, encouraging mothers in coming together with us, bonding with us, so that they have a healthy baby at the end of it all, and tell them the basics and facts about HIV, so that even if you are giving a service, whereby they have all the information, even the incentives associated with it (PMTCT), and the mothers therefore know what they are doing.*

*As a lay counsellor, I do group health education, rapid HIV tests, and DBS testing for babies exposed (to HIV). I do spotting of those women who require being on AZT, Nevirapine and Combivir, and those who need to be on treatment and those who come before the eligibility gestational age. I also do retesting for those women who come after three months that is the window period. I do the HIV, adherence counselling and also the infant and young child counselling.*

In terms of specifically supporting disclosure, one lay counsellor described their current practice as:

*The counselling for disclosure is done on the first day of antenatal. When the mother tests HIV positive, we talk. We tell them...whom are you going to disclose? Some people go as far as saying I will tell my mum, I will tell aunty...but you have to bring them back...because there is one partner who is just too close to them, were (with whom) re-infections may occur...so we try to find if there is way, if they can tell the partner, if the partner can be informed, and then if they don't tell them, usually they come back after a week, for their CD4 result, and then usually we ask them, is your partner aware, of the HIV result. And then we go as far as inviting them for a couple counselling, which is undertaken during Saturday and Sunday, whereby they come in as a couple...and that one is helping.*

*(Health worker no.3)*

*In terms of support groups, I do not know of any that help with disclosure, there is one I know, but it is only for people living with HIV already...within the health centre, I think*

*the psychosocial (lay)counsellors are best placed to support a woman when she decides that today, I am going to disclose to my partner.*

*(Health Worker no.1)*

In the following chapter the findings of the study, informed by other findings in the literature on the relevant issue will be discussed, and where possible comparisons made to inform the subsequent conclusions and recommendations.

In following chapter, the results will be discussed, and comparisons made with the literature reviewed.





## **CHAPTER 5: DISCUSSION**

### **5.1 Introduction**

The study embarked on identifying and describing the experiences – specifically in relation to the timing of disclosure to male partners - by PMTCT clients attending KHC in Lusaka for whom disclosure *has* been possible. In gathering these insights together it was hoped that the PMTCT programme will then be able to improve the support it offers to its PMTCT clients as it encourages them to disclose their HIV status to their partners.

### **5.2 Importance of disclosure to male partners as a necessary step in MTCT and adherence to HIV care**

From the in-depth interviews conducted with the 15 women and 5 health workers it was evident that along with the HIV counselling and testing that is provided when pregnant women report for their 1<sup>st</sup> ANC visit, all the women interviewed understood and appreciated the importance of disclosing an HIV positive test result to their male partners. The women interviewed in this study shared how they felt that there were a number of positive benefits in disclosing to their male partner: that once someone had disclosed, it was possible for them and their partner to discuss and initiate safer sex, thus avoiding re-infection. Further, the women felt that disclosure would result in getting the partner's support, hence helping the women in adhering to ARVs. Ultimately, these benefits were viewed as a means to reduce the chances of transmitting HIV from the HIV positive mother to her baby. This finding is in agreement with the results obtained in Uganda in a similar study which found that the beneficial outcomes of disclosure include risk reduction behaviour, partner testing, increased care-seeking behaviour, anxiety relief, increased sexual communication and motivation to plan for the future (King et al. 2008). Additionally, disclosing the HIV positive result to the partner was felt to be liberating to the woman and a necessary step to enable the couple to potentially enter into continued HIV care, including the testing of the partner and initiation of treatment with ARVs if needed, which is consistent with the findings by Igwegbe & Ugboaja (2010), Varga et al. (2006) and Serovich et al. (2008).

The interviews illustrated how all the respondents had known that they would be tested for HIV at the ANC reflecting possibly both the wider dissemination of information about the issue and

the acceptance of HIV testing as part of the routine ANC care in Zambia. Not surprisingly, in 2010 testing coverage was found to be more than 95% among pregnant women attending their 1<sup>st</sup> ANC visit according to the national progress reports by the government (National AIDS, STD, TB Council of Zambia (NAC), 2011). Related to this, the majority of respondents stated that they did not find any difficulty in the partner knowing that they would be tested for HIV when they attend ANC. Some dissent to this view emerged, as 2 of the 15 women felt that the male partner would deter them from testing. The apparent increased knowledge among women and their partners of routine offer of HIV testing in ANC may contribute to increased disclosure rates of the test result.

### **5.3 Perceptions and experiences on the best timing of disclosure**

In the study, all but one of the respondents were married and had disclosed their HIV status to their partners either on the same day they were told they were HIV positive, or within a few days thereafter. Whilst the intention was to get a sample of women with a range of relationships from never married, divorced/separated, widowed, staying together and has a boyfriend but not staying together given 14 of the 15 women were in fact married the findings of this study can really only be considered to be reflective of the experiences of a group of women who were, for the most part, all within a formal relationship (a marriage). Of the 8 out of 15 women who had volunteered the duration of their marriages, as it was not specifically requested, 7 had been married for more than 5 years largely showing they were in more or less stable relationship. The fact that all but one of respondents disclosed their positive HIV test results to their partner within a week of their diagnosis also ought to be acknowledged – and as such, the perceptions and experiences of disclosure recorded in this study relate to that timing of disclosure (what I have referred to previously as what can be characterised as ‘immediate’ disclosure). In addition, the respondents were also those that were *willing* to participate in the study – and inevitably might have been those that had had a positive experience of disclosure to their partner. This positive link between ease of disclosure and duration and stability of a relationship has been shown to be significant according to results from a recent study conducted among HIV positive men and women living in a high risk area of Southern China, which showed that a relationship of more than 2 years duration and a regular partner enabled 95% disclosure rates, compared to 13% disclosure rates for respondents perceived to be in a casual relationship (Wang et al., 2010)

Despite the study including a spectrum of women, from those in the early stages of pregnancy to those who had given birth 6 months earlier, the study results showed that the preferred time of disclosure amongst the sample was within a week of receiving an HIV positive test result from the ANC facility. This finding differs from that which was found by Brou et al. (2007) in their Cote d'Ivoire study which suggested that there were 3 peak times of disclosure, namely: just before delivery, at the time of weaning the baby and at the resumption of sexual activity. This apparent difference could be attributable to the different methods used, because Brou et al., (2007) had a large sample size of 546 women who were followed up over a period of more than 2 years from 2001 to 2003, whereas in this study, the sample size was limited to 15 women and depended on recall by the women. Moreover, when the data from the health workers in the current study was added to give more context, it emerged that other women apart from those in the sample do time their disclosure at other periods, such as after delivery, when the baby is free of any continued exposure to HIV. The range of periods of disclosure based on the key informants' experiences parallels the finding in the Brou et al., (2008) Cote d'Ivoire study. The respondent who did not disclose early was engaged to be married, and when she suffered a miscarriage within a month of the test, she felt no imperative to disclose, which may again reflect the view of Wang et al. (2010) that a stable relationship plays a significant role in facilitating the ease of disclosure.

The concept of the disclosure of an HIV positive result as a *liberating event* was consistent throughout the interviews. It was evident that woman perceived knowing they were HIV positive and not disclosing to their partners, as an unnecessary burden for the woman to carry alone, and that this burden was alleviated by disclosing to the partner, thus making it a shared burden, a viewpoint that is also held by Serovich et al. (2008).

Encouragingly, the study results revealed that HIV positive pregnant women view themselves as having *responsibility as the index person*, by recognizing that the woman is usually the first person in the family to know that she is HIV positive, through being tested at the ANC and thus bearing the responsibility to bring the rest of the family into HIV care as early as possible. This finding echoes the results from Brou et al. (2008) and acknowledges the role that HIV testing in ANC can play in increasing access to HIV care for the family. Related to this was the finding

that women viewed *immediate disclosure as an imperative*, because it simply had to be done notwithstanding any perceived possible adverse outcomes.

The type of relationship that a couple has and its effect on either the woman disclosing her HIV positive status or not has been documented in the literature, in studies for example, by Varga et al. (2006) and Jasseron et al. (2010). Results from this study were in agreement with this literature, with reportedly poor relationships and a prior history of regular misunderstandings being perceived by both women and health workers as linked to delayed disclosure. The findings of this study also suggest that fear or an environment which is perceived to be characterized by mistrust delays disclosure. Somewhat unusually, the results showed no evidence of any negative outcome(s) occurring as a result of the respondents disclosing their HIV positive status to their partners. In fact, all the respondents reported that there were beneficial outcomes of an early disclosure. The review of studies done by Medley et al. (2004) had reported 4-17% of women suffering a negative outcome, however more recently, Igwegbe & Ugboaja (2010) found similar results as the current study at a PMTCT clinic in Nigeria where 272 (90%) of the 280 HIV positive pregnant women participating in the study experienced a supportive and understanding reaction from the partner. This may reflect findings from a self-selected and highly motivated sample of HIV positive women that were willing to share their disclosure process and outcomes based on the favourable experiences they have had.

Nevertheless, this finding was borne out by the health workers who reported that they had very rarely, if ever, been confronted with the situation of a woman who had suffered adverse events due to disclosure, and may suggest an improvement in acceptance and support from male partners that is a very positive development for PMTCT services. The results also revealed that in hindsight the respondents carried no regrets about the timing of disclosure, which supports the assertion by Varga et al., (2006) that voluntary or direct disclosure is associated with better outcomes, compared to involuntary disclosure, which is associated with negative outcomes. Involuntary disclosure is more likely to occur with delays in disclosure, and the woman is inadvertently found out by the partner, commonly when taking medicines (Discussion with MCH manager, June 2011)

Not surprisingly, findings from the study supported health workers playing a role in timing of disclosure, particularly in providing counselling that specifically encourages immediate

disclosure, by highlighting the benefits, and explaining the difficulties that arise when women delay in disclosing. The results showed that women and health workers believed that the longer it takes to disclose to the male partner, the more difficulty it becomes, and this information should be given to women as soon as they get their test results. The data from the women's beliefs revealed that when they expect a negative reaction, based on their assessment of the partner's temperament, they would rather not disclose. A similar conclusion was reached in the findings of the review of literature focussing on disclosure, that disclosure is closely related to expectations of support, and it is lower when the women expect blame and discrimination (Obermeyer, Baijal & Pegorri, 2011).

Furthermore, respondents felt that health workers should be able to coach women as soon as possible after testing them for HIV on *setting the mood*, and helping a woman to recognize an atmosphere that was conducive for disclosure to their partners. Varga et al. (2006) recognised this phenomenon and concluded that for PMTCT programmes, consideration ought to be given to assisting those living with HIV to disclose under conditions affording them maximum control over its timing, mode, and impact.

In addition, the results from the women's interviews showed that the MCH where PMTCT is offered is considered the best place for partners to also be tested for HIV and commenced on treatment if found eligible, as it would function like a single place where family care would be given, rather than partners having to be referred to another place. This approach is endorsed in the Zambian PMTCT guidelines, as a means for providing holistic HIV care to the woman, male partner and the other children in the family (Ministry of Health of Zambia, 2010). Such care should include integrated services and should include HIV, sexual and reproductive health, care for the partner and infant feeding counselling. This is suggested so as to reduce complications and facilitate access to services according to a report based on a multi-country review of PMTCT services published by International Treatment Preparedness Coalition (ITPC), a world-wide coalition of people living with HIV, their supporters and advocates (International Treatment Preparedness Coalition (ITPC), 2009).

Interestingly, though the majority of women supported the involvement of health workers in assisting them prepare for disclosure by giving them adequate information, arranging couple counselling and testing and 'making them strong', the women's beliefs about the involvement of

health workers in the *timing* of the disclosure were more cautious. Two respondents went further and suggested that it was the women's prerogative to decide upon the process and time of disclosure because the women knew best their circumstances and were best placed to make this call.

Regrettably, in spite of the health workers suggesting that they were adequately trained and competent to provide PMTCT services, they faced a major challenge of a high workload due to shortage of person-power. Results from the interviews with health workers revealed that they believed the high workload is impacting negatively on their efforts to optimally assist HIV positive pregnant women disclose to their partners, as they do not have adequate time to give quality attention on an individual basis. At KHC, at the time of the study, there were 4 nurses who managed MCH, including the PMTCT services, instead of the required 8 (Communication with Health Centre In-Charge, June 2011). This shortage of person-power in KHC was to some extent mitigated by the availability of 4 lay counsellors. The lay counsellors are trained provide voluntary counselling and testing, support for disclosure and prevention of new infections. They are trained for and expected to provide couples counselling, and supporting disclosure. One key informant (a nurse) stressed that the psychosocial (lay) counsellors were the best equipped to support women *at the time of disclosure*. Lay counsellors were trained to provide information about the benefits of disclosure, potential disadvantages, couple counselling and support around the timing of disclosure. The study revealed that lay counsellors were already providing support that could facilitate timely disclosure to partners.

Health workers also noted a need for them to be equipped with psychosocial skills, to enable them develop a better understanding of a particular woman's situation, to be better able to connect with the woman's emotional state, as it would help improve the support women need for disclosure.

However, the lay counsellors were limited in the roles they could perform, as they were not trained nor allowed to draw blood for HIV care related tests, or to refer patients directly to obtain ARVs from the dispensary. All the pregnant women and their partners that a lay counsellor attended to were still required to be reviewed by a nurse who then performed these exclusive functions. Expanding the roles of lay counsellors would help ease the workload of the nurses and potentially improve disclosure rates. In addition, from the results, it emerges that they are already

conducting couples counselling, including over weekends, and this service could be expanded to include the lay counsellors setting up and assisting in running support groups.

It emerged from the interviews that health workers have innovatively used couples counselling and testing to facilitate disclosure, even when the pregnant woman had been tested on a previous visit and found to be HIV positive. This supportive response to women who felt they could not disclose immediately to their partners on their own is likely to be an important strategy, and the benefits of disclosure are likely to far outweigh the cost of an extra HIV test administered to the woman when she comes with her partner. The use of couples counselling and testing to facilitate timely disclosure for women who faced such a challenge has been implemented and documented, though with difficulty as few women managed to bring their partners, according to a study done in 10 antenatal clinics in 4 districts in Uganda (Medley & Kennedy, 2010). Further documentation of use of couples counselling in a PMTCT setting is provided by a review of the literature available via Pubmed, EMBASE and PsycINFO published between 1990-2010 that focussed on studies and programme models which had extended PMTCT services beyond the woman, to increasingly more comprehensive services for the partner and the rest of the family. This review shows that in 7 of the 14 studies the authors highlighted, couples counselling had been used as a means for facilitating partner testing, counselling on safer sex, increasing spousal communication and promoting women's adherence to ARVs (Betancourt, Abrams, McBain & Fawzi, 2010).

Finally, 1 woman volunteered that women who have benefitted from PMTCT services and have experience in disclosing to their partners would be willing to mentor pregnant women who are newly diagnosed as HIV positive. This would provide an additional resource (and importantly, one that is based on peer education and counselling) that could help HIV positive pregnant women disclose their status to their partners in a timely manner. This methodology (of using peers) has been used with success by mothers2mother, an NGO which delivered services in South Africa and Lesotho and in 2007 received the Impumelelo platinum award, which is given in South Africa for 'innovative service delivery projects that inspire replication of best practice' (Dalberg Global Development Advisors, 2007).

#### 5.4 Limitations of study

Given that this study was only conducted in one urban site (the KHC) and used qualitative research methods, the findings of this study are limited to the particular experiences and opinions of those HIV positive female respondents, the majority of whom were married and had disclosed their positive status to their husband within a week after getting an HIV positive test, and a group of 5 health workers working within this health facility. The data therefore did not include much of experiences from women who disclosed later at different time periods apart from data from key informants, and from women in a different type of relationship apart from marriage. The HIV disclosure experiences described in this study cannot therefore be generalized to *all* the HIV positive women attending the PMTCT programme in this facility – whether they had disclosed to their partners or not – nor to all the health workers working at the KHC facility. They also cannot be generalised to women attending a PMTCT programme in other settings, for example a rural area of Zambia or, for that matter, to PMTCT clients in other African countries. Another limitation to the study is that the duration of marriage or relationship was not specifically requested, although 8 of the women volunteered it. This information could have shed more light on the stability of the relationship. The study was also limited by a lack of in-depth enquiry into the specific strategies women used at the time of disclosure, and the outcomes of disclosure in terms of actions taken by the partner, such as getting tested for HIV, obtaining results and being enrolled into HIV care. These important potential outcomes of disclosure were beyond the scope of the study, but would be worthwhile exploring in subsequent research.

Finally, any possible bias in the selection of participants by the PMTCT focal point nurse who assisted the researcher was minimised by making her thoroughly understand the aim of the research, as well as the principle of voluntary informed consent. The researcher is male but the effect of this may have been minimal, as the 2 lay counsellors who routinely provide counselling services at KHC are also male, and normally engage the participants in issues of disclosure to their partners.



## **CHAPTER 6: CONCLUSION AND RECOMMENDATIONS**

From this study it is suggested that HIV positive women who were attending PMTCT services at KHC and had disclosed their status to their male partners shortly after receiving their HIV positive test results, understood and appreciated the benefits of disclosure. However, the 15 women interviewed are part of a group of women that represent approximately half of all the PMTCT programme members – given that, according to 2 of the health workers interviewed, only about half of their PMTCT clients disclose their HIV status to their partners.

The other half of (i.e. those clients who do not disclose) are therefore likely missing out on what most of the respondents described as the liberating effect of their immediate disclosure. Their lack of early disclosure to their partners also means that they do not access the benefits traditionally ascribed to disclosure such as risk reduction behaviour, partner testing, increased care-seeking behaviour, anxiety relief and increased sexual communication and motivation to plan for the future (King et al. 2008). A major reason given for failure to immediately disclose was a poor relationship between a couple, characterised by misunderstandings and mistrust.

Providing post-test counselling to HIV positive pregnant women that emphasises immediate disclosure, and delivers a robust package of information detailing the benefits associated with immediate disclosure and the potential adverse outcomes of delayed disclosure was seen as a key strategy in motivating the women. An innovation with the potential to overcome part of the poor relationship barrier to immediate disclosure was provision of couple's HIV counselling and testing, regardless of whether the woman already knew her status or not. Health workers felt that they would be able to successfully implement this approach but would need additional human resources and, in the case of lay counsellors, additional skills and authorization to take up increased roles.

Finally, HIV positive women who have experienced disclosure to partners constitute a ready empathetic resource to act as mentors to newly diagnosed HIV positive pregnant women. A combined response that utilises nurses, lay counsellors and the client mentors would likely offer a more sustained and robust strategy to facilitate a PMTCT client's decision-making about the process, context and time for disclosure.

## 6.1 Recommendations

The recommendations that follow are based on the results of the study and it is hoped that they could assist in addressing some of the barriers that HIV positive women face in disclosing their results to their partners in the future:

1. *Provide ongoing counselling for HIV positive women during pregnancy and after giving birth that supports, informs and equips them with the necessary skills to make an informed and timely decision about disclosure to a partner.*

There is a need to package the information provided to HIV positive women during pregnancy and after birth, during post-test and ongoing counselling, in a way that gives them motivation to disclose to their partners, so that women and their family can reap maximum benefits from the PMTCT services. The information should highlight the potential benefits of disclosure to facilitate good psychological, social and health outcomes.

2. *Encourage the implementation of couple counselling as a strategy to facilitate disclosure.*

The pilot being undertaken at KHC in which couples are tested for HIV and counselled during the weekend when there is traditionally no ANC should be considered for expansion and institutionalisation if found feasible. The initiative could also be replicated in similar settings, as it appears to be promising in relation to facilitating mutual timely disclosure at KHC.

3. *Strengthen the establishment of a peer support network for HIV positive pregnant women in PMTCT programmes.*

Encouraging women who consent, to be mentored by other HIV positive women who have personal experience in disclosing to partners would provide an added resource to facilitate disclosure. This approach would potentially contribute to mitigating the shortage of health workers and enable more one on one support from an empathetic mentor who has a rich personal

experience. Mentor mothers should be deployed in a manner that would infuse their efforts within broader HIV positive mother support groups affiliated to the health centre. This approach could prove to be empowering, as it can embed the view that ultimately, it is the HIV positive woman's decision when and if she discloses her status to her partner and all the health system can do is to equip her with information and support (International Community of Women Living with HIV/AIDS (ICW), 2008).

Care needs to be applied when using this approach, as it implies shared confidentiality about HIV status, and may lead to conflict for the newly diagnosed woman and her mentor, if for some reason the relationship degenerates, and they live in the same community.



## REFERENCE LIST

- Barbour, R. S. (2001). Checklists for Improving Rigour in Qualitative Research: a Case of the Tail Wagging the Dog? *British Medical Journal*, 322: 1115-1117.
- Betancourt, T., Abrams, E., McBain, R. & Fawzi, S. M. (2010). Family-centred approaches to the prevention of mother to child transmission of HIV. *Journal of the International AIDS Society*, 13 (Supplement 2), S2.
- Brou, H., Djohan, G., Becquet, R., Gerald, A., Ekouevi, D. K., Viho, I., Leroy, V. & Desgrees-du-Lou, A. (2007). When Do HIV-Infected Women Disclose Their HIV Status to their Male Partner and Why? A Study in a PMTCT Programme, Abidjan. *PLoS Medicine*, 4 (12); 1912-1920. Available: <http://www.plosmedicine.org/article/pmed0040345> (7/09/2011)
- Central Statistical Office. (2007). *Zambia Demographic and Health Survey*. Calverton, Maryland: CSO and Macro International Inc.
- Creswell, J. W., & Miller, D. (2000). Determining Validity in Qualitative Inquiry. *Theory Into Practice*, 39 (3): 125-130.
- Dalberg Global Development Advisors. (2007). *Business Guide to Partnering with NGOs and the UN*. Dalberg Global Development Advisors.
- Deribe, K., Woldemichael, K., Wondafrash, M., Haile, A., & Ambebir, A. (2008). Disclosure experience and associated factors among HIV positive men and women clinical service users in southwest Ethiopia. *BMC Public Health* , 8 (81): 1-10. Available: <http://www.ncbi.nlm.gov/pmc/articlesPMC2275263> (4/10/2011)
- Igwegbe, A., & Ugboaja, J. (2010). Rate and correlates of HIV serostatus disclosure among HIV positive pregnant women in Nnewi southeastern Nigeria. *Journal of Medicine and Medical Science* , 1 (7): 293-301.
- International Community of Women Living with HIV/AIDS (ICW). (2008). *ICW Briefing Paper on Maternal Mortality* . London: ICW. Available : [http://www.icw.org/files/briefing paper-motherhood](http://www.icw.org/files/briefing%20paper-motherhood) (16/09/2011)

International Treatment Preparedness Coalition (ITPC). (2009). *Failing Women, Failing Children: HIV Vertical Transmission and Women's Health*. ITPC.

Jasseron, C., Mandelbrot, L., Dollfus, C., Trocme, N., Tubiana, R., Teglas, P., et al. (2010). Non-disclosure of maternal HIV status to the father during pregnancy : risk factors and cosequences. *17th Conference on Retroviruses and Opportunistic Infections CROI 2010* (p. 894). San Fransisco: CROI. Available: <http://www.retroconference.org/2010/PDFs/894>

King, R., Katuntu, D., Lifshay, J., Packel, L., Batamwita, R., Nakayiwa, S., et al. (2008). Processes and outcomes of HIV serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS Behaviour* , 12 (2): 232-243.

Makin, J. D., Forsyth, B. W., Visser, M. J., Sikkema, K. J., Neufeld, S. & Jeffery, B. (2008). Factors Affecting Disclosure in South African HIV-Positive Pregnant Women. *AIDS Patient Care and STDs*, 22(11): 907-916. Available: <http://www.ncbi.nlm.nih.gov/pubmed/1905485> (3/08/2011)

Medley, A. M. & Kennedy, C. E. (2010). Provider Challenges in Implementing Antenatal Provider-Initiated HIV Testing and Counselling Programmes in Uganda. *AIDS Education and Prevention*, 22 (2): 87-99. Available: <http://www.ncbi.nlm.nih.gov/pubmed/20387980> (3/08/2011)

Medley, A., Garcia-Moreno, C., McGill, S. & Maman, S. (2004). Rates, Barriers and Outcomes of HIV Serostatus Disclosure Among Women in Developing Countries: Implications for Prevention of Mother-to-Child Transmission Programmes. *Bulletin of the World Health Organisation*, 82 (4): 299-307. Available: <http://www.who.int/bulletin/volumes/82/4/299> (3/10/20110)

Ministry of Health of Zambia. (2010). *2010 National Protocol Guidelines for Integrated Prevention of Mother-to-Child Transmission of HIV*. Lusaka: Ministry of Health.

Ministry of Health of Zambia. (2003). *Strategic Framework for the Expansion of PMTCT Services in Zambia*. Lusaka: Ministry of Health, Zambia.

Ministry of Health, Zambia. (2008). *Integrated PMTCT and Paediatric HIV Guidelines*. Lusaka: Ministry of Health, Zambia.

National AIDS, STD, TB Council of Zambia (NAC). (2011). *UNGASS Zambia Country Report 2010*. Government of The Republic of Zambia. Lusaka: NAC.

Norman, D., Chopra, M. & Kadiyala, S. (2007). Factors Related to HIV Disclosure in 2 South African Communities. *American Journal of Public Health*, 97 (10): 1-7.

Obermeyer, C., Bajjal, P. & Pegurri, E. (2011). Facilitating HIV disclosure across diverse settings: a review. *American Journal of Public Health*, 101 (6): 1011-1023.

Pope, C. S. & Mays, N. (1995). Qualitative Research: Reaching the Parts Other Methods Cannot Reach: An Introduction to Qualitative Methods in Health and Health Services Research. *British Medical Journal*, 311:42-45 [online], Available: <http://www.bmj.com/cgi/content/Full/3116996/42> (10/11/2010)

Pope, C., Ziebland, S. & Mays, N. (2000). Qualitative research in Health Care: Analysing Qualitative Data. *British Medical Journal*, 320: 114-116. Available: <http://www.bmj.com/conyent/320/7227/114> (10/10/2011)

Semrau, K., Kuhn, L., Vwalika, C., Kasonde, P., Sinkala, M., Kankasa, C., et al. (2005). Women in Couples Antenatal HIV Counselling and Testing are Not More Likely to Report Adverse Social Events. *AIDS*, 19 (6): 603-609. Available: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1201374> (10/10/2011)

Serovich, J., McDowell, T. & Grafsky, E. (2008). Women's Report of Regret of HIV Disclosure to Family, Friends and Sex Partners. *AIDS Behaviour*, 12 (2): 227-231. Available: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2265070> (14/09/2011)

Siegal, K., Lekas, H., & Schrimshaw, W. (2005). Serostatus Disclosure to Sexual Partners by HIV-infected Women Before and After the Advent of HAART. *Women Health*, 41: 63-85. Available: <http://www.ncbi.nlm.nih.gov/pubmed/16260414> (10/10/2011)

UNAIDS and WHO. (2009). *AIDS epidemic update*. Geneva: UNAIDS.

UNAIDS. (2007). State of the Epidemic. *AIDS Update*. Geneva : UNAIDS

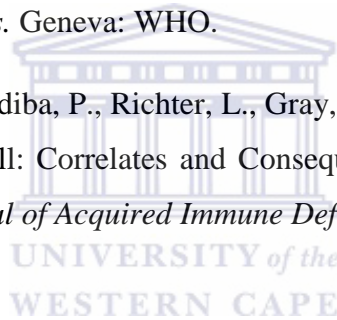
Varga, C. A., Sherman, G. G., & Jones, S. A. (2006). HIV-Disclosure in the Context of Vertical Transmission: HIV-Positive Mothers in Johannesburg, South Africa. *AIDS Care*, 18 (8), 952-960. Available: <http://www.ncbi.nlm.gov/pubmed/17012085>

Wang, L., Shan, D., Chan, S., Chen, H., Ge, Z., Ding, G., et al. (2010). Disclosure of HIV-positive Serostatus to Sexual Partners and Associated Factors in Southern China. *International Journal of STD & AIDS* , 21 (10): 685-690.

WHO. (2010). *Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infections in Infants*. Geneva: WHO.

WHO. (2009). *Rapid Advice: Use of Antiretroviral Drugs for Treating Pregnant Women an Preventing HIV Infection in Infants*. Geneva: WHO.

Wong, L. H., Van Rooyen, H., Modiba, P., Richter, L., Gray, G., McIntyre, J. A., Schetter, D.C. & Coates, T. (2009). Test and Tell: Correlates and Consequences of Testing an Disclosure of HIV Status in South Africa. *Journal of Acquired Immune Deficiency Syndrome*, 50 (1): 215-222.



## Appendix 1



University of the Western Cape

### Faculty of Community and Health Sciences

P/Bag X17, Bellville 7535, South Africa Tel.: +27 21 9592163 Fax: +27 21 9592755

#### **Informed Consent Form (for all participants)**

##### **Title of Research**

Timing of disclosure to male partners by HIV positive women attending a health care centre in Lusaka, Zambia.

As was mentioned in the *Participant Information Sheet*, your participation in this research is entirely voluntary i.e. you do not have to participate. Refusal to participate or withdrawal from the study will not result in penalty nor loss of any benefit to which you are otherwise entitled.

If you choose to participate, you may stop at any time. You may also choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, feel free to say so.

The information collected in this interview will be kept strictly confidential.

If you choose to participate in this research study, your signed consent is required before I proceed with the interview with you.

---



I have read the information about this study on the participant information sheet, or it has been read to me. I have had the opportunity to ask questions about it and any questions have been answered to my satisfaction.

I consent voluntarily to be a participant in this project, and I understand that I have the right to end the interview at any time, and to choose not to answer particular questions that are asked in the study.

My signature says that I am willing to participate in this research.

-----

Participant name (printed)

-----

Participant signature

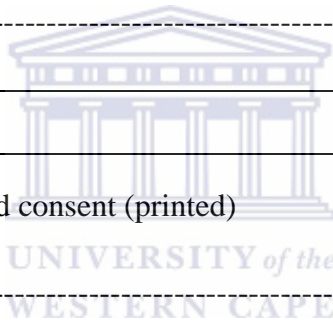
Consent date

Researcher conducting the informed consent (printed)

-----

Signature of researcher

Date



## Appendix 2



University of the Western Cape

### Faculty of Community and Health Sciences

P/Bag X17, Bellville 7535, South Africa Tel.: +27 21 9592163 Fax: +27 21 9592755

#### Participant Information Sheet (for Health Workers)

January 26<sup>th</sup> 2011

Dear Participant,

Thank you for your willingness to hear about this research. What follows is an explanation of the research project and an outline of your potential involvement. The research is being conducted for a mini thesis. This is a requirement for the Masters in Public Health which I am completing at the University of The Western cape. If there is anything you do not understand or are unclear about, ask me. My contact details and those of my supervisor are recorded at the end of this memo.

#### **Title of Research**

Timing of disclosure to male partners by HIV positive women attending a health care centre in Lusaka, Zambia.

#### **Purpose of the Study**

This research is trying to understand the timing of disclosure of HIV positive status to male partners, by women who are HIV positive and who are or have attended the prevention of mother to child transmission (PMTCT) services at Kalingalinga health centre. It is hoped that with your

participation, a better understanding of the disclosure process will be gained, of the reasons for many women failing to disclose their status to their partners. This research will contribute to helping health workers support women more effectively in helping them disclose their status, and increase the number of women who disclose. This will contribute to making the PMTCT services more effective; by enabling Health workers provide services with an added understanding of the disclosure process. Disclosure to male partners has been found in most studies, to help women adhere to the PMTCT services, including ARVs.

### **Description of the Study and Your Involvement**

The study will include individual interviews with service providers who are involved in the PMTCT programme, and can shed more light on the disclosure process, from their involvement with women who are currently attending or have attended PMTCT services at Kalingalinga health centre. The experiences gained in providing support to women on the issue of disclosure will guide the discussion.

### **Confidentiality**

Your name will be kept confidential at all times. I shall keep records of your participation, including a signed consent form which I will need from you should you agree to participate in this study, locked away at all times and will destroy them after the research is completed.

### **Voluntary participation and withdrawal**

Your participation in this research is entirely voluntary i.e. you do not have to participate. If you choose to participate, you may stop at any time. You may also choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.

### **Benefits and costs**

You may not get any direct benefit from this study. However, the information we learn from you as a participant in this study may help in guiding PMTCT service providers support HIV positive women, and contribute to making PMTCT services more effective. There are no costs to participating in this study other than the time you will spend in the interview.

Your signed consent to participate in this research study is required before I proceed to interview you. I have included the consent form with this information sheet so that you will be able to decide whether you would like to participate in this study or not.

## Questions

Should you have further questions or wish to know more, I can be contacted as follows:

Maximillian Bweupe

Student number: 2707211

Cell phone 0977775089

Email: [bweupem2001@yahoo.com](mailto:bweupem2001@yahoo.com)

I am accountable to Nikki Schaay, my supervisor at UWC. Her contact details are

Nikki Schaay

The School of Public Health

University of the Western Cape

Private Bag X17

Bellville, 7535

South Africa

<http://www.uwc.ac.za/publichealth>

Mobile: 084 211 5544

Work/home office& fax: 021 788 4186

SOPH (Mondays): 021 959 2632



## Appendix 3

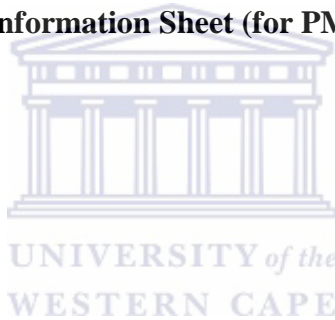


University of the Western Cape

### Faculty of Community and Health Sciences

P/Bag X17, Bellville 7535, South Africa Tel.: +27 21 9592163 Fax: +27 21 9592755

#### Participant Information Sheet (for PMTCT clients)



January 2011

Dear Participant,

Thank you for your willingness to hear about this research. What follows is an explanation of the research project and an outline of your potential involvement. The research is being conducted for a mini thesis. This is a requirement for the Masters in Public Health which I am completing at the University of The Western cape. If there is anything you do not understand or are unclear about, ask me. My contact details and those of my supervisor are recorded at the end of this memo.

#### **Title of Research**

Timing of disclosure to male partners by HIV positive women attending a health care centre in Lusaka, Zambia.

## **Purpose of the Study**

This research is trying to understand the timing of disclosure of HIV positive status to male partners, by women who are HIV positive and who are or have attended the prevention of mother to child transmission (PMTCT) services at Kalingalinga health centre. It is hoped that with your participation, a better understanding of the disclosure process will be gained, of the reasons for many women failing to disclose their status to their partners, as well as for some managing to do it. This research will contribute to helping health workers support women more effectively in helping women who are HIV positive, disclose their status, and increase the number of women who disclose. This will contribute to making the PMTCT services more effective.

## **Description of the Study and Your Involvement**

The study will include individual interviews with women who are currently attending or have attended PMTCT services at Kalingalinga health centre, as well as some service providers. Questions about your experiences of the timing of disclosure to your partner will guide the interview that I have with you.

UNIVERSITY of the  
WESTERN CAPE

## **Confidentiality**

Your name will be kept confidential at all time. I shall keep records of your participation, including a signed consent form which I will need from you should you agree to participate in this study, locked away at all times and will destroy them after the research is completed.

## **Voluntary participation and withdrawal**

Your participation in this research is entirely voluntary i.e. you do not have to participate. If you choose to participate, you may stop at any time. You may also choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.

## **Benefits and costs**

You may not get any direct benefit from this study. However, the information we learn from participants in this study may help in guiding PMTCT service providers support HIV positive women, and contribute to making PMTCT services more effective. There are no costs to participating in this study other than the time you will spend in the interview.

Your signed consent to participate in this research study is required before I proceed to interview you. I have included the consent form with this information sheet so that you will be able to decide whether you would like to participate in this study or not.

## **Questions**

Should you have further questions or wish to know more, I can be contacted as follows:

Maximillian Bweupe

Student number: 2707211

Cell phone 0977775089

Email: [bweupem2001@yahoo.com](mailto:bweupem2001@yahoo.com)



I am accountable to Nikki Schaay, my supervisor at UWC. Her contact details are

Nikki Schaay

The School of Public Health

University of the Western Cape

Private Bag X17

Bellville, 7535

South Africa

<http://www.uwc.ac.za/publichealth>

Mobile: 084 211 5544 & Work/home office & fax: 021 788 4186

SOPH (Mondays): 021 959 2632

## Appendix 4



University of the Western Cape

### Faculty of Community and Health Sciences

P/Bag X17, Bellville 7535, South Africa Tel.: +27 21 9592163 Fax: +27 21 9592755

#### **Guide for Interviews with Women (participants)**

Good morning, my name is Maximillian Bweupe, a student of Public Health with the University of Western Cape, South Africa. I'm here to see if you would mind if I ask you a few questions which are part of my student research project but that will also, hopefully, help to improve the support that women, especially those that test positive for HIV, can get from the health services. I am specifically interested in finding out what support the staff at a facility like this ought to give to women living with HIV in order to assist them to disclose their HIV positive status to their partners.

Here is some information about the research that I am doing. This is for you to keep but I will explain all of the information that is on that sheet to you now.

**[Give potential participant the information sheet]**

I would like to assure you from the onset that, should you agree to take part in the interview, that whatever information we discuss here will be solely for the purpose of my studies and to suggest to the district health management team in Lusaka how they and health workers might be able to offer more support to HIV positive women in relation to disclosure.



If you agree to take part in this interview, the information that you provide me with will be treated in the strictest confidence and your name will not be referred to in the recording of the interview nor will it be included in the research report.

The proposed interview will last approximately 45 to 60 minutes. During the course of the interview I would like to ask you to share with me your experiences and opinions about:

- What women go through when they learn that they are HIV positive and have to share their HIV positive results with their male partners
- What you think is the time (for example, during the pregnancy or after giving birth) – during which women find it easiest to tell their partners about their HIV test result
- What you think makes it easier for the women to share their HIV positive results with their partners during this time (as opposed to the other times)
- What kind of support you think women would require from the health services in order for them to feel sufficiently comfortable to share their results with their partners.

If you agree to take part in the interview, you are very free not to answer any question that you feel uncomfortable with. You can also tell me that you would like to stop the interview at any time. Please understand that there will be no negative implications for you if you decide not to participate in this study, or if you do not want to answer any of the questions, or if you decide you would like the interview to stop at any point. In order to help me remember what you have said during the interview I will want to tape record the interview but I will not be recording your name on tape. Immediately after I complete my research study and receive feedback on my work, the tape of this interview will be destroyed.

I have talked about quite a number of things. Is there anything that I have said so far that you would like me to explain, or repeat - or perhaps you would like to ask me a question about something that I have said up until now?

I would now like to ask if you are willing to participate in this research study.

If **YES**: thank you for agreeing to participate in the study. I would now like to ask you to sign the informed consent form. I will read it with you now so I am sure that you are comfortable with giving your consent to be interviewed.

If **NO**: [Thank the potential participant for their time in listening to you, re-assure them that they are perfectly welcome to make such a choice, and wish them well].

**1. Background data**

**1.1 How old are you?**

Age category (Years)	<15	15-24	25-34	35-44	45+	Doesn't know – but estimates her age as...
----------------------	-----	-------	-------	-------	-----	--

Tick as appropriate



**1.2 What level of education have you attained?**

Education level	None	Primary	Secondary	College/ University
-----------------	------	---------	-----------	---------------------

Tick as appropriate

**1.3 What is your relationship status?**

Marital Status	Never married	Married	Divorced or separated	Widowed	Staying Together	Has a boyfriend but do not stay together
----------------	---------------	---------	-----------------------	---------	------------------	--

Tick as appropriate

**1.4 How many pregnancies have you had before this one?**

Number of pregnancies	1 <sup>st</sup>	2 <sup>nd</sup>	3 <sup>rd</sup>	More than 3 (and write down the number)
-----------------------	-----------------	-----------------	-----------------	---

Tick as appropriate

**1.5 How many months is this pregnancy? (If she has already delivered, skip this question 1.5 and 1.6)**

Stage of pregnancy (months)	1-3	4-6	7-9
-----------------------------	-----	-----	-----

Tick as appropriate

**1.6 During your current pregnancy how many ANC visits have you made to this clinic or to any other clinic? (Ask to see client's ANC card to verify these details)**

No of ANC visits to this clinic to date

No of ANC visits to another / other clinics to date

**1.7 How old is your current baby**

Age of baby	Baby not yet born	0-6 days	7days-6weeks	7weeks-6months	7months – 12months+ 12 months
-------------	-------------------	----------	--------------	----------------	----------------------------------

Tick whichever is applicable



1.8 How long have you known that you are HIV+?

**2. Specific questions on HIV positive disclosure to Partners**

2.1 Do you think it is beneficial for pregnant women to be tested for HIV?

*(Probe: If Yes, ask 'what do you think are the benefits for pregnant women to be tested for HIV?' and probe further about:*

***Beneficiary: any benefits for the woman, the baby or her partner?***

2.2 Do you think a pregnant woman should tell her partner that she is going to go for an HIV test? *(Probe: Why or Why not)*

2.3 And if a pregnant woman learns that she *is* HIV positive, do you think she should inform her partners about her HIV positive status? *(Probe: Why/ why not?).*

2.4 When do think is the *best* time for a woman to tell her partner about her HIV positive status?  
(Probe: why that time/ why not any other time; is it during pregnancy or after delivery)

Further Probes, after getting the response of whether during pregnancy or after delivery:

**WHAT:** What makes it the best time?

**TIMING:** When do you think is the best time?

**WHO:** Who initiates HIV discussion at that particular time? Is it easier if the partner starts the HIV status discussion or the woman initiates it? Why?

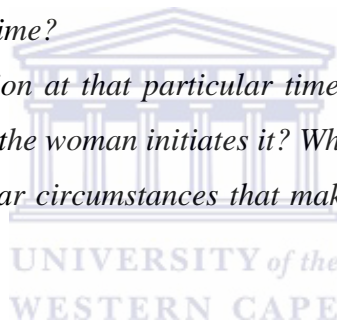
**SETTING:** are there any particular preparations a woman has to make when planning the time to disclose?

2.5 When do you think is the worst time for a woman to tell her partner about her positive HIV status? (Probe: why that time/ why not any other time; is it during pregnancy or after delivery)

**WHAT:** What makes it the worst time?

**WHO:** Who initiates HIV discussion at that particular time? Is it more difficult if the partner starts the HIV status discussion or the woman initiates it? Why?

**SETTING:** are there any particular circumstances that make it a bad idea to disclose positive HIV status?



2. 6. What do you think would help a woman choose the time when to share her HIV positive results with her partner?

2.8. It may not be easy for a woman to decide when to disclose her HIV positive status to her partner. What do you think makes it difficult for a woman to choose the time to disclose their HIV positive results to their partner?

2.9 Going by your own experience, when did you disclose your status to your partner?

(probe: how long after her test, relation to duration of pregnancy, why she chose that time)

2.10 From your experience, what was the benefit of your timing of disclosure (probes: was it the best time for you? How did your partner take it, in hindsight, would you have done things differently)

2.11 From your experience, what has been the consequence or what happened as a result of your disclosure to your partner? (*Probes: did your partner make you suffer? How? Or did you have his support? How?*)

2.12. What do you think health workers should do to help HIV+ pregnant women to choose the timing when to disclose their results to their partner?

(*Probes: just after learning the result, later in the pregnancy, at the time of delivery, when baby is born, when resuming sexual activity*)

**WHAT:** *What information and help do you think is beneficial to get when choosing the time to disclose to your partner?*

**TIMING:** *When during your pregnancy (or after delivery) do you think it would be most beneficial to get this help? Why?*

**WHO:** *Who do you think can best help with this information and support? Why?*

**SETTING:** *Do you think the health workers should make arrangements for partners to HIV positive women receive HIV related services like testing and counselling?*

We have come to the end of the interview. I would like to thank you for taking time to answer my questions, and reassure you again that whatever information we have discussed here will be only for the purpose of fulfilling my studies and to help the health workers to support you better.

I would like to remind you that this information will be treated in the strictest confidence and your name will not be referred to in the interview transcription nor will it be included in the research report.

Do you have any questions to ask me?

I would like to thank you for participating in this interview and I wish you well.

**End of Interview**

## Appendix 5



University of the Western Cape

### Faculty of Community and Health Sciences

P/Bag X17, Bellville 7535, South Africa Tel.: +27 21 9592163 Fax: +27 21 9592755

### Guide for Interviews with Health Workers

Good morning, my name is Maximillian Bweupe, a student of Public Health with the University of Western Cape, South Africa. I'm here to see if you would mind if I ask you a few questions which are part of my student research project but that will also, hopefully, help to improve the support that women, especially those that test positive for HIV, can get from the health services. I am specifically interested in finding out what support the staff at a facility like this ought to give to women living with HIV in order to assist them to disclose their HIV positive status to their partners.

Here is some information about the research that I am doing. This is for you to keep but I will explain all of the information that is on that sheet to you now.

**[Give potential participant the information sheet]**

I would like to assure you from the onset that, should you agree to take part in the interview, that whatever information we discuss here will be solely for the purpose of my studies and to suggest to the district health management team in Lusaka how they and health workers might be able to offer more support to HIV positive women in relation to disclosure.

If you agree to take part in this interview, the information that you provide me with will be treated in the strictest confidence and your name will not be referred to in the recording of the interview nor will it be included in the research report. In asking these questions I would like to find out what your experiences and thoughts are about the timing when women choose to disclose their HIV positive results to their partners. Also I would like to know as health workers what your experiences have been in supporting the disclosure process. My focus will be on the timing of the disclosure process by HIV positive women as a way of understanding this aspect of the disclosure process.

If you agreed to participate in this interview, you do not have to answer any or all of the questions that are uncomfortable with. You can also tell me that you would like to stop the interview at any time.

Please understand that there will be no negative implications if you decide that you do not want to participate in an interview or if you decide to be interviewed and do not want to answer any of the questions or would like the interview to stop at any point.

In order to help me remember what someone has said during an interview I will want to tape record the interview but I will not be recording your name on the tape.

Immediately after I complete my research study and receive the results, the tape of this interview will be destroyed. This interview will last about 30 - 45 minutes. There will be no money for your participation in the interview.

I have talked about quite a number of things. Is there anything that I have said so far that you would like me to explain, or repeat - or perhaps you would like to ask me a question about something that I have said up until now?

I would now like to ask if you are willing to participate in this research study.

If **YES**: thank you for agreeing to participate in the study. I would now like to ask you to sign the informed consent form. I will read it with you now so I am sure that you are comfortable with giving your consent to be interviewed.



If **NO**: [Thank the potential participant for their time in listening to you, re-assure them that they are perfectly welcome to make such a choice, and wish them well].

First I would like to find out some background information about your services here:

### **3 Background data**

3.1. How long have you been working in the field of PMTCT?

3.2. How long have you been working in the PMTCT program in this particular clinic?

3.3 What is your specific role in relation to the above programme? (Testing, counselling, providing medicines, in-charge or more or less all the above)

3.5 What proportion of HIV positive women who are PMTCT clients that you see at this clinic disclose their results HIV results to their partners? Can you estimate if you don't know?

### **4. Specific questions about timing of disclosure**

4.1 What do you tell or inform your clients about the issue of disclosing their HIV results to their partners? When is this done?

4.2 In your experience, when during the pregnancy or after giving birth do women disclose their HIV status to their partners? Why that time/those times?

*(Probes: just after learning the result, later in the pregnancy, at the time of delivery, when baby is born, when resuming sexual activity)*

**WHAT:** *What do the women tell their partners?*

**TIMING:** *When during the women's pregnancy (or after delivery) do you think women mostly disclose? What information or help would be most beneficial for women at that time?*

**WHO:** *Who do you think can best help with this information and support? Why?*

**SETTING:** *Do you think the health workers should make arrangements for partners to HIV positive women receive HIV related services like testing and counselling? Why?*

4.4 Why do you feel that it is important for pregnant women to disclose their HIV results to their partners?

4.5 What do you think are the reasons why women choose certain times to disclose to their partners, and not other times?

4.6 What support or follow up action do you currently provide for women that have not disclosed their results to their partner?

4.7 For women that have disclosed their HIV results to their partners, what do you think made it easier for them to do so?

4.8 How do you think that you can improve your support to women on the PMTCT programme around the timing of disclosure?

*Prompts:*

***When; during which routine visit to the health centre, should the disclosure process be discussed, and when the partners should be brought into HIV care as well.***

***What kind of extra skills if any, or training, or information or job aids do health workers need to assist women beneficially time their disclosure to. What information do women need for them to time their disclosure?***

***Who would best be placed within the health centre to assist women plan their timing of disclosure, and the women with providing them with appropriate information they need to have.***

***Where would the partners be seen from to provide HIV related services including testing and counselling, if it is desired, following disclosure?***

4.9 What additional support would you need as health workers to provide this type of support?

*(Probe: more training on couple counselling, understanding the disclosure process, neighborhood mother support groups*

5.0 *Couple counselling- could you describe what you do in terms of supporting timing of disclosure through couple counselling?*

***Where is couple counselling done? Is couple counselling helpful in helping with the timing of disclosure?***

***How often is couple counselling done for any particular couple, and how often is it available in the health centre?***

*Which support groups can couples be referred to in the community*

***Who actually does the couples counselling?***

I want to sincerely thank you for allowing me to interview you, and taking time to answer to my questions. Let me re- assure you again that whatever information we have discussed here will be solely for the purpose of my fulfilling my studies, and contribute to health workers more beneficially support women who are HIV positive.

This information will be treated in the strictest confidence as your name will not be referred to in the interview nor will it be included in the research report. Do you have any questions for me?

I would like to thank you for participating in this interview and I wish you well.

**End of Interview**

