

FACTORS INFLUENCING DISCLOSURE OF HIV STATUS TO SEXUAL PARTNERS IN BOTSWANA

by

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DECLARATION

I declare that **FACTORS INFLUENCING DISCLOSURE OF HIV STATUS TO SEXUAL PARTNERS IN BOTSWANA** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.



.....
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FACTORS INFLUENCING DISCLOSURE OF HIV STATUS TO SEXUAL PARTNERS IN BOTSWANA

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ABSTRACT

The study aimed to explore and describe the factors influencing disclosure of Human Immunodeficiency Virus (HIV) status to sexual partners by people infected with HIV in Botswana, by undertaking an exploratory and descriptive qualitative study. Data was collected through in-depth interviews with people infected with HIV who had disclosed their HIV status to their partners.

The major findings of the study confirmed disclosure as a multi-stage process. People infected with HIV experienced mainly positive and some negative outcomes following disclosure. Disclosure was associated with the discloser's motivations, personal and cultural beliefs, risk-benefit assessment, individual circumstances (context), previous experiences, and perceived degree of control over private information.

The communication privacy management (CPM) theory helped explain the findings. The key factor influencing disclosure was protecting others. Non-disclosers had also seriously considered disclosing to partners.

Key concepts

Communication; disclosure; HIV status; HIV testing; communication privacy management theory; privacy; private information; reactions; sexual partner.

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CHAPTER 1

ORIENTATION TO THE STUDY

1.1	INTRODUCTION	1
1.2	BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM	2
1.2.1	The source of the research problem.....	2
1.2.2	Background to the research problem.....	3
1.3	STATEMENT OF THE RESEARCH PROBLEM	4
1.4	PURPOSE AND OBJECTIVES OF THE STUDY	5
1.4.1	Purpose of the study.....	5
1.4.2	Study objectives	5
1.5	SIGNIFICANCE OF STUDY	6
1.6	DEFINITIONS OF KEY CONCEPTS.....	6
1.6.1	Disclosure: Theoretical definition.....	6
1.6.2	Disclosure: Operational definition.....	7
1.6.3	Sexual partner	7
1.7	FOUNDATIONS OF THE STUDY	7
1.7.1	Theoretical framework	7
1.7.1.1	Theory of disease progression	7
1.7.1.2	Theory of competing consequences.....	8
1.7.1.3	Communication privacy management theory	8
1.8	THE RESEARCH METHODOLOGY	8
1.8.1	Research design.....	8
1.8.2	Study population.....	8
1.8.3	Sample and sampling technique.....	9
1.8.4	Method of data collection.....	9
1.8.4.1	The interview schedule.....	9
1.8.4.2	Field notes.....	9
1.8.5	Method of data analysis.....	9
1.8.6	Ethical considerations.....	10

Table of contents		Page
1.9	STRUCTURE OF THE DISSERTATION.....	10
1.10	CONCLUSION.....	11
CHAPTER 2		
RESEARCH METHODOLOGY		
2.1	INTRODUCTION.....	12
2.2	PURPOSE AND OBJECTIVES OF THE STUDY.....	12
2.3	RESEARCH CONTEXT.....	12
2.3.1	The context.....	13
2.3.2	The setting of the study.....	13
2.4	RESEARCH DESIGN.....	14
2.4.1	Qualitative approach.....	14
2.4.2	Phenomenology.....	14
2.4.3	Exploratory design.....	15
2.4.4	Descriptive design.....	15
2.5	POPULATION.....	15
2.6	SAMPLE AND SAMPLING.....	16
2.6.1	Sample size.....	16
2.6.2	Sampling.....	16
2.6.2.1	Purposeful sampling technique.....	17
2.6.2.2	Eligibility criteria.....	17
2.7	DATA COLLECTION.....	18
2.7.1	Data collection approach.....	18
2.7.1.1	Unstructured in-depth interview.....	18
2.7.1.2	Pilot interview.....	19
2.7.1.3	Field notes.....	19
2.7.2	Data collection process.....	20
2.8	DATA ANALYSIS.....	21
2.8.1	Familiarisation with the data.....	22
2.8.2	Transcription.....	23
2.8.3	Organising data.....	23
2.8.4	Coding.....	24

2.8.4.1	Open coding and delineation of emergent concepts	25
2.8.4.2	Conceptual coding and refinement of conceptual coding schemes.....	25
2.8.4.3	Categories and subcategories	26
2.8.4.4	Identifying themes	26
2.8.4.5	Literature control.....	27
2.9	TRUSTWORTHINESS OF THE STUDY	27
2.9.1	Credibility.....	27
2.9.2	Dependability.....	28
2.9.3	Confirmability.....	29
2.9.4	Transferability.....	29
2.9.5	Authenticity.....	30
2.10	ETHICAL CONSIDERATIONS	30
2.10.1	Voluntary participation	30
2.10.2	Informed consent to participation.....	31
2.10.3	Anonymity and confidentiality	31
2.10.4	Deception	32
2.10.5	Analysis and reporting of data	32
2.10.6	The Medical Research Council (MRC) ethics.....	32
2.10.6.1	Autonomy	33
2.10.6.2	Beneficence.....	33
2.10.6.3	Non-maleficence.....	33
2.10.6.4	Justice	34
2.11	CONCLUSION.....	34

CHAPTER 3

DATA ANALYSIS AND PRESENTATION OF RESULTS

3.1	INTRODUCTION	35
3.2	DATA ANALYSIS PROCESS	35
3.3	BIOGRAPHICAL DATA	36
3.4	OVERVIEW OF THEMES AND CATEGORIES FROM INTERVIEWS	37
3.4.1	Theme 1: Reasons for HIV testing.....	37
3.4.2	Theme 2: Pre-disclosure deliberations	39

Table of contents		Page
3.4.2.1	Negative thoughts.....	40
3.4.2.2	Positive thoughts	40
3.4.2.3	Indifference.....	41
3.4.3	Theme 3: Process of disclosure	42
3.4.3.1	Pre-disclosure clues	42
3.4.3.2	Time taken from knowing results to disclosing results.....	44
3.4.3.3	Mode of communication	44
3.4.4	Theme 4: Reasons for disclosing HIV status.....	46
3.4.4.1	Others-focused factors	46
3.4.4.2	Self focused.....	47
3.4.5	Theme 5: Reasons against disclosing HIV status	50
3.4.5.1	Discloser perceptions	50
3.4.5.2	Partner perceptions	50
3.4.5.3	Other perceptions	51
3.4.6	Theme 6: Initial reactions to disclosure	52
3.4.6.1	Self	52
3.4.6.2	Partner.....	53
3.4.7	Theme 7: Consequences of disclosure	54
3.4.7.1	Positive effects	55
3.4.7.2	Negative effects.....	55
3.4.8	Theme 8: Participants' recommendations	57
3.4.8.1	Supportive measures.....	58
3.4.8.2	Punitive measures.....	59
3.5	CONCLUSION.....	60

CHAPTER 4

DISCUSSION OF FINDINGS AND LITERATURE REVIEW

4.1	INTRODUCTION	62
4.2	DISCUSSION OF THEMES AND LITERATURE CONTROL	62
4.2.1	Reasons for HIV testing.....	63
4.2.2	Pre-disclosure deliberations	64
4.2.3	Process of disclosure	65
4.2.4	Reasons for disclosing HIV status.....	68
4.2.5	Reasons against disclosing HIV status.....	70
4.2.6	Initial reactions to disclosure.....	71
4.2.7	Consequences of disclosure.....	72

Table of contents	Page
4.2.8	Participants recommendations 72
4.3	THEORIES OF HIV DISCLOSURE 73
4.3.1	Disease progression 73
4.3.2	Theory of competing consequences 74
4.3.3	Communication privacy management (CPM) theory 74
4.4	COMMUNICATION PRIVACY MANAGEMENT (CPM) THEORY AND DISCLOSURE OF HIV STATUS IN DISCLOSURE TO SEXUAL PARTNERS 79
4.5	CONCLUSION 80
CHAPTER 5	
CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS	
5.1	INTRODUCTION 81
5.2	MAIN FINDINGS 81
5.2.1	Factors which relate to disclosure of HIV status to sexual partners 82
5.2.1.1	Impact of demographic characteristics 82
5.2.1.2	HIV testing and its impact on disclosure 83
5.2.1.3	Influence of pre-disclosure deliberations on disclosure 84
5.2.1.4	The process of disclosure 85
5.2.2	Factors influencing disclosure of HIV status to partners 87
5.2.2.1	Reasons for disclosing HIV status 87
5.2.2.2	Others focused 88
5.2.2.3	Self-focussed 88
5.2.3	Barriers to disclosing HIV status 91
5.3	FINDINGS AND CONCLUSIONS IN RELATION TO THE CPM THEORY 92
5.4	STUDY LIMITATIONS 97
5.5	RECOMMENDATIONS 97
5.5.1	Recommendations for evidence-based guidelines to enhance disclosure 97
5.5.1.1	Recommendations from CPM theory privacy rule management criteria 98
5.5.1.2	Recommendations for practice and health education 101
5.5.2	Recommendations for further research 101
5.6	CONCLUSION 102
LIST OF REFERENCES 104	

List of tables	Page
Table 3.1 Demographic data of the participants	36
Table 3.2 Summary of Theme 1: Reasons for HIV testing.....	39
Table 3.3 Summary of pre-disclosure deliberations.....	42
Table 3.4 Process of disclosure.....	45
Table 3.5 Factors influencing disclosure of HIV status	49
Table 3.6 Reasons against disclosing HIV status	51
Table 3.7 Initial reactions to disclosure.....	54
Table 3.8 Consequences of disclosure.....	56
Table 5.1 Findings based on CPM theory.....	96
Table 5.2 Recommendations based on CPM theory	100

List of abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral treatment
BAIS	Botswana Aids Impact Survey
BBC	British Broadcasting Corporation
CPM	Communication privacy management
HAART	Highly active antiretroviral treatment
HIV	Human Immunodeficiency Virus
MRC	Medical Research Council
NACA	National Aids Coordinating Agency
PPP	Public-Private-Partnership
SAT	Southern African Aids Trust
UNISA	University of South Africa
USA	United States of America
WHO	World Health Organization
1Y	Yellow
2O	Orange
3LG	Light Green
4LB	Light Blue
5DB	Dark Blue
6DG	Dark Green
7R	Red
8P	Purple

List of annexures

Annexure A	Research clearance certificate from UNISA Ethics Committee
Annexure B	Permission letter from Ministry of Health, Botswana
Annexure C	Permission letter from GMT Surgery
Annexure D	Interview schedule
Annexure E	Reflective diary
Annexure F	Consent form – Setswana
Annexure G	Consent form – English
Annexure H	Field notes: an example
Annexure I	Setswana interview script
Annexure J	English interview script
Annexure K	Data analysis illustration of interview script

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

This study aims to gain a deeper understanding of the reasons why Human Immunodeficiency Virus (HIV) infected people in Botswana choose whether to tell or not to tell their partners that they are HIV positive. Secrets exist because people decide to keep private certain information about them. Disclosure of private information is likely to be complex, and even more so in the context of disclosing one's HIV status, which involves sensitive, potentially life-threatening information and the stigma that can be associated with the condition.

Disclosure of HIV status to sexual partners has increasingly gained prominence in management of Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS). According to Simoni and Pantalone (2004:109), many public health officials have shifted their HIV prevention methods from targeting populations at risk of HIV infection to those infected with HIV. The thinking behind this policy is based on the premise that if those infected with HIV disclose their status, then safer sex will occur and lead to reduced HIV transmission. Norman, Chopra and Kadiyala (2005:1) also observe that in some resource-limited settings, disclosure of HIV status is one of the prerequisites for enrolment into national HIV programmes. In Botswana, the National Aids Coordinating Agency (NACA) operates a "buddy system" whereby each patient is encouraged to form a special bond with someone close, to enhance adherence to HIV treatment. The patients therefore are urged to disclose their HIV status to the buddy (Botswana's high-stakes assault on AIDS 2002:4). Such a buddy could be the partner of the HIV infected person.

In the past 8 to 10 years, there has been a lot of research on the concept of disclosing HIV sero-positive status to sexual partners. There are, however, no recent qualitative studies investigating disclosure of HIV status to sexual partners in Botswana.

This study therefore aimed to determine specific factors which could influence disclosure or non-disclosure of HIV status to sexual partners among those infected with HIV in Botswana. The study was prompted by the scarcity of qualitative studies examining factors which influence disclosure of HIV status among people infected with HIV, especially in Botswana.

1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH PROBLEM

1.2.1 The source of the research problem

The ideas about the research problem have come from a variety of sources, including personal experiences, working with young people in a religious establishment and academic discussions with other health care professionals at the Botswana branch of the Southern African HIV Clinicians Society, who also faced challenges of dealing with problems arising from non-disclosure of HIV status to sexual partners. According to Zuiderduin and Melville (2000:3), the concept of shared confidentiality was introduced as part of the law in Botswana in 1999 through the Statutory Instrument number 77 of 1999. The authors indicate that the Botswana Medical Council (professional conduct) regulations 1988 were amended in 1999 by inserting a new sub-regulation which provides that “a person taking care of, living with or otherwise coming into regular close contact with the patient shall be informed (by medical professionals) of such patient’s medical condition where the said patient is suffering from a communicable disease or has an infection which may be passed to such person if appropriate precautions are not taken”. A person coming into regular close contact with an HIV infected person could be their partner. This amendment has caused concern among human rights groups in Botswana, who argue that the number of persons falling in “the close contact” category could be unlimited and that this regulation might lead to abuse. There is also a concern that the law, as it is, might reduce voluntary HIV testing, because if one does not go for the test, then there is no requirement for one’s private information to be disclosed to others.

1.2.2 Background to the research problem

In 2007, the Botswana government undertook the Botswana Aids Impact Survey III (BAIS III), a study aimed at providing up-to-date information about the HIV/AIDS pandemic in the country with respect to prevalence, incidence, knowledge, care and support for people living with HIV/AIDS. Prevalence and incidence rates in the survey were estimated by actually taking blood samples from more than 8 000 households. The study (BAIS III 2008:3) estimated a country HIV prevalence rate of 17.6% and an incidence rate of 2.89%, equating to an estimated total of 10 587 new HIV cases in Botswana in 2008. The incidence rate of more than 10 000 new cases in a country with a population of 1.6 million is a cause for concern which calls for measures to strengthen the public health efforts to prevent HIV transmission.

This research is important for several reasons. The first HIV positive case in Botswana was diagnosed in 1985 (WHO 2005:1). Twenty years later Botswana had the second highest prevalence rate of HIV in the world, according to the (WHO 2005:1). New cases of HIV infection are still high, as estimated by the BAIS III study. It is also interesting to note that disclosure issues or rates were not even included as part of the outcomes of the BAIS III study.

The Botswana government launched the MASA (meaning new dawn) national HIV programme in 2002. This is a programme whereby a cocktail of antiretroviral drugs, called the highly active antiretroviral treatment (HAART), is provided by the government to treat those with HIV/AIDS. HAART suppresses HIV but does not eradicate it. This form of therapy has been shown to increase life expectancy of AIDS patients (Crum, Riffenburgh & Wegner 2006:196). Statistics compiled by the WHO (2005:1) show that by October 2005, 55 829 people were receiving HAART in Botswana. While these patients live longer and do not show the common signs and symptoms of AIDS, they are still able to transmit the virus and can infect others. Kalichman and Nachimson (1999:281-287) found in their study in America that men and women who did not disclose their HIV status were also more likely to engage in unsafe sex.

Only one study on disclosure of HIV status to others done in Botswana was found in the published literature. Wolfe, Weiser, Bangsberg, Thior, Makhema, Dickinson, Mompoti

and Marlink (2006:932) investigated disclosure of HIV status in 112 patients receiving antiretroviral treatment (ART) in private clinics. The study respondents had to be over the age of 18. Out of the 112 respondents, only 10 were under 30 years old. In this study 94% of respondents reported keeping their HIV status secret from their community; 69% withheld this information even from their family, while 12% had told no one. This was a quantitative study.

Simoni and Pantalone (2004:110) reviewed 15 published studies which tried to find an association between disclosure of HIV status and practising of safe sex. The evidence they found was contradictory, with some studies suggesting that disclosure of HIV status does not always lead to practice of safe sex (Serovich & Mosack 2003:78). Other studies suggested that non-disclosure does not necessarily lead to unsafe sex, as some HIV infected people may practise uninformed protection. (This is when they take stringent precautionary measures to practise safe sex without telling their partners that they are HIV positive) (Crepaz & Marks 2003:379). In some developed countries such as the United States and some European countries, the law requires disclosure of HIV status before engaging in sexual activities. Recently a German pop star was in court charged with knowingly engaging in sexual practices with various partners without disclosing her status to them (BBC One. 2010. *The Ten o'clock News*. 26 August 2010, 22:00).

The above background information shows that disclosure of HIV status is not an issue in Botswana alone, but it is also a problem in developed countries.

Effective prevention efforts ought to involve and engage HIV infected people in a way that they understand and closely identify with. Such efforts could bear fruit if they are at a suitably tailored level. Therefore identifying the factors which those infected with HIV consider important in their decision on whether to disclose their HIV status to others, and incorporating such factors into HIV prevention policies and messages, could reasonably be expected to help in HIV prevention efforts.

1.3 STATEMENT OF THE RESEARCH PROBLEM

The Botswana government introduced HIV treatment for all in 2002. With the availability of free HIV treating drugs, more people will live longer and risk transmitting the virus to

others. This statement appears to be validated by findings from the Botswana Aids Impact Survey III carried out in 2007 (BAIS III 2008:3), which estimates a national HIV prevalence rate of 17.6% that was shown to peak among the 30-45 year age group at around 40%. The survey also estimates an incidence rate of nearly 3%, which equates to more than 10 000 new cases of HIV infection in 2008. Such a high incidence rate of HIV infections in a developing country with limited resources is a cause for concern and requires further urgent public health interventions to bring it down. Given that disclosure of HIV status by HIV infected people is increasingly being adopted as one of the public health strategies to reduce HIV transmission, it becomes critical to understand the factors promoting or discouraging disclosure of HIV status if this strategy is to have an impact on reducing HIV transmission.

1.4 PURPOSE AND OBJECTIVES OF THE STUDY

In order to gain more insight into the lived experiences of participants associated with disclosure of HIV status to sexual partners, the following purpose and objectives were stated:

1.4.1 Purpose of the study

The purpose of this study was to explore and describe the factors influencing disclosure of HIV status to sexual partners by people infected with HIV in Botswana.

1.4.2 Study objectives

The objectives of the study were to

- explore and describe positive and negative factors which relate to the disclosure of one's HIV status to sexual partners
- provide evidence-based recommendations which could assist HIV infected people in disclosing their HIV status to their sexual partners

1.5 SIGNIFICANCE OF THE STUDY

The expected benefits of this study can be divided into policy enhancement, practice improvement and additional knowledge for scholarly research. Data from this research will be locally generated and therefore more relevant to the setting of HIV prevention in Botswana. It is also expected that it will improve use of resources by coming up with relevant, evidence-based recommendations for addressing issues surrounding disclosure of HIV status among those infected with the virus. It will also help inform policy makers regarding the probable impact of adopting the strategy of HIV disclosure as a public health measure when planning HIV prevention programmes. Information from the study could help towards developing counselling tools to identify those likely to encounter difficulties when faced with disclosing their HIV status, as part of both pre- and post-HIV testing and counselling. The information could also be of help to those responsible for setting curricula at institutions which train health care workers, especially those working with vulnerable people in community-based health care services. The research is also expected to highlight gaps in this area of research and add to the existing body of knowledge by stimulating further research in this area.

1.6 DEFINITIONS OF KEY CONCEPTS

1.6.1 Disclosure: Theoretical definition

Greene, Derlega, Yep and Petronio (2003:5) define self-disclosure as a process which consists of voluntary sharing of personal information between two individuals involved in a social interaction, each with their own feelings, beliefs, attitudes and values.

The Southern African Aids Trust (SAT) identifies five types of disclosure. These are: involuntary disclosure; voluntary disclosure; full disclosure; partial disclosure; and non-disclosure. Involuntary disclosure happens when someone else reveals someone's HIV status without their approval or even their knowledge. Voluntary disclosure defines disclosure which occurs when clients share information about their HIV status with others; it may be full or partial. Full disclosure is defined as a type of voluntary disclosure whereby the client reveals their HIV status to a person or organisation such as a family member, support organisation or the media. Partial disclosure is defined as

disclosure which occurs when the client will only tell certain people, such as a partner or spouse, about the HIV status. Non-disclosure occurs when the client does not reveal the HIV status to anyone (SAT 2004:1).

1.6.2 Disclosure: Operational definition

For purposes of this study, the concept of disclosure was used to describe voluntary, partial disclosure whereby the HIV infected individual voluntarily reveals their HIV status to their sexual partner after sexual contact has occurred.

1.6.3 Sexual partner

Sexual partner (also referred to as partner in this study) is taken to mean a person with whom there is engagement in acts of sexual nature including voluntary sexual intercourse within or outside of a committed relationship.

1.7 FOUNDATIONS OF THE STUDY

1.7.1 Theoretical framework

Three theories which have been advanced to explain the behaviour involved in disclosure of HIV status have been identified in the literature. These theories and their applicability will be discussed in more detail in chapter 4.

1.7.1.1 *Theory of disease progression*

Serovich (2001:356) cites Babcock and Kalichman, who indicate that the premise of this theory is that individuals disclose their HIV diagnosis as they become ill because as the illness progresses they can no longer keep it a secret.

1.7.1.2 Theory of competing consequences

According to the consequences theory, the relationship between disclosure and disease progression is moderated by the consequences one anticipates resulting from disclosure (Serovich 2001:356). It postulates that as the disease progresses, evaluations of likely outcomes of disclosure take place; disclosure then occurs once rewards outweigh costs.

1.7.1.3 Communication privacy management (CPM) theory

This is a theory initially postulated by Petronio in 2004, which examines why people make decisions about revealing or not revealing private information about themselves. Petronio (2004:196) first thought of privacy as the key to understanding disclosure and looked at disclosure from two aspects: content and process. The theory assumes a mutually exclusive relationship between disclosure and privacy, whereby one cannot exist without the other.

1.8 THE RESEARCH METHODOLOGY

1.8.1 Research design

Babbie (2007:87) defines research design as a plan which details and determines how the research is going to be carried out. This study will be in the form of an exploratory and descriptive qualitative design, which will be described in more detail in chapter 2.

1.8.2 Study population

Population is defined as the entire aggregation of cases in which the researcher is interested (Polit & Beck 2008:237). The study population is made up of people infected with HIV attending the selected private medical clinic in Gaborone, Botswana.

1.8.3 Sample and sampling technique

Polit and Beck (2008:338) define sampling as the process of selecting a portion of the population to represent the entire population so that inferences can be drawn.

The sampling technique used in this study was a non-probability, purposive sampling technique based on the eligibility criteria set for the study (see chapter 2).

1.8.4 Method of data collection

Burns and Grove (2005:539) describe data collection as a precise and systematic gathering of information which is relevant to the research purpose, objectives and questions. Data collection can therefore be seen as a means to achieve the objectives of the study and fulfil the purpose of the study. Data may be structured or unstructured. In this study, unstructured interviews were used as the main method of data collection. This was augmented by field notes (see annexures H) and a reflective diary (see annexure E).

1.8.4.1 The interview schedule

The interview schedule contained a grand tour question to the participant and the study objectives (see annexure D). There were no further pre-set questions. The researcher used probing questions as the discussion evolved. The responses and conversation that followed were all tape recorded.

1.8.4.2 Field notes

Data collected during interviews were augmented by field notes, which were also used as part of the data analysis (see annexure K).

1.8.5 Method of data analysis

Qualitative data analysis, which involves the non-numerical examination and interpretation of observations for the purpose of discovering underlying meanings and

patterns of relationships was undertaken (Babbie 2007:378). Detailed description of data analysis will be provided in chapter 3.

1.8.6 Ethical considerations

This research collected information about people's backgrounds, knowledge, attitudes and behaviour. The researcher was interacting with human subjects whose human rights and privacy had to be protected. The Medical Research Council (MRC) of South Africa promotes the four main principles of biomedical ethics. These are:

- Autonomy (respect for the person – a notion of human dignity)
- Beneficence (benefit to the research participant)
- Non-maleficence (absence of harm to the research participant)
- Justice, which refers to equal distribution of risks and benefits between communities (South Africa (Republic) 2000:para 1.3.1)

Throughout the study these ethical principles were observed. In addition, scientific honesty was held in the highest esteem, with unexpected or negative results given the same priority in data analysis and interpretation as positive results.

1.9 STRUCTURE OF THE DISSERTATION

This section gives an outline of the organisation of the report.

Chapter 1

Chapter 1 introduced and gave an overview of the study.

Chapter 2

Chapter 2 will discuss the methodology to be followed in the study.

Chapter 3

In this chapter a presentation of results and analysis of data from the study will be undertaken.

Chapter 4

This chapter discusses and reviews the literature on the concept of disclosure based on previous studies exploring this concept.

Chapter 5

The final chapter will discuss the results, come up with conclusions, identify study limitations and suggest further areas of research on disclosure of HIV status.

1.10 CONCLUSION

Disclosure of HIV status has been put at the forefront of the fight against transmission of HIV. Public health specialists have switched prevention measures from targeting those at risk to those who are already infected. This is due to the belief that increasing rates of disclosure of HIV status will result in safer sexual behaviour and reduction in HIV transmission rates. Any studies exploring reasons why people disclose or do not disclose their HIV status have mainly been done among adults in developed countries. No qualitative studies directly exploring reasons for disclosure and non-disclosure to sexual partners by people infected with HIV in Botswana have been identified. This chapter has introduced the study by looking at the purpose, objectives and significance of such a qualitative study. The next chapter will discuss the methodological aspects of the study.

CHAPTER 2

RESEARCH METHODOLOGY

2.1 INTRODUCTION

This chapter introduces and elaborates on the methodological aspects which were used to conduct the study in order to meet the research objectives. Aspects of the methodology such as research design, sampling technique used, data collection methods and proposed methods of data analysis are discussed, as well as ethical considerations undertaken during the research.

2.2 PURPOSE AND OBJECTIVES OF THE STUDY

The purpose of this study was to explore and describe the factors influencing disclosure of HIV status to sexual partners by people infected with HIV in Botswana.

The objectives of the study were to

- explore and describe positive and negative factors which relate to the disclosure of one's HIV status to sexual partners
- provide evidence-based recommendations which could assist HIV infected people in disclosing their HIV status to their sexual partners

2.3 RESEARCH CONTEXT

This section describes the research setting and the context within which the study took place.

2.3.1 The context

Botswana is a landlocked country in sub-Saharan Africa with an estimated population of 1 882 000 in 2007 (UNAIDS/WHO 2008:4). The capital city is Gaborone, where the study was conducted. The country has an estimated HIV prevalence rate of 23.9%; 280 000 adults 15 years and over and 15 000 children under the age of 15 are infected with HIV/AIDS (UNAIDS/WHO 2008:4-16).

2.3.2 The setting of the study

The study was conducted among a population of people infected with HIV attending a selected private clinic in Gaborone, Botswana. The clinic was chosen as a population base for several reasons. The research topic was first conceived while the researcher worked at the clinic. The researcher and other clinicians in the area had experienced ethical dilemmas resulting from non-disclosure of HIV status to sexual partners.

Observations were made which indicated that older, married HIV-infected men were fathering children with younger girls who were unaware of the men's HIV status. The clinic was also chosen because it provides health care services to a wide area of the city and to patients from varied social backgrounds and therefore provides the opportunity for collection of the kind of rich information that the study aimed to obtain.

Some of the participants in this study belong to the Public-Private-Partnership (PPP). The partnership came about as a government initiative to relieve congestion in the government facilities and to reduce waiting times for access to HIV treatment and care. The public patients have all their HIV care needs paid for privately by the government. Most of the patients are either unemployed or in low-paid jobs and could not otherwise afford the HIV treatment and care.

2.4 RESEARCH DESIGN

Babbie (2007:87) defines a research design as a plan which details and determines how research is going to be carried out. This study was in the form of an exploratory and descriptive qualitative design.

2.4.1 Qualitative approach

According to Burns and Grove (2005:747), qualitative research is a systematic, interactive subjective approach used to describe and give meaning to life experiences. Being diagnosed with HIV infection is a traumatic event which dictates that some life-changing decisions have to be made. One of those decisions is whether to disclose one's HIV status to others.

The qualitative approach is the one most suited to studying the phenomenon of disclosure, because, as mentioned by Polit and Beck (2008:56), the information gathered in qualitative studies is in the form of narrative descriptions which may help to gain deep understanding of human experiences. The qualitative approach enabled participants to describe their experiences in real terms and in great detail. It also enabled the researcher to interact with, probe and observe participants in a setting familiar to them.

There are several qualitative research traditions, including grounded theory, phenomenology and ethnography. The phenomenological approach was used in this study.

2.4.2 Phenomenology

Polit and Beck (2008:64) describe phenomenology as a qualitative research approach used to gain an understanding of what life experiences of people are like and the meaning of a phenomenon to those who experience it. Burns and Grove (2009:54) reinforce this definition by indicating that the purpose of phenomenological research is to capture the lived experiences of participants. The researcher considered this the most suitable approach because it allowed people infected with HIV to describe their

experiences associated with the phenomenon of disclosure of their HIV status in detail. Some of the experiences described and the emotions associated with the descriptions left a lasting impression in the researcher's mind. Burns and Grove (2009:55) go on to argue that phenomena occur only when there is a person who personally experiences the phenomenon and that the language used by people in a phenomenological approach study helps to illuminate the nature of the phenomenon of interest.

2.4.3 Exploratory design

Exploratory studies are used to gain insight into situations, phenomena, communities or persons (De Vos, Strydom, Fouche & Delpont 2005:134). Babbie (2007:88) describes exploratory studies as those which researchers can use to familiarise themselves with the topic, or to develop a new interest in a topic. Exploratory studies also give approximate answers to questions about persistent phenomena by finding out why things occur the way they do. By adopting an exploratory approach the researcher was able to gain more insight into the lived experiences of HIV infected participants associated with disclosure of their HIV status.

2.4.4 Descriptive design

According to Babbie (2007:89), descriptive studies are those used to describe situations and events. Descriptive studies tend to use small samples, which help in examining research situations in more depth (Burns & Grove 2005:356). A descriptive study was therefore suitable for this research because the study aimed to understand and describe the experiences of people infected with HIV associated with disclosure of their HIV status to their sexual partners. The participants voluntarily described their experiences following disclosure in detail during the interviews.

2.5 POPULATION

A population is defined as the entire aggregation of cases in which the researcher is interested; it may be as narrow as possible or may be broadly defined (Polit & Beck 2008:237). This study population was made up of patients infected with HIV attending a private medical clinic in Gaborone, Botswana.

2.6 SAMPLE AND SAMPLING

This section describes the process of sampling as undertaken in this study including sample size, sampling technique and the eligibility criteria used to select the sample.

2.6.1 Sample size

According to Patton (2002) in De Vos et al (2005:328), there are no rules for sample size in qualitative studies. Qualitative research involves looking deeply at a few things rather than looking at the surface of many things. It therefore involves studying and looking at few individuals, sometimes just one person (Litchman 2009:17).

Burns and Grove (2009:361) assert that the number of participants in a qualitative study is adequate when saturation of information is achieved in a study area. Saturation of data occurs when additional sampling provides no new information. The sample size in this study was therefore determined by saturation of data collected. A total of nine interviews from participants who met the eligibility criteria were completed successfully during the study.

2.6.2 Sampling

Polit and Beck (2008:338) define sampling as the process of selecting a portion of the population to represent the entire population so that inferences can be drawn. However in qualitative studies, sampling occurs subsequent to clearly establishing the circumstances of the study, according to De Vos et al (2005:328).

There are two main approaches to sampling: probability and non-probability approaches. The non-probability approach is used in qualitative studies, as it does not aim to produce a statistically representative sample or draw statistical inferences (Wilmot 2007:2). This approach also tends to rely on availability of subjects (Babbie 2007:183). The non-probability approach was used to select participants for this study, using the purposive sampling technique.

2.6.2.1 Purposive sampling technique

This is a sampling technique whereby the units to be observed are selected on the basis of the researcher's knowledge of the population, its elements and the purpose of the study (Babbie 2007:184). This sampling technique was chosen because the researcher had a good working knowledge of the population under study and anticipated that the study participants would be able to provide the type of information required to meet the study objectives. Purposive sampling is used when researchers want to obtain in-depth understanding of a complex experience or event (Burns & Grove 2009:355).

Disclosure of HIV status by HIV infected people to their sexual partners is considered a complex experience, the depth of which could be more appreciated and understood by interviewing those who have lived it. Participants in this study were therefore purposefully selected.

2.6.2.2 Eligibility criteria

Eligibility criteria are the criteria designating the specific attributes of the target population by which people are selected for inclusion in a study (Fink 2003:35). To be included in this study the participants had to meet the following eligibility criteria:

- Aged between 18 and 39
- Male or female
- Being in a relationship with at least one sexual partner
- Having disclosed their HIV status to their sexual partners
- Regularly utilising the index private clinic from which the population was taken as the health facility providing their HIV treatment

In this study the senior doctor in the clinic facilitated entry to the research setting and access to the population. Once access was gained to the population, the process of collecting data was embarked upon.

2.7 DATA COLLECTION

This section will give a detailed description of the approach and processes used to collect information relevant for the study purposes from participants who met the eligibility criteria. Burns and Grove (2005:539) describe data collection as a precise and systematic gathering of information which is relevant to the research purpose, objectives and questions.

2.7.1 Data collection approach

In research studies, information can be collected in structured or unstructured form. An unstructured in-depth interview approach was used to collect the information in this study. The in-depth interviews were complemented by field notes (see annexure H). This study did not utilise a specific data collection instrument because, according to Litchman (2009:16), the researcher in qualitative research is the primary instrument of data collection and analysis. The researcher was therefore the primary data collection instrument in this study. A tape recorder was used to capture the content of the in-depth interviews.

2.7.1.1 Unstructured in-depth interview

Polit and Beck (2008:392) describe a completely unstructured approach to data collection, whereby the researcher begins by asking a broad question, called the *grand tour* question, relating to the topic. Subsequent probing questions are then more focused and guided by the responses to the broad question. An interview schedule was used which contained the *grand tour* question and study objectives to help the researcher to explore all relevant information without losing focus on the study objectives (see annexure D).

In-depth interviews are research techniques used to elicit a vivid picture of the participant's perspective on the research topic (Mack, Woodsong, MacQueen, Guest & Namey 2005:29). In-depth interviews are also effective for getting people to talk about their personal feelings and experiences as well as addressing sensitive topics (Mack et al 2005:30). An unstructured in-depth interview therefore combines the openness and

freedom afforded by the unstructured approach with talking to the participant and delving deeper into the issues being researched, which enhances a fuller understanding of the issues. The in-depth interviews conducted by the researcher in this study enabled her to gain a deeper understanding of the experiences lived by HIV infected participants following disclosure of their HIV status to their partners. In-depth interviews with the study participants were preceded by a pilot interview.

2.7.1.2 Pilot interview

The researcher conducted one pilot interview before commencing the actual study interviews. A person infected with HIV but not within the study sample was interviewed at her home. This helped the researcher to identify deficiencies in the researcher's interviewing skills; check that the tape recorder to be used during in-depth interviews was in working order; estimate the probable length of interview; and pre-empt any logistical problems that could potentially arise during the main interviews. The pilot interview highlighted the difficulties of conducting interviews at home. There were several disruptions including a baby crying, neighbours passing by to say hello and a mobile phone ringing several times. Following the pilot interview, the researcher welcomed participants' choice of attending the interviews away from their homes. No problems were identified with the equipment.

2.7.1.3 Field notes

Data collected during interviews was augmented by field notes, which were also used as part of the data analysis (see annexures H and K). The field notes represent the researchers' efforts to record information synthesise and understand the data that they have collected (Burns & Grove 2009:405) The field notes helped the researcher to capture and describe the non-verbal cues observed during the interview and use the information to give a complete representation of each interview. The field notes were written down as soon as possible following completion of the in-depth interviews because, as observed by Burns and Grove (2009:408), delays in recording field notes could result in some of the information being forgotten or distorted, which could affect the internal validity of the study. Very little writing was done during the interview recording in order to maintain eye contact and observe non-verbal cues as much as

possible, but it was done soon afterwards.

2.7.2 Data collection process

The data collection process describes the various steps followed by the researcher in the field, which enabled data collection to take place. Data was collected at a private medical clinic in Gaborone, Botswana, from 20 July to 31 July 2009. This was a location chosen by participants as they felt it afforded them privacy, familiarity and comfort, given the nature of the research topic to be discussed.

A total of two working weeks were required to complete data collection. The first week was spent gaining access to the population, making initial contact by telephone and conducting the pilot interview. During each contact via telephone, issues relating to purpose of the study, informed consent and ethical considerations such as voluntary participation were discussed. Twenty-five participants were initially contacted by phone. Seventeen initially agreed to participate; however, when dates for interviews were set, four participants indicated that they could not participate, giving various reasons including family bereavements, unforeseen travel plans and change of heart. Three participants indicated that they would be willing to take part at a later stage if needed. The researcher therefore decided to proceed, with the provision that she could contact more potential participants as the study progressed if the need arose.

Participants were given the opportunity to ask questions regarding the study at each contact. The second week consisted mainly of recording in-depth interviews and completing field notes. Following the initial telephone contact, the participants were contacted by the researcher the day before the interview and on the morning of the interview by phone to check that they were still available, and also to obtain further verbal consent. Only one participant became unavailable on the day, owing to unforeseen work commitments.

Each participant arrived at the clinic a few minutes before the agreed time on the scheduled day of their interview. They were shown to the interview room by the researcher. Face-to-face introductions and pleasantries were exchanged to make participants relax and feel welcome. The researcher then introduced the topic by briefly

summarising the aim and objectives of the study to ensure that the participant understood these and was still willing to participate in the study. Participants were also informed of the availability of a counsellor should they find interviews provoked feelings of anxiety or distress.

Written consent was then obtained at the start of the interview. Participants were given time to read the consent form and ask questions first. Consent forms could not be sent to participants earlier because most participants preferred their home addresses to remain anonymous for purposes of the study. Their confidentiality was therefore further protected. Consent was completed by participants signing the consent form. Once written consent had been obtained, the tape recorder was switched on, signalling the formal beginning of the interview (see annexures F and G).

The *grand tour* question was introduced, which was as follows: **Tell me about your experiences, feelings and thoughts about disclosing your HIV status to your partner.** The responses and conversation that followed were all tape recorded. Where necessary, responses were followed up with probing questions for clarification and further exploration of the issues raised by participants. Non-verbal cues were observed and later noted as field notes. The duration of the interviews ranged from thirty minutes to one and a half hours. Water, tea or coffee and comfort breaks were provided to the participants as required.

2.8 DATA ANALYSIS

Lacey and Luff (2007:6) describe data analysis as a process by which researchers describe and summarise accumulated information generated by interviews or observations to look for relationships between various themes identified; relate behaviour or ideas to specific characteristics of participants; and even develop trends and patterns from the analysis. The process begins while still in the field through emergence of ideas for making sense of the data (De Vos et al 2005:336).

Lacey and Luff (2007:3-4) describe several stages of data analysis in qualitative research, some of which were used to guide data analysis in this study, as follows:

- Familiarisation with data through reading, review and listening
- Transcription of tape-recorded material
- Organisation and indexing of data for easy retrieval and identification
- Making sensitive data anonymous
- Coding
- Identifying themes
- Re-coding
- Development of provisional categories
- Exploration of relationship between categories
- Refinement of themes and categories
- Development of theory and incorporation of pre-existing knowledge
- Testing of theory against data
- Report writing, including excerpts from original data if appropriate

The data analysis in this study was guided by following the relevant steps as described by Lacey and Luff (2007:3-4) above.

2.8.1 Familiarisation with the data

Familiarisation with the data occurs through review, reading and re-reading of transcripts and listening to tapes of recorded material, making memos and summaries before the data is coded (Lacey & Luff 2007:23). This process began during data collection by listening to tape-recorded interviews and reading the field notes after each interview. In this study the familiarisation process continued during and after transcription and translation of recorded interviews. All the nine eligible interviews in Setswana and English were read in conjunction with listening to the corresponding tape-recorded interviews and then reread several times until the researcher felt familiar with each interview.

2.8.2 Transcription

This involved the researcher transcribing recorded interviews verbatim into written text to prepare the data for analysis. The interviews were conducted and recorded in Setswana, the language spoken by all the participants and the researcher. Although participants preferred the English version of the consent form, they spoke in their native language during interviews. This was not entirely surprising to the researcher, as participants felt comfortable expressing themselves in their own language.

The interviews were transcribed directly in Setswana, which was the language used in the recordings. Then they were translated from Setswana to English by the researcher. This was aimed at reducing transcription errors, which can take the form of deliberate alterations of data; accidental alterations of data and unavoidable alterations (Polit & Beck 2008:509). The translation also had to take into account the context in which the words were spoken and the non-verbal cues from the field notes accompanying them in order to maintain an accurate representation of the interview.

Each interview was therefore made up of three sets of data, each given a descriptive label, such as Interview number one, then 1Es for Setswana and English version and 1E for English-only version. For quality control purposes, two Setswana interviews were also sent off to a Setswana-speaking secondary school teacher who was very experienced in translating between Setswana and English. There were no significant differences between his translation and the researcher's translation. The process of transcription and subsequent translation took several months to complete due to the volume of data involved, identifying of the second translator and getting feedback from him.

2.8.3 Organising data

This is a method of classifying and indexing the data to enable easy access to parts of the data when required. Polit and Beck (2008:509-510) describe the process as essentially reducing the data to more manageable units so that data can be retrieved and reviewed. After transcription and translation of interviews, an inventory of the data available was undertaken. Three computer file folders were then created. One folder

contained Setswana interview transcripts, the second folder contained interview transcripts in both Setswana and English; and the third folder contained English-only transcripts.

The English transcripts were printed out and attached to each corresponding set of handwritten field notes. This paved the way for easy retrieval of transcripts and familiarisation with the data. Burns and Grove (2009:206) advise that all raw data collected for the study should be coded so that the participant's identity is not revealed. The study participant's details should also not be revealed when the study is reported or published, and all data collected should be stored securely and not shared with any other person without permission being given by the study participant.

In this study the original interview tapes were stored securely and would be destroyed once the study was fully completed. Once the researcher became well acquainted with the interview transcripts, only English transcripts were focused on. Notes of ideas that occurred to the researcher while reading the transcripts were made in the margins of the printed transcripts. Each interview was also correlated with the accompanying field notes.

2.8.4 Coding

Marshall and Rossman (1999) in De Vos et al (2005:338) describe coding data as the formal representation of analytic thinking. Babbie (2007:385-386) identifies three types of coding: open coding, axial coding and selective coding. During open coding, data is broken down into discrete parts, closely examined, then compared for similarities and differences (Babbie 2007:385). The following coding steps described by Lacey and Luff (2007:7) were adapted and used for coding interviews from this study:

- Open coding
- Delineation of emergent concepts
- Conceptual coding (using emergent concepts)
- Refinement of conceptual coding schemes
- Clustering of concepts to form analytical categories

- Core categories leading to identification of major themes
- Testing of emerging themes by reference to other research (literature control)

2.8.4.1 Open coding and delineation of emergent concepts

Common concepts of everyday life were identified and examined in relation to context, meanings and circumstances surrounding disclosure of HIV status to partners by those infected with HIV. Open coding allowed for breaking up of the data into meaning units. From reading the interviews it became clear that participants started their interviews by narrating circumstances leading to their finding out that they were infected with HIV. They all seemed to want to lay a background to the circumstances leading up to disclosure. One of the initial codes was therefore the concept of prelude. Words, phrases and paragraphs describing this concept (meaning units) were colour coded the same in all the interviews where this was expressed.

Participants also used a variety of words and phrases to describe their varying experiences during disclosure to their partners. The concept of disclosure as a process emerged. The participants went on to give vivid narratives of their experiences after disclosing to partners. The idea of a post-mortem as a concept, describing experiences after disclosure, also emerged. During coding, the researcher considered the people involved in each participant's narrative; the events; language used; the quotations; expressed emotions and non-verbal cues from field notes. The concepts which emerged were very general and therefore needed further exploration.

2.8.4.2 Conceptual coding and refinement of conceptual coding schemes

The concepts identified during open coding as well as the words describing them were explored and analysed further to look for more insight into their meanings. For example, analysing the concept of prelude above showed that there were matters of concern to participants which made them think of going for the HIV test and therefore coming to know that they were infected. Such matters included health concerns; family planning issues and information available to participants. Exploration, reflection and comparison of similarities and differences within the initial concepts resulted in breaking down of the general concepts, recoding and refining them, then organising them into similar clusters,

leading to emergence of broad categories. The categories therefore comprised concepts with similar meanings. Conceptual saturation was deemed to be reached when no new categories could be generated.

2.8.4.3 Categories and subcategories

Further analysis and comparison of the categories indicated that the categories contained further meanings within themselves. Within these categories, convergence and divergence of opinions, beliefs and experiences between participants were identified. The categories were therefore re-coded, leading to emergence of subcategories. Similar categories and their subcategories were then grouped together to form major themes.

2.8.4.4 Identifying themes

A theme is an abstract entity that brings identity to a current experience and its variant manifestations (Polit & Beck 2008:515). Eight themes emerged following data analysis and coding as described in the preceding section. Each theme was allocated a number and letter code. Themes identified were: reasons for HIV testing (1Y); pre-disclosure deliberations (2O); process of disclosure (3LG); reasons for disclosing (4LB); reasons against disclosing (5DB); initial reactions to disclosure (6DG); consequences of disclosure (7R); participants' recommendations (8P). The letters in brackets denote colour codes given to these themes.

A discussion of the main themes, categories and sub-categories that were obtained during data analysis will be presented in chapter 3.

The stages of data analysis described above did not proceed in a linear fashion but involved frequent revisiting of raw data in the light of new emerging ideas. To enhance the trustworthiness of the study, the services of a co-coder were employed. He is a researcher experienced and qualified in the field of qualitative and quantitative research. Themes were then used to provide a full description of the experiences and factors influencing disclosure of HIV status to sexual partners by those infected with HIV. Validation of themes which emerged from the data was done by making comparisons

with data from existing literature through a literature control.

2.8.4.5 Literature control

The timing and purpose of the literature review depends on the type of study. Burns and Grove (2009:91) indicate that literature review in phenomenological studies is best done *after* data collection and analysis so that it does not affect the researcher's openness. The literature control for this study was done after data analysis. It was used to inform the study conclusions and to compare findings from this study with those from the literature regarding the phenomenon of disclosure of HIV status to sexual partners.

2.9 TRUSTWORTHINESS OF THE STUDY

The essence of soundness of qualitative research is captured by Marshall and Rossman (1999) in De Vos et al (2005:345), who identify canons which stand as criteria that qualitative research must meet if it is to be deemed trustworthy. Polit and Beck (2008:540) suggest five criteria for developing trustworthiness (validity and reliability) of qualitative research, based on a Lincoln and Guba framework (1985). These are credibility, dependability, confirmability, transferability and authenticity.

2.9.1 Credibility

The goal of credibility is to demonstrate that the study was conducted in a manner which ensures that the subject was accurately identified and described (De Vos et al 2005:346). In this study, which aimed to explore and describe factors influencing disclosure of HIV status, the researcher stated and described the parameters of the study setting clearly, including population; social groupings; process of data collection and analysis; and also undertook a literature control to enhance credibility of the study findings. The researcher also established a relationship with participants before the day of the interview by talking to them telephonically about the study and also about general issues before the day of the interview.

On the day of the interview, the researcher allowed each participant to accompany her to the kitchen to make refreshments before the interview began if they wished. The

interview recording was only started when the participants felt ready, as some of them could be put off by the recording. The researcher also spent time with participants after the interview if they were not in a hurry to go, talking about general matters such as the weather. This was to show participants that they were not just a number in a research study, but were regarded as respected members of society who could have opinions about other issues outside the world of HIV.

Participants were also patients at the clinic where the researcher had worked previously. These factors helped establish prolonged engagement with the study participants. During interviews, the researcher carried out meaning checks by reflecting statements back to participants and asking for clarification where necessary to ensure correct understanding of the meaning of the statements.

2.9.2 Dependability

Dependability refers to stability or reliability of the data over time and over conditions (Polit & Beck 2008:539). Their observation is that credibility cannot be achieved without dependability, just as validity in quantitative research cannot be achieved without reliability. In this study, data was collected under neutral settings without manipulation by the researcher. Other authors, however, raise concerns about the assumption of an unchanging world that seems to be at odds with the interpretative/qualitative assumption that the social world is always being constructed (De Vos et al. 2005:346-347).

In the context of HIV disclosure it is possible that perceptions and experiences of people infected with HIV will change over time, depending on advances in areas such as treatments and diagnostics. Dependability would therefore have to be defined taking into consideration such changes. In this study the advent of antiretroviral treatment with improved life expectancy appears to have impacted on participants' experiences and decision to tell their partners. In this study, the researcher ensured dependability by collecting, recording, transcribing and translating information as accurately as possible.

2.9.3 Confirmability

According to Polit and Beck (2008:539), this concept is concerned with establishing that the information participants provided and the interpretations of those data are not figments of the researcher's imagination. It is a test of traditional objectivity (De Vos et al 2005:347). To enhance objectivity to external readers, the researcher's perspective in terms of views, perceptions and assumptions that could influence the research findings were acknowledged and included in the form of a reflective diary in reporting of results.

In her study on the influences on the data of the multiple identities occupied by a career researcher in qualitative interviews, Gunasekara (2007:464) concludes that researchers may assume multiple identities in the field which are fluid and changing and may influence what data is collected and how.

In this study participants were aware of the researcher's occupation. The researcher was now wearing identities of a student, a researcher and doctor. It is possible that these identities may have interacted with one another to influence the data collected. The researcher used the practice of bracketing to reduce the influence of any prior experiences or perceptions regarding disclosure of HIV status. The raw data is available on tape, as are the original transcripts in both Setswana and English, so that they are accessible for confirmation. The input from academic supervisors also added to the study's confirmability. The study limitations have also been recognised and acknowledged in the final chapter.

2.9.4 Transferability

Transferability refers to ability to generalise research findings to other settings or groups (Polit & Beck 2008:539). De Vos et al (2005:346), however, argue that this could be problematic for the qualitative researcher. They suggest that the researcher can counter this by providing as much information as possible about the context of the research so that other people can evaluate it and decide whether it applies to their contexts. Triangulation is suggested as another method of enhancing transferability. Triangulation means gathering and analysing data from more than one source to gain a fuller understanding of the situation under investigation (Lacey & Luff 2007:27).

Campbell and Fisk (1959) in Burns and Grove (2009:231) indicate that triangulation can be said to be present if two or more of the following methods have been used: theories, data collection methods, data sources, investigators or data analysis methods during the study of a phenomenon. In this study the following were undertaken to achieve triangulation: two data collection methods using in-depth interviews and field notes, two coders, a reflective diary and literature control.

2.9.5 Authenticity

Authenticity refers to the extent to which researchers fairly and faithfully show a range of realities by conveying the feeling and tone of participant's lives as they are lived (Polit & Beck 2008:540). To demonstrate this criterion, the researcher has included some direct quotations from participants' interviews, accompanied by background information such as time of the day, facial expressions and other non-verbal cues during data analysis and results presentation.

The trustworthiness of this study has therefore been enhanced by paying attention to factors which influence credibility, transferability, dependability, confirmability and authenticity as these are recognised building blocks of trustworthiness of a qualitative study

2.10 ETHICAL CONSIDERATIONS

According to Babbie (2007:62), *Webster's New World Dictionary* defines ethics as conforming to the standards of conduct of a given professional group. Five main ethical agreements in social research are identified. These are voluntary participation, informed consent, anonymity and confidentiality, deception, analysis and interpretation of data.

2.10.1 Voluntary participation

Voluntary participation occurs when research participants take part in the research of their own free will, knowing the potential risks and benefits of participation. According to this principle, participants should be informed of their right to opt out of participating in a

study should they wish to do so. This is particularly pertinent in this research, as it potentially involves patients who attend the clinic for their HIV-related care and may feel they have to take part in the research so that their care is not adversely affected by non-participation. None of the participants expressed this concern. Those who opted out cited other reasons such as busy schedules as reason for not participating.

2.10.2 Informed consent to participate

The participants were given a written informed consent form which explained the nature of the research, risks and benefits to them, reasons for the study and how the information collected would be used (see annexures F and G).

Participants were also afforded the opportunity to ask questions about any issues they were not clear about concerning the study, at the initial telephone contact, during the interview itself and following the interview. This ensured that participants gave informed, understanding consent. They were provided with the researcher's contact details to facilitate informed written consent.

2.10.3 Anonymity and confidentiality

Anonymity is guaranteed when both the researcher and the people who read the research cannot link a given response to a particular respondent (Babbie 2007:64). In this study, participants have been identified by codes and no personal details other than general demographic data such as age and relationship status were included in the study.

Confidentiality occurs when the researcher can identify a given person's responses but promises not to do so publicly (Babbie 2007:65). It was unlikely that this would be necessary in this study, as no names or addresses were collected during the study, but if the need should arise then participant's confidential details would remain protected. Although the senior doctor at the clinic facilitated initial access to the population, he did not know which of the patients eventually became the study participants.

Confidentiality and anonymity were maintained by coding data collected from participants to protect their identity. There will be no sharing of data beyond the purpose of the study. The participants' identity will not be revealed while the study is being conducted, reported and published.

2.10.4 Deception

Babbie (2007:67) describes deception as occurring when researchers do not say why they are doing the research and for whom. He argues that lying about research purposes raises serious ethical questions. In this study the informed consent form covered the purpose of this research and why it was being done. Further clarification was provided at the start and at the end of the interviews. Providing clarification at the end of the study gave participants who had disclosed sensitive information to the researcher the opportunity to withdraw consent even at that stage.

2.10.5 Analysis and reporting of data

Babbie (2007:69) contends that researchers should be familiar with the technical limitations of the study and report these to the readers. Unexpected and negative findings should also be reported. Limitations of this study will be discussed in detail in section 5.4.

2.10.6 The Medical Research Council (MRC) ethics

This research involves patients in a medical setting for purposes of completing a master's dissertation which will be awarded by the University of South Africa (UNISA). The research is therefore approved by UNISA Research Ethics Committee (see annexure A) and governed by the South African MRC code of conduct and ethical guidance. Permission to conduct the study in a particular clinic was granted by the Ministry of Health, Botswana (see annexure B) and the manager of the clinic (see annexure C).

All medical doctors practising in South Africa are required to register with this body. As a medical doctor, the researcher was required to register with this body when practising

in South Africa, hence the use of the body's ethical guidance in this study. The MRC of South Africa (South Africa (Republic). MRC 2000:para 1.3.1) promotes the following ethical principles: autonomy, beneficence, non-maleficence and justice. These principles will also be abided by during the research.

2.10.6.1 *Autonomy*

This principle holds that people have a right to self-determination and this should be respected at all times. In the study context, it means participants have the right to refuse or to participate in the research being undertaken, and their decision either way will be respected.

2.10.6.2 *Beneficence*

This principle requires the researcher to endeavour to do good. The study should directly or indirectly aim to benefit research participants or communities. Participants in this study were aware of the anticipated community benefits of the study as opposed to individual benefits. Some participants reported benefiting by just being able to tell their story.

2.10.6.3 *Non-maleficence*

The researcher should aim to do no harm to the study participants. This was achieved in this study by respecting participants' autonomy, by voluntary participation and by maintaining their confidentiality. Participants may have had concerns with regard to possible unforeseen negative emotional outcomes following reliving their experiences during the interviews.

A counsellor was made available to support participants if this situation was to arise. Only one participant was deemed to need this provision, which he was offered. He did not take it up. Provision for the researcher to access emotional support was also in place should the need arise.

Participants were allowed breaks and refreshments during interviews when required. Those who require feedback from the study once it is concluded will be provided with grouped anonymous results.

2.10.6.4 Justice

This principle refers to equal distribution of risks and benefits between communities and fair treatment for all. This study did not involve vulnerable minorities who could be harmed by participation in the study. Participants were adults who were competent to make decisions and had an awareness of risks and danger.

2.11 CONCLUSION

This chapter described in detail the methodology employed during this study. The chapter described the type of research design used for the study, sampling methods, data collection methods, pilot interview, study population, ethical issues around data collection and proposed data analysis methods. It concluded by discussing ways of establishing validity or trustworthiness of the study as well as ethical considerations.

The next chapter will discuss the data analysis and presentation of results.

CHAPTER 3

DATA ANALYSIS AND PRESENTATION OF RESULTS

3.1 INTRODUCTION

This chapter presents the findings from the study. The chapter begins by presenting the biographical details of the participants. This will be followed by analysis and tabulation of main themes, identification of categories and sub-categories, following verbatim transcriptions and coding of phenomenological in-depth interviews conducted in the study.

3.2 DATA ANALYSIS PROCESS

The interview transcripts were organised into three computer folders, one folder containing Setswana transcripts (see annexure I), a second folder containing transcripts in both Setswana and English, and the third folder containing English-only transcripts (see annexure J). The process of coding, guided by the steps identified by Lacey and Luff (2007:7), was then undertaken. Open coding was used, which involved reducing information from the English transcripts by looking for meaning units in each interview. Words, sentences or paragraphs used by the participant to convey a particular meaning or concept were highlighted and colour coded. The colour-coded words were transferred on to a table and used as the units of analysis. The general concepts which emerged from the units of analysis were then analysed further by exploration, reflection and comparison of similarities and differences within them. This led to breakdown of the general concepts, re-coding and refining, then reorganising the concepts into similar clusters. This process resulted in the emergence of broad categories from the data (see annexure K). Within these categories, divergence and convergence of opinions, experiences, beliefs and conclusions among participants were looked for. The categories were therefore further broken down into subcategories. To gain a bigger picture which would address study objectives, similar categories and their subcategories were grouped together to form major themes. Eight themes emerged from the data. The

main themes were then validated through a literature control based on information from a review of literature. The themes identified were:

- (1) Reasons for HIV testing (1Y)
- (2) Pre-disclosure deliberations (2O)
- (3) Process of disclosure (3LG)
- (4) Reasons for disclosing HIV status (4LB)
- (5) Reasons against disclosing HIV status (5DB)
- (6) Initial reactions to disclosure (6DG)
- (7) Consequences of disclosure (7R)
- (8) Participants' recommendations (8P)

3.3 BIOGRAPHICAL DATA

This section describes the characteristics of the participants who took part in this study. A full description of the attributes which made the participants best suited for the study is given. The demographic information collected includes age, gender, marital status and employment status. All the participants were HIV infected.

Table 3.1 Demographic data of the participants

Characteristic	Value	Frequency	Percentage
Age	18-20	0	0
	21-25	0	0
	26-30	4	45
	31-35	2	22
	35-39	3	33
Gender	Male	2	22
	female	7	78
Marital status	Married	3	33
	Co-habiting	4	45
	Casual relationship	2	22
	Divorced	0	0
	Widowed	0	0
Employment status	Full-time employee	8	89
	Part-time employee	0	0
	Self-employed	0	0
	Unemployed	1	11

The participants' age range was between 26 and 39 years. This age range fell well within the age criteria for inclusion into the study. There were more females than males, with two out of nine participants being male. Nearly half of the total number of participants were not married but were co-habiting. There were two who considered themselves as being in casual relationships. There were no divorcees or widowers. Only one out of nine participants was unemployed. All participants had at least one child with their current partner or from a previous relationship. None of the participants was in a same-sex relationship. The participants' demographic variables are summarised in table 3.1.

3.4 OVERVIEW OF THEMES AND CATEGORIES FROM INTERVIEWS

Main themes emerged after the participants were enabled to narrate their stories during in-depth interviews. The narratives included describing the circumstances that were prevailing in their lives at the time; the places where they were; the people in their lives and, crucially, the experiences, thoughts, and feelings they went through as a result of telling their partners or finding out about their partner's HIV status. Categories and subcategories emerged from initial data analysis, which were then clustered together to form the main themes, which will be presented below.

3.4.1 Theme 1: Reasons for HIV testing

During narration of their lived experiences, the participants were keen to give as complete a picture as possible of that chapter of their lives. One of the ways they did this was to tell the story of how they came to find out that they were infected with HIV, thus laying a background to the narratives. This was a recurring theme amongst the participants. The participants' narratives when analysed revealed that there were several factors which led to participants going for the HIV test. These included health concerns for either themselves or their partners. Testing because of ill health was reported as one of the most important factors influencing the decision to undergo HIV testing. Some of the participants tested because health care professionals treating them for recurring illnesses advised them to do so, while others decided to test on their own initiative, taking into consideration their health or their partner's health-related problems. One of the participants related that she knew that her husband had been running

around with younger girls, and his health was slowly declining for no apparent reason. She suggested to him that he should go for the test, which he did and later disclosed his results to her. This is part of her narrative: *“things started off with my husband ... He was the one who became ill. The results showed that he had the virus ... (Short pause, clears her voice) following the results, it occurred to me that as I have been sleeping with my husband ...”*.

Another category describing reasons leading to HIV testing included those to do with family planning. The subcategories which emerged indicated that HIV testing was done when participants and their partners were either planning to start a family, increase their family or during pregnancy. This was the second most important factor influencing the decision to go for an HIV test. One participant described how she persuaded her partner that they should go for the test because his health had not been good and yet he wanted them to have a second child. Another participant underwent the HIV test because she was already pregnant and this was part of routine antenatal care. She was not expecting to find she was HIV positive and had therefore not prepared herself for the shock of a positive test.

Another category which emerged was HIV testing as a result of public health campaign messages. This category, however, was not reported as important by all participants. One participant described how she tried to persuade her first partner to go for the test, citing public health campaigns. Her partner refused until he eventually died from, presumably, AIDS-related illness. Another participant told that her husband had shingles. She said to him: *“I heard that shingles can be associated with HIV so ... let’s test first”*.

From these descriptions the researcher identified how important the participants felt it was to convey as complete a picture as possible, possibly to also make the point that there was a reasoned, well-thought-out pattern to their subsequent actions when they were faced with disclosing to their partners.

The main reasons why participants went to have their HIV test done are summarised in the table below:

Table 3.2 Summary of Theme 1: Reasons for HIV testing

Main theme	Categories	Subcategories	Meaning units
Reasons for HIV testing	Health	Own illness	I had been having recurring illnesses for some time. I decided that I needed to know what was causing this.
		Partner illness	Things started off with my husband. He was the one who became ill.
	Family planning	Pregnancy	Then I became pregnant in 1997 because my son was born in 1998. That's when it became apparent that I was also ill. I was generally unwell, feeling weak all the time. I was then investigated and asked if I would agree to have an HIV test. So I agreed to the test.
		More children	The first issue was that we wanted to try for another baby.
		Partner needs	My husband was very keen to have a second child. I proposed that we have the tests first.
	Public health campaign	Media	Yes, they kept telling us about this illness and suggesting people should know their status. I said to him, I heard that shingles can be associated with HIV so let's go for a test first.

3.4.2 Theme 2: Pre-disclosure deliberations

In this theme, thoughts, concerns, debates and deliberations that went through the minds of each participant after finding out their HIV status and before disclosing their status to their partner were identified. The participants described how they tried to prepare themselves for the reaction they could potentially get from their partner by either remaining positive, worrying about it or feeling indifferent. The categories which informed this theme were negative thoughts, positive thoughts and those who were not concerned either way. The general feeling among participants was dominated by positive thoughts of hope and acceptance from their partner.

3.4.2.1 Negative thoughts

The participants described the fear, anxiety and worry that went through their minds in anticipation of their partner's reaction. One woman even went as far as leaving her marital home to live with her brother and his children while thinking of how she would break the news to her husband, who was away on a trip at the time when she found out her results. It is interesting to note that she declared herself as someone who had a negative perception about those infected with HIV and therefore expected a similar negative reaction from her husband. Her preconceived ideas and beliefs appear to have influenced her subsequent reaction to her positive test. She describes her feeling of relief when her husband simply accepted her disclosure positively by saying *"we hear about this illness on the radio quite a lot ... So don't worry ... just get the treatment"*. Another participant, a male, described his fear of telling his partner, given their already strained relationship. His fears appear to have been realised when she ended the relationship.

3.4.2.2 Positive thoughts

An overwhelming degree of the positivity of the human spirit in the midst of turmoil was reported by participants. A recurring expression was that of self-counselling to prepare themselves for the results or after the results. Participants described sitting down and thinking about the positives because the first step they took before learning of their status was to make a conscious decision to accept themselves first, as no one could accept them if they didn't accept themselves. One participant said: *"I kept asking myself, "How will I react if I am found to be positive?" ... This was before I went for my test. So I... em ... decided to counsel myself and to prepare myself in case ... em ... my results came back positive"*. This feeling was captured across the board during the interviews. When this participant and others made statements like this, they had a striking expression on their faces, of an inner peace and calm, almost unimaginable given their situation. The researcher was left with a lump on her throat at such a deep, calm and positive outlook as these participants had displayed. Another positive outcome was described by one participant who indicated that after she found out about her HIV status, she immediately made a conscious decision that she would change her lifestyle

for the better, regardless of her partner's reaction. Her partner's reaction was a positive one, which reinforced her positive attitude for the future.

3.4.2.3 Indifference

A feeling of indifference and lack of any concern was also described. On closer exploration it emerged that the participants experiencing this feeling had either been aware of their partner's positive HIV status or had a strong suspicion about it. There were also those who felt indifferent because it had not occurred to them that they could be positive and therefore they had not thought ahead about the implications of an HIV positive test, such as disclosing the results to partners. One participant said that in her opinion "*HIV was like any other illness and should therefore be treated as such*". The participants who had no concerns also had a partner who had already been ill, or went for the test accompanied by the partner, and therefore knew of the results at the same time as their partner.

The pre-disclosure deliberations as described by participants also appeared to play an important role in setting a background to let the researcher in on their real lives and make sure that the picture of what they went through during the disclosure process was as complete as possible. Their narratives projected a sense of the experience of disclosure as a process rather than a one-stop decision.

The findings in this theme are summarised in table 3.3.

Table 3.3 Summary of pre-disclosure deliberations

Main theme	Category	Subcategory	Meaning units
Pre-disclosure deliberations	Negative thoughts	Fear and anxiety	I was scared that ... eh ... as soon as I tell him he might leave me ... I was also unsure as to what he would do.
	Positive thoughts	Self-counselling	I kept asking myself, "How will I react if I am found to be positive"? ... This was before I went for my test. So I em ... decided to counsel myself and to prepare myself in case my results came back positive.
		Life style changes	I also decided that if I am negative, I will review my lifestyle accordingly.
	Indifference	Resignation to fate	I: At the time, did you have any ...? P: No, not at all ..., I was clueless. I was so blank I had no idea that I could have the virus. I didn't even think about what I would do or what effect it would have on me if I was told I was positive.
No concerns		I didn't have problems when it came for me to tell him, I am a married woman ... I had no concerns at all.	

3.4.3 Theme 3: Process of disclosure

In this theme, participants described the actual steps and actions they took immediately before and during disclosure to partners, highlighting how they went about telling their partner. These actions and deliberations were geared at preparing the partner emotionally and psychologically for receiving "bad news"; there was some detective work and information gathering to aid decisions regarding when HIV infected partners should tell their partner; how they would communicate the information to them and under what circumstances the disclosure would occur.

3.4.3.1 Pre-disclosure clues

The interviews reveal that the process of disclosure started even before the HIV test results were known. Participants first decided how they would deal with a positive test

result by accepting their status and dealing with it positively before telling others. This appeared to be one of the major decisions they felt they had to make before the actual act of disclosing. This would suggest that the infected persons felt they needed to feel ready in their own minds before they told their partner and perhaps anyone else. This would appear congruent with any major decisions that anyone in life has to make. Participants then prepared themselves for a positive or negative partner reaction accordingly. Before they got the test results they also undertook a fact-finding mission to discover what prejudices, if any, their partners had about HIV. This was done by priming their partners through clues and discussions about ill-health or discussions related to HIV testing in general. One participant reported that she initiated a general conversation about the issues to see what her partner's reaction was likely to be. She said: *"You listen to him ... yes ... when you have general conversation about the public health messages about the disease"*.

Another participant described how she gave her children clues by introducing the concept of long-term medication, then finally telling her children what the medication was for. This is what she said: *"What I did was introduce the subject gradually. First I ... em ... told them I had tablets that I needed to take in the mornings and evenings every day ... yes ... and asked them to remind me if I forgot a dose. So they got used to the idea that I take medication first. Later on I told them what the medication was for"*.

Another experience involved telling the partner that they (the HIV infected partner) were going for the HIV test, and then informing the partner that they were going to get the results, which they would need to talk about afterwards. This could be likened to a running commentary before a big football game such as the World Cup, where commentators share the amassed knowledge about teams, but then pass it on to the viewers bit by bit till kick-off time. The more information viewers get, the more prepared they become for a probable outcome. Such preparation appears to have helped prepare both partners for the actual act of giving the news and receiving the news during direct disclosure.

3.4.3.2 Time taken from knowing results to disclosing results

Following receipt of their HIV test results, participants reported a sense of urgency to tell someone and therefore disclosed their HIV status to their partners shortly after they received their test results. Disclosure occurred either on the same day or within a few days. Participants expressed the feeling that delaying the disclosure would be detrimental to their psychological well-being. Disclosure shortly after getting the result also appears to have been influenced by the pre-disclosure considerations already described in the preceding section. Expectations of a positive outcome before disclosure were described by participants as giving them the courage to disclose as soon as practically possible. One participant reported fear of disclosing to subsequent partners. She had disclosed her status to her first partner, and received a very negative response, which she interpreted as *“blaming me for bringing the disease into the household”*. She never found the courage to disclose to her second partner, who subsequently died from a road traffic accident without knowing her HIV status. She eventually disclosed to her third partner only after he had disclosed to her first. She felt reassured that the likelihood of rejection was significantly reduced if the partner was also positive and was the type who had accepted his condition and lived with it positively. She had been together with the third partner for over two years before she told him.

3.4.3.3 Mode of communication

This sub-category relates to the actual news delivery method used by participants to disclose to their partners. All the participants who had to disclose reported using either telephone or a face-to-face discussion as a mode of communication. In all cases disclosure was direct. This is to say that the participants told their partner without using a third party such as a health care professional, friend or relative. The feeling was that non-verbal communication was important to the discloser, to see their partner's facial expressions and body language at the precise moment of disclosure. The participants strongly felt that such an observation would enable them to judge whether the partner's non-verbal communication was congruent with the verbal communication. One woman who had attempted to commit suicide after she found out her HIV status described how her then partner remained emotionless, unconcerned, not in shock like her, when she

disclosed her status to him. As she was later to find out, her partner had known his own status for more than a year and, as she put it, “*he must have known he had given it to me*”. When she describes her experience, she becomes motionless, moves her hands less. She stares into space, then shakes her head in disbelief and obvious anguish, even though this experience occurred nearly five years ago.

The table below summarises the process of disclosure of HIV status to partners as described by participants.

Table 3.4 Process of disclosure

Main theme	Category	Subcategory	Meaning units
The process of disclosure	Pre-disclosure clues	HIV discussions	<p>What I did was introduce the subject gradually ... First I told them I had tablets that I needed to take in the mornings and evenings every day ... and ... asked them to remind me if I forgot a dose. So they got used to the idea that I take medication first ...</p> <p>You listen to him when you have general conversation about the public health messages about the disease.</p>
		The HIV test result	For me it was easy because we both went for the test at the same time, so there were no issues of disclosure to deal with.
		Ill health	It was easy for me to explain to him by just saying “as you know I have not been very well recently. I therefore decided to go for HIV testing at Tebelopele. The results came back showing that I am HIV positive.
	Time scale	Immediately	Immediately after I came back from Tebelopele, I called him and asked him to go to the hospital for his test because I had done mine and I was positive.
		Days	I told her my results the next day.
		Never	I didn’t tell him at all.
	Mode of communication	Phone	I called his land line to make sure he was in the office. He didn’t share his office. So i went ahead and told him.
		Face-to-face	<p>I got to her place and told her everything.</p> <p>You have to be direct with him and go straight to the point. All I said to him was “I went to Tebelopele today, they told me I have HIV and this is my plan going forward”.</p>

3.4.4 Theme 4: Reasons for disclosing HIV status

In this theme, factors influencing the disclosure of HIV status as reported and experienced by HIV infected persons are described and explored. Categories describing reasons why disclosure occurred emerged under this theme. The main categories describing the factors which influenced participants to tell their partners that they were HIV positive were coded by the researcher as others-focused and self-focused. Deeper exploration of the categories yielded subcategories including reasons to do with responsibility; living together; current perceptions about HIV; relationship and safer sex; financial support; emotional support; treatment availability; freedom and dealing with the physical aspects of the illness. These will now be discussed in detail.

3.4.4.1 Others-focused factors

There was a strong feeling from participants that they had to disclose their status to protect others close to them from getting HIV. It became very important to the disclosers that they needed to protect their loved ones by reducing the risk of HIV transmission from them to loved ones. One participant described feeling a need to even take it to a higher level by going public with her status to protect everyone who could potentially come into contact with her such as paramedics who might need to attend her in case of an emergency. Another participant wanted to tell her family so that she could educate them about measures to protect themselves from catching HIV, including the use of gloves to handle her when she became very ill *“to avoid killing them with the virus which would be killing me at the time”*. She needed them to stay healthy for her children when she was gone. A strong sense of responsibility came across as a very important factor that participants considered in their deliberations about whether to tell or not to tell. Participants also felt that they could not continue living in the same household with someone they had not disclosed to. Keeping such a secret was considered too heavy and possibly selfish if others were not provided with the necessary information to make informed choices, even if such information sharing could result in negative consequences. This is how eloquently one participant described this sense of responsibility:

“It will be a terrible thing to em ... em ... sleep with your partner without a condom especially if he is used to sleeping with you without one ... yes ... when you know your status and you haven’t told him. You could pass the virus on to him, which em ... will be a bad thing to do” ...

This subcategory scored very high in participants’ motivation to disclose to partners.

Another sentiment expressed by participants was that if the partner knew, they would be more inclined to use condoms than if they did not know. The feeling among some participants was that disclosing could actually help in those relationships where males were domineering and against condom use. However, one of the participants whose first partner died from presumed AIDS-related illnesses reported that even towards the end, her partner still refused to use a condom despite knowing her status.

The researcher got a very strong feeling from participants who described how their concern for others was the prime factor driving them towards disclosure. It seemed that potential negative outcomes were regarded as less important in their quest to protect others from HIV transmission.

3.4.4.2 Self-focused

Self-focused reasons revolved around what the participant hoped to gain by going through the process of disclosing to the partner. The universal feeling from participants was the hope of gaining acceptance and emotional support from their partners following the disclosure of their HIV status. Emotional support was flagged as much more important than any other support, such as monetary support or support in dealing with the physical effects of the illness. This conviction seemed to suggest that in the participants’ hierarchy of needs, emotional well-being was a much higher need than physical well-being.

The emotional freedom that would come with not keeping such a big secret from their partners was also rated very highly by participants as a key factor when decisions to disclose were made. The participant who could not bring herself to disclose to her third successive partner described an overwhelming feeling of freedom when she finally

managed to tell him. The difficulties which she had to overcome due to having to take medication in secret all disappeared.

The participants also anticipated and hoped for help and support they would get from their partner. Such help could be in the form of assistance when participants who had disclosed had to deal with the physical aspects of the illness, including side-effects from the antiretroviral medication, or financial support. One participant described how she demanded money from her partner to enable her to travel to get her HIV treatment after she had disclosed her status to him. She expected her partner to provide the financial support. In her words: *“I told him unless you give me money to go seek treatment, I won’t leave you alone all night”*.

Availability of ART also appeared to influence disclosure. One participant expressed the view that in the pre-antiretroviral treatment era a positive HIV test was considered a death sentence. The implications socially, occupationally and emotionally took a toll on the infected individuals and probably killed them before the disease itself. With HIV treatment, this sentence was removed somewhat; participants therefore felt strongly that there was more to be gained from disclosing than not doing so.

The factors influencing participants to disclose their HIV status to their partners as described in this section appear to have been aimed at helping those who were HIV infected to accept themselves, to gain acceptance from others; to achieve a sense of emotional inner peace and freedom while also feeling supported physically and financially.

The table below gives a summary of the main factors that participants reported as influencing their decision to disclose their HIV status to their partners.

Table 3.5 Factors influencing disclosure of HIV status

Main theme	Category	Subcategory	Meaning units
Reasons for disclosing HIV status	Others focused	Responsibility	It will be a terrible thing to sleep with your partner without a condom especially if he is used to sleeping with you without one ... when you know your status and you haven't told him ... You could pass the virus on to him, which will not be em ...a good thing to do.
		Living together	My first thought was that I had to tell those who lived in the same household as me. Tell your partner so that you don't feel guilty keeping a secret from them. It is not nice to keep a secret like that from a person that you live with.
		Current perceptions about HIV	Nowadays we take the illness as similar to any other diseases ... I am not afraid to tell my friends that I am positive ...
		Relationship	When you are in a relationship with someone you have to tell them everything ...
		Safe sex	Yes ... it's better you tell him ... so that he cannot be tempted to ask you to have sex with him without protection.
	Self-focussed	Financial support	I told him unless he gave me money to go seek treatment, I wouldn't leave him alone all night.
		Emotional support	Because we were close. She made me feel free to talk about my feelings, which I did. It transpired later on that actually this woman didn't have any sympathy for me. Your partner will still love you and will appreciate that you have been honest with him.
		Treatment availability	These days the treatment is so much better.
		Freedom	The main benefit of disclosing to your partner is that you feel ... free afterwards. If you don't tell him ... you cannot be free.
		Dealing with the physical aspects of the illness	If you tell the partner they may be able to advise you about how to look after yourself. You need someone close during such a time ... so I was telling her these things because I felt that while there was a close relative who knew... she also had to know as she was someone I was going to live within the future. So when I found myself in that situation where I had started treatment and was experiencing some problems ...

3.4.5 Theme 5: Reasons against disclosing HIV status

This theme describes reasons advanced by participants which explained why they felt they could not disclose their HIV status to their partners. The three main categories forming the theme were coded as those relating to the HIV infected person's perceptions about themselves, their perceptions about their partner and about other people such as family members, friends and colleagues at work.

3.4.5.1 *Discloser perceptions*

This category describes how the HIV infected persons felt and perceived themselves in the light of knowing themselves to be HIV infected. The infected person's beliefs about HIV/AIDS as a disease appear to have been a key factor influencing disclosure to others. One participant described her feeling of low self-esteem, almost a sense of self-loathing after she realised she was infected. During the interview her body language projected a feeling of disbelief that she could have this illness, which she had all along associated with promiscuity and prostitution. She looked the researcher in the eye, hesitated for only a split second and uttered the words: *"I felt like a prostitute"*.

Another reason for non-disclosure was the perception of lack of readiness to disclose by the participants. There was a strong message coming from participants that to be able to divulge such sensitive information to others, including their partners, they had to be ready to do it. Disclosure only occurred when they felt ready to do so.

3.4.5.2 *Partner perceptions*

This relates to how the HIV infected person thought their partner would react to the disclosure. Negative perceptions of possible rejection, non-acceptance, blame, lack of support from partner all contributed to non-disclosure. One participant cited a past negative experience with disclosing to her first partner as the reason that deterred her from telling her second and third partners. She was, however, able to tell the third partner only after she formed the opinion that he would not react negatively. Non-disclosure due to concern for others related to disclosure to family rather than partners in this study. In this sub-category participants indicated that they didn't tell their family in

order to protect them from the negative connotations associated with being HIV positive. The overall message coming out appeared to be that even though they had not disclosed, this was done with good intentions.

3.4.5.3 Other perceptions

This category of attributes relates to disclosing to partners as well as family. Some participants viewed disclosure to partners as inherently related to disclosing to relatives. Negative public perceptions about HIV in general were also raised as contributory factors to non-disclosure.

The table below summarises the reasons influencing non-disclosure of HIV status to partners by the participants.

Table 3.6 Reasons against disclosing HIV status

Main theme	Category	Subcategory	Meaning units
Reasons for non-disclosure	Discloser perceptions	Self-respect	I felt like a prostitute ... I always associated having the virus (stressing the word) with a person who slept around.
		Fear	I was too scared to tell him.
		Readiness	He still doesn't seem ready to disclose.
	Partner perceptions	Rejection	This means if he had not told me first, I was going to keep it quiet (eyes wide open) I was going to wait and see what type of person he was and whether he was likely to accept my status or whether he would reject me.
		Relationship end	I even thought he would end the relationship.
		Blame	Whether he will say that I will pass the virus to him.
		Lack of support	I also told them that if he becomes ill and he still hasn't told me his status, I will not be able to give him all the care that he needs.
		Worry others	The reason we have not told them is because in our experience when you tell adults that you have the virus ... and you are HIV positive ... they immediately assume that you are about to die. Then they become ... frustrated and in some cases they can even worry and develop

Main theme	Category	Subcategory	Meaning units
			conditions such as high blood pressure.
		Past experiences	At the moment I do not feel that a new partner will be any different from my old partner. I do not believe that things will be any different.
		Non-acceptance	I didn't know whether he would accept my situation. You work out his feelings and decide whether he is the type who will accept you or not.
	Other perceptions	Stigma	I also feel that it would have a negative impact on their lives especially at work. One of my brothers is a doctor; I think he would be discriminated against. There is an English word called STIGMA (laughing). I don't want my relatives to be stigmatised because of my public disclosure.
		Views on HIV	Yes, they were valid because the reason why you fear to tell a person is because of the way they talk about the issue.

3.4.6 Theme 6: Initial reactions to disclosure

This theme describes the initial reactions by both the HIV infected participant and the partner being disclosed to, following disclosure. Participants described their own feelings rather than actions, but described how their partners reacted to the news rather than the partner's feelings. There were descriptions of both positive and negative feelings, which appeared driven by the partner's reaction or actions.

3.4.6.1 Self

This category describes how the participants actually felt following disclosure by their partners or to their partners. Feelings varied from relief to sadness, disappointment, deflation and emotional trauma. One participant attempted suicide with a clear intention of taking her life, as opposed to a cry for help. This participant described her initial reaction as follows:

“Heyish ... I have bad memories about that you know ... (shaking her head) ... (Long pause) for me it was very traumatic ...”.

“It was traumatic to me ... heyish... my family and relatives ... even though people couldn’t tell how I was really feeling ...”.

Later on during the interview she talks about her suicide attempt, and this is what she said:

“(laughs) I was sorry I didn’t die. I really wanted to die that day because I was in so much pain”.

Another male participant described how he had noticed that he was emotionally weaker ever since his experience following disclosure to his partner, as shown below:

“Not really all I can say is ... the only problem I have seems to be with controlling my emotions. I seem to lose my patience easily these days ... em ... especially when I am supposed to sit and discuss something ... em ... I realised in the end that my experiences with that lady did affect me. I now avoid discussions etc ... I am aware that I could easily start being emotional and em ... end up not putting my point across. I believe the kind of life that I lived did significantly affect me emotionally”.

3.4.6.2 Partner

This category describes the emotional reaction which was displayed by partners following disclosure to them by their HIV infected partners. The spectrum ranged from acceptance and supportiveness to denial, lack of support and outright display of anger. The support was varied both emotionally and materially, as described by one participant who said: *“This man took his time to look after me. He spoilt me with anything I wanted”.*

Another participant described how her partner *“went absolutely mad on the phone”.*

The table below gives a summary of initial reactions to disclosure by both partners.

Table 3.7 Initial reactions to disclosure

Main theme	Category	Subcategory	Meaning units
Initial reactions to disclosure	Self	Deflation	This was followed by a feeling of defeat.
		Disappointment Sadness	It really made me feel sad, very sad. I felt sad because as you know when one is married ... my husband did a lot of running around.
		Emotional trauma	I actually tried to commit suicide but was unfortunate because I was rushed to hospital where they managed to save me.
		Relief	Then I started to relax.
	Partner	Acceptance/supportive	He said don't worry, we are always told that this virus attacks everyone. There is nothing to be scared of. My partner accepted the news when I told him without any difficulty.
		Anger	I called him and asked him to go to the hospital for his test because I had done mine and I was positive. Still on the phone, he went mad.
		Unsupportive	She seemed intent on showing me that she didn't want to be in the relationship any more.
		Disbelief/denial	As you know what men are like, he became very difficult.

3.4.7 Theme 7: Consequences of disclosure

In this theme the effects of disclosure on the participants and their relationships with their partner subsequent to disclosure are described. The preceding section gave a glimpse of the emotions, reactions and experiences which occurred on initial disclosure of sensitive information. This section looks at how those initial reactions shaped the relationship in the longer term. Categories describing both positive and negative consequences of disclosing their sero-status to partners emerged. The subcategories emerging under these categories include emotional support; good mental well-being; increased condom use; financial support and relationship strengthening or breakdown.

3.4.7.1 Positive effects

Results from the interviews indicate that there were significant positive experiences among participants following their disclosure. They experienced emotional and financial support from both partners and families. Condom use was mentioned by two participants as a positive outcome because of the perceived public health benefits. Disclosure to partners also had a positive impact on some of relationships, which were further strengthened following disclosure. One of the participants who described this outcome was the one who had attempted suicide when she found out about her partner's status. They went on to get married and remain so up to this day. The researcher could not have envisaged such an outcome based on the experience undergone by this participant. Other participants described how their partners and relatives stepped up their support measures once they knew of their status.

3.4.7.2 Negative effects

Negative outcomes following disclosure of HIV status did not score high among participants' experiences. Two out of the nine participants had negative experiences, mainly affecting their psychological well-being. One participant's partner openly had an affair after her partner disclosed to her, and even became pregnant by the other man while still in a relationship with the participant. This participant reported undergoing emotional suffering which continues to affect him to date. Another participant experienced blame and rejection, which influenced her decisions regarding disclosure to future partners. Despite being in a new relationship, she still had not come to terms with the rejection by her first partner.

Table 3.8 summarises the effects of disclosure on participant's relationships.

Table 3.8 Consequences of disclosure

Main theme	Category	Subcategory	Meaning units
Consequences of disclosure	Positive effects	Emotional support	<p>He said we are always told that this virus attacks everyone. There is nothing to be scared of.</p> <p>He never even suggested we stop sleeping together just because I have the virus. He still treats me very well.</p>
		Mental well-being	Disclosing your status to your partner gives you freedom. You don't live in fear of....and if something happens ... You would feel guilty just because you never told him in the first place ... that there is such and such issue ...
		Condom use	<p>Disclosure can encourage safer practices.</p> <p>We have agreed to use condoms. He has no problems with that.</p>
		Financial support	<p>They even give me money to travel for my checkups if I don't have the money.</p> <p>He encourages me to adhere to treatment. He even buys me fruit and milk.</p>
		Relationship strengthening	<p>Yes, he is the only issue. We have plans to marry in the future. His family is aware of our plans. They also know my HIV status.</p> <p>Right now we live together in harmony. We don't have fights about his previous life style of running around.</p>
		Negative effects	Psychological abuse
Physical abuse	In the meantime, my partner not only refused to do the test but also refused to use condoms. It became such an abusive relationship.		
Relationship breakdown	Our relationship was not perfect at the time but after I told her things seemed to get worse.		

Main theme	Category	Subcategory	Meaning units
			I also told him that when he returns the relationship will not continue. I told him it was over because of my status.
		Rejection	May be counselling may help because I was rejected by my partner when I told him. He kept saying “not me, I am not ill” and he didn’t want anything to do with me after that.

3.4.8 Theme 8: Participants’ recommendations

This theme deals with recommendations based on participants’ views following the experiences they went through. This theme is very important because essentially participants are making recommendations based on evidence. They have lived the experience; they have not read somewhere about it and formed unfounded opinions. Overall participants were able to recommend that disclosing to partners is the right thing to do, regardless of their individual experiences, whether positive or negative. Here are some of the comments participants made:

“Just disclose ... You never know what a human being will doit’s only em ... 2 or 3 who may leave but most will just accept it ... yes”.

“All we can do is encourage them not to fear ... and to be brave ... em ... If they are afraid they could ask another close friend who knows their status to tell their partner on their behalf ... yes”.

Two main categories were identified within in this theme, describing how those infected with HIV could be encouraged to tell their partners. Participants suggested measures which were supportive and other measures which were punitive. Further analysis of the categories yielded the subcategories which included counselling, legislation and withdrawal of services.

3.4.8.1 Supportive measures

◆ Professional counselling

There were diverse views on the likely impact of professional counselling and education, focusing on issues relating specifically to disclosure, being provided to HIV infected people as part of pre-test counselling. Participants expressed varied opinions on this issue. There was support for such an intervention, as in the view expressed by one participant who said: *“may be counselling may help because I was rejected by my partner ... when I told him He kept saying “not me, I am not ill” and he didn’t want anything to do with me after that. That leaves you with a question mark about why he reacted that way, so counselling may help hurt feelings. She goes on to say, “I think they should include it as part of ongoing counselling. People should be advised on what to do in case they are positive and how to approach the issue of disclosing to partners”.*

She did not, however, hold the view that disclosing through a third party such as a health care professional, close friend or relative would be beneficial. There were two participants who did not think counselling would help. This is the view expressed by one of those participants:

“For me counselling was not relevant because I had counselled myself before going for the test”.

“I swear by my God ... ok ... I went for the test fully prepared for any outcome and ready to accept whatever the result was ... ok ... I don’t think there is anything that another person can tell me which would have changed the way I felt about the process or my intentions ... I do appreciate that other people may find it beneficial ... but it is not for me. I am one person who has self counselled ... ok”.

Although this participant does not believe in counselling, she gives good reasons why. Essentially she is saying that professional counselling is not for everyone, which would appear a reasonable conclusion, as with emotional issues there is no one-size-fits-all solution.

◆ **Couple HIV testing at the same time**

This subcategory describes a situation where both partners go for their HIV testing together. One participant expressed the sentiment that simultaneous HIV testing of partners could also reduce the likelihood of blame.

◆ **Third party mediation**

Another subcategory which emerged described a provision whereby those who are HIV infected and are afraid to disclose to others could be helped to do so through third parties acting as mediators. Such third parties would be health care professionals, friends or close relatives. This provision did not have strong support from participants.

3.4.8.2 Punitive measures

This category describes opinions expressed by participants with regard to whether any kind of forceful measures would make those infected with HIV think harder about their actions. Strong opinions were expressed both in support of and against punitive measures to force people to disclose their status to others. It was interesting that participants who supported punitive measures were those who held positions of responsibility in the workplace.

◆ **Legislation**

This subcategory describes the use of the rule of law to effectively punish those found intentionally transmitting HIV by not informing those with whom they were having sexual contact. Some participants expressed very strong opinions regarding legislation. One participant said:

“Not really ... (long pause) there is nothing the government can do if I am not prepared to tell my partners even though I should ... do you understand?”

“It all depends on what the person wants to do ... It also has to come from deep down the person’s heart. If as an individual I am not prepared to tell my partner ... There is nothing the government can do about it”.

Other participants felt strongly that the government needs to get involved, as exemplified by one participant’s views *“I am not sure.. if ... em ... serious measures have to be taken against them ... yes ... because they help to spread the virus. At least a person who doesn’t know their status has an excuse ... yes ...”.*

◆ **Withdrawal of services**

In this subcategory, participants expressed the view that those accessing HIV-related treatment services such as the government antiretroviral programme should have measures taken against them if they are found to be practising behaviour deemed likely to spread HIV. Some views were particularly strong, especially those advocating withdrawal of services from those judged to be behaving irresponsibly. Here are some of the views:

“I would like the government to reconsider the situation where by a person is on the program and becomes pregnant outside wedlock, even those who are married ...”.

“Those people who know their status and fall pregnant should be taken to the side by the nurses when they register and be talked to sternly. May be that will reduce the spread of the virus”.

The views described in this subcategory were not expressed by all participants but those who expressed them appeared to hold them very strongly.

3.5 CONCLUSION

This chapter analysed and presented findings from the research study. Demographic data of the participants was presented first. This was followed by presentation and analysis of interview findings using content analysis. Paragraphs communicating a meaning were identified using colour codes from the coded interviews. These then

informed the categories and subcategories. Main themes were then built from categories and subcategories. The data was presented in tables for ease of clarity. The next chapter will present the literature review, which will be used to contextualise and validate the research findings and to inform the discussions and conclusions in the final chapter.

CHAPTER 4

DISCUSSION OF FINDINGS AND LITERATURE CONTROL

4.1 INTRODUCTION

This chapter discusses the findings from the study with reference to the existing body of knowledge on the concept of disclosure of HIV status to partners and elaborates on the theoretical framework informing the study conclusions. Burns and Grove (2009:91) define a literature review as consisting of all written sources relevant to the topic selected for study. These authors go on to state that the purpose of a literature review is to convey what is currently known about the topic of interest. According to Flick (2009:48), Glasser and Strauss (1967) suggested in their grounded theory that qualitative data should be collected before searching for existing literature. Flick (2009:49) then suggests various types of literature review in qualitative studies, which include theoretical literature about the topic, methodological literature about how to do the research and theoretical and empirical literature to contextualise, compare and generate findings. Other authors argue for a review of literature as part of the initiation of a qualitative study to identify the significance of the study and inform methodological aspects (Marshall & Rossman 1999:46). The literature review in the current study was undertaken and used for quality control purposes to contextualise, compare and inform conclusions from the current study, as suggested by Flick (2009:49). The literature review will therefore be guided by discussion of the main themes identified from the data analysis and the CPM theory of disclosure of private information.

4.2 DISCUSSION OF THEMES AND LITERATURE CONTROL

Eight themes which emerged following analysis of data obtained during participant interviews in the preceding chapter were identified. These were:

- (1) Reasons for HIV testing
- (2) Pre-disclosure deliberations
- (3) Process of disclosure

- (4) Reasons for disclosing HIV status
- (5) Reasons against disclosing HIV status
- (6) Initial reactions to disclosure
- (7) Consequences of disclosure
- (8) Participants' recommendations

4.2.1 Reasons for HIV testing

Participants in this study identified three main reasons why they went for the HIV test. They reported going for the test due to health concerns, usually because of illness affecting them or their partners. They also reported undergoing the HIV test for reasons related to family planning, such as an existing pregnancy or when planning to increase the family size. HIV testing due to public health campaigns was also reported in this study (see section 3.4.1). In a study done in Botswana to assess reasons for HIV testing following introduction of routine HIV testing in Botswana from 2004, Steen, Seipone, De la Hoz Gomez, Anderson, Kejelepula, Keapoletswe and Moffat (2007:486) reported that the main reasons given by respondents for undergoing routine HIV testing were due to the patient's wish (50.1%); pregnancy (24.7%); medical examination (6.5%); with the rest of the figures being due to other reasons. Other reasons identified in the literature for HIV testing included being required to have the test by, for example, health provider-initiated HIV testing, as reported by Mugisha (2008:93). This was not one of the reasons for undergoing the HIV test among participants in the current study. Weiser, Heisler, Leiter, Percy De Korte, Tlou, DeMonner, Phaladze, Bangsbeng and Lacopino (2006:1017) conducted a cross-sectional study based on 1268 adults in Botswana to assess knowledge of and attitudes towards routine HIV testing, correlates of HIV testing, and barriers and facilitators to testing 11 months after introduction of the policy of routine HIV testing. They found that factors associated with HIV testing included older age, female gender, higher education, higher income, self reported excellent health status, access to good health care, access to HIV testing and respect from health care professionals. There are several significant differences in the factors influencing HIV testing in this study compared with the current study. In the current study, health status was a significant factor associated with HIV testing but not in the positive sense reported by the cross-sectional study above. Access to HIV tests and respect from

health care professionals was also not reported as important factors influencing HIV testing among participants in the current study.

4.2.2 Pre-disclosure deliberations

Participants described their feelings, thoughts and concerns before disclosing their HIV status to their partners (see section 3.4.2). The participants thought about themselves, how prepared they were; how they would actually deliver the news and how the news could be received by their partners. These deliberations are reflected in the findings by Greene (2006:14), who describes a situation where the disclosers (HIV positive partners) battle to reconcile their need for personal autonomy by having control over their private information against their loyalty to their partners by not keeping a secret such as their HIV status from the partner. Another study reported feelings of worry, doubt about whether to disclose or not, hurt, acceptance and courage (Greeff, Phetlhu, Makoae, Dlamini, Holzemer, Naidoo, Kohi, Uys & Chirwa 2008:319). Their study, which was done among people living with HIV/AIDS in five African countries, did not report deliberations regarding mode of news delivery. This is in contrast to the current study, which found that a significant part of pre-disclosure deliberations was occupied by disclosers preparing themselves for the process, by, for example, self counselling or making positive decisions about lifestyle changes. The authors (Greeff et al 2008) reported denial as a significant pre-disclosure concern leading to non-disclosure. In the current study, although denial was reported, it did not lead to non-disclosure. Sheon and Crosby (2004:2111) reported an interesting glimpse of the diversity of pre-disclosure considerations in their study on men having sex with men in San Francisco. One of the participants in their study narrated that he hoped to be told he was HIV positive when he went for his test results, just so that he could stop worrying about possible infection and also be able to tell his sexual partners that he too was HIV positive, so they could stop excluding him. It seems that when he had these thoughts before getting his HIV results, a sense of belonging and hope for acceptance by the gay community he lived in were overriding factors in his deliberations, rather than concern for his health.

4.2.3 Process of disclosure

This theme emerged as a result of the descriptions given by participants of how they actually went about revealing their HIV status to partners (see section 3.4.3). It soon became clear that there was a build-up of thoughts, deliberations and actions leading to the actual moment of “telling”. In the narratives, participants related their story by first getting the researcher to understand how they found themselves in a situation where they had to disclose. They described the preparations they made such as holding general discussions about HIV issues with partners to work out what their views were; informing partners that they were going for the HIV test and when they were going to collect the results to try and prepare partners for the actual disclosure of bad news. They also describe pre-test result self-counselling, and self-acceptance, which had to be achieved before they could feel ready to break the news. They then had to decide how and when disclosure would occur. The narratives would seem to reflect the findings according to Maman and Medley (2004:4), where they describe disclosure as a process rather than a one-off decision and also suggest a framework to describe the decision-making process during disclosure. Six steps are identified which include:

- ◆ **Adjustment to the diagnosis, characterised by a need by the individual to adjust and reach a level of acceptance**

One of the participants gives a very good example of this when she says: “*So I ... em ... decided to counsel myself and to prepare myself in case ... em ... my results came back positive*”.

- ◆ **Evaluation of personal disclosure skills**

The individuals undertake a self evaluation to see if they have the necessary skills to enable them to disclose their status to others. “*I kept asking myself, how will I react if I am found to be positive ... This was before I went for my test*”.

◆ **Evaluation of the appropriateness of disclosing to a potential recipient**

Decisions regarding who can be told are formed at this stage. Rutledge (2007:1046) observed in his study on enacting personal HIV disclosure policies by gay men that if a romantic relationship is deemed likely then the individual will be more inclined to tell. In the current study the participant who was afraid to tell her subsequent partners was able to disclose to her third partner until after he disclosed to her first. Armed with the information about his status, she calculated that a positive outcome was now more likely to result from her disclosure to this partner compared with the experience she had had with her previous partners.

◆ **Evaluation of circumstances for disclosure**

In this step, the individual decides on the circumstances which prohibit disclosure to others. Moskowitz and Roloff (2007:6) assert that HIV infected people will carry out a cost/benefit analysis before a decision to disclose is made. If the analysis suggests that friendships could be negatively affected, then disclosure does not occur. One of the participants had experienced a negative outcome after disclosing to her first partner. As a consequence she was not able to disclose to her second partner. She only managed to tell her third partner when she had information which led her to conclude that the circumstances prevailing were now right for her to tell the partner she had not told for two years. Negative outcomes following disclosure to others by a group of pregnant women in South Africa were reported by Visser, Neufeld, De Villiers, Makin and Forsyth (2008:1142). These outcomes included being physically hurt, abandoned and even given death threats. This was, however, reported in less than 10% of the sample, with the rest reporting positive outcomes. Medley, Garcia-Moreno, McGill and Maman (2004:302), following their synthesis of literature on barriers, rates and outcomes of disclosure, concluded that perceived negative outcomes were often not realised in practice, with disclosers receiving more support than rejection.

◆ **Anticipation of reactions by potential recipients whereby anticipated benefits are weighed against potential negative outcomes of disclosure**

Rutledge (2007:1044) describes the process of disclosure as experienced by gay men in his study, which starts with the discloser applying his personal disclosure policy to the sex environment, then assessing the prospective sexual partner to try and gauge his potential reaction to disclosure. This is followed by evaluation of reactions and consequences of disclosing. Rutledge (2007:1044) also describes a three-stage process of timing, staging and enacting disclosure. In this study, one participant described how she introduced the subject to her children in a step-wise manner. First she introduced the issue of her having to take some pills and asking the children to remind her daily. When they were comfortable with the knowledge and arrangement, she then told her eldest daughter what the pills were for first, telling the younger ones as they also grew older. She felt she had to tell them when the time was right, when they were mature enough to understand and accept her situation.

◆ **Identification of the motivators for disclosure occurs in the final step**

Perceived risks and benefits of disclosing one's HIV status are likely to be formed at this stage. A falling CD4 count has been described as instilling a sense of urgency to disclose in certain circumstances (Moskowitz & Roloff 2007:18). This was exemplified by the description of one participant in this study who said that she told her partner, who was trying to avoid the subject, insisting that they needed to talk about it because she needed him to give her some money towards the travel costs to attend the antiretroviral clinic. Another participant decided to tell her family so that they could look after her children when she was gone.

This framework highlights the complex nature of decisions regarding disclosure of one's HIV status. It confirms the interaction of different factors influencing this process. The process is also clearly unique for each individual.

4.2.4 Reasons for disclosing HIV status

The main factors described by participants as having influenced them to tell their partners that they were HIV positive were divided into others-focused and self-focused (see section 3.4.4). The others-focused reasons included a sense of responsibility to protect loved ones against HIV transmission; because they lived together, a reluctance to keep a secret of such importance from a partner; and probable improvement in practising safer sex. The self-focused reasons were mainly in relation to what the discloser hoped to gain by disclosing to the partner. The perceived benefits of disclosure to partners were hope of acceptance and the emotional and financial support that comes with it; a sense of freedom from the burden that comes with living and keeping such a secret; conviction that the relationship was strong enough to withstand such an issue; and anticipated support in dealing with the physical aspects of the illness. Participants also reported being influenced by the current perceptions about HIV. They felt there was a better understanding of the disease and it was starting to be seen like any other chronic illness. The availability of HIV treatment meant that they would get help if they told someone.

These findings appear to be in keeping with studies from the literature. Kebede, Woldemichael, Wondafrash, Haile and Amberbit (2008:81) found that disclosure of HIV status to sexual partners is more likely if the partner's status is known; the discloser has high self-esteem; partners are living in the same house; the disease is at an advanced stage; and if there have been prior discussions about HIV testing before the test. Advanced stage of disease was not reported as a factor influencing disclosure in the current study. This could be because the participants in this study were all on ART and therefore not at the advanced stage of HIV infection. Norman et al (2005:8) have identified readiness as a contributory factor to disclosure of HIV status. Other positive experiences such as feelings of unburdening and freedom resulting from disclosure were also described in their study based in two villages in South Africa.

Similar factors contributing to disclosure were identified by Serovich and Mosack (2003:70-80). They came up with a four-factor set of reasons for disclosing. These were:

- Responsibility and sense of duty
- Instruction which involved teaching others about HIV
- Relationship consequences
- Emotional release

They indicate that safe sex as a reason for disclosure was not loaded as significant in their study. Serovich and Mosack's (2003) study was a quantitative study. In the current study, participants considered safer sex an important reason for disclosing. They believed that disclosure would encourage condom use, especially in male-dominated relationships. Disclosure to partners has also been found to result in increased social support for people living with HIV/AIDS (Zea, Reisen, Poppen, Bianchi & Echeverry 2005:20). These authors (Zea et al 2005:20) also noted in their study among gay Latino men that disclosure was related to increase in self-esteem. Increased levels of social support and reduced levels of depression were also reported. This is a helpful finding, because the participants in the current study were hoping to experience increased partner and social support by putting themselves through this process. Maman and Medley (2004:3) also identify both public health and personal benefits of HIV status disclosure to sexual partners. The public health benefits include expanded awareness of risk which may lead to reduced sexual risk taking. It is presumed that this would in turn lead to decreased transmission of HIV. In the United States of America (USA), young people were found more likely to disclose to another HIV positive partner than a sero negative one (Rice, Batterham & Rotheram-Borus 2005:281). Being on HAART, being Caucasian, time having elapsed since diagnosis and having a non-casual partner were also identified as positive predictors of disclosure among men having sex with men in the same study.

Menon, Glazebrook, Campain and Ngoma (2007:349) carried out a study to investigate the relationship between mental health and disclosure of HIV status in Zambian adolescents. They reported positive mental health outcomes among those who disclosed their status. This would be in keeping with findings from the current study, where participants reported a sense of relief and freedom following disclosure to partners.

4.2.5 Reasons against disclosing HIV status

This study identified factors acting as barriers against HIV disclosure to partners; these were motivated by perceptions of the risk involved in undertaking such an action. Participants took into consideration their perceptions about themselves and about their partners regarding the issue of HIV when considering whether to tell or not. Negative preconceptions about who gets HIV seemed to act as an important barrier towards disclosure. A participant who associated HIV with promiscuity and prostitution could not face telling her partner. She described feeling “dirty”. Feeling a lack of readiness to disclose, fear of rejection, loss of self respect, being blamed for bringing the virus into the home and possible relationship breakdown were all reported as factors leading to non-disclosure in this study. The way participants thought about their partners’ views about HIV also significantly influenced whether disclosure would occur or not. If a partner’s views on HIV related issues were perceived as negative, then disclosure was unlikely to occur. Past negative experience with disclosing HIV status to previous partners and not wanting to worry loved ones were also reported as a reason influencing non-disclosure in this study.

Studies from the literature would appear to identify similar factors acting as barriers towards disclosure. The individual risks identified in women who disclosed to their partners, according to Maman and Medley (2004:3), include loss of economic support; blame; abandonment; abuse; discrimination and disruption of family relationships. The study also reports that lovers are likely to become angry and withdraw following disclosure. One participant reported emotional abuse following disclosure in the current study. Physical abuse, loss of economic support and discrimination were, however, not reported by the participants in the current study. Fear of rejection and abandonment and concern for others were also identified as factors resulting in non-disclosure (Norman et al 2005:6). Another study reported fear of loss of employment as a major factor causing non-disclosure among HIV patients receiving ART in private clinics in Botswana (Wolfe et al 2006: 932). These authors reported that 27% of 112 HIV sero-positive adults they studied on antiretroviral medication had not disclosed for fear of loss of employment. Participants in the current study did not describe specific concerns about loss of employment if they disclosed. However, disclosure in the context of the study by Wolfe et al (2006) was to others, not necessarily partners, which could explain the difference

in terms of concern for loss of employment. According to Circcarone, Kanouse, Collins, Miu, Chan, Morton and Stall (2003:949), legal and ethical considerations have also been postulated as contributors to non-disclosure. They indicate that from 1999, 31 states in the USA had statutes making sexual contact without disclosure a criminal offence, which could contribute to non-disclosure.

In the context of this study, no concerns were voiced about legal implications being considered a barrier to disclosure. The fact that there is a Public Health Act in Botswana which can be used to prosecute those thought to be knowingly infecting others by not disclosing their status did not seem of particular concern to the participants in this study. It may be that awareness of legal implications of non-disclosure was lacking among participants in this study.

4.2.6 Initial reactions to disclosure

Emotional reactions by the participants to their own disclosure and to the way their partners received the information were described (see section 3.4.6). Feelings of defeat, disappointment, emotional trauma, sadness and relief were among those reported by participants. Partner reactions to disclosure were also described, including acceptance, supportiveness, anger, denial and outright lack of support. Similar reactions were identified by Visser et al (2008:1145) in their study of disclosure during pregnancy by South African women. They also found that some disclosing partners received no reaction from their partners following disclosure. Lack of reaction was not reported by participants in the current study. Greeff et al (2008:317) reported reactions including negative perception of self, loss of self-esteem and social withdrawal, name calling and blame for promiscuity. Caughlin, Brashers, Ramey, Kosenko, Donovan-Kicken and Bute (2008:656) argue that understanding how others will respond to disclosure is important for disclosers, who may feel prevented from disclosing by uncertainty regarding reactions to disclosure by recipients. Disclosers may also have hopes and expectations of how recipients of disclosure will react and may be very disappointed if reactions do not meet expectations. This was certainly important in the current study, because participants indicated uncertainties regarding potential partner reactions, which in some cases were better than hoped for but in others not so positive.

4.2.7 Consequences of disclosure

Following disclosure of HIV status to their partners, participants in this study reported mainly positive and to a lesser degree negative outcomes, as described in section 3.4.7. The positive outcomes can be summarised as emotional and financial support; improved emotional well-being, strengthening of relationships and anticipated increase in safer sexual practices through condom use. The negative effects following disclosure as reported by participants in this study were rejection, emotional trauma and abuse and relationship breakdown. The relationship breakdown occurred on the back of an already troubled relationship. Similar outcomes were described in the literature by Medley et al (2004:303). These authors identified and synthesised data from 17 studies investigating disclosure rates, barriers and outcomes among HIV infected women in developing countries. Fifteen of the studies they identified were done in sub-Saharan Africa. Positive consequences of disclosure reported in their paper include encouraging attitudes, acceptance, understanding, kindness and relationship preservation. The negative consequences reported were physical abuse, disputes, violence and relationship breakdown. The number of studies reporting relationship breakdown was reported to be in the minority. While their findings were similar to those from the current study, there are some differences. Participants in the current study did not report any overt physical violence. Disputes following disclosure were also not reported as significant in the current study. One participant even described reduction in disputes about her partner's involvement with other women after they found out he was HIV positive.

4.2.8 Participants' recommendations

In this theme, participants gave their views, advice and words of wisdom in relation to the pitfalls of disclosure, usefulness of disclosure in controlling HIV transmission, and methods that should be considered to encourage disclosure and also make the process easier for disclosers (see section 3.4.8). There were diverse views but all participants agreed that disclosing HIV status to others should be encouraged. Reflecting on this, the researcher holds the view that while disclosure should be encouraged; there have to be appropriate safeguards and support systems in place to enable disclosure. Ideally an individual risk assessment should be carried out by suitably qualified health care

professionals so that potential disclosers are well equipped for this process. The researcher's view is that disclosure is so personal that when faced with it, even the participants giving this advice might find it hard to follow it themselves. Methods to help disclosers prepare for disclosure and through the process of disclosure were suggested, including professional counselling and simultaneous HIV testing of partners. Other participants suggested punitive measures to deter non-disclosure, such as withdrawal of access to HIV treatment services and use of the law. Studies in which HIV infected people have suggested punitive measures as a way of enhancing disclosure have not been identified in the literature. In their study exploring reasons for disclosure of HIV status among people living with HIV/AIDS in care in Uganda, Ssali, Atuyambe, Tumwine, Segujja, Nekesa, Nannungi, Ryan and Wagner (2010:7), recommend measures which could empower those considering whether to disclose their HIV status to make the right decisions at the right time by analysing their personal circumstances carefully. The recommended measures include tailoring of intervention strategies to address concerns about disclosure that vary depending on the target. They also suggest making material provision available for those living with HIV, which will secure their livelihoods and independence, given that some of the barriers to disclosure are related to material dependence on others and therefore loss of livelihood if the discloser was rejected by the partner. Professional counselling with emphasis on disclosure issues: possibly trauma-focused cognitive behavioural therapy, would be one intervention which could be used to empower those wishing to disclose their status to others.

4.3 THEORIES OF HIV DISCLOSURE

Given the varying outcomes from the literature regarding positive and negative outcomes and predictors of disclosure of HIV status, researchers have tried to theorise and gain better understanding of reasons behind the process of disclosure. Three such theories will be considered in the next section.

4.3.1 Disease progression

According to Serovich (2001:356), Babcock and Kalichman argue that the premise of this theory is that individuals disclose their HIV diagnosis as they become ill because as

the illness progresses they can no longer keep it a secret. With the advent of highly active antiretroviral therapy, most of the overt clinical signs of HIV occur less frequently. There was no evidence from the current study that disclosure was motivated by disease progression. It is for this reason that this theory will not be used as the main basis for the current study. Serovich, Lim and Mason (2008:28) re-tested the theory of disease progression and consequences theory. Their findings supported a revised consequences theory but concluded that disease progression may not be a direct predictor of HIV disclosure.

4.3.2 Theory of competing consequences

According to the consequences theory, the relationship between disclosure and disease progression is moderated by the consequences one anticipates resulting from disclosure (Serovich 2001:356). It postulates that as disease progresses, evaluations of likely outcomes of disclosure occur once rewards outweigh costs of disclosure. The rewards could include social, physical, psychological and emotional dividends. The negative consequences suggested include anxiety, threat to personal well-being, ostracism and degradation, rejection, fear of loss of employment, insurance, medical services, child custody and right to education (Serovich & Mosack 2005:257). Other authors have expanded on the consequences theory in their CPM theory, which is discussed in the next section (Greene et al 2003:17).

4.3.3 Communication privacy management (CPM) theory

This is a theory initially postulated by Petronio in 2004 which examines why people make decisions about revealing or not revealing private information about themselves. Petronio (2004:196) first thought of privacy as the key to understanding disclosure and looked at disclosure from two aspects: content and process. The content is described as the private information to be disclosed. The private information to be disclosed in the current study is HIV positive status. The process refers to how the information is disclosed. The process is demonstrated in the current study by identification of initial reasons for HIV testing, pre-disclosure deliberations following receipt of the test results, initial reactions to disclosure and outcomes of disclosure. Petronio (2004:196) concluded that it was difficult to understand disclosing of private information without

really defining the dialectical tension between disclosure and privacy. This dialectical tension was experienced by the HIV infected participants during pre-disclosure deliberations in the current study. They had to deal with self-preservation versus a sense of duty to others when considering whether or not to disclose their HIV status. Petronio also argued that the confidant or recipient of information is an integral yet unique part of the communicative process. At its inception the theory focused on married couples, because they engaged in extensive interactions deemed private. This helped with the understanding of how people are able to regulate the dialectical tension of privacy and disclosure through decision criteria that generate privacy rules. Ownership and control are seen as critical in understanding the way people define and handle private information (Petronio 2004:198).

According to Greene et al (2003:20), the CPM theory is described as consisting of privacy boundaries which shift throughout life, depending on the sensitivity of the information to be revealed. The theory assumes a mutually exclusive relationship between disclosure and privacy whereby one cannot exist without the other. The theory would therefore seem to suggest that as long as private information exists, disclosure remains an issue that needs to be addressed. The participant who went through two relationships without disclosing to her partners in the current study eventually found peace and experienced freedom after she told her third successive partner. This would indicate that there was always an inner tension related to withholding private information from her partners. The tension was released when there was no longer a secret to keep. The theory describes a rule management system which governs disclosure of information. The rule management system determines whether full access to private information is allowed (full disclosure) or partial access (selective disclosure) or restricted access, which leads to non-disclosure. It also proposes five criteria used to develop privacy rules in order to decide whether to disclose or conceal private information. The criteria are: culture, motivation, gender, context and risk benefit. The researcher's reflections before the study debated whether some of the disclosure issues could be determined by the situation between individual partners and perhaps their views on moral issues as well. Cultural perspectives can certainly encompass moral issues.

Culture

The theory argues that culture is paramount to development of privacy rules. Cultural expectations may influence disclosure decisions. An illustration of this cultural influence is given by Raganya (2003:12), who reports the observation of Lerc-Madlala, that when a person who is HIV positive dies in the African culture, the death is blamed on witchcraft. Witchcraft is considered a specialist African practice. One participant and her partner in the current study were treated by a traditional healer with a mixture of coke and traditional tea. Her ailment was thought to be a consequence of her sexual relationship with a widower. She remembered that her partner had lost a wife and suspected it was related to HIV infection, despite her partner never having told her so. This narrative by the participant sounded very familiar. On several occasions, the researcher had treated patients infected with HIV at the brink of death because they had spent time receiving this very kind of treatment from traditional healers. The narrative aroused mixed emotions in the researcher's mind because of personal experiences of similar nature involving relatives who had lost their lives due to delays in accessing conventional HIV treatment. The emotions were mixed because at least this participant had lived to tell the story. The researcher had to consciously make sure that her response to this particular part of the conversation remained neutral and did not jeopardise the rest of the interview. The culture criterion was also demonstrated by the participants who decided to disclose hoping that their partners, who were male and dominant in the relationship, would be convinced to practise safer sex by use of condoms.

Motivation

Motivations people have concerning privacy have a significant influence on whether they will disclose their private information. This criterion is used to explain how personal needs, achievements and goals influence privacy rule making. This is exemplified in issues such as preservation of a relationship. The partner of one of the participants in the current study was reported to have known his HIV status and started treatment but never told his partner. She discovered his status from her parents, who literally forced him into disclosing. He said he was afraid that the relationship would end. The interview with this participant was heart wrenching; yet while at the time of the interview even the

researcher may have felt that his motivations had been dishonourable and selfish, on reflection he was also probably terrified not only for his life but also for possible relationship breakdown. Under the circumstances, there was no motivation for him to reveal his HIV status to his partner.

Gender

Gender and sexual orientation is also deemed a powerful influence in decisions to disclose. In men having sex with men, the added stigma is alleged to contribute to non-disclosure. However, Rice et al (2005:164) found in their study of predictors of sero-status disclosure in young people aged 13-24 that Caucasian gay men were more likely to disclose their status to sexual partners. There were no gay or bisexual participants in the current study. There were two male and seven female participants. The numbers involved are such that no specific conclusions can be drawn about the impact of gender on disclosure in this study. One of the male participants gave the shortest interview, while the other male participant gave the longest interview. The difference was due to their very different experiences in relation to disclosing their status to partners.

Context

The contextual criterion indicates decision making based on the prevailing situation. This takes into account situational changes such as the timing for revealing status, and a place where one is unlikely to be overheard. Raganya (2003:15) suggests that situations such as geographical separation or having to use a telephone to break the news may create a less favourable context for disclosure to occur. During pre-disclosure deliberations (see section 3.4.2) participants considered how they would reveal the news, including the mode of communication. Mode of communication varied, depending on the individual participant's situation. One participant called her partner at his workplace; another used email to communicate the news to her outside-wedlock partner, who lived abroad. Even the distance could not stop her, which goes to show that if an individual is determined to disclose it will happen regardless of the distance. Another participant knew that her partner was always busy, so she waited for him to come home to talk to him while he was having his meal, as she knew that this was the best time to catch his attention.

Risk benefit

The risk-benefit criterion describes perceived outcomes of such an exercise. If the risk of rejection is too high, for example, disclosure may be withheld. The researcher has the view that this criterion can be contentious. In the background to the study (see chapter 1), the researcher observed that some older men were having sexual relationships with younger girls without disclosing their status to them. It may well be that on evaluation, the risk of rejection because of their HIV status was deemed too high. Issues surrounding legal and ethical considerations as well as confidentiality may also fall under this criterion. This may be true to some extent, but the experience from the current study would lead to the conclusion that disclosure can still occur despite real or perceived risk. An argument can be made that this could be a risk stratification situation whereby, even though there is perceived risk of adverse outcome following disclosure, adverse outcome carries less risk than not disclosing. It is still not a straightforward, easy assessment.

The theory also argues that as information is disclosed to others, they become drawn into a collective privacy boundary which needs to be coordinated. According to Petronio (2004:203), the disclosers then have certain expectations from the confidants, who are now shareholders of the private information. The degree of disclosed information within each boundary may vary (Greene et al 2003:20). Turbulence may arise within boundaries due to factors such as using wrong rules, misunderstanding expectations, intentional rule violations, fuzzy boundary lines or being caught in privacy dilemmas (Petronio 2004:204). As a result the more risky the private information is, the greater the need to control the boundaries. Greene et al (2003:20) also observe that the boundaries can shift over a lifetime. This would suggest that different rules and boundaries could apply at various stages in life from childhood, adolescence, teen years, mid life and later in life.

Findings from a recent survey carried out countrywide by the Botswana government indicate that people were more likely to undergo HIV testing if they had assurance that the knowledge regarding their HIV status remained under their control. They were also in the same survey indications that fear of exposure of HIV status could cause individuals not to reveal their status. The survey concludes that while individuals have

the responsibility to protect others from HIV, it is important for the individuals to feel that they are in control of their HIV status information, whom to disclose to, and when and how (Botswana Parliament 2007:11). In the current study, participants demonstrated that disclosure as a process required careful planning and execution. Following receipt of their HIV test results, they needed time to reflect on how they would deal with the issue of telling others about their status. Self-acceptance and readiness were reported as important prevailing factors that had to be present before disclosure occurred. It can be inferred, therefore, that to achieve acceptance and readiness to share information participants would have needed to deal with the sensitive information privately, away from the prying eyes of others, which can only occur if they are in control of the private information.

4.4 COMMUNICATION PRIVACY MANAGEMENT (CPM) AND DISCLOSURE OF HIV STATUS IN DISCLOSURE TO SEXUAL PARTNERS

This theory has been chosen as the most suitable theory on which to base the theoretical framework of the current study for several reasons. The CPM theory was initially conceived after studying married couples engaged in highly intimate relationships. This study explores issues of HIV status disclosure to sexual partners who were also involved in intimate relationships. The CPM theory is conducive to understanding disclosure of private information because it also identifies two key aspects which significantly aid understanding of the concept of disclosure of private information. These are content and process. The content aspect addresses the nature (what) of the private information to be shared and the process aspect deals with the methodology of sharing the information: the how, why, where, when, to whom and by whom of disclosure. Within these key components, the CPM theory also identifies privacy rules governing control of private information. Five key criteria used to formulate the privacy rules are described, which are: culture, gender, motivations, context and risk-benefit. The theory also puts emphasis on personal and collective boundaries, which recognises that while private information is personal, those infected with HIV have to operate within a community and collective boundaries are bound to play a significant part in their decisions relating to sharing of their private, sensitive information.

The CPM theory therefore allows for a multi-dimensional approach to understanding how decisions to share private and sensitive information such as one's HIV status are reached. The theory will therefore be utilised to inform study conclusions and recommendations in the next chapter.

4.5 CONCLUSION

This chapter reviewed the literature on the concept of disclosure of HIV status to sexual partners and compared findings from this study with the available body of knowledge from the literature. There were several similarities and some differences identified between findings from this study and those from studies described in the literature.

Three theories which have been applied in studies on disclosure of HIV status were then discussed. The CPM theory was chosen for the theoretical framework of the study and integrated into the findings of this study. The theory of disease progression was deemed less relevant to the current study, while the theory of consequences was viewed as encompassed within the CPM theory currently favoured by disclosure theorists. Reasons why CPM theory was deemed more relevant to the current study were expounded on. In the next chapter conclusions and recommendations from the study are made. Limitations of the study are also discussed.

CHAPTER 5

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

5.1 INTRODUCTION

This chapter will focus on discussion of the main themes in the context of the study objectives. The study objectives were to

- explore and describe positive and negative factors which relate to the disclosure of one's HIV status to sexual partners
- provide evidence-based recommendations which could assist HIV infected people in disclosing their HIV status to their sexual partners

The CPM theory, which was used as the theoretical framework for the study, will be applied to inform the conclusions and recommendations.

5.2 MAIN FINDINGS

Following in-depth interviews and verbatim transcriptions of these interviews, eight main themes were identified. The themes were informed by narratives from the participants as they took the researcher through their personal experiences relating to disclosing their HIV status to their sexual partners.

The themes will be discussed relative to the objectives of the study and integrated into the CPM theory. This will be followed by recommendations as a result of the study findings.

5.2.1 Factors which relate to disclosure of HIV status to sexual partners

5.2.1.1 *Impact of demographic characteristics*

The age of the participants in the current study ranged from 26 to 39. There were two males and seven females. Of the males, one gave the longest interview, while the other male gave the shortest interview. Their willingness to volunteer information and their experiences following disclosure appear to have influenced the length of their interviews. The male participant who gave the shortest interview reported no negative outcomes, while the male participant who gave the longest interview reported significant negative experiences. One of the criteria described in the CPM theory is gender. There were more females than males in this study. The sample was, however, not selected randomly.

There were three participants who were married, two in casual relationships and four co-habiting. This was surprising data, as the culture in Botswana tends to encourage marriage and discourage co-habitation. This may be a reflection of the changing times in the society. It is unclear as to whether the era of HIV that we live in has resulted in people deciding to half commit rather than commit fully to the marriage institution. Hattori and Doodoo (2007:1068), prompted by the idea that marriage offers sexual exclusivity and by implication should therefore reduce the risk of HIV transmission to married women, undertook a quantitative study to explore whether marriage indeed offers protection from risky sexual behaviour. Hattori and Doodoo (2007:1074) found that unmarried co-habiting women in Kenya were 9.5 times more likely to report multiple partners than married women living with their husbands. They also found that 11% of cohabiting women reported two or more partners compared with 2% of married women living away from their husbands and 1% of married women living with husbands. Their findings would seem to suggest that marriage remains protective of HIV transmission by virtue of its sexual exclusivity. Another study done in Uganda a decade ago at the height of high HIV prevalence in Uganda, however, concluded that while marriage had been considered desirable by most people in the past, this was not the case currently. Young people were avoiding commitment to marriage because of the fear of not knowing the potential spouse's HIV status, the promiscuity that they had seen occurring within modern marriages and associated increased risk of HIV, as well as society's

condoning cohabitation (Mukiza-Gapere & Ntozi 1995:203). No clear conclusion can therefore be drawn with regard to what the impact of marital status is likely to be on disclosure of HIV status to partners. This could be an avenue to explore through future studies.

5.2.1.2 HIV testing and its impact on disclosure

Health-related concerns were described as the main reason for undertaking an HIV test. The illness usually involved either the participant or their partner. Exploring the reasons why people go for testing has a direct bearing on disclosing of HIV status, because those infected have to face this issue once they know their sero-positive results. It can therefore be argued that factors which influence an individual to undergo an HIV test would indirectly influence disclosure of HIV status. It can also be argued that perhaps some people may not go for their HIV testing for fear of having to deal with the consequences of a positive HIV test, one of which will be telling others about their status. Fear of having to deal with issues of disclosure was not directly reported as a barrier to HIV testing in the current study, however. Greeff et al (2008:312) observe that while most people have disclosed in the past, with both negative and positive experiences, HIV infected people will still have concerns about HIV-related stigma, which could result in people being less willing to undergo HIV testing. Further qualitative studies exploring whether there is a direct relationship between reduced HIV testing uptake and perceived disclosure issues could help define this relationship. The CPM theory sheds light on this subject if it is analysed in terms of the content and process components of the CPM theory. Going for an HIV test leads to knowledge of one's HIV status. This knowledge forms private information and therefore the content. The CPM theory also indicates that privacy cannot exist without disclosure. Once a result is received which shows HIV infection is present, the infected person now has to deal with decisions regarding disclosure or non-disclosure of such information. This situation now describes the process component as described by the CPM theory and it deals with how disclosure will be carried out. It is therefore possible that an individual who does not wish to have to deal with the "process" aspect of disclosure may avoid a situation which creates information to be disclosed (content), by not undergoing an HIV test.

It is also interesting to see that despite intense media campaigns encouraging people to visit voluntary counselling and testing centres, the most important reason why participants in this study had the HIV test was that their health was under threat, as opposed to being influenced by public health messages. Boyd, Murad, O'Shea, De Ruiter, Watson and Easterbrook (2005:65) indicate that Fenton et al (2002) concluded from their study of black Africans resident in the UK that the black Africans did not access HIV testing despite prevailing education campaigns on HIV testing and availability of ART. The CPM theory helps to explain this through the context criterion of privacy management rules. The education campaigns, which under the CPM theory would fall under the content aspect, may not be relevant to the prevailing individual circumstances (context) and therefore lack a positive impact on encouraging access to appropriate services (process). Some of the reported reasons for not undergoing an HIV test included not knowing where to go for the test and uncertainty over entitlement. There was no association with length of period of residence in the UK and uptake of HIV testing. HIV prevention messages (content) perhaps need to be much more targeted (process) than they currently are if they are to reach the intended audience.

5.2.1.3 Influence of pre-disclosure deliberations on disclosure

Participants reported both positive and negative thoughts when considering whether or not they should disclose their HIV status to their partners. The driving force appears to have been the prevailing situation at the time or the context, which is another criterion identified by CPM theory as informing rules for disclosure of private information. Those participants who were in a relationship and knew their partners' HIV status reported no concerns prior to disclosing to their partners. It can be surmised that because they knew they were in the same situation as their partners, the risk of negative outcomes following disclosure were perceived as minimal. Knowing a partner's HIV status is therefore described as an important factor when it comes to decision making about disclosing to partners in this study. This correlates with findings by Kebede, Woldemichael, Njau, Yakob, Biadgilign and Amberbir (2010:34) and by Dave, Stephenson, Mercey, Panahmand and Jungman (2006:119). The risk-benefit criterion of the CPM theory indicates that people will weigh risks against benefits to disclosing private information. Disclosure will occur if benefit outweighs risk.

Another key consideration reported by participants was self-counselling, aimed at self-acceptance, before asking others to accept them and readiness to disclose. This is what one participant said, which seemed to echo what others were also thinking before disclosure : *“I kept asking myself, “How will I react if I am found to be positive? This was before I went for my test. So I decided to counsel myself and to prepare myself in case my results came back positive”*. One participant went so far as to say she couldn't face telling her husband who was away on a trip or her children, because she couldn't accept that she had a disease which has historically been associated with promiscuity. This would appear to be supported by Maile (2003:79) in his study of legal aspects of disclosure among teachers in Cape Town, South Africa. He concluded that teachers did not disclose their HIV status because HIV positive status was associated with promiscuity and a feeling that those who were positive got what they deserved. This belief was also echoed by a Muslim AIDS support group based in Cape Town, who were quoted as expressing the sentiment that “the idea that HIV and AIDS is a punishment from God runs in all religions and people who are HIV positive are being punished for leading a promiscuous or immoral life (Cloete, Strebel, Simbayi, Van Wyk, Henda & Nqueto 2010:3). Cultural beliefs are described by the CPM theory as influencing disclosure of private information. It is unlikely that such beliefs will help move the issue of disclosing HIV forward in a positive direction, especially that they are still being expressed in 2010 when there have been further developments in HIV treatment and management.

The pre-disclosure deliberations carried out by the participants in this study illustrate the dialectical tension between privacy and disclosure as described in the CPM theory. The tension is created by HIV infected participants' need to protect their privacy while taking into consideration the needs of others, in this case their partners. The tension ceases to exist when disclosure has occurred, as evidenced by the feeling of relief and freedom described by some of the participants.

5.2.1.4 The process of disclosure

This theme describes how the participants went about the process of disclosing their HIV status to their partners. Findings from the study show that there were at least four stages to self-preparation to disclose, and only when these were satisfied would

disclosure be more likely to occur. The initial stage involved the participants going through a self-counselling process to make sure they were mentally fit to cope with disclosure; this was then followed by a partner-priming fact-finding mission to test the waters, to try to gauge the likely reaction and to gently lead them towards the actual moment of disclosure; considering modes of delivering the news; and finally delivering the news. The participants in this study delivered their news either in person through face-to-face conversation, by telephone or email. It is interesting that none of the participants reported giving their partners silent clues as a way of communicating their HIV status, such as leaving antiretroviral medication and test results where partners could see them. This form of silent indirect disclosure was reported by Rutledge (2007:1045). It is likely that any factors which disrupt this preparation stage could negatively influence disclosure. Factors which give support to the preparation stage could be expected to enhance disclosure and lead to execution of the disclosure plan. The CPM theory aids the understanding of these actions. The actions clearly fall under the “process” aspect of the CPM theory. In this theme participants are describing the how, when, why and to whom of disclosure of private information in the light of their HIV status (the “what” or content).

The preparation stage was completed when the news was then communicated to the partner when the study participant deemed circumstances to be conducive to doing so. The time scale varied from immediately to several days later. All but two participants reported that they disclosed immediately after they got their test results, which is encouraging in terms of prevention of HIV transmission. Of the two who did not disclose immediately, one disclosed several days later while the other disclosed after years in a relationship. Even the participant who had an extramarital relationship was able to tell that partner within a few days of finding out, despite the fact that he lived abroad and she had to send him an email. Lack of proximity to him did not appear to deter her from telling him. She told him because she had made a decision to break the relationship *“I also told him that when he returns the relationship will not continue. I told him it was over because of my status”*. This would be in contrast to findings by Raganya (2003:12), who concludes that being far away from the partner could prevent disclosure. It may be that if this participant had wanted to continue with the relationship, she might have delayed or never told him, especially as he was living far away from her. Her actions would suggest that once the discloser has gone through the deliberations for and

against disclosing and has come to their own conclusion regarding what needs to happen next, then disclosure is enabled. This would be in keeping with the context, motivations and risk-benefit criteria of the CPM theory regarding ownership and control of information to be shared. The theory suggests that ownership and control are critical to understanding the way people define and handle private information (Petronio 2004:198). The findings from this study confirm that disclosure is a process rather than an event. The CPM theory helps to explain this process, taking into consideration the nature of information to be disclosed (content) and individual circumstances (context, cultural beliefs, motivations, and gender and risk-benefit assessments).

5.2.2 Factors influencing disclosure of HIV status to partners

These have been classified in two groups, reasons for disclosing and barriers to disclosure.

5.2.2.1 Reasons for disclosing HIV status

The common reasons why the participants decided to tell their partners about their HIV status included others-focused motivation, such as a sense of responsibility or living in the same household with the partner; and self-focused, such as a need for emotional support, not wanting to keep a secret and needing financial support. The “self focus” versus the “others focus” is the key to understanding and appreciating the dialectical tension that exists between privacy and disclosure as described by the CPM theory. While non-disclosure may be beneficial to the person infected with HIV by virtue of allowing them to maintain control over their private sensitive information, there also exists the fear of being found out while keeping such a secret. As long as these two are out of balance, the dialectical tension will prevail. The findings from the current study correlate with those by Kebedi et al (2008:81) and Chandra, Deepthivarma and Manjula (2003:207). Other factors leading to disclosure which were not reported in the current study were advanced disease stage, fear of murder and fear of breach of confidentiality (Kebede et al 2008:87) Rutledge (2007:1042) linked an individual’s history before and after HIV infection with the likelihood of disclosure, which was also not reported by participants in the current study. Kebede et al (2010:33), in their study based in Ethiopia to assess the effect of gender on disclosure, found fear of legal accusation motivated

disclosure in both men and women. Legal implications were not reported as having influenced decisions to disclose to partners in the current study. The above findings from various studies add to the notion that factors influencing disclosure are very varied and made up of multiple permutations. The CPM theory helps make sense of these permutations through its classification of private information in terms of content, process and its five criteria used to enact privacy rules for managing private information

5.2.2.2 Others focused

The level of commitment to the relationship was described as the most important reason for disclosure if partners lived together. One participant summed it up when she said: *“When you are in a relationship with someone you have to tell them everything ...”*. This is encouraging, because even if the relationship ends then at least both partners will be aware of their status and would hopefully disclose to the next partner that they decide to co-habit with. This sentiment was expressed by one of the participants when she concluded that disclosure encompasses the sense of responsibility felt towards the partner by the discloser. Responsibility towards others’ health was also a very significant factor which influenced disclosure among the participants. The participants’ interviews revealed that actually sense of responsibility to other people, especially those close to the participant, was the overwhelming reason for disclosing. Disclosure due to living together was also an important consideration by participants. There is no obvious reason to conclude that this was as a direct result of participants being in a marriage or co-habiting relationship. Although participants went for their HIV test because of illness, it is interesting to see that illness was not one of the major factors influencing disclosure. The theory of disease progression was discounted as a key factor influencing disclosure decisions by Serovich et al (2008:28), who retested the theory of disease progression and consequences theory and concluded that disease progression may not be a direct predictor of HIV disclosure. The findings from this study would appear to concur with that.

5.2.2.3 Self-focused

The perception of the probable reactions following HIV disclosure has been shown to influence disclosure of HIV status. Perceived positive outcomes have been shown to

encouraging disclosure. Norman et al (2005:8) have identified expectations of socio-economic support as the major reason for differences in disclosure rates. The same study also identified readiness to disclose as a contributory factor to disclosure of HIV status. Other positive outcomes such as feelings of unburdening and freedom resulting from disclosure were also described. In this study the following perceived reactions to disclosure were found to influence disclosure of HIV status:

◆ **Emotional support and mental well-being**

This was eloquently expressed by one participant who said: *“Disclosing your status to your partner gives you freedom. You don’t live in fear of ... and if something happens you would feel guilty just because you never told him in the first place that there is such and such issue”*. Living with any secret is hard, as described above by the participant. Her experience captures the essence of the dialectical tension which exists between privacy and disclosure as described by the CPM theory. According to Petronio (2004:203), the CPM theory also suggests rules which govern disclosure and which confidants are expected to abide by. After sharing the information, the disclosers then have certain expectations from the confidants, who are now shareholders of the private information. The expectation among others is that partners will respect these rules and boundaries once they know the private information and not take actions which would lead to emotional trauma, regrets and the loss of that freedom to the disclosers.

◆ **Adopting safer sex through condom use**

One participant was very pleased that her disclosure led to both her and the partner adopting safer sex practices by using condoms. This is what she said: *“We have agreed to use condoms. He has no problems with that”*. Such findings are encouraging, but disclosure was also found to result in continued refusal to practise safer sex by using condoms, as was the experience of one of the participants who said: *“In the mean time, my partner not only refused to do the test but also refused to use condoms, it became such an abusive relationship”*. Evidence from the literature regarding the relationship between disclosure and safe sex remains inconclusive. Simoni and Pantalone (2004:109) found in their study that up to one-third of HIV positive people continue to have unprotected sex, sometimes without informing partners who may be of unknown

status. Parsons, Schrimshaw, Bimbi, Woltski, Gomez and Haltikis (2005:S88) on the other hand, found that increased disclosure is associated with reduced sexual risk behaviour.

◆ **Financial support from the partner**

The participant who attempted suicide when she found out that her partner had contracted HIV long before her and never told her, ended up marrying him. One of the key reasons for the relationship surviving was her realisation that although she still felt betrayed by this man, he had made many financial sacrifices towards the cost of her health care which she might not have had if she had left him or had been infected by someone else. She described several ways in which he provided material support, including providing healthy food, taking her to private doctors so that she could access the best possible care, and spending a lot of his money in the process. Applying the CPM theory in this case, this participant found out new information about her partner's HIV status (content) through her parents (context, process). She decided to stay with him because of what she had already gained from him (motivation) and what she expected to gain in the future (risk-benefit, motivation).

◆ **Strengthening of the relationship**

Fear of a relationship's ending can be a significant factor in decisions to disclose. While it was deemed so by participants, the actual outcome after disclosure by the participants was mainly strengthening of the relationship. Some participants described it as follows: *"Right now we live together in harmony. We don't have fights about his previous life style of running around"*. Another participant said: *"We have plans to marry in the future. His family is aware of our plans. They also know my HIV status"*.

The outcomes from this study show that relationship strengthening can occur after disclosure and that perceived negative outcomes are not always realised in practice. This is in keeping with findings from the literature, as evidenced by the findings from a study done by Parsons, VanOra, Missildine, Purcell and Gomez (2004:462), who found that disclosure resulted in increased intimacy with partners among a group of HIV positive drug users. Sheon and Crosby (2004:2112) reported gay men in San Francisco

who perceived that disclosure would negatively affect intimacy by ruining the spontaneity of the sexual encounter, which could in turn lead to a short relationship lifespan.

◆ **Reactions to disclosure**

This outcome can be explored in relation to reactions by the discloser and reactions by the partner to the disclosure. This is a dynamic situation because the discloser will be reacting to the partner's reaction and the experience can be negative or positive.

Reactions to disclosure were overwhelmingly positive, with participants reporting acceptance and support by their partners and families. While the scope of the study is limited and the findings cannot be generalised to other situations, these findings are encouraging for the local community from which the sample was taken, as they indicate that more often than not those who disclose will be given support and be accepted by others close to them. As one participant put it: *"Just disclose; you never know what a human being will do ... it's only 2 or 3 who may leave but most will just accept it"*. The CPM theory explains this through the risk-benefit and motivation criteria as considerations regarding disclosure of private, sensitive information. According to the theory, perceived positive outcome of disclosing private information such as HIV status would be enhanced by findings such as those from this study.

5.2.3 Barriers to disclosing HIV status

The main reason contributing to non-disclosure as reported by the participants in this study appears to be the fear of a negative outcome.

The most significant negative perceptions leading to non-disclosure among the participants in this study before disclosing, or when thinking about disclosing, their HIV status to their respective partners and/or family members and friends, include fear of rejection and being considered an outcast; marriage/relationship breakdown; financial loss; worrying others and infecting others.

The barriers to disclosing HIV status to partners can be considered as being driven by perceived outcomes following disclosure. Perceived negative reactions were very significant during the initial stages of the disclosure process. It is interesting to note that while participants reported fear of negative outcomes, they still went ahead and told their partners. The question is why this happened. Studies looking specifically at how many HIV infected people who reported fear of disclosing to their partners went on to disclose anyway and why they did so have not been identified in the literature search. The CPM theory could also help explain this conundrum, as will be discussed in the next section.

5.3 FINDINGS AND CONCLUSIONS IN RELATION TO THE CPM THEORY

According to this theory, the confidant or recipient of the private and sensitive information is considered an integral yet unique part of the communicative process. According to Greene et al (2003:20), the theory also describes a rule management system which governs disclosure of information. The rule management system determines whether full access to private information is allowed (full disclosure) or partial access (selective disclosure) or restricted access (non-disclosure). Greene et al (2003:20) add that to understand how people with HIV handle the management of concealing or revealing their private information, it is useful to know and understand the privacy rule foundations which are the criteria upon which the rule management system is based. The five criteria described under this theory are: culture; motivation; gender; context and risk-benefit ratio.

◆ Culture

The cultural norms and beliefs prevailing within the discloser's world at the time they are dealing with disclosure of private information can influence the subsequent course of action. Issues such as whether they believe in the traditional explanations of HIV infection and treatments used or in the modern explanation and use of antiretroviral medicines have an influence. One participant was treated with a combination of Setswana herbs and coffee by a traditional healer, as she was made to believe that her ill-health was as a result of sleeping with a widower who had not received treatment from traditional healers to release the curse of death, but she eventually gave up and

commenced ART. Based on the researcher's own personal experience, adults in Botswana tend to avoid discussions of a sexual nature. This conclusion seems to be echoed by Maile (2003:79), who observes that talking about sex is probably taboo in most African countries. HIV is sexually transmitted and to reach the stage of disclosure, acts of a sexual nature would have to be admitted. Strongly held cultural beliefs about discussing sex could therefore negatively affect disclosure of HIV status, in keeping with the premise of the CPM theory.

◆ **Motivation**

The motivators can be viewed in terms of what the disclosers believe they will gain from disclosing. In the context of this study these were the perceived positive outcomes, including emotional and financial support; a feeling of freedom and mental well-being; safer sexual practices and strengthening of the relationship. If these are identified early, then counselling could help target and positively reinforce these. Health-care professionals could also assist their HIV infected patients to achieve some of the motivators as part of ongoing HIV treatment support and counselling. Counselling should not end at the VCT (voluntary counselling and testing centre), but there should be ongoing reinforcement.

◆ **Gender**

This criterion refers to the whether the individual is male or female, and their sexual orientation. This study sample is too small to make any conclusions about the applicability of this criterion. Kebede et al (2010:33), in their study based in Ethiopia to assess the effect of gender on disclosure, found that disclosure rates were the same between women and men in their sample, at 94.6% for men and 94.3% for women. Their study sample size was 705, half of which was male and the other half female. Fear of legal accusation was reported as a motivator for disclosure in this study. Reasons for non-disclosure were, however, varied, with men being more concerned about the partner's anger and not wanting to worry her, while women were more worried about relationship breakdown and physical attacks, including murder. Sexual behaviours were found to differ between men and women recently diagnosed with HIV in South Africa, according to Olley, Seedat and Steine (2004:72). Their findings showed

that non-disclosers were more likely to be male and were associated with not having used a condom in their last sexual encounter. Counselling methods will therefore clearly need to address such gender differences.

◆ **Context**

The context in which disclosure occurs, such as the appropriateness and availability of opportunities and means to communicate; being on ART; pre-disclosure counselling; prevailing beliefs about HIV; personal beliefs about HIV; relationship strength and proximity of partners, all influenced disclosure in this study.

◆ **Risk-benefit ratio**

Weighing the benefits and risks of disclosing, which consist mainly of perceived positive and negative outcomes following disclosure of private information, was also found to have influenced disclosure among participants in the current study. Perceived and experienced negative outcomes included fear of rejection; stigma; not being ready to disclose; loss of financial and emotional support; past negative experiences following disclosure; relationship breakdown and loss of self-respect. The CPM theory argues that the outcome of risk-benefit assessments is likely to influence the rules of privacy management which the person may use when making decisions on whether to disclose or not. Greene et al (2003:25) illustrate this observation by relating it to the first-date rule enacted by a gay man. He had one rule, which was to disclose his status to all his first dates to avoid wasting time on a relationship that was not going to progress because of his HIV status.

◆ **Uniqueness of recipient of information**

The CPM theory also argues that the uniqueness of the recipient of private information is another important factor which influences whether disclosure will occur or not. It is possible to conclude, given the findings of the study, that the uniqueness of the recipient becomes the major overriding factor in deciding whether to tell or not when outcomes of disclosure are perceived rather than experienced. Perhaps the discloser considers the partner so unique that he or she can be trusted to abide by the rules governing the

privacy boundaries of managing private information, and therefore in the main deserves the honour of being told the private, privileged information, even if not all the rules and criteria are satisfied. Medical practitioners who treat HIV infected patients are likely to be their family doctors as well. They are therefore in a position to work with the partner who wishes to disclose, to identify whether those characteristics perceived as meeting the criteria for uniqueness do exist in the proposed recipient. This would help avoid disappointments if these have not been objectively assessed by the HIV infected partner.

One participant could not bring herself to disclose to two of her consecutive partners, following negative experiences after disclosing to her first partner. She only disclosed to the third partner after he told her he was also HIV infected and on treatment. This participant made the decision not to disclose based on actual negative experiences following disclosure to her first partner, rather than perceived outcomes/experiences. Another participant whose relationship broke down after his disclosing his status to his partner indicated that he would find it difficult to disclose in the future as a result of his experiences. In these two situations, it appears that even the uniqueness of the partner can be insufficient to override all the other rules and criteria under CPM theory and enable opening the privacy boundaries. The significance of previous negative experiences regarding disclosure of HIV status should therefore not be underestimated and should be addressed as part of ongoing HIV management and care.

The recent survey carried out countrywide by the Botswana government (Botswana Parliament 2007:11) concluded that people were more likely to undergo HIV testing if they had assurances that the knowledge regarding their HIV status remained under their control. In the same survey there were indications that fear of the consequences of revealing HIV status could cause individuals not to reveal their status. The survey findings also conclude that while individuals have the responsibility to protect others from HIV, it is important for the individuals to feel that they are in control of their HIV status information and whom to disclose to, when and how (Botswana. Parliament 2007:11). These findings would be in keeping with findings from this study.

The findings from the study in relation to the CPM theory are summarised in table 5.1.

Table 5.1 Findings based on CPM theory

CPM Criteria	Content (What)		Process (How)	
	Positive factors/impact on disclosure	Negative factors/impact on disclosure	Positive factors' impact on disclosure	Negative factors' impact on disclosure
Culture	Sex education Female independence from males	Traditional beliefs about causes of HIV Sex discussions being taboo	Financial support of females Rejecting traditional beliefs	Accepting traditional treatments for HIV
Motivation	Financial support Emotional support Relationship strengthening	Loss of financial support Lack of emotional support Relationship breakdown	Positive pre-disclosure deliberations Successful partner priming	Negative partner reaction Negative pre-disclosure deliberations
Gender	Liberal laws	Laws against gays and lesbians Perceived double stigma	Societal acceptance & understanding	Societal exclusion
Context HIV testing	Health under threat Personal gain Know what is wrong with them Access to ART	Fear of a positive test HIV-related stigma Individual beliefs about HIV, e.g. association with promiscuity	Relationship strengthening Opportunity for face-to-face communication	Relationship breakdown Partner unavailable
Risk/benefit	Knowing partner's HIV status Positive pre-disclosure deliberations	Negative outcome of pre-disclosure deliberations	Readiness to disclose Self-counselling is completed Positive partner reaction	Not ready to disclose Ready but partner not available at the right time Negative partner reaction

5.4 STUDY LIMITATIONS

Participants were aware that the researcher was a health-care professional. This may have influenced the information captured, depending on whether participants thought it was deemed appropriate or not for them to share some of the information. The researcher tried to reduce this by allowing participants to talk freely and not making statements which participants could deem judgemental. A reflective diary of thoughts and feelings which occurred to the researcher was kept. The diary helped contextualise the issues raised by the study participants, allowed for bracketing and maintaining neutral objectivity during interviews. The researcher also made sure that participants understood the purpose of the study very clearly, with emphasis on collective benefit rather than individual gain from the study. The narratives provided by the participants in this study were not corroborated with those of their partners. Their narratives were taken at face value. The field notes were used to make observations of congruency between what was being described and non-verbal cues being displayed. The use of field notes therefore helped to reduce but not eliminate possible “lack of sincerity”.

5.5 RECOMMENDATIONS

Recommendations based on the study findings are divided into those based on the second objective of the study, which was to develop evidence-based recommendations which could assist HIV infected people in disclosing their HIV status to their sexual partners, and recommendations relating to further research.

5.5.1 Recommendations for evidence-based guidelines to enhance disclosure

These recommendations will be based on both the main components of content and process of the CPM theory as well as the rule management criteria described under the CPM theory.

5.5.1.1 Recommendations from CPM theory privacy rule management criteria

(1) Culture

Public health messages should tailor their content towards the cultural sensitivities prevailing in the communities they are aimed at. The language used should be such that it conveys the appropriate message without being offensive. For example, in Botswana there are two types of marriages, legal and traditional. Some messages aimed at legal marriages may not be positively received in traditional marriages.

(2) Motivators

The study has demonstrated the very personal nature of factors influencing disclosure of one's HIV status to one's partner. Efforts to encourage disclosure should attempt to personalise disclosure-related messages from public health specialists. This can be achieved to some degree by involving the patients' family doctors, who have the opportunity for one-to-one regular consultations for health-related reasons with those who are HIV infected, such as medication reviews.

(3) Gender

Counsellors should receive, as part of their training, literature from research regarding the effect of gender and sexuality on disclosure of HIV status. This would help them provide better targeted, more acceptable counselling.

Although homosexuality is outlawed in Botswana, it is inevitable that homosexuals will access health care services. Health care professionals and counsellors should be considered less as the enemy and should be bound by their professional code of conduct. Familiarisation with some of the sexual issues pertaining to homosexual practices would help health care professionals and counsellors to deliver relevant counselling services to homosexual people. Such practices may contribute to positive uptake of disclosure-based HIV prevention messages.

(4) Context

HIV prevention messages advocating disclosure should be tailored to suit the target in the right place at the right time. For example, TV messages may not reach those in the villages even though they would easily reach those living in cities. Use of text messaging to distribute HIV prevention messages may well be better received by younger generation, compared with the older generation.

Pre-HIV testing and counselling should also aim to address issues related to disclosure of HIV status in more depth. Initial introduction of the subject could be done at the VCT. Further discussion to address concerns relating to disclosure of HIV status could then be continued during subsequent access to medical services by those who are HIV infected.

(6) Risk-benefit

HIV infected individuals should be empowered on how to recognise their own individual situations, such that they know when it is right to tell and when it is not. This way negative experiences following disclosure could be minimised.

The above recommendations are summarised in table 5.2.

Table 5.2 Recommendations based on CPM theory

CPM criteria	Content (What)		Process (How)	
	Enhances disclosure	Prevents disclosure	Enhances disclosure	Prevents disclosure
Culture	Culture-sensitive HIV prevention messages	Culture-insensitive HIV prevention messages	Being sensitive to cultural practices e.g. traditional marriages compared with modern marriages	Incorrect mode of HIV prevention message delivery e.g. tone and language Insensitivity to cultural norms
Motivation	Personalised public health messages for age, sex, marital status, employment status, financial situations	Very generalised public health messages	Identifying individual motivating factors Identifying and targeting right audience - cohabitation, singles or married Closer collaboration between VCTs and family doctors	Delivering “one-size-fits-all” messages
Context	Contextualise HIV disclosure-related messages e.g. married couples, cohabiting couples and traditional marriages	HIV prevention messages inappropriate for the occasion or individual groups	Target village meetings, schools, health posts for villagers TV, text messaging, bill boards for town/city dwellers and younger generation	Delivering “one-size-fits-all” messages
Gender	Health care service provision and counselling services which are gender sensitive	Sexual differences Other sexualities (e.g. homosexuals) carrying double stigma	Appropriately trained counsellors Providing for other sexualities	Ill-equipped counsellors/health care professionals Neglecting sexual differences/orientation
Risk-benefit	Individual circumstances; financial and emotional dependence; nature of relationships	Financial/emotional dependence Abusive relationships	Empowerment of those infected with HIV to risk-assess their situation correctly before disclosure occurs. Involve family doctors	Failure to recognise individual circumstances and put appropriate provisions in place

5.5.1.2 Recommendations for practice and health education

- (1) One of the recommendations is that, where appropriate, sexual partners could be offered same-time HIV testing. Partners will need to be counselled first, especially in cases of sero-discordance.
- (2) Disclosure considerations have been shown to have the capacity to indirectly influence uptake of HIV testing services. There is a significant need for HIV disclosure issues to be given increased prominence during HIV test counselling, because telling people to go for the test while not addressing the emotional burden resulting from knowing their status and dealing with issues such as disclosure is unlikely to be effective in encouraging effective use of the voluntary counselling and testing centres.
- (3) There is a need to set up personalised local support systems for those dealing with the consequences of both disclosure and non-disclosure. Such systems could include a confidential help-line accessible 24 hours a day most days of the week, and local support groups made up of those who have experienced negative outcomes from disclosure of their HIV status.
- (4) A statistically validated screening tool which captures factors identified as influencing disclosure of HIV could be produced and administered as part of the pre-HIV test to identify those at risk of negative outcomes following disclosure, because it is a given that after the test results are out, disclosure issues become pertinent.

5.5.3 Recommendations for further research

- (1) While it may be tempting to advise those infected with HIV who are afraid to disclose that disclosure could contribute to reducing HIV transmission through adopting safe sex, caution will need to be exercised, as the current evidence remains inconclusive. Further research is therefore recommended in this area, through a quantitative study to investigate the rates of condom use following

disclosure of HIV status to partners among sexually active HIV infected individuals in Botswana.

- (2) A qualitative study to explore the effect of the HIV epidemic on the institution of marriage in Botswana is suggested. The study could help inform researchers and others whether the values attached to marriage have changed as a result of the HIV epidemic and, if so, what the probable impact of such a change has been on disclosure of HIV status to partners.
- (3) Quantitative studies are suggested for comparing rates of disclosure among married couples with those of co-habiting partners and to understand whether such differences have implications for public health efforts to encourage disclosure of HIV status as a means of reducing HIV transmission. The study findings could also be used to inform a need to review current disclosure messages.
- (4) A qualitative study is recommended to investigate whether increased material provision to enhance financial security of people living with HIV could promote efforts to reduce HIV transmission by removing the fear of loss of financial security as a barrier to disclosing to their partners.
- (5) Some participants suggested punitive measures to be taken against those who do not disclose to partners. Further studies to assess the understanding by those infected with HIV of the legal implications of non-disclosure in the Botswana setting would shed more light on how likely it is that such punitive measures would be acceptable to those infected and what effect the measures would have on disclosure rates.

5.6 CONCLUSION

HIV infected people have to deal with the issue of disclosing sensitive personal information as soon as they take that first step: to have an HIV test. Disclosure is therefore a process which begins much earlier than the actual moment of telling. Findings from the study reveal that disclosure is a process which begins before the HIV

test and probably continues beyond the moment of disclosure. It is fluid in nature and does not follow rigid steps. HIV infected people think about it and take it very seriously, so that if they do not disclose, it is because of several layers of deliberations and experiences and not purely because of selfishness or irresponsibility. The most important factor influencing disclosure, based on the findings from this study, remains a sense of responsibility to others, followed by personal emotional and financial gain. The CPM theory goes a long way to clarify and help explain decisions regarding sharing sensitive personal private information such as disclosure of HIV status.

The study began as a journey to explore and understand the first-hand experiences of those infected by HIV following disclosure of sensitive private information to partners regarding their HIV status. The study has provided insight and illumination of those experiences and a better understanding of the factors that influence decisions to disclose HIV status. The study findings have enabled recommendations to be made which could enhance disclosure of HIV status.

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ANNEXURE A

Research clearance certificate from UNISA Ethics Committee

ANNEXURE B

Permission letter from Ministry of Health, Botswana

ANNEXURE C

Permission letter from GMT Surgery

ANNEXURE D

Interview schedule

ANNEXURE E

Reflective diary

ANNEXURE F

Consent form – Setswana

ANNEXURE G

Consent form – English

ANNEXURE H

Field notes: an example

ANNEXURE I

Setswana interview script

ANNEXURE J

English interview script

ANNEXURE K

Data analysis illustration of interview script

UNIVERSITY OF SOUTH AFRICA
Health Studies Research & Ethics Committee
(HSREC)
College of Human Sciences

CLEARANCE CERTIFICATE

Date of meeting: **22 June 2009** Project No: **3488 7393**

Project Title: **FACTORS INFLUENCING DISCLOSURE OF HIV STATUS
AMONGST THE YOUTH IN BOTSWANA**

Researcher: **Dr T Masupe**

Supervisor/Promoter: **Dr GH van Rensburg**

Joint Supervisor/Joint Promoter: **Prof SP Human**

Department: **Health Studies**

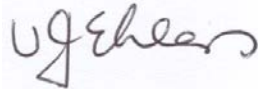
Degree: **MPH**

DECISION OF COMMITTEE

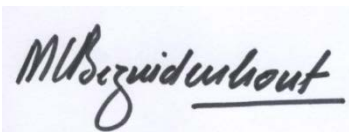
Approved

Conditionally Approved

Date: ...22 June 2009.....



Prof VJ EHLERS
RESEARCH COORDINATOR: DEPARTMENT OF HEALTH STUDIES



Prof MC Bezuidenhout
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

Telephone: (267) 363200
FAX (267) 353100
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD



MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE

REPUBLIC OF BOTSWANA

REFERENCE NO: PPME 13/18/1 PS V (103)

14 April 2010

Health Research and Development Division

Notification of IRB Review: New application

Dr Tiny Masupe
P.O. Box 45445
Riverwalk
Gaborone

Protocol Title:	FACTORS INFLUENCING DISCLOSURE OF HIV STATUS AMONGST THE YOUTH IN BOTSWANA (VERSION 1 24/3/10)
HRU Protocol Number:	HRU 00616
Sponsor:	N/A
HRU Review Date:	12 April 2010
HRU Expiration Date:	11 April 2011
HRU Review Type:	HRU reviewed
HRU Review Determination:	Approved
Risk Determination:	Minimal risk

Dear Ms Jorosi

Thank you for submitting a new Application for the above referenced Protocol.
This approval includes the following:

1. Application form
2. Proposal
3. Data collection tools

This permit does not however give you authority to collect data from the selected sites without prior approval from the management. Consent from the identified individuals should be obtained at all times.

Gmt Surgery

Plot 18586, Gaborone West, Phase 2

P O Box 80599
Gaborone
BOTSWANA
Phone 3956099/3938999
Fax 3956099

Dr Tiny Masupe
PO Box 45445
Gaborone
Botswana

16th June 2009

Dear Dr Masupe

RE: PERMISSION TO CONDUCT A RESEARCH STUDY

This is to confirm that you have been granted permission to conduct your research study entitled: factors influencing disclosure of HIV status amongst the youth infected with HIV in Botswana at GMT Surgery, Gaborone, Botswana.

Permission is valid for a period of 12 months beginning 1st July 2009 ending 30th June 2010.

You are to contact Dr G Tsie, senior partner at GMT Surgery for further assistance.

Thank you



Dr Gaobamang Tsie

The interview schedule

Grand tour question:

Tell me about your experiences, feelings and thoughts about disclosing your HIV status to your partner.

Study objectives

- To identify, explore and describe positive and negative factors which relate to the disclosure of the sero-status to sexual partners.
- To develop evidence based guidelines which can assist HIV infected people in disclosing their HIV sero-status to their sexual partners

Researcher's reflective diary

Preconceptions

- Disclosing to partners should be a good thing to do
- May depend on other issues between individuals
- Is it morally right or wrong? - Probably right but depends on perceptions of morality. Who defines morality anyway?
- Is it really going to help reduce HIV transmission?-it's better than nothing I think...
- The problem of human rights- I am all for protecting those infected with HIV (hey I was after all vice chairperson of BONELA (Botswana Network of People living with HIV/AIDS) but if they don't behave responsibly then may be they don't deserve such protection???)
- If I had HIV I would do the right thing, just tell regardless but that's me!

During interviews

- After day 1, interviews (1) and (2) these people were treated so bad I am wondering if it is worth it, but there are always two sides to a story. Too early to judge really, not a good start though. I'm pleased there were only two interviews to do today!
- is this turning out to be blame and vent exercise
- need to keep an open mind
- After interview (3, 4 and 5) - disclosure may not be such a bad thing
- I am not so sure now. Mixed emotions
- After interview (8), this lady is concerned about older men and younger women relationships just as I am. As a parent I am for disclosure in this situation. I feel it is not right for older men who have enjoyed life to do this to young girls. These young girls also need to stop chasing after the money
- Parental responsibility and upbringing? May be we wouldn't be here if these were adequate or am I being judgmental. I feel strongly about this though

After completion of interviews

- My views seemed to fluctuate (yo-yo would describe me ha ha ha ha I laugh at myself) depending on participant's experiences and how well I connected with them during interviews (I am getting soft in my old age maybe.....)
- One day I feel disclosure has to occur regardless but after interviews with participants with bad experiences I am not so sure. This is why I did this study.....to become a bit surer....

TUMALANO YA GAGO YA TSAYA KAROLO

KETAPELE

Leina la me ke ngaka Tiny Masupe. Ke modiri bo bongakeng ja sekgoa mme gape ke mo di thutong tse dikgolwane tsa go tlamela botsogo js sechaba.

Dithuto tse ke di ithutela le sekole se se golo sa Afrika Borwa. Nngwe ya tse di tlhokahalang gore ke wetse dithuto tse ke mokwalo wa bukana e e tsamaelalng le se ke se ithutang. Gore ke kgone go kwlala bukana e, ke dira patlisiso maikutlo ka go seka seka le go leka go tlhaloganya tsela e e neng ya tsewa ke bao ba ba tshelang le mogare wa HIV ha ba leka go bolelela ba ba tshelang le bone ka seemo sa bone sa HIV.

Maikaelelo a mokwalo o ke gomgo neela tshedimose tso e e lekaneng go go thusa ha o dira tshwetso ya gore a o dumela go tsaya karolo mo patlisiso maikutlo e. Ke gakolola gore tshedimose tso e, e ka tswa e sa tshola tlhaloso yotlhe e o e tlhokang. Ka jalo ke go rotloetsa gore o nkitsise ka ape matshwenyego a o ka tswang o na le one mabapi le tlhaloso e gore ke leke go araba tsotlhe dipotso tsa gago ka bophara. Sesupo sa ka ka ha o ka ntshwarang ka teng ka mokwalo le mo megaleng ke seno ha tlase ha:

Tiny Masupe

P O Box 45445

Riverwalk

Gaborone

Botswana

Phone: 3937601 mobile: 71812082 email: taezor@hotmail.com

SETLHOGO SA DITHUTO TITLE OF THE STUDY

Ke a he mabaka a a ka dirang gore motho yo o tshelang ka mogare a kgone go kgosta a seka a kgona go itsesi mokapelo wa gagwe ka seemo sa gagwe sa gore o na le mogare wa HIV?

DIELO TSA DITHUTO

Dielo tsa dithuto tse ke di dirang ke gore ke tle ke kgone go rarabolola le go tlhalosa mabaka one a a ka rotloetsang kgotsa a tshabisa ba ba tshelang le mogare wa HIV go bolelela bakapelo ba bone ka seemo se. Maikaelelo ke gore ko bokhutlong jwa patlisiso maikutlo le le dithuto tse, ke kgone go ntsha dikgakololo tse disupang ka ha ba ba tshelang le mogare ba ka thusiwang kgang e e matswakabele e ka teng.

KE MANG YO O KA TSAYANG KAROLO MO PATLISISO MAIKUTLO E?

Mongwe le mongwe yo o nang le mogare wa HIV wa dingwaga tse di tshwanetseng, yo gape a tsamayang bongaka jwa go amana le kalafi ya HIV mo kokelwaneng e e tlhophilweng mo Gaborone. Batsaya karolo gape ba tshwanetse ba bo ba na le bakapelo mme e bile ba kile ba tshwanelwa ke go itsise bakapelo bao ka seemo sa bone sa mogare wa HIV.

DITSAMAISO

Patlo maikutlo e tla a bo e le ya mothale wa puisano e e tseneletseng magareng ga moithuti le mo tsaya karolo yo o tshelang le mogare wa HIV. Bokopano jo bo tla diragala hela ka nako le ko lehelong le le siametng motsela le mogare go netehatsa gore sephiri sa gagwe se sireletsegegile ka nako tsotle. Puisano e e tla a bo e gatisiwa ka setsaya mantsewe. Ba tsaya karolo bat la a bob a itsiwe hela ka dinomoro tse moithuti a tla di ba hang go itsa gore maina a bone kgotsa sepe hela se se ka lemotshang motho ope gore motsaya karolo ke mang se se ka sa nna teng.go tsaya karolo mo patkisiso maikutlo e, go tla a bo go sa patelediwe. Motshela le mogare yo o tlhophilweng o na le tshwanelo e e tletseng ya go seka a dumela go tsaya karolo. Ga sepe se se bosula se se ka mo diragalelang ha a sa dumele go tsaya karolo. Thebolo le tumalano ya go tsaya karolo le yone e kgona go hetogelwa dipatlisiso di ntse ditsweletse. Go ka nna ga tlhokahala gore moithuti a eletse go tshwara puisano ya bobedi le mo tsaya karolo. Ha se se

ka diragala, mo tsaya karolo o tla neelwa sebaka se se lekaneng go re a ikakanye a ba a itsise moithuti gore a se se ka kgonega.

DITUELO LE DITLAMORAGO TSA PUISANO E MO MOTSA YA KAROLONG

Jaaka mo tsaya karolo, ga go na madi ape a o tlhokang go a duela. Se se tlhokwang hela ke nako ya gago go nna ha hatshe mo puisanyong le moithuti. Botsogo ja gag obo na go tlhoka tshireletsego ka ntlha ya puisano e. Ha mowa wag ago o ka amega ke go gakologela tse di bosula tse di di diragetseng ka ntlha ya puisano e, o tla a neelwa leina le megala ya mokaedi yo o thusang ba mewa e e amegileng ka epe hela tsela gore a go he thuso e o e tlhokang. O tla a neelwa megala le leina la gagwe ka yone nako ya puisano..

DITLA MORAGO TSE DI MOLEMO MO GO WENA

Go tsaya karolo ga ga gago go solohetswe gore go tla a thusa sechaba ka kakaretso go lebilwe dikgakololo tse di tla a tlang morago ga puisano e le ba ba tshelang le mogare jaaka wena. Ga go na dituelo tsa madi. O tla sielwa metsenyana.

SEPHIRI

Mekwalo le megatiso ya puisano e tla a tshwarwa le go bewa ka mo go sirelesegileng thata. Morago ga dithuto di sena go wela, tse tsotlhe di tla a nyelediwa. Bangwe ba ba berekang le moithuti jaaka bathatheledi ba gagwe ba ka nna le gone go batla go bona mekwalo e go nna sesupo sa gore e le ruri moithuti o dirile tiro e e tlhokwang. Mme le ha go ka nna jalo, ga bake ba kgona go lemoga gore mekwalo ke wag a mang ka e tla a bo e le dinomoro hela e seng maina a batho.

DIPOTSO LE MATSHWENYEGO

Dipotso le dikakgelo le ape hela matshwenyego di a amogelesega mme e bile di tla a reeediwa di be di arabiwa ka ha go tshwanetseng.

THEBOLO E E SEDIMOGILENG

Nna ke le mo tsaya karolo ke dumalana gore ke badile mekwalo o, e bile ke o tlhalogantse sentle. Morago ga go o bala ke dumela go tsaya karolo mo patlisisong maikutlo e. Ke tlhaloganya gore key a go tshwara puisano le moithuti e e batlisisang maikutlo a me mabapi le kgang ya go bolela semo sa HIV. Se ke thebolo ya me ya gore ke dumela go tsaya karolo. Ke tlhaloganya gore ken a le tshwanelo ya go seka ke dumela go ntsha thebolo kgotsa go fetogela thebolo e ka nako nngwe le nngwe.

LEINA:

SAENA:

LETSATSI

INFORMED CONSENT FORM

INTRODUCTION

My name is Dr. Tiny Masupe; I am a medical doctor studying for a master's degree in public health with the University of South Africa. As part of my degree program, I am required to complete a research project. For this project, I am interested in exploring and describing experiences that people infected with HIV have had in relation to disclosing their HIV status to partners. The aim of this consent form is to provide you with enough information about the study, so as to enable you to make an informed decision about participating in the study before you do so. The information provided here may not be exhaustive. You are encouraged to raise any concerns or to seek any further clarifications you may have with the researcher. The researcher' contact details are as follows:

Tiny Masupe

P O Box 45445

Riverwalk

Gaborone

Botswana

Phone: 3937601 mobile: 71812082 email: taezor@hotmail.com

TITLE OF THE STUDY

Factors influencing disclosure of HIV status to sexual partners in Botswana

STUDY OBJECTIVE

The objective is to explore and describe the factors which influence decisions by HIV infected people to disclose their HIV sero-status to their partners, so that recommendation may be drawn from the study conclusions on how they can be supported through this complex process.

WHO IS ELIGIBLE FOR INCLUSION IN THE STUDY?

All HIV infected patients falling within the chosen age, who attend the identified health care facility in Gaborone for their HIV care and treatment.

They also have to be in sexual relationships and have should have disclosed their HIV sero-status to their partners.

PROCEDURES

Information from identified eligible participants will be collected in the form of in-depth interviews. The researcher will conduct the interviews at an agreed time and location which ensures privacy and confidentiality are maintained at all times. The interviews will be recorded. Participants will be identified by codes to protect their personal details and confidentiality. Participation will be voluntary. Consent and participation can be withdrawn at any time during the study. There may be a need for more than one interview, but the participants will be given ample notice if this becomes necessary.

COSTS AND RISKS

There will be no monetary cost to you only your time. Your health will not be harmed by participating in this study. If your psychological well being has been affected by the issues that came up during the interview, you will be provided with contact details of a counsellor to help you.

POSSIBLE BENEFITS

Your participation will help to achieve the study objectives and possible recommendations from the study results. The benefit may be collective rather than individual. There will be no monetary compensation for participating in the study. Refreshments where required will be mad available.

CONFIDENTIALITY

Records will be coded and stored securely. They will be destroyed once the study is complete. Some members of the research team may require viewing some of the records as part of assessing the quality of the study. There will be no details in the records that could make you identifiable.

QUESTIONS, CONCERNS

These will be welcome and will be given the appropriate attention.

INFORMED CONSENT

I have read and understood the above information. I agree to take part in the above named study. I understand I will be asked to undergo an interview that asks for my views about disclosure of HIV status. I consent to taking part in

this study. I understand that I am entitled to decline to take part in the study or to withdraw at anytime.

NAME

SIGNATURE:

DATE:

Field notes-an example

Interview 1

38yrs

Diagnosed 2003

First partner died 2005

Second partner 2006-2008 died RTA

Third partner 2009

Setting: office at GMT surgery

Appearance: smartly dressed lady carrying an expensive looking hand bag

Behaviour: pleasant, smiles a lot, seems rushed as well

She avoids eye contact when discussing non disclosure to her 2nd partner. She briefly looks at the recording device as if to say pause it please.

Looks distracted when talking about death of her second partner and looks away momentarily. She still feels the pain. She looks at her glass of water but does not drink from it.

Eyes light up as she describes the feeling of relieve after disclosing to her third partner. She puts her handbag on the floor beside her chair as if she now feels safe to relax. This is the first time she has looked relax since the interview started.

More relaxation and a suppressed sigh as the tape recorder is switched off. She stands by the door to wave as she leaves the clinic.

Communication: slow, soft voice but becomes pitchy when she talks about his anger and denial after she told him. Clutches hand bad tightly when she mentions abusive relationship.

Interview no 1

Interviewer: E mma jaaka ke sa tswa go bolela ke mo patlisisong maikutlo o ne a o. so wena hela o ka mpolelela ka gore e rile o sena go nna o utlwa seemo sa gaggo ga diragala jang gore o bolelele yoo bogolo jang yo o tshelang le ene e le partner ya gago

Participant: ee gone ke itestile ka 2003, ha ke itesta ke ha ke le positive.

Interviewer: hm

Participant: Ha ke le positive go bo go raya gore ke ya go bolelela partner yo ke nnang le ene. Ene e le ene rraagwe ngwana. Ha ke mmolelela, A ke re o itse gore banna ba dingalo jang? A ba a re nna e bile ga ke kake ka ba ka nna positive".nna ke siame"

Interviewer: hm.

Participant: Ga ke kake ka ba ka nna positive.A ba a gana a ba a gana le go ya sepatela. Ke bo ke boela gape ko ngakeng ke mmolelela, ngaka a ba a re "a ha motho a gana ga gona gore o ka mo reng"

Interviewer: hm

Participant: nna o mo leke hela gongwe o ta dumela go itesta. Ngaka go tswa ha a ba re mme go ray a gore re dire CD count re bone gore CD e tsamaya ha kae. Ke bo keya go dira CD count e bo e wela ha go,e E ne le 200. he le 200 a ba a adviser gore mme ha e le 200 go raya gore o simolole medication gore o seka wa dropela below 200. gone that same year 2003 ke bo ke simolola medication, ke simolola go tsaya treatment. Rre ke ha ke mmoleletse o a gana go ya testing, ha a gana go tsaya test(pause) ka na go raya gore le di condom o gana go di dirisa. E ne e le mo gotweng go abusiwa hela, go abusiwa, ha o re o bua se o molato. Ga a bate go dumela se o se buang

Interviewer: hm

Participant: e be go rata gore ga re utwane, go helela e ke te re a kgaogana. A nna koo ke nna koo

Interviewer: E le yone kgang ya teng

Participant: E le kgang ya teng re lwela yone. Gore at least ha a sa bate go ya sepatela re dirise di condom. Ene a sa bate go di dirisa. Go raya gore 2004 a ba a simolola a nna a lwala. A tswa dikaku. A tshewnyega mme a ntse a gana go itetsa. 2005 go bo go raya gore bolwetse bo a gakala, o a hupela... (long pause) a ba a helela a thokahetse. O ne a thokahala

Interviewer: a ntse a gana

Participant: a ntse a gana go itesta. O thokahetse a ntse a gana go itesta E be go raya gore ke nna ke le nosi jaanong a kere o thokahetse. 2006(long pause) ke bo ke bona relationship e ncha. Mme mo relationshiping e ncha e le kene ke tsaba go re ke bolelele rre yo ken nang le ene gore ka na nna ke tsaya medication.

Interviewer: mhm

Participant: Ke di nwela mo sephiring ee mo e reng motho a emelela, (cough)Ha ka emelea ke gone ke bonang chance ya go tsaya dipilisi ke e nwa, ke tshaba go mmolelela.

Interviewer: O ne o tshaba eng thatathata?

Participant: Gore a o ta accepta situation e ke mo go yone. Ee, a ga a na gore ke ta mo tsenya bolwetse.

Interviewer: ee

Participant: Ke ne ke santse ke le ko Orapa ka 2006, e be go raya gore ka 2006 December ke be ke movilea mo Gaborone.

Interviewer: Le ene o ne a le ko Orapa?

Participant: ene a ba a sala kwa e be e le gore because of distance ga re bonane thata. A ba a helela a le koo. Le ene nna ga ke itse gore ke dilo tsa eng, 2008 le ene a ba a thokahala mme e ne e le car accident. Go bo go raya gore o a thokahala

Interviewer: mh, go ray a gore a sa itse

Participant: A sa itse, ene o thokahetse a sa itse gore ke mo treatment ke nwa dipilisi. Ke n eke dinwela he la mo sephiring ke tshaba go mmolelela. E be e le gore this year 2008 February ke bo ke bona relationship e ncha. Fortunately motho yo ke neng ke kopane le ene, ke be ke hithela le ene a le mo medication. Ene o kgonne go mplolelela gore "I am positive ke tsaya medication" go bo go raya gore le nna jaanong ke kgona go open up ke bo ke mmolelela gore le nna kana go raya gore we are singing the same song. Go raya gore re tshela hela jalo.

Interviewer: botshelo bo bo bo tswelala

Participant: Ee Jaanong botsehlo bo botoka thata.

Interviewer: ee mma. Mme ke bata o boela ko ya 2006 ya ga rraagwe ngwana.

Participant: E ne e le ene wa ntha yo ke simolotseng hela le ene ke hetsa sekole ke nna le ene

Interviewer: ee, yo le neng le kopane ka 2003

Participant: en eke sale ke kopana le ene ka bo 90's. Re tshotse nwgana ka 1992. affair ya rona je ya bo 90

Interviewer: ok ee

Participant: re hetsa sekole. Ke ntse ke nna le ene hela, ke nna le ene. Go ne go na ;e distance mo go rona, a nna ko Serowe ke nna ko Orapa, re ntse re meeta. 2003 ke gone ke be ketsaya tshwetso ya gore key a go itesta. Kene ke ya go itetsa hela ke sa lwale, ke sa tshwenyege gope hele

Interviewer: Ok

Participant: Ee

Interviewer: O ne o utule hela melaetsa ya bo tebelopele

Participant: Ee gontse go twe ka na go na le bolwetsi, go a ichekiwa. Ke be key a go itesta

Participant: Ee . Ha ke itetsa ke bo ke hithela ke le positive

Interviewer: hm

Participant:: ee

Interviewer: So o new a di tsaya jang dikgang tsa teng? O ne wa ikutwa jang

Participant: Ah... ha e sena go nna ngaka e mplolelela, Ke ne ka accepta situation, ka bolelela cousin ya me. Ke ene a ne a le close le nna.Ke be ke mmolelela gore kana situation ke ye A ba a re nnyaya mme ga se bohelelo ja botshelo, gab o helele gone ha. Tsaya medication hela o ta siama.

Interviewer: And then rrabo ene ga tsaya nako e e kae gore o mmolelele?

Participant: Ha ke tswa sepatela hela ke sena go nna ke bolelelwa gore kana "o positive" kene ka mo founela. Ke ka tshooletsa mogala hela ke be ke re ke kopa gore o ye sepatela o ye go icheka.Ke tswa go icheka maduo ga a nna sente. Mo mogaleng hela a ba a kelema.

Interviewer: A reng?

Participant: Nna ga nkake ka nna positive! Nna ke siame.

Interviewer: So a akanya gore wean o ka tswa o o tsere kae?Go raya gore o ne a akanyetsa gore nna ke o tsayaya kae.

Participant: go raya gore ene o ne a akanyetsa gore ke o tsere koo, ko ke nnang teng ka gore o ne a le ko Serowe wean o le ko Orapa A ba a re nnyaya nna ke siame mma, go raya gore mogare ke wa gago

Interviewer: Mabaka a mangwe a a neng a go tshabisa go mmolelea , le ga le ka ene o new a mmolelela immediately ka phone. O new a mmotsa gore o ha kae pele o sa tseye gore kana o toga a idibala kana....

Participant: Ee nnyaya Kene ke mo tshwere ka landline ya mo tirong a ke re ke utwa gore o mo ofising. O ne a theogela a le nosi mo ofising. Nnya ke bo ke tswelela hela ke mmolelela.

Interviewer: A ba a ta a go leletsa later kana ga bo go diragala jang after wards.

Participant: nya a ba re nna ke siame hela, ga go kake ga nna jalo. A ba adididmala hela after few days a aba re kante wa re golo hale wa re o positive? Ke be ke re ee, maduo a re a positive. A ba a re nnyaya nna mma ke siame

Interviewer: And then ha re yak o 2008 ,ka 2006 a ke re go raya gore o newa simolola relationship e ncha?

Participant: Ee, e ncha,

Interviewer: yone eo ke gone o neng o tshaba

Participant: A ke re mo go ele ya ntho motho o ne a nkgaphela kgakala ke mmolelea. E ya bobedi ke saitse gore tota jaanong key a go simolola ke reng. A motho yo o ta accepta se ke se buang? A ga a na gore ke ta mo tsenya bolwetsi? Ke n eke akanya gore o toga a re nnyaya mma a re togele.

Interviewer: Ok, hm, so it never happened?

Participant: Ga ke a mmolelela hela gothelele

Interviewer: Jaanong wa gompieno ene le simolotse jang?

Participant: Wa gompieno ene o napprochiitse hela a mpata.nnya hela re bo re dumalana. Ha re sena go nna re dumala, Ke ene a simolotseng a ithalosa gore nna ke ntse jaana.Ke enema simolotseng hela a ithalosa. Ke bo ke re nnya le nna ke ntse jalo. Go ray a gore ha a ne a sa ithalosa pele ken e eke ya go ddidimala(eyes wide open) ken e key a go lebelela pele gore motho yo o ntse jang. A e ta re ke bua o ta accepta se ke se buang. A ga a na go nrejecta.ee

Interviewer: Fortunately ga go a nna jalo.

Participant: Ga go a nna jalo.

Interviewer: So ha o compare ka ha o neng o tshela ka teng mo sephiring seo ka partner ya bobedi le gompieno, o se mo sephiring le itsane gore le ntse jang mmogo, ha o compare botshelo jag ago go harologana jang?

Participant: Hey (big smile) nnya Ha le ke ne ke sa tshela sente, go ne go le bokete. ken e ke bona hela le nna ke le mmolai. Ke gore ke ipotsa gore ha a ka lemoga, go ya go nna jang? O ne a ya go bona ke le motho yo o ntseng jang? But gompieno ke bona ke tshela sente hela, ka gore le yo ke gona gore nako e cjaile a re new. Gompieno ke nako ya check up, a re ye check up. Gompieno ke siame hela botshelo bo free.

Interviewer: Ga go sa thola go le bokeke

Participant: Ga go bokete. La ntha mma, ee go ne go le dingalo. Thata. Le nako ya gore ke tseye medication ken e ke tshaba go tsaya ke tshabe gore o ta mpotsa gore tse ke tsa eng jaanong tse o di nwabg?

Interviewer: Go raya gore o ne o sa di tseye ka nako e e beilweng.

Participant: Ee, ha gongwe ken e ke eta ke skipa

Interviewer: Malatsi?

Participant: Nnya, ke raya dinako, ke kgona go hitisa ka di houranyana.

Interviewer: Hey nnya mme o thusegile

Participant: Thata

- Interviewer: Jaanong ha o akanaya hela dikakyo tse o ne o nale tsone before o bolelela motho leha o sena go mmolelea e be botshelo botswelela, a din e di le valid. Ke raya dilo tse di neg di go tshabisa go ka bolelelela motho yo mongwe?
- Participant: Ee Tsone ke ta re divalid ka gore kana gore o tshabe go bolelela motho, a ke re o tab o o utwa dipuo tsa gagwe tse a di buang. o utwa maikutlo a gagwe gore motho a e ta re ke molelela, a o ta go accepata kana o ta go rejecta. O utwa pele mo go bueng ga gagwe, ha gongwe le tsere dikgang. Gore ha gontse gotwe kana go na le bolwetse ke jo a re testing ene a reng.
- Interviewer: So yole o ne o utwa gore dikgang tsa gagwe...
- Participant: Ee yolew o ne a gogela go sele hela. Yo o reng nnyaya nna ga ke ka ke ka nna le mogare; goraya gore ke loilwe kana o ta ka one.
- Interviewer: Ok. So ha o soboloka hela re labile gone go boloka nako, di experience tsa gago in terms of gone go discloser to your partners tse di positive le tse di negative, o ka re ke eng?
- Participant: Gone mme tota re tshwanetse go discloser ka gore ha o disclosiste le wean o utwa o nna... o nna free.Ke raya gore le motho yo o nnang le ene o a thaloganyaa situation e o leng mo go yone. Ga go nne bokete jaaka o le mo sephiring.
- Interviewer: Go nna mothoho.
- Participant: Go nna mothoho thata.
- Interviewer: Go thohohatsa eng hela
- Participant: O a thaloganya gore kana motho yo ke tshela le ene mme o tshela jaana. Re tshwanertse go dira jaana gore re iphemele. Re tshwabetse gore re je mo le mo le mo, gore mmle e nonohe. Ha o re o seka way a bojalweng, le ene o thaloganya gore ke eng a ka se new bojalwa. Where as yo mongwe yo mo lehihing ga a na go thaloganya gore ke eng o rialo.
- Interviewer: So O ka advise bae leng gore ba tshela le babagwe mme baise bababolelelo, wean o ka ba advisa o reng hela ka kang ya teng? Especially ba ba tshabang
- Participant: Ke gore hela o leke, o bone go re o ka mo tsena jang? Ka gore that way go ne go botoka o mmoleleltse.

Interviewer: Thuso e ba ka e boning ke eng especially ba e leng gore ba a tshaba go bolelela ba bangwe? O bona ba ka thusiwa ka tsela e e ntseng jang go bolelela ba bangwe

Participant: Gone gongwe counseling e ka thusa jaaka ke go raya ke re ken e ke rejectilwe hela ke re ke bolelela motho, a ba a nkgaphela kgakala. A re e seng nna, nna mma ke siame. Jaanong o sala o na le di question mark tsa gore ka nte motho yo ke eng a riana. Gongwe go sidila maikutlo go ka thusa.

Interviewer: A mme gone ha motho a ya go testa jaaka wean o new a tsamaya hela o sa lwale, go na le counselling e e buang ka go thusa batho gone go disclosa?

Participant: Nnya e ne e seo, more so ngaka ya me ene e re ga go thokahale gore o ka bolelela your partner. E ta re wean o le ready, o ta mmolelela ka nako e wean o leng ready ka yone. Go raya gore re ne re sa hiwa counseling e e tseneletseng.

Interviewer: nnya mm eke lebogile. Any other last comments

Participant: Hey, (laughs nervously) go raya gore jaaka di counseling di tswelletse go nne go tsennngwa mo teng. wa mo teng, gore in case you are positive, o di re se le se le se gore o kgone go bolelela your partner. Ka na ha e le gore go a kgonahala re tsamae rothe re ye go itesta rothe nako e le nngwehela , gore le ene a iponele ka nako yone eo ha maduo a tswa.

Interviewer: Go na le ba bareng ba ka bitsa mpngwe gore ke ene a te go bolelela yo mongwe.gore gongwe wean ha o itse o ka bitsa mongwe yo o mo tshepahng gongwe counselor, wean o e bona jang?

Participant: Ee, (shaking head) A a ke fila gore go botoka le tsamaya lothe ka nako e one, gore maduo a tswe ka nako e le one, le iponele lothe, ka gore yole ha a direla kwa yole le ene a direla kwa go nna di ngalo go bolelela yo mongwe ha go sa nna sente

Interviewer: Nnya mm eke lebogile thata. Le ka moso

Participant: ee mma. (she laughs with relief)

Interview no 1E

Interviewer: As I have indicated, I am doing a research on this issue of disclosure to partners. So if you could just start by telling me what happened and how you came to tell your partner about your status.

Participant: Ok, I went for my test in 2003 and it came back positive

Interviewer: mm

Participant: after I found out that I was positive, I went to tell my partner. He was the father of my child. When I told him...as you know what men are like, he became very difficult. He told me that he could not be positive too and he was well

Interviewer: really

Participant: he insisted that he could not be positive and refused to go for his test. I went to see the doctor and told him what happened and that my partner refused to test. The doctor told me that there was really nothing I could do if he refused to test.

Interviewer: hm

Participant: he advised that I keep encouraging my partner to do the test. The doctor then advised me to check my CD4 count, which I did. It was at 200 so he advised that I started medication so that it doesn't drop below 200. So I started medication that same year in 2003. In the mean time, my partner not only refused to do the test but also refused to use condoms. It became such an abusive relationship. He found fault with anything I said or suggested.

Interviewer: hm

Participant: in the end we couldn't live together so we ended the relationship. We then lived separately

Interviewer: so the relationship ended because of the issue of condoms?

Participant: that was the main issue. He didn't want to use condoms at all. In 2004 he became ill with boils. He continued to have minor illnesses but refused to do the test. His condition deteriorated in 2005. He developed breathing problems.....(long pause) he ended up dying. He died

Interviewer: even then he still refused to go for the test

Participant: he refused the test. He died before he did the test. So I was single for a while after he died. 2006....(long pause) I started a new relationship. In this new relationship I was afraid to tell my new partner about my status and the fact that I was on medication.

Interviewer: mhm

Participant: I used to take my medication in secrecy. I would wait until I was alone before I took them. At times I would take them later than I should because of the secrecy (coughs)

Interviewer: what were you really afraid of?

Participant: I didn't know whether he would accept my situation or whether he would say I will pass the virus to him.

Interviewer: ok

Participant: I was living in Orapa in 2006. Then I moved to Gaborone in 2006, December

Interviewer: was he also in Orapa?

Participant: He remained in Orapa. Because of long distance we didn't see each other much. He also...I don't know if its bad luck, he also died in 2008. He had a car accident

Interviewer: Mh so he never got to know

Participant: he never knew that I was on treatment. I continued to take them in secrecy, afraid to tell him. Early in 2008 I found another partner. Fortunately this person was also on medication. He was upfront with me he just said "I am positive and on medication" that's when I was able to tell him that we were singing the same song as I was also on medication. We lived together without any problems.

Interviewer: so life continued

Participant: Yes, my life is so much better now

Interviewer: ok... let's go back to year 2006 when you were with the father of your child

Participant: He was my first love from high school

Interviewer: Ok, the one you met in 2003?

Participant: we met in the 90's our child was born in 1992

Interviewer: ok

Participant: we finished our high school together. He then lived in Serowe while I lived in Orapa which put some distance between us. We continued to meet from time to time. In 2003 I decided to go for the test. I wasn't ill or anything I just wanted to know my status

Interviewer: Ok

Participant: yes

Interviewer: was it because of the public health campaign messages from Tebelopele?

Participant: yes they kept telling us about this illness and suggesting people should know their status. I went for my test as result.

Participant: so when I took my test, that's when I found out that I was positive

Interviewer: hm

Participant:: yes

Interviewer: so how did you react to the news? How did you feel?

Participant: ah after the doctor told me, I just accepted my situation. I then told my cousin because we were close. She said it was not the end of the world and told me to take the medication and I will be fine

Interviewer: so how long did it take you to tell your partner?

Participant: immediately after I came back from Tebelopele, I called him and asked him to go to the hospital for his test because I had done mine and I was positive. Still on the phone, he went mad!

Interviewer: what did he say?

Participant: "I can't be positive. I am not ill"

Interviewer: so did he have any ideas as to where you could have got the virus from?

Participant: I think he thought that I got it where I was in Serowe when he was in Orapa. So he just said no I am not ill, you must be the one bringing the virus into the relationship.

Interviewer: what were the other reasons for you not telling him? Oh but then you told him over the phone as you said. Did you find out where he was first before you told him, just in case he fainted or...

Participant: yes, I called his work land line to make sure he was in the office. He didn't share his office. So I went ahead and told him

Interviewer: did he offer to call you back afterwards or what exactly happened?

Participant: no he just told me he was fine and didn't say much for a few days. He then asked me again after a few days whether I said I was positive. I told him yes, the test says I am positive. He just said he could not be affected

Interviewer: if we now go to 2008, as I recall, you started a new relationship in 2006?

Participant: yes a new relationship

Interviewer: is that the one where you were afraid to disclose your status?

Participant: yes, because in the first relationship, my partner dismissed me when I told him my status. With the second one, I didn't really know where to begin. I was not sure if he would accept what I said or whether he would think I would pass the illness to him. I even thought that he would end the relationship.

Interviewer: Ok, hm, so it never happened?

Participant: I didn't tell him at all

Interviewer; so how did you get on with the current one?

Participant: my current partner simply approached me and we agreed to have a relationship. He initiated the disclosure by telling me his status. Then I said to him I was also like him. This means if he had not told me first, I was going to keep it quiet (eyes wide open) I was going to wait and see what type of person he was and whether he was likely to accept my status or whether he would reject me.

Interviewer: Fortunately it worked out fine

Participant: he didn't reject me.

Interviewer: so when you compare how your life was when you lived with the secret when you were with your second partner and your life now with the current partner who knows your status, what's the difference?

Participant: Hey (big smile) then my life was difficult. It was tough. I felt like a murderer. I was scared all the time not knowing what he would do if he found out. I didn't know what sort of person he was going to think I was if he found out. But right now, my life is much better. He even reminds me to take the medication if I am late for my dose. When it is time for check up he also reminds me. Life is free now.

Interviewer: it is no longer difficult.

Participant: not at all. Life used to be very tough. When I had to take my medication, I was afraid in case he asked me what it was

Interviewer: that means you must have taken them later than the allocated times

Participant: Yes, at times I even missed doses

Interviewer: Days?

Participant: no I would miss doses by a few hours.

Interviewer: hey this is now a better situation for you

Participant: a lot

Interviewer: now when you look back and remember the thoughts you had which prevented you from telling your partner, were they valid?

Participant: yes, they were valid because the reason why you fear to tell a person is because of the way they talk about the issue. You work out his feelings and decide whether he is the type who will accept you or not. You listen to him when you have general conversation about the public health messages about the disease. You also work out what their views are on testing for the disease.

Interviewer: So with your other partner his views were...

Participant: yes, that one had negative views including the fact that someone would have put a curse on him or that he would never have it or that I am the one who brought the disease into the home

Interviewer: Ok. So in summary, bearing in mind your time constraints, what was your positive and negative experiences following disclosure to your partners?

Participant: I believe that we need to disclose to our partners because when you have disclosed you feel.....you feel free. You feel free because your partner will now understand your situation. Life is not as difficult as when you kept your status a secret.

Interviewer: life becomes easier

Participant: it becomes much easier!

Interviewer: what makes it feel easier?

Participant: you begin to understand how the other person lives, what the two of you need to do to protect yourselves, what foods to eat to stay healthy etc. when you tell them not to drink alcohol they understand why you say that whereas someone who doesn't know these things may not be so understanding

Interviewer: so what advice can you give those who are afraid to disclose their status to their partners?

Participant: I would advise them to keep trying, find best ways to approach the issue because you are better off telling them than not telling them.

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Interviewer: is there a counselling facility to help those like you to disclose, given you went for the test not because you were ill but just to know your status?

Participant: no there was no provision like that., more so my doctor told me that I didn't need to tell my partner until I was ready. I don't think I was given adequate counselling

Interviewer: you have been very helpful, thank you so much. Do you have any last comments?

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case they are positive and how to approach the issue of disclosing to partners. Or better still advice partners to go for their test together if possible, so both can get their results at the same time.

Interviewer: what do you think of the suggestion that perhaps people can involve a third party such as a trusted friend or a counselor to do the disclosure on their behalf?

Participant: No (shaking head) I feel that it is best if partners go together at the same time so they get the results and see the results together there and then. This is because if people go for testing at different times, it creates problems when the results are not expected ones.

Interviewer: I am really thankful to you for this interview.

Participant: Yes madam, (laughs with relief)

Interview no 1E-ANALYSIS

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Interviewer: I am really thankful to you for this interview.

Participant: Yes madam, (laughs with relief)

PROCESS OF ANALYSIS

Words expressing similar meanings were colour coded. For example, words describing how the participant and her partner reacted to the disclosure were highlighted as red. A concept of "reaction" was identified. More meaning words describing "reaction" were identified and highlighted throughout the interview transcript. The words were then grouped together as meaning units. Further analysis of the meaning units led to identification of categories of partner reaction (PR) and her reaction (HR). Words describing each category were grouped together under PR or HR. These were then further analysed to look for new meanings within each category. These actions led to emergence of subcategories. The categories and subcategories were re-analysed and combined together to develop a theme.

The process is illustrated below

Concept: reaction

Words describing reaction:

- He became very difficult. (PR)
- He told me that he could not be positive too and he was well (PR)
- I went to see the doctor and told him what happened and that my partner refused to test. (HR)
- He refused to use condoms. (PR)
- He found fault with anything I said or suggested (PR)
- accept my situation (HR)
- say I will pass the virus to him (PR)
- Still on the phone, he went mad! (PR)
- No he just told me he was fine and didn't say much for a few days. He then asked me
- again after a few days whether I said I was positive (PR)

- **You feel free.** You feel free because your partner will now **understand** your situation. (PR)
- **Life is not as difficult as when you kept your status a secret.** (HR)
- **you begin to understand how the other person lives, what the two of you need to do to protect yourselves, what foods to eat to stay healthy etc. when you tell them not to drink alcohol they understand why you say that whereas someone who doesn't know these things may not be so understanding** (HR)
- **He kept saying "not me, I am not ill" and he didn't want anything to do with me after That** (PR)

CATEGORIES

Partner reaction (PR)

Positive

- **No he just told me he was fine and didn't say much for a few days.** (initial acceptance)

Negative

- **He became very difficult.** (rejection)
- **He told me that he could not be positive too and he was well** (denial)
- **He refused to use condoms.** (unsafe sex)
- **He found fault with anything I said or suggested** (PR) say I will pass the virus to him (blame)
- **Still on the phone, he went mad!** (anger)

Her reaction (HR)

Positive reaction (HPR)

- **I went to see the doctor and told him what happened and that my partner refused to test.** (seeks advice)
- **You feel free. You feel free** because your partner will now **understand** your situation.
- **accept my situation** (self acceptance)

- Life is not as difficult as when you kept your status a secret. You begin to understand how the other person lives, what the two of you need to do to protect yourselves, what foods to eat to stay healthy etc. when you tell them not to drink alcohol they understand why you say that whereas someone who doesn't know these things may not be so understanding (unburdening, supportive)

Negative reaction (HNR)

- I even thought that he would end the relationship. (rejection)
- I didn't tell him at all (non disclosure)
- Life used t be very tough. When I had to take my medication, I was afraid (fear)

Subcategories

Unburdening
 Advice
 Anger
 Blame
 Unsafe sex
 Acceptance
 Support
 Rejection
 Fear
 Non-disclosure

The above describes an overall reaction to the news of partner sero-positivity

Theme: initial reactions to disclosure

A similar analysis was undertaken for other concepts identified throughout this interview to arrive at other themes. The process was repeated for the other interview scripts