

**UNIVERSITY OF KWAZULU – NATAL**

**TITLE: EXPLORING THE PROCESS OF HIV DISCLOSURE  
AMONGST HIV POSITIVE EX – OFFENDERS**

**BY**

**PRAGASHNEE MURUGAN**

**203502378**

**A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE MASTER OF ARTS**

**HEALTH PROMOTION**

**SCHOOL OF PSYCHOLOGY**

**FACULTY OF HUMANTIES**

**SUPERVISOR: PROFESSOR YVONNE SLIEP**

**2009**

## **DECLARATION**

Submitted in partial fulfillment of the requirements for the degree Master of Social Science in the Graduate Programme in Health Promotion Psychology, University of KwaZulu Natal, Durban, South Africa.

I declare that this dissertation, is my own work. All citations, references, and borrowed ideas have been duly acknowledged. It is being submitted for the Degree of Master of Social Science in the Faculty of Humanities, Development and Social Science, University of KwaZulu Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

**Name:**                    **Pragashnee**

**Surname:**                **Murugan**

**Student No:**            **203502378**

**Date:**                    **27<sup>th</sup> November 2009**

**Signature:** \_\_\_\_\_

## ACKNOWLEDGEMENTS

Many individuals formed a very important part of this project and I would like to take the opportunity to thank.

Firstly, I would like to thank the participants who displayed much courage and bravery when they came forward and decided to share their experiences and stories. These participants are clear examples of individuals who provided support and care to both other ex-offenders, offenders, and their wider community. What I found common amongst these individuals is that they were strong – minded, took on an activist – role, and were very cooperative at all times. They also took the research seriously, were very patient, and shared their experiences whole – heartedly. Throughout these interviews, these participants gave more than 100%. Due to the sensitivity surrounding this research, these participants have displayed immense confidence despite the many social challenges they faced. What impressed me was the fact that they knew they had a story to tell and I really appreciate that they trusted me as a researcher to give a voice to their experiences. On a personal level, these participants also showed respect for the research and carried themselves out with dignity and pride. Many many thanks and much appreciation goes out to these participants because without them, this thesis would have not been possible!!!!

Secondly, the Treatment Action Campaign (TAC) who provided me with background information about the prison conditions as well as the sample. They also provided me with physical space as they allowed me to interview the participants at the TAC offices. The TAC were very supportive during the initial planning phase of this research project and also alerted me to the various challenges and advised on ways to overcome them. I owe lots of gratitude to them.

Thirdly, my family who provided me with financial support for this study as well as emotional support especially when times were challenging and difficult to overcome. I would also like to thank my partner Malcolm who provided a source of comfort and motivation to complete this study. I would also like to thank my sister – in – law Merisha

who helped me with the technical side of my project. Many thanks also goes out to Heleen Sliep who edited my work at such short notice and gave me very valuable feedback.

Fourthly, I would like to thank the health promotion team from the University of KwaZulu – Natal for also providing me with academic support during the proposal writing stages. Also, this thesis will not be complete without mentioning my fellow students who were in the health promotion class of 2007. They made the year enjoyable, pleasant, and memorable. A special thanks also goes out to my dear friend Annette Kasimbazi who encouraged me along the way and provided me with much wisdom.

Finally, and most importantly, lots of gratitude and many thanks go out to my supervisor Professor Yvonne Sliep. She not only acted as an excellent source of academic support and guidance but also maintained the faith in the fact that I could carry out this project even though others had doubts. She has the confidence in me to overcome any challenges and over these years provided me with effective skills to conduct myself professionally. She was always willing to assist me, showed me much patience and motivated me to persevere. She always gave me opportunities to share my experiences during the research process, and she always valued my academic opinions and inputs. Overall, this process was manageable because of Professor Sliep's involvement. Many thanks to you!!!

Therefore, this thesis is dedicated to all of these individuals who formed a significant part of this study. If it wasn't for the participant's participation, the Treatment Action Campaign's professional guidance, the emotional support from my family, friends, the academic support from the health promotion team and Professor Yvonne Sliep this thesis would have been possible.

It is appropriate to mention that this research is dedicated to the participants as well as the TAC because they made this research process enjoyable and possible.

# CONTENTS

<b>ACKNOWLEDGEMENTS.....</b>	<b>2</b>
<b>ABBREVIATIONS.....</b>	<b>8</b>
<b>DEFINITIONS.....</b>	<b>9</b>
<b>ABSTRACT .....</b>	<b>11</b>
<b>CHAPTER 1: INTRODUCTION.....</b>	<b>12</b>
<b>1.1 Overview.....</b>	<b>12</b>
<b>1.2 Background.....</b>	<b>13</b>
<b>1.3 Problem Statement.....</b>	<b>15</b>
<b>1.4 Research Problems &amp; Objectives.....</b>	<b>17</b>
<b>1.5 Significance of the study.....</b>	<b>18</b>
<b>CHAPTER 2: LITERATURE REVIEW.....</b>	<b>19</b>
<b>2.1 Introduction.....</b>	<b>19</b>
<b>2.2 Theoretical Frameworks.....</b>	<b>19</b>
<b>2.3 Prison Conditions.....</b>	<b>21</b>
<b>2.3.1 Drug – Abuse.....</b>	<b>21</b>
<b>2.3.2 Overcrowding.....</b>	<b>22</b>
<b>2.3.3 Gangs.....</b>	<b>23</b>
<b>2.3.4 Consensual &amp; Coercive sexual relationship.....</b>	<b>24</b>
<b>2.3.5 Responses by international organizations and local government.....</b>	<b>24</b>
<b>2.4 Voluntary Counselling &amp; Testing.....</b>	<b>25</b>
<b>2.4.1 Barriers to VCT.....</b>	<b>25</b>

2.4.2 Reasons for VCT.....	28
2.5 Disclosure of HIV status.....	29
2.5.1 Factors that motivate and hinder disclosure.....	30
Social support & type of relationship.....	30
History, circumstances of HIV and marginalization.....	31
Emotional and psychological well – being.....	34
Reactions from significant others.....	35
Access to treatment and care.....	37
Parental Disclosure.....	37
Intimate relationships.....	37
2.6 Strategies for disclosure.....	40
2.7 Concluding paragraph.....	41
<b>CHAPTER 3: RESEARCH METHODOLOGY.....</b>	<b>42</b>
3.1 Research Design.....	42
3.2 Ethics.....	42
3.3 Type of Sampling.....	41
3.4 Sample Size.....	44
3.5 Data Collection Technique.....	46
3.6 Instrument.....	47
3.7 Data Analysis.....	49
3.8 Validity.....	50
3.9 Concluding Paragraph.....	50

<b>CHAPTER 4: FINDINGS.....</b>	<b>51</b>
<b>4.1 Introduction.....</b>	<b>51</b>
<b>4.2 Prison conditions.....</b>	<b>51</b>
<b>4.3. Disclosure within prison: Place &amp; Timeline.....</b>	<b>52</b>
<b>4.3.1 Reasons for disclosing within prison.....</b>	<b>52</b>
<b>4.4 Methods for disclosing within prison.....</b>	<b>53</b>
<b>4.4.1 Intentional disclosure.....</b>	<b>54</b>
<b>4.4.2 Unintended disclosure.....</b>	<b>54</b>
<b>4.5 Experience of prison life overrides HIV Status.....</b>	<b>56</b>
<b>4.6 Experience of VCT.....</b>	<b>56</b>
<b>4.5.1 Reasons for VCT.....</b>	<b>57</b>
<b>4.5.2 The process of VCT.....</b>	<b>57</b>
<b>4.5.3 Reactions to HIV diagnosis.....</b>	<b>58</b>
<b>4.5.4 Psychological Adjustment to HIV/AIDS.....</b>	<b>59</b>
<b>4.6 Role of significant others.....</b>	<b>59</b>
<b>4.6.1 Significant others that were disclosed too.....</b>	<b>60</b>
<b>4.6.2 Responses by significant others.....</b>	<b>60</b>
<b>4.6.3 Negative responses by significant others.....</b>	<b>60</b>
<b>4.6.4 Positive responses by significant others.....</b>	<b>61</b>
<b>4.6.5 Current relationship with significant others.....</b>	<b>62</b>
<b>4.6.6 Outcomes of Disclosure.....</b>	<b>62</b>
<b>4.7 Factors that influenced disclosure.....</b>	<b>63</b>

<b>4.7.1</b>	<b>Factors that motivated disclosure.....</b>	<b>65</b>
<b>4.7.2</b>	<b>Barriers to HIV disclosure.....</b>	<b>67</b>
<b>4.7.3</b>	<b>Perceived Advantages of HIV disclosure.....</b>	<b>70</b>
<b>4.7.4</b>	<b>Perceived disadvantages of HIV disclosure.....</b>	<b>72</b>
<b>4.9</b>	<b>Strategies of disclosure.....</b>	<b>74</b>
<b>4.9.1</b>	<b>Direct strategies.....</b>	<b>74</b>
<b>4.9.2</b>	<b>Indirect Strategies.....</b>	<b>76</b>
<b>4.10</b>	<b>Summary of findings.....</b>	<b>76</b>
<b>Chapter 5: Discussion.....</b>		<b>78</b>
<b>5.1</b>	<b>Introduction.....</b>	<b>78</b>
<b>5.2</b>	<b>Theoretical Framework.....</b>	<b>78</b>
<b>5.2.1</b>	<b>Stage 1.....</b>	<b>78</b>
<b>5.2.2</b>	<b>Stage 2.....</b>	<b>79</b>
<b>5.2.3</b>	<b>Stage 3.....</b>	<b>80</b>
<b>5.3</b>	<b>Factors that contribute to VCT.....</b>	<b>80</b>
<b>5.4</b>	<b>Prison conditions.....</b>	<b>82</b>
<b>5.5</b>	<b>Community Mobilization.....</b>	<b>83</b>
<b>5.6</b>	<b>Social Support.....</b>	<b>83</b>
<b>5.7</b>	<b>Role of intimate relations.....</b>	<b>84</b>
<b>5.8</b>	<b>Stigma and discrimination.....</b>	<b>85</b>
<b>5.9</b>	<b>Concluding Comments.....</b>	<b>86</b>



**Chapter 6: Conclusion Recommendations & Limitations.....86**  
**REFERENCES.....91**  
**APPENDICES.....100**

## ABBREVIATIONS

<b>HIV</b>	Human immunodeficiency Virus
<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>STI</b>	Sexually Transmitted Infection
<b>ARV</b>	Antiretroviral Therapy
<b>VCT</b>	Voluntary Counselling and testing
<b>WHO</b>	World Health Organisation
<b>UNAIDS</b>	United Nations Joint Programme for HIV/AIDS
<b>DCS</b>	Department of Correctional Services
<b>DOH</b>	Department of Health
<b>DDM</b>	Disclosure Decision – Making Model
<b>IV</b>	Intravenous

**Keywords:** HIV, ex – offenders, disclosure, prison

## **DEFINITIONS**

### **Offender**

An individual who commits a crime.

### **Ex-offender**

An individual who has been in prison and has been released.

### **Prison**

A building where individuals are kept if they have committed a crime.

### **Prison Cell**

A room within the prison where offenders are kept during their sentencing.

### **Incarceration**

To place an individual in prison whereby they cannot escape.

### **Wyfies**

A male prostitute with female traits. It is a form of slang that is used within prison.

## **ABSTRACT**

This study focuses on the process and complexities of disclosure and decision-making amongst HIV-positive ex-offenders. In addition, this study highlights the history and circumstances of HIV infection and how this influences disclosure. The process of disclosure was explored amongst seven HIV positive male ex-offenders who fell in the African racial category. Data was collected through qualitative in-depth interviews and analyzed using thematic analysis. Results revealed that within this target group disclosure initially occurred within prison and thereafter upon release from prison, continues depending on the contextual factors. Because disclosure initially took place within prison, the prison environment was a defining feature during the process of disclosure. Factors that enabled ex-offenders to disclose their HIV status included social support, witnessing of HIV – related deaths amongst other offenders, as well as the challenging nature of the prison environment. Factors that compromised the disclosure process included their access to treatment and a more nutritional diet. Upon release from prison, access to financial and material support and responsibility to significant others were reasons that facilitated the process of disclosure. Overall, stigma was a main barrier that contributed to non - disclosure. These findings highlight that the process of disclosure is a relational factor as it depends largely on the availability and accessibility of significant others. The conclusion that can be drawn from this study is that HIV disclosure is a process that occurs on a continuum whereby there is no clear end-point as ex-offenders weighed up the enabling factors against the barriers before disclosing. Once disclosure had occurred, ex-offenders had to integrate the outcomes and reactions from significant others into their lives. The process of HIV disclosure is also a never – ending process as there are always significant others to disclose to. It is recommended by this study that more research is conducted regarding how prison conditions influence HIV-positive offenders, how HIV-positive ex-offenders can be better re-integrated into the community and how significant others deal with the ex-offenders HIV disclosures.

# **CHAPTER ONE**

## **INTRODUCTION**

The purpose of this chapter is to introduce the area of research that will be presented in this dissertation. This chapter provides an outline about the whole dissertation, the background of the study, the problem statement, the research objectives, the research questions that have been answered in the study, a brief summary of what each chapter entails, as well as the significance of the study.

### **1.1 OVERVIEW**

The structural barriers of the prison system have fueled the high rates of HIV infections within South African prisons. Evidently, the unique role that the prison system plays in the HIV pandemic suggests that prison should become the entry point for HIV prevention and educational programmes. Upon release from prison, being an HIV positive ex-offender demands an integration of at least two life experiences namely the history as an offender and the current HIV status. One of the factors that enable HIV positive ex-offenders to integrate their life experiences is disclosing their HIV status to their social networks. HIV disclosure is a distressing situation that involves the individual undergoing transitions between various support networks. For an HIV positive ex-offender the process of disclosure is dynamic in nature as it involves the benefit of social support and a healthier lifestyle or the risk of rejection and isolation.

The central focus of this dissertation is to examine the process of HIV disclosure amongst a particular target group, which are HIV positive ex-offenders who are now living in the community. This dissertation is divided into seven chapters. The first chapter is the introduction, which focuses on a general outline of the study. It provides HIV statistics on the general population as well as for the incarcerated population within Africa and for the region of South Africa. It also provides a detailed description about the background of the study, the rationale for the study, and the importance of conducting the study.

Chapter two contains the literature review. Within this chapter, the theoretical models such as the HIV Disclosure Decision-Making Model and the Disclosure Decision-Making Model (DDM) are outlined as it was used for this study. This chapter also consists of previous research conducted on prison conditions, Voluntary Counselling and Testing (VCT), factors that motivate and hinder the process of disclosure, which includes a section on the effects of an individual's historical background on HIV disclosure, as well as the strategies for disclosure.

Chapter three focuses on the research methodology that was used for the study. It includes the sample for the study, data collection techniques, validity, and ethical considerations. Chapter four presents a description of the findings accompanied by the participants' stories. Chapter five presents the discussion. Finally, chapter six includes the conclusions, recommendations as well as limitations for the study.

## **1.2 BACKGROUND OF STUDY**

According to the United Nations Joint Programme for HIV/AIDS (UNAIDS) report, there are an estimated 39.5 million people worldwide who are living with HIV/AIDS. Within Sub - Saharan Africa 27.4 million people are HIV positive with an estimate of 5.5 million living in South Africa (UNAIDS, 2006b). South Africa is currently rated as the country with the highest HIV infection rate in the world with KwaZulu-Natal showing a prevalence rate of 16.5% (Department of Health, 2005).

Within prisons across the globe, prevalence rates of HIV/AIDS are increasing at an alarming rate. According to The World Population Prison List, 668,000 men and women are incarcerated in Sub-Saharan Africa (Walmsley, 2007). Specifically in 2006, 186,739 offenders were housed across 241 prisons in South Africa. In addition, in the year 2006, the HIV prevalence rates within the South African prison population stood at 45% (UNAIDS 2007). As of the 1<sup>st</sup> of January 2009, the estimated offender population stands at 165230 with male offenders comprising 161574 of the total population. This shows that the prison population is predominantly male. The bed capacity for offenders currently stands at 89822, which clearly indicates that South African prisons are about

143.3% overcrowded (Department of Correctional Services, 2009).

In 2000, it was estimated that 95% of the deaths were related to HIV/AIDS in a hospital in KZN. It was also estimated that 90% of the deaths were HIV-related across all prisons in South Africa. It was also recorded that there were 1,087 natural deaths in prison which indicates an increase of 584% from 1995 to 2000. Using figures from 2000, and presuming that the high rates of HIV infections will continue within prison, it was projected that the HIV infection rates from 2000 to 2004 would be as follows: 2001: 38.2%; 2002: 41.4%; 2003: 43.5%, 2004: 45.2% (DCS, 2009). Although these are the only known available statistics, the accuracy can be questioned as there are limited knowledge and information that shows the complete picture of HIV/AIDS within South African prisons. In addition, the reliability of these results may be inaccurate as reports on the exact cause of deaths are associated with either TB or pneumonia. By doing so, the lack of accurate reporting on HIV – related deaths does not capture a consistent as well as comprehensive indication on the number of HIV deaths within prison (Goyer & Gow, 2001 & UNAIDS, 2007).

Attempts were made to examine the extent of HIV infections within Westville prison, which is a prison that is situated in KwaZulu-Natal. Researchers from the Health and Economic Research Unit and Medical Research Council (MRC) conducted a study titled “HIV/AIDS at Westville Medium B: An Analysis of Prevalence and Policy”. To date, the result of this study has not been published as it was alleged by a Judge that 60% of the prison population was HIV positive. Consequently, this study was prohibited by the DCS and the judge had to retract whatever was said due to the pressure from governmental authorities. The DCS found this study as inappropriate, false, and stated that this research was a prime example of researchers trying to obtain financial support. The research team responded to the concerns of the commission at DCS however, the DCS were evasive and the study to date remains prohibited (Goyer, 2002). In addition, those who are among the most likely to contract HIV are similar to those who are most likely to go to prison: young, unemployed, un- or under-educated, black men. This is because many of the same socio-economic factors which result in high risk behaviors for

contracting HIV are the same factors which lead to criminal activity and incarceration. What's even more concerning is that these prisoners are then released into their communities which are also plagued by the HIV epidemic. Despite all of these challenges that HIV positive offenders and ex-offenders face, the government failed to effectively curb HIV/AIDS within prisons (Goyer, 2003).

## **1.2 PROBLEM STATEMENT**

One of the strategies to curb the HIV pandemic is HIV testing, which is advocated by local governments, UNAIDS and the World Health Organisation (Department of Health, 2000; UNAIDS, 2006a; WHO, 2007). The underlying reasoning behind this strategy is that if an individual knows their HIV status then it will lead to behavior change, this in turn will reduce HIV infections. Another assumption of HIV testing is that if individuals know that they are HIV positive they will then disclose their status to significant others. HIV counselling services have also emphasized the importance of health care workers disclosing a positive HIV status to sexual partners. It has been legislated that health care workers have a duty to disclose to the affected partner if the partner is at risk for HIV infection (Allen, 2001). More importantly, HIV disclosure is regarded as being beneficial as it could lead to prevention, psychological well-being, timely treatment and care and support from significant others. Factors that influence the decision about disclosure include the availability of support networks, how stigma and discrimination is perceived at that particular time and place, the perception of self-efficacy in relation to disclosure, and the negotiation of safer sex practices (Shehan, Uphold, Bradshaw, & Bender, 2005; Serovich & Mosack, 2003; Paxton, 2002).

Current literature and research have mainly focused on the process of HIV disclosure within marginalized groups like homosexual and bisexual men and with injection drug users (Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Parsons, VanOra, Missildine, Purcell, & Gomez, 2004; Latkin, Knowlton, Forman, Hoover, Schroder, Hachey, & Celentano, 2001; Serovich, 2000; Zea, Reisen, Poppen, & Diaz, 2003). No known studies have been conducted on the process of HIV disclosure amongst male ex-prisoners who are a high risk group in terms of HIV infection. HIV disclosure for this



particular group is very complex as these individuals are socially defined by their status as an ex – prisoner as well as being HIV positive. Moreover, the history behind contracting HIV may also influence the decision to disclose (Holt, Court, Vedhara, Nott, Holmes, & Snow, 1998; Parsons, VanOra, Missildine, Purcell, & Gomez, 2004). In the case of ex – prisoners this may include forced sexual practices within the prison, gang rapes, gang violence and drug use or occurrences of men having sex with other men (Booyens, Hesselink, & Mashabela, 2004; Goyer, 2003, Luyt, 2003). In reality, HIV disclosure of one’s HIV positive status is a significant yet complex concept in the prevention of HIV transmission. HIV disclosure takes place within various social relationships ranging from the community, significant others, partners, and friends (Biaran, Taylor, Blake, Akers, Sowell, & Mendiola, 2006). Amongst the wide array of experiences that a HIV positive ex-offender faces such as HIV testing, the experience of prison conditions, the process of disclosure was viewed as important as disclosure can be an overwhelming process that causes much distress for the HIV positive individual. Indeed, there is much concern surrounding the psychological and emotional strain that HIV disclosure can take out from the individual (Corona, Beckett, Cowgill, Elliot, & Murphy, Zhou, & Schuster, 2006).

According to Medley, Garcia –Moreno McGill, & Maman (2004), HIV disclosure is a vital process that affects both the individual as well as the social context that the individual is embedded in, both positively and negatively. Increasing number of families are living with an HIV positive individual which in effect creates challenges for these individuals on whether they should disclose their HIV status, how they should disclose their HIV status, and when they should disclose their HIV status (Lee & Rotheram-Borus, 2002). In addition, HIV disclosure is viewed as being crucial because it informs partners of potential risks and benefits (Batterham, Rice, & Rotheram-Borus, 2005). In other words, HIV disclosure is beneficial for both the HIV positive individual and their partner as they will be able to adopt healthier lifestyles. These benefits have the potential to diminish stigma and discrimination but also reduce anxiety for both the HIV positive individual and their sexual partners (Skogmar, Shakely, Lans, Danell, Andersson, Tshandu, Oden, Roberts, & Venter, 2006; Medley, et al., 2004).

Paxton (2002) also mentions that HIV disclosure creates a space whereby individuals are empowered to challenge prevailing myths and misconceptions about HIV/AIDS. In effect, both the HIV positive individual and the general public are able to examine some of the social barriers and obstacles that not only exacerbates HIV/AIDS but also prevents HIV disclosure. Furthermore, through sharing one's HIV status with others, it also leads to a change in the negative attitudes of the general public as well as reinforce the idea that HIV positive individuals can also play fundamental role in education campaigns (Paxton, 2002). HIV disclosure also leads to increased social support, which is an essential component of increasing psychological and emotional well-being (Kalichman, DiMarco, Austin, Luke, & Difonzo, 2003; Norman, Chopra, & Kadiyala, 2007; Parsons et al., 2004).

### **1.3 Research problems and objectives**

The central research focus is to explore the process of disclosure amongst HIV positive ex – prisoners.

The key questions are:

1. What is the perception of HIV positive ex-offenders about the benefits and disadvantages about ex – offenders HIV disclosure?
2. What motivates ex-offenders to disclose?
3. Who are the people that are disclosed to and what were the reactions of these people?
4. What was the experience of disclosing?
5. How has the history of becoming infected influenced the process of disclosure?
6. What would enable this target group to disclose earlier and to more people?
7. What recommendations do they have for different stakeholders?

In sum, this study investigated both the process and experience of HIV disclosure amongst HIV positive ex- prisoners. It also focused on identifying the individuals who were disclosed to and the content of the disclosure. This study also looked at factors that

have influenced an individual's decision to disclose or not to disclose. Furthermore, this study examined how the prison setting has affected HIV disclosure.

### **1.5 Significance of the study**

The process of HIV disclosure amongst HIV positive ex-offenders provides information about past risky behaviors as well as future preventive behaviors. In addition to this, there is also a growing need to recognize that HIV positive ex-offenders are also faced with many life challenges when they decide to disclose their HIV status. HIV disclosure for this particular group is an example of how marginalized groups can overcome boundaries through becoming positive role – models and HIV activists in spite of their history of criminal activities. This study is also important as it will provide more knowledge into factors that limit and enhance this particular population group's ability to disclose their HIV status. In addition, within this specific context, this study can alert us to ways and methods in which HIV/AIDS can be reduced within the prison setting and thereafter within the broader community.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter begins with a conceptual description of the theoretical frameworks that were used in this study as well as previous research conducted on issues that are related to HIV/AIDS, disclosure, and the prison setting. The literature review consists of the following sections namely: prison conditions, Voluntary HIV testing and counselling (VCT), factors that motivates and hinder disclosure, which includes the history of HIV infections, stigma, and discrimination. Prison conditions follows after the theoretical frameworks as it provides a comprehensive understanding of the historical background for this particular target group. In other words, the ex-offenders' background highlights that the process of disclosure is interconnected with their history of being incarcerated. Indeed, the prison experience adds uniqueness to the process of disclosure amongst ex-offenders and has the potential to affect it in a number of ways.

It is also important to note that the majority of the literature that will be reviewed in this chapter is related to HIV disclosure amongst the general population. Currently, there is limited literature that focuses on HIV positive ex-offenders and their experiences of the process of HIV disclosure. Therefore, the issues covered in this chapter rely heavily on available literature within the general population. These areas have been chosen as it can inform and shed some light into the experiences of HIV disclosure amongst this particular target population as well as provide some contextual basis to this study.

#### **2.2 Theoretical Framework**

The Model of HIV Disclosure Decision – Making and the Disclosure Decision model (DDM) were chosen as theoretical frameworks that informed this study. Indeed, the Model of HIV-Disclosure Decision-Making is an expansion of the Disclosure Decision model, which was developed by (Omarzu, 2000). This model was developed from the general framework of the DDM, however differs due to it's primary focus on HIV/AIDS.

The DDM emphasizes the pivotal role that significant others and interpersonal relationships play in decision-making but also argues that the depth of information and the content of the disclosure is dependent upon the individual (Omarzu, 2000).

The model of HIV Disclosure decision-making depends on a myriad of factors. These factors include the social environment, which focuses on the cultural attitudes and scripts of the community, the relationship and the connectedness between the individual and their community, and stigma within that community. There is also the relational component that is evident in this model, which focuses on the individual's relationship with family, friends, intimate partners and the availability of support networks. This model looks at the exact period of time that the individual was diagnosed with HIV and how long it took the person to disclose their status to a significant other. In the model this is referred to as the temporal component. The model further highlights that individual factors such as physical health, age, gender or sexual orientation also influence the process of disclosure. The last component of this model is the proximate conditions that refer to the availability of significant others when the person is ready to disclose (Derlega, Winstead, Greene, Serovich & Elwood, 2004).

According to (Omarzu, 2000), the DDM consists of three stages that determine the types and levels of disclosure. The first stage is the establishment of a disclosure goal that is encouraged by a particular situation. In other words, the first stage focuses on the situational cues that increase an individual's chances of disclosure. The environmental factors that are most likely to influence disclosure are those that show the highest degree of social rewards, social approval, intimacy, relief from distress and social control. The second step is the selection of a strategy and the searching of targets so that the individual will be able to disclose to this target using a particular strategy. This stage is largely based on examining whether disclosure is actually the most effective strategy within that particular situation ensuring that disclosure is achievable. In addition, another distinguishing feature of this stage is the selection of significant others that an individual would like to disclose to. The person chosen to disclose to could influence the type of strategy used. The third stage deals with the individual's subjective evaluation of the disclosure that is used to determine the breadth, duration and depth of the disclosure.

While the breadth of the disclosure focuses on the issues that emerged as result of the disclosure, duration focuses on the length of time it is spoken about and depth focuses on the amount of information that is revealed. The breadth, duration and depth of information determine how the individual perceives the situation and the target. According to this model, subjective utility and subjective risks are important factors that are responsible for disclosure. In subjective utility, before engaging with the actual process of disclosure, the individual evaluates the potential benefits of disclosure. Once the individual is aware of the potential benefits, the individual will then decide on how to disclose, who to disclose to, and the content of disclosure. The risk that people feel they take during the process of disclosure in terms of social rejection and betrayal is also explored (Omarzu, 2000).

Considering these factors, this theoretical framework lends itself to the research problem that was investigated. The model illuminates the process of disclosure as multi-layered which takes into consideration the complex lives of HIV positive ex-offenders. This model is a description of some of the pertinent issues that may arise when an HIV positive ex-offender considers HIV disclosure.

### **2.3 Prison conditions**

The factors that influence the high rates of HIV/AIDS within prison are also likely to act as barriers to HIV disclosure or even facilitate the process further. Factors that contribute to the high rates of HIV/AIDS within prisons both locally and internationally are substance-abuse, overcrowding, consensual and coercive intercourse, and gang – related behaviors. Furthermore, there will be a brief discussion about how organizations such as the World Health Organisation (WHO), UNAIDS, and local government have responded to HIV/AIDS within prison.

#### **2.3.1 Drug – abuse**

Studies within South African prisons have maintained that the high rates of HIV/AIDS are largely due to the socio-political structure of the prison system. The availability of drugs is a significant factor that contributes to gang-related violence and HIV/AIDS

within prisons. In one particular study it was found that prisoners use drugs such as mandrax, dagga and injections because their daily lives within prison was described as being mundane (Luyt, 2003). An average day for prisoners begins at 7:00 for breakfast; a couple of hours in the courtyard, supper at 3:00, then at 5:00 they are placed back into their cells. Indeed, drug use overcomes the boredom that these prisoners face on a daily basis. The use of contaminated needles and instruments also exacerbate the spread of HIV/AIDS within prison. The needles are used for intravenous (IV) drug-use while instruments such as razor blades are used for engraving tattoos. A survey conducted on juveniles aged between 12 -18 in a prison in Western Cape found that 5% had used IV drugs. In Westville prison, 274 prisoners were interviewed and the results showed that six had tried IV drugs and three had used IV drugs since entering prison. Although these are not high rates of drug-use, it cannot be ignored as there is a potential for increased IV-drug usage in prisons. In addition, IV drug use is mainly within Western prison environments. In South African prisons, there is a strong reliance on marijuana (dagga). In Westville prison, it was reported that 72% of the prisoners smoke marijuana while 5% take mandrax (Goyer, 2003). In addition, when prisoners are tattooed, the skin is punctured and as a result the razor blades are contaminated by blood. Thereafter, these razor blades are shared amongst the prisoners. Consequently, the continuous use of unhygienic needles and cutting instruments will fuel the spread of HIV/AIDS within prisons (Belenko, Langley, Crimmins, & Chaple, 2004; Booyens, Hesselink, & Mashabela, 2004; Luyt, 2003; Minnie, Prins, & van Niekerk, 2002).

### **2.3.2 Overcrowding**

Overcrowding is currently a major challenge, which affects the transmission of HIV/AIDS within prisons. This is because prisons cannot withstand the large number of prisoners that are entering South African prisons as they are estimated to be 300% overcrowded. At the end of the financial year in 2006, it was found that the total offender population was 150 302 and the approved offender capacity was 114 796. This represented a 76.3% rate of overpopulation. This leads to increased stress, malnourishment, and unhygienic conditions which favors the spread of HIV/AIDS even

further (Belenko et al., 2004; Booyens et al., 2004; Goyer, 2003; Goyer & Gow, 2001; Luyt, 2003; Minnie et al., 2002; Singh & Maseko, 2006).

### **2.3.3 Gangs**

The two most dominant gangs in South Africa are known as the 26s and 28s. These gangs are defined as the 26s and 28s due to their means of asserting authority and conducting themselves within prison. The term “hierarchical phakama” was coined for the 26s as they draw blood from their inmates or prison guards by attacking them with weapons. The 28s declare their power through their involvement with male prostitutes commonly referred to as “wyfies”. The term “wyfies” is a local prison slang for a male prostitute with female traits. “Wyfies” resume the role of a sexual partner as it provides an outlet for sexual needs. Both gangs can wield control over all aspects of prison life, including access to food, cell assignments, and the acquisition of a prisoner, which is made possible by the assistance of a corrupt prison guard or official. What also appears to be a common occurrence within prison is that these gangs are part of a constant cycle of exploiting younger and weaker offenders. In some instances, the younger and weaker offenders will become the passive partner to those who have power so that they have protection and financial support. However, research conducted in prisons has not adequately targeted gang and gang-related behavior as they are restricted to American gangs (Booyens et al., 2004; Goyer, 2003; Luyt, 2003).

### **2.3.4 Consensual and Coercive Sexual Intercourse**

It has been reported by the lawyers for Human Rights across South African prisons, 65% male offenders are engaging in sex with offenders of the same sex (Goyer, 2003). Similarly, social workers at Westville prison have mentioned that prisoners participate in either consensual sex or coercive sexual activity. A social worker from Westville Medium B has reported that both homosexual intercourse and rape are widespread although it is a situation, which is often ignored by prison authorities. Offenders themselves have also explained that within South African prisons incidents of sexual intercourse occur daily (Goyer, 2003; Niehaus, 2002). There are three aspects of sexual activity that have been identified as risk factors for HIV/AIDS transmission within



prison: anal intercourse, rape and sexually transmitted infections. Those individuals who are the receptive partner rather than the insertive partner stand higher chances of becoming HIV positive as there is a longer period in which the semen makes contact with the mucous membranes. Both consensual and coercive anal intercourse leads to the tearing of the rectum which makes the individual more susceptible to HIV/AIDS. Evidently, male- on-male rape is a result of the construction of power relations between prisoners and the prison culture. These findings have been consistent within prisons such as Westville, Pollsmoor and Barberton prison (Goyer, 2003; Niehaus, 2002). Research on rape within prisons both locally and internationally have also been limited. However, many prisoners will feel reluctant to report sexual violence because of fears about social stigma, embarrassment, and further intimidation. In general, whether sex is consensual or coercive in nature, it is highly prohibited within the prison system. It should also be noted that consensual sex amongst prisoners is a direct consequence of the prison culture, as prisoners need sexual fulfillment. In comparison, coercive sexual activities are products of asserting power and authority in prison rather than about sexual fulfillment (Booyens et al., 2004; Goyer, 2003; Luyt, 2003; Niehaus, 2002).

### **2.3.5 Responses by International Organisations and Local Government**

According to Goyer (2003), there have been many attempts made by organizations such as WHO and UNAIDS to develop policies that would adequately deal with HIV/AIDS within prison. These were some of the problems that were identified: firstly, mandatory HIV testing and the segregation of HIV positive offenders are viewed as an infringement on the rights of HIV positive individuals. Secondly, educational programmes within prisons are lacking due to limited research and knowledge surrounding prison life and HIV/AIDS. Thirdly, if condoms and lubricants were to be distributed within prison this implies that prison authorities and associated organizations such as UNAIDS and WHO will have to accept the prevalence of homosexual activities. Finally, even though policies can be devised at a political level, there still remains a problem pertaining to limited resources and maintenance of these programmes within prison. Within South Africa, the Department of Correctional Services has devised policies to curb HIV transmission

however these policies and programmes are not implemented effectively (Goyer, 2003; Goyer & Gow, 2001).

## **2.4 Voluntary HIV testing and counselling (VCT)**

According to van Rooyen, Heywood, & Strode (2005), the main aims and goals of VCT is to provide care and support to those individuals who are considering undergoing VCT, to ensure that ongoing support is provided to those who are HIV positive following VCT, and to encourage individuals to undergo VCT by overcoming any uncertainties that the individual may have. VCT is regarded as an important channel within HIV prevention campaigns that can reduce the high rates of HIV infections. It has also been argued that VCT has many benefits. Firstly, it is assumed that if individuals undergo VCT then they would be able to adopt healthier lifestyles and make healthier decisions (Kenyon, Heywood, & Conwood, 2001; Mwamburi, Dladla, Qwana, & Lurie, 2005; Fylkesnes, 2000; Van de Perre, 2000). In other words, VCT prevents secondary infections as, if individuals are aware of their status then they will be able to protect their partners and prevent re- infections. Secondly, it assists individuals with coping with the social and psychological aspects of being HIV positive (van Rooyen et al., 2005; Van de Perre, 2000; Kenyon et al., 2001). What follows is literature on the barriers as well as factors that contribute to an individual's decision to go for VCT.

### **2.4.1 Barriers to VCT**

Many challenges and barriers prevent individuals from going for VCT. These barriers have been identified by current literature as stigma low perceived risk and confidentiality of the results.

#### **VCT & Stigma**

The onset of stigma has been identified by research as the most common barrier that prohibits an individual from undergoing VCT. Stigma mainly exerts itself within the social context that the individual is embedded in. Studies have indicated that stigma manifests itself through social rejection, discrimination, and isolation that exist within the social and cultural settings. All of these factors in combination prevents the individual

from getting an HIV test because of the negative connotation that is attached to an HIV positive test result (Daftray, Padaychti, & Padilla, 2007; Kalichman & Simabyi, 2003; Ford, Wirawan, Sumantera, Sawitri, & Stahre, 2004; Hutchinson & Mahlalela, 2006; Lliyasu, Abubakar, Kabir, & Aliyu, 2006; Obermeyer & Osborn, 2007; Oknokwo, Reich, Alabi, Umeike, & Nachman, 2006; Stein & Nyamathia, 2000).

The prevalence of stigma was also consistent in a South African study conducted by Day Miyamura, Grant, Leeuw, Munsamy, Baggaley, & Churchyard (2003), who pointed out that participants made reference to a Sotho word known as "Kgetholla" whenever they spoke about VCT. "Kgetholla" is a term that is associated with either 'isolation' or 'neglect' which was what prevented participants from considering VCT (Day et al., 2003). In another study conducted in a Black Township in Cape Town, it was highlighted that individuals who have not been tested for HIV/AIDS had experienced higher rates of stigma in comparison to individuals that did go for tests regularly. This study utilized the information-motivation behavioral skills model of health behavior, which suggests that an individual's decision to undergo an HIV test is influenced by their knowledge and information as well as their attitudes and beliefs. An individual's knowledge, information, attitudes, and beliefs acts as a source of motivation for behavior change. This study also found that knowledge about HIV testing which happens through individual counselling is insufficient especially when there is evidence of social barriers that are largely exercised through stigma and discrimination. Given the importance of understanding HIV/AIDS within a contextual basis, this study has argued that the discrimination associated with HIV/AIDS is similar to the history of discrimination that Black South Africans faced during apartheid. The basic argument is that VCT constrains the individual's ability to exercise control over their lives similar to what apartheid did. By knowing your HIV status, there is risk of being segregated and discriminated similar to apartheid laws (Kalichman & Simbayi, 2003). More importantly, VCT poses a major challenge within the healthcare setting because within the African context, there is a lack of financial infrastructure that could make VCT ore readily available to everyone (Lliyasu et al., 2006; van Rooyen et al., 2005). More importantly one study in particular has focused on stigma and discrimination within a South African prison. In this study,

participants explained that positive HIV test posed potential stigmatization as inmates would immediately receive a special diet of fruits which was collected daily from health workers. Thus, participants referred to this special diet as the 'AIDS diet' because only offenders that were HIV positive would receive this diet (Sifunda, Reddy, Braithwaite, Stephens, Ruiter, & van den Borne, 2006).

### **Low Perceived Risk and Confidentiality**

Within the general population, studies have revealed that individuals will not undergo VCT as they perceive that they have a low susceptibility to contracting HIV. This perception arises from the fact that they are not sexually active or have never engaged in sexual intercourse (Obermeyer & Osborn, 2007; van Dyk & van Dyk, 2003). However a study by (Njagi & Maharaj, 2006), found that individuals still had a low perceived risk to HIV/AIDS even though they engaged in highly risky behaviors. Similarly, within the prison setting, offenders seem did not go for VCT as they perceive that they have a low susceptibility to contracting HIV (Burchell, Calzavara, Myers, Schlossberg, Millson, Escobar, Wallace, & Major, 2003; Kacanek, Eldridge, Nealey – Moore, MacGowan, Binson, Flanigan, Fitzgerald, & Sosman, 2007). Furthermore, confidentiality within the prison setting and within the general population also served as a major deterrent to VCT. Studies have shown that individuals do not trust the VCT counsellors and fear being recognized by the VCT clinics that are usually based within the community. Counsellors were also judgmental which is another factor that prevented VCT in a prison setting (Burchell et al., 2003; Ginwalla, Grant, Day, Dlova, MaCintyre, Baggaley, & Churchyard, 2002; Njagi & Maharaj, 2006; Sauak, & Lie, 2000; van Dyk & van Dyk, 2003). In contrast to the above, another study reported that in some instances although counsellors are able to provide support and be non-judgmental, they experience high levels of stress and work-load due to the demands of their jobs (Grinstead & Van der Straten, 2000).

Another study has also pointed out that the implementation of VCT is dependent upon both the client's and the counsellor's characteristics. This study argues two points. Firstly, building rapport with the clients may be viewed as ineffective if clients are

uncooperative. Secondly, the testing sites and institutional norms can also affect the encounter between the counsellor and the client (Roberts, Grusky, & Swanson, 2008). Individuals also did not want to go for VCT because they did not receive the results on the same day, which also added to their high levels of stress (Beckwith, Cohen, Shannon, & Raz, 2007). It is therefore recommended in the above mentioned studies that rapid HIV testing which could provide same day results should be offered as an alternate during the testing process (Ginwalla, et al., 2002). It has also been highlighted that offenders as well as individuals within the general population were reluctant to go for VCT because of the inadequacy in the VCT services as individuals only received post-test counselling if they were HIV positive (Ginwalla et al., 2002; Grinstead, Seal, Wolitski, Flanigan, Fitzgerald, Nealey – Moore, Askew, & the project START Study Group, 2003; Kacanek et al., 2007; Pronyk, Kim, Makhubele, Hargreaves, Mohlala, Hauseler, 2002; Sifunda et al., 2006). Additional reasons for not wanting to be tested included lack of treatment options, lack of follow-up support, as well as the inability to deal with the actual trauma undergoing an HIV test (van Dyk & van Dyk, 2003).

#### **2.4.2 Reasons for VCT**

Previous literature has also pointed out the reasons that individuals want to go for VCT. Within the prison setting specifically, the structure of the prison as well as the laws that govern prison also contributes to an individual's decision to undergo VCT.

##### **Structural & Institutional Factors within prison**

Within prison, an offender's decision to go for VCT is determined by structural and institutional factors (Kacanek et al., 2007). Studies have also noted that most offenders went for an HIV test because they lacked resources outside of prison such that in prison HIV testing was free, convenient and many thought that it was mandatory (Kacanek et al., 2007). Given the alarming statistics of HIV/AIDS within South African prisons, a study by Sifunda, et al. (2006), emphasized the prison setting as a useful context for curbing the high rates of HIV infections. However, the extent to which offenders went for VCT to gain access to treatment is unknown. It is interesting to note that this study has argued that programmes within prison are efficient and continue in spite of the

various challenges confronted by healthcare workers. The main concern about prevention programmes within the prisons was equipping the offenders with skills so as to promote safer sex and reintegration into the community upon release (Sifunda, et al., 2006). In effect, it is recommended that structural factors and individual reasoning should be implemented in the formulation of theoretical models in HIV prevention programs. Furthermore, it was also recommended that VCT should include a program on how offenders should go about informing their partner's about their HIV status when they are released from prison as well as act as a source of motivation for their partners (Sifunda et al., 2006). However, it was pointed out that HIV testing can also occur if an individual believes that their test results have the potential to reduce the risks of infection to themselves and others. Most importantly, it is recommended that theoretical models of HIV testing and behavior should consider that VCT occurs within multiple levels. By doing this, we are able to consider the structural level which focuses on the socio – economic and socio – political influences and an individual level which focuses on how the individual's attitudes, beliefs and knowledge affects decisions to undergo VCT (Ford et al., 2004).

The structural level is especially relevant to the influence of the prison environment as it has hindered individual's decisions to undergo VCT during incarceration and upon release (Kacanek et al., 2007). In addition, individuals mainly went for an HIV test due to the onset of HIV/AIDS symptoms (Solomon, Kouyoumdjian, Cecelia, James, James, & Kumarasamy, 2006). Moreover, it was the younger age group being tested as part of a medical check-up and follow-up testing in combination that promoted VCT within prison. In addition, the fears of infection inside of prison through contact with blood during fights and casual contacts dominated offender's decisions to go for VCT (Burchell et al., 2003).

## **2.5 Disclosure of HIV status**

HIV disclosure depends on various factors that either hinder or facilitate the process further. The process of HIV disclosure will unfold when the benefits outweigh the cost, when situations are perceived as favorable, or when individuals lack control over their

HIV disclosure decision - making.

### **2.5.1 Factors that motivate and hinder the process of disclosure**

Many enabling factors as well as obstacles could influence a person's decision to disclose their HIV status. On the one hand, these enabling factors can be influenced by accessibility to support networks, relationships with significant others and the importance of personal relationships to the individual, emotional and psychological well-being, and access to treatment are factors that favors the process of disclosure more positively. On the other hand, the obstacles focus on an individual's emotional issues surrounding disclosure, stigma from significant others, threats to personal relationships, reactions from significant others, and parent-child disclosure. HIV disclosure also depends on the types of methods that individuals choose which will also be discussed in this section.

#### **Support & Type of relationship**

According to Norman, et al. (2007), HIV disclosure is an ongoing process that is complex and fluid and should not be regarded as being uniform. Indeed, this highlights that there is no end-point to the process of disclosure. Instead, the process of disclosure continues over a period of time and varies across different social networks and is dependent upon different enabling factors. Current literature has argued that the availability of support by family members and friends is viewed as an enabling factor that influences the decision to disclose. Studies have also highlighted that disclosure occurs whenever there is a high degree of social support (Kalichman, DiMarco, Austin, Luke, & Difonzo, 2003; Norman et al., 2007; Parsons et al., 2004).

Studies conducted within the South African context argue that individuals will choose to disclose their HIV status to family members or partners rather than friends. Studies conducted on HIV positive African men found that individuals mainly disclosed to mothers or sisters first before disclosing to other members of the family. Similar results have also been found in Western literature whereby individuals choose to disclose to mothers and sisters rather than fathers and brothers (Kalichman et al., 2003). Therefore, it was argued in these studies that mothers and sisters provided a source of support and

were less likely to stigmatize or reject the individual. It has been therefore recommended by these studies that future research should consider how families provide assistance to HIV positive individuals (Kalichman et al., 2003, Shehan et al., 2004; Skogmar et al., 2006; Wadell & Messeri, 2006). In contrast to South African literature, Western literature has argued that individuals choose to disclose to their friends rather than their families (Kalichman et al., 2003; Serovich, Esbenson, & Mason, 2007). Another study that highlights this was conducted by (Serovich et al., 2007) over a 15-year lifespan which highlighted that friends were disclosed to more than family members. The purpose of examining disclosure rates over a 15-year lifespan was to understand the rates of disclosure not only within specified time intervals but rather the long-term patterns. This study is in direct contrast to previous studies which argue that HIV disclosure occurs more commonly amongst family than friends. Factors such as age, gender, race at the time of disclosure, level of satisfaction, and the age of the participants did not affect the process of disclosure (Serovich et al., 2007). The relationship between social support and disclosure has also been emphasized in a study by (Wong, et al., 2009). This study has argued that family provides the most amount of support followed by friends, doctors and then sexual partners. It is therefore recommended that HIV interventions should also include teaching families skills for coping with AIDS stigma and training on caregiving (Wong et al., 2009).

### **History, circumstances of HIV infection and marginalization of communities**

The decision on whether to disclose one's HIV status can also be understood if the context of the person's life, circumstances, and the history of the HIV infection is taken into consideration (Serovich, 2000; Shehan et al., 2005). The circumstances in which individuals are infected are characterized by behaviors that are regarded as deviant by societal norms and standards. These 'deviant behaviors' include individuals who are homosexual, bisexual and injected drug users which implies that if individuals disclose their HIV status then they are also at risk of significant others being aware of their sexual orientation or their drug use. In other words, within a behavioral level, lack of disclosure is directly related to the fear of exposing marginalized communities such as being a homosexual, a drug user, or within this study, an ex-offender. Indeed, individuals will



not disclose their status because they fear that their behaviors within society will be revealed thus they face a double stigmatization (Cloete, Simbayi, Kalichman, Strebel, & Henda, 2008; Latkin et al., 2001; Parsons, et al., 2004; Simoni & Pantole, 2004; Zea, Reisen, Poppen, & Diaz, 2003). Specifically, one study addressed the effects of stigma and discrimination on marginalized communities. It has been argued that marginalized communities are stigmatized not only because their behaviors are regarded as ‘deviant’ by society but also because sex is regarded as taboo. In other words, these marginalized communities are blamed for transmitting HIV because their behaviors such as being homosexual, a drug-user and/or engaging in sex with prostitutes are not accepted within society. This is also true for HIV positive ex-offenders as they are also part of a marginalized community like drug-users, homosexuals and those who engage with commercial sex workers. More importantly, stigmatization and discrimination has the potential to reinforce behaviors that contribute to HIV/AIDS. As a result of stigmatization many drug-users remain in their drug communities as they face social isolation and rejection. Hence safe sex practices and drug rehabilitation are compromised. It has been recommended for future research that prevention programmes must include marginalized communities and have a comprehensive understanding of the community’s reputation. It has also been noted that these “deviant” behaviors construe an automatic HIV/AIDS diagnosis from significant others. One study has indicated that significant others automatically believe that if you are a drug-user or a homosexual then you are HIV positive. Thus, participant’s non-disclosure of their HIV status comes as no surprise (Deng, Li, Seingeryaung, & Zhang, 2007).

This notion of stereotypical behaviors and deviancy is further supported in a study by (Abadi` a – Barrero & Castro, 2005). Their argument is that stigma should be understood within the context of structural power and inequalities. In addition, their argument proposes that stigma is not merely a situation in which an individual is isolated or rejected. Instead, stigma is influenced by the presence of political, economical and cultural power imbalances that maintain distinct categories of what is acceptable versus what is unacceptable. By doing this, stigma heightens the inequalities amongst the races, genders, and sexuality that lack power (Parker & Aggleton, 2003). Specifically, for an

HIV positive ex-offender, stigma exists at the level of the prison, community, and significant others. Consequently, stigma arises from these levels and are maintained through these levels. Similarly, Goffman's theory of social stigma has been identified as a common theory within literature that focuses on stigma, HIV/AIDS and power. According to this theory, within society those who hold power, categorize people as "accepted" or "different". In doing so, individuals who are regarded as "different" will then be stigmatized and construct a negative view of their social and individual identity. However, (Parker & Aggleton, 2003), argue that by explaining stigma through means of "normal" and "abnormal", there is a lack of understanding how stigma changes throughout an individual's experience of HIV/AIDS. Instead, stigma in relation to HIV/AIDS should be considered as a socially constructed event that results in rejection, status loss and discrimination (Cloete et al., 2008). More importantly, research has argued that an offender's history shows that high-risk behaviors that influence HIV infections occur before they enter prison. This highlights the conditions that the offenders are living under such as engaging with multiple partners, having unprotected sex, substance abuse, poverty, unemployment and under-education (Braithwaite & Arriola, 2003).

### **Disclosure & Stigma**

A recurrent theme in the literature on HIV also concerns the role of stigma in impeding an individual's decision to disclose their HIV status. Studies have revealed that factors such as coping with the distress of the reaction from significant others, blame from others, the need to protect others, fear of abandonment, and social isolation outweigh the benefits of disclosing (Hereck, Capitonio, & Widaman, 2002; Maman, Mbwambo, Hogan, Weiss, Kilonzo, & Sweat, 2003; Medley, Garcia – Moreno, & Maman, 2004; Norman et. al., 2007; Parsons et al., 2004; Skinner & Mfecane, 2004; Petrak, Doyle, Smith, Skinner, Hedge, & Simoni, 2001; Wong et al., 2009). In another study that was conducted by (Serovich, Brucker, & Kimberly, 2000), tested a barrier theory of HIV disclosure. According to the barrier theory, if an individual perceives that there are barriers to gaining social support then they would choose not to disclose their HIV status. The barriers that have been identified include lack of access to family members, lack of

acceptance, lack of intimacy, negative interactions, feeling smothered, and wanting to protect family members. Indeed, the above factors in combination were viewed as obstacles to HIV disclosure (Serovich et al., 2000). Studies have also shown that disclosing one's HIV status to significant others may not only disrupt broader social networks but may also lead to rejection from these networks. Studies have also revealed that stigma and discrimination from significant others are important factors that exacerbate non-disclosure (Derlega, et al., 2004; Hereck et al., 2002; Kirshenbaum & Nevid, 2002; Petrak, et al., 2001; Winstead et al., 2002). The incidence of stigma occurs because of how it manifests itself in the HIV positive individual's life as well as the high rates of becoming infected (Winstead et al., 2002). In comparison a study by Paxton, (2002), has found that public disclosure can reduce the possibility of stigma and discrimination. "The paradox of coming out openly as an HIV-positive person is by facing AIDS-related stigma, one finds psychological release - liberation from the burden of secrecy and shame" (Paxton, 2002, p. 559 ). This study concludes that even though disclosure can result in stigma and discrimination, the reality is that it can in some ways be liberating as the individual reduces the stress and burden of carrying the disease on their own (Paxton, 2002). Moreover, (Jewkes, 2006), also argues that HIV/AIDS within South Africa has introduced a collection of social mobilization and normalization. It should be noted that social mobilization and normalization has not attributed to denying the presence of the disease but rather has challenged the ways in which society have been thinking and responding to stigma and discrimination (Jewkes, 2006).

### **Emotional & Psychological Well – being**

Within an emotional and psychological level, studies have pointed out that individuals disclosed their HIV status in order to improve their health status, which in effect increases the chances of becoming long-term survivors and improve their quality of life. Studies have concluded that whenever individuals decided to openly disclose their HIV status, they are involved in a process of weighing the costs against the benefits. (Clerigh, Ironson, Antoni, & Schneiderman, 2008; Chandra, Deepthivarma, Jairam, & Thomas, 2003; Norman et. al., 2007; Paxton, 2002; Wong et. al, 2009). One study in particular utilized Pennebaker's theory of inhibition, which is based on the notion that an

individual's disclosure of their HIV status has the potential to increase the individual's health and immune system because the emotional distress that is associated with being HIV positive is expressed. Although this theory has included factors such as cognitive change, it has been limited as it is too individualistic and does not include the wider socio-economical and socio-political networks that the individual is embedded in. The results of this study indicated that disclosure contributed to participants becoming long-term survivors as they were able to disclose their HIV status and express their emotional distress. However, more research is needed to determine how the depth of individuals expressing their HIV disclosure affects disease progression (Clerigh et al., 2008). In a separate study conducted by (Serovich, Lim & Mason, 2008), has mentioned that during the process of weighing the costs against the benefits, it was found that the fear of death that participants usually associated with being diagnosed with HIV motivated HIV disclosure. This study utilized the disease progression model which states that individuals will be motivated to disclose their HIV status if they perceived their health to be deteriorating. The disease progression model has been criticized in the study as HIV positive individuals are also able to live healthier lifestyle if medical, socio-political and socio-economical support is available. This study adopted a consequences theory of explaining why individuals disclose their HIV status which states that individuals examine the costs and benefits of disclosing their HIV status to significant others. Additional research is needed to understand how individuals go about weighing the costs and benefits, the reasons for disclosing to that particular significant other, and how to assist the individual during their process of disclosing their HIV status (Serovich et al., 2008).

### **Reactions from significant others**

Studies have shown that individuals fear anxiety-provoking reactions whereby significant others and themselves may not manage the disclosure (Murphy, Roberts, Hoffman, 2005; Serovich, Kimberly, Greene, 1998). However, (Serovich et al., 1998) suggests since HIV positive individuals are aware that significant others react in a complex manner with mixed emotions such as anger, withdrawal, and disappointment which in turn does not favor disclosure. This is on the grounds that HIV positive individuals have encountered

situations in which significant others have known other individuals who are HIV positive (Serovich et al., 1998). Another barrier that hinges on HIV disclosure is that some individuals do not disclose their status as their health has not deteriorated hence do not find a reason to disclose (Skogmar et al., 2006).

### **Access to Treatment & Care**

Literature has also identified the following common factors that promote participants' decision to disclose their HIV status: firstly, disclosure would lead to access to healthcare resources in the form of ARV treatment and care (Wadell & Messeri, 2006). Secondly, it was found in another study that individuals disclosed their status as they found it difficult to conceal their HIV positive status because they were receiving ARV treatment and care (Skogmar et al., 2006). This is evident especially in studies on parental disclosure as parents usually disclose their status when their health has deteriorated (Corona et al., 2006; Lee & Rotherum-Borus, 2002; Winstead et al., 2002). Thirdly, disclosure meant that individuals gained material support from the family and wider networks such as the community (Wadell & Messeri, 2006). Lastly, these participants stated that they have become more actively involved in the community and have created a chain of support within their communities as they are able to assist others who are HIV positive. This is evident in many studies that are conducted within a South African context whereby community support is pivotal to an individual's decision to disclose their HIV status. When individuals disclose their status to the community, it is argued that it leads to more positive role-modeling and gaining support from the community. For instance one study has argued that when individuals disclose their status within their respective communities, it motivated the use of condoms and reduced the high rates of casual sex. Overall, what this study has argued is that during the cost-benefit analysis, participants also "feel out" how the disclosure of their status will affect their social networks and also what positive outcomes can be achieved (Norman et al. 2007).

### **Parental Disclosure**

Even though individuals are surrounded by negativity in terms of HIV disclosure, a study has revealed that individuals experience low levels of regret and a sense of relief upon disclosure (Serovich, Mason, Bautista, & Toviessi, 2006). Studies have also revealed that parents do not disclose their HIV status to their younger children because they fear that the children will not understand their illness and will tell others. Parents also spoke about the sensitivity of the topic surrounding both their HIV status and the emotional consequences of their disclosure on the children. Moreover, these studies have indicated that parents experience anxiety over finding caregivers for their children. (Corona et al., 2006; Lee & Rotherum-Borus, 2002; Winstead et. al., 2002). Another study has indicated that children are disclosed to mainly due to the level of the child's maturity, emotional, psychological stability and their ability to make sense of the disclosure. However, what is evident from this study is that the age of the significant other influences the process of disclosure as the age of the child determines the maturity, psychological, emotional and mental levels of the child (Ostrom, Serovich, Lim, & Mason, 2006). Individuals will also choose not to disclose their HIV status due to the need for privacy (Wong et al., 2009).

### **Intimate relationships**

Disclosure to a partner is an even more complex process as HIV positive individual's will face the possibility of a loss of intimacy, rejection from their partners as well as a disintegration to their well-being. Studies have also shown that disclosure can lead to the loss of intimate partners or personal intimacy (Biaran, et al., 2007; Parsons et al., 2004). The nature of the relationship between partners also affects non-disclosure. If a relationship was casual rather than long-term or serious then disclosure was viewed as being unimportant in such a relationship (Derlega, et al., 2004; Serovich & Mosack, 2003). The extent to which the individual perceives the relationship as committed influences an individual's decision to disclose. In other words, the more committed the relationship the more likely the individual will disclose their HIV status. Individuals will also not disclose their status if they are involved in casual relationship. Committed relationships are identified as being married or being in a long-term, same-sex

relationship (Biaran et al., 2006; Camblin & Chimbwete, 2003; Mola, Mercer, Asghar, Gimbel - Sheer, Micek, & Gloyd, 2006; O' Brien, Richardson – Alston, Ayoub, Magnus, Peterman, & Kissinger 2003; Simoni & Pantalone, 2004). A study by (Batterham, et al. (2005), has also identified age as a factor that contributes to disclosure whereby it is the younger age group that are likely to disclose their HIV status to their partners but within a committed relationship rather than a casual relationship. However, these participants agreed that they have more casual relationships as sex with friends and commercial sex workers had increased over a period of six months of the study (Batterham et al., 2005).

From research, it is evident that the process of disclosure is often associated with feelings of shame and worthlessness and is experienced as a traumatic event for both partners and HIV positive individuals. Studies have cautioned that the ability for both partners and HIV positive individuals to negotiation safe sex practices was compromised due to HIV positive individual's disclosure a year or two after diagnosis (Ateka, 2006; Batterham et al., 2005; Mohamed & Kissinger, 2006; Skogmar et al., 2006). These studies have also argued that even though the participants disclose their status – this does not necessarily lead to safe sex practices. The reasoning behind this is that the participants either wants to reinforce their commitment in the relationship or they fear that their behaviors (such as promiscuity and substance abuse) will be exposed (Ateka, 2006; Marks & Crepaz, 2000; Mohamed & Kissinger, 2006; Serovich & Mosack, 2003; Skogmar et al., 2006). However, this does not mean that non-disclosure leads to unsafe sex. This is what Skogmar et al., 2006, termed “uniformed disclosure” which is based on the notion that HIV positive individuals may facilitate the negotiation of safe sex either because of personal responsibility or because of wanting to protect the partners. Thus, the relationship between disclosure and safe sex emphasis that disclosure does not necessary lead to safe sex yet it is legislated and continuously revised within policies (Marks & Crepaz, 2000; Skogmar et al., 2006; Serovich & Mosack, 2003).

Research within the South African context has argued that factors such as trust, feeling a sense of responsibility, and an obligation to their partners had promoted the participant's decision to disclose. In effect, the outcome of disclosing their HIV status to their partners

was beneficial to both the participant and their partner as it made them aware of safer sex practices (Holt, et al., 1998; Latkin et al., 2001). In a separate study Wong et al. (2008), compared the disclosure rates between family members and partners. This study found that 87% had disclosed their status to at least one person, while 13% had never disclosed to anyone. The majority had disclosed to their partners as compared to their family members. This study also indicated that participants who disclosed their HIV status to their partners did so 16 months after diagnosis while those who did not disclose their status were diagnosed for only 9 months. Since this study has also argued that social support facilitates disclosure, it is recommended by this study that further research is needed to understand the reasons behind why individuals received less support as compared to those that do (Wong et al., 2009). In a separate study conducted by Petrak et al. (2001), showed that participants disclosed in the following order: first to partners, then to friends and lastly to family. Other studies have pointed out that individuals were motivated to disclose their HIV status as it led them to provide knowledge about HIV/AIDS to significant others. In effect, this enabled individuals to challenge and remove any myths and misconceptions that significant others had. Through informing others about their HIV status, participants also felt that they would reduce previously held prejudice about the disease (Holt et al., 1998; Latkin et al., 2001).

Researchers have found it difficult to determine whether disclosure leads to safe sex solely due to the methodological reasons. Practically, it is not possible for researchers to simultaneously create and investigate conditions for safe and unsafe sex. In addition, decisions about safe sex and sex in general vary across relationships and partners hence decisions cannot be homogenized (Skogmar et al., 2006). Marks & Crepaz (2000) have highlighted that no design has and can control for the third variable which is ethical responsibility which will permit couples to always wear a condom. More importantly, theoretical hypotheses have not been tested empirically and there is no evidence of a specific theory – related to HIV disclosure. This does not mean that disclosure should be ignored however; disclosure should be regarded as a source for communication whereby safe sex options are discussed and agreed upon (Marks & Crepaz, 2000). In one particular study, disclosing one's HIV status was viewed as both a short - term and long -



term stressor whereby the infected individual needed time to come to terms with their own diagnosis before they started the emotive process of disclosing to significant others (Holt, et al., 1998). Self-blame was also perceived as a barrier to disclosure. Currently, the responsibility for disclosure is placed on the individual in order to protect privacy rights. One major gap within literature that needs to be considered is the fact that the negotiation of safe sex practices are dependent upon how well HIV positive ex-offenders are re-integrated back within the community.

## **2.6 Strategies for Disclosure**

Research has identified that individuals either opt for direct or indirect strategies for disclosure. Direct methods refer to the individual verbally disclosing their HIV status while indirect methods refer to the individual using other sources to mediate the process of disclosure. In some instances, indirect channels such as letters were used by individuals to disclose their HIV status (Campbell, Foulis, Mainmane, & Sibiya, 2005). Some individuals also choose to use symbolic hinting whereby they would place HIV – related material in common areas of their household. Some of the participants also chose to inform their partners via chat rooms through the internet. Both symbolic hinting and the use of chat rooms were classified as indirect methods. This study highlighted that these methods could pose as a danger to safer sex practices as the participants assumed that the significant other was aware of their status. Moreover, participants also spoke of another technique known as buffering whereby they would use a third party to disclose their HIV status to significant others. Other examples of buffers include taking significant others for HIV/AIDS workshops and rallies (Serovich et. al., 2005). A study by Serovich, Oliver, Smith & Mason (2005) found that individuals use point-blank disclosure and In-person disclosure whereby they directly expressed their disclosure. So within direct disclosure there are different possibilities. The difference between these two types of direct methods of disclosure was that direct face to face was more overt and blunt while In-person took place more in public spaces, usually in bars or clubs, as it reduced the chances of violent outbreaks (Serovich et al., 2005).

## **2.7 Concluding paragraph**

The areas covered in this chapter provide a guideline on how factors such as stigma, the history of HIV infection, and social support influence the process of HIV disclosure. Most of the literature reviewed refers to the general population. Therefore, within the area of HIV positive ex-offenders, literature is limited.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1 Research Design**

This study utilized a qualitative research design as it created a space for the subjective accounts of the participant's process and experiences of disclosure. Because the research question focused on understanding the process of disclosure, the qualitative design provided in-depth and rich accounts from the perspective of the participants. During the interviews, it was found that this type of design enabled participants to recreate the process or processes and experiences that they had undergone when they had disclosed their HIV status (Arthur & Nazroo, 2003; Flick, von Kardorff & Steinke, 2000; Robinson, Tolley, & McNeil, 2002). Moreover, qualitative research describes social reality as a product of contexts and meanings that are established through the interconnectiveness of our social worlds. By understanding the context of the study, we are then able to understand the reasons of how and why participants have attributed certain meanings to certain events or situations (Flick et al., 2000; Henning, Rensburg, & Smit, 2003).

#### **3.2 Ethical Considerations**

Before the commencement of data collection, a research proposal consisting of a brief outline of the study was submitted to the University of KwaZulu – Natal Ethics Review Committee for ethical clearance. Thereafter, the Treatment Action Campaign (TAC) was contacted as it is a non-governmental organization that is publicly known for their work with HIV positive ex-offenders and offenders. The researcher then had a meeting with the project co-ordinator from the TAC who then assisted with getting a sample. The main aim of the meeting was to find ways to gain a sample without compromising the HIV status of the participants. It was then discussed that participants who had disclosed to the TAC will be contacted to participate in the study. The TAC had decided to liaise with participants directly before contact names and numbers were given to the researcher. In other words, contact details of the participants were only given to the researcher once

TAC had contacted the participants and they were comfortable with the idea of the researcher knowing their HIV status. Furthermore, a letter from the TAC was given to the researcher that outlined the above process and also stated that the participants will be contacted to participate in the study. (See Appendix 1). Thereafter, only participants that had disclosed to the TAC and did not have a problem with the study were contacted by the researcher. By doing this the principle of nonmaleficence was practiced in this study as it ensured that the participants were not psychologically harmed in any way. All participants were asked to fill out an informed consent form (See Appendix 2). In this form, it stated that participation was voluntary and that they could withdraw if they wanted too. This ensured that respect, the right to chose, and freedom was given to the participants without them being psychologically and physically forced to take part in the study. This protected the autonomy of all participants. In addition, the informed consent form also provided a clear explanation of what was expected from the participants. The informed consent form outlined the reasons for the study, the reasoning behind why this particular sample was chosen as well as what the study aimed to do. In addition, the informed consent form made participants aware and also assured the participants about the parameters of confidentiality. This was important as participants could express themselves honestly and freely without the fear that the information supplied by them will be compromised. Participants were also told of how the data was recorded and stored.

Pseudonyms were also used when the data was analyzed. (Kvale, 1996), also adds that the different ways and means that have the potential to harm the participants needs to be identified beforehand. Therefore, participants were provided with the names of social workers and psychologists as careful attention had to be paid to this group especially because of their experience as an HIV positive individual and ex-offender. In effect, this group was a particularly vulnerable group. These participants were not deceived in anyway to participate and were provided with clear instructions as well as financial support. It is also important to add that participants had requested to be referred to as ex-offenders rather than ex-prisoners. The participants stated that the term ‘ex – prisoner’ acts as a label in which they are defined by prison life and their history of criminal

activities. The term 'ex – offender' shows recognition within the public spectrum that the participants are sources of rehabilitation.

### **3.3 Type of Sampling**

Snowball sampling was used as a method for sampling in this study. Indeed, snowball sampling is especially useful when you are trying to reach samples that are inaccessible or hard to find. HIV positive ex-offenders that had been in prison were a particularly difficult sample to find within the general population. What made this sampling technique useful was that it was based on a recommendation or referral basis. After the TAC provided the researcher with willing participants, the researcher then met with these participants and spoke to them about other individuals who shared similar experiences.

Two participants who were involved in a support group at the TAC were referred. These participants thereafter recommended other individuals that were HIV positive ex-offenders. It is important to note that the participants who were referred by the TAC, made contact with other participants who had disclosed to them and were willing to participate in the study. In this way, the participant's HIV status was not compromised. This method of sampling showed how the study began with a small sample and then encompassed more participants due to the referral chain that was created by the first participant. Moreover, homogenous sampling was also used as a sampling technique as the referral chain was formed due to the participants sharing similar experiences (Babbie & Mouton, 2001; Ritchie, Lewis, & Elam, 2003; Terre Blanche & Durrheim, 2002).

### **3.4 Sample Size**

Initially, this study had made contact with 15 participants. Only seven participants were willing to participate. During the telephonic conversations between the participants and the researcher, it was found that the participants were reluctant to participate mainly because of their HIV status as well as their history as an offender. Some of the participants had told the researcher that since a part of the interview dealt with prison conditions, it had the potential for them to be harmed in some way by prison authorities as they may find out the information that they had disclosed. Furthermore, participants also feared that their communities would become aware of their HIV status through this

research. Many of the participants feared that they would not only lose the support from the TAC but will also not be able to provide current offenders with ongoing care and support. In addition to this, these participants also feared discrimination and victimization as they believed that the results would be published and that their status as an HIV positive ex-offender will be exposed. Other participants seemed reluctant to talk to the researcher as the researcher was a young woman from a different race group to theirs. In August of 2007, the first participant who was a member of the support group at the TAC was contacted. An informal meeting was conducted between the researcher and the participant regarding the research and other participants that will volunteer for the study. The researcher had then contacted the participant after a few days as it gave the participant sufficient time to consider whether they wanted to participate in the study. The participants varied in ages between 25 – 41 years. All were African HIV positive ex-offenders as a racial category. At the time of the study, three participants were involved in relatively new relationships while four were single. All participants were unemployed at and relied heavily on significant others for financial and material support. The study was conducted in English. The study was conducted at the TAC offices and in clinics where the participants had resided. In effect, seven HIV positive male ex-offenders were used for this study because these participants volunteered for the study. Indeed, it also provided a detailed account of the participant's processes and experiences of disclosure. The researcher followed up the names that were given by the TAC and participants for a possible interview.

Participants were chosen according to the following criteria:

1. Was HIV positive.
2. Were an ex-offender.
3. Had disclosed to at least one significant other whether it was within prison or outside.
4. Had to also be English-speaking as participants had refused to have a translator present during the interviews. Participants felt intimidated and uncomfortable with a translator as they felt that they were unable to speak to two individuals about their experiences. In addition, these participants felt that the translator will

not be able to capture the full extent of their narratives as some of the isiZulu words have different meanings when translated into English. This is on the grounds that the researcher decided to telephonically and physically meet with the participants so that trust and rapport was established and maintained.

It was also intended at the beginning of the study that offenders would be interviewed within the prison. However, due to the controversies surrounding HIV in prison, permission was not obtained from prison authorities to enter the chosen prisons. For practical and ethical reasons, this study focused on HIV positive ex-offenders. Specifically, men were chosen as a sample because it was a convenient gender to access because the TAC worked mainly with HIV positive male offenders.

### **3.5 Data Collection Technique**

Semi-structured interviewing was used as a method for collecting data. This method of data collection was chosen as it established a one-on-one relationship between the interviewer and the participants. This did not restrict the participants during the research process. Indeed, this technique was chosen as the research questions could not be narrowly defined as this study reinforced the idea that the process of disclosure is complex. A list of issues and sub-questions that were considered relevant were guided by literature and were investigated further during the interview process. This technique was also useful during the interviewing process as it offered flexibility to the participant's stories hence did not restrict the participant's stories in any way. In other words, this method of collecting data allowed for subjective viewpoints and also led to a deeper interpretation of findings during data analysis. With this method of collecting data, the participants were able to speak about the phenomena under study in an open, free, and spontaneous manner. What was also important was that the researcher had to ensure that the interviews were balanced evenly between the research aims of the study as well as the free expression of the participants. Thus, during the interviews the researcher had to constantly decide when and how to support the participants especially when in – depth and sensitive issues such as safe sex and prison conditions were ventured into. By mediating the interview process, the semi-structured interviewing style was very useful as

it offered flexibility to the participant's accounts by not restricting them in any way. (Babbie & Mouton, 2001; Kvale, 1996).

The researcher's role during the interview process was to clarify the main issues as well as probe into the necessary issues about safe sex, disclosing to significant others, and the comparisons that participants made between prison life and being HIV positive. By doing this, the open style of semi-structured interviewing allowed the participants to relate their own experiences without being forced to take on a particular direction. This was useful as during the interviews questions did not follow a systematic order as participants had brought forward issues on their own. On their own, participants had decided on the structure of the interview by either talking about issues on prison conditions, the stigma that they had experienced or significant others. This highlighted that participants shared their experiences differently which made the semi-structured interview work more efficiently and captured the unique experience of each participant. The interview guide acted as a checklist that ensured all questions were answered irrespective of the ordering of the questions. The questions were derived from a variety of sources such as the Model of HIV disclosure decision-making and the literature review. Every answer was probed deeper in order to gain deep understandings of the broader issues. This method of collecting data was useful as it created a space whereby participants were able to add on issues that they felt were significant and personal during the process of disclosure. The interviews lasted between 60 – 90 minutes each. This type of interviewing was effective within the context of this study because it ensured a complete and in-depth investigation of the experiences from the perspective of these participants. In addition, semi-structured interviewing captured the uniqueness of the participant's shared experiences as well as experiences that they differed in (Babbie & Mouton, 2001; Kvale, 1996; Terre Blanche & Durrheim, 2002).

### **3.6 Instrument**

The instrument that was used in this study included a semi-structured interview guide (See Appendix 3). This interview guide was referred to during the interview as a guideline to the questioning. It consisted of issues that were covered during the interview



process. Questions were informed by the research objectives, Model of HIV disclosure, and some of the gaps that were found within the literature review.

### **3.7 Data Analysis**

Interpretative thematic analysis was used to analyze the data (Ulin, Robinson, Tolley & McNeil, 2002). Transcribed interviews with the participants were analyzed according to the Model of HIV – Disclosure Decision Making and the Disclosure Decision Making Model. Themes that emerged which were not highlighted in these models were also included during the data analysis stage. The following steps were completed

Step 1: Before transcription began, the tapes were listened to about 3 or 4 times in order to gain an overall understanding of the participant's words.

Step 2: The data was then transcribed.

Step 3: Immersion into the data was made possible by reading through the transcripts several times in order to capture the participant's words. At this stage the data was read in order to achieve an understanding of the participant's words rather than for developing themes.

Step 4: When coding of the data began, it was coded according to the Model of HIV disclosure decision-making as it informed the interview questions. Themes that dealt with the three stages of the DDM were coded. In addition, themes that dealt with the HIV – Disclosure Decision – Making model was also coded such as the role of significant others, the availability of significant others, relationship with significant others, and the temporal component. (See Appendix 5). Themes that also linked together or were similar in nature were formatted in tables and matrices for easier reading and analyses. (See appendix 6).

Step 5: All emerging themes that were not included within the theoretical framework were also analyzed. Coding was done manually as it created a more comprehensive

understanding of what the participants were saying.

Step 6: The data was then categorized into their respective themes.

Step 7: Some themes and sub-themes had to be merged because these themes were redundant and similar in nature. This led to a more summarized and synthesized version of the data analysis.

Step 8: The themes were then linked to describe the process of disclosure according to the emerging patterns.

### **3.8 Validity**

The credibility of the study was increased by ensuring that there was a strong correspondence between the participant's construction of social events and the way that the researcher had displayed their viewpoints. Plausibility of the study was ensured through the use of supportive evidence from the participant's accounts. In other words, the findings were grounded and substantiated by the data from the interviews. There were also thick descriptive accounts from the participants and more than one participant's narratives were included wherever similar experiences were found. The authenticity of the study was enhanced by displaying the varying viewpoints of the participants. To increase the dependability of the results the methodology of the study is consistent with the research question and design (Henning et al., 2003). Reflexivity was another technique used to ensure validity. During the interview process and the overall research process, the researcher had to be mindful of the ways in which being a young Indian woman who has never been in prison and is not HIV infected could cause barriers during the interview process. The researcher dealt with this by first fostering a trusting relationship telephonically before the interview and during the interview to overcome this barrier and be mindful of other barriers that may emerge. There were instances whereby my age, gender, race and cultural background was a bit problematic however it was dealt with by being flexible and being mindful of the participant. During the period of December 2007 and January 2008 the participants were contacted telephonically in order

to give participants an opportunity to include or exclude data. This made use of respondent validity. It's important to note that although participants had not added anything to the research, they had spoken about the challenges that they were currently facing. Participants spoke about how they were living in poverty-stricken conditions and how they were finding it difficult to obtain basic needs like food and shelter. Participants also felt that they provided thick descriptions of their experiences during the interviews (Flick et al., 2000; Henning et al., 2003;).

**3.9 Concluding paragraph:** The above methods that were used to conduct the study effectively dealt with most of the research objectives that were initially set out. In addition, by paying careful attention to the methodology, the interview aims were also met which is clearly shown in the results chapter that follows.

## CHAPTER FOUR

### FINDINGS

#### 4.1 Introduction

This chapter presents the results from the data analysis. Five main themes with subthemes have emerged which includes factors within the prison setting that influenced disclosure, the experience of VCT, the role of significant others and the strategies used during the process of disclosure. These themes emerged during the data analysis stage and engaged with the idea that the process of HIV disclosure involves active – decision making despite the challenges that ex-offenders have encountered.

#### 4.2 Prison conditions

The way in which participants described their experience of prison conditions shows how prison as an institution has contributed to the high rates of HIV/AIDS infections.

Participants made reference to overcrowding and sexual violence as major problems within prison. Participants were housed in cells with 60 other offenders although these cells could only accommodate 18. Due to overcrowding, the cycle of sexual violence was a result of seeking revenge and exerting authority. Consequently, if an offender was sexually assaulted, he will then continue to rape other offenders.

*P1: it is about 60 prisoners in one cell, that cell is made for 18 prisoners you are sharing one toilet, one bathroom one sink one TV those are the dynamics that you face while you are in prison and the worst part of it with me like life prisoners two years prisoners six month prisoners are both together in one cell, some are like behaving very rude....*

*P2: more particularly inside prison some of them the majority the rape cases inside, sodomy rapes some get infected because of rape. I got cases pending cases that are still people who were raped and they were infected while they were in prison. It has affected their disclosure because once you were sexually abused sometimes you feel like paying revenge that. I have seen I have shared information with some of the fellow inmates that have undergone that. I have seen that they feel like revenge.*

*P3: They become like themselves like gangster. They revenge it because they want to pass it on to others. Yes, in most cases these those offenders that sleep with other offenders are offenders who were sexually abused so it is like revenging. This thing is going on and on.*

Participants have alerted to the various channels in which the high rates of HIV/AIDS remains within prison. These factors range from the structure of the prison environment to the way in which power infiltrates the system.

### **4.3 Disclosure within prison: Place and Timeline**

Most of the participants had disclosed their HIV status to significant others in prison.

*P1: When I was behind the bars I told my mother, my sister, father and friends I told them that I am HIV positive.*

*P2: to the [New York] prison to check that I am HIV positive or not and then I am going there to [New York] prison I told the doctor for [New York] prison...*

The timeline for disclosure differed amongst the participants as it ranged between one to seven years.

*P1 :In 2000. Diagnosis was in 1994. So the rest of my community I told them in 2006 when I came out.*

*P2: I told my brother when I came out of prison in 2006 6th December. Now he knows about 10 months. Yes, it took me five years.*

*P3: ..it was five years later so I found out in 2002 and disclosed this year...*

Both place and the temporal component in which HIV disclosure occurred provides a clear indication on the prominent role that prison played during the process of disclosure. These findings further highlights that in spite of the circumstances that participants faced, they managed to disclose their HIV status.

#### **4.3.1 Reasons for disclosing in prison**

Social support from both significant others as well as the social workers within prison acted as a motivating factor for participants to disclose within prison. Participants agreed that the main reason that they had disclosed their HIV status after a long period of time

was due to the fear of losing support from significant others. Support from significant others was especially important because they were still in prison. In addition to this, participants also referred to the perilous conditions within prison, which contributed to their decision to disclose. Participants also witnessed other deaths within prison that led to participant's decision to disclose their HIV status.

*P1: My main concern was about I was going to loose the visits because I had to explain them while I was with them so that no whenever I am telling them while I am inside here they gonna say that is why you are going to die in prison so why are we worrying ourselves about visiting him so just leave him like that so that was what was my worry.*

*P2: The worst of it when you are coming out of prison you know sometimes to disclose you status you are looking to that problem of loosing your parents and like...*

*P3: First of all he told the social worker that I told him and then the social worker called me in about 30 minutes later the social worker called me in. Then I went in I saw on his face he was smiling and he shook my hand and I saw that he accepted everything. I think that the social worker gave him all the information...*

*P4: And then I saw what is happening in prison and said to myself hey I am not going to stay like that. It is hard to disclose. I spent a long time with them and I didn't want to disclose and then I told them but I saw the people that are sick ...*

*P5: But when I was in prison I saw many diseases that confused me. Like I saw this man he fell down and he only got up the after three days and he was blank. He forgot everything. He forgot his family.*

Participants outweighed the risk of loosing social support within prison with the potential benefits during the process of disclosure. By doing this, participants were motivated to disclose within prison because of the challenges that they faced on a daily basis.

#### **4.4 Methods of disclosure within prison**

The participant's had experienced disclosure within prison as both intentional and unintentional. Participants either had a choice in their decision to disclose or had encountered situations where their HIV status was compromised.

#### **4.4.1 Intentional disclosure within prison**

Participants had verbally and directly disclosed their HIV status to prison wardens, prisoners, and other offenders who were part of their support group.

*P1: I can never get that I am HIV positive I just tell my guards I say no I am HIV positive.*

*P2: It was some of my colleagues that we were we had undergone the training. When the Ugandans came into prison those people that we had undergone the training it was a training on training where we had to train other offenders on HIV/AIDS. Those are the people that I first disclosed my status to...*

*P3: I told the people that were together in the support group. I told them that I am HIV positive and wardens. There were also guys that I was staying with inside the cell that I told.*

The verbal and direct means of disclosure show again, how the availability of social support can enable the process of disclosure. Moreover, the complex nature of HIV disclosure shows how participants were able to disclose to other prison wardens although power and authority was asserted.

#### **4.4.2 Unintended means of disclosure in prison**

The structure of the prison environment compromised the participants HIV status largely due to the way in which the prison authorities had managed the ARV treatment, referred participants to social workers, and managed meals for the participant.

#### **Access to treatment and care**

Participants argued that other offenders became aware of their HIV status during cell inspections and by an alarm clock that was used to remind them to take their ARV's. In addition to this, participants also stated that they were moved to another cell block which was solely for offenders that are on ARV treatments.

*P1: sometimes there is this thing called the strip search where authorities will come to your section...and then they will turn everything upside down when you come back into there will be medicine that will be thrown all over and then prisoners will say How what's this tablets what's*

*these pills [ARV'S] and they are all over spitted all over tramped upon some are crushed*

*P2: And some of the prisoners will be Why you got this clock and automatically your status is disclosed. Everyday you have to take the treatment at 6 'o' clock and everyday it will ring at 6 'o' clock and then 60 of you in one cell the cell is very small and then they would ask what is this then you will see that they are running for their treatment.*

*P3: once you get to Medium 101 treatment [ARV'S] is only rolled out in Medium 100 and then now when this offenders date comes nearby for him to go for ARV treatment once the authorities in Medium 101 finds out that he is on treatment they will say NO, NO, NO go back go back, go back to Medium 100...So, it is an unconsented disclosure because now they will get to know.....*

### **Access to social workers & nutritional diet**

Participants also complained that the prison wardens had forced them to disclose their HIV status as it was the only way that they could access the social workers. Furthermore, each offender had to take a specific diet if they were HIV positive. Consequently, participant's had to keep a pink ticket that not only represented their diet, but also that they are HIV positive.

*P1: So the prison warden has to write down why you want to see the social worker so when you get to the social worker the social worker is aware that's where the problem starts because now you have to disclose to the prison warden and the prison warden not aware that you came through and it has happened alot of times, several times where you tell them the warden that you are HIV because of the HIV, he will start telling all the other prisoners about your status*

*P2: when you go there they will say hey milk and peanuts must come this side the other offenders will stay this side and then for TB they take them for 6 months after 6 months you are discharged and then for HIV it is one way and for others who were once with you in TB they ask you why are you not getting discharged. It's two years and you still taking peanuts that is where you have automatically disclosed. There are alot of these things, we have to deal with these things while we are still in prison.*

Within prison, the poor management and lack of accommodation for HIV positive offenders highlights the ways in which these offenders HIV status was compromised. The implications of this are that the prison system focuses more on rehabilitation rather



than the reality of HIV/AIDS.

#### **4.5 Experience of prison life overrides the experience of HIV**

When participants compared their HIV experience and prison experience, they argued that the prison experience was much more stressful and difficult to integrate into their life. However, participants also argued that the prison experience enabled them to disclose their HIV status.

*P1: I tell them no I never got across the HIV thing I just telling them about crime doesn't pay like to show them how so hard whenever you are committing yourself to crime so crime doesn't pay like me I told them like me I have been in prison....*

*P2: it has been a bit difficult because being in prison that is where I gained experience of disclosing my status and I gained confidence in myself and that is where I gained more information on HIV/AIDS. So it helped and that is where I learned to interact with negative people, people who are very rude, people who are diversified in their cultural backgrounds. That's why in one room you stay with 60 prisoners with different attitudes and different colors, different race some are gangsters...*

The emphasis on the prison experience by participants suggests that these participants are continuously dealing with their history of criminal activities and their HIV status. The difficulty with the integration of the prison experience implies that their identity was distorted due to the struggles that they faced while they were imprisoned.

#### **4.6 Experience of VCT**

Participants had described their experience of HIV testing in the following ways: their personal reasons for VCT, the actual process of VCT, and their reactions when they had received their test results. Overall, the process of VCT and reactions to the results were determined by the level of support that the participants had received from healthcare workers. As far as the reasons for taking the HIV test are concerned, it was determined by the circumstances surrounding the prison environment as most of the participants had undergone VCT within prison.

#### **4.6.1 Reasons for VCT**

Participants mentioned different reasons for undergoing an HIV test. Indeed, participant's decision to undergo a HIV test was largely influenced by the conditions of the prison environment. Specifically, participants had stated that HIV positive individuals received a special diet that consisted of peanuts and milk, hence they decided to test for HIV so that they would be able to receive the special diet. Participants had also witnessed HIV/AIDS related deaths within prison, which had reinforced their decisions to test for HIV.

*P1: I didn't take the test because I was sick. I was like as I told you I was looking for this peanuts to eat. Why are those people eating the peanuts so I was to eat this peanuts.*

*P2: When I see the people they got holes in the back I say to myself hey I also got HIV and I am going to end up like that man. Then I take the blood again I take the test again they say that I am HIV that is when I am starting to get pressure hey I am going to die....*

*P3: Things that I saw inside things that were happening inside. I saw people dying inside by that time then I was fit and having no problem and there I wasn't coughing anything that you can think that I am HIV positive other they didn't know that I was HIV positive but the things that I saw inside it makes me realise that I have to go and do another test.*

The influence of the prison environment is a central theme that was interwoven in the participant's decision to undergo VCT. Therefore, the prison environment needs to be re-evaluated in order to become an entry point for HIV diagnosis, treatment, care, and reintegration of offenders into the community.

#### **4.6.2 The process of VCT**

During the process of VCT, participants argued that the degree to which they had received adequate support and counseling from healthcare workers had affected the way that they experienced the HIV test. The participant's the provision of support and counseling by healthcare workers not only reduced the stress and trauma that the participant's experienced but also motivated the participant's in a positive manner. Most of the participants agreed that their process of HIV testing was a negative

experience as healthcare workers did not effectively conduct the pre- and post-test counselling stages.

*P1: When I went for the test the nurse that was there was not giving me enough counseling she was just told she just asked me can I take your blood I said ok. In McCords [the participant knew of his status before he went into prison at McCords Hospital]. She took the blood she didn't tell me for what she was taking the blood.*

*P2: Then the blood test came back and then I was HIV positive and then she told me that I must not join the other people who are HIV positive. But the nurse told me that some people they are alive with HIV and she told me you too you are also going to be alive.*

*P3: I told the doctor for Westville prison then the doctor sent me to the nurse to check then the nurse send me to the counselor, the counselor and then they check they counsel me and then they check me they called for those people that they were supposed to check me and then they check me and they found out that I am HIV positive but when they counsel me they didn't counsel me proper because the time they come and tell me they came with the results and after they gave me the results but they didn't counsel me after that yes they told me there is your results, you are HIV positive and after that I was shocked.*

In the above narrative, participants have outlined how healthcare workers mediate the process of VCT. The positive or negative attitudes of the healthcare workers directly affected the experiences of the participants.

#### **4.6.3 Reactions to the HIV diagnosis**

All participants had met the HIV diagnosis with negativity. Participants became distressed which was due to the fear of immediate death. Participants also began to question the time that they had to left to live.

*P1: I was like I couldn't believe it and I couldn't sleep that day and in the middle of the night I used to wake up and get those shocks and those feelings like I am going to die tomorrow. I couldn't sleep for a whole week thinking about those things that I am HIV positive how come, where did I get this thing from.*

The association between an HIV diagnosis and death arises from the various ways in

which these participants and society in general have encountered HIV/AIDS. The fear of an HIV diagnosis leads to an automatic negative reaction because there is a lack of exposure on how the disease can be effectively managed.

#### **4.6.4 Psychological adjustment to HIV/AIDS**

Clearly, religion had allowed participants to make sense of their experience as well as contributing to participants' acceptance of their HIV diagnosis. Furthermore, participant's interpretation of the Bible portrayed their belief in the idea that GOD had chosen them to carry the HI virus.

*P1: I'm the luckiest one because I'll even quote from the bible, the bible says that there are those days whereby there will be those cure of those diseases that diseases as the bible says of which from GOD, I must have this diseases so I had to fulfill that statement that GOD say's upon his prophet so as I have that uncured disease so I take it as a blessing as like whenever you are quoting from the bible in this things so you can say that that is the one that has the uncured disease you can say it so of which GOD says so I may be the luckiest one so how can I blame myself how can I be ashamed of being HIV positive of which I may not be HIV positive but GOD made me the one of showed me the example of what he said that is how I see HIV like that.*

*P2: I was keep on searching myself, making this introspection about this things but as time goes on I just told myself just be a man and handle everything because my time is there to go to die I will die...*

*P3: I can die with anything I can die in a car, I can die silently...want to die then GOD doesn't want me to die so I take it like that that is HIV/AIDS.*

The Bible was used as a means to which ex-offenders made sense of their HIV status as well as the whole concept of death. The availability of religious texts acted as a source in which ex – offenders accepted their HIV status.

#### **4.7 The role of significant others in disclosure**

Significant others played a prominent role throughout the participant's process of disclosure. Significant others had reacted both positively and negatively to the participant's disclosure and was primarily influenced by age and gender. Indeed,

participants also showed that their process of disclosure is ongoing as they mentioned significant others that they would like to disclose to in the future. Participants also spoke about the sense of ease and relief that they had experienced once they had disclosed their HIV status to significant others.

#### **4.7.1 Significant others that were disclosed too**

Participants had disclosed to a variety of social networks which included brothers, sisters, extended family, friends, and their partners.

*P1: My small brother, whose the one that I live with most so I told him and I disclosed my status....*

*P2: I only spoke to my brother and current girlfriend.*

*P3: My sisters and mother know, they all know at home.*

*P4: I disclosed to my family. My aunties, uncles, my neighbors, cousins.*

*P5: my small brother I saw him two months ago at the bus stop he lives in Claremont.*

*P6: My girlfriend, my family at home and fathers. My two sisters, my older one.*

Participants had chosen to disclose to significant others who had visited them during incarceration and had made contact with, upon release. This further points out to the importance that accessibility to significant others played during the process of disclosure.

#### **4.7.2 Responses by significant others**

Participants argued that significant others had responded both negatively and positively to the HIV disclosure. Participants stated that gender was the main reason for the differences in the responses of significant others.

#### **4.7.3 Negative responses by significant others**

Significant others had mainly responded with denial and disbelief to the participant's disclosure. Significant others reacted in this manner as they believed that the participants were physically healthy thus, they cannot be HIV positive. Specifically, it was the older and younger males that had reacted negatively as compared to the females. On the one hand, the older males stated that the participant's are not showing any evidence of nearing death and by labeling HIV as a 'thing'. On the other hand, the younger males responded by accounting for the participant's disclosure as a joke.

*P1: Then I told him that it was positive and then he said no you are lying how can you be positive so healthy he even touched my skin so healthy like this.*

*P2: It seems like my brother don't trust me because of the way that he looks at me because he got old roots he don't believe that what I am telling is true.*

*P3: Then he just said no you are not HIV positive, you don't have this thing.*

*P4: He was very shocked at the time. He took it as a joke. He said HIV positive....*

The differences in reactions between the older and younger generations are attributed to the widespread myths and misconceptions surrounding HIV/AIDS within society. Denial and the use of labels are common myths misconceptions that are used when significant others encounter an HIV diagnosis.

#### **4.7.4 Positive responses by significant others**

Essentially, the female members of the participant's social networks supported and motivated the participants to accept their HIV status. The females acted as a source of encouragement and were able to recognize the distress that the participants were experiencing. The positive responses from the females reduced the anxieties that the participants felt during the process of disclosure.

*P1: the females those are the people like every time I talk to them they sometimes they give me time and they listen to what I am saying it is only the men's now.*

*P2: Because they, when I got a problem to help me you see and to know that they will encourage me. When I got a problem they come and ask me what is wrong. Hey, I had to tell them about this disease. After that, I never think too much because hey I used to get stressed too much. But now when I tell them, I feel free now.*

*P3: I told my sisters because they used to ask me all the time what I was thinking because they were sitting in my room they come sometimes they give me some food and I told them I don't want food and then they will ask me hey why don't you want food what's the problem so I was very worried and then I decided to tell them.*

Evidently, females provide a stronger support system as well as a source of comfort. This is also typically, what society expects from females whereby, mothers and sisters have to play a nurturing role even within difficult situations.

#### **4.7.5 Current relationship with significant others that were disclosed too**

Participants argued that the disclosure of their HIV status has strengthened their relationship with significant others. Significant others are said to motivate, support and show more togetherness with the participants. In terms of the community, the participants now act as a source of information on issues related to HIV/AIDS.

*P1: We are living equal they don't say no you are HIV positive and HIV negative and you must do this and that no. They are supportive and even when I do good they tell me to keep on doing it.*

*P2: But the current community now people that didn't know me before they are good they have accepted my status. They always come to my room even in the late hours they want to know more. One lady she even phoned from Chesterville she is saying that her child is very sick I must just come and have a look at her then maybe I might know what is happening so those are the responses. So I help the community with awareness on HIV.*

*P3: I was sick they were for me and they helped me with many things taking me to hospital, doctors and I came right. And then I told them that I want to continue with my studies because I didn't finish it inside and then they promised me that if I want to do it it is up to me next year they will help me to study further. So ya you can say that they accepted me....*

The availability of information as well as education by the participants are factors that promoted significant others as well as the community to accept the HIV diagnosis. In some instances, the use of information and education diminished some of the barriers surrounding HIV disclosure.

#### **4.7.6 Outcomes of disclosure for the participants**

Participants felt less burdened after they had disclosed their HIV status to significant others. Moreover, participants had also reacted in a very suggestive manner as they

advised significant others to go for a HIV test. Specifically, after participants had disclosed to their partners, they began to negotiate safer sex practices within their relationship.

### **Reducing stress, feelings of relief**

It is generally agreed upon by all the participants that they felt a sense of relief and reduced stress levels after they had disclosed their HIV status. Participants also argued that they were able to overcome the burden of carrying the disease in effect they were able to share their HIV status with others. In addition, participants also argued that they were able to set an example because they were able to show significant others that they can survive with the disease.

*P1: But now when I tell them, I feel free now. I was stressed because I was thinking about being HIV positive. And I felt that I wasn't free. I felt a lot of fear as well.*

*P2: But I feel happy because when the people can see that I am HIV positive and I give the person the living hope. I give the person the living hope. When I tell people I am giving hope to myself and others and I can feel myself again.*

*P3: I was relieved, I was relieved because they were the first they are my first priority my family is my first priority and then my friends they become second.*

### **Advice to significant others about VCT**

Participants advised significant others to go for an HIV test, as they believed that having knowledge of one's status has the potential to lead a healthier lifestyle and exercise control over their lives. Interestingly, participants stated that partners that had a difficult time accepting the advice from the participants.

*P1: I advised her to go and she said that she would go and now she didn't go. She said she'll go she'll go and she keeps on saying ya, next week next week.*

*P2: I tell them you must go to the doctor to get a HIV test and they say no I am not going there they are screaming everything and say no so sometimes I....*



*P3: there are many many people that when I see them I talk to them and I ask them do you have a test and they say no, and I say why and they say no I am not going there I am worried. I say no you must go to the hospital and you can found out and the doctor he can monitor your situation.*

### **Negotiation of safe sex**

It was evident that the participants were able to negotiate safe sex with their partners. Participants also took it upon themselves to ensure that their partners were protected by either using a condom or by not having penetrative sex. Although the participants stated that they always had protected sex, some of partners were ambivalent as they wanted flesh-to-flesh contact.

*P1: It is a very difficult part, yes I am able now but it started very difficult because everytime when we negotiated the sexual part of it, she always tell me she always ask me is that going to be the thing for the rest of our life that is where we are getting stressed. That is where we get stressed out because now we no more enjoy natural as well so we feel she feels that it is no more natural because it is like taking a sweet with it's cover...*

*P2: as well that is what she always tell me and we look at the issue of having children as well we look at... and all that and that is the worst part that we are facing so we are no more enjoying sex.*

*P3: I say it how can now if we sleep we don't have a protected sex if you use a condom because sometimes she is sick sometimes I am sick sometimes if we are using a protected sex we can protect each other from the disease if we are sick we can use condom to protect us. But she doesn't worry about using the condom. She is right with the condom.*

Within a personal level, reducing stress, feeling a sense of relief, the advice given to significant others, and negotiation of safe sex points out that participants had a positive orientation towards disclosure. This shows evidence that participants felt little or no regret upon disclosure.

### **Significant others that the participants want to disclose too**

Participants had prioritized the need to disclose to mainly their children and mother.

*P1: Ya, for now because I can tell my mother, I got the most about the most problem about telling my mother about that...*

*P2: I know that there is a time that I have to tell her that I am sick but the time is not now. I want to her to I'll tell her maybe if she is 12 years I can tell her because at the moment she is doing grade 4 standard 3 ya or grade 5 maybe if she is in grade 8 when she is bigger.*

The difference in age appears to be another significant factor that suggests that the process of HIV disclosure is continuous. In other words, participants are still making decisions about those individuals that they would like to disclose to in the future.

#### **4.8 Factors that influenced disclosure**

Participants referred to both factors that motivated disclosure and factors that acted as barriers to disclosure. After participants had disclosed their HIV status, they also spoke about the advantages and disadvantages of disclosing their HIV status.

##### **4.8.1 Factors that motivated disclosure**

The fear of death, trust and the relationship with significant others were seen as important reasons that motivated participants to disclose their HIV status to significant others. Participants also argued that because significant others had knowledge about HIV/AIDS, it increased their motivation to disclose. Another important factor that motivated participants to disclose was their personal readiness to disclose.

#### **The fear of death and trust**

Participants had experienced a sense of urgency to disclose their HIV status as they argued that if they passed away in prison then significant others would have been aware that their death was caused by HIV/AIDS. Another important factor was that participants had a trusting relationship with significant others thus it enabled them to disclose their status.

*P1: I had to tell my brother because if I die in prison because they were not giving us ARV'S the drugs inside prison then I thought that it was the best idea that I disclose to my brother because if I die then my brother will know exactly what had happened that led to my death.*

*P2: He is that character which I do trust because I'm the one who raised him up. Because he is*

*my younger brother so I raise him up I know everything about him I make him strong for me he is youngest so he just become older when he is putting his trust on me so whenever I am telling him I am making him stronger..*

### **Relationship with significant others**

The extent to which participants perceived the strength of their relationship with significant others, influenced their decision to disclose. This implies that the stronger the relationship, the more participants were motivated to disclose.

*P1: There is no such thing because he is the one that told me that my mother wouldn't accept that I am HIV positive because our older brother too had it and so that is the real problem so I just found that this man is so mature. I said no I can tell him everything he is the one that ask me if I feel right I said no there is nothing wrong.*

*P2: He sounded so positive that is why I said he give me some strong words that I can get from the mature man because I keep those words for me even now today I do like those words.*

### **Positive role-modeling and self-motivation**

From a personal perspective, participants stated that positive role-modeling and self-motivation contributed to their decision to disclose their HIV status. Participants stated that although they did not have individuals to set an example for them, they believe that it is their responsibility to be positive mentors for others. Self-motivation was also an important factor that influenced disclosure as it personally motivated the participants to disclose their HIV status by accepting it themselves.

*P1: I was doing on my own so it's like that so whenever you got someone who is a mentor from you do as he say's so you must keep doing accordingly even now I see everything that is going out.*

*P2: Don't ever let yourself sick because then if you let yourself sick you wouldn't be able to disclose your status. It is so easy to disclose your status but you have to make sure that you level your calms whenever you want to disclose...*

*P3: you must be positive. You must do things with a proper plan. You can't just do things with no plan. You must do things that are positive if you are HIV positive.*

*You calm down so you stay longer because HIV is killing no one and many people with HIV they survive.*

### **Readiness to disclose**

Participant's readiness to disclose their HIV status was determined by the circumstances surrounding prison life as well as the support that they received from significant others. Overall, all the participants were ready to disclose their HIV status as they felt that they had a responsibility to disclose to significant others.

*P1: I was actually I was ready to disclose although I was having those elements which are my barriers to disclose my status*

*P2: Up until 2005, that is where I was ready that's where I was like really really ready.*

*P3: I was ready at that time because in my mind when I disclose I can say that when I disclose because of those people who are in denial or who go and check their blood or whatever and who they know they are positive that is problem. When I was in prison I was ready that time because of the experience I get in prison and because of what I saw in prison what I saw in prison I remind my mind when I was in prison...*

Through these narratives, it is outlined that participants were continuously outweighing the risks against the benefits of disclosing their HIV status. In some instances, although the fear of death is characterized as a negative factor, participants had used it to motivate them during the process of disclosure.

### **4.8.2 Barriers to HIV disclosure**

Culture and tradition, the age of significant others, witnessing the consequences of other individual's disclosure and accessibility to significant others contributed to non-disclosure.

#### **Culture and traditional medicine**

Participants argued that their cultural values and belief systems made it difficult for them to disclose their HIV status. This is on the grounds that the older members of their families advised the participants to take traditional medicine as a form of treatment for HIV/AIDS. In effect, participants took the traditional medicine to satisfy the older

members of their families.

*P1: they know they are willing to learn and they like not too much on the traditional part of the culture that is why it is easy for them to understand and to learn but my father's the older the elders they very stereotype they like believe in the traditional herbs, they belief in all the muti's, the zulu medicines and if you tell them about this scientific things they don't want to hear about it.*

*P2: My uncle when he was visit me at Westville I told him that I am HIV positive them too they got the mind that the bejane is going to help he said that hey even if you are HIV positive it is ok you got bejane. Bejane is helping everyone outside. I said ok I am HIV positive. Don't be angry and don't be afraid I am going to bring you the bejane before I come out I do the training when I do the training they keep on counseling me I hear about how the bejane is killing people.*

*P3: when I came out my father says no I must take out all the bad luck coz being in prison is bad luck, I must take out the bad luck so he gave all the medicines I must do I couldn't oppose my father...*

The nature and reality of HIV/AIDS is such that the cultural and traditional systems that the individual is embedded in influences the process of disclosure. The participant's description of their culture and tradition shows that in some instances culture and tradition lays the foundation to which participants encounter HIV/AIDS. The issue raised in these findings needs to be included more efficiently within HIV/AIDS campaigns.

### **Age of Significant others**

According to the participants, the age of significant others had hindered their ability to disclose their HIV status. On the one hand, participants felt that their children were too young to disclose their HIV status because they would not be able to understand the implications of being HIV positive. On the other hand, participants felt that they were unable to disclose to their mothers because they were concerned about their mother's health.

*P1: Because I stayed 9 years or 10 years in the institution so you see he still is a kid I do care for him but me and his mother we are trying to say that he is still young we mustn't tell we must keep*

*on doing the good for HIV but we mustn't facing it straight you see both of us are HIV positive you know maybe it is going to affect him in school or what we are trying to do everything right we are keep on talking to him about HIV we make him learn a lot about HIV.*

*P2: Even my mother I didn't tell her because my mother is too old. She can be shocked you see. You see my mother I didn't tell her because she is too old. She doesn't know about this disease because she is from the olden era. But then when I told my sister and asked hey how can I tell my mother she said hey my mother can die if I tell her you.*

### **Understanding the implications of disclosure through significant others**

Participants were reluctant to disclose their HIV status because they feared that they would be in a similar situation as other individuals who disclosed their HIV status. Participants had been aware of situations where individuals faced death due to the disclosure of their HIV status.

*P1: People what are they going to say therefore if they do something so funny like they did because she just told them that she is HIV positive throw the stones over her.*

*P2: This former hero that is HIV positive Dlamini Phato there was men who were parking at the workshop for her after her of which they throw stones over her and then she died because she told them that she was HIV positive. They kill her like that because of HIV status because....*

### **Accessibility of significant others**

The extent to which participants had access to significant others affected the participant's decision to disclose. All participants had limited access to significant others when they were an offender and an HIV positive offender.

*P1: You know from the period of five years being diagnosed after I find out about my status, they were not behind me they were not supporting me even in prison you know even the physical support you know coming to prison, coming to see me often. They were not coming to see me that is why I got sick in all cases and that is why I was shy about my status.*

*P2: Hmm, my brother but unfortunately he passed away last month. My brother was the first guy that I disclosed my status to. [Hmmm], in fact while I was in prison I lost my mother, my grandfather, my father also passed away last month also my brother. So before I could disclose to*

*them, I only spoke to my brother and current girlfriend. Those are the only persons that I have disclosed my status too.*

The age of significant others, encountering other HIV positive individuals, and accessibility to significant others shows how the process of disclosure occurs in a context that is driven by the role – played by significant others. Furthermore, these barriers indicate that disclosure also occurred due to their exposure to other HIV positive individuals. Even though participants had limited access to significant others during incarceration, their decision to disclose their HIV status was largely defined by their sense of urgency.

#### **4.8.3 Perceived advantages of disclosure**

Participants argued that they disclosed their HIV status to significant others so that they would receive basic needs from them. Furthermore, participants also stated that through disclosure they were able to become more actively involved within their community.

##### **Disclosure driven by basic needs**

One of the main reasons that participants chose to disclose their HIV status was so that significant others could provide them with financial and material support.

*P1: That other three one they didn't tell me nothing but they hear what I say and they told me that if I have something that I need then I can tell them like the issue was working where I needed the money to go to the hospital because everytime I go to King George Hospital and King Edward.*

*P2: the reason why I disclose to them was that I didn't want to hide to hide this because at the end of the day they will find out and then they will ask me why I didn't inform them maybe they will help me someday you know what it is like money, treatment those diet things to keep myself healthy so I was not prepared to hide those things.*

*P3: I had to inform them if they come and visit me they can bring me those fruits because there is no fruits there where I was so they assisted me with all those things. And also they have the sympathy for what I was going through inside bars.*

### **Being actively involved in the community**

Within their respective communities, the participants have taken on an active role due to their disclosure of HIV/AIDS. Participants are currently involved in their community clinics and are educating, motivating, encouraging and advising other members in the community about HIV/AIDS. Participants were motivated to be part of the education programmes in the clinics because they were part of educational programmes within prison and at TAC.

*P1: He in our location there is a clinic which is a community clinic of which in schools they like to invite them just to let them know about the HIV because of the scholars are the one that are dying left and right so they like them to be apart of their progress against HIV/AIDS...*

*P2: I go an teach the community about HIV/AIDS and when it comes to my family they don't even want to concentrate, they don't even want to listen to me.*

*P3: currently within my community I have disclosed because my current activities is to go to clinics and educate people about HIV/AIDS and in most cases some people they come to my house later on and then I have to share more and more until I have to disclose my status. I have disclosed too many people around the community.*

### **Significant others that are also infected**

It became evident that the participant's HIV disclosure became a channel through which they became aware of significant others infection of HIV/AIDS and sexually transmitted infections (STIs). Therefore, participants became a source of information and provided support and guidance that assisted significant others to manage the disease.

*P1: STI's some of my families some of them were experiencing the STI's so when I told them at a later stage not the first time after the conversation then one of my fathers took me out and we went for walk and he kept on asking me about this STI's and I suddenly realized that he had a STI.*

*P2: These girls in my community. One told me they have no support but they are working but in some families they work but there is a stigma.*

*P3: Even in my family there are people that are HIV positive. Because I suspect my sister because*



*she always participate in this what I am doing. She want to participate she want to join the infected group talk about HIV always when I am explaining something she didn't show that she is scared she just keep quiet.*

It can be viewed from the above, that the role that support played during the participants' process of disclosure has extended to material and financial support. In addition, it is also apparent how participants have utilized their HIV experiences to educate significant others on the disease itself. This finding proposes that participants were able to use their experiences, their knowledge, and information to guide their process of re – integration into their communities in some way.

#### **4.8.4 Perceived disadvantages of disclosure**

Stigma is the underlying reason that participants gave as a negative consequence of their HIV disclosure. Stigma existed within their social networks and mainly within their families. Furthermore, what was significant was that participants also spoke about stigma in relation to being both an HIV positive individual and an ex-offender.

##### **Stigma from significant others**

Participants had faced isolation, rejection and criticism from significant others when they had disclosed their HIV status. Participants had also been told directly about the negative effects that their disclosure had on the family.

*P1: you see the people outside they are criticizing the people that are HIV positive. I hear when you are talking sometime when you are next to the people sometime they are making something very bad, you hear that they don't like the people that are HIV positive. They are criticizing so...*

*P2: I hugged him and I saw him pushing me away because he didn't have information about HIV/AIDS. He says no, no, no don't hug me yet, I want to talk to you seriously...*

*P3: they are all at your house all my fathers and they say ya son come here and then they ask me why like now you are embarrassing us in the entire community like you are saying that in the whole family you are the person that is HIV positive.*

*P4: it like now you are no more a human it is someone who you treat like a dog you see that is*

*why most people are dying like ants. You see in the manner that they are not even in that state they can die but because the background is treating them like dogs.*

### **Stigma within prisons**

Participants had faced the most extreme forms of stigma within the prison by other offenders and prison wardens. Stigmatization was so demeaning that participants had to change cells and even contemplated suicide. In addition, participants also stated that there was a risk involved whenever offenders wanted to go for an HIV test because the prison wardens would become aware of their test results and stigmatize them.

*P1: They will wash everything I touch the sink, the toilet shacks the shower after I bath they would always wash it maybe with jik with omo with a scrubbing brush. Hey that was the worst part, that was the worst part. I had to change the section....that is where I had a piece of mind stigmatize not only by prisoners even by prison wardens as well. The prison wardens were like go away, you are HIV positive, get out from here. Don't come close to me. You know they would be negative, their negativity....*

*P2: I was sick I was dying I didn't know that I was going to survive that is why I said hey with this HIV I must talk that is what was in my head but it was hard because of stigma coz of the stigma.*

*P3: because sometimes when you go into the shower or in the toilet or the bathroom they start swearing you about the same things. They will say this and that don't come near me. Then they isolate you after that, you feel like you are lost. You feel like killing yourself at that stage. I used to experience that alot.*

*P4: And also many prisoners will not volunteer to go for a test because of stigma. More particularly the issue of how the prison wardens will handle you the results as well.*

### **Stigma as an HIV positive ex-offender**

Participants argued that they face a double burden as they are stigmatized because they are HIV positive as well as an ex-offender.

*P1: it is a double burden on our necks and shoulders that we need to tackle because hey it is a big problem. The community they don't accept us now citizens as now people who have served what we have done ya there is two problems now the stigma of HIV and being in prison.*

*P2: you are coming into community where you did the wrong things people know you as a criminal and then you come back with a stigma of you are HIV positive, ex- offender you are not working you did maybe a serious crime maybe you murdered somebody amongst the community.....*

*P3: and you went to prison you come out you are going to face all those things people don't want to associate with you even when you are serving children at the shop they say look out for Mike if you see that particular person you must run away and you see children walking away and now you like for the first three months I had that problem. The first three months when I was in the community I had that problem people are keeping away even children are running away from me. And in most cases those people that you left some of them are dead some that are alive they don't want to accept you.*

Due to the double – bind nature of the participant’s identity as an offender and being HIV positive, stigma permeated throughout the participant’s experiences within prison and upon release. In other words, stigma exerted itself within prison and continued once the participant was released due to negative ways in which significant others viewed the disease.

#### **4.9 Strategies of disclosure**

Participants had utilized indirect and direct strategies when they decided to disclose their HIV status. On the one hand, direct strategies imply that participants verbally disclosed their status primarily due to their own personal choice. On the other hand, indirect strategies imply that participants used the media or journals to mediate the process of disclosure.

##### **4.9.1 Direct Strategies of disclosure**

Participants had directly disclosed their HIV status in two main ways. Firstly, participants had confirmed their disclosure to significant others who had found out through indirect means such as the media and significant others. Secondly, participants had used empowerment as an important tool to disclose their HIV status.

## **Empowerment and knowledge**

Participants had utilized empowerment and knowledge about HIV/AIDS as a way to disclose their HIV status. Participants argued that the reason behind this was that misconceptions about HIV/AIDS were dispelled.

*P1: So before we go straight to that topic about my HIV status of which he saw on the notes that he wrote so we were just talking about empowering telling him....*

*P2: First of all I told him that you know life's changing the world always changes [hmmm], and then I started introducing the topic of HIV/AIDS... and then I started telling him the side effects and sicknesses, infections and opportunistic infections related to HIV and the death and I even showed him the statistics about how many people are infected in KwaZulu - Natal alone and then we started talking more about that, the modes of transmission ..... and then he wants to know how was your result that was his second question. Then I said again that I am HIV positive then I even took out the results and showed him...*

## **Verbal disclosure**

Participants had verbally disclosed their status to significant others. In some instances although significant others had found out about the participant's HIV status through indirect means such as the media and through significant others, the participants had also confirmed their HIV status when asked by significant others.

*P1: he came across that statement that was saying I found myself HIV positive while I was in prison and so that thing keep his mouth shut then when I came across him he ask me is that I saw the real thing I said what thing about your HIV status I say ya ya ya you saw that I am HIV positive....*

*P2: first time I told him that I am not HIV positive, I was just in the programme but I told him no we will talk about that later. Then I went in I saw on his face he was smiling and he shook my hand and I saw that he accepted everything.*

Essentially before participants disclosed their HIV status, empowerment and knowledge and verbal disclosure was used as mediating techniques to directly disclose their HIV

status. In other words, when significant others were selected for disclosure, the participants did not immediately disclose rather used positive thinking and the media.

#### **4.9.2 Indirect Strategies of disclosure**

Participants had chosen three methods to disclose their HIV status which included: the media, writing in their personal journals and using significant others to disclose their HIV status. Significant others became aware of the participant's HIV status through a TV program whereby they had openly disclosed their HIV status. Participants also said that during incarceration, prison experiences and HIV/AIDS were documented in their personal journals. When participants were ready to disclose, these journals had been placed where significant others could find them. Moreover, when participants disclosed their HIV status to significant others, they also told significant others to disclose their status to other family members.

*P1: Others have seen me in a program that was conducted by CHMT - Inkoba - beat it. It is the Community Health Media Transit.... through the media, TV a lot of people they know but some they don't believe me they think that I am just making a program.*

*P2: writing everything in terms of motivating so he [the participant's brother] came across that statement that was saying I found myself HIV positive while I was in prison and so that thing keep his mouth shut then when I came across him he ask me is that...*

*P3: they [his family members who he had disclosed to first] must tell it was as I called I wanted them to deliver this message to all my family so that they can know that if anything happens I'm sick...*

For these participants, the use of indirect strategies appeared to be the most secure and comforting means to disclose their HIV status. This further highlight that participants managed to utilize the opportunities that were provided to them especially when they appeared in the media.

#### **4.10 Summary of Findings:**

It is evident from these findings that the prison conditions, social support and the availability of significant others influenced the process of disclosure amongst HIV positive ex-offenders. These findings are also illustrative of the idea that the process of disclosure occurred on many complex levels namely within prison, with significant others, and within the community. Indeed, HIV disclosure for this particular target group is an indication of how ex-offenders disclosed their HIV status to overcome the sense of urgency that they experienced due to the prison conditions.

## **CHAPTER FIVE**

### **DISCUSSION**

#### **5.1 Introduction**

HIV disclosure is a process that unfolds across time and depends on the context in which it takes place. HIV disclosure is also a complex phenomenon that is influenced by various enabling as well as hindering factors (Norman et al., 2007). Indeed, the process of HIV disclosure amongst ex – offenders within a prison setting adds more layers of complexity.

#### **5.2 Theoretical Formulation**

The process of HIV disclosure amongst HIV positive ex-offenders should be viewed as a multi – faceted process that emphasizes the interconnected roles of the individual, the social environment, as well as their social networks. This has also been clearly articulated by (Derlega et al., 2004) in the Model of HIV Disclosure decision–making. According to this model, the process of disclosure is relational as the process of disclosure is informed, shaped, and structured by significant others. This model also highlights that when individuals are ready to disclose their HIV status, they do possess agency over the depth and content of information when HIV disclosure occurs (Derlega et al., 2004). However, the dynamics and complexities of the ways in which power relations has infiltrated through the process of disclosure for ex-offenders has not been captured by this model and will be discussed in this chapter.

##### **5.2.1 Stage 1: The presence of a situational cue or environmental factor**

According to stage one of the DDM, the prison context is a representation of a situational cue or environmental factor that increases the chances of disclosure (Omarzu, 2000). In essence, an ex-offender’s decision to undergo both VCT and HIV disclosure was largely influenced by their encounters with HIV-related deaths within prison. (Burchell et al., 2003), has also focused on how HIV – related deaths within the prison system has reinforced decisions to undergo VCT for an ex - offender. Moreover, factors that facilitated HIV disclosure within

prison amongst ex-offenders are as follows: Firstly during incarceration, ex-offender's lacked financial and material support thus had decided to disclose their HIV status in order to achieve material and financial stability. Similar findings were found in a study by (Wadell & Messeri, 2006). Secondly, ex-offenders were motivated to disclose their HIV status as they wanted significant others to know the cause of death if they passed away while they were imprisoned. Thirdly, the prison context was also viewed as a significant factor that also promoted the ex-offender's readiness to disclose their HIV status. In other words, ex-offender's readiness to disclose underlies how their decision was influenced by the circumstances surrounding prison life. Therefore, these factors showed the highest degree of relief from distress, social rewards, and social approval which combine to highlight the situational cues that make HIV disclosure possible (Omarzu, 2000).

### **5.2.2 Stage 2: The selection of a significant other and strategy**

According to the results of this study, the selection of female significant others augments stage two of the DDM. This study and other similar research, has also made reference to the stark difference when disclosure occurs within the African and Western context. Within the African context, HIV disclosure is more family-orientated whereby the family is disclosed to more often than the friends (Kalichman et al, 2003). This is also consistent with this study whereby the ex-offenders chose to disclose to family and only disclosed to friends upon release from prison. Specifically, in terms of gender it was found in South African literature and in this study that African men mainly disclose to mothers, sisters or daughters first before disclosing to other members of the family. This has also been identified in Western literature as individuals chose to disclose their HIV mainly to female members. It can be argued then that female members are perceived to show more positive responses, display more compassion, and have a tendency to take on more of a motherly role (Kalichman et al., 2003, Shehan et al., 2004; Skogmar et al, 2006; Wadell & Messeri, 2006). In comparison, this study showed that male members reacted negatively to the HIV disclosure



through their portrayal of denial and disbelief. Reacting with denial and disbelief emerges from the idea that since ex-offenders appeared to be physically healthy then they are not HIV positive (Serovich et al, 2008). Furthermore, the selection of a strategy is also part of stage two of the DDM. While indirect methods focused on utilizing the media and writing in personal journals, direct methods included a verbal disclosure. These methods have also been identified within literature by Campbell et al. (2005). However, ex-offenders also used empowerment as a strategy to disclose their HIV status.

### **5.2.3 Stage 3: Breath, duration, and depth of the disclosure.**

Within this stage, HIV disclosure was orientated towards a short and simple disclosure. The depth, breadth, and duration of HIV disclosure could have been influenced by the presence of social workers as well as time constraints in visiting hours (Omarzu, 2000). In addition, many of the ex-offenders disclosed to significant others in the presence of a social worker. The breath, duration, and depth could have also been influenced by the indirect strategies of disclosure whereby significant others had been aware of the ex – offender’s status through these means.

## **5.3 Factors that contributed to VCT**

During incarceration, ex-offenders faced a double – bind situation whenever they opted to undergo VCT and when they lacked personal choice during the process of HIV disclosure. The findings from this study show that ex-offenders were encouraged to undergo VCT so that they would receive a diet that consisted of peanuts and milk. As reflected by the participants, this diet was viewed as being more nutritional as compared to the average meal that was provided in prison. Conversely, the prison context compromised the confidentiality of the HIV status as ex-offenders had to carry a pink ticket and eat a special diet that consisted of peanuts and milk. The pink ticket and the dietary recommendation denoted that which offender was HIV positive. Similarly, a study by (Sifunda et al., 2006) confirmed that HIV positive offenders receive a special

“AIDS – diet” which compromised their HIV status. This adds another dynamic to the process of HIV disclosure as the confidentiality of the ex – offender’s HIV status was further compromised as a result of random prison cell inspections, the use of alarm clocks as well as exploitation by prison wardens rather than access to ARV treatment and care. Literature has also pointed out that disclosure is motivated by accessibility to healthcare treatment in the form of ARVs (Wadell & Messeri, 2006). A study by (Skogmar et al., 2006) has also mentioned that individuals disclosed their HIV status as they found it difficult to conceal their HIV positive status either because their health was deteriorating or because they were receiving ARV treatment. Within this study, the ex-offender’s HIV status was compromised during prison cell searches whereby their ARV treatment was exposed. Moreover, since an alarm clock was provided as a reminder to ex-offenders for ARV treatment, it also alerted other offenders to those individuals who are HIV positive. The exposure of the offenders HIV status within prison without consent has reinforced ways in which privacy rights of offenders HIV status has not been protected adequately at the level of both government and correctional services. This view is also expressed by Sifunda et al. (2006), as they argue that prevention programmes continue in spite of being riddled with issues of confidentiality and inadequate resources. Essentially, the imbalances of power has asserted itself whenever the ex-offenders’ HIV status was compromised due to the structural norms within prison and through the prison wardens who exercised their power. This provides a clear indication that prison as an institution has dominated ex-offender’s process of disclosure. In effect, it is limited to think that ex-offender’s had complete agency over their process of HIV disclosure as it was informed by those who wield power.

### **5.3.1 VCT and HIV disclosure**

Ex-offenders within this study as well as in other literature has also argued that the lack of resources outside of prison, VCT being offered as a free service within prison and its convenient nature, are factors that influenced VCT (Kacanek et al., 2007). In contrast to the decisions that prompted VCT, the ex-offenders within this study argued that VCT was a negative experience for them as healthcare workers did not effectively conduct the pre-test and post-test counseling stages.

In other words, ex-offenders became aware of their HIV status only because they reached the post-test counseling phase of VCT. (Sifunda et al., 2006) has also emphasized the importance of healthcare workers and their role in their study on VCT and prison. It can be concluded then that within the context of this study, the institutional norms of prison have highlighted that HIV disclosure and VCT are two processes that are intertwined with each other. The reason for this is that both VCT and HIV disclosure occurred within prison because of the devastating circumstances surrounding incarceration (Burchell et al., 2003).

#### **5.4 Prison conditions**

This study offers significant implications for the role that prison conditions played in the ex-offender's experience of HIV disclosure. Throughout this study, a central theme that was interwoven was the idea that prison experience was a key defining feature of the ex-offender's process of HIV disclosure. This theme was further supported by the ex-offender's mentioning that the prison experience was so unsettling that it was difficult to integrate into their lives, and it took precedence over being HIV positive. The availability of drugs, the prevalence of gang-related behaviors, boredom, the reality of both consensual and coercive sexual activities, and overcrowding are factors that not only combined to increase the high rates of HIV/AIDS within prisons but also contribute to the ex-offender's stressful experiences within prison. This study has shown that prison cells were overburdened by a population of 60 offenders, yet it could only accommodate 18. It was also found that the cyclical nature of sexual violence is a direct consequence of seeking revenge and asserting authority over other offenders. These factors were also identified in studies by (Belenko et al, 2004; Goyer, 2002; 2003; Luyt, 2003; Singh & Maseko, 2006). Moreover, this study also highlights the urgent need for implementing educational programs as a medium to curb the high rates of HIV/AIDS within prison. The need for educational programs was also supported by organizations such as WHO and UNAIDS but is severely lacking due to limited research and knowledge surrounding prison life and HIV/AIDS (Goyer, 2003).

## **5.5 Community mobilization**

The differences between African and Western literature suggests that African literature move towards collective mobilization (Jewkes, 2006) and community involvement. South African studies have highlighted that HIV positive individuals chose to become more actively involved in the community. Community support is pivotal to an individual's decision to disclose their HIV status. When individuals disclose their status to the community, it is argued that it leads to more positive role-modeling and gaining support from the community. One study in particular has argued that when individuals disclose their HIV status within their respective community, it motivated the use of condoms and reduced the high rates of casual sex (Norman et al. 2007). The findings from this study also showed similar results on community involvement as an outcome to HIV disclosure. HIV disclosure also became a channel to which ex-offenders provided information, support, and guidance to significant others who were either infected with STIs or HIV/AIDS (Holt et al, 1998; Latkin et al., 2001). Within the context of this study, the cultural scripts referred to by Derlega et al. (2004), has reinforced its relationship to HIV disclosure. This was evident by the fact that ex-offenders took traditional medicine as a way to satisfy the elders within their families. Therefore, culture and tradition also provides differences between the Western and African worldviews.

## **5.6 Social support**

Current literature has also argued that the availability of social support by significant others is viewed as an enabling factor that influenced the decision to disclose (Derlega et al., 2004; Parsons et al., 2004; Wong et al., 2009). Within this study, social support existed within the level of the prison environment as well as with significant others. Interestingly, ex-offenders lacked social support and had limited access to significant others when they were both an offender and an ex-offender. In other words, even though ex-offenders did not receive the social support they chose to disclose. Thus, this contrasts with previous studies that argue that individuals will disclose their HIV status due to a high degree of social support. Support from social workers and being involved in a support group were also key elements that drove the process of disclosure for ex-

offenders. Furthermore, during the process of disclosure ex-offenders also took the opportunity to provide knowledge about HIV/AIDS to significant others and to challenge and remove any myths and misconceptions that significant others may have. Therefore, these factors provide an indication that HIV positive individuals including ex-offenders disclose their HIV status in order to improve their quality of life and become long-term survivors. A trusting relationship and the perception of having a strong relationship with significant others facilitated HIV disclosure in this study. From this then we can argue that HIV positive ex-offenders undergo a process of weighing the costs against the benefits (Clerigh, et al., 2008; Chandra, et al., 2003; Norman et. al., 2007; Paxton, 2002; Wong et. al, 2009). While social support was identified as a factor that leads to psychological adjustment (Pakenham & Rinaldis, 2001); this study has linked religion to psychological adjustment and acceptance of HIV/AIDS. The availability of religious texts within prison became the foundation to which ex - offenders made sense of their experience. Religion not only assisted participants with acceptance of their HIV status but also showed participants that the concept of death is inevitable and individuals can die by different means and methods and HIV is one of them. This allowed the ex-offenders to develop meaning – making systems that in turn lead to a sense of integrating their HIV status into their lives.

### **5.7 The role of intimate relationships**

There remains some uncertainty surrounding whether disclosure leads to safe sex practices. On the one hand authors such as (Ateka, 2006; Marks & Crepaz, 2000; Mohamed & Kissinger, 2006; Serovich & Mosack, 2003; Skogmar et al., 2006) have stated that disclosure does lead to safe sex practices. On the other hand, disclosure is a source of communication that does not necessarily enhance safe sex practices. In this study, ex-offenders mentioned that disclosure was motivated by a sense of personal responsibility and the fact that they were in a committed relationship. This has also been indicated by previous research because individuals will disclose their HIV status if they are in committed relationships rather than casual relationships (Biaran et al., 2006; Camblin & Chimbwete, 2003; Duru et al., 2003; Mola et al., 2006; Simoni & Pantalone, 2004). Some of the benefits included reducing the burden of carrying the disease and the

negotiation of safer sex. However, the ongoing nature of disclosure also outlines the fact that individuals still consider and are deciding upon other individuals that they would like to disclose to. Within this study, ex-offenders wanted to disclose to mothers and their children which captures the notion that disclosure does not reach an endpoint.

Specifically, literature has pointed out that parents do not disclose their HIV status to their younger children due to the child's level of maturity, emotional, psychological stability, and their ability to make sense of disclosure (Ostrom et al., 2006). Similarly, this study has also alerted that ex-offenders did not disclose their HIV status as they felt that their children were too young.

### **5.8 Stigma and discrimination**

Stigma and discrimination are arguably the most common factors that were identified as barriers to HIV disclosure. Studies have shown that disclosing one's HIV status to significant others may not only lead to rejection from these networks but also disrupt broader social networks (Hereck et al., 2002; Petrak et al., 2001; Norman et. al., 2007; Medley, et al., 2004; Maman et al., 2003;; Parsons et al., 2004; Skinner & Mfecane, 2004; Wong et al., 2009). This was also consistent in this study however ex-offenders also faced stigma within prison. Ex-offenders faced the most extreme forms of stigma within prison from other offenders and prison wardens. More importantly, ex-offenders faced stigma as an HIV positive individual and an ex-offender. Indeed, the history of an individual's HIV infection, the circumstances of their life, and the context of the individual's life are factors in combination that influences the process of HIV disclosure (Serovich, 2000). Historically and circumstantially being an HIV positive ex-offender has led to the marginalization of this particular group. In other words, marginalized communities such as drug-users and homosexuals cannot be understood without their history of drug-addiction or sexual orientation, similarly an HIV positive ex-offender cannot be understood without their history as an offender. Being part of a marginalized community suggests that behaviors such as drug-addiction, being homosexual as well as being an offender are examples of "deviant behaviors" that goes against societal norms and standards. Non – disclosure amongst ex-offenders existed due to the fear that their history of incarceration and HIV will be revealed within society thus face double

stigmatization (Simoni & Pantole, 2004; Zea, Reisen, Poppen & Diaz, 2003; Latkin et al., 2001; Parsons, et al., 2004; Cloete, Simbayi, Kalichman, Strebels, Henda, 2008). For the HIV positive ex-offender their history is defined by their high-risk behaviors before and during incarceration. Before ex-offenders are incarcerated, it has been identified by research that they engage with multiple partners, have unprotected sex, are substance-abusers, are poverty-stricken, unemployed and under-educated (Braithwaite & Arriola, 2003). During incarceration, ex-offenders face sexual violence, and drug – abuse. These behaviors are considered outside of the societal norms and values. Overall, the process of HIV disclosure involves an oscillation between achieving the benefits such as social support and liberation, or the risk of being stigmatized and ostracized. The paradoxical nature of HIV disclosure focuses on the fact that even though the individual is at risk of stigma and discrimination, it can reduce stress levels which in turn lessens burden for the individual (Paxton, 2000).

### **5.9 Concluding comments**

From this discussion, it is evident that HIV disclosure amongst ex – offenders is a multi – faceted process that takes place within different times and with different significant others. The cultural and traditional backgrounds of these participants undoubtedly capture the diversity of HIV disclosure, which is especially relevant within a South African context.

**CHAPTER 6**  
**CONCLUSION**  
**RECOMMENDATIONS**  
**&**  
**LIMITATIONS**

**6.1 Conclusions**

In conclusion, this study documents how the prison context is a social environment in which HIV positive ex – offenders experience the infectious nature of HIV/AIDS, VCT, and their process of HIV disclosure. In addition, HIV disclosure is a process that cannot solely be defined as a single event in the ex-offender’s experiences. It is cyclical in nature as it involves active decision – making, weighing the costs against the benefits, and dealing with the outcomes of HIV disclosure. Indeed, being an HIV positive individual and an ex-offender has infiltrated through the process of disclosure as both identities are interconnected with other and are not void of meaning. What this implies is that for these participants there is never an endpoint to their process of disclosure. Thus, HIV disclosure is an ongoing process as the HIV positive ex-offender is embedded in various networks and relationships with significant others. It shows that to some extent ex-offenders were able to exercise active decision - making when they disclosed to significant others. What is particularly important is that we can find that the participant’s experience of disclosure is influenced by the level of support that the participants received both within and outside of the prison environment. While HIV/AIDS initially leads to debilitating effects on the ex-offender, it later becomes an experience of acceptance, self – motivation and positive role – modeling.

Although ex-offenders were able to exercise agency over their process of HIV disclosure, it is also vital to note that it also occurred where there are imbalances in power. This also highlights that those who control power within the prison context exercise their authority and practice within a politically – structured agenda. In addition, HIV disclosure amongst ex-offenders takes place at multiple levels such as within prison, community and with significant others. In effect, HIV disclosure is continuous and is complex in nature.



To assume that HIV disclosure is uniform simplifies the process of disclosure. In sum, HIV disclosure is crucial for ex-offenders to gain insight into available prevention interventions.

## **6.2 Recommendations:**

Based on this study, these are some of the recommendations:

### **6.2.1 Prison Conditions and VCT:**

More research needs to be conducted on the extent to which South African prisons have played a role in the proliferation of HIV/AIDS. There also needs to be more efficient services provided at Government level as the government cannot ignore the crisis that is currently affecting South African prisons. Wellness programmes need to also be implemented in order to identify which prisoners are in need for ARV treatment and care. Government needs to acknowledge that prison should be the entry point for curbing HIV infection rates. In addition, South African prisons need to do regular HIV and CD4 count testing as well as tests for opportunistic infections. This implies that there needs to be a drastic change to the prison infrastructure.

### **6.2.2 Re - integration into the community and HIV disclosure**

South African prisons also lack programmes which can assist offenders with developing skills in order to re-integrate themselves into the community as well as promote HIV disclosure. Upon release, offenders are merely placed into the community without appropriate skills on how to adapt to their new environment and progress in this environment. Offenders should be empowered so that they will be able to deal with stigma and discrimination when they are released from prison. Offenders also need to be provided with skills on how to disclose, when, as well as the possible benefits of disclosure upon release from prison.

### **6.2.3 Access to ARV treatment and Care, employment opportunities**

Future research also needs to look at whether ex-offenders have access to ARV treatment and should also alert ex-offenders on how they can promote their care as well as their physical, psychological and emotional well – being. Moreover, programmes should be implemented on how ex-offenders can take advantage of employment opportunities.

### **6.2.4 Significant other's perspective**

Although it is important to gain insight from the HIV positive ex-offender, it is also valuable to understand how significant others are managing the HIV disclosure as well as the status of an ex-offender. This was not within the scope of this study which needs to be explored further.

### **6.2.5 Policy**

It is recommended that policy should be implemented within prison that addresses issues around HIV disclosure. More importantly, guidelines should be established on how prisons can protect the offender's HIV status. This implies that all the necessary prison authorities as well as relevant stakeholders should be involved in maintaining confidentiality of testing for HIV in prisons. It can be suggested that all offenders should be given a nutritional diet irrespective of their status. In addition, the roll – out of ARV's within prison should be done more systematically and this can be addressed by more efficient healthcare staff within prison. This can be made possible by involving stakeholders such as non – governmental organizations, prison authorities, DCS.

### **6.3 Limitations:**

The extent to which participants did disclose their HIV status to their partners and effectively negotiate safe sex is unknown as participants may have stated they were able to negotiate safe sex based on being part of the TAC and being positive role-models within their communities. In addition, being an Indian female could have also been problematic as participants may have felt discomfort when exploring issues around safe sex, intimacy, and prison life. Furthermore, if permission had been granted the research

could have taken place within the prison setting but at the time of the study it was not possible.

Research has also indicated that there is no evidence of a specific theory – related to HIV disclosure. This poses many limitations with the model of HIV disclosure decision – making. Firstly, it has ignored how VCT influences the process of disclosure. Secondly, it has ignored the socio-political and socio-economical context in which disclosure and the individual are embedded. By doing this, the way in which power influences HIV disclosure is downplayed. Thirdly, it reduces HIV disclosure as a simplistic process how the individual goes about doing a cost – benefit analysis, is ignored. Finally, it can be solely adopted for HIV positive individuals and not marginalized communities such as ex-offenders.

## REFERENCES

- Abadi` a – Barrero, C.E. & Castro, A. (2005). Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil. *Social Science & Medicine*. 62 (5), 1219 – 1228.
- Allen, A. (2001). *The law for psychotherapists and counsellors*. Somerset West. Inter- Ed Publishers.
- Arthur, S. & Nazroo, J. (2003). *Designing Fieldwork Strategies and Materials*. In Ritchie, J. & Lewis, J. (eds). *Qualitative Research Practice*. London: Sage Publications.
- Ateka, G. (2006). HIV status disclosure and partner discordance: A public health dilemma. *Public Health*. 120 (6), 493 – 496.
- Babbie, E. & Mouton, J. (2001). *The Practice of Social Research*. South Africa: Oxford University Press.
- Batterham, P., Rice, E. & Rotheram – Borus, M.J. (2005). Predictaors of Serostatus Disclosure to Partner Among Young People Living with HIV in the Pre – and Post – HAART Eras. *AIDS and Behavior*. 9 (3). 281 – 287.
- Beckwith, C.G., Cohen, J., Shannon, C. & Raz, L. (2007). HIV testing experiences among male and female inmates in Rhode Island. *Correctional Health*. 17 (9). 459 – 465.
- Belenko, S., Langley, S., Crimmins., S., & Chaple, M. (2004). HIV risk behaviors, knowledge and prevention education among offenders under community supervision: A hidden risk group. *AIDS Education & Prevention*. 16 (4). 1 – 16.
- Biaran, A., Taylor, G., Blake, B.J., Akers., Sowell, R. & Mendiola, R. (2007). A model of HIV disclosure: Disclosure and types of social relationships. *Journal of the American Academy of Nurse Practitioners*. 19 (5). 242 – 250.
- Booyens, K., Hesselink, A. & Mashabela, P. (2004). Male Rape in prison: an overview. *Acta Criminologica*. 17 (3). Unisa: Department of Corrections Science. 1 – 13.
- Braithwaite, R.L. & Arriola, K.R.J. (2003). Male prisoners and HIV prevention: A call for action ignored. *American Journal of Public Health*. 93 (5). 759 – 763.
- Burchell, A.N., Calzavara, L.M., Myers, T., Schlossberg, J., Millson, M., Escobar, M., Wallace, E. & Major, C. (2003). Voluntary HIV Testing among inmates: sociodemographic, behavioral risk, and attitudinal correlates. *Journal of Acquired Immune Deficiency Syndromes*. 32, 534 – 541.

- Campbell, C., Foulis, A., Maimane, S. & Sibiyi, Z. (2005). "I have an evil child in my house": stigma and HIV/AIDS management in a South African community. *American Journal of Public Health*. 95 (5). 808 – 815.
- Camlin, C.S. & Chimbwete, C.E. (2003). Does knowing someone with AIDS affect condom use? An analysis from South Africa. *AIDS Education & Prevention*. 15 (3), 231 – 244.
- Chandra, P.S., Deepthivarma, S. & Jairam, K.R. (2003). Relationship of psychological morbidity and quality of life to illness – related disclosure among HIV – infected persons. *Journal of Psychosomatic Research*. 54 (3), 199 – 203.
- Cleirgh, C.O', Ironson, G., Fletcher, M.A., Schneiderman, N. (2008). Written emotional disclosure and processing of trauma are associated with protected health status and immunity in people living with HIV/AIDS. *The British Psychological Society*. 13, 81 – 84.
- Cloete, A., Simbayi, L.C., Kalichman, S.C., Strebel, A. & Henda, N. (2008). Stigma and discrimination experiences of HIV – positive men who have sex with men in Cape Town, South Africa. *AIDS Care*. 20 (9), 1105 – 1110.
- Corona, R., Beckett, M., Cowgill, B.O., Elliot M.N. Murphy, D.A., Zhou, A.J., Schuster, M.A. (2006). Do children know their parent's HIV status? Parental reports of child awareness in a nationally representative sample. *Ambulatory Pediatrics*. 6 (3). 138 – 144.
- Daftray, A., Padayatchi, N., Padilla, M. (2007). HIV testing and disclosure: a qualitative analysis of TB patients in South Africa. *AIDS Care*. 19 (4), 572 – 577.
- Day, J.H., Miyamura, K., Grant, A.D., Leeuw, A., Munsamy, J., Baggaley, R. & Churchyard, G.J. (2003). Attitudes to HIV voluntary counseling and testing among mineworkers in South Africa: will availability of antiretroviral therapy encourage testing? *AIDS Care*. 15 (5), 665 – 672.
- Department of Correctional Services. (2009). Incarceration levels as on the last day 2009/07. <http://www.dcs.gov.za/WebStatistics/>. Accessed on October 2009.
- Department of Health. (2000). Rapid HIV Tests and Testing HIV and AIDS & STD Directorate. <http://www.doh.gov.za/search/index.html>. Accessed on 22nd August 2007.
- Department of Health. (2005). The South African National HIV Survey, 2005 <http://www.avert.org/safricastats.htm>. Accessed on 22nd August 2007.
- Deng, R., Li, J., Sringeriyuang, L. & Zhang, K. (2007). Drug abuse, HIV/AIDS and stigmatization in a Dai community in Yunnan, china. *Social Science & Medicine*. 64 (8), 1560 – 1571.

- Derlega, V.J., Winstead, B., Greene, K., Serovich, J., & Elwood. (2004). Reasons for HIV disclosure/non - disclosure in close relationships: testing a model of HIV - disclosure decision making. *Journal of Social and Clinical Psychology*. 23 (6). 747 – 767.
- Flick, U., von Kordorff, E. & Steinke, I. (2000). *A Companion to qualitative research*. London: Sage Publications.
- Ford, K., Wirawan, D.N., Sumantera, G.M., Sawitri., & Stahre, M. (2004). Voluntary HIV Testing, Disclosure, and Stigma among Injection Drug – Users in Bali, Indonesia. *AIDS Education and Prevention*. 16 (6). 487 – 498.
- Fylkesnes, K., (2000). Consent for HIV counseling and Testing. *The Lancet Perspectives*. 356.
- Ginwalla, S.K., Grant, A.D., Day, J.H., Dlova, T.W., Macintyre, S., Baggaley, R. & Churchyard, G.J. (2002). Use of UNAIDS tools to evaluate HIV voluntary counseling and testing services for mineworkers in South Africa. *AIDS Care*. 14 (5), 707 – 726.
- Goyer, K.C. & Gow, J. (2001). Confronting HIV/AIDS in South Africa prisons. *Politikon*. 28 (2), 195 – 206.
- Goyer, K.C. (2002). *HIV/AIDS in prison*. [www.iss.co.za/Pubs/Monographs/No79/Chap1.pdf](http://www.iss.co.za/Pubs/Monographs/No79/Chap1.pdf). Accessed 23rd August 2007.
- Goyer, K.C. (2003). *HIV/AIDS in prison: problems, policies and potential*. Institute for Security Studies. Pretoria: Brooklyn Square.
- Grinstead, O.A., van der Straten, A. & The Voluntary HIV - 1 Counseling and Testing Efficacy Study Group. (2000). *AIDS Care*. 12 (5), 625 – 642.
- Grinstead, O., Seal, D.W., Wolitski, R., Flanigan, T., Fitzgerald, C., Nealey – Moore, J., Askew, J. & The Project START Study Group. (2003). HIV AND STD Testing in prisons: perspectives of In – prison service providers. *AIDS Education and Prevention*. 15 (6), 547 – 560.
- Herek, G.M., Capitanio, J.P. & Widaman, K.F. (2002). HIV – related stigma and knowledge in the United States: Prevalence and trends, 1991 – 1999. *American Journal of Health*. 92, 371 – 377.
- Henning, E., Van Rensburg, W. and Smit, B. (2003). *Finding your way in qualitative research*. A beginner's guide. Pretoria: Van Schaik's Publishers.
- Holt, R., Court, P., Vedhara, K. Nott, H., Holmes, J. & Snow, M.H. (1998). The role of disclosure in coping with HIV infection. *AIDS Care*. 10 (1). 49 – 60.

- Hutchinson, P.L. & Mahlalela, X. (2006). Utilization of voluntary counseling and testing services in the Eastern Cape, South Africa. *AIDS Care*. 18. (5), 446 – 455.
- Jewkes, R. (2006). Beyond Stigma: social responses to HIV in South Africa. *The Lancet*. 368.
- Kacanek, D., Eldridge, D., Nealey – Moore, J., MacGowan, R.J., Binson, D., Flanigan, T.P., Fitzgerald, C.C., & Sosman, J.M. (2007). Young incarcerated men's perception of and experiences with HIV testing. *American Journal of Public Health*. 97 (7). 1209 – 1215.
- Kalichman, S.C., DiMarco, M., Austin, J., Luke, W. & Difonzo, K. (2003). Stress, social support and HIV – status, disclosure to family and friends among HIV – positive men and women. *Journal of Behavioural Medicine*. 26 (4). 315 – 331.
- Kalichman, S.C. & Simabyi, L.C. (2008). HIV testing attitudes, AIDS stigma and voluntary HIV counseling and testing in a black township in Cape Town, South Africa. *Sex Transmission Infection*. 79, 442 – 447.
- Kenyon, C., Heywood, M., & Conway, S. (2001). Mainstreaming HIV/AIDS: Progress and challenges. *South African Health Review*. 69 – 172.
- Kirshenbaum, S.B. & Nevid, J. (2002). The specificity of maternal disclosure of HIV/AIDS in relation to children's adjustment. *AIDS Education and Prevention*. 14 (1). 1 – 16.
- Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. Thousand oaks: Sage Publications.
- Latkin, C.A., Knowlton, A., Forman, V.L., Hoover., D.R., Schroder, J.R., Hachey, M. & Celentano, D.D. (2001). Injection Drugs users' of HIV seropositive status to network members. *AIDS and Behaviour*. 5 (4).
- Liyasu, Z., Abubakar, I.S., Kabir, M. & Aliyu, M.H. (2006). Knowledge of HIV/AIDS and attitude towards Voluntary Counseling and Testing among adults. *Journal of the national Medical Association*. 98 (12). 1917 – 1922.
- Luyt, W.F.M. (2003). Harm and Reduction in Prisons. *Acta Criminologica*. 16 (2). 88 – 106.
- Maman, S., Mbwambo, J.K., Hogan, N.M., Weiss, E., Kilonzo, G.P., & Sweat, M.D. (2003). High rates and Positive Outcomes of HIV – Serostatus Disclosure to sexual partners: Reasons for Cautious Optimism from a Voluntary Counseling and Testing Clinic in Dar es Salaam, Tanzania. *AIDS and Behavior*. 7 (4). 373 – 381.

Marks, G. & Crepaz, N. (2001). HIV – positive men’s sexual practices in the context of self – disclosure of HIV status. *Journal of Acquired Immune Deficiency Syndromes*. 27 (1). 1 – 7.

Medley, A., Garica – Moreno, C., McGill, S. & Maman, S. (2004). Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother – to – child transmission programmes. *Bulletin of the World Health Organization*. 82 (4), 299 – 307.

Minnie, M., Prins, A., van Niekerk, E. (2002). The role of prison gangs as precipitating agent in the spread of HIV/AIDS in South African prisons with special emphasis on socio – cultural factors. *Acta Criminologica*. 15 (1). Unisa: Department of Corrections Science. 51 – 62.

Mohammed, H. & Kissinger, P. (2006). Disclosure of HIV Serostatus to sex partners in rural Louisiana. *AIDS Care*. 18 (1), 62 – 69.

Murphy, D.A., Roberts, K.J. & Hoffman, D. (2005). Young children’s reactions to mother’s disclosure of maternal HIV positive serostatus. *Journal of Child & Family Studies*. 15 (1), 39 – 56.

Mwamburi, D.M. Dladla, N., Qwana, E., Lurie, M.N. (2005). Factors associated with wanting to know HIV results in South Africa. *AIDS Patient Care and STDs*. 19 (5). 518 – 525.

Niehaus, I. (2002). Renegotiating masculinity in the South African lowveld: narratives of male – male sex in labor compounds and in prisons. *African Studies*. 61 (1). 77 – 96.

Njagi, F. & Maharaj, P. (2006). Access to voluntary counseling and testing services: Perspectives of young people. *South African Review of Sociology*. 37 (2). 113 – 126.

Norman, A., Chopra., M., Kadiyala., S. (2007). Factors related to HIV Disclosure in 2 South African Communities. *American Journal of Public Health*. 97 (10). 1775 – 1781.

O’ Brien, M., Richardson – Alston, G., Ayoub, M., Magnus, M., Peterman, T., & Kissinger, P. (2003). Prevalence and correlates of HIV serostatus disclosure. *Sexually Transmitted Diseases*. 30, 731 – 735.

Obermeyer, C.M. & Osborn, M. (2007). The utilization of Testing and Counseling for HIV: A review of the social and behavioral evidence. *American Journal of Public Health*. 97 (10). 1762 – 1774.

Okonkwo, K.C., Reich, K., Alabi, A., Umeike, N. & Nachman, S.A. (2007). An evaluation of awareness: attitudes and beliefs of pregnant Nigerian women toward Voluntary Counselling and Testing for HIV. *AIDS Patient Care and STDs*. 21 (4). 252 – 260.



- Omarzu, J. (2000). A Disclosure Decision Model: Determining how and when individuals will self - disclose. *Personality and Social Psychology Review*. 4 (2), 174 - 185.
- Ostrom, R.A., Serovich, M., Lim., J.Y., Mason., T.L., (2006). The role of stigma in reasons for HIV disclosure and non – disclosure to children. *AIDS Care*. 18 (1), 60 – 65.
- Pakenham, K.I. & Rindalis, M. (2001). The role of illness, resources appraisals and coping strategies in adjustment to HIV/AIDS: The direct and buffering effects. *Journal of Behavioral Medicine*. 24 (3). 259 – 279.
- Parker, R. & Aggleton, P. (2003). HIV and AIDS – related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*. (57), 13-24.
- Parsons, J.T., VanOra, J., Missildine, W., Purcell, D.W. & Gomez, C.A. (2004). Positive and negative consequences of HIV disclosure among seropositive injection drug users. *AIDS Education and Prevention*. 16 (5). 459 – 475.
- Paxton, S. (2002). The paradox of public disclosure. *AIDS Care*. 14 (4), 559 – 567.
- Petrak, J.A., Doyle, A.M., Smith., A., Skinner, C. & Hedge, B. (2001). Factors associated with self – disclosure of HIV serostatus to significant others. *British Journal of Health Psychology*. 6, 69 – 79.
- Pronyk, P.M., Kim, J.C., Makhubele, M.B., Hargreaves, J.R., Mohlala, R., Hausler, H.P. (2002). Introduction of voluntary counseling and rapid testing for HIV in rural South Africa: from theory to practice. *AIDS Care*. 14 (6), 859 – 865.
- Ritchie, J., Lewis, J. & Elam, G. (2003). Design Issues. In Ritchie, J. & Lewis, J. (eds). *Qualitative Research Practice*. London: Sage Publications.
- Roberts, K.J., Grusky, O. & Swanson, A. (2008). Client encounters in alternative HIV testing sites: counsellor’s perceptions and experiences. *Behavioral Medicine*. 34. 11 – 18.
- Sauka, M. & Lie, G.T. (2000). Confidentiality and disclosure of HIV infection: HIV – positive person’s experience with HIV testing and coping with HIV infection in Latvia. *AIDS Care*. 12 (6), 737 – 743.
- Serovich, J.M., Brucker, P.S. & Kimberley, J.A. (2000). Barriers to social support for persons living with HIV/AIDS. *AIDS Care*. 12 (5), 651-662.
- Serovich, J.M., Esbensen, A.J., Mason., T.L. (2007). Disclosure of Positive HIV Serostatus by Men who have sex with Men to Family and Friends Over Time. *AIDS Patient Care and STDs*. 21, 492-500.

Serovich, J.M., Kimberly, J.A., Greene, K. (1998). Perceived Family Member Reaction to Women's Disclosure of HIV – positive Information. *Family Relations*. 47, 15 – 22.

Serovich, J.M. & Mosack, K.E. (2003). Reasons for HIV disclosure or non - disclosure to casual sexual partners. *AIDS Education and Prevention*. 15 (1). 70 – 80.

Serovich, J.M., Mason, T.L., Bautista, D. & Toviessi, P. (2006). Gay men's report of regret of HIV disclosure to family, friends, and sex partners. *AIDS Education and prevention*. 18 (2). 132 – 138.

Serovich, J.M., Oliver, D.G., Smith, S.A. & Mason, T. (2005). Methods of HIV disclosure by Men who have sex with men to casual sexual partners. *AIDS Patient Care & STD's*. 19. 823 – 832.

Serovich, J.M., Lim, J., Mason, T.L. (2008). A Retest of Two HIV Disclosure Theories: The Women's Story. *Health & Social Work*. 33 (1). 23 – 31.

Serovich, J.M. (2000). Helping HIV- positive persons negotiate the disclosure process to partners, family members and friends. *Journal of Marital and Family Therapy*. 26 (3). 365 – 372.

Shehan, C., Uphold, C., Bradshaw, P., Bender, J., Arce, N., Bender, B. (2005). To tell or not to tell: men's disclosure of their HIV - positive status to their mothers. *Family Relations*. 54 (2). 184 – 196.

Sifunda, S., Reddy, P.S., Braithwaite, R., Stephens, T., Ruiters, A.C., van den Borne, B. (2006). Access point analysis on the state of health care services in South African prisons: A qualitative exploration of correctional health care workers, and inmates' perspectives in KwaZulu – Natal and Mpumalanga. *Social Science & Medicine*. 63, 2301 – 2309.

Simbayi, L.C., Kalichman, S.C., Strebel, A., Cloete, A., Henda, N. & Mqeketo, A. (2008). Stigma and discrimination experiences of HIV – positive men who have sex with men in Cape Town, South Africa. *AIDS Care*. 20 (9), 1105 – 1110.

Simoni, J. & Pantalone, D. (2004). Secrets and safety in the age of AIDS: Does HIV disclosure lead to safer sex? *Topics in HIV Medicine*. 12, 109 -118.

Singh, A. & Maseko, T.W. (2006). The protection of prisoners' rights to healthcare services in South African law: is it adequate? *Journal of Judicial Science*. 31 (1), 81 – 100.

Skogmar, S., Shakely, D., Lans, M., Danell, J., Anderson, R., Tshandu, N., Oden, A., Roberts, S. & Venter, W.D.F. (2006). Effect of antiretroviral treatment and counselling on disclosure of HIV – serostatus in Johannesburg, South Africa. *AIDS Care*. 18 (7), 725 – 730.

Skinner D. & Mfecane, S. (2004). Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of Social Aspects of HIV/AIDS*. 1 (3). 157 – 164.

Stein, J.A. & Nyamathia, A. (2000). Gender differences in behavioral and psychosocial predictors of HIV test and return of test results in a high risk population. *AIDS Care*. 12 (3), 343 – 356.

Solomon, S., Kouyoumdjian, F.G., Cecelia, A.J., James, R., James, L. & Kumarasamy, N. (2006). *AIDS & Behavior*. 10 (4). 415 – 420.

Terre Blanche, M. & Durrheim, K. (2002). (eds). *Research in practice: Applied methods for the social sciences*. Cape Town: University of Cape Town Press.

Ulin, P.R., Robinson, E.T., Tolley, E.E. & McNeil, E.T. (2002). Qualitative Methods: The field guide for applied research in sexual and reproductive health. *Family Health International*. USA: North Carolina.

UNAIDS. (2006a). Counseling and testing - Technical Policies of the UNAIDS Programme. [http://www.unaids.org/en/Policies/Testing/HIVtesting\\_UNAIDS\\_policies.asp](http://www.unaids.org/en/Policies/Testing/HIVtesting_UNAIDS_policies.asp). Accessed on 22nd August 2007.

UNAIDS. (2006b). HIV Data. [http://www.unaids.org/en/HIV\\_data/](http://www.unaids.org/en/HIV_data/). Accessed on 22<sup>nd</sup> August 2007.

UNAIDS. (2007). HIV/AIDS in African Prisons. [http://www.unodc.org/documents/hiv-aids/Africa%20HIV\\_Prison\\_Paper\\_Oct-23-07-en.pdf](http://www.unodc.org/documents/hiv-aids/Africa%20HIV_Prison_Paper_Oct-23-07-en.pdf). Accessed 22<sup>nd</sup> October 2007.

van Dyk, A.C. & van Dyk, P.J. (2003). “What is the point of knowing?”: Psychosocial barriers to HIV/AIDS Voluntary Counseling and Testing programmes in South Africa. *South African Journal of Psychology*. 33 (2), 118 – 125.

Van de Perre, P. (2000). Commentary: HIV voluntary counseling and testing in community health services. *The Lancet*. 356.

van Rooyen, H., Strode, H. & Heywood, M. (2005). Scaling up HIV testing in resource constrained settings: debates on the role of VCT and routine ‘opt – in’ or opt – out’ HIV testing. *The South African Journal of HIV Medicine*. 45 – 48.

Wadell, E.N. & Messeri, P.A. (2006). Social support, disclosure, and use of antiretroviral therapy. *AIDS Behavior*. 10 (3), 263 – 272.

Walmsley, R. (2007). World Prison Population list.  
<http://www.kcl.ac.uk/depsta/law/research/icps/downloads/world-prison-pop-seventh.pdf>.  
Accessed 22<sup>nd</sup> October 2007.

Winstead, B.A. & Derlega, V.J., Barbee, A.P., Sachdev, M., Antle, B. & Greene, K. (2002). Close relationships as sources of strength or obstacles for mothers coping with HIV. *Journal of Loss and Trauma*. 7, 157 – 184.

Wong, L.H., Van Rooyen, H., Modiba, P., Richter, L. Gray, G., McIntyre, Schetter, C.D. & Coates, T. (2009). Test and Tell: correlates and consequences of Testing and Disclosure of HIV status in South Africa. *Acquired Immune Deficiency Syndrome*. 50 (2). 215 – 222.

World Health Organisation. (2007). HIV Testing and counselling: the gateway to treatment, care and support.  
[http://www.who.int/3by5/publications/briefs/hiv\\_testing\\_counselling/en/](http://www.who.int/3by5/publications/briefs/hiv_testing_counselling/en/). Accessed on 22<sup>nd</sup> August 2007.

Zea, M., Reisen, C., Poppen, P., Diaz, R. (2003). Asking and telling: communication about HIV status among Latino HIV - positive gay men. *AIDS and Behaviour*. 7 (2). 143 – 152.

## **APPENDIX TWO**

### **SEMI – STRUCTURED INTERVIEW**

1. Who have you disclosed too?
2. How did you go about disclosing?
3. How long after you found out that you were HIV positive did you disclose?
4. When you were ready to disclose how accessible were the people you wanted to disclose to?
5. Why did you disclose to them?
4. What did you say to them when you disclosed?
6. What was the reaction of the person that you have disclosed too?
7. Have you disclosed to anybody else like for example the community, family?
8. Who else would you like to disclose to?
9. What needs to happen before you could disclose to this person?
10. What advise would you give other people that are in a similar position around disclosure of their HIV status?
11. What role, if any, has the circumstances surrounding your infection affected your decision on disclosure?
12. How did you feel after you had disclosed?
13. Describe your relationship with the person you disclosed to currently?

## APPENDIX THREE

### A: Informed Consent:

## CONSENT TO PARTICIPATE IN RESEARCH

**RESEARCH PROJECT: Exploring the process of HIV disclosure amongst HIV positive male ex- prisoners in KwaZulu - Natal.**

1. We are asking you to take part in this research study so that we can understand
  - Who you have disclosed to so far.
  - How you went about disclosing your HIV status.
  - The reactions from other individuals upon hearing that you were HIV positive.
  - The reasons that you decided to disclose.
  - If you disclosed to anyone else.
  - The thoughts that you had before disclosure.
  - How has the circumstances surrounding your infection affected disclosure.
2. The research will be conducted by a student from the University of KwaZulu – Natal/
3. If you agree to participate in this study, you will be asked questions about how you are experiencing your life currently.
4. If you decide not to take part in the study, you can withdraw at any stage from the study.
5. All information will be held confidential and you will be protected by the use of pseudonyms.
6. You will not be forced to take part in the study and your participation is voluntary.
7. You may ask any questions about the study. Professor Yvonne Sliep is available on 031-2607982 or [sliepy@ukzn.ac.za](mailto:sliepy@ukzn.ac.za) to answer any queries that you may not think of now.
8. Signing your name at the bottom means you agree to participate in this study.

I, ----- agree to participate in the study investigating your current life experience as well as the dominate narrative that emerges during the research process.

I understand that my participation is entirely voluntary and that I can withdraw at any time. If I have any questions after today I can call Professor Yvonne Sliep on 031-260 7982 or [sliepy@ukzn.ac.za](mailto:sliepy@ukzn.ac.za)

-----  
Participant signature                      Date

-----  
Researcher signature                      Date

## APPENDIX FOUR

### TRANSCRIPT

A: Interviewer

B: Interviewee

A: I would just like to start off by saying that whatever you will be saying will be held strictly confidential. I will not be using your name when I am going to write up the report of this study. I will be changing your name. I will be using pseudonyms. Let me tell you a little bit about the study. This study will look to understand how you went about disclosing your HIV status to the people in your life. It will also look at how you went about it, what was actually said as well as how you felt afterwards.

B: Ok, no problem

A: Do you have any questions for me before we start?

B: No, I just want to know [hmmm] that this eh programme that we are starting now, do you think at the end will it assist eh will it improve the life of prisoners inside or ex-offenders in any way. How would you think it can improve our lives or the situations that many offenders and ex-offenders are facing.

A: I think that the first step that this study is going to do is to look at you know is to look at disclosure, this is the first step by merely doing the study it will be the first step towards contributing to more knowledge about HIV positive ex-offenders. But I can't promise you anything on what it is going to do but we can take this information and show the important parties on what is needed and how we can assist your'll.

B: I will appreciate that because there is a lot of things that are happening around offenders and ex-offenders in terms of HIV/AIDS that we have started that not even the government itself they are not even taking steps, they are not it seriously so that we are calling anyone who has some sort of intervention to eradicate the current situation for ex-offenders.

A: Ya, I think that it is a problem especially if the government does not assist with curbing the epidemic and it is also very difficult because of the lack of resources and the way that society views being an HIV positive ex-offender.

B: Ya.

A: Ok, can I begin with the questions if you don't have anymore questions.

B: Ya, that's fine.

A: Being HIV positive, who have you disclosed to so far?

B: Hmm, my brother but unfortunately he passed away last month. My brother was the first guy that I disclosed my status to. [Hmmm], in fact while I was in prison I lost my mother, my grandfather, my father also passed away last month also my brother. So before I could disclose to them, I only spoke to my brother and current girlfriend. Those are the only persons that I have disclosed my status too.

A: So, it is your brother from your immediate family and your current girlfriend.

B: Yes, and the other part is that some people, some of my relatives heard from other people. Others have seen me in a programme that was conducted by CHMT - Inkoba - beat it. It is the Community Health Media Transit. They came to Westville in 2006 no, 2005. They interviewed us and the programme was broadcast in 2006. It was in September so some they have seen me talk about HIV disclosing my status but they didn't believe it that is why verbally I have disclosed to two people but through the



media, TV a lot of people they know but some they don't believe me they think that I am just making a programme.

A: Oh, so they thought that you were contributing to the programme.

B: That's it. Exactly.

A: And how did you go about telling them that you are HIV positive?

B: It started off as it seem, you see my girlfriend is the girl that I met after coming out of prison because my former girlfriend before I got incarcerated the first one passed away and my child I can't get a hold of her. And my child mother I can't get a hold of her now. My spouse if you can put it that way. She went to Joburg and I can't get a hold of her now. I don't know where she is now. So what had happened is that my brother saw the programme on TV and when I came out he actually, what had happened is that he approached me while I was still in prison. He visited me the following day after seeing the programme on TV. and he wanted to know more about this and I had to arrange with the social worker itself. Fortunately, the social workers that was there that side, that time she understand me coz she was also currently conducting my life skill programme. So she brought my brother in. She helped me disclose my status.

A: So the social worker assisted you to disclose to your brother?

B: Yes.

A: And how did you go about disclosing to your girlfriend?

B: It took, that was the hardest part. When I came out the girl that I met, I loved her and we got involved with the TAC opening a branch in Mayville because when I went out I was staying in Mayville we opened a branch, we established a TAC branch and she was interested in the branch that is why I was getting used to her and we spoke a lot. And she started asking me questions, why I am involved in TAC, why I am mobilizing the community and then I told her the story. She was very ashamed with me and then she knew all the precautions of HIV and how it is transmitted and I started approaching her that maybe she knows. She accepted my status as I am, she accepted my status as I am.

A: Why did you specifically choose to disclose to your brother and girlfriend. Ok, let's speak about your brother first.

B: I didn't specifically choose. It happened like because of the TV programme, the CHMT programme. So my brother came too and I had no choice. I wouldn't lie to my brother in that way. I knew I was not too sure about my life because of being in the prison environment so I decided that when my brother approached me, I decided no, I had to tell my brother because if I die in prison because they were not giving us ARV'S the drugs inside prison then I thought that it was the best idea that I disclose to my brother because if I die then my brother will know exactly what had happened that led to my death.

A: If your brother had not seen you on TV would it have been possible that you disclose to him?

B: Absolutely not. Looking at my family right now, my other relatives my brother or my father's brother ya, it is very they don't even want to hear about HIV. And when I am trying to talk as a professional but I, I am not saying that I am professional but when I go my current activities I go and teach the community about HIV/AIDS and when it comes to my family they don't even want to concentrate, they don't even want to listen to me. It is very difficult and they like rule out people they just don't hear that if I tell them about HIV they it is like two different things they look at my health now they don't even

believe that I am HIV positive and I because of the cultural beliefs as well it is very hard, it is very hard, it is very hard. When I tell them when they see the programme on TV they don't believe it that I am HIV positive and they don't like that I go off and discuss about HIV/AIDS. [Silence]. So my uncles they hear from people that saw me on TV and some they have seen me on TV and even here in the community it was in English they also now but I have told them that it was real, it was true. [silence] But it wasn't easy for me, I didn't say that it was true first of all my father asked me about it and I told him I started saying ya the doctors say that I am HIV positive. And you see he kept on asking me what did you say if they doctor said that and he asked me what did you say. And I said that this is scientific I can't deny it and I am currently monitoring my CD4 counts and it keeps on deteriorating up down, up down and that is proof that I am HIV positive. Then he just said no you are not HIV positive, you don't have this thing. That was what he thought till he passed away.

A: How has the family's response to you telling them that you are HIV positive affected you?

B: It is actually it is really, really really giving me a problem I am not feeling good about this because what I am trying to tell the people to practice my own family are not in contact with that. I don't know how to explain it. Eh, it is a big problem eh, it is like people they say in Jesus teachings you remove what is in your yard first before seeing what your neighbor has, I don't know how they put it in a Biblical way but you have to clean your home first before cleaning other people's home. That is the problem that you are faced with because my own family is not accepting my current status, I don't know maybe I have to get sick so that they can see that it is really true I am HIV positive. At this current stage they are not accepting my status.

A: Do you see yourself not trying to educate your family about your status?

B: No, until I die everytime. What I got hold of it now is my younger brothers that are from my younger fathers now they like me coz they listen to me because everytime I teach them they really know about HIV and the modes of transmission and they are taking the necessary precautions. It is only my older parents that are not listening to me. But my young brothers they are with me so I am like pushing to them now. I am trying slowly to get to my other families, the females those are the people like everytime I talk to them they sometimes they give me time and they listen to what I am saying it is only the men's now.

A: Why do you think that there is a difference between the older and younger people when it comes to them listening to you about your status?

B: Hey, that is a difficult question. At this point in time, when I look at the way the younger are growing now I don't know it is like they know more they understand they know they are willing to learn and they like not too much on the traditional part of the culture that is why it is easy for them to understand and to learn but my father's the older the elders they very stereotype they like believe in the traditional herbs, they belief in all the muti's, the zulu medicines and if you tell them about this scientific things they don't want to hear about it. They are saying now that you are now like the new born Christian, you know they are pushing on that. They are saying you are like a new born Christian, they are pushing on that, you are coming with all the new stories now.

A: Have they said that you must go for the traditional medicines?

B: Yes, they keep on telling me to take ubejane, to take thematic now this herb has

created a lot of communication problems with the TAC and the Department of Health and the government and a traditional healer from Umlazi who initially said that this medicine was treating HIV/AIDS. He said that it boosts the immune system. So in most cases there are encouraging me to take them and Emmanuel, they call it plaza incarta in Zulu. But this they are mostly using in the rural areas and they always encourage me to use that.

A: But have you tried it?

B: [LAUGHS]. But I have tried one but I didn't see the difference, I felt the same. [laughs]. But to be honest I have tried that one, when I came out my father says no I must take out all the bad luck coz being in prison is bad luck, I must take out the bad luck so he gave all the medicines I must do I couldn't oppose my father, I couldn't argue with my father. I did all what he asked me to do. [Silence]. The worst of it when you are coming out of prison you know sometimes to disclose your status you are looking to that problem of losing your parents and like myself if I didn't tell my brother first because when I started my brother accepted it and when I was disclosing it to my parents and when they asked him because he was staying in Durban so it was like just a story so he kept on laughing and he didn't take it seriously so therefore my mother the females of the family they look at my brother not being serious so they also take it for granted.

A: And your girlfriend.

B: I thought of prevention because we are more like encouraging prevention and I took it upon myself after being infected with the virus coz I didn't know where the point of infection when and how I was infected. So I decided to protect her and the entire South Africans as well. Being involved with the TAC the knowledge and information that is given me I realized that it was important that the alarming statistics of South Africans being infected and the transmission of HIV/AIDS amongst the youth so I took it upon so I thought that it will be the best idea that I disclose my status to my girlfriend rather than infecting her if I don't tell her my status.

A: Has disclosing to your partner led to the negotiation of safer sex practices?

B: Can you repeat the question?

A: Has telling your partner that you are HIV positive, are you'll able to speak openly about ways to protect yourselves?

B: It is a very difficult part, yes I am able now but it started very difficult because everytime when we negotiated the sexual part of it, she always tell me she always ask me is that going to be the thing for the rest of our life that is where we are getting stressed. That is where we get stressed out because now we no more enjoy natural as well so we feel she feels that it is no more natural because it is like taking a sweet with it's cover as well that is what she always tell me and we look at the issue of having children as well we look at the expenses of doing this what you call this artificial insemination where they take out the sperm and all that and that is the worst part that we are facing so we are no more enjoying sex.

A: How do you handle the situation where your girlfriend feels this way about using protection?

B: It is just that I keep on telling her that maybe sooner or later the cure for HIV will come scientific studies still gives hope that there might be some cure so we might get rid of using this condoms. That is the promise that keeps on reviving my spirits that gives her confidence as well as myself.

A: Where there any instances where you did not use protection?

B: No, not yet.

A: When you found out that you were HIV positive, how long afterwards did you disclose your status?

B: 5 years.

A: So it was five years ago that you found that you were HIV positive and you disclosed five years later?

B: Yes, it was five years later so I found out in 2002 and disclosed this year.

A: How about your current partner?

B: It was this year {the year was 2007}.

A: Why do you think that you have taken so long in disclosing your status to both your brother and your current partner?

B: Ya, because of the information I was not well educated only until recently in 2005 that is when I got more information when I was first diagnosed there was no educational programme that encouraged me that taught me exactly what it is what is happening exactly around HIV/AIDS. So ya, I think that it was basically no educational programme that taught me how to disclose my HIV status.

A: Which educational programme influenced you to disclose?

B: Getting involved with the TAC and CHMT and the Inkogba Beat It and in prison in 2002 there was the Ugandans the Ugandans came to prison and they told us about HIV/AIDS and we had and they carried on coming on new information on HIV/AIDS through via the social workers.

A: So it was these programmes and visits from people that gave you more confidence to disclose.

B: Exactly.

A: When you were ready to disclose where you able to have access to these people like your partner?

B: Yes, that was the problem, thank you for asking that question. Hmmm, they were not available at the time.

A: And this was after you were ready to tell them.

B: No, this was before I was ready. You know from the period of five years being diagnosed after I find out about my status, they were not behind me they were not supporting me even in prison you know even the physical support you know coming to prison, coming to see me often. They were not coming to see me that is why I got sick in all cases and that is why I was shy about my status. Up until 2005, that is where I was ready that's where I was like really really ready.

A: And in 2005, did you have access to them?

B: Yes, I got hold of them through telephonically while I was still inside. And after the CHMT programme my brother saw me on TV and then he start seeing me because it was like two years not seeing me because he saw me when I was got sentenced the following day he came to prison then he stayed about two years not seeing me the he came in 2003 then he left again and then he saw the programme on TV and then he came back in 2005.

A: What was your first reaction when you saw him after such a long time?

B: You know first of all I didn't know that he saw the article on TV. I thought that it was just a regular visit. I hugged him and I saw him pushing me away because he didn't have information about HIV/AIDS. He says no, no, no don't hug me yet, I want to talk to you

seriously, I want to talk to you seriously, he was serious even his facial appearance he was not like the normal brother that I know. Then he sat down he ask me so I saw you on TV saying that you are telling the whole world that you are HIV positive what were you doing, what are you telling, are you HIV positive, even your he is referring to his wife saying your squeezer we call them squeezer is really concerned about this and she wanted me to find out more about this and that was a difficult part. I told him that I can't talk to him at this moment so I would rather that I talk to him later on, the social worker will phone him then we can talk upstairs. Up stair that is where the social workers lab because I didn't know then I told him that I will phone him later but I told him that it is not true that we will talk later on then he carried on telling me about the programme that my family saw.

A: So did you tell him that you were not HIV positive.

B: Yes, first time I told him that I am not HIV positive, I was just in the programme but I told him no we will talk about that later. I said that I will give him more information why I did that later, that is where I will refer to the social worker.

A: So, the social worker also helped you to disclose your status.

B: Yes.

A: When you had your second meeting with him with the social worker and you told him, how did he react?

B: First of all he told the social worker that I told him and then the social worker called me in about 30 minutes later the social worker called me in. Then I went in I saw on his face he was smiling and he shook my hand and I saw that he accepted everything. I think that the social worker gave him all the information, it was just a matter of adding up so when I popped in I just added up, I told him the story and he told me he says you know my brother I have heard everything about you, now you are a man now so I realize now Oh, now he knows that is where we started interacting and giving each other information to learn more about HIV/AIDS.

A: So through the media you were able to disclose to your brother.

B: Yes.

A: When you disclosed to your brother what did you say to him?

B: First of all I told him that you know lie's changing the world always changes [hmmm], and then I started introducing the topic of HIV/AIDS asking him as he tested for HIV/AIDS and then he says why should I test and then I started telling him the side effects and sicknesses, infections and opportunistic infections related to HIV and the death and I even showed him the statistics about how many people are infected in KwaZulu - Natal alone and then we started talking more about that, the modes of transmission and then I told him that I have undergone the HIV test and then he wants to know how was your result that was his second question. And then I told him that it was positive and then he said no you are lying how can you be positive so healthy he even touched my skin so healthy like this. Then I said again that I am HIV positive then I even took out the results and showed him and he was shocked and he was very shocked because I don't know what they have spoken before with the social workers and when I showed my results he was very shocked he read and read and read and go over and over again and then for that from that he says that is going to go for HIV test after that. And I told him the direction I told him the sites that I know outside town and then after that he came back with his wife and I also told the wife as well, my brother's wife that I am HIV

positive and she was ready because I think that she was already informed by my brother and she did not have a problem.

A: So she didn't react negatively to you.

B: Exactly. She wasn't so shocked she wasn't so surprised.

A: And what about your partner, what did you say to her?

B: Yaw, she actually asked me why I was so much involved in HIV/AIDS programmes why can't I look at other programmes available outside, why do I want to involve myself in HIV so much so that is where the conversation started. I told her that it was because because we were not in love at that time so I didn't care whatever she may react so I just told her you know what it was just because of my status and I just want to protect other people. I want people to know what HIV is like what it is to live with HIV/AIDS so that is where we started. But then when we started approaching for being in love with me she was very negative coz she knew her status she was negative and she wanted and she asked me what is it you are going to me we are just going to look at our eyes at each other what is the use of falling in love with her because I can die anytime because she didn't have more information and that is where I had to tell her no, no, that there is a life beyond being HIV positive. And I even told her that we can still get children and there is a possible cure in the next coming years because now there are prevention there are treatment that prolongs life because there has been scientific proof.

A: What did you say to the older people in your family.

B: They actually asked me about the article that was published that was the first thing they asked me they asked me if it was real then you know sometimes it is fearful because they are all at your house all my fathers and they say ya son come here and then they ask me why like now you are embracing us in the entire community like you are saying that in the whole family you are the person that is HIV positive. And how do you think that relates to us that is actually passed the message that in our family we are like HIV positive and now that is where I started talking. That is where I started the talk more than three hours talk eish. Ya, first of all I didn't just say ya I am HIV positive it was like indirect speech, indirect indirect indirect and now I went all the way telling them teaching them giving them the whole information about HIV how it is transmitted how it is prevented and then now the treatment that is now coming and that is where and then the most part that they were interested on that up until they accepted when I told them I am HIV positive is because of the STI's some of my families some of them were experiencing the STI's so when I told them at a later stage not the first time after the conversation then one of my fathers took me out and we went for walk and he kept on asking me about this STI's and I suddenly realized that he had a STI. He had gonnereha and then I took him to the hospital and he got treated and ya even though now they are not so negative but they are not yet in that stage of accepting HIV/AIDS as a fatal disease that is killing people in most cases that it can't like be treated. They not believing in it so much that this other Zulu and traditional medicine can't help they are not so negative on that. Now, they do understand that there is HIV because they have seen other people and other neighbors dying because they have heard that it is because of HIV/AIDS so now they are like at that stage. But I think that they are coming closer to accepting it. That is why I looking at the current programmes now the educational programmes they are more like in urban areas I am thinking how we can take it to rural areas so that my family can also be accommodated because when I look at my family they have no educational

programmes.

A: Have you disclosed to anyone else like your community?

B: Ya, currently within my community I have disclosed because my current activities is to go to clinics and educate people about HIV/AIDS and in most cases some people they come to my house later on and then I have to share more and more until I have to disclose my status. I have disclosed to many people around the community.

A: Being part of a bigger community how did they react?

B: Their reactions were very good, positively. Because many people have gone for testing now many people are on treatment now they have left the traditional medicine, even the white councilor as well is aware of my programmes so they are supporting me in the area.

A: Is there anyone else that you would like to disclose?

B: Ya, my child's mother because when I got arrested she disappeared with my child and I can't get a hold of her and I don't know where my child is. They are in Joburg.

A: What do you think needs to happen before you disclose to them.

B: Ya, I think I that I need to first of all apologize for wrong that I did that led me in prison and for not contributing to my child's upbringing because when I left my child it was about 7 years and now she is about 14 years she doesn't know me. She has not seen me for the past 8 years. That is the people that I would like to tell you know to get a hold of them.

A: How will disclosing to them be?

B: It will be difficult. more particularly the child. I don't know how she is going to react. The mother I got no problem because I know that she has continued with her life so I just need my child because I don't know of her status because I don't know when I was infected maybe when I fell in love with her mother or I already had the virus when I fell in love with the mother. She maybe living with the virus and she don't know, I don't know. That is why I need to find her.

A: What do you think you will need that will make the situation less hard?

B: I think that I would need a social, somebody who is professional who can help me. I don't know maybe a social worker maybe a psychologist I don't know between the two but somebody maybe a counselor somebody who is professional who can help me. The first part of it I don't just want to go there and disclose to them but we need to iron out the programme that I did you know the family programme first, the social programme first address that before I come to HIV and my health.

A: What advice would you give to people who are in a similar position and who want to disclose their HIV status?

B: Hmmm, is to get involved they must get more information on HIV before they are disclosing their status their status to their families and they must ensure that their families are well - informed about HIV/AIDS not particularly because they want to disclose their status to them but they must first empower them with the knowledge and they must like expose the problems to them that HIV/AIDS causes first so that they can believe in it because currently many people they don't believe that many problems are being caused by HIV/AIDS, the high rate of death in South Africa is being cause by HIV/AIDS so I think they must make sure that those families people are exposed to that they know they must get see people the impact of HIV/AIDS in our society before disclosing their status and they must get professional first because sometimes they can loose their family more

particularly you are coming out of prison, you are coming with HIV people will stigmatize you a lot they will dislike you like now some of my former community members those people that I am staying with they are still keeping me there because they still regard me as a criminal now the worst part of it is that they have heard that I am HIV positive some are still pushing me away that I will be honest I will tell you and I think that that is the worst part that I need to be assisted with I don't know how. I am trying by all means now to do good things so that my community can see that I am really dedicated that I am really a citizen a law abiding citizen now. And the stigma now in many companies where I go seeing ex- offenders even in some of the communities when you want to do things like in my family like when my father passed away they wanted to slaughter a cow they send me because they say because [Brain] has been to prison he is brave give it to him, give it to him give him the knife those are the kinds of things that we need to deal with as ex- offenders. I don't know how but those are the problems that we are facing in our community.

A: So you face a double challenge being an ex- offender and HIV positive.

B: Exactly, it is a doable burden on our necks and shoulders that we need to tackle because hey it is a big problem. The community they don't accept us now citizens as now people who have served what we have done ya there is two problems now the stigma of HIV and being in prison. Ya, it is becoming a big problem because you know if you are being in prison all of the things when you come out of prison all the things you are like a born again person, you have to start all over again now just think of that you are coming into community where you did the wrong things people know you as a criminal and then you come back with a stigma of you are HIV positive, ex- offender you are not working you did maybe a serious crime maybe you murdered somebody amongst the community and you went to prison you come out you are going to face all those things people don't want to associate with you even when you are serving children at the shop they say look out for [Brain] if you see that particular person you must run away and you see children walking away and now you like for the first three months I had that problem. The first three months when I was in the community I had that problem people are keeping away even children are running away from me. And in most cases those people that you left some of them are dead some that are alive they don't want to accept you. [silence]. And being HIV positive that is the worst thing around Durban it is more because a lot of people are HIV positive there are a lot of educational problems that did have a bad impact but it is just that the love relationship that is the most difficult part to get people to love unless you join support groups then you will get people that are at your same status.

A: Have you given any advice to other ex- offenders who are HIV positive and want to disclose?

B: No, we don't have the platform we don't have a place where we can meet where we can discuss the problem that is where we are currently facing because some I meet them in town and they say [Brain] where are you I have this and this problem and the current ex-offenders that I have on my phone we talk over the phone and when we meet we meet at a noisy place and we can't discuss the problem because some of them are really in trouble like the other one he is gone back to prison now another one in a taxi rank here and he is trying to establishing himself but one of my colleagues he has succeeded in his life.

A: Have being in prison affected your decision to disclose?



B: This question is quite difficult because I only found out while I was in prison that I am HIV positive.

A: Why did you decide to go for the HIV test?

B: Oh, they in prison, they don't like visitors in prison. They organize from time to time counseling and testing. It is only when you get sick then they take you for a test. So I was sick. I had suffered from chicken pox and then I had TB and then the doctor advised me to go for an HIV test voluntary, that's how I found out and then after that I had to help myself, counsel myself because there was no educational programs that time, there was no support groups that time, no counselors, no support group and no access to social workers there was only two social workers at that time for 4500 prisoners it wasn't that easy. You couldn't just wake up and say can I go to a social worker and go. There was a whole lot of processing. In prison up to this far, you can't just say I want to see the social worker. The prison wardens in the section level they will first ask you what is it they have to register it down I don't know the name of the form but there is a form that you have to fill to register the complaint, you have to complete a record register that you have to write down first. So the prison warden has to write down why you want to see the social worker so when you get to the social worker the social worker is aware that's where the problem starts because now you have to disclose to the prison warden and the prison warden not aware that you came through and it has happened a lot of times, several times where you tell them the warden that you are HIV because of the HIV, he will start telling all the other prisoners about your status. It has happened with a lot of cases and has been reported up to the general prison. Ya, that was the difficult part. I had to disclose to the prison warden to get to the social worker. I don't know how the government can eradicate that situation.

A: How did you feel towards the other prisoners knowing that you were HIV positive?

B: They will wash everything I touch the sink, the toilet, the shower after I bath they would always wash it maybe with jik with omo with a scrubbing brush. Hey that was the worst part, that was the worst part. I had to change the section. I had to go to isolation then I went down to a section where you had the maximum offenders only and then I had to speak to the supervisor, he was the only person who took me to a cell where there was a prison committee of offenders and then that is where it was a non-smoking cell prisoners that were there like were very sickly so that is where I started to relax, that is where I had a piece of mind.

A: So, the stigma was so bad that you had to change cells?

B: Exactly, stigmatize not only by prisoners even by prison wardens as well. The prison wardens were like go away; you are HIV positive, get out from here. Don't come close to me. You know they would be negative, their negativity they like hey, when I think of prison even though hey it is very difficult for me. The first 1999, 2000, 2001 it was very difficult. Now when I left it was a little bit better, now they were like after we had the case now they are starting to change their mindset even though they still stigmatize us, it is indirect. It's not like physical visible like the past.

A: Are you aware of how you got infected?

B: Not too sure, not exactly. I really don't know [silence]. I suspect maybe it is because of sharing razor blades in terms of cutting our hair and beard while I was in prison. I think it might have happened there or maybe I went into prison being infected. I was infected before I was in prison because I only found out while I was in prison after I got

sick. That was the only time that I found out that I was HIV positive.

A: While you were in prison did you every want to or consider getting an HIV test?

B: Not at all. Ya, it is because of the prison environment, it is not conducive for getting testing. In the prison clinics they don't have a program of that nature where you can just volunteer and go for a test. And also many prisoners will not volunteer to go for a test because of stigma. They also feel that if they are healthy then they should not go. More particularly the issue of how the prison wardens will handle you the results as well. Ya, because in most cases after we have developed the prisoners went for test in 2005 some medical practitioners in the clinic they couldn't handle it sometimes when you come with developing opportunistic infections they will tell you, you know your status why you coming here, you know your status how can I help you because you know that you are HIV positive this is why you got headache, this is why you got thrush and now sometimes, and the way she/he speaks you are standing in a queue with some other pioneers behind you and they hear all that. Prisoners that are terminally ill are bed-ridden are being look aftered by others prisoners even when the doctor comes your file will be handled by prisoners, the prisoner will take you to the doctor and this prisoners they tend to stigmatize us and tell others and disclose our status to others. That is the worst part in prison.

A: That makes it very difficult to fight the illness.

B: Ya, that makes it very difficult and once you find out that you are HIV positive and the only thing you do in prison more particularly in Westville we don't have educational programs where we have the skills and power program and even the school there it's only if you have a report, if you don't have a report you can't go and it is only it is two classes for 4500 prisoners and you can't and there is not much activity and programmes that you can get involved in you go in the morning for Puga you come back and sleep and then you go 12 'o' clock for supper that's it closed after that. There is nothing else that you can do there and then you suffer from being locked behind bars, the stigma attached and it is about 60 prisoners in one cell, that cell is made for 18 prisoners you are sharing one toilet, one bathroom one sink one TV those are the dynamics that you face while you are in prison and the worst part of it with me like life prisoners two years prisoners six month prisoners are both together in one cell, some are like behaving very rude. Ya. You have to argue over the TV programmes and when you are there the only thing that is available there is the Zulu dance and football and then it is not for everybody and if you not, if you don't like that you can't you got no option, no alternative. And you have to stay there like myself I had to stay there for the rest of my 8 years doing nothing. I tried to register to attend school, no because I didn't have a matric report. I didn't have my pervious report. Ya. Those are the things that you face when you are there and once prisoners know that you are HIV positive it becomes a big problem because in this activities that are taking place you can't just pop in they will push you away even if we the authorities force them but they will try and keep you there even if you are playing they will try and keep you there.

A: How did you respond to that situation?

B: That is why I had to change sections until I had to go to a section where I was put in a non - smoking cell, disciplined, very disciplined offenders that is where I had my life. I stayed there until I came out.

A: Do you think that the way a person get's HIV affects their disclosure?

B: Yes, more particularly inside prison some of them the majority the rape cases inside, sodomy rapes some get infected because of rape. I got cases pending cases that are still people who were raped and they were infected while they were in prison. It has affected their disclosure because once you were sexually abused sometimes you feel like paying revenge that. I have seen I have shared information with some of the fellow inmates that have undergone that. I have seen that they feel like revenge. They become like themselves like gangster. They revenge it because they want to pass it on to others. Yes, in most cases these offenders that sleep with other offenders are offenders who were sexually abused so it is like revenging. This thing is going on and on.

A: It is like an ongoing cycle.

B: Ya, it affects them to disclose because they will not want to disclose and the prison environment itself is not conducive for that.

A: There is nothing in place to make disclosure easier on offenders?

B: Exactly, there is no support inside and outside of prison. That is why more prisoners have died. If you go to the other Medium C prison you will find prisoners that have been transferred from Medium B to Medium C once you get to Medium C treatment [ARV'S] is only rolled out in Medium B and then now when this offenders date comes nearby for him to go for ARV treatment once the authorities in Medium C finds out that he is on treatment they will say NO, NO, NO go back go back, go back to Medium B we got no place to keep you here. Who are you going to worry every month to take you to Medium C. Who must escort you to Medium C. Those are the cases that I faced in Medium C. Now when the authorities shout they are shouting in front of other prisoners and the when this prisoner packs up his clothes they want to know why you gone. So, it is an unconsented disclosure because now they will get to know that it is because he is HIV positive that is why they send him back to Medium B. Ya, those are the cases that we are currently facing in Medium C.

A: So Medium B is where they are giving out the ARVs.

B: Exactly. And the way prisoners keep the way that prisoners keep their treatment inside your cell sometimes there is this thing called the strip search where authorities will come to your section maybe early early as 4 pm in the morning and when they come they don't tell know we come to search they don't even. They just open the door and say everyone against the wall imagine 60 prisoners once you are against they say take out your clothes. You take out your clothes and leave it once side and come out naked you go out the cell they will be left alone all the wardens will be left alone inside the cell and then they will turn everything upside down when you come back into there will be medicine that will be thrown all over and then prisoners will say How what's this tablets what's these pills and they are all over spitted all over tramped upon some are crushed those are the cases that we face there and some prisoners now when you are in prison when you take the treatment you get the clock you know the alarm system sometimes they give you the clock and thats the worst part because this clock always ring when you have to take the medication. And some of the prisoners will be Why you got this clock and automatically your status is disclosed. Everyday you have to take the treatment at 6 'o' clock and everyday it will ring at 6 'o' clock and then 60 of you in one cell the cell is very small and then they would ask what is this then you will see that they are running for their treatment. Everyone there finds out. In prison you are forced to disclose your status. And they give out all HIV offenders and TB offenders they are taking a separate diet just

a unique diet that is peanuts and milk and in the kitchen when you go there they will say hey milk and peanuts must come this side the other offenders will stay this side and then for TB they take them for 6 months after 6 months you are discharged and then for HIV it is one way and for others who were once with you in TB they ask you why are you not getting discharged. It's two years and you still taking peanuts that is where you have automatically disclosed. There are a lot of these things, we have to deal with these things while we are still in prison. Those are the problems that the department has to deal with, I don't know how. Ya, the tablets, the strip search and also in the clinic. In the clinic, there are days ok we have got about 16 sections for the whole medium B and then each section has got its own specific day has to be attended to and then when they come when it is your day everybody will just go to the front gate where the prison warder will take you to the prison clinic and maybe about 100 of prisoners will come imagine there is only one doctor there and when you get there some prisoners will just come for minor things they will come for headache and you are HIV positive you got serious side-effects maybe serious opportunistic infections sometimes you don't get them, sometimes you are not the first preferences, you are not going to be attended to first because who knows how they are going to know that you are here, you are HIV positive that you will need to be attended to first unless you tell them. So everyone stands in a queue if you unfortunately come late in the queue maybe you are number 70 the clinic will only take 50 people a day. You will stay there until the next round. When is the next round, after the 16th week. That's 3 months. You have to wait three months to go back to the hospital unless you get seriously sick in such a way that you are bed-ridden. Then the clinic will attend you even though it is not your date.

A: Apart from the bad ways that you have experienced disclosure, did you disclose to anyone at prison because of your own personal decision?

B: Yes, I did. It was some for my colleagues that we were we had undergone the training. When the Ugandans came into prison those people that we had undergone the training it was a training on training where we had to train other offenders on HIV/AIDS. Those are the people that I first disclosed my status to because we wanted to implement a programme where we can go run throughout the whole prison and conduct awareness campaigns in the whole prison so I then decided that I disclose my status to them, start establishing a support group inside prison and then all these campaigns to encourage other offenders to disclose I was part of.

A: Would you say that other offenders disclosed as a result of these campaigns?

B: Yes, majority of them disclosed. That is where the support group grew big. It was very helpful. When I started disclosing it was three of us that were there. We knew of each other's status and then suddenly when I left last year [2006] we had a majority of 350 HIV ex-offenders in support group in the period of three years we had 350 join the group.

A: Did the support group make it easier for you to live inside prison.

B: Yes, it made it easy because we had a lot of support in a section you find 10 members 15 members in one section so if the others give you a problem you can always anytime after morning you can see all the fellow colleagues, you sit down and share your problems if not that day then the day that we meet. And we could face the prison wardens because if they don't take us to the prison clinic we can challenge them it was more easy. We had the power and confidence to bargain with them so that they don't ill-treat us. Other

prisoners that is where now they started seeing it in the other eye to know more they would come to know more. That is where it grows up.

A: How would you say disclosure is outside of prison.

B: Outside, finance travel to the hospital, food because when you come out you are not working and your families have gone on with their lives and in actual fact they are used now like taking care of five people and when you come back after 8 years they have to squeeze you in. You know your sister was young she now got a child at home she is not married and your room has been used, you don't even have - that is where hatred starts and they start pushing you with this plus you are HIV positive, you have to be reminded of your treatment all those things. more particularly, and food the worst part of it is the food and if you develop TB because TB treatment makes you hungry and where is the food, you are not working.

A: Has been in prison made it difficult for you to disclose your HIV status?

B: To whom.

A: The community, family members?

B: Not really, it has been a bit difficult but not really because being in prison that is where I gained experience of disclosing my status and I gained confidence in myself and that is where I gained more information on HIV/AIDS. So it helped and that is where I learned to interact with negative people, people who are very rude, people who are diversified in their cultural backgrounds. That's why in one room you stay with 60 prisoners with different attitudes and different colors', different race some are gangsters and you have to interact with all of them that is where I get more experience. And now outside I find it easier like now I don't even care like when people get to know my status if he tries anything I push him away. Instead of him pushing me away, I push him away.

A: How did you feel after you had disclosed?

B: You feel like relaxing. Ya, you feel relaxed. Also even in your mind you feel stress free because you don't have that. You get more support as well. My brother now he is supporting me he is giving me money to check my CD4 counts, busfares to monitor my CD4 count. My family they have not openly accepted but I think that there is room for development. Ya, my partner we are still having that problem. She still feels that it is like taking a sweet with it's wrapper on for the rest of your life. Even though I always tell her positive things and that it is possible that in the next few years we would have a possible cure but she still you know no more enjoying natural sex. Ya.

A: Although you got some negative reaction for your family, how did you feel after you had told them?

B: You know I was more relaxed even though they were negative. I knew that I have told them about myself so whatever may happen to me they will know why. And after that I knew that even if they keep me away I have somebody who will support me. I t would have been worse if I didn't have my brother on my side and my partner on my side. But because I had this two people supporting me I didn't have much fear in telling the other.

A: How would you describe the relationship with your girlfriend at the moment?

B: It's good; it's good because she has shown love to me. She is treating me like a man yaw.

A: What about your community?

B: My community, the response is good coz everytime I go to the clinic people want to

even if I didn't come like the last week Thursday I didn't go so they like why didn't you come. We want to hear more, we want to hear more. It is just those people that knew me before those old ones that knew me before I was in prison they still believe that I am still bad that they still have the negativity because I was in prison. But the current community now people that didn't know me before they are good they have accepted my status. They always come to my room even in the late hours they want to know more. One lady she even phoned from Chesterville she is saying that her child is very sick I must just come and have a look at her then maybe I might know what is happening so those are the responses. So I help the community with awareness on HIV.

A: So, you are the person that is providing the community with knowledge, support and advice around HIV/AIDS.

B: Exactly, they gain more trust and confidence in me. Some of the community are actually disclosing in me. Some of them I have assisted them for VCT majority.

A: Do you advise them to disclose when you are giving them talks?

B: Now, I am at the verge of doing that. I am still trying to get the relatives and the partners of being aware of HIV. Those that have disclosed to me I am trying to get their families now to try to get to know more about HIV and trying to get them to get hope and HIV information so that when that particular person discloses to them they are ready. But now because I don't have a proper platform and funds to do that.

A: What do you think is needed for a person to disclose their status?

B: One, you need to instill a sense of confidence in the person she/he has to know that support is there after disclosing and they have to know the disadvantages and advantages about disclosing. And you need to make them aware that why do you need to disclose the status and then look at the community where she/he is going to be disclosing and the relatives as well. You have to psychologically prepare them. You also need to give them information.

A: Based on the reactions that you received from your family, partner, do you think that you would have done anything different if you told them that you are HIV positive now?

B: What do you mean?

A: Will you do anything different now if you told your family that you are HIV positive?

B: Yes, I feel that at this time in moment I would disclose in a very good way because of the experience that I got and the confidence that I have now. The experience now I have seen the people how their life is outside and within the aspect of HIV/AIDS because when I was inside I didn't know exactly what was happening through the news because like now I am more dynamic I am more there to people you know once you encourage someone to, once someone discloses to you you need to be there for them in the first week or month just to encourage them take him into some workshops where there would be some HIV talks you know getting him or her involved in some programmes available.

A: And your girlfriend?

B: There is a lot of things. Like now sometimes I got I got some money that TAC gives me. I would have taken her out and I wouldn't have disclosed at the place where I have disclosed. I should have taken her out and told her about my status in a nice place and enjoyed. Even my family I should have done the same. Because when my brother that time he was seriously concerned about me being in prison for such a huge sentence. At the same time that I am telling him about my status my family they are passing away, at the same time was worried that my mother will pass away and father and sister. Now

myself being in prison and now I am telling him about HIV status at the same time my family is passing away. I am not at the burial services. Now I am telling him about HIV ya, it wasn't a good time. I didn't think so I didn't see it that way. Ya, but my elders for my elders that time when I told them that was was about 6 months ago I was very shy I had an inferiority complex within myself within my mind. They see me as a person from prison that I am cooing from prison. They don't see me that I am born again that I am really born again and that I have left all my criminal conduct behind and even myself the way that I should speak to them I have more confidence in the way that I speak to them. So it would have been more different. Now because of my experience I think that it would have had a good impact than when I told them.

A: For those people that you have encouraged to disclose and they have, how are they at the moment?

B: Now, they are more brave. They are looking after themselves. Some of them they even not even washing themselves. Now they are thinking I am still alive I am still a human so now they are looking after themselves they are doing some jobs. But I do alot for the community.

A: Do you have any questions for me?

B: I just wanted to know out of my responses did you find anything interesting or good?

A: Yes, of course. You have alot to offer. I think that you have alot of experience and a positive outlook on life. You should be proud of yourself that being HIV positive you still offer yourself to teach others and make others aware. You are also not staying silent about your experience and you have showed that in this study.

END!!!!!!

**APPENDIX FIVE**  
**TRANSCRIPT: CODING**

A: Interviewer  
B: Interviewee

A: I would just like to start off by saying that whatever you will be saying will be held strictly confidential. I will not be using your name when I am going to write up the report of this study. I will be changing your name. I will be using pseudonyms. Let me tell you a little bit about the study. This study will look to understand how you went about disclosing your HIV status to the people in your life. It will also look at how you went about it, what was actually said as well as how you felt afterwards.

B: No not at the moment.

A: Who have you disclosed to so far?

B: I disclosed to my family. **(Person who was disclosed to)**

I think that one person that I did not disclose to is my kid at home **(Person left to disclose to)**

because I am scared for the others because she is still young. I can't make it to tell her because I carry it **(Reason for not disclosing)**

but I advise about it what is happening but I didn't tell her but everyone I told open because I want to see the teenagers who must stop to sleep around and be more about safe sex because I have been seen this they run around without safe sex because I have been seen this even when I was behind bars because I was a volunteer for everyone who was around 15 and they pass because I was a volunteer there and it makes my heart sore so I commit myself to tell everyone **(Positive role-modeling)**

except my kid ya I won't tell her. **(Person left to disclose to)**

But you know he can see that there is something wrong with me, he can see in this case in July when he was attending this case he was always seeing me on TV, I was wearing the same T-shirt that I am wearing now about HIV when they were started talking on TV they were saying that people living with HIV or ex-offenders who are HIV positive there is an experience which they go by TAC to talk at court. **(Indirect means of disclosure)**

You see they do understand that but I didn't confront but I like to tell everyone that HIV is killing everyone but if you behave right the HIV is killing no one it is in your mind. **(Positive role-modeling)**

A: How old is your son?

B: He will be 17 next week.

A: Why don't you want to disclose to your son?

B: Because I stayed 9 years or 10 years in the institution so you see he still is a kid I do care for him but me and his mother we are trying to say that he is still young we mustn't tell we must keep on doing the good for HIV but we mustn't facing it straight you see both of us are HIV positive you know maybe it is going to affect him in school or what we are trying to do everything right we are keep on talking to him about HIV we make him learn alot about HIV **(Reason for not disclosing)**



so no matter what we are talking about I am always preaching about HIV always talking and I tell him that I am willing to help everyone in the community. Even in the community I also make my son go and speak and I go and speak but in the community there is no counselling still. All the kids they are just doing what they want they know no going fishing only think they know they promote they call it nomoknato in Zulu it means you can say that you can drink then you can throw yourself in whatever you want to do you can throw yourself in both girls and boys because they are drinking too much. The things that I hear is hey very bad because I can see there is no reputation there but when I come out in prison they told me they rehabilitate me when I come outside I have to talk to the children but now I don't know where I must go what I must do but I can see I see that I am like a comedian now I look at the boys I say hey boys I don't want to hear that there is something that you are doing wrong. I see these kids they have nice shirt and trousers and I always tell these kids when I see them about HIV and don't steal when you come in prison the crooks when you come into prison they are going to do this they are going to make you a girl. I tell them the experience that I experienced but now I have got no platform but even many people they know me I am wearing this T-shirt I am facing the stigma. I don't know what I must do I think people like you can advise me. **(Positive role-modeling)**

A: Do you think that you will ever disclose to your son?

B: Ya, because when I never saw much of my son but soon I will talk with the mother but she say hey he is still young I must not confuse him. I listen to her. I just told him what I am doing with HIV. **(Reason for not disclosing)**

A: Do you think that being so actively involved in HIV he suspects that you are HIV positive?

B: Hey, he shows me nothing because he is my he always keep quiet he just listen always focused too. I don't know exactly because even this morning he didn't stay with me he stay in Umlazi he came to collect something so when I always do something about HIV I am wearing this shirt I am just looking outside and I tell him that I am going to the clinic he just looking that I am wearing a normal T-shirt like that but I don't want that.

**(Indirect means of disclosure)**

In my mind I always want to tell him that I am HIV positive. But I don't know what I am going to do whether I am going to disturb him or what. **(Reason for not disclosing)**

A: But do you think that any stage would you be ready to disclose?

B: Ya, I would. When I came out last year I was willing to tell him but the mother stopped me. Even next year I can tell. But it is not that I don't want to tell him but it the mother because even the mother she didn't disclose but even when I am with her the last meeting I told the community even that they must talk and I look at her and tell her that she too must talk but when I look at her I was explaining the people and motivating the people and she is also free and when we come back she always tell me that hey you spoke a good thing. **(Reason for not disclosing)**

A: What do you think needs to happen before you disclose to your son?

B: Hey, I think maybe my son because he growing up like I wasn't next to him he was always keep on asking what about my father so I think he can say the naughty things I will counsel him from the beginning before I tell him that I got HIV. I think he will listen to me but me myself I need to convince my wife the thing in people's mind that HIV is

killing people that is in the mind but me I need to counsel my wife first then I can tell my son. There is nothing that I am waiting for from my own experience nothing; nothing is going to change too. Same like with my neighbors when I tell them that I am HIV positive they say no, no, no, I am ok I am ok I will be alright. Even when I talk in the community they are also like that. **(Factors that will promote disclosure)**

A: So before you tell your son that you are HIV positive you need to sit down with your wife and then you'll will do it supportively.

B: Exactly.

A: In terms of your family, you disclosed to your family can you give an example of who you told?

B: My aunties, uncles, my neighbors, cousins. **(Person who was disclosed to)**

A: How did you go about telling them?

B: Ok, it depends there are many ok there are many cases some of my nieces they are sick some of my nieces I ask them that I am sick I say what for. **(Understanding the experience through significant others)**

They tell me I got this TB and HIV some they tell me that they test negative.

**(Understanding the experience through significant others)**

Me that time I used to tell everyone that I am HIV positive and I saw that everyone that I tell in my family they deny it many I got two girls now they are married they I saw in the paper they writing HIV positive but I didn't tell you are HIV positive but I asked them they didn't tell three of them only one tell me that I am HIV positive when I met them first time. These girls in my community. One told me they have no support but they are working but in some families they work but there is a stigma. There is this one girl in the community that has three sisters and one brother and I ask her you got a sisters and brother and mother and you can't tell no one. She tell me that she didn't eat from yesterday and I am lying in the bed. You see all these things makes it very hard.

**(Understanding the experience through significant others) & (Stigma against those that are HIV positive)**

A: When you disclosed to your family, what did you say to them?

B: I was sick I was in prison. I was always sick it was in May 2000 I saw my mother she said that TB it doesn't want to leave you always TB, TB. I said that it is not the TB only I am HIV positive that is how she get the disease from that day that I told her she got the disease. **(Process of disclosure) & (Significant other's health)**

She went into hospital for 4 weeks she got sick because she wasn't ready some people they must learn about HIV and being HIV positive because they must know that there is no cure secondly they must know that HIV is killing so you see how far we as a community it is just taking HIV further and showing people about HIV. **(Significant other's health)**

Even in my family there are people that are HIV positive. Because I suspect my sister because she always participate in this what I am doing. She want to participate she want to join the infected group talk about HIV always when I am explaining something she didn't show that she is scared she just keep quiet. **(Understanding the experience through significant others)**

A: When you had the TB in Westville when your mother came to see you you told your

mother that you had also had HIV?

B: Yes.

A: And other family members.

B: Some say they are happy because when they saw me talking in TV they always talking to each other. **(Indirect means of disclosure)**

They say this brother and this brother-in law some I can suspect they have HIV like my uncle I don't want to mention any names because they just tell me indirectly you see hey I want to tell they just didn't finish. **(Understanding the experience through significant others)**

People you see are denial there is nothing where you can get that people can say that hey I am HIV positive from this year till now. **(Disbelief/denial towards HIV/AIDS)** I am still alive I don't know what we are going to do. But I can blame the government I think each and every one and in every house there must be someone who can explain on HIV. **(Structure of institutions/politics/the role of the government)**

In the outside there is a stigma each and every person who are from the denial but there is a stigma because even now people they talking about they are not officially HIV positive because are not jolling. If you are not HIV positive hey there is a stigma I didn't get even one who they are supporting when you are HIV everyone should be supporting even one I didn't get even me in my family they were happy when I came out but as time went I can see that things changed that is why I am staying alone now. I see the things have changed. I come out with a rash just getting the TB there was rash everything when I came out I can see the sign language I am an old man I can see hey they did not want to help me my family. There was stigma around. **(Stigma associated with HIV/AIDS)**

A: Ya, that is a very difficult situation to be placed in especially when it comes to stigma.

B: Exactly.

A: With regards to your community what did you say to them when you told them that you were HIV positive?

B: No, actually when I am going to tell my community about the HIV because when I was coming out I didn't come out with my HIV and just sitting like that I want to help in the community that is how I always commit myself. I am going to tell and tell until I don't know when that I am HIV HIV HIV even now I tell them I am HIV. **(Disclosure to the community)**

I got diagnosed with HIV in 1994 they didn't allow me to say anything. They didn't want me to say anything. I can go everywhere and talk about this thing they will say no you are alright there is no such a thing as that. **(Denial & Disbelief by others)**

But I want to talk about this HIV because what I saw inside it make me my heart sore until now that is why when I came out I go once a month to visit the people in Westville. **(Prison Conditions)**

I always come there I get the memory of who passed who passed like this money there was 11 people who passed away. One thing we got no food for people who are living there but for those that are HIV positive there is only peanuts and milk that's all and normal food. You see that is the wrong way to go. **(Prison Conditions)**

The government they should give the food parcels you can take when you on the ARV's and for the TB. But then the government is saying that they can't give the people the ARV. Like Monto she is saying that you can't give the HIV people ARV's just give them garlic for those that got the STD you can't just eat the garlic the people they keep on wanting the ARV'S but you can get depression. You see everything is upside down. Because there is nothing from the government. They say the different thing and they do the different thing. Even here is Chestville everything is so overcrowded and many people think that it is the nurses who don't want to do the job but it is the government that is lacking. Even in Prince Masheni hospital it is a government and it is overcrowded. I have seen it with my own eyes and the nurses they can't help because there is too much.

**(Structure of institutions/politics/the role of the government)**

A: When you told your family that you were HIV positive did they see you on TV first?

B: No. I told my mother first and then they say me on TV.

A: What did you tell them your mother?

B: No, I told my mother I think that I was talking about because it was in 2000 she already know that I was HIV positive.

A: How did she know?

B: When I was behind the bars I told my mother, my sister, father and friends I told them that I am HIV positive. **(Place of disclosure)**

When they saw me in February I was always talking to the TAC with what was happening. When they saw me I was with Sfiso we were going to be interviewed outside Westville prison because we were ex-offenders. My family they were ready to see what we were going to talk. . **(Place of disclosure)**

Even the one that I didn't get a chance to explain to them that I am HIV positive they already know. Like my sister she knows someone else told her. Like she saw me on TV and she saw me and she told me she asked whether I know about HIV/AIDS and I said yes and the people next to him. **(Indirect means of disclosure)**

I told my mother straight everything that is the first person that knows everything. I am starting from the first when I got diagnosed about HIV that it is a virus that you can live with the virus it is not a disease so people so when you get HIV you were supposed to treat it. I told mama this is HIV, HIV is killing no one only I was straight and I told her about TB and about coughing and must get treatment and that you must live healthy and stop fooling around having too many girlfriend and boyfriend and must use a condom the same thing I told my son that he must stay away from the girlfriend. He must live so HIV is killing no one you see. Then I just told my mother. But she is aware of HIV. She is aware. **(Direct means of disclosure)**

A: After you told her the background about HIV how did you come to the point where you told her that you are HIV positive?

B: Because when I think that it is in people's mind. They know that they are HIV positive. When I tell the person about HIV I have to start there to take it out of the mind first and then you must focus on because I don't want to talk to a person where I seem that I am just bluffing just telling the story. **(Disbelief & Denial significant others).**

I tell my mother you see the HIV is killing no one. Secondly you are weak your immune system is weak there is a tablet different tablets that you have to eat then you immune

system and the viral load come down. Many people with HIV they don't die. Many survive. **(The role of medicine)**

If your immune system is weak there are different tablets that you must take to eat then your immune system come up the viral load. **(The role of medicine)**

You calm down so you stay longer because HIV is killing no one and many people with HIV they survive. **(Self - motivation)**

Many people with HIV they can't die you must treat what you got then when you die GOD must take you. **(The role of religion)**

You see when that issue about HIV when you sleep without a condom one soldier maybe ten soldiers will die they are dying. **(Modes of transmission)**

When the tablet comes when they take the tablet their blood they must know that tablet to understand the tablet like bejane alot of people are taking bejane but people are dying. It can cure the other virus but HIV it can't cure. Take the bejane today and then the virus will stop and then when like next week the virus will come back and it will be worse. So I told my mother all of this. One guy he told my mother that there is a muti to cure HIV I told her hey all this is not true because there is no cure. There is no one in South Africa who can cure. I am HIV positive and I am staying with HIV for five years. I keep on making that point there is no one that I can say that took became and are alive. I can say that all of them they are dead. That muti is everywhere. They are selling it for R500.00. They are saying that that is the cure for HIV. The doctors they know they are always saying that many people are dying because of bejane. Some of the community they are taking it but there is not one that can live with the bejane. Hey, alot of people are having the bejane because even inside they didn't allow anyone to bring the bejane because you suffer with the diahorrea one way until you feel like you are going to die. No one inside prison who took bejane are right now they are dead. Even in the supporting group in McCords they don't want to sit and talk about HIV because they are scared but they want to take the bejane. **(The role of culture)**

Some people even the one's on ARV's they don't want to listen they feel very scared about HIV. They say that there is a stigma about poor people with HIV. **(The role of culture & Stigma)**

A: When did you feel was the right time for you to tell your mother that you were HIV positive?

B: When I told my mother that I am HIV positive the first thing that she asked me what kind of TB you always have. **(Indirect means of disclosure through an illness like TB)**

That is why I say ma it is not the TB it is also HIV because inside the Westville already you are telling the people that you are HIV positive inside because you are carrying this pink ticket and the pink ticket shows that you can have the milk and the peanut then everyone knows that you are HIV positive so that is the stigma. **(Prison conditions and stigma associated with HIV within prison)**

At that time I was not willing to tell the people that I am HIV positive because I think at that time I was in the window period because I also didn't want to tell anybody because in my head too I was in denial. **(Medicine & denial & reaction towards HIV testing)**

Then I told her hey ma I am HIV positive. **(Direct means of disclosure)**  
When I came out I was doing the HIV interviewing on TV. I was truly motivated because they come with the Ugandans they were training us. I was free I was understanding they helped me to be free the Ugandans and then I told her. **(Reason for disclosure through significant others)**

But my mother told me that there is the tablets for HIV and I told her that the tablets is a cure for other viruses and not HIV. So I was wanting to understand what is in her mind first before I can tell her. Then when I came out and told her I was free as I coming out too about HIV I was also understanding. I was not shy to tell her. **(Direct means of disclosure & knowledge and disclosure)**

A: So you told your mother that you were HIV positive while you were in prison?

B: Yes, she came and visited me.

A: And when you came out of prison your other family members?

B: My family member because it was a short time so when I come out of prison because I come out on 8th June 2006, July the TAC they were ready the case was already on for the prisoners because I was coming out so I was trying to tell everyone next to my family to know that I am HIV positive because I knew that they are going to see it on TV that is why I had to explain to everyone. **(Reason for disclosure)**

I told everyone the same like I told the uncle and the family. **(Direct means of disclosure)**

My uncle when he was visit me at Westville I told him that I am HIV positive them too they got the mind that the bejane is going to help he said that hey even if you are HIV positive it is ok you got bejane. Bejane is helping everyone outside. I said ok I am HIV positive. Don't be angry and don't be afraid I am going to bring you the bejane before I come out I do the training when I do the training they keep on counseling me I hear about how the bejane is killing people. **(The role of culture)**

I come out. I want to counsel the people but me myself I make the people stay strong.

**(Self - motivation)**

I want to see the HIV positive people as long time survivors because there is many things that I choose to cut it off you see. I was drinking I stopped completely to drink I can't drink anymore in my life. **(Lifestyle changes associated with being HIV positive)**

I need to eat the fresh food. **(Basic Needs)**

A: You also told your uncle that you were HIV positive within prison?

B: Yes.

A: When you came out of prison who did you tell?

B: Yes, I told my aunties, uncles, cousins. **(Significant others that were disclosed too)**

Many of my family before I come out of prison they know that I am HIV positive before I come out of prison. Because from 2000 I told that I am HIV positive that I am HIV positive. **(Indirect means of disclosure)**

When I come out I was reminding that I am HIV positive, I was just making strong. I was trying to explain to them that they must not feel sorry for me because me I know they must be saying that they must feel sorry for me because they don't know what they got

still they are scared **to make the test that is wrong. (Self - motivation & advice on HIV testing to significant others)**

I also explain them that you can test later when your CD4 count is down it is hard to survive you see my immune system is working well. **(Advice on HIV testing to others)**

I am not sick I got a TB but I am not sick I am living with HIV and I am trying to make a difference. Me I got the virus but I am not sick. **(Self - motivation)**

A: When did you find out that you were HIV positive?

B: My first test was in 1994 my mind was that I didn't know that it was a disease that was killing people. **(Knowledge and HIV)**

When I went for the test the nurse that was there was not giving me enough counselling she was just told she just asked me can I take your blood I said ok. In McCords [the participant knew of his status before he went into prison at McCords Hospital]. She took the blood she didn't tell me for what she was taking the blood. Already I was being treated for TB but I wasn't aware for what they were taking the blood. Then the blood test came back and then I was HIV positive and then she told me that I must not join the other people who are HIV positive. But the nurse told me that some people they are alive with HIV and she told me you too you are also going to be alive. **(The process of HIV testing)**

I wasn't afraid of the news I wasn't scared of the news because I didn't know what was that that HIV because I was know there is with AIDS they are still living that is how I blanked it out of my mind. **(EO reaction to the diagnosis)**

The nurses they were saying that I must stay away from those people who are walking around at the point. Those prostitutes at the point. **(Female epidemic)**

Then when they told me that I got HIV I said what is that I didn't know the difference between HIV and AIDS. **I wasn't care. (Knowledge about HIV & reaction to HIV)**

**After three weeks I come out I stay at home. I tell no one that I am HIV positive but I forget it too I carry on with my life drinking and sleeping with the girls (Reaction to HIV diagnosis)**

until I arrested in 1996 in August until I went in prison and see them dying in prison in 1996. When I see the people they got holes in the back I say to myself hey I also got HIV and I am going to end up like that man. **Then I take the blood again I take the test again they say that I am HIV** that is when I am starting to get pressure hey I am going to die because I can see it that I am going to die. **(Prison conditions & HIV testing)**

Even in 2000 I was saying rest in peace the way I was sick because we were take a shower with a cold water but in July we were drinking the juice but there was no food there was running stomach everywhere even there was no outside food that is why they were closing that year that month. I was sick I was dying I didn't know that I was going to survive that is why I said hey with this HIV I must talk that is what was in my head but it was hard because of stigma coz of the Westville stigma. **(Stigma in prison and prison conditions)**

A: So you were diagnosed in 1994.

B: Exactly.

A: In 1996 you went into prison when did you tell your mother?

B: In 2000. **(Temporal frame for diagnosis)**

A: So you were in prison at that time.

B: Exactly.

A: So the rest of your community you told them in 2006 when you came out.

B: Exactly.

A: When would you say that you were ready to tell your mother that you are HIV positive?

B: I was ready at that time because in my mind when I disclose I can say that when I disclose because of those people who are in denial or who go and check their blood or whatever and who they know they are positive that is problem. **When I was in prison I was ready that time because of the experience** I get in prison and because of what I saw in prison what I saw in prison I remind my mind when I was in prison but how I was outside there are people who are doing what I was doing when I was outside that is how I get myself in saying that really I am going to tell that experience in prison everything. When I was outside even now because I am doing my thing the thing that always make me my spirit down is when I go back and think what happened in prison. There are many things that are happening in prison and outside. **(Prison conditions, factors that promoted readiness to disclose, reason for disclosure)**

A: When you were ready to disclose did you have access to the people that you wanted to disclose?

B: I don't understand the question.

A: How often did your mother visit you when you were in prison?

B: Maybe once a month because my mother she was a domestic worker maybe once a month. **(Accessibility to significant others)**

A: Why did you choose to tell your mother first?

B: Because my mother in 1993 when I was sick before I got very sick. I was starting sick in 1993. In 1994 I was getting sick for the TB she came first from Montclair where she was working she come and grap me here in my armpit she was feeling after that she didn't leave me after two days you know what I was doing I said no she said if you are going to feel pain here from my previous experience if you feeling pain here you are HIV positive. If you are not feeling pain that mush. If you feeling really pain then definitely you are HIV positive, that is why it was easy for me to tell her that I am HIV positive **(Reason for disclosure, factors that promote disclosure & gender difference [female])**

Because that time this HIV was not on my mind that HIV it was for the prostitutes at that point not for us. But I was wrong. **(Female epidemic)**

A: Why did you disclose to the prisoners?

B: In prison I can say because I was joining the supporting group because I needed support so I can see the people of the supporting group especially the executive member he was healthy he went to school because me I said that I can't go to school because I am going to die and they took that out of my mind. They were talking about HIV openly and said hey I can't manage to do this they counselled me but they convinced me and they



told me that it is up to me. We are doing our job. . **(Place of disclosure)**

And then I saw what is happening in prison and said to myself hey I am not going to stay like that. It is hard to disclose. I spent a long time with them and I didn't want to disclose and then I told them but I saw the people that are sick they deny wanting to join us I even saw some of the people they didn't know that they are HIV positive that just died so I saw that **I was going to be a hero** if I disclosed to them. . **(Place of disclosure & Positive role-modelling)**

I see some of people they know some they come next to me and ask me how do you survive You see in prison I saw that if you keep quiet the casket is coming out once you keep quiet. Because when you keep quiet this thing is in your mind then you can't survive that is why I told other prisoners. You can get free when you tell others. You can say this man he is talking and now he is free. **(Reason for disclosure within prison & feelings after disclosure within prison for the EO)**

You can say that I saw this man on TV and now he is free to talk once you suspect something make you have to disclose because you can't survive in prison. **(Reason for disclosure within prison)**

But I was free but they knew I was HIV because of the pink ticket. Then I asked these prisoners how did they know they said because of the pink ticket. **(Indirect means of disclosure within prison)**

**But some of them they are talking bad about HIV you know the moment they are talking** what kind this people with HIV all those things then you must counsel yourself and make yourself a long term survivor. **(Stigma & Self - motivation to deal with HIV/AIDS)**

You got no chance you must talk so that you can live. **(Self-motivation)**

In the community it is easy for me to disclose but inside prison this person is staying with you 3 years 10 years and if you tell the person and if they don't like you you can't runaway. You got no chance if you don't want to see him because he is there. That behavior you got you can't do nothing. That is hard in prison. **(Difference between the community and prison disclosure OR Prison conditions)**

Here I think it is easy that is why I got spirit to tell. That my aim and my spirit because alot of the teenagers they are dying with HIV and I want to tell them about HIV.

**(Positive role-modeling)**

A: How did you go about disclosing in prison?

B: When I was in prison you are doing something called the road show on Human rights day. On that day the road show prisoners come forward and they disclose to each other. They stand one side and then we speak about what we have to do if you are HIV positive and what you must not do. **(Indirect means of disclosure within prison)**

A: So you told the other prisoners that you were HIV positive at this road show?

B: Yes. But in the show there are both HIV positive prisoners and HIV negative prisoners. Everyone is there. **(Indirect means of disclosure)**

A: So you disclosed to other prisoners because of the road show.

B: Yes.

A: Has being in prison made it hard for you to disclose?

B: In prison it was difficult. It was hard in prison. Here outside I think it is easy.

**(Disclosure within prison)**

The prison experience and what I saw in prison it make me strong in the community it make me strong. I saw that it is too easy in the community I told that I am HIV positive in prison and outside. **(Difference between disclosing in the community and outside)**

I always tell the people in the community that even if there is a cure for TB there are still people that are dying of TB even for HIV if there is a cure there will still be people that are dying of HIV because they don't take the tablet. **(The role of medicine)**

A: When you told your mother that you were HIV positive how did she react?

B: No, when I told in prison she didn't believe that is how she get sick. She didn't told me that she is sick. I hear inside myself she told me that she is sick I said what is wrong she said that when you told me that you are HIV positive she said that after I told her that I am positive she got sick. She was shocked and get sick. **(Reaction form**

**significant others, choice of the person that was disclosed to specifically females OR gender difference & Significant other's health)**

But with my other family members they just acted normal but I did give them strong advice that is why they were not so shocked like my mother. With my family too I told them what is this HIV and I didn't just disclose I told them everything about HIV and then I told them that I am positive. **(Reaction from significant others)**

A: What about your community, how did they react?

B: The community I can't say that much because I done this twice in the hall few of them they come and say they want to talk to you some they say I am HIV positive how can I get help because they keep on asking me how can I get help. They ask me where I must go. I got many of the people coming to me. **(Reaction from the community)**

A: What advice would you give other people who want to tell their family members or community that they are HIV positive?

B: Ok, I ask him first in your family who is the person that you trust maybe you say mother or what my advice must tell one of the family members that you are HIV positive you must tell who you trust because there comes a time if you are sick get someone that will help you to go everywhere and if you are sick with something else they can come with you to hospital. Even if you got a girlfriend if you trust no one in her family. But I do advise to at least tell one person in your family. Mustn't stay alone because no one can stay alone. But what I found is that the ladies they disclose the men they deny so the men don't believe that they are HIV positive they are always pointing to the ladies. The men always find a problem to tell. In the community the ladies always say to me that she is HIV positive and they say my husband he is going to kill me that is a problem too same like when I go around in the supporting group, I can't find the men I find the women. If there is 15 women there will be 1 man or two men. They all deny that is what I think we are going to fight with. Some women when they tell that they are HIV positive they don't want to use a condom I think that is 10 maybe 1 uses a condom that is the case that I know. The men they don't want to use the condom they blame the women. **(Advice from EO)**

A: Do you know how you became infected?

B: I can say because I was jolling too many girls. But I can't say who infect me. I can't

blame no one because I can't say how it came and from who. **(Modes of transmission)**

A: Has having many partners made it difficult for you to disclose?

B: Ya sometimes I can feel. People say that I am sin. Some people when I tell that I am HIV positive they say that I am wrong but with my own experience I always use condom I am no longer jolling with everyone. But you see I always am talking to other people that they must use a condom same like people who I say that I am HIV positive they deny because they can see that I am healthy all those things hey I don't know what I must do.

**(Positive role-modelling)**

A: Same question.

B: I always do this I always tell people who are jolling too much I tell that you must stop it and be like me I haven't got all of these girls now. Some of them say that they can't use condom especially the ladies they say that they can't use condom but they keep on doing it. But I tell the people more I can't blame the partner who I was sleeping with but I can blame because I don't know how I get this thing maybe it's me or maybe it is from someone else because I was jolling with everyone now I got this thing that is the cost that is the cost. So it is important to tell people that you are HIV positive so that they can stay away from all these things. **(Positive role-modeling)**

A: How did you feel after you disclosed?

B: Actually in prison I felt pressure because the first time I wasn't ready I was pushing it later when it is coming in my heart when I get power when I commit myself to tell those people when I get stronger and stronger I say hey let me blow the whistle on this thing and you got to talk because you see what is happening in front of me. But I feel happy because when the people can see that I am HIV positive and I give the person the living hope. I give the person the living hope. When I tell people I am giving hope to myself and others and I can feel myself again. **(Reaction from EO after disclosure)**

A: Are you in a relationship at the moment?

B: Yes, with my child's mother.

A: Everytime you have sex with her do you use a condom?

B: Yes.

A: How do you negotiate safe sex or using a condom?

B: No, because I was sick too much so she was aware of that. She is also positive.

When I was inside Westville she was also using the muti. I took her to the hospital and saw that she was also HIV positive. **(The role of the partner)**

A: Is she your only partner?

B: Yes, exactly because I have the child. Also when I am with my partner I want to show the community that I am telling them to use a condom and stay faithful and that I am also doing it. So I can't say to the community to do all of these things when I am not doing. **(Positive role-modelling)**

But when I was in prison I saw many diseases that confused me. Like I saw this man he fell down and he only got up the after three days and he was blank. He forgot everything. He forgot his family. **(Prison conditions)**

A: How could you describe you relationship with your family now that you told them?

B: I can say that my family is getting strong because of me. Because they can see that a person because he is HIV positive as I told you everyone they want to deny. Even my

family some they deny they don't want to say that they are HIV positive because of stigma. So now when they see people that are HIV positive they don't point fingers. Even in the community especially with the mothers it is strong. **(Positive role-modelling)**

But the teenagers they don't believe that I am HIV positive. **(Disbelief and denial about HIV)**

Even with my partner it's good because when I came out of prison she had too much STI's but she couldn't run away because of the advice that I give the people and she stays with me because of the advice that I give. **(Positive role-modelling)**

A: Looking at the way that your mother reacted do you think that you would have done anything different if you disclosed to her now?

B: No, I don't think that because already when she always when she someone who is not healthy I am go and talk to someone. So she is strong so I don't think that anything will change.

A: I just wanted to thank you very much for your participation in this study. I think coming forward shows what a brave person you are. The information that you have given is very important to us. Just remember that all your information will be held strictly confidential.

The End!!!!!!

**APPENDIX SIX  
TABLES & MATRICES**

**Prison conditions**

Factors that contribute to HIV/AIDS	Overcrowding, boredom
Power	Sexual Violence, cycle

**Disclosure within prison**

Place	Timeline	Reasons
Disclosure took place within prison	Between 1 – 7 years while incarceration	Social support from social workers Prison conditions

**Methods of disclosure within prison**

Intentional	Unintentional
Verbal and direct disclosure	Exposure of ARV treatment Nutritional diet: peanuts and milk Pink ticket for diet Access to social workers

**The process of VCT**

Reasons for VCT	Prison conditions, nutritional diet
Process of VCT	Positive experience and negative experience determined by social workers. Pre and post test counselling inefficient.
Reactions to diagnosis	Negative, associated with immediate death.
Psychological adjustment	Religion used to make sense of the experience