



**AN INVESTIGATION INTO THE CHALLENGES FACING SINGLE PARENTS  
IN DISCLOSING THEIR HIV/AIDS STATUS TO THEIR TEENAGE CHILDREN.  
A CASE OF THE VULINDLELA AREA IN THE UMSUNDUZI LOCAL  
MUNICIPALITY.**

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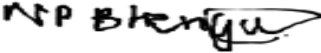
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**Dissertation submitted in fulfilment of the requirements for the degree of Masters in  
Sociology, School of Social Sciences, College of Humanities, University of  
KwaZulu-Natal, in 2019**

## DECLARATION

I, Nomfundo Precious Bhengu, declare that this study, *an investigation into the challenges facing single parents in disclosing their HIV/AIDS status to their teenage children. A case of the Vulindlela area in the uMsunduzi Local Municipality*, is my own work, it has not been submitted for any degree or examination at any other university. The sources that I have used have been fully acknowledged.

This study is submitted in fulfillment for the requirements for the degree of Masters in Sociology in the Faculty of Humanities, School of Social Science, University of Kwa Zulu Natal, Pietermaritzburg Campus, South Africa.

Signature 

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Date                      09/01/2020

## **DEDICATION**

I dedicate this work to God, for his has granted me the strength and opportunity to do this work. He is the God Almighty, without Him, none of this would have been achieved. Amen

## **ACKNOWLEDGEMENTS**

A sincere thanks and appreciation to my Supervisor Dr Mariam Seedat-Khan for your support, co-operation and encouragement throughout this whole dissertation. I am solely indebted to you, as you were my pillar of strength during this whole process. In a time that I thought there was no hope you came to my rescue as being my supervisor. God bless you and your family.

To my parents, thanks for your encouragement and support

To the community of Vulindlela as well the Clinic Operational Managers, none of this would have been accomplished without your support and participation during my studies.

## **LIST OF TABLES**

TABLE 1: SUMMARY OF RESEARCH QUESTIONS.....	60
TABLE 2: PERCEPTIONS OF STATUS DISCLOSURE EFFECTS ON THEIR CHILDREN.....	73
TABLE 3: CHALLENGES FACING SINGLE PARENTS.....	73
TABLE 4: SUPPORT RECEIVED BY SINGLE PARENTS POST DISCLOSURE.....	74
TABLE 5: SUPPORT FROM THE COMMUNITY, GOVERNMENT AND HEALTH FACILITIES PROVIDE.....	74

## **LIST OF FIGURES**

FIGURE 1: DEALING WITH AN HIV POSITIVE RESULTS.....	62
FIGURE 2: BREAKDOWN OF SUPPORT STRUCTURES.....	65
FIGURE 3: TIME PERIOD IT TOOK TO DISCLOSE HIV STATUS.....	67
FIGURE 4: CHILD'S AGE AT TIME OF PARENT DISCLOSURE.....	68
FIGURE 5: CHILDREN'S RESPONSE TO PARENTS DISCLOSURE.....	69
FIGURE 6: PARENT-CHILD RELATIOSHIP AFTER DISCLOSURE.....	70

## **LIST OF ACRONYMS**

SA – South Africa

HIV – Humane Immune Virus

AIDS – Acquired Immune Deficiency Syndrome

WHO – World Health Organization

US – United States

ARV – Antiretroviral

VCT – Volunteering, counseling and testing

HCT – HIV Counseling and testing

HSSREC – Humanities and Social Sciences Research Ethics Committee

## **DEFINITION OF TERMS**

Parents – a person who brings up and cares for another; a parent can take different forms such as stepparent, grandparent or legal guardian.

HIV – Humane Immune Virus that attacks a person's immune system, making a person more vulnerable to other infections and diseases.

HIV disclosure – the action of telling someone that he/she is living with HIV

Single parents – male or female who are single (not married), aged thirty and above in this study

Illness - a disease or period of sickness affecting the body or mind.

Diagnosis - the identification of the nature of an illness or other problem by examination of the symptoms.

Challenges – something new and difficult which requires great effort and determination

Teenage children - a boy or girl aged between twelve to twenty-four in this study

HIV infection - when a person's immune system is damaged by a virus that is transmitted through contact

Partial disclosure - a term used for the deceit when only part of a story or the facts are told with infected blood, semen or vaginal fluids.

## **ABSTRACT**

The continuing spread of HIV/AIDS has brought about unprecedented challenges to the ailing South African health care system, as well as the people infected and affected with HIV/AIDS. The study is qualitative in nature and it aims to explore and understand the challenges facing single parents when disclosing their HIV status to their teenage children, at the Vulindlela Area, in the uMsunduzi Local Municipality which falls under the jurisdiction of the uMgungundlovu District Municipality. The enquiry was conducted at Songonzima, Taylors and Mafakatini Clinic. Approximately twenty respondents were selected using a purposive sampling technique which is also referred to as judgmental sampling. An interview schedule was used as a research instrument in this study. An informed consent was issued to participants informing them that participation in this study is voluntary and that they are free to withdraw their participation should they feel uncomfortable to continue. It is envisaging that the findings of this study will go a long way in assisting the health practitioners in uMsunduzi to understand the challenges facing single parents who are HIV positive when it comes to disclosure of single parent's HIV status to their children.

**Keywords** – HIV, single parents, teenage children, disclosure, HIV status, partners support, parental challenges



## TABLE OF CONTENTS

<b>DECLARATION</b> .....	1
<b>DEDICATION</b> .....	2
<b>ACKNOWLEDGEMENTS</b> .....	3
<b>LIST OF ACRONYMS</b> .....	5
<b>ABSTRACT</b> .....	7
<b>CHAPTER ONE: INTRODUCTION</b> .....	16
<b>1.1. OVERVIEW OF THE STUDY</b> .....	16
<b>1.2 INTRODUCTION</b> .....	17
<b>1.2 AIMS AND OBJECTIVES OF THE STUDY</b> .....	18
<b>1.3 POSITIONING OF RESEARCHER</b> .....	19
<b>1.4 RESEARCH PROBLEM</b> .....	20
<b>1.5 SIGNIFICANCE OF THE STUDY</b> .....	20
<b>1.6 RESEARCH QUESTIONS</b> .....	20
<b>1.7 METHODOLOGY</b> .....	21
<b>1.8 ORGANIZATION OF THE STUDY</b> .....	21
<b>CHAPTER TWO: LITERATURE REVIEW</b> .....	22

2.1	INTRODUCTION .....	22
2.2	CONCERNS ABOUT PARENTAL HIV STATUS DISCLOSURE.....	22
2.3	MOTIVATIONS FOR DISCLOSURE .....	23
2.4	CONCEPTUAL CLARIFICATION: HIV DISCLOSURE .....	23
2.5	LEGISLATION ON HIV DISCLOSURE.....	24
2.6	DEFINING QUALITIES OF HIV STATUS DISCLOSURE.....	25
2.7	IDENTIFYING ANTECEDENTS AND CONSEQUENCES .....	26
2.8	CONSEQUENCES OF HIV STATUS DISCLOSURE.....	26
2.9	REASONS FOR HIV NON-DISCLOSURE.....	27
2.10	PARTNER SUPPORT.....	27
2.11	IMPORTANCE OF DISCLOSURE .....	28
2.12	THE INFLUENCE OF GENDER AND SOCIETAL NORMS ON HIV DISCLOSURE .....	29
2.13	EXPERIENCES OF DISCLOSURE.....	29
3.	SUB-SAHARAN AFRICA .....	32
4.	SOUTH AFRICAN LITERATURE .....	37
4.1	LITERATURE REVIEW SUMMARY.....	41
4.1.1	Factors that influences parental HIV status disclosure .....	41

4.1.2 Advantages of disclosing to a child.....	42
4.1.3 When is the perfect time to disclose or delay disclosure? .....	42
4.1.4 The process of disclosure between the child and the parent is discussed .....	42
4.1.5 Good ways to disclose.....	43
4.1.6 Ways not to disclose .....	43
5. SUMMARY OF CHAPTER.....	43
 CHAPTER THREE: THEORETICAL FRAMEWORK .....	 45
3.1 INTRODUCTION .....	45
3.2 AN OVERVIEW OF USING A THEORY IN QUALITATIVE RESEARCH .....	45
3.3 THE IMPORTANCE OF THEORIES IN RESEARCH .....	45
3.4 APPLICABLE PERSPECTIVE.....	46
3.5 THEORETICAL FRAMEWORK: COLLECTIVE FINGERS THEORY .....	46
3.5.1 SURVIVAL .....	47
3.5.2 SOLIDARITY SPIRIT .....	48
3.5.3 COMPASSION .....	49
3.5.4 RESPECT AND DIGNITY .....	49
3.6 SUMMARY OF CHAPTER.....	50
 CHAPTER FOUR: RESEARCH METHODOLOGY .....	 51

<b>4.1. INTRODUCTION .....</b>	<b>51</b>
<b>4.2 RESEARCH DESIGN .....</b>	<b>51</b>
<b>4.3 LOCATION OF THE STUDY .....</b>	<b>52</b>
<b>4.4 RESEARCH APPROACH .....</b>	<b>53</b>
<b>4.5 DESCRIPTIVE APPROACH .....</b>	<b>53</b>
<b>4.6 EXPLORATIVE APPROACH.....</b>	<b>53</b>
<b>4.7 RESEARCH PARADIGM/PHILOSOPHY .....</b>	<b>54</b>
<b>4.8 INTERPRETIVISTS APPROACH.....</b>	<b>54</b>
<b>4.9 THE RESEARCH METHODS – QUALITATIVE RESEARCH .....</b>	<b>54</b>
<b>4.10 TARGET POPULATION.....</b>	<b>54</b>
<b>4.11 SAMPLING TECHNIQUE, SELECTION AND SIZE .....</b>	<b>55</b>
<b>4.12 ETHICAL CONSIDERATIONS.....</b>	<b>56</b>
<b>4.13 DATA COLLECTION METHOD .....</b>	<b>56</b>
<b>4.14 THE INTERVIEW METHOD.....</b>	<b>56</b>
<b>4.15 LIMITATIONS OF THE STUDY.....</b>	<b>58</b>
<b>4.16 SUMMARY OF CHAPTER .....</b>	<b>58</b>
<b>CHAPTER FIVE: DISCUSSION AND ANALYSIS.....</b>	<b>59</b>

5.1	INTRODUCTION .....	59
5.2	KEY RESEARCH QUESTIONS .....	60
	TABLE 1: SUMMARY OF RESEARCH QUESTIONS .....	60
5.3	METHODOLOGY .....	60
5.4	THE DATA COLLECTION PROCESS.....	61
5.5	THE INTERVIEWS.....	61
5.6	THE FINDINGS .....	61
5.6.1	HIV STATUS .....	61
	FIGURE 1: DEALING WITH AN HIV POSITIVE RESULTS.....	62
5.6.2	SUPPORT .....	63
	FIGURE 2: BREAKDOWN OF SUPPORT STRUCTURES .....	65
5.6.3	DISCLOSURE OF STATUS.....	66
	FIGURE 3: TIME PERIOD IT TOOK TO DISCLOSE HIV STATUS.....	67
	FIGURE 4: CHILD’S AGE AT TIME OF PARENT DISCLOSURE.....	68
	FIGURE 5: CHILDREN’S RESPONSE TO PARENTS DISCLOSURE.....	69
	FIGURE 6: PARENT-CHILD RELATIONSHIP AFTER DISCLOSURE .....	70
5.6.4	VULINDLELA COMMUNITY.....	71

<b>5.7</b>	<b>PARTICIPANT RESPONSES .....</b>	<b>72</b>
	<b>TABLE 2: PERCEPTIONS OF STATUS DISCLOSURE EFFECTS ON THEIR CHILDREN .....</b>	<b>73</b>
	<b>TABLE 3: CHALLENGES FACING SINGLE PARENTS .....</b>	<b>73</b>
	<b>TABLE 4: SUPPORT RECEIVED BY SINGLE PARENTS POST DISCLOSURE .....</b>	<b>74</b>
	<b>TABLE 5: SUPPORT FROM THE COMMUNITY, GOVERNMENT AND HEALTH FACILITIES PROVIDE .....</b>	<b>74</b>
<b>5.8</b>	<b>CONCEPTUALIZING HIV DISCLOSURE AND SOCIAL STIGMA CONCERNS.....</b>	<b>75</b>
<b>5.9</b>	<b>EMERGENT THEMES .....</b>	<b>77</b>
<b>5.9.1</b>	<b>Perceptions related to initial HIV testing .....</b>	<b>77</b>
<b>5.9.2</b>	<b>Positive effects relating to HIV testing: Receiving pre- and post-counselling and initiated to medication immediately .....</b>	<b>78</b>
<b>5.9.3</b>	<b>Different types of medication .....</b>	<b>78</b>
<b>5.9.4</b>	<b>The significance of support and medication adherence .....</b>	<b>79</b>
<b>5.9.5</b>	<b>HIV status disclosure effects to children .....</b>	<b>80</b>
<b>5.9.6</b>	<b>CHILD’S PRIOR KNOWLEDGE TO HIV/AIDS .....</b>	<b>80</b>
<b>5.9.7</b>	<b>EMOTIONAL SUPPORT .....</b>	<b>81</b>
<b>5.9.8</b>	<b>HEALTHY PARENT-CHILD RELATIONSHIP .....</b>	<b>82</b>
<b>5.9.9</b>	<b>SUPPORT GROUPS.....</b>	<b>82</b>

5.9.10	PARENTAL SEXUAL PARTNER AND INFLUENCES ON DISCLOSURE.....	83
5.9.11	MAIN AREAS OF ASSISTANCE.....	83
5.10	FUTURE RESEARCH.....	87
5.11	SUMMARY OF CHAPTER .....	87
CHAPTER SIX: CONCLUSION .....		87
6.1	INTRODUCTION .....	87
6.2	SUMMARY OF FINDINGS.....	88
6.3	ETHICAL CONSIDERATIONS IN RESEARCH .....	89
6.4	RECOMMENDATIONS .....	90
6.5	SUMMARY OF CHAPTER .....	94
REFERENCES .....		94
APPENDICES .....		104
Appendix A – Informed Consent.....		104
Appendix B Translated Informed Consent .....		107
Appendix C – Ethical Clearance Certificate .....		109
Appendix D – DoH Approval Letter.....		110
Appendix E - Translated Interview Schedule .....		112

**Appendix F - Turn it in Report ..... 114**

**APPENDIX G - PARENTS AND CHILDREN..... 115**

**APPENDIX H – TRANSCRIPTS..... 116**



## CHAPTER ONE: INTRODUCTION

### 1.1. OVERVIEW OF THE STUDY

The disease HIV/AIDS has been significantly prevalent since 2002 and is one of the most life threatening and socio-economic issues we face in South Africa (Abdool Karim, 2017). Statistics indicate that the disease was more common (Abdool Karim, 2017) in parents compared to children, thereby making it problematic for parents to decide whether to tell or not tell their children about their infection- positive HIV status. Disclosure of HIV status is an essential part of behavior modification. A parent's disclosure of their HIV-positive status can occur at different levels. It can be limited to sharing of health information between the parent and child which then happens to result in the child knowing the parent's status.

When one thinks about parents talking to children about their HIV status, they may feel many different emotions. Some emotions experienced are fear, anxiety and guilt. It may help to discuss feelings with people they trust, such as a health care provider, counsellor, family member, or friend. Parents may want to talk with that person about how and what he/she will say. They may also want to share their disclosure (telling someone) plans with those who already know their HIV status, so they will be prepared to give accurate, reassuring, calm responses if their children bring it up with them.

It can be helpful to prepare themselves by thinking about how they will react and what they will want to know based on their age and maturity. They may probably ask about their health. However, their main concern may be what will happen if you get sick. They will most likely need reassurance that they will be taken care of if something happens to you. Children may also want to know how you got HIV and if they might get it too. Depending on their ages, they will have different questions. They may not have any questions at all or ask questions later as they arise.

If children have already learned something about HIV at school or through the media, parents can use that as a chance to build on what they already know. Older children or teenagers sometimes learn about HIV in school. If your children already suspect something, they may feel angry that parents have kept it from them. Telling them may help them talk about HIV openly. This study examines the challenges single parents face when disclosing their HIV status disclosure to teenage children in the Vulindlela area. The area has been

reported with most HIV infections according to the CAPRISA (Centre for the AIDS Programme of Research in South Africa) research findings (Abdool Karim, 2017).

## 1.2 INTRODUCTION

South Africa (SA) remains the epicentre of the global HIV epidemic. Mother to child HIV transmission is a problem in countries with endemic HIV infections. Acquired Immune Deficiency Syndrome (AIDS) is the leading cause of death among all age groups (Lopez, Mathers, Ezzati, Jamison and Murray, 2006). Prevalence of HIV is very high in the country and statistics showed that in the year 2009, prevalence rate was 17% (Doherty, Hailekiros, Biadgilign, Amberbir and Beyene, 2013). Mahloko and Madiba (2010:85) confirmed that from the Human Sciences Research Council's 2012 household survey that an estimated "HIV prevalence of 2.4% in women between the ages of twenty and forty years and 1.7% in children less than five years of age exist. This equates to 369 000 HIV-infected women and children, of whom 166 000 were on antiretroviral (ARV) therapy (45.1%)."

The disclosure of parental HIV transmissions of parents to their children is increasing (Armistead and Forehand, 2015). Numbers of families living with an HIV positive parent are increasing, and in doing so it creates a challenge for them to decide whether, how, and when to disclose their HIV status to children. In 2009, the International Centre for AIDS Program recommended that school-aged children know their parent's HIV status. However, disclosure of a child's responses to HIV status presents unique challenges that needs to be focused on. Therefore, it is significant to look at the psychological and social impacts to the child's behaviour. Moreover, because most HIV infection is due to vertical transmission, disclosure implies revealing parental HIV status and may suggest a stigmatized "risk" behaviour in one or both parents (Abrams et al., 2011: 84). HIV infection is highly stigmatized condition where there could be considerable misinformation that persists among children's relatives, teachers and even community members (Wiener et al., 2007).

Furthermore, according to the World Health Organization (WHO, 2012), children, after disclosure of their parental HIV status find it hard to accept. Denial is the first reaction they may come to, many deny that their parents are infected, (Tascker, 2012: 47). In addition, they may need the intervention of a psychologist to help them cope with coming to terms with the disclosure. Support groups with similar children may be helpful. Sadness and depression are also common responses but is usually short-term. The child requires reassurance and assistance in exploring and coming to terms with his or her feelings, fears and anxieties. In

addition to this, suicidal tendencies are high, and should there be an expression of suicidal ideation, a mental health professional needs to be consulted. Therefore, disclosure of the diagnosis of HIV infection or AIDS to a child is a controversial and emotionally burdened issue (Lesch, Goto, Lindgren, Bidla, Dushay and Theopold, 2007).

The disclosure of HIV infection status to children and adolescents should take into consideration their age, psychosocial maturity, the complexity of family dynamics, and the clinical context. Parents who have disclosed their HIV status to their children experience less depression than those who do not. It also becomes a controversial and emotionally laden issue in the pediatric health-care community. According to the World Health Organization (WHO, 2014:33), prenatal transmission is defined as “the transmission of HIV from a HIV-positive mother to her child during pregnancy, labour, delivery or breastfeeding is called mother-to-child transmission”.

Despite mounting evidence (Vreeman, Scanlon, Inui, McAteer, Fischer, McHenry and Nyandiko :2015), argued that recommending disclosure of HIV status to young people as a central motivating factor for parents is adherence to antiretroviral therapy. Lipson (2014) asserts that, “disclosure of the diagnosis may also aid in preventing high-risk behaviour, thereby decreasing the further spread of the disease” (Lipson., 2014: 46). There are parents who have taken it upon themselves to care for the children suffering and affected by HIV/AIDS related illnesses. Moreover, disclosure implies that revealing parental HIV status and may suggest a stigmatized “risk” behaviour in one or both parents (Abrams et al., 2011: 84). However, McCausland and Pakenham (2008) discovered two important things, that parents/caregivers play a vital role in the community where there is an increase in survival periods for persons living with the disease, and that proper disclosure guidelines are lacking.

Therefore, this study will look at single parents’ lived experiences and the challenges they face when disclosing their parental HIV/AIDS status to children in a rural community of Vulindlela District. It is also hoped that the study will highlight some needs of these parents and children and discover solutions to those needs.

## **1.2 AIMS AND OBJECTIVES OF THE STUDY**

The aim of this project was to investigate into the challenges faced by single parents in disclosing their HIV status to children in the Vulindlela rural area. Single parents in this study meaning unmarried people, who may or may not be cohabiting.

An objective of the study is to determine whether there is an appropriate age at which to disclose to children the HIV positive status of their parents.

A concept analysis is a guide that is used to show actual traits of a specified thought to put a clearly applied explanation to guide operation for purpose of improving interaction through effective communication among health workers as they perform their role (Walker & Avant, 2005).

Although many efforts made by HIV/AIDS research and stakeholders to reduce the number of incidents of people infected with HIV, it has been reported that in the United States is it 15% higher in 2014 (UNAIDS, 2014). Most of the people who have been diagnosed with HIV find it difficult to communicate with someone about their HIV positive status. This is probably because it has serious concerns for the future. Different scholars have come up with different definitions on HIV status disclosure.

This study will utilize the views of Sutterheim (2014) and those of Greef, Phetlhu, Makoe, Dlamini, Holzemer, Naidoo, Kohi, Uys and Chirwa (2017).

i. Disclosure of HIV by Sutterheim et al, 2014 is defined as a selective process that occurs based on the individual's belief about the truth of honesty and confidentiality by those who will have received the information.

ii. Greeff et al, (2007) defines disclosure as telling someone that one is living with HIV. The above definitions vary in terms of the author's beliefs.

The researcher criticizes the definition of disclosure by Obermeyer et.al., (2011) because, it has been observed that, no one is forced to disclose their HIV status. Obermeyer et.al., (2011), defines disclosure as a process whereby an individual is supposed to reveal his or her own HIV status whether positive or negative. It is every individual's right to choose to disclose their status or not, to family members, children or sexual partners. However, existing scholarship are in support of those who do disclose their status, for improved medication adherence and support.

### **1.3 POSITIONING OF RESEARCHER**

Before elaborating on the research problem, it is essential to state the researcher's skills and experience with a view of grounding some of the views put forward throughout the study. The researcher worked as a research

fellow in Vulindlela for the CAPRISA (HIV/AIDS Research organisation) for more than two years. This includes working within the area as well as clinics, which are crucial in this study.

#### **1.4 RESEARCH PROBLEM**

The review of existing literature has identified insufficient evidence on specific challenges single parents face when disclosing their HIV positive status to their teenage children. The Vulindlela district has consistently experienced the most severe rates of infection of the HIV pandemic. This investigation explores extensive observations in the community and seeks to discover psychological challenges, depression and suicidal ideation which have not been adequately understood by scholars and practitioners in the field. The challenges facing single parents are prioritized in relation to seeking solutions and clinical interventions.

#### **1.5 SIGNIFICANCE OF THE STUDY**

The key objectives of the study to gauge the responses of a carefully selected, all-inclusive, perceptions of whether the teenage child needs to know their parent's status and discover how it affects them. Secondly, the researcher seeks to investigate the components that influences the parent's decision in status disclosure. Single parents should consider child's maturity if they will be able to understand what is happening when are told about their parents' status. The researcher also seeks to assess the challenges facing parents and the ways on how they overcome challenges and maintain a healthy parent-child relationship.

#### **1.6 RESEARCH QUESTIONS**

Parental HIV status disclosure is an unfamiliar practice in South Africa. Hence, the researcher has identified a gap in identifying and exploring the challenges faced by single parents within the local, Vulindlela Area guided in the research.

Key questions included:

1. How does the disclosure of HIV positive status of single parents affect their teenage children's everyday lives daily lives?
2. What are the challenges facing HIV positive single parents' everyday lives, and how does it affect them?
3. What support is available to single parents after they have disclosed their status to their children and face challenges?

4. What assistance does community members, the Government and health facilities provide?

## **1.7 METHODOLOGY**

The study applied qualitative research methods and the inquiry was explorative. Hence, in using the qualitative research methods, the researcher was able to connect with participants in their natural setting, create shared meaning of reality and make sense of phenomena “in terms of the meanings people bring to them” (Snape and Spencer, 2013:3). This design is relevant to this study to generate a wealth of descriptive data. Creswell (2013) asserts that explorative qualitative research allows the researcher to collect data from persons who are expert about phenomenon and helps develop a composite description of the essence of the experience for all individuals. Semi-structured interview schedule was used as a strategy for data collection. Data was recorded with the use of an audio recorder and taking field notes. The interview schedule was translated from English into IsiZulu for the benefit of the respondents who were not English speaker to gain more insight into the study. The study population consisted of 20 respondents (10 male and 10 female). This study was conducted in three local Clinics in Vulindlela.

## **1.8 ORGANIZATION OF THE STUDY**

**Chapter One** gives an overview of the study, clearly introduces and provides a background for HIV status disclosure, globally and locally. **Chapter Two** investigates in-depth literatures that had investigated HIV status disclosure internationally. **Chapter Three** analyses and interprets relevant theoretical frameworks in relation to sociological theories in HIV status disclosure. This chapter explored Mbigi and Murry (1997) five finger theory. **Chapter Four** provides an overview of the methodology that has been adopted for this study. It provides the detailed report of the fieldwork segment. **Chapter Five** presents the discussion and analysis of the data collected during the fieldwork. **Chapter Six** provides an overall summary, conclusions, and recommendation for further academic studies.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 INTRODUCTION**

The purpose of the literature review was to acquire and compare findings in the international, the Sub-Saharan and local, South African context. Whilst surveying the literature, the researcher identified gaps which allowed her to be able to identify at what level research appears to be deficient. Creswell (2012) argues that a literature review takes a form of a tunnel.

### **2.2 CONCERNS ABOUT PARENTAL HIV STATUS DISCLOSURE**

In September 2004, West African legislators developed a model of AWARE-HIV/AIDS legislation at a workshop in N'djamena, Chad, with the expressed aims of defending the rights of individuals who are HIV positive, and those close to them who are affected by HIV (Sanon, Kabore and Wilen, 2009). However, it is also argued that some requirements of the model law threaten the human rights of individuals living with HIV. Sanon et al. (2009) cited concerns about an obligation that individuals disclose their positive HIV status to sexual partners within six weeks of diagnosis.

The Original Article Journal of Social Aspects of HIV (McCausland and Pakenham 2008) asserts that health workers should notify sexual partners and children if the HIV positive patient does not; that compulsory testing be carried out during certain circumstances that includes pregnancy; and that HIV transmission by someone who had previously tested positive should be considered a criminal act. In terms of questions about consent or granting permission to disclose someone's HIV status, literature suggests that test results are sometimes shared with church leaders, local authorities or spouses without the agreement even before they are given to the individuals tested (Luginaah et al., 2005).

A case study of mandatory premarital testing in the Democratic Republic of Congo (DRC) found that, local churches in Goma arranged for test results to be sent directly from the laboratory or clinic to the church pastors who would then disclose the results to the couple (Rennie and Mugenda 2008). In countries such as Senegal and Zimbabwe, proponents of mandatory premarital HIV testing have argued that such policies are needed to protect girls and women, particularly when they have little control over whom they marry (Burns 2010; Rennie and Mugenda (2008). Rennie and Mugenda (2008) argued that, apart from evidence that such policies have questionable public health value – the consequences for young women who test positive during premarital testing may be more severe than for young men.

## **2.3 MOTIVATIONS FOR DISCLOSURE**

Considerable research has examined factors such as the social, physical and economic consequences of HIV disclosure. It poses both positive and negative impact. Evidence suggests that HIV disclosure may positively influence behaviours that protect the health of people living with HIV, their partners and their children. This is exemplified by research from other parts of the continent such as Cameroon, South Africa and Uganda, where it was found that most persons who disclosed their HIV status to sexual partners were expressively more likely to report safer sex behaviours. These behaviours include practicing safe sex, reducing the number of sexual partners, and becoming committed to one partner (Wong et al. 2009). In addition, HIV positive women diagnosed with HIV within their pregnancy and who disclosed their status to partners were more likely to convince their partners to get tested than women who did not disclose to their partners (Brou et al., 2007). Furthermore, HIV status disclosure has been linked to improved adherence to medication, and to replacement feeding as a means of preventing HIV transmission to infants as spread of new mother to child infections (Betancourt, 2010).

## **2.4 CONCEPTUAL CLARIFICATION: HIV DISCLOSURE**

A concept analysis is a guide that is used to show actual traits of a specified thought to put a clearly applied explanation to guide operation for purpose of improving interaction through effective communication among health workers as they perform their role (Walker & Avant, 2005).

Although many efforts made by HIV/AIDS research and stakeholders to reduce the number of incidents of people infected with HIV, it has been reported that in the United States is it 15% higher in 2014 (UNAIDS, 2014). Most of the people who have been diagnosed with HIV find it difficult to communicate with someone about their HIV positive status. This is probably because it has serious concerns for the future. Different scholars have come up with different definitions on HIV status disclosure.

This study will utilize the views of Sutterheim (2014) and those of Greef, Phetlhu, Makoae, Dlamini, Holzemer, Naidoo, Kohi, Uys and Chirwa (2017).

i. Disclosure of HIV by Sutterheim et al, 2014 is defined as a selective process that occurs based on the individual's belief about the truth of honesty and confidentiality by those who will have received the information.



ii. Greeff et al, (2007) defines disclosure as telling someone that one is living with HIV. The above definitions vary in terms of the author's beliefs.

The researcher criticizes the definition of disclosure by Obermeyer et.al., (2011) because, it has been observed that, no one is forced to disclose their HIV status. Obermeyer et.al., (2011), defines disclosure as a process whereby an individual is supposed to reveal his or her own HIV status whether positive or negative. It is every individual's right to choose to disclose their status or not, to family members, children or sexual partners. However, existing scholarship are in support of those who do disclose their status, for improved medication adherence and support.

## **2.5 LEGISLATION ON HIV DISCLOSURE**

There are very low rates associated with HIV disclosure, which makes it difficult for ethical and human rights. There are concerns to one about how to stabilize the medical secrecy, safety and well-being of people already diagnosed with HIV with the rights of partners and children to be protected from HIV transmission.

In many governments, in the sub-Saharan region, laws or policies have been promulgated that stresses respect for an individual's informed consent and medical confidentiality. Contrariwise there are governments in the region that have considered laws to criminalize HIV transmission by HIV positive persons, that orders disclosure to sexual partners, or involuntary partner notification by health workers (Kerlinger, 1986). Since 2004, similar provisions have been passed into law in countries, including Benin, Burkina Faso, Burundi, Cape Verde, the Central African Republic, Chad, the Democratic Republic of the Congo (DRC), Djibouti, Equatorial Guinea, Guinea, Mali, Niger, Sierra Leone, Senegal and Togo (Kazatchkineand Pearshouse, 2008a).

In other African countries, such as Zimbabwe, policy-makers and women's groups have supported criminalizing transmission to shield women, change male behaviour and punish men who spread HIV to female partners (UNAIDS & UNDP, 2008). However, some researchers argue that, in practice, women may be more likely than men to be accused of nondisclosure or criminal transmission, because they are more likely to be HIV positive. Therefore, the UNAIDS Reference Group on HIV and Human Rights concluded that, "in the irresistible popular cases, applying criminal law to the spread of HIV does more harm than good" (UNAIDS Reference Group on HIV and Human Rights, 2008:33). The group called for, 'encouraging a social and legal environment that is supportive of and safe for voluntary disclosure of HIV status' as well as for expanding evidence-informed programmes that prevent HIV transmission while, 'protecting the human rights

both of those living with HIV and those who are not infected' (UNAIDS Reference Group on HIV and Human Rights, 2008 :34). These arguments have persuaded parliamentarians in some parts of the region to reject criminalization. Although this is the case, provisions of criminalization continue to exist in many regions.

While policies in these countries mentioned respect for confidentiality, some did so within certain restrictions. In Swaziland, Zambia and Zimbabwe, policies referred to 'shared confidentiality' – the belief that patients' HIV status should be shared with health workers or family members involved in care and support. In Swaziland, Zambia and Zimbabwe, policies allowed patients' HIV status to be shared among health-care workers; and in some countries, including Kenya, Tanzania and Zimbabwe, policies authorized health workers to disclose a pregnant woman's HIV status to her spouse or sexual partner without her consent, if she refused to tell her partner herself (Obemeyer, Baijal and Pegurii, 2011). Furthermore, ethical considerations according to the South African Constitution (Act 108 of 1996) and the law always recognizes the importance of maintaining the confidentiality of the HIV status of a patient. South African law dictates that the right to human dignity is one of the core constitutional rights, because human dignity is what gives a person their essential worth (Hepple, 2000). Another important factor regarding the Legislation to HIV/AIDS is in the workplace.

The status of HIV positive patients should always be treated as highly confidential including their medical records. The system with the sensitive information should be accessed by specified individuals. Sharing information of a patient who is HIV positive in clinics, hospitals and between Doctors is only permitted if the patient has given consent or agreed or if it is clinically indicated. This is not the case within the sub – Saharan region. Governments have laws that criminalize HIV transmission, and order disclosure to sexual partners, or involuntary partner notification by health workers.

In South Africa, it is important that the health care practitioners give due consideration of a patient even to other health care professionals involved in the supervision of one patient.

The test results of HIV positive patients should be treated with the highest possible level of confidentiality. Confidentiality regarding a patient's HIV status extends to other health care practitioners.

## **2.6 DEFINING QUALITIES OF HIV STATUS DISCLOSURE**

According to Walker and Avant (2005:53) "there are traits or characteristics of a concept that are closely linked with it in order to assist in differentiating a concept from any related concept". These traits include

communication with people, the appropriate time to communicate, protecting someone from knowing certain details, relationship status of one or both, having significant health related information, assistance to cope, tolerance for unpredictable results and expectance of serious response to HIV status disclosure (Eutace et al., 2010).

## **2.7 IDENTIFYING ANTECEDENTS AND CONSEQUENCES**

Antecedence are those events that must take place before the concept being described take place (Walker & Avant, 2005). Some antecedents are psychosocial factors and expected effects and support systems. If individuals perceive that they are going to be judged and discriminated, then they are certainly not going to disclose their HIV status. However, the moment they feel that they will be accepted by others in the society then they will be motivated to disclose.

## **2.8 CONSEQUENCES OF HIV STATUS DISCLOSURE**

There are positive and negative consequences to HIV status disclosure. These include advanced stage of HIV supervision, job discrimination and job loss which are more prevalent in remote areas. Nevertheless, parents may choose not to disclose “non-disclosure” of their positive HIV status.

Researchers have recognized negative consequences of disclosure for both sexes. This results in isolation, criticism and exclusion by family member’s, separation amongst married couples, violence from partners, and rejection by friends. Scholarship reflects that some of these consequences are reported by women, and women were victims as they experienced a violent reaction from their partners when they disclosed their status (Medley et al. 2004). The rates of consequences following disclosure have been reported to be difficult to compare across studies. This is due to the wide range of negative reactions, from relatively mild examples due to the lack of emotional support, and severe cases of abandonment or physical violence. Studies by Hepple, 2001 have had difficulty determining whether adverse events resulted from HIV disclosure itself. Nonetheless, fears about negative reactions from partners, family members, children and communities are a major barrier to both testing and disclosure.

Children are adversely affected by parental disclosure of a positive HIV status. The impact of this may be psychological. In cases where children are young and are still instil in school, it had been reported that children suffer and lack performance in their grades at school (Lopez et al., 2006). This is particularly from denial that the parent is “sick”, or parents used improper guidelines in the process of disclosure. It is also crucial to consider the event, and time of disclosure as a parent, to observe whether the child is ready to

receive the news. Suicidal reaction is another consequence of parental HIV disclosure to children. Children respond differently to disclosure, some may find it easy to accept that their parents are HIV positive and the affected this has on their lives, while others may really struggle to accept this. Therefore, it is important to have systems in place to cater for the psychological effects to the child after disclosure.

## **2.9 REASONS FOR HIV NON-DISCLOSURE**

A parent's decision whether to disclose their HIV-positive status to their children may be affected by several factors. A fundamental centrality is based in the ability to overcome any difficulty that is associated with fear of rejection, accusations of unfaithfulness, judgement, violence and possibly any loss of partner's financial support. Although both parents face fear, fears experienced by mothers are justified. Farquhar and Kiiare, (2017) argued that women who work away from home or who are more sexually experienced fear disclosure because of the belief that they will be blamed for infidelity. Due to this perception, these women are less likely to disclose their HIV status to their partners and children. Disclosure is also influenced by the nature of the couple's relationship, family support and a bond between a child and the parent such that disclosure may only be a pointer to the state of the relationship. It is believed that, married women and their partners who have good communication, who do practice and discuss HIV testing prior to the test, are more likely to disclose their diagnosis of HIV/AIDS. The dimension of a relationship, ranging from the level of trust and honesty, and the level of communication some of the other relationship factors that may influence disclosure. Hence, partner support is crucial in this instance, argued (Farquhar and Kiiare, 2017), this is discussed below.

## **2.10 PARTNER SUPPORT**

The ability to recognize a diversity of factors that enlighten whether an individual will disclose their status or not, further extends to the need for several strategies in place to address these factors that will promote safe disclosure to a partner ought to be put in place. In the sub-Saharan Africa, there are guidelines that have placed an unjustified burden of disclosure on the tested individual. This is an approach that has not resulted in satisfactory disclosure rates in many settings. An approach of restructuring the burden of disclosure from the women is needed because it would improve disclosure between partners.

The disclosure of a positive HIV status becomes easy if it is properly facilitated. The process of a facilitated disclosure includes the presence of a counsellor during the testing process, as they assist with disclosure process. HIV testing of couples is a widely-used strategy that in addition to removing the burden of disclosure from the woman, it also provides a safe disclosure environment. Couple testing also enhances male partner

support for uptake and adherence, the same could be applied for the disclosure between a parent and a teenage child. Another effective method that is safe and acceptable is, however, the counsellor should be available to prevent any challenges that may arise, for instance stigma. Home-based testing may cause stigma resulting in erroneous disclosure where there is a disjoint within a family between the person infected with HIV and other family members.

It is then crucial to also consider that gender and societal norms prevents women from having a voice. They become a marginalized group in society. These factors may prevent women from disclosing their HIV-positive status. We need women empowerment programmes in society to address such factors and community-based programmes that will address stigma associated with HIV. Support groups for infected women have also been shown to help women in their efforts towards disclosure (Lipson, 2014) according to the reviews by scholars on Global Literature

In addition, involvement of the male partner is somewhat accountable for the association between non-disclosures of HIV status. Barriers have been reported and found to have an impact on male partner involvement. This has been classically divided into health system factors, socio-economic and cultural factors. Health system factors include long hospital waiting times, unfriendly staff and female-dominated services at the hospitals. Socio-economic difficulties have discouraged men from getting involved because of time spent at the hospital could be used to work, and the double transport cost implications. Consolidated male partner involvement has the double effect on greater adherence to medication as well as a safe path for disclosure of a positive HIV status by eliminating the burden of disclosure from women.

## **2.11 IMPORTANCE OF DISCLOSURE**

There are some identified fears in the process of disclosure and the facilities especially in the sub-Saharan African countries. These fears include stressors about lack of anonymity and instinctive HIV status disclosure. It represents challenges and barriers to health facilities in many parts of the sub-Saharan Africa. However, there is insufficient literature on the breaches of HIV medical confidentiality within health facilities in the region. One of the few studies on this topic was conducted among health-care providers. The study found that 38% of professionals reported giving confidential information about an HIV positive patient to family members without their consent (Anyamele et al., 2005). In addition, a population-based study in Botswana found that some respondents who tested for HIV reported a breach of confidentiality by a health-care worker to their family and sexual partners.

## **2.12 THE INFLUENCE OF GENDER AND SOCIETAL NORMS ON HIV DISCLOSURE**

The influence of socio-economic factors and gender on parent-child disclosure rates are significant. In South Africa, studies have found higher disclosure rates in urban areas with more institutional services prevalent compared to rural areas. This is due to differences in socio-economic status. Similarly, in Nigeria, researchers found that the most educated individuals disclosed more often than less-educated people. Hence, there is a clear association between disclosure and economic position (Akani and Erhabor 2006).

Research from Kenya found that women were knowingly more likely to disclose and notify their partners and children if they had limited resources or relied on their families for economic support that suggests that women may feel compelled to disclose to them to ensure continuing economic support. Meanwhile, socio-economic difficulties have discouraged men from getting involved in HIV disclosure, medication adherence because of the time they spend in clinics and hospitals. They lose time at work and incur double transport costs.

## **2.13 EXPERIENCES OF DISCLOSURE**

In identifying international research, it was found that Gerson (2001) conducted a study in Burkina Faso, which studied factors that are associated with the parental disclosure. Gerson (2001) studied factors including female sex, parent's age profile, parental past and number of children. This study argued that, parents must consider and understand the role of age in HIV disclosure. Burkina Faso is one of the rural areas in the study and results show a significant finding in that the low rates of disclosure that amounted to 7%. This was due to most of the children were still in school (Gerson et al., 2001).

Vreeman (2010) in a resource-limited setting, conducted a study about beliefs in disclosing a parent's HIV status, and the following impacts of the disclosure have not been well studied found that, "the most commonly cited problems, for instance with medication adherence included delaying or skipping doses because parents did not want to take medicines in front of their children" (Vreeman, 2010:642). His results showed that even though their setting lacks standardized guidelines and resources for undertaking disclosure, children were informed about parent's positive HIV status.

Campbell (2017), in a study on community-based assessments with children of single parents living who are HIV infected, reported substantial depression and suicidal ideation. The study relies on relationships with community-based organizations and AIDS service organizations to connect HIV-affected families to mental health services. These are put in place in order to be utilized when proper solutions are needed and applied to situations like when children are depressed.

Moreover, Julianne's (2015) literature on rural HIV positive women, investigates perceived teenage children's reaction to single parent's disclosure of HIV-positive information. Julianne (2015) found that there were three forms of intellectual or cognitive reactions. To better understand them, he used the following examples where children would ask questions such as: i)"How long have you been infected?" ii)"Who infected you?" or iii) "Are you OK?" (Julliane, 2015:17). The similarity of perceived reactions by the HIV positive individual with the actual reactions of teenage children deserves further exploration in this study.

Clarke (2010) on a joint study between the University of Edinburgh and Children in Scotland, found that very little is known in Scotland about affected children on parental HIV status disclosure. Study recommendations included "the need for the establishment of joint service plans between local authorities and health panels, the coordination of assessment and intervention; and the targeting of additional services to meet the need and reduce inequality" (Clarke, 2010:111).

In addition, a study on disclosing parental HIV status to children on lessons learnt through an involvement by Haung (2011), found that, HIV positive single parents when deciding whether and how to disclose their illness<sup>1</sup> to their teenage children is a major stressor. It further discussed the results comprised of severe stigma experienced by father's need for both parents to agree on how to go about the disclosure process, and parents' fears about the values of the disclosure (Haung et al., 2011).

In the United State (US), more than 60 000 single women have been reported to be diagnosed with HIV/AIDS. During their HIV illness stage, these parents face challenges<sup>2</sup> of being both a parent and a caregiver of the family (Hackl, 2015). Findings, in a study conducted by Hackl (2015) on "Women Living with HIV/AIDS: The Dual Challenge of Being a Patient and Caregiver", show that single parents are not only faced with clinical depression when disclosing their HIV status to children, but also, faced challenges such as stigma, the disbelief of the diagnosis and the unwillingness of family members to act as a guardian for their children (Hackl, 2015:53). However, conclusions indicated that a model for multidisciplinary intervention is proposed to mainly focus on parents' needs within their family systems.

Another study in the US by Converse (2013) on Disclosure and Impact of Maternal HIV Positive on Mothers and Children in Rural Haiti's main objective was to identify factors that influence parental HIV disclosure. The study revealed that, the main challenge for single mothers living with HIV to disclose their status is the decision to disclose (Converse, 2013). Results showed that impact of disclosure included emotional reactions for children and mothers, children's desire to assist their mothers with the illness and become involved in day to day activities. Conclusions on this study suggest that there is a need to provide more psychosocial support to assist both parents and children, in order to achieve a healthy relationship between the parent and the child (Converse, 2013).

Dwivedi (2013) investigated the relationship between the parent and the child after disclosure. Findings of the study revealed that most of the parents reported feeling less fearful of death. Over half of the parents reported that they feel less stressed about shame, about blame and judgments. Both parents and children in this study communicated positive outcomes, such as healthy and improved relationships in the family (Dwivedi, 2013). This is consistent with the study conducted by Converse (2013). Therefore, emphasis on the importance of parent-child disclosure seems to be a positive step for the families participating in the home-based care programs in rural areas.

Existing literature by the World Health Organization (WHO, 2011) advised that parents should disclose their HIV status to children, even though there is a lack of evidence concerning the potential inferences in resource-limited settings. Clifford (2013) in his study on Mothering at a distance and disclosure of maternal HIV to children in Kingston, Jamaica found that, lived experiences of parents talking to their children about parental HIV presented additional challenges for HIV positive mothers who are trying to establish emotional intimacy when talking to their children about their positive HIV status (Clifford, 2013). Conclusions were made that a policy needs to identify culturally-specific family formations which will include absent fathers, protecting at a distance and pampering non-biological children (Clifford, 2013:42).

Chaudhary et al. (2016) in a study on HIV status disclosure through family-based intervention supports parenting and child mental health in Rwanda. The study analyzed the efficiency of a randomized controlled trial comparing a family-based intervention compared to normal social work care to support HIV disclosure among parents and children in Rwanda. Findings indicated that parents and children become highly stressed through the process of disclosure. The authors declared that the family intervention assisted in offering



structured support for improved relationship between the parent and the child as well as communication which resulted in enhanced family trust and child's mental health (Chaudhury et al., 2016).

A study conducted at the Department of Pediatrics (2016) by academics in the University of California, USA had an aim to determine factors related to the timing and possibility of nondisclosure of HIV status to prenatally HIV-infected children. A cross sectional study found that, the probability of earlier age of parental HIV disclosure is linked with higher child's intellectual capacity (Department of Pediatrics, 2016). Results showed that factors associated with increased parent-rated anxiety in HIV infected children in univariate analyses other major life events. The findings revealed that higher child's intellectual capacity may not necessarily minimize emotional distress, indicating the need for further evaluation of the appropriate timing and type of disclosure for pediatric HIV (Department of Pediatrics, 2016: 33).

"Are Mothers telling their children"? A study on disclosing parental HIV status by a PhD student in Georgia State University (Odoh, and Frankish, Campbell and Foulis, 2015). Reports continue to reveal high HIV AIDS rates in American women. Mothers in this geographic area, do not only face child rearing stress, but also, a difficult decision when it comes disclosing their HIV status to their children. The study was conducted amongst HIV positive mothers and their uninfected children. Results shows that, very few mothers did disclose their status to children. Disclosure is found to be associated with parent's level of income, however, unrelated to child's functioning. Conclusions revealed that the low disclosure rates in the area should be noted and handled by professionals.

In 2012, a study was conducted at a University Hospital in North-eastern Brazil, which aimed to assess the social support for people with HIV/AIDS. It was a cross-sectional study, with 215 patients (Moretti, 2015). Results showed that average scores of social, emotional and instrumental support was satisfactory and not influenced by sex education, marital status and length of antiretroviral therapy. People diagnosed for less than three years had more instrumental support than those diagnosed over three years. Neighbors, employers and health professionals provided less support. Conclusions were made that, people with AIDS have reasonable social support, especially from friends and family not living in the same household (Moretti, 2015).

### **3. SUB-SAHARAN AFRICA**

There are persistent rates on consequences and social context of disclosure with special attention to gender issues and the role of health services in the sub-Saharan Africa. Sarah Bott, Carla Makhoulf Obermeyer

(2017) reviewed the policies and practices within the social and gender regarding the HIV/AIDS status disclosure. Findings revealed that, the persistent rates of choosing not to disclose the HIV status by people who are living with HIV, raises difficult ethical, public health and human rights interrogations in terms of protecting medical confidentiality, health and well-being of people living with HIV. Conclusions were made that, even though there are initiatives to encourage intended HIV in the sub-Saharan Africa, health workers continue to contend difficult challenges in the face of nondisclosure, and often express a need for more guidance and support.

According to Zhao, Li, Qiao, Zhao, Zhang, and Stanton, (2016), culture and developmentally appropriate parent's HIV disclosure has been shown to be meticulously related with the happiness between the parents and their children. However, existing practices of parent's HIV disclosure continue being poorly understood in countries like China because of their low standard of living (Zhao et al., 2016). Therefore, a quantitative study was conducted from 626 children who were affected by parent's HIV status disclosure. These children included orphans and vulnerable children in Henan, China. The aim of this study was to examine children's perceptions and information regarding their parents' HIV disclosure practices, as well as to assess the links of these practices with children's demographic and psychosocial factors. Findings revealed that, a small proportion of children had learnt about parental HIV infections directly from them, whilst many reported unplanned disclosures, they found out of own observations and suspicions. Results support the conception that parent's HIV status disclosure is a multifaceted process and can only be helpful if it is planned accordingly. Conclusions suggests an urgent need cultural and developmental approach in parent's HIV disclosure in order to maximize benefits to both the children, parents, and the family functioning (Zhao et al., 2016).

A study by Kanyamura, Belitha and Ncube (2016) aimed to clarify HIV status disclosure and to identify characteristics, backgrounds and values attached to it. According to Kanyamura et al. (2016:105), disclosure is a process that includes; communicating amongst one another, whether it is perfect timing for disclosure, relationship status, experiencing the event, and protecting someone. The experiences identified were, a sample drawn from Zimbabwean scholars in the University residents. Psychosocial factors, projected consequences and social support systems. Consequences revealed both positive and negative outcomes in terms of the disclosure.

Furthermore, in Uganda, literature indicated HIV-infected parents experienced challenges with HIV status disclosure. Parents in Uganda were found to be afraid of the discrimination they faced from the community they live in. This resulted in feeling shame and guilt-related emotions because of unprotected sexual intercourse and possibly the loss of certain privileges in society (Kyaddondo et al., 2013). However, without disclosure, results show that they also lose access to the healthcare systems, societal resources, and potential treatment which results from failure to express their need for HIV care (Kyaddondo et al., 2013).

Another study in rural Uganda found that, there are very limited facts on the experiences of single parents in disclosing their HIV status. Barriers to parents' disclosure included perceptions that children are too young to understand what HIV infection means and fears of secondary disclosure (Amaran, 2015:35). Findings show that immediate outcomes of disclosure included children getting scared and crying (Amaran, 2015). Furthermore, recommendations were made that country-specific interventions are needed to improve the process of parental HIV disclosure to children and this should involve preparation on how to deal with the instant emotional challenges associated with the parent-child disclosure process.

HIV status disclosure through family-based intervention supports parenting and child mental health in Rwanda. About 40 households were randomized to family-based intervention and 40 households to care as usual. Parenting, family unity, and child mental health during the process of disclosure were studied using quantitative and qualitative research methods. Inclusive findings suggested the need for adjustments in parenting styles, family unity, and trust surrounding the disclosure process. Conclusions were made that family-based interventions may support parenting and promote child mental health during adjustment to caregiver after HIV status disclosure. Further investigation is required to examine the role of family-based intervention in supporting parenting and promoting child mental health in HIV status disclosure.

Cornell (2009) conducted a study in the Democratic Republic of Congo where the objective of the study was to develop a culturally appropriate approach in attaining assent (child's agreement to participate in the study) for teenage children to participate in the study. Results showed that teenage children should be informed about their parents and own HIV status prior to the research study and giving assent (Cornell, 2009:10). Moreover, conclusions were made that several parents and some health professionals when explaining HIV-related research to teenage children, the term HIV should be excluded, especially if it concerns the status of their own single parents (Cornell, 2009:11).

A study conducted in Tanzania on HIV status disclosure among postnatal women in a rural area found that the HIV status disclosure is a key support strategy to start and maintain HIV care and treatment (Ostermann, 2015:417). Results of this study discovered patterns that showed that mothers frequently disclosed their status to husbands or female relatives and experienced mostly positive reactions. Conclusions were made where nurses facilitated disclosure which was feasible in this low resource setting and was used by patients to help them with both first-time disclosure and disclosure to new persons (Ostermann, 2015).

A study in Uganda, cited by Dr. Edward Kirumira, entitled Making a difference for children affected by AIDS revealed that, the impact of a parent's HIV status disclosure imposes education and emotional setbacks to teenage children (Gilborne, 2011). Teenage children aged between 13 -18 years of age reported a decline in school attendance. Results showed that material support is required. "When single mothers were asked what they need in order to look after their children, both parents and guardians were most likely to say that they need material assistance or support" (Gilborne, 2011:33).

In the study by Gachanja (2018), he found that partial disclosure was suitable for teenage children, and full disclosure is delayed until the child reached adolescent stage. Full disclosure was best found to be performed by parents, caregivers and with the support of healthcare practitioners.

Kalembo (2018) conducted a study in Malawi that accessed perceptions and challenges of single parents of HIV status disclosure to children aged between six to twelve. Results showed that a "working together" model emerged from the data analysis where participants expressed the need for them to work as a team in order to promote safe and effective HIV status disclosure through talking about HIV, sharing responsibility and open communication" (Kalembo et al., 2018:16). Global resources are required to better support children and their parents through the disclosure process.

Namukwaya et al., (2017) in a study in Uganda found that factors motivating disclosure by parents included curiosity by young people. Results reported protecting no anger despite their parent's pre-disclosure fears. Recommendations were made that disclosure to young people should occur as a planned process with parents receiving support from health care practitioners and not as a mistake or at the heat of anger within the family (Namukwaya et al., 2017).

Okawa et al. (2017) in a study on adolescents' experiences and their suggestions for HIV status disclosure in Zambia examined adolescents' perspectives on the best HIV disclosure practices. This is one of the highest

HIV-burdened countries in Sub Saharan Africa. Adolescents reported being emotionally impacted by disclosure but that has also improved their parent's self-care, adherence to medication, and ability to speak about HIV openly (Okawa et al.,2017).

Odiachi (2017) conducted a study on the impacts of disclosure on health and related outcomes in HIV infected children on the association between pediatric HIV disclosure and health outcomes in Sub Saharan Africa. Findings revealed five major health outcomes that included physiological, psychosocial, adherence to HIV treatment, sexual and reproductive health, and disclosure of their status to others. The author recommended larger longitudinal studies focused on health outcomes of pediatric disclosure and the creation of policies/guidelines aimed at promoting and improving the low rates of disclosure among this population, especially in the Sub Saharan Africa (Odiachi, 2017).

Contrary to this, a study conducted in the sub-Saharan Africa on the social and gender context of HIV disclosure found that there are legal and policy related matters that should be considered when disclosing a diagnosis (Bott and Obeermeyer, 2013). Hence, some people may decide not to disclose their status at all. Findings revealed that “despite initiatives to encourage voluntary HIV disclosure and to increase partner testing in sub-Saharan Africa, health workers continue to be faced with difficult challenges in the face of nondisclosure, and often express a need for more guidance and support in this area” (Bott et al., 2013:66).

A study of uncontrolled and post intervention evaluation in Sub-Saharan Africa, had an objective to support single mothers to disclose their status to their uninfected children. The research of the Amagugu intervention, under the Africa Centre for Health and Population Studies discovered that single mothers in the Region need support when they disclose their HIV status. 281 mothers living with HIV were included, as well as their uninfected children between the ages of 6-10 years. This study also aimed at measuring the outcomes from full, partial or non-disclosure to children. Results show that, 60% of the mothers had fully disclosed their status, 40 of them partially disclosed to their children (Rochat et al., 2014). Furthermore, these mothers reported that most children were calm, compared to the ones who had been fully disclosed to, they were asking many questions about mother's death. Conclusions revealed that, this is one of the suitable interventions to be implemented in areas that are in resource limited settings.

Having highlighted the above, a study on anonymity on disclosure in the sub – Saharan Africa, Uganda found that 38% of professionals reported giving confidential information about an HIV positive patient to family members without their consent (Anyamele et al., 2005). In addition, a population-based study in Botswana

found that some respondents who tested for HIV reported a breach of confidentiality by a health-care worker to their family and sexual partners. A qualitative study conducted in Botswana, on the discussions of sexual health with children, shows that keeping family secrets from children, including those who are related to a parent's HIV status, can be detrimental to their psychological well-being and to the structure of the family, Osrom (2016). Findings revealed that most parents found it hard to disclose their status to children, others did not disclose at all (Ostrom et al., 2016).

#### **4. SOUTH AFRICAN LITERATURE**

In South Africa, very few studies have examined disclosure of parental HIV status and infection to children and its effect, as well as the challenges parents are facing when disclosing their status (Palin, 2008). In a qualitative study, on parental HIV infection in South Africa on description and relationship to teenage functioning, findings showed that “a total of 44% of mothers had disclosed to their children, and those who had most typically perceived children's reactions to disclosure to be sadness and worry” (Palin, 2008:33). Conclusions were made that single mothers were less likely to disclose their status than married or widowed mothers.

In addition, about 2.3 million children are orphaned by AIDS. These numbers will increase by 2020, according to the Actuarial Society of South Africa (2005). Little is known about the impact of AIDS-related mourning on children, to offer proper assistance in terms of services. A study titled: Psychological distress amongst AIDS-orphaned children in urban South Africa, investigates emotional and mental effects on HIV/AIDS to orphaned children in urban township areas of Cape Town (Cluver, 2015). This study sample included 1025 children aged between ten to nineteen years. Children were interviewed using depression, anxiety, stress, peer problems, delinquency and conduct problems were assessed using standardized scales. It is important to explore and understand the causes and effects of HIV/AIDS to children. Results shows that factors such as age, gender, age at losing parents and children orphaned due to HIV were more likely to report signs of depression, peer pressure amongst other children, stress, and actions of delinquency. Anxiety showed no differences. AIDS-orphaned children were more likely to report suicidal ideation. Compared to Western norms, AIDS-orphaned children showed higher levels of internalizing problems and delinquency, but lower levels of conduct problems. The study concluded that orphaned children are a defenseless group in terms of emotional and behavioral difficulties. Recommendations were made where there is an urgent need to implement programs to prevent extensive reactions to children due to parents dying from HIV.

As antiretroviral therapy becomes more widely accessible in developing countries, increasing numbers of HIV infected parents survive into later stages in life. As they grow older, HIV status disclosure presents a unique challenge to health care workers and care givers of children affected by HIV/AIDS. Disclosure is a vital component of the variety of HIV care with confirmed health benefits, it is poorly addressed in routine clinical practice. Therefore, there is an urgent need for applied interventions, for instance developmental guidelines that will support HIV disclosure to children with developmentally appropriate information about the disease (Okawa, 2017).

Madiba (2015) literature on HIV-infected single mothers in the Ekurhuleni District Gauteng Province which investigates the parental disclosure of HIV positive status to HIV-uninfected teenage children and their reactions to disclosure, determined the prevalence of parental disclosure of HIV status to uninfected children. The results showed that there were more females two hundred and thirty-five (69%) than males one hundred and five (31%) who had disclosed their HIV status to children (Madiba, 2015). The rate of parental disclosure to children was very low and consistent with rates of much earlier studies conducted in South Africa and sub-Saharan countries.

While Mazibuko (2007) in his work empowering women for gender equity, found the HIV/AIDS status disclosure process as a healing step. Magwaza (2012), one of the participants interviewed reported that she was diagnosed with HIV eleven years ago, at the age of twenty-three. Currently, she had described her life as happy. However, she admitted it wasn't easy for her to accept that she was infected with a life-threatening disease (Mazibuko, 2007).

Nicholay (2010) literature regarding cultural beliefs on single parents in South Africa, explains that their cultural beliefs make them not disclose their HIV positive status to their children. Moreover, apart from proper guidelines, there are structural factors that include guidelines based on cultural factors, national realities and individual family circumstances, such as its communication style. Research shows that keeping family secrets from children, including those related to a parent's HIV status, can be harmful to their psychological well-being and to the structure of the family (Nicholay et al., 2010).

Rochat (2016) in a study of communication on parental reports of primary school-aged children's questions after parental HIV disclosure in rural South Africa, supported HIV positive single mothers to disclose their HIV status to their children aged 6 -10 years of age. Findings shows that children were mostly concerned

about the threat of death, their mother's survival, and past family deaths. Communication about death did not have instant negative consequences on child behaviour according to parental reports (Rochat et al., 2016).

A study by Tisall (2018), in identifying the teenage children needs and listening to teenage children whose parent is HIV Positive in Dundee, KwaZulu Natal, South Africa, revealed that services are not in place to address the needs for teenage children who are affected by their parent's HIV/AIDS disclosure. Tisall (2018:110) concluded that:

*Teenage children do say, however, that they want the opportunity to talk about parental HIV openly, more information about HIV illness, better support and understanding in school, better relationships with social workers and health professionals, and more activities where they can meet with other children and young people in similar circumstances.*

Armistead (2007) found that disclosure of parent's HIV status was more common with older children. "The parent-child relationship was significantly associated with older child functioning when disclosure was considered within the content of the family processes. A more positive parent-child relationship was related to lower levels of child depression and externalizing problems and to better grades in school" (Armistead, 2007:48).

Kennely (2010) in a study on Parents' Disclosure of Their HIV Infection to Their Children in the Context of the Family interviewed 33 HIV infected parents and 19 teenage children. Findings revealed that both parents and children reported accidental disclosure experiences with positive and negative outcomes. Some discussed disclosure as necessary to maintain an honest family relationship "you don't want the child to find out from somebody else" (Kennely, 2010:111). Some parents delayed disclosure because they were overcome by guilt and were afraid of hurting their children. The study concluded that, disclosure may be difficult for parents, but certainly it helps the whole family to adjust to reality of living with HIV not only the children.

Schrimshaw (2012) in his study on HIV-Infected Mothers' Disclosure to their Uninfected Children: Rates, Reasons, and Reactions found that 66% of the mothers had disclosed their HIV infection to one or more of their children. Disclosure rates varied according to age of the child, mother's current disease stage, and whether the child lived with the mother or not. Other findings by Schrimshaw (2012:66) revealed that:



*Mothers reported many reasons for disclosing their HIV infection to their children, including wanting to educate their children about HIV, wanting their children to hear it from them, wanting their children to know before they became very ill, and wanting to be honest with their children. Reasons for nondisclosure included believing that their children were too young or immature, believing it would be too much of an emotional burden for their children, not wanting their children to experience rejection, not wanting their children to fear losing their mother, and wanting their children to recover from previous losses.*

However, the study conclusion reported that, although children were emotional about the disclosure, their relationship with their parent's had become closer following disclosure. Contrary to this, a study by Armistead (2011) titled *Disclosing HIV status: Are Mothers Telling Their Children*, results showed that mothers' disclosure of their HIV status to their children were associated with level of income and perceived severity of physical symptoms (Armistead, 2011).

Chaudior (2010), study found that parents who disclosed their status to children report more positive reasons at first disclosure experiences, which in turn related to higher self-esteem. This is because first disclosure experiences lessen fear of chronic HIV (Chauder, 2010). The results showed the importance of motivational antecedents for disclosure in impacting well-being and suggest that positive first disclosure experiences may have psychological benefits over time because they increase level of trust in others.

Cooper et al. (2016) documented unexpected shifts in reactions expressed by study participants in South Africa. The authors assumed that richer data can be collected with several participant interviews over time as opposed to one-time cross-sectional interviews. During data collection, the possibility of ethical dilemmas arising when participants confide in researchers thereby blurring the researchers versus a counselor's role during qualitative research was revealed (Cooper et al., 2016).

However, HIV status disclosure does not only take place between the parent and the child, but also, a pregnant woman faces challenges when it comes HIV status disclosure to their families, partners and children. HIV positive pregnant women would visit health facilities more frequently than women who are HIV negative (Periods, Knippler, Knettel and Sikkem, 2017). There is a specific procedure in terms of protecting the baby when the time of birth arrives. This study was conducted amongst HIV positive women in a prevention program called mother-to-child transmission program. Many of these women argued that they did not disclose their HIV status. Therefore, non-disclosure of their HIV status was a significant barrier to constant

HIV care appointments. Repeated in-depth interviews were conducted to 20 pregnant women in Cape Town. Three domains were examined using thematically, disclosure experiences, challenges linked with partner disclosure, as well as consequences of nondisclosure (Periods et al., 2017). Most of these women had disclosed their status to at least one person by the time they gave birth. However, this was limiting to trusted individuals only. Few had disclosed their status to the father of the child, while others chose not to disclose as they were worried and stressed over possible negative outcomes. They used pregnancy as an explanation for using medication and attending frequent clinic appointments when partners raised suspicions about their regular clinic visits. Results suggest that prevention of mother-to-child programs have an important role in assisting individuals to make decisions about HIV disclosure and will assist people living with HIV to navigate the disclosure process without any major challenges to their partners (Periods et al., 2017).

In addition, a study on non-disclosure of HIV positive status to a partner and mother to child transmission of HIV from a case study conducted in a rural area in Kenya found that it is not always a good thing to disclose. Findings discovered that, it is every person's decision to choose whether to disclose their status or not. Results shows a high percentage of male respondents favoring non-disclosure.

#### **4.1 LITERATURE REVIEW SUMMARY**

A review of the various studies and literature available gives context to a number of pertinent issues. These are summarized below:

##### **4.1.1 Factors that influences parental HIV status disclosure**

The review of literature made the researcher aware of the discrimination that occurs against people living with HIV by their peers after they have disclosed their positive HIV status, to their families, partners and teenage children. Hence, the persons infected with HIV thought that they were being honest and truthful about their status as they understood the importance of disclosure. However, the people they disclose to, respond differently, mostly negatively.

Another influencing factor to HIV disclosure is the fear of anger that parents might get from the child when they disclose their status. It is important to consider possible good or bad reactions from the child. The review of literature in this study, has divulged a number of different perspectives with regards to this.

Parents face a number of challenges during the disclosure process and its outcomes. They had to consider child's age in terms of accessing if they will be able to live with the truth, knowing about parental positive HIV status. In addition, there is fear that parents get from the diagnosis, that it will negatively affect the child's will

to live. Teenage children also respond differently; some tend to underperform in school, as an example. Many international countries have proper mechanisms in place to deal with such children after the disclosure process. In South Africa as well as in most sub-Saharan countries, there is extensive resolutions that must be made, most importantly that includes the works of professional doctors and psychologists, to eliminate any psychological effects imposed to children.

#### **4.1.2 Advantages of disclosing to a child**

The decision of parents to disclose does not only come with negatives or disadvantages, but there are advantages, as well. Some of these include a greater ability to cope and provide support to each other between the infected and affected persons from HIV. Emotional support is one of the best coping mechanisms to be used. Caring for the infected person makes life easier, and they can live longer through constant medication intake, family support and community support in some instances.

Disclosing to the partner or the teenage child, increased intimacy and the bond is maintained that the relationship always remains healthy. For some, it is not only parents who are HIV infected, but their teenage children too through mother-child transmission. In this instance, the parent by disclosing to the children allows them to be empowered and have confidence to participate in health care from the time they had known about their status. However, some children will not find it easy to accept. They will be in denial, and do not initiate to medication, be depressed and possibly end up committing suicide. However, on the positive side, disclosure forms an essential part of good health.

#### **4.1.3 When is the perfect time to disclose or delay disclosure?**

It is advisable to delay disclosure if a child is very young child. Studies confirm that age plays an important role that parents, and healthcare professionals need to consider when parents decides to disclose their HIV status to their children. It is important to note that when a child has severe emotional disturbances, disclosure should be delayed until the parent and child goes through proper guidelines and have solutions to account for the disturbances that may be caused.

#### **4.1.4 The process of disclosure between the child and the parent is discussed**

- i The child

Some schools have programs that teach children about topics such as sex, teenage pregnancy, HIV, from lower grades. If parents do not feel comfortable to discuss these topics with their children; teachers in school make their lives much easier, hence, children spend most of their time in school. Therefore, the parent should consider information appropriate to the age and mental capability of the child, in response to questions that may arise during the disclosure process.

ii The Parent

Secondly, the parent needs to consider disease stage. They need to make it clear to children that they will not be around forever, there will be a time where they will leave this world should the disease progresses, and they are no longer able to fight it. Parents need to make sure that children aware of this. This can be achieved through good communication style within the family and if the parent stays at home with their children.

#### **4.1.5 Good ways to disclose**

Disclosure should be driven by the child's schema<sup>3</sup>. After considering their schema, parents must make sure that it is planned and private. Children who are not grown enough, may accidentally speak about their parent's HIV status to other children, face discrimination and stigma. The presence of a health care practitioner is another way of practicing good ways to disclose. They will make it easier for the child to understand and be of assistance to the parents should they be getting questions from the child that seems to be hard to respond to.

#### **4.1.6 Ways not to disclose**

Parental HIV status disclosure is a sensitive topic; it needs to be carefully prepared before deciding to share with other people. It should not happen accidentally, as people respond differently to the situation. It should not happen when one is angry. Every person needs to be calm and collected, so that it is clearly explained and understood by the other person or people.

## **5. SUMMARY OF CHAPTER**

This chapter introduced and explained the concerns, motivations, anonymity of HIV disclosure, gender and societal norms, international, sub-Saharan as well as South African review of literature. It concludes with the

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<sup>3</sup> child's schema – patterns of repeated behavior that allows children to and express developing ideas and thoughts.

literature review findings, which made it easier for the researcher to have a clear understanding about the study research problem. Furthermore, this chapter has summarized important aspects of the existing body of literature, evaluated the current state of the literature reviewed, outlined areas of future study and linked study research to existing knowledge. To sum up, considerable research has examined factors such as the social, physical and economic consequences of HIV disclosure. It poses both positive and negative impacts. Evidence suggests that HIV disclosure may positively influence behaviours that protect the health of people living with HIV, their partners and their children. The following chapter discusses the theoretical framework used in the study.

## **CHAPTER THREE: THEORETICAL FRAMEWORK**

### **3.1 INTRODUCTION**

This Chapter discusses the theoretical framework under which the study and research problem is better understood. It is important to reiterate the research problem. The review of existing literature has identified insufficient evidence on specific challenges single parents face when disclosing their HIV positive status to their teenage children. The Vulindlela district has consistently experienced the highest reported incidences of HIV in South Africa ((Abdool Karim, 2017). The study seeks to discover psychological challenges, depression and suicidal ideation have not been adequately understood by scholars and practitioners in the field. The challenges facing single parents are prioritized in relation to seeking solutions and clinical interventions. The study seeks to unravel the perceptions of whether the teenage child needs to know their parent's status and discover how it affects them. The researcher seeks to investigate the components that influences the parent's decision in status disclosure. Single parents must consider the child's maturity and if they will be able to understand what is happening when they are told about their parents' status. The researcher also seeks to assess the challenges facing parents and the ways on how they overcome challenges and maintain a healthy parent-child relationship.

### **3.2 AN OVERVIEW OF USING A THEORY IN QUALITATIVE RESEARCH**

A theory extracts research into a statement about “social life that holds convenient applications to other settings, context, populations, and possibly time periods” (Gray, 257). These assumptions about social life are accompanied by explanations such as predicts and controls action through an if-then logic, accounts for discrepancy, explains how and why something happens through-causation, and provides insights for improving social life. There are at least three key applications of theory in qualitative research, which include theory of research paradigm and method, theory building because of data collection and theory as a framework to guide the study – this notion is most applicable in addition to and applicable to what this study intends (Gray, 2013).

### **3.3 THE IMPORTANCE OF THEORIES IN RESEARCH**

A theoretical framework is the use of a theory/theories in a study that concurrently conveys deep values of the researcher(s) and that provides a clearly expressed marker for how the study will process new knowledge. A theoretical framework is composed of knowledge that exists and previously formed thoughts about a

complex phenomenon, a researcher's epistemological outlooks, and a lens and a methodically analytic approach (Lincoln and Guba, 1994:33). According to Zita (1998:207), "a theory can live within us and emerge from our lived experiences, moving from our lips to the streets". The use of theoretical frameworks should seek to provide prospects for scholars to realize their own voices, along with the academic resources to construct the stories that seeks to release, rather than control new ideas.

### **3.4 APPLICABLE PERSPECTIVE**

Theories in sociology provide us with different perspectives with which to better understand our social world. There are three main Sociological perspectives, that is the functionalist perspective, conflict perspective and symbolic interactionist perspective. A perspective is merely defined as a way of interpreting the world. Therefore, each of these perspectives offer a variety of explanations about the social world and human behaviour.

As the community of Vulindlela is rife with HIV infections, it needs strong family structures, health care institutions that always deliver the best services, it needs local authoritarian and war counsellors who strive only the best for the community members (Abdool Karim, 2017). In addition, it needs structures put in place to maintain a standardized society and its functions. The community members themselves, need to look after one another through community support groups, as they form part of the research questions examined in this study.

Furthermore, the study chose to extend this understanding by employing the collective fingers theory of Mbigi and Murray (1997). It holds the notion that, the hand cannot function properly without one finger. It needs all fingers in order to function well. According to Mbigi and Maree (1995), Ubuntu is a concrete manifestation of the interconnectedness of human beings; it is the embodiment of South African culture and lifestyle. Ubuntu is defined by Mbigi (2011:13) as "a form of human engagement that allows for critical thinking, non-domination and the optimal development of human relationships". He further defined Ubuntu as everyone's humanity, which is ideally expressed in relationship with others, Ubuntu is then to be aware of one's own being but also of one's duties towards one's neighbour.

### **3.5 THEORETICAL FRAMEWORK: COLLECTIVE FINGERS THEORY**

The focus of this chapter will be Ubuntu in the community of Vulindlela, single parents and their children, as well as HIV facilities in the community. Ubuntu in the South African context or society is seen as the act of

being human, caring, sympathy, empathy, forgiveness or any values of humanness towards others. Ubuntu is a capacity in South African culture that expresses i) compassion, ii) reciprocity, iii) dignity, iv) harmony and humanity in the interests of building and maintaining a community with justice and mutual caring. The consequences of failure to embrace Ubuntu any community manifest itself through community member's indiscipline not respecting each other.

Ubuntu lies at the heart of the African way of life and impacts on every aspect of people's well-being. This chapter seeks to explore the notion of being human by grounding discussions around the concept of what is generally referred to as Ubuntu in South African health and society. The issue of discipline in any community is selected to demonstrate the concept of Ubuntu. Ubuntu is regarded as the soul force that drives almost every side of societal life in African societies and that creates the relationship between the African community (Mgibi and Maree 1995). In Sociology, this is expressed through a social constructionist perspective. Social constructionism is a theory of knowledge and communication theory that examines the development of jointly constructed understandings of the world that form the basis for shared assumptions about reality (Vygotsky, 1962).

### **3.5.1 SURVIVAL**

At the heart of Ubuntu is survival. Survival is being described as the ability to live and exist despite difficulties. South Africa has a long history of ethnic wars, racial, segregation, and political organization along racial lines. Despite their differences and confrontation African communities realized that survival could only be achieved through reliance on each other. In the case of the research, it is important that even if the Vulindlela community experience the most deaths, they should be able to survive through disclosing their HIV status, adhering to medication and being able to engage into community support groups. In addition, the African people learn how to survive through "brotherly" care and not individual self-reliance. Africans are socialized to think in collective and collaborative way (Mbigi and Maree, 1995).

The researcher will emphasize Mbigi and Maree's (1995) argument through reference to a social theory called structuration theory by Giddens (2012). This is based on structure and agency. For a community to survive, there must be a structure put in place, that will also guide agents (people) in the society. "Structure exists as knowledge about how things are to be done, said or written" (Giddens, 2012:55). Thus, Durk (2007) argued that one of the key ideas in structural functionalism is that society is made-up of groups or institutions, which are cohesive, share common norms, and have a definitive culture. Therefore, social cohesion



describes the bonds that bring people together in a society. For groups to be cohesive in a social context, positive membership attitudes and behaviors must be produced and maintained (Friedkin, 2004).

In the Vulindlela community, for its people to be able to live regardless of their HIV status, there needs to be a structure put in place for the community to get that knowledge about how things are to be done. For instance, for people who believe that it is every child's right to know about their parent's HIV status, approaches to deal with psychological impacts, discrimination and prejudice should be implemented. Agents are expected to abide to those implementations and act according to specific norms and expectations in society for survival in a community that has high HIV infection rates. As a community, they must be able to deal with discrimination that may be experienced by people living with HIV.

### **3.5.2 SOLIDARITY SPIRIT**

A closely related concept to survival is solidarity spirit and was created through the combined efforts of everyone for the survival of the community. An example is, some African communities like the township and squatter camps where accommodation, food, water, and other resources are still shared. The status of a person in an African community once again expressed by the meaning of Ubuntu: "I am because we are", it is the opposite of selfishness and hostility. The people of the community of Vulindlela should be able to assist one another in times of need. Solidarity, which to an African consist of interpersonal, biological and non-biological bonds that are created and maintained by spiritual values. This can be expressed through singing, traditional dancing, hymns storytelling, body painting celebrations, hunting, and rituals and family life.

This way of life is evident to what Emile Durkheim (1893) expressed social solidarity in his work, structural functionalism theory, where he introduced his terms of mechanic and organic solidarity. This is a sociological theory that attempts to explain why society functions the way it does by focusing on the relationships between the various social institutions that make up society Therefore, the community of Vulindlela form part of an organic solidarity that is reflected on Mbigi and Maree (1995) argument. Durkheim originally wanted to explain social institutions as a shared way for individuals in society to meet their own organic needs. He wanted to understand the value of cultural and social traits by explaining them regarding their contribution to the operation of the overall system of society and life. In addition, this approach sees society as a complex system whose parts work together to promote solidarity and stability. It declares that our lives are guided by social structures, which are relatively stable patterns of social behavior (Friedkin, 2014). Social structures give shape to our lives - for example, in families, the community, and through religious organizations. The

Vulindlela community can best practice this approach through the works of support groups that cater for the parents who are infected with HIV, their children as well as their families affected.

### **3.5.3 COMPASSION**

Compassion is another key social value of Ubuntu, it is also a human quality of understanding other persons' dilemmas and wanting to help them. Therefore, the social value compassion is important in the African culture and to an African. Through the acts of compassion Africans have created a foundation on which a culture of sharing, and caring is built. Mbigi and Maree (1995:18) stated that:

When one is socialized within a culture that encourages helping others it becomes part of one's psychological makeup and it is difficult to unlearn such a quality. For an African, these compassionate acts show a kind love, which is an important part of the communal lifestyle. Therefore, these acts of compassion highlight the warm and expansive nature of the community. These acts show a kind of love, which is an important part of communal lifestyle.

For instance, if someone is too ill to go to the clinic to collect their medication, another member of the Vulindlela community should be able to assist them if they have a car, take them to clinic facilities and not charge them for their doing so. Love for another community member in the community means that you do not search for good for yourself, but also for others around you. It is important to note that compassion even becomes a person's desire (Broodryk, 2012). Compassion enables Africans to achieve meaning in life and maintain meaningful human relationships.

HIV as one of the social issues our country is faced with, therefore, everywhere, every day, we learn of people suffering, in our own communities and in communities throughout the world. It is difficult not to be aware of all this suffering, yet most of us manage to keep it from the forefront of our everyday lives. While we often rely on our government and social agencies - local, national, and international to deal with the many issues that cause people to suffer, it is evident that something more is needed. In our communities, we are now confronted with an urgent need to listen to and understand each other, to empathize with all those who suffer, and to act with compassion for the health and well-being of all people.

### **3.5.4 RESPECT AND DIGNITY**

Respect and dignity are considered as important values in most societies and cultures, (Mbigi and Maree, 1995). It is even considered as one of the building blocks. Respect can range from people exhibiting great respect towards each other to no respect at all. "Ukuhlonipha" , meaning respect in the African language is

one of the most central values of the Ubuntu world view as it stipulates the social position of an African society. When parents have gone through the disclosure process with their children, they should not feel less important and find that their children no longer respect them. Parent – child relationship should not be compromised simply because of the disclosure. If they had a good relationship, that good relationship must always be maintained. In addition, respect is one of the foundations on which the African culture is built and therefore it determines the life of an African.

Dignity is part of Africa's daily life because they always consider the human and interconnectedness of people. Africans are known for dignifying the aged by allowing them to reside with families, the immediate and extended. These descriptions show that respect and dignity are central values which highlight a distinct African way of life. As more and more, Africans are empowered to progress within, and work in.

This theory is further understood through the sociological lenses using Bourdeu's (1987) argument. In this work, where he speaks of Habitus – describes who you are as a person based on the people and situations that has influenced you while growing up. He speaks of structure and agency; this is the idea that we are dealing with human beings in a society. However, human beings' behavior is constrained and enabled by structure – the context we find one in, and social arrangement. Dignity and respect are one of the examples in this instance that are stressed by Mbigi and Maree (1995). The youth and teenage children in the Vulindlela community are taught to respect their elders, this is reality that the people are socialized within the structure that represents and shape social actions of an individual. It is also hoped that, the parents of the teenage children after the while disclosure process, between them and their children, respect is maintained.

### **3.6 SUMMARY OF CHAPTER**

This chapter explained in detail the research problem, an overview of using theory, the importance of using a theory in research, explained the applicable perspective, the different theoretical perspectives and the collective finger's theory used to better under the study and its aims and objectives. The theory was founded by Mbigi and Maree in 1995, it played an important role in understanding the research under study primarily based on the research problem. The following Chapter will discuss the methodology used in the study.

## **CHAPTER FOUR: RESEARCH METHODOLOGY**

### **4.1 INTRODUCTION**

This chapter discusses the research methodology employed in conducting this study. It will illustrate the research design, the location of study, the sampling population, the sampling methodology, the research procedures and data analysis. The researcher having collected the data, qualitative researchers do data analysis that is inductive, one was able to establish themes that emerge from the data (Creswell, 2007). “The final written report or presentation includes the voices of participants, the reflexing of the researcher, and a complex description and interpretation of the problem, and it extends the literature or signals a call for action” Creswell (2007:37). The internal reality of the subjective experiences of single parents emerged when exploring their beliefs and challenges. The following methodological approaches were used to analyze the data obtained from the respondents of this research.

### **4.2 RESEARCH DESIGN**

A research design is a blue print or master plan about how the entire study will be conducted (Abiwu, 2015). Lotz et al., (2009) in an evaluation Centre describes research as the systematic process of collecting and analyzing information to give a thorough understanding of the subject in context. Bhattacherejee (2012) describes a research design as a detail plan about how the researcher will go about conducting the study in terms of how data will be collected. The major purpose of the study has been explored above, which lead to the exploration of the research design utilized in the study. “Qualitative research involves an interpretive, naturalistic approach to the world” (Spencer and Snape, 2010:3). Hence, this study used qualitative research methods, the researcher was able to connect with participants in their natural setting, create shared meaning of reality and make sense of phenomena “in terms of the meanings people bring to them” (Snape and Spencer, 2013:3). The researcher was able to spend time engaging with HIV positive parents in clinics, where the respondents felt comfortable and open to share their experiences about their challenges in their disclosure. From their frame of reference, the researcher was able to make sense of single parents concerns when participating in the research. The research design is the complete scheme or programme of the research which expresses the hypothesis, their operational implication and the final analysis of data (Kerlinger, 1986). It is the link between the data that has been collected and the conclusion that is to be drawn in relation to the questions raised for the study. Gaining an understanding and interpreting parent’s

perceptions, challenges and experiences allowed the researcher to form a good understanding of the actions and values attached to why they feel the way they do. The purpose of the research design is to make sure that the data collected from the respondents enable the researcher to answer the initial research question as unambiguously as possible

### 4.3 LOCATION OF THE STUDY

uMgungundlovu is one of the 11 district municipalities of KwaZulu-Natal Province. The city of uMgungundlovu is Pietermaritzburg. The majority of its over 1 million residents speak isiZulu (based on 2001 Census). The district code is DC22 under the uMsunduzi Municipality.

Vulindlela area is located within the greater uMsunduzi Municipality. Because of its location in this municipality and the fact that it was in fact known as Zululand as a previous homeland of KwaZulu, the area and its people have remained under-developed. This interprets into high levels of unemployment, low levels of education, a youthful population profile and limited access to income generating opportunities.

**Table 1: Gender breakdown uMsunduzi Municipality (2014 statistics)**

Gender	Population	%
Female	531 843	52.26%
Male	485 920	47.74%

Due to the fact, the study is based on the responses from single parents who reside at the uMsunduzi Local Municipality, the location concentrated on the Vulindlela area because the researcher had to travel between the clinics in this area. Potential respondents were personally approached and asked if they would like to participate in the study while they were in clinics for their treatment. The study was clearly defined before the respondents consented. All interviews took place within the time of their consultancy with the HIV counsellor and the duration of the interview was approximately twenty minutes, depending on how much information was given by the respondents. Since the study aimed at attaining rich qualitative data the researcher conducted and recorded all interviews. Overall it took a period of three weeks to collect the data required for the study as all participants had other tasks and commitments to fulfil as part of their duties and responsibilities. The data gathered from the respondents was frank, and respondents were open and honest about their challenges. In undertaking research, ethical considerations play an important role. In all cases informants participated voluntarily and they were ensured that their identity will remain anonymous. All the

informants in this research were shown the ethical clearance form thereby ensuring anonymity and confidentiality. Anonymity and confidentiality had to be maintained because it allowed for the protection of the respondents' identities.

#### **4.4 RESEARCH APPROACH**

In academic research, there are two main paradigms of research methodology that have been prominent, qualitative and quantitative research. For the purposes of this research, the researcher used a qualitative research approach. There are various approaches to research namely descriptive, explanatory, exploratory, participatory action and archival research (Strydom, 2014; and Abiwu, 2015). However, this study utilized descriptive and exploratory study approach as they are the most appropriate for the study.

#### **4.5 DESCRIPTIVE APPROACH**

The main rationale behind the use of descriptive study is to accurately describe a phenomenon (Dane, 2011; Royse, 2011 and Abiwu, 2015). Descriptive research is evolving and it is more concerned with the collection of facts. It attempts to discover facts or describe events or situations in the more accurate manner as they exist or occur in their natural sittings by helping the researcher to gain more insight into the phenomenon. In addition, the use of descriptive study in this research enable the researcher to gain more insight into the phenomenon under investigation. This approach has provided the researcher with more information about the parents regarding the challenges and the disclosure grievances to be looked at through the District.

#### **4.6 EXPLORATIVE APPROACH**

The purpose of exploratory study was for the researcher to gain better understanding of a phenomenon or situation as this one on the challenges faced by single parents (Abiwu, 2015). In this study, exploratory study was used to investigate the topic under discussion which assisted the researcher to gain more understanding about the perceptions of the various respondents, HIV positive single parents, regarding the challenges face when disclosing their status to teenage children.

#### **4.7 RESEARCH PARADIGM/PHILOSOPHY**

According to Abiwu (2015), there are several approaches to the research paradigm which includes constructivist, epistemology, non-positivist, ontology, positivist and interpretivist. Creswell (2009: 6) defines the main research philosophical paradigms in the practice of research as positivist, constructionist and interpretive approaches. Since the study is a qualitative method design, the research paradigm and interpretivists, it is of an inclusive notion that captures the embodiment of the theory and the necessity of reflexivity in researchers.

#### **4.8 INTERPRETIVISTS APPROACH**

Interpretivist approach is also one of the research paradigms that were used to analyze the perceptions of single parent and teenage children towards a solution in the challenges they face in the disclosure process. The interpretivist approach believes that meanings are socially constructed and can reveal hidden aspects of the phenomenon being studied. The use of this approach enabled the researcher to solicit the view or the perceptions of the respondents, (Snape and Spencer, 2013).

#### **4.9 THE RESEARCH METHODS – QUALITATIVE RESEARCH**

According to Abiwu (2015), qualitative researchers often begin with a self-evaluation and reflection with regards to them as situated in a social historical–context. Qualitative research is a type of research which deals with how individuals perceive their own world and the extent to which the researcher interacts with them in relation to what is being researched. Qualitative research further has the advantages, such as improving the relationship and dialogue between researchers and subjects in their communities (Ponterotto, Mathew and Raughley, 2013; and Abiwu, 2015).

#### **4.10 TARGET POPULATION**

Population refers to a group of people with common features that a researcher is interested in (Salaria, 2012; and Abiwu, 2015). The researcher recruited unemployed single parents, both male and female who have been tested infected with HIV in the rural Vulindlela area. They are patients who attend the local clinics: Taylors, Songonzima and the Mafakatini Clinic. The study will select those members who had been in the community for longer than two years. The researcher recruited respondents who met the inclusion criteria;

male or female who are single (not married), age thirty and above, have teenage children (aged twelve to twenty- four years), and those who are already on treatment Antiretroviral therapy (ARVs).

#### **4.11 SAMPLING TECHNIQUE, SELECTION AND SIZE**

According to Odoh (2015), purposive sampling is a nonprobability sampling technique whereby the respondents or participants are chosen based on their knowledge or judgment regarding the topic under investigation. Purposive sampling was the chosen method, as judgement was made to scrutinize the basis of presented information, which was provided by Vulindlela residents chosen from the local clinics to participate. Purposive sampling relies more on subjective considerations. When considering possible participants for the study, sample selection of people within the community was useful, as they are “in the position to apply the profession practice the researcher is interested in” (Flick, 2007:28). There are two type of sampling method namely probability and non-probability sampling. The use of this technique was informed by structure of targeted population of the respondents in the rural Vulindlela community.

Abiwu (2015) indicates that sampling is the process of choosing from the population a small group of persons to allow for valid judgment to be made. Respondents recruited into the research by voluntary counseling and testing (VCT) counselors in the clinics as well as the researcher. According to Odoh (2015), purposive sampling is a nonprobability sampling technique. The researcher chose these sampling methods because it occurs where elements selected for the sample were chosen by the judgment of the researcher, therefore the researcher was aware of the type of respondents to select. The researcher also liaised with HIV Counselling and Testing registers and counsellors. Criteria for disclosure - both male and female respondents were asked whether they had disclosed their HIV status to children and are willing to participate in the study. Nondisclosure, confidentiality was assured, respondents consented prior the interviews.

The researcher believes that having twenty respondents was beneficial in achieving data saturation. This was confirmed through the use patient’s file and their biographical information. Three respondents will be a minimum target per day for interviews. The study excluded participants who did not want to be part of the study. Same process was being applied for the following days.



## RESPONDENTS AGE BREAKDOWN

AGE CATEGORY	MALE	FEMALE
30 - 40	3	5
40 - 50	5	1
50 - 60	1	5

**TOTAL = 20 RESPONDENTS**

## ETHICAL CONSIDERATIONS

As part of the preparation for this study, ethical clearance was attained from the University's Research Office (see Appendix C). Issues of informed consent; clearance of the research instrument; the anonymity of sources together with the undertaking not to use detectable names or positions. The aim of the study was clearly defined and elaborated, with all the necessary information pertaining to the study, as well as the institution and supervisor's details for any further information. Participants were asked to sign an informed consent form before they participate in the study. Confidentiality is crucial; therefore, audio recordings will be destroyed five years after the research report is presented. The researcher strived for honesty, objectivity, integrity and openness during the research process. This Ethical Clearance application was inspected at the Research Office (HSSREC) for the issuance of an Ethical Clearance as well as that of the Department of Health full research study permission (gatekeepers' letter) (see Appendix D).

### 4.12 DATA COLLECTION METHOD

Face-to-face interviews and an interview schedule were used to collect data from the respondents in this study. The researcher used an audio recording device and take notes, which is important, as it helped with remembering and reflecting on what was said in the interview (Creswell, 2013).

### 4.13 THE INTERVIEW METHOD

Phenomenological research is a design of inquiry coming from philosophy and psychology in which the researcher describes the lived experiences of individuals about a phenomenon as described by participants. This description culminates in the essence of the experiences for several individuals who have all experienced the phenomenon. The selection of interviewee should be in line with the outlined subject of the research and the intended outcome of the entire study (Rubin and Rubin, 2011). The adoption of face to face

interviews in this process will ensure that the unique nature of the study is taken into consideration (Ritchie, 2013). The research instrument for this study was a semi-structured interview guide using an interview schedule. This approach to knowledge inquiry values interaction as a medium to generate thick descriptions of a social phenomenon.

Face to face interviewing was used as a data collection method. In research, data collection is an important essential element in order to complete any study. There are several methodologies, qualitative and quantitative, for substantial data collection (Akbarak, 2000). Interviews are a significant qualitative data collection method for social researchers as a research instrument to attain extensive data. They also become a useful option to utilize, in cases where there are limited respondents and a good return rate is important (Gray, 2004). According to Collis and Hussey (2003), the main advantage of interviews is their capability to offer a broad description and analysis of a research subject under study. Hence, the researcher in this study chose to use this instrument in order to achieve data saturation to complete the study, as well as gaining more information and insight into the topic to reach conclusions. In an interview, there is freedom for respondents to describe what is most important to them, thus makes it easy for their responses as useful quotes and stories can also be collected in during the interviews. When conducting face to face interviews, the researcher can capture verbal and non-verbal cues in the data collection process, while paying attention to body language and expressions which may indicate a range of emotions brought about by certain questions.

The researcher invited and explained the study to men and women who come for a routine clinic visit for their medication. All respondents had to be willing to talk, hence were included in the study. The researcher then recruited respondents who met the inclusion criteria; male or female who are single (not married), age thirty and above, have teenage children (aged twelve to twenty-four), and those who are already on treatment (ARVs). Scientists have announced that teenage stage, previously thought to end at 19, now stretches to 24. This is evident because, young people continuing their education for longer, as well as delayed marriage and parenthood, has pushed back popular perceptions of when adulthood begins. Therefore, a definition of 12–24 years corresponds more closely to teenager's growth and popular understandings of this life phase and would facilitate extended investments across a broader range of settings. Hence the researcher used this age in this study. The inclusion criteria and eligibility of respondents was validated by the counsellor against the patient cards, patients who had come to collect their medication. The study aims and objective was clearly defined to the patients, while the counsellor prepared medication, it was clearly stated that they are not forced

to participate in the study. those who were interested and wanted to take part, were asked to sign an informed consent form before they enroll in the study. Confidentiality was ensured, and the use of audio recording was explained. The researcher interviews patients who agreed to all.

#### **4.14 LIMITATIONS OF THE STUDY**

Despite great care taken in the design of this study, there are limitations which were found. The scarcity of literature about HIV status disclosure in Vulindlela area which is the physical setting of the study posed a limitation to the conceptualization of the study.

Data interference which may result from the interviewing process should be acknowledged even though, as explained, all possible measures were taken to avoid interference with data during interviewing by way of minimal interruptions by the researcher and by interviewing participants in their Clinic consultations room which may be viewed as private. Nonetheless, interviewing can still result in some data interference and this is duly acknowledged. Interviews were conducted in isiZulu, the vernacular language for Vulindlela residents. While this was thought to be the language in which all participants were most at ease, and while all measures were taken to ensure the accuracy of translation, it is honorable to acknowledge that the translation process may have slanted some of the data and accordingly, information may have been misrepresented or lost in translation. Finally, it is perhaps significant to note and admit that the researcher found it rather challenging to separate her researcher role to that of professional counsellor/ researcher. While these two attributes complimented each other at sometimes, at other times they may have confounded the research process for both the researcher and respondents, particularly the researcher being known by most respondents residing in the area. However, confidentiality and anonymity were clearly defined and maintained throughout the study.

#### **4.15 SUMMARY OF CHAPTER**

The chapter discussed the research processes and procedures that were followed in carrying out this study. In this chapter the sample, population and the data collection methods and limitations to the study were discussed. The methods employed in this study were used to allow the researcher to gain extensive data, and to perhaps reach data saturation in connection with the study aims and objectives. Ethical considerations were used as confidentiality and protection of respondent's identity and information is important. Information

gained from the face to face interviews was recorded and field notes were taken to capture every important detail. The following chapter discusses the research discussions, findings and analysis.

## **CHAPTER FIVE: DISCUSSION AND ANALYSIS**

### **5.1 INTRODUCTION**

The researcher after having collected the data and ensured extensive data analysis is inductive was able to establish themes that emerge from the data (Creswell, 2007). “The final written report or presentation includes the voices of participants, the reflexing of the researcher, and a complex description and

interpretation of the problem, and it extends the literature or signals a call for action” (Creswell, 2007:37). The internal reality of the subjective experiences that single parent’s face emerged when exploring their beliefs and challenges. This chapter will critically present the findings of the research in a manner that stimulate interest and further need for investigation into the context in which the importance of HIV status disclosure is in Vulindlela.

The interpretation of the information collected from interviews of twenty respondents was followed by a thematic content analysis procedure that carefully read through the transcripts and field notes to identify the challenges classified into similar patterns and finally conceptual themes for further discussion. This research explores the challenges facing single parents when disclosing their HIV status to teenage children.

## 5.2 KEY RESEARCH QUESTIONS

**TABLE 1: SUMMARY OF RESEARCH QUESTIONS**

How does the disclosure of HIV positive status of single parents affect their teenage children's daily lives?	This question examines how parental HIV status disclosure impacts on the children psychological and wellbeing.
What are the challenges facing HIV positive single parents, and how does it affect them on their daily lives?	This question examined the main areas that parents needed assistance on their daily lives.
What support is available to single parents after they have disclosed their status to their children and face challenges?	This question examined the availability of support for parents from the challenges they could possibly have encountered during the HIV disclosure process.
What assistance do community members, the Government and health facilities provide?	This question examined the support that single parent receives and require in with regards to their medication adherence.

These questions guided the research process and were crucial in seeking relevant responses that formed the findings of the study.

## 5.3 METHODOLOGY

It is important to have a review of the methodology employed for this study. The study relies broadly on face to face qualitative interviews to gather information. This has been given proper attention in the methodological

section, but it is crucial to have a review to understand the methodological parlance from which this interpretation strands.

#### **5.4 THE DATA COLLECTION PROCESS**

The researcher made appointments with various Clinic Operational Managers to introduce oneself, the study and the significance of the study. The next day, the researcher was introduced to VCT counsellor per clinic to work with. Data collection took three weeks for the researcher to complete. On selection of participants, the researcher on each day, had to consult each day's register on expected patient visits. The study was introduced and explained to patients while they were in the waiting area. Consent was given once the respondent was in the counselling room and interviews commenced with the respondents who showed interest. HIV counselor assisted in identifying those who fall under the study inclusion criteria; age. The study included respondents who showed interest and were already on treatment (ART) – many of the male patients would send their partners and relatives to clinics to collect their medication.

#### **5.5 THE INTERVIEWS**

The core section of the interview questions was open-ended collected using closed ended questions. The interview adopted a semi-structured instrument that contained seventeen questions that assisted in getting the information that is critical in this study.

#### **5.6 THE FINDINGS**

The study found that HIV status disclosure between parents and their teenage children is very common in the Vulindlela area. Parents find it easy to communicate with their children about HIV, because it is no longer a stigmatizing disease compared to the early years dating to 2002.

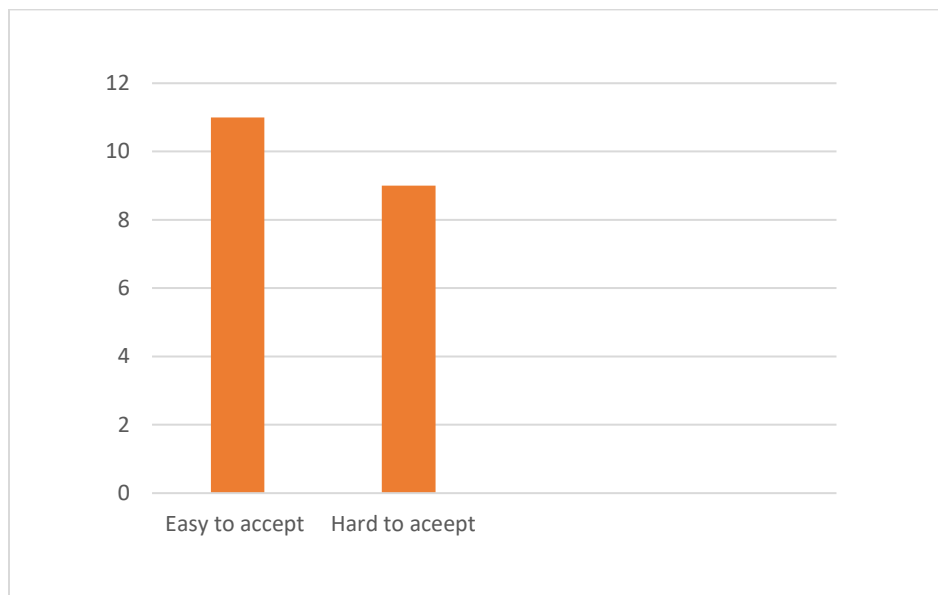
##### **5.6.1 HIV STATUS**

When respondents were asked why they decided to get tested, twenty out of twenty respondents reported that they were sick when they were first diagnosed with HIV in their local health clinics. These included both male and female respondents. This research found that, there are several patients that would attend the clinic to just get tested for HIV and AIDS. People had the belief that they would only get tested once they become sick:

*“I got sick, really got sick then I decided to go to the clinic”. “I had flu, it had been going on for quite some time. I decided to go to the clinic for an injection, but sometimes I would go and leave the clinic without any help”. “I was very ill, that is why I decided to come to the clinic. I got tested for HIV”.*

When respondent was asked about how they dealt with the status results, below is a graphical representation of the responses. Eleven respondents reported that it was easy for them to accept that they are HIV positive, while nine respondents felt otherwise – it was hard for them to accept.

**FIGURE 1: DEALING WITH AN HIV POSITIVE RESULTS**



Those who reported easy to accept, reported *“It was easy for me to accept. Because I know that being HIV positive is not a death sentence”. “It was not hard because most people in my family were already infected. It was easy for me to accept. Being sexually violated was the only trauma I had encountered.”*

Those who felt it was hard to accept reported:

*“It was hard for me to accept; I don’t want to lie. Because I knew that I am well behaved. But then, I had to accept”. “Well, I found out in a very strange way. My partner is the one who got ill first, I found his HIV status results at home where he had hidden them. This is when I confronted him and told*

*him that we need to go to the clinic and get tested together. This is when he also started his medication. It was hard to accept but eventually I did”.*

Literature confirms the fact that single parents do not only face the challenge of whether to disclose their positive HIV status or not to disclose to teenage children, but they also faced with the challenge of accepting that they are diagnosed with the disease. Some had mentioned that, their partner had been deceased a while back, and were later diagnosed with HIV, but only found out to be HIV positive after some years. That alone, posed many questions and disbelief upon the infection.

### **5.6.2 SUPPORT**

When respondents were asked, what support was available to them when they tested HIV positive, all the respondents reported that they received counselling – pre-and post-counselling and were initiated to medication immediately. *“I received medication same day I was diagnosed with HIV”. “I received counselling from the nurses”, that is how I learnt to come to terms with being tested positive”.*

When respondents were asked about the support they require daily, respondents reported that they require assistance when it comes to their medication intake, hence they should make sure that they stick to eight o'clock if it is eight o'clock daily. Literature restate parent's disclosure is a central motivating factor to adherence to antiretroviral therapy (Lipson, 2014). Disclosure of the diagnosis may also aid in preventing high-risk behaviour, thereby decreasing the further spread of the disease. This means that both the parent and the child take it upon themselves for the parent's longer survival periods, the study recommends disclosure to younger children.

When respondents were asked what support, they received from their families and the community of Vulindlela, seven respondents reported that they only get support from their family, four believed they receive no support from both the structures, nine respondents reported they receive support from both their families and the Vulindlela community.

The challenges faced were similar amongst male and female parents. It became difficult for one male parent who did not stay in the same house with his child. Making a decision whether or not to inform the child about his positive HIV status became a stressor. However, the parent believed that the child had the right to know and figured out how he and the mother of the child made arrangements to sit down and inform the child and of course, because the mother is also living with HIV, before they become too ill. They are just not married

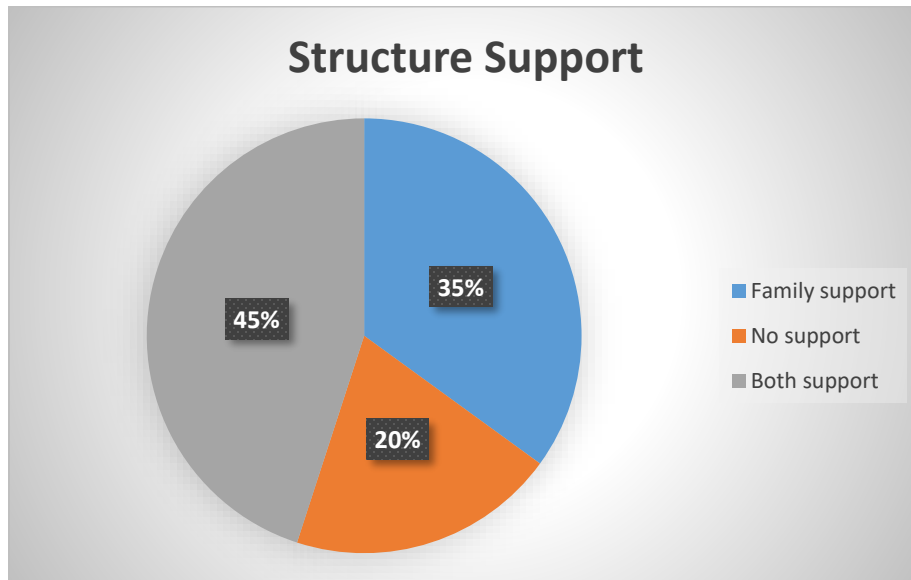


or cohabiting. The female parents are believed to be best when it comes to parenting hence this is why it was difficult for the male parent to inform the child on his own but to involve the mother figure in the process.

The reactions were significantly different between the age groups. All the teenage children below the age of twenty showed love and they had accepted being told that their parent/s are living with HIV. This is because, some parents had reported that, it is quite easy to sit down and educate a young child and disclose a status of HIV then older ones who think they know it all. Young children supported their parents the most even their grandchildren whenever it is time to take the medication, they were quick to remind their parents when it is time.

One parent whose child's age was above twenty had a different reaction from a child. The parent was blamed for being HIV positive, it was thought that 'she got what she wanted' which is not true. This could be because the older child assumed that the female parent had been seeing many partners at that time which is not always the case that a person gets HIV only by having multiple sexual partners. There are other ways of acquiring HIV besides having multiple sexual partners. This was a reaction from an older male child. Contrary, an older female child had a different reaction because she was married and had to take her parent to love with her and her husband to make sure that her parent is taken care of and not just abandoned. Maturity plays a huge role, one would definitely conclude that female children are matured enough to handle such matters as of accepting a single parent's status and living with HIV. No one should be blamed, however, takes a situation as is and learns to accept and continue living a healthy parent-child life.

**FIGURE 2: BREAKDOWN OF SUPPORT STRUCTURES**



Respondents who reported they received no support, “*No, I am doing well on my own*”. These were respondents who play no vital role in the community. They are negative about everything and everyone around them, this was discovered through the face to face interviews. Some were keen to be part and parcel of the community they come from, besides the issue of feeling less important and judged in the community: “*I wish that the residents of the Vulindlela community will accept me as I am, I am still a human being like everyone else*”. Literature recall for the establishment of joint service plans between local authorities and health boards, in the targeting of services to meet the need and reduce inequality amongst the Vulindlela residents. Literature found that most single parents were found to be afraid of discrimination from the community they live in, as a result, they experienced shame and guilt-related feelings to unprotected intercourse and loss of societal privileges (Kyaddondo et al., 2013).

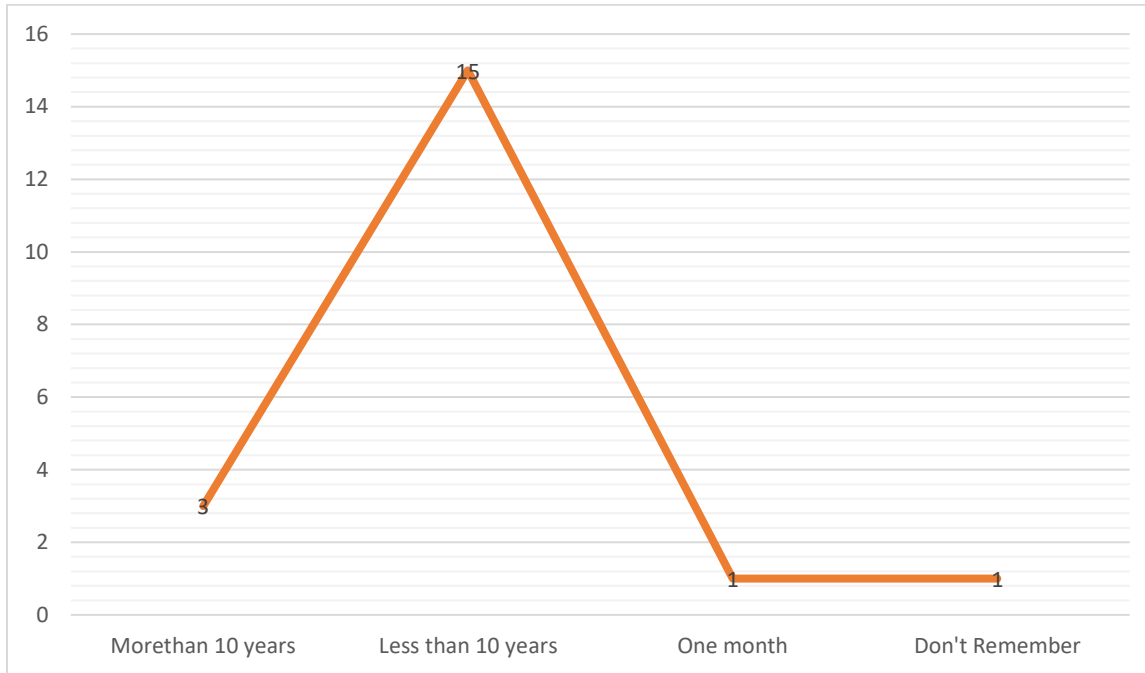
Other respondents had reported that they do get support from Government Departments. Free medication is a vital offer of support they were grateful to have. Ten of these respondents reported they receive free medication, which they believe is from their Government: *I receive free medication, I am grateful that every time when I go to the clinic for my medication, I receive at no cost*. Despite living with fear of being infected with one of the life-threatening diseases, having access to free medication seems to be a relief to the

respondents, as they are unemployed. Seven respondents believed they do not receive support, two are in possession of Social grants related to their HIV status, one felt otherwise. For those who are in possession of social support grants, it is mostly associated with some sort of a disability, one of the respondents had a limp on his left leg. This is evident to one's study conducted women in a rural area where it was found that the HIV status disclosure is a key support strategy to start and maintain HIV care and treatment.

### **5.6.3 DISCLOSURE OF STATUS**

This led to the gist of the study on research, parents' responses on how long it took them to disclose their HIV status to teenage children. This will be best described by the graphical representation below:

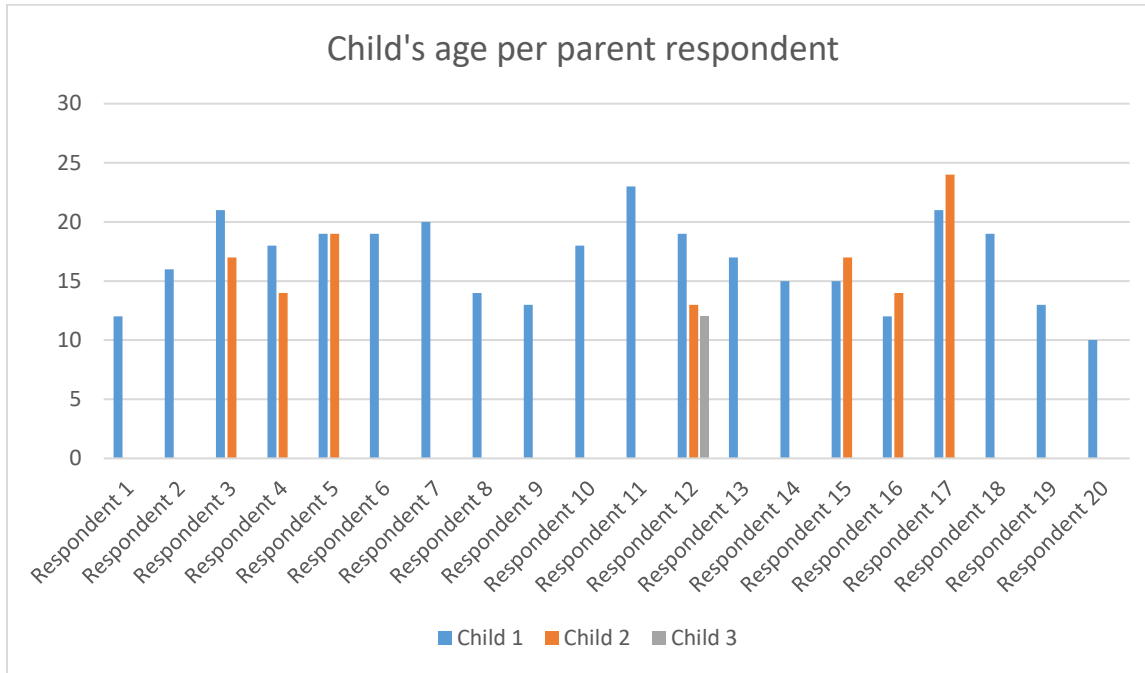
**FIGURE 3: TIME PERIOD IT TOOK TO DISCLOSE HIV STATUS**



Fifteen respondents felt that it took them less than ten years after they have become aware of their status to disclose it to their teenage children: *“It took me four years. I did disclose to all my children.”* Three reported it took them more than ten years, one took only a month to disclose and the last one could not recall how long it took to disclose her status. Findings where participants expressed the need for them to work as a team in order to promote safe and effective HIV status disclosure through talking about HIV, sharing responsibility and open communication.

Literature (Palin, Aneshensel, and LeBlanc, 2008) expresses the need for global resources to better support children and their parents through the disclosure process. Parent’s challenges when disclosing their HIV status included age of the child. Age is the most common factor that the study took into consideration throughout. Respondent’s child’s age range between the inclusion criteria; twelve to twenty-four years.

**FIGURE 4: CHILD’S AGE AT TIME OF PARENT DISCLOSURE**



Thirteen parents have disclosed their status to their teenage children.

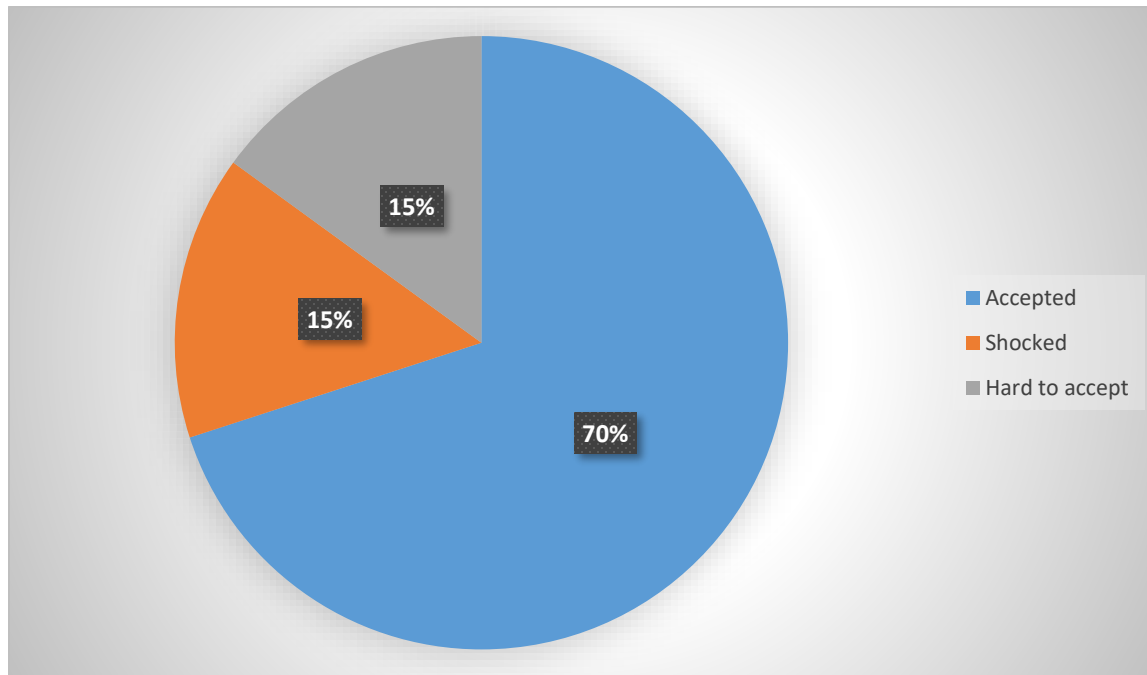
Literature (Palin, Aneshensel, and LeBlanc, 2008) revealed that parents who have disclosed their HIV status to their teenage children experience less depression than those who do not. Most respondents reported that they receive family support, hence, their decision to disclose was worth it. Some respondents reported they felt depressed, some reported that their older children could not care because they felt they deserve what they got: i) "How long have you been infected?" ii) "Who infected you?" emerged.

*"My son did not seem to be supportive, at first. It was like I got what I wanted."*

*"I am afraid the older will judge me. Which is why I decided to disclose only to the young one."*

Parents had reported having disclosed to all their teenage children. However, responses from children varied. Fourteen parents reported it was hard for their children to accept that they are infected, they expressed feeling of sadness and worry, three were shocked when they got the news and another three was quite hard for them to accept, results showed that impacts of disclosure included emotional reactions.

**FIGURE 5: CHILDREN'S RESPONSE TO PARENTS DISCLOSURE**



The study revealed that, the main challenge for parents living with HIV to disclose their status is the decision to disclose.

*“At first, I did not want to be sorry about it, I struggled with deciding whether to tell them or not. I was also worried about the confusion this was going to have to my child, and that maybe he has questions to ask that I cannot even have answers to.”*

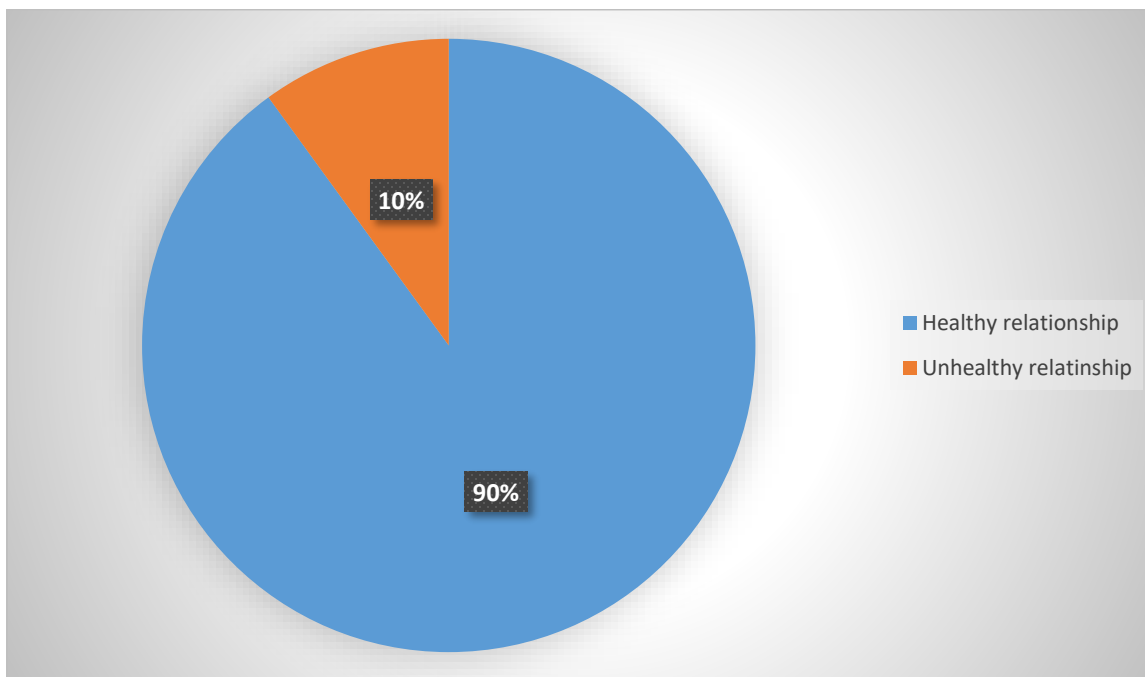
Parent-child relationships after disclosure varied, two respondents felt that their relationship with their children changed after the disclosure, *“My child did not care much, she just sat there and kept quiet. She does nothing for me. It’s just a relationship, I don’t know how to explain it”*. Communication style plays a huge role in terms of disclosing to older children.

Teenage stage is characterized by substantial neural, intellectual and sociopsychology growth (Rochat, Bland, Coovadia, Stein and Newell, 2016). With the advance of teenage stage, children tend to spend most of their time with other children, then to be around their parents. However, parents are there, and they

continue to play an important role in promoting their teenage children's growth. During this process, a parent and the child form an attachment, this attachment has profound effects the psychological wellbeing of the child (Moretti and Peled, 2015). The typical characteristic of teenage stage is change by social scientists and mental health professionals' psychiatrists, psychologists and other teenage health specialists have long recognized this. Changes continue to occur as the child grows, reaching adult stabilization levels at almost 16 years of age (Moretti and Peled, 2014).

It is argued that, parents vary according to the nature and quality of care they provide to their children. The ability of parents to maintain a healthy parent-child partnership with their children is critical because of the challenges between parents and children increases during the teenage stage.

**FIGURE 6: PARENT-CHILD RELATIONSHIP AFTER DISCLOSURE**



Eighteen parents felt that their relationship was healthy with their children after HIV status disclosure. Parents felt some feelings of love, support and care from their children. Their relationship bond seemed to be stronger than ever: (...) *"It is the same. They are very supportive, they still love and show me respect as their mother"*.

Both parents and children who had healthy relationship communicated positive outcomes such as healthier and improved relationships. Only two out of twenty parents felt otherwise. Overall findings suggest adjustments in parenting, family unity, and trust surrounding the disclosure process.

#### 5.6.4 VULINDLELA COMMUNITY

Respondents reported that they do not have support groups in Vulindlela. Only two respondents felt otherwise:

*“We usually meet at some crèche in the area. We have a support group called ‘Siyathuthuka’<sup>4</sup>, where we discuss our challenges and possible solutions to those challenges. Yes, we do. They teach us how to grow crops for instance in our homes because vegetables are healthy”.*

Respondents reported they need material for assistance or support. *“I wish our ward councilor could give us some social support grants as most of us are unemployed and unable to take good care of our children”.*

Parents also wanted assurance that their children will be taken care of once they are no longer in this world. Education is most common concern for most of the parents, they believe education is the key to success. Food and shelter, also came as a huge concern for the unemployed respondents *“Besides the free medication that we receive, I wish that our local councilors could do something about us poor families. And provide us with food and shelter as well”.*

The findings are categorized into major themes and sub themes, which include the following:

- a) I was sick
- b) I received counselling and was initiated to medication immediately
- c) I need support to be reminded when to take my medication
- d) My children accepted that I am HIV positive
- e) Challenges
  - i)Child’s age
  - ii)Depression
- f) Healthy Parent-Child Relationship
- g) No community support groups
- h) Free medication

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<sup>4</sup> *Siyathuthuka* – going forward



i) Family support grant

The perception presented in this study reflect the challenges and factor to consider when deciding whether to inform the children about parents' HIV status. However, some perceptions reflect the importance and the advantages of informing the children about their parent's HIV status at a younger age, than to delay until they are much older.

## **5.7 PARTICIPANT RESPONSES**

The following profile provides a brief description of the twenty participants interviewed for this study. This table shows the demographic distribution of the sample and presents their thought on the parental HIV status disclosure to teenage children. Participants thoughts are presented as articulated without editing.

**TABLE 2: PERCEPTIONS OF STATUS DISCLOSURE EFFECTS ON THEIR CHILDREN**

	NAME	SEX	AGE	PERCEPTIONS OF STATUS DISCLOSURE EFFECTS ON THEIR CHILDREN
1	Agrippa	M	43	<i>"I struggled to inform him, because he lives with his mother. His mother and I are not in good speaking terms. I thought my son is too young to understand what my illness is, but he is a brave young man he understood and accepted"</i>
2	Hlengiwe	F	35	<i>"After I had disclosed to him, it was hard for him to accept it, he would not eat at times, but he then understood that I am not going to be around for long and learnt to accept."</i>
3	Zikhethele	M	54	<i>"They accepted, because I made sure that I disclose to them in a way that they understand it. I made it clear that I did not choose to be infected, but it happened."</i>
4	Ben	M	46	<i>"They accepted it, because it is no longer shameful to be infected with HIV."</i>
5	Ntombizonke	F	48	<i>"They did not judge me. I am their mother; I guess they felt sorry for me."</i>

**Pseudonyms are used**

**TABLE 3: CHALLENGES FACING SINGLE PARENTS**

	NAME	SEX	AGE	CHALLENGES FACING SINGLE PARENTS
6	Ncamsile	F	50	<i>"The younger one is too young to understand. I will inform her when she is older."</i>
7	Tholakele	F	52	<i>"Sometimes I am too ill, I struggled, I did not have the right words or the correct manner to disclose my status to my children."</i>
8	Dorrah	F	39	<i>"I did not know where to begin, and most importantly, I was more worried about the younger one. But I am taking my medication, he will grow up and I will disclose to him as well."</i>
9	Ntombenhle	F	32	<i>"Besides the age difference between them, there are no challenges that I faced."</i>
10	Dolizile	F	35	<i>"I was afraid the older will judge me. Which is why I decided to disclose only to the young one."</i>

**Pseudonyms are used**

**TABLE 4: SUPPORT RECEIVED BY SINGLE PARENTS POST DISCLOSURE**

	NAME	SEX	AGE	SUPPORT RECEIVED BY SINGLE PARENTS AFTER DISCLOSURE
11	Tholakele	F	35	<i>"It took me 2 years, but they were aware even before because they are the reason why I am infected today. No, we do not have support groups in Vulindlela"</i>
12	Octavia	F	57	<i>"It took me 11 years to disclose my status. Yes, they are all aware I did disclose my status to them. No, we do not have support groups on our community."</i>
13	Barbara	F	56	<i>"It was after 7 years. I disclosed to them. No, we do not have support groups."</i>
14	Buyisile	F	46	<i>"After 2 years. No, we do not have support groups."</i>
15	Bhekimbeko	F	57	<i>It took me 8 years, yes all of them. No, we do not have support groups in Vulindlela ."</i>

**Pseudonyms are used**

**TABLE 5: SUPPORT FROM THE COMMUNITY, GOVERNMENT AND HEALTH FACILITIES PROVIDE**

	NAME	SEX	AGE	SUPPORT FROM THE COMMUNITY, GOVERNMENT AND HEALTH FACILITIES PROVIDE
16	Nkosi	M	40	<i>"After the HIV test tested positive, the clinic facility further tested me for Tuberculosis (TB), from there I did so many blood tests on HIV. I can say that I do everything for myself I receive no support from anyone. Also, the community does not support me because they do not know about my HIV status"</i>
17	Sbusiso	M	31	<i>"I can say my family is very supportive, and also the clinic counsellor initiated me free medication. My family is always there for me. Our community does not support us. We are on our own, I can say."</i>
18	Mbhele	M	47	<i>"I got counselling and started treatment same day I was diagnosed with HIV. I receive no support from my family and the community."</i>
19	Sphelele	M	39	<i>"I was initiated to medication same day I was diagnosed with HIV. I am independent. I do not rely on anyone for support."</i>
20	Ezra	M	39	<i>"I received my medication, went for therapy classes regularly. I do not have a family. Some families in the community do support me by giving me piece jobs and do cleaning in their homes as I am unemployed. In that way, I get something to eat every day and I survive"</i>

**Pseudonyms are used**

The varying responses on the perceptions of HIV status disclosure effects on their children are an indicator that disclosure can be viewed as positive and negative. Parents themselves find it hard to speak to children about their status, it has never been easy. Some parents had to consider their children if they are old enough

to understand what was going to be said to them. It is encouraging to see that, while parents had to be worried about their lifespan, adhering to treatment, they also had to think about the future and the effects of disclosure it enforces to their children.

Eighteen respondents reported that they do not have support groups in the community. This becomes a concern, since the community is continuously experiencing high mortality rates due to HIV/AIDS. Parents have taken it upon themselves to disclose their HIV status to children without materialistic support and appropriate guidelines throughout the disclosure process.

Furthermore, these respondents receive no direct support from their families, government departments as well as the community they live in. There are counselors in the community and they are reported to only attend to issues that benefits them. HIV/AIDS as one of the economic issues facing South Africa as a whole, is not attended to including the people who are infected and affected by the diagnosis.

Parents continue to face challenges and suffer from depression, anxiety and feel like their world is coming to an end. Disclosing a positive HIV status is good, but when it comes to the Vulindlela community, people need to consider their family structures, the effects it brings on their children, and the benefits from which they gain from the process of disclosure, rather than to bring bad outcomes to them.

## **5.8 CONCEPTUALIZING HIV DISCLOSURE AND SOCIAL STIGMA CONCERNS**

An overview of social response to HIV/AIDS is characterized by high levels of stigma. Stigma is conceptualized as a problem of interactions perspective (Chaudoirand Quinn, 2010). In the absence of an effective medical intervention, the social factors like stigma attached to HIV/AIDS are a major obstacle in the reduction of the disease that requires urgent action. HIV/AIDS is being viewed as not merely a medical problem, but a social problem.

Even though HIV is almost two decades old, the existence of stigma and discrimination are still strongly prevalent in society. People are murdered, called names and horrifically beaten up due to the act of discrimination and stigma. Goffman (1963:5) defines stigma as a social relation between a stigmatized person constructed on a shared belief that a person's identity is 'spoiled.' Burris (1999) contends that stigmas also constitutes a powerful tool of social control as it can be used to downgrade, individuals who show certain characteristics.

The absence of a cost-effective therapy, the behavioral change for preventing HIV transmission remains a viable option. Empowerment plays an important role in the dynamics of HIV, that the community of Vulindlela is lacking since, they do not have community support groups. People living with HIV are stigmatized leading to severe consequences related to depression and anxiety. Some infected people are blamed for causing the illness through their risky behavior by their own children, as discussed earlier from the responses of interviewees after they have disclosed their positive status of HIV to older children. The AIDS epidemic has often been associated with severe negative public reactions ranging from banning entry of HIV infected individuals to isolating an individual in the family (Mawar, 2015). Literature (Chaudoir and Quin, 2010) had defined HIV/AIDS stigma as varied in ways starting from understanding it as a social construct existing in relation to a deviance. Future researcher could expand on this, in relation to children's responses on their parental HIV status disclosure.

Earlier on, the research had mentioned survival as one of the components in Mbigi and Maree's Five finger theory, is being described as the ability for the community to live and exist despite difficulties. However, this is not the case within the Vulindlela community. Formal support is lacking amongst people in this area, people who live with HIV do not have support groups where they can meet and share experiences. Only one respondent out of twenty mentioned that 'they had' a community support group but it is no longer functional. A closely related concept to survival is solidarity spirit and was created through the combined efforts of everyone for the survival of the community. Respondents reported that their community members do not seem to care; including their ward counsellors, no one intervenes and be a stepping stone for people who are suffering and living with HIV/AIDS. Not only does the community lack formal support, also, a sense of compassion is lacking. A quality of understanding other persons' dilemmas and wanting to help them. Love for another community member in the community means that he/she does not search for good for themselves, but also for others around them. A moral support is only showed when a person dies and the close community members attend the burial. Respect and dignity. When parents have gone through the disclosure process with their children, they should not feel less important and find that their children no longer respect them. Parent – child relationship should not be compromised simply because of the disclosure. The overall disclosure was not a problem to teenagers. These children showed love and respect for their parents although it was not always an easy step to accept. Dignity is also one of the values of 'ubuntu' that is particularly maintained in South Africa; especially the rural areas like the Vulindlela community. Overall, the use of this theory made one gain insight on how single parents respond when faced with challenges and their children to the disclosure process of parent's HIV status.

## 5.9 EMERGENT THEMES

Face-to-face interviews were analyzed using thematic content analysis to identify themes and sub-themes.

### 5.9.1 Perceptions related to initial HIV testing

When respondents were asked why they decided to get tested, most respondents felt that they were sick, hence decided to go tested at the clinics. Some respondent had mentioned that *“I got sick, very sick then I decided to go to the clinic. I had flu, it had been going on for quite some time. I decided to go to the clinic for an injection, but sometimes I would go and leave the clinic without any help”* (Transcripts). Only one respondent had mentioned they had decided to get tested other than the reason that they were sick.

There is a procedure one observed in the clinics that is followed in the HIV testing process. Steps observed include:

- a) Getting tested for HIV, this is when a person or partners have a one on one conversation with the counsellor responsible for HIV testing. Pre-and post-counselling is essential, however, if the patient does not need counselling, it is their right to do to and continue with just testing.
- b) When a patient tests positive, (Reactive) to the tester, they go through what is called a Baseline – where their sputa is taken to the lab for further testing to confirm the HIV positive results
- c) On the very same day, blood samples are drawn and referred to the lab for the CD4 count, to see if it is low or high – however, despite the results, the patient is initiated to medication immediately.
- d) After two weeks, the patient visits the clinic for the CD4 count results and the viral load results, to better understand which medication they should be initiated to.
- e) Thereafter, a patient visits the clinics after every three months, for bloods to check if they are responding effectively to the medication, also to check if the medication does not harm their kidney. if the medication does harm to the kidney, a patient gets switched to a different pill.
- f) It is important to collect bloods, after six months. To maintain a lower viral load and an increasing CD4 count so that a person lives longer and a healthy life on treatment.
- g) If a patient takes medication correctly, and there is progress on their system, bloods are then taken only once a year. The viral load must remain lower, to a point of being undetected at all. When the virus is undetected, it means it cannot be transmitted to a person who is HIV negative. This is a time where a female patient who wants to fall pregnant can try for a baby with a partner who is negative, and they remain negative with the baby, provided that proper procedures are followed.

### **5.9.2 Positive effects relating to HIV testing: Receiving pre- and post-counselling and initiated to medication immediately**

When respondents were asked about the support that was available to them, they mentioned that they had received pre-and post-counselling and were initiated to treatment immediately. It is unlike in the past, where a person who diagnosed HIV positive had to take bloods to the lab and return to find results of their CD4 count and viral load, before they start treatment. *“I got counselling and started treatment same day I was diagnosed with HIV. I received medication same day I was diagnosed with HIV. I received medication same day I was diagnosed with HIV” (Transcripts).*

### **5.9.3 Different types of medication**

In terms of the medication, there is one pill, but produced and supplied by different companies. Improvements have been made when it comes to the single dose pill, compared to the many tablets that were usually issued to people living with HIV in the couple of years ago.

To illustrate an example, the pill produced called Tribuss highlights some important information on the treatment. Tribuss is a film-coated tablet, it contains tenifor<sup>5</sup>, efavirence<sup>6</sup> and emtricitabine<sup>7</sup> (fixed dose) – these are three drugs combined on to one tablet to fight against any opportunities infections and assist in preventing the further spread of the virus in the health system of a person who is already diagnosed with HIV.

The tablets are film-coated and contains a black, red iron oxide and are pharmacologically classified as antiviral agents. Antiretroviral (ARVs) medication, is not meant to cure HIV but to treat the virus from multiplying, this means increasing the CD4 count cells and decreasing the viral load to a point where it is undetectable. This is only achieved if a person adheres to medication intake, and, practices safe sexual intercourse always.

When patients came for their medication, they seemed confused when they were given a different container from the ones they received previously. However, the counsellors made it clear that the container does not mean that the tablets are not the same, it is only that, these tablets are produced by different companies hence the packaging varies from time to time.

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<sup>5</sup> Tenifor – is an acyclic nucleoside phosphonate diester analogue of adenosine monophosphate

<sup>6</sup> Efavirence – is a selective non-nucleoside reverse transcriptase inhibitor of HIV

<sup>7</sup> Emtricitabine – is a synthetic nucleoside analogue of cytidine

In addition, some company produces a white tablet, others produce a pink one, but it does not matter because the pill is targeting the same as antiviral agents in the system. The fixed dose tablet has been of great assistance to many patients, since they used to complain in the past years when it was still separated drugs, for instance a person would be given 3 different tablets to take same time.

#### **5.9.4 The significance of support and medication adherence**

Nine out of twenty respondents had mentioned that it was not for them to accept that they are HIV positive, hence, they need feel the need or support to be reminded when to take their medication daily. *I require assistance in relation to my medication intake. For now, my medication is important to me* (Transcripts). From the extensive review of literature, studies such as of Amoran (2015) and Madiba and Letsoalo (2013). internationally as well as in the sub-Saharan Africa, revealed the importance of a partner support to cope with the effects of the disclosure. This study has also discovered that, patients, with the assistance from their partners, families and children, tend to adhere to their medication.

For a patient to live a healthy life whilst on treatment, they need to maintain a standard medication intake routine. For them to respond positively to the treatment, they need to adhere to medication. It is advisable that a patient takes medication on a daily basis. Timing of the dosage is important because the medication taken comes with side effects, but they are short-lived. Possible side effects include, hallucination, rash, vomiting, diarrhea, feeling tired and nausea amongst others. However, these side effects can be overcome easily. Scientists and doctors recommend that a patient takes a lighter meal at night for the medication to function properly throughout the night, and for the patient not to feel as tired the next day because of the combination if the drugs contained in the pill.

Medication stored in the clinics is stored in a restricted area as the medication must be kept in a cool dry place, always locked. Only a pharmacist enters the room and attends to each days' register to prepare medication to be collected by patients on each day.

When respondents were asked how the clinic facilitates and assists them, they indicated that receiving their medication in these local clinics is essential to them. They mentioned that there was never a time when they went to clinics and find their medication unavailable, they always get their medication.

*“At the clinics, we get counselling and free medication. I get my medication free of charge. I receive my medication and get the best attention that I require from the clinic staff. I receive treatment, and*



*they always remind me and encourage me to take my medication according to their instructions".* One respondent was excited about the study, he added *"It helps to go to the clinic whenever I am not feeling well. And, to get such opportunities as this one where our educated children do research amongst their own community, meaning they do care about us"* - "spoke about me the researcher" (Transcripts).

### **5.9.5 HIV status disclosure effects to children**

When respondents were asked how their children responded throughout the disclosure process, they had mentioned that it was easy for them to accept that they are living with the disease. Particularly since their children are younger, hence they respect their parents, and others due to the education, awareness and knowledge they get from school. *"They accepted, because I made sure that I disclose to them in a way that they understand it. I made it clear that I did not choose to be infected, but it happened. They accepted it, because it is no longer shameful to a person infected with HIV". They did not judge me. I am their mother; I guess they felt sorry for me. They were hurt in the beginning, and it was hard for them to believe. But then, fortunately there is HIV education in schools, my children are well educated about HIV/AIDS"* (Transcripts).

Fifteen out of twenty respondents mentioned that it took them less than ten years to disclose their HIV status to their children, three took them more than ten years and two respondents mentioned that it took them months to disclose their status. Respondents had mentioned that; younger children would be more supportive and less judgmental as compared to the older ones. It became a challenge to most parents in deciding when to tell the children or not, whether to delay disclosure and male respondent had mentioned that, it was difficult for him as he believes that, women would be able to disclose status easier to a child.

*"My son did not seem to be supportive, at first. It was like I got what I wanted. The younger one is too young to understand. I will inform her when she is older. I am afraid the older will judge me. Which is why I decided to disclose only to the young one. I was afraid of how they would respond, as a result I delayed for so long"* (Transcripts).

### **5.9.6 Child's prior knowledge to HIV/AIDS**

Most parents reported that they did not encounter challenges when going through the disclosure process, because the children were aware of the illness. Their children are believed to be in grades that have already been educated about the HIV/AIDS virus, they have a better and clear understanding of what the disease is,

and what the outcomes of being HIV positive status to their parents. Therefore, they found it easy to accept their parental HIV status disclosure. Schools are playing a vital role in educating children about HIV. For some parents, it is hard for them to talk about sexual behavior and HIV

*“Yes, he does understand, he is a smart child he told me about the knowledge about HIV he gained in school. However, some children are young and not yet have had this topic in school. One parent reported that “I was also worried about the confusion that I brought to my child, and that maybe he has questions to ask that I cannot even have answers to”.*

### **5.9.7 Emotional support**

Emotional support plays an important role in the family. Some parents reported that they need emotional support from their children. Being HIV infected brought about emotions such as anger, pain and depression to most parents, thus then best thing they need from their children is emotional support. Others reported to be too ill to be able to take care of themselves, children in this case become burdened in taking care of their parents, *“Yes, I need my child to be able to support me emotionally, that’s all that matters”.*

Literature, according to Zhao, Li , Qiao , Zhang and Stanton (2016) on this practice denotes that their age and psychological maturity allows the children to accept the situation as is and support their infected parents. With proper guidelines and solutions, this can be maintained and prevent major effects to children that can even interfere with their performance in school. For instance, we need a society that will be able to refer children to counsellors and psychologists for the ‘damage’ caused.

Parents have mentioned that they are depressed, it took them others some time to accept that they are HIV positive, *“I sometimes blame them, especially when I am depressed. Sometimes I do not have money to give them to carry at school. I only have challenges with the one who is deaf. I am stressed and depressed most of the time. I feel like the world is coming to an end. For the younger one, sometimes I get so moody and not give attention to her. I think that affects her. I need to deal with my emotions properly” (Transcripts).* Some respondents have mentioned that they are unemployed, they are depressed since they cannot afford to do whatever they want at any time, they do not have means.

Unemployment is a huge stressor to the Vulindlela population. Respondents reported that, they sometimes go on days without food. Its defined as hard when it’s time to take their medication on an empty stomach and

suffer from the medication intake side effects. This needs further exploration, in terms of the porridge some respondents reported they used to get from their local clinics.

Most respondents mentioned that they need family support grants. As they are unemployed single parents, their children and most of them are still in school, hence they need to be able to at least give them some pocket money to carry to school, have food to eat when they come home and not sleep on an empty stomach. They believed that it is already depressing to some of them living with HIV, but a family support grant would be really appreciated, to cover up where there is a gap.

### **5.9.8 Healthy Parent-Child Relationship**

Parents, after they had disclosed their status mentioned their relationship with their children did not change. *“We have a good relationship, because he respects me. No, our relationship is still the same we live a healthy life. Our relationship is still the same, we are family and we look after each other. No, I am still the mother they respect”*. Contrary, one respondent felt otherwise *“My child does not care much, I think maybe it’s because I am old, and he is also infected he cannot say much about it. He just focuses on his treatment; I do the same because I do not know how he got infected”* (Transcripts).

### **5.9.9 Support groups**

Eighteen out of twenty respondents mentioned that they do not have community support groups. One respondent believed that there was one before, some time ago and two respondents believed that they do have a community group in his sub-area *“Yes, we do. They teach us how to grow crops for instance in our homes because vegetables are healthy. We usually meet at some crèche in the area. We have a support group called ‘Siyathuthuka<sup>8</sup>’, where we discuss our challenges and possible solutions to those challenges”* (Transcripts).

These responses had to be relooked at, together with the previous research conducted by the research on the challenges faced by voluntary caregivers in the Vulindlela community. When the single parents believe that they do not have support groups in the community, there are individuals in the community who have taken upon themselves to take care of the people living with HIV, voluntarily. They are called community caregivers. However, this could be due to the previous study conducted at Honour’s level sample, on only on

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<sup>8</sup> Siyathuthuka – going forward

the Songonzima Clinic, the study titled *“Exploring the challenges facing rural home-based HIV/AIDS voluntary caregivers at the Vulindlela area in the uMsunduzi Local Municipality”*

McCausland and Pakenham (2008) in their work discovered that voluntary caregivers play a dynamic role in the communities that there is an increase in survival periods for a person living with the disease. In rural areas, caregivers provide care to their patients voluntarily and sometimes it is mainly found under difficult environment. Caregivers have become the most vulnerable persons; they bare a heavy burden of HIV/AIDS burden in rural communities.

#### **5.9.10 Parental sexual partner and influences on disclosure**

One respondent mentioned that their sexual partner encouraged her to disclose their status to the children. It is believed that the more support one gets, the easier it is to be able to decide to disclose HIV status disclosure to children. Some respondents are single but had mentioned that they are involved in romantic relationships.

*“I have a new sexual partner, she is aware of my HIV status and I know hers. It’s been two years since we disclosed to each other. My family and my son are aware of my HIV status as well Thanks to my love who actually encouraged me to do so” (Transcripts).*

From the extensive review of literature, studies of Tasman, (2015) Globally as well as Vreeman (2010) in the sub-Saharan Africa, revealed the importance of a partner support to cope with the effects of the disclosure. Research has also shown that, patients, with the assistance form their partners, families and children, tend to adhere to their medication. Sometimes what seem to be a problem to one, may easily be resolved with the assistance of another person.

#### **5.9.11 Main areas of assistance**

Respondents reported that they need social support grants. It can assist in taking care of their basic needs, and most importantly they will be able to maintain a living and have something to eat daily. They say education is the key to success, but it does not seem to be the same for most. Some of the respondents recruited in this study, fall into the proportion of those who had the opportunity to get standard ten (Matric) as the highest level of education, and the few who had the chance to complete their tertiary education, but still, they are jobless, and poverty stricken. Even though Vulindlela is a developing area, most households are poor, and

they do not have proper houses. Most of them fall into the smaller proportion of those who do not have RDP houses. The community lacks proper infrastructure, including proper roads for the people who are living with HIV to travel to and from the clinics effortlessly.

One respondent pleaded to have their medication delivered to their homes, some of them are quiet far from the clinics, they must take taxis or hire a car to get to the health care facilities. It is not only the people living with HIV who face challenges in this community, but even their voluntary community caregivers are deprived of required resources to utilize when taking care of the sick. In addition, these individuals who visit those who are sick in their homes, do it voluntarily. There are no incentives in their caregiving job, hence they end up committing to debts they cannot pay.

Other concerns include the longer waiting hours' patients spend in the clinics. They sometimes spend the entire day before they finish with all the procedure followed for that day. This is the reason most male patients do not go to the clinics, they would rather have someone to collect their medication for them.

People who are HIV positive, and those who are affected by HIV in rural areas face challenges. Challenges that includes lack of awareness about HIV as an economic issue, values that increase the act of stigmatizing people living with HIV, privacy and confidentiality concerns, insufficient services, and transport issues amongst others (Mahery, 2016).

In many rural areas there are high rates of lack of awareness about HIV/AIDS. This means that the disease is rarely discussed due to religion and lack of knowledge about the disease. The more people have conservative values about HIV/AIDS, the less open they are to various populations. In addition, there few campaigns that cater for people living with HIV in the rural areas (Majila, Hoosen, Stoltz & Cameron, 2008). There is a tendency amongst people in rural areas that they conclude and say HIV is not a social problem but a challenge, therefore this perception may be reinforced by the notion that there are few HIV campaigns in rural areas. People stigmatize one another that HIV prevention becomes an obstacle with people in rural areas as well as accessing treatment services (Majila et al., 2008)

Therefore, people living with HIV may have an amplified fear of stigma. Fear of stigma makes them fear disclosing their HIV positive status, hence, this limits chances of benefiting from support groups. People do not only fear stigma, but they are also ambivalent about disclosing their status because of the fear of discrimination and being isolated in their communities. According to some qualitative studies, women and children living with HIV are the ones who experience more social rejection, shame, discrimination, violence

and perceived stigma than their male counterparts (Mahery et al., 2016). Rural areas are rife with these challenges and feelings of not belonging.

Therefore, women experience more disclosure concerns than men. They are reluctant to feeling depressed and experience increased anxiety concerning their HIV status disclosure. Privacy and confidentiality are major concerns for people with or at risk of HIV in rural areas. They are afraid of getting tested and being recognized by someone in their community or by clinic and hospital staff. This is especially true in areas that do not provide anonymous testing (Nkonki, Dpherty, Chopra, Schaay and Kendall, 20017). To protect their confidentiality, rural residents may seek HIV testing in other communities or avoid testing completely, this delays the chances of the disease detected earlier and prevents the progression of the virus in the human body.

Primary care medical doctors and HIV specialists are found in urban areas. They provide care for people with progressive HIV (Nkonki et al., 2017). Because of low population density, rural communities often have shortages of medical doctor's infectious disease specialists and mental health professionals. (Nkonki et al., 2007).

Some respondents have mentioned that transportation to get to clinics is a challenge. Most of the patients are unemployed, hence, it is hard to have money to travel to the clinics for medication or treatment. Many people in rural areas experience an issue of traveling long distances. Residents who lack accessible transportation are less able to access the appropriate medical care they need (Majila et la., 2008:35).

There is an urgent need to respond to practices to serve the rural and isolated populations. These are culturally diverse areas with unique needs that needs to be recognized. For interventions to breach community cultural norms and influence residents, both those living with HIV and those at-risk, must be tailored to the communities. Educational programming must also be sensitive to individual risk factors in each community (Nkonki et la., 2017). While interventions should be tailored to each community, there is evidence that the following best practices are effective.

Operative interventions include educating rural communities to reduce stigma, increasing the number of people involved in HIV information activities, and introduce community support groups for people living with HIV. Faith-based organizations would initiate discussions about HIV, as an attempt to reduce stigma. Interventions that reduce fear and stigma can also reduce social isolation by fostering better connections among people living with HIV and expanding social support networks (Stevens, Sinanovic, Regensberg and

Hyslop, 2007). Being able to find peers and disclose one's HIV status helps to reduce psychological stress and risk of depression. Reducing the stress and isolation associated with HIV may open the door to interventions that can then focus on helping people developing the skills to prevent HIV or to manage HIV and maintain their health.

It is argued that people with HIV living in rural areas favor Interventions that combine motivation and skill building. Therefore, it is essential to deal with the need for privacy among people living with HIV in rural areas (Stevens et al., 2007). Some rural areas try to increase love, trust and care amongst each other testing and counselling in the community spaces that are not associated with HIV places like colleges and counselling centers as well as churches in some countries, several strategies have been used effectively to expand access to HIV testing services for people in rural communities by providing transport for volunteers to take part in their study or HIV testing to improve the volume of health care providers in rural areas.

In a society that we live in today, we rely heavily on technology-based interventions, they can be the most effective way to deliver HIV services in rural areas where there is increase access and transport barriers to reduce costs to health care. An example would be the use of internet which would allow people to access HIV information while protecting their privacy and confidentiality and to communicate with peers conveniently without fear of being seen or noticed by people who know them (Stevens et al., 2007).

Internet use in rural areas can also be used to provide HIV intervention programs at minimal cost, overcoming some barriers that are associated to stigma and confidentiality concerns and remain anonymous. It has been found that the most common internet-based HIV prevention program are chat rooms where it is easier to access information and testing referrals in real time at a minimal cost (Wiener et al., 2007). The use of telephones, to refer people to clinics is an effective way of delivering the message and overcoming geographical barriers and ensure that the message does get passed from one person to the other.

In the United States, one study conducted among people living with HIV using a telephone-delivered intervention was successful in reducing through telephonic support groups, and access was easily made through public phones through toll-free numbers. In rural areas, it is particularly challenging to reach the most at-risk populations due to lack of funding. To overcome these barriers, AIDS service organizations and other agencies must use their funding cautiously and deliberately to reduce the duplication of efforts and address community health always (Weiner et al., 2007).

## **5.10 FUTURE RESEARCH**

In this study, teenage children have not been interviewed, and thus another perspective has not been brought to the fore. There are much more ethical considerations that are concerned with the research of children. However, it must be considered for future research the impact of disclosure from children's perspective in terms of their parent's HIV status disclosure.

## **5.11 SUMMARY OF CHAPTER**

This chapter has critically analyzed each respondents' views, their challenges, possible solutions and ways on how to tackle the challenges that they face. The researcher after analyzing each respondent's interview views, made sense of the natural setting of its respondents, therefore, found themes and sub themes that emerged.

# **CHAPTER SIX: CONCLUSION**

## **6.1 INTRODUCTION**

Despite the limitations, the researcher believes that this exploratory study adds critical information to the very limited knowledge base about the challenges facing single parents in the Vulindlela area when disclosing their HIV status to their children. These unemployed single parents and their children have clear psychosocial needs related to adolescence and parents living with HIV and are interested in interventions, particularly those focused on medication adherence, disclosure support, family relationships and communication. Given the support received from medical providers, strength of family bonds and the expressed need for peer support, a multiple family-based group intervention offered within clinics might be helpful especially to those single parents who are going through depression.



## 6.2 SUMMARY OF FINDINGS

This study, similar to Odoh and Frankish, Campbell, and Foulis (2015) study from international sources found that parents need to understand the role of age in HIV status disclosure, especially since most of the children were still in school. The Vulindlela area is also defined as a resource-limited location. When comparing to what I identified from the Global literature, it was revealed that the most commonly cited challenges are medication adherence that includes delaying or skipping doses because parents did not want to take medicines in front of their children. This study found that, children were informed about parent's HIV status, and parents do not skip doses, infect, their children assist them in adhering to medication.

This study found significant depression ideation. Hence, it also failed to capitalize on positive international studies on community-based evaluation with children of single parents living with HIV. The Vulindlela community does not have support groups.

Moreover, this study found that, older children pose some forms of cognitive reactions. For example, results show that older children did not care much or did not show any love or sympathy with their parents after disclosure. It was more like they got what they deserve. Some have shown that their children are infected with HIV as well, hence they did not worry about their parents but themselves.

Furthermore, this study found that very little is known in Vulindlela about affected children on parental HIV status disclosure. This could be due to the lack of the establishment of joint service plans between local authorities and health facilities. In addition, this study found that HIV positive single parents when deciding whether and how to disclose their illness to their teenage children is a major stressor. This further extends to severe stigma experienced by parents. The study found children emotional, reactions were on both children and parents. However, children had a desire to assist mothers and fathers with the illness and become more involved. When investigating the relationship between the parent and the child after disclosure, findings of this study revealed that mostly, both parents and children communicated positive outcomes such as healthier relationships.

In this study, conclusions were made that, a policy needs to be made to recognize culturally-specific family formations. Experiences of single parents in disclosing their HIV status disclosure included perceptions that children are too young to understand what HIV infection means. Immediate outcomes of disclosure included

children being shocked and worried. None of the parents in this study reported the impact of their disclosure on education and emotional setbacks to teenage children.

Both men and women had disclosed their status to their children. One man reported that he found it hard to disclose his status to his children, he believed it's a woman's duty to talk about topics like sexual intercourse, HIV and pregnancy to children. Parents in this study did not keep a secret about their status from children, although it took them different amounts of time to disclose from the time they had known to be diagnosed with HIV.

Disclosure is beneficial. In this study, parents did disclose to children, however, psychological effects were not defined in detail and whether it is all parents who are HIV positive who have disclosed their status to children. This could perhaps be further explored in future. Some parents delayed disclosure because they were overcome by guilt and afraid of hurting their children. The researcher postulates that richer data can be collected with several participant interviews over time as opposed to one-time cross-sectional interviews

### **6.3 ETHICAL CONSIDERATIONS IN RESEARCH**

It is important to consider research ethics in the study. These are a set of principles about how researchers should conduct themselves when dealing with research participants, the users of their research and society in general. All permissions and approvals were received. The researcher had the following ethical considerations for not choosing to include children in this study. For research or evaluation to be considered ethical, consent must be voluntary and must be based on enough understanding of the research or evaluation and the suggestions of participating in it (National Health and Medical Research Council, 2007). The researcher felt that, including children in this study would deprive them their right to consent or give assent voluntarily. It was also important to consider the age of the children, as it has assumed that single parents will have teenage children who are between the ages of twelve to twenty-four t. There had to be proper mechanisms in place to be in place in case children were to be involved. This includes psychological effects, the researcher chose not to include children because of these considerations in mind.

Research ethics stipulates that if the child is younger than 18 years of age, their parents should consent for them to participate in a study. Therefore, the researcher assumed that parental consent alone will not be enough for older children and young people who must also assent to participate in the study. In order to give informed consent or assent, participants must have adequate information in a format they can easily

understand. This study for instance, used an interview schedule that is meant for parents and requires parental responses alone. However, it was later discovered in this study that majority of the teenage children are matured, and they can easily accept their parent's HIV status based on their parents' responses.

The researcher did not include children in the study, because she felt that, children deserved adequate time for the recruitment and consent process and give them enough time to consider their participation. Perhaps in the future research, children will be included.

#### **6.4 RECOMMENDATIONS**

Considering that most responses from the respondents indicated that they go to clinics when they were sick, this is when they were first diagnosed with HIV. People are encouraged to get tested for HIV regularly, to prevent the delay and the progression of the disease in their system, however, it is highly appreciated that, today health care facilities no longer wait for the infected persons' CD4 count to be low in order to be initiated to treatment. No matter the CD4 count, each person is initiated to treatment which makes it possible to fight the infection and live longer.

Furthermore, most respondents had mentioned that they need support to be reminded daily when it's time to take their medication. This is a matter of a stronger social structure: families and the concerned community to express the act of 'Ubuntu'. Some infected persons come from disadvantaged families, which makes it harder to adhere to treatment i.e. if they do not have food to eat or money to travel to and from their local clinics.

On the positive side, most respondents felt that their children accepted that they are HIV infected and are taking care of them. However, in a case where children are too young to take burden of taking care of their own families, the community health care workers together with the local/ward counsellors should always intervene and make it easier to achieve a healthy parent-child relationship. It is recommended we consider child's age, as they responded differently to their parent's disclosure.

The parent's depression is real and is a stressor and one of the challenges they are facing. Proper measures within the community must be implemented as they have indicated that they do not have support groups in the Vulindlela area. I believe they would play an important role in their lives hence, they will be able to express and share with other people. However, every time they go for visits in the clinics, they do receive their medication free of charge.

We need to have implemented programmes that work with men on various HIV-related issues. These programmes have demonstrated the importance of engaging men to boost women's uptake in the process of HIV status disclosure to children. Strategies to enhance male partner involvement must be put in place to empower women in Vulindlela who take the initiative of being the ones who disclose to their children. Health facilities can also support this role by initiating male-friendly services as well as offering services that are exclusively for men including support groups that are not found at Vulindlela. Male involvement may also be enhanced by use of behaviour change as well as communication through the media. These will serve as an attempt to change gender stereotypes. Opinion leaders, such as village elders and pastors, have also been successfully used to deliver educational sessions on importance of male involvement and participation. Health system factors include long hospital waiting times, unfriendly staff and female-dominated services at the hospitals.

This research has identified several gaps when comparing to what other countries have mastered when it comes to parental HIV/AIDS disclosure to their teenage children. We need to have support groups in the Vulindlela community, in this way, parents will be able to share their experiences with others and come out with solutions from other parents. Depression rates amongst them will also be minimized.

We need a society that will allow children to consent themselves if they need to be informed about parent HIV status, if they do, we need to implement strategies that will help promote and maintain a healthy relationship between the child and the parent. South Africa, especially in the rural areas, is not aware of the importance of the disclosure process. The researcher needs to show the Vulindlela community the importance of this, together with the community counsellors and the Department of Health. Perhaps, one could even initiate or introduce a programme in the community regarding disclosure. It will be voluntarily and enlightens the community members that it should exist and will benefit the whole society.

The study sought to untie the perceptions of whether the teenage child needs to know their parent's status and discover how it affects them. This study successfully addressed this objective. From extensive researcher observation and exploratory of the perceptions, the study managed to untie perceptions, such as when parents believed that they need assistance from their children when they need to take their medication. When parents adhere to their medication, with of course a help from their children, they live longer healthy lives. Parents also mentioned that they need emotional support, they received it throughout the HIV status disclosure process.

Children of these parents are brave, they managed the burden that was on them, they managed to overcome obstacles that came with their parents coming and informing them about one of the most life-threatening diseases in South Africa. Even without proper disclosure guidelines, (that the Global countries are in possession of) between the parent and the child, it was easy for the children to accept the conditions in which their parents live, hence it did not affect them negatively that much, the effects were short-lived from being shocked, which is not that intense.

The researcher sought to investigate the components that influence the parent's decision in status disclosure. This study revealed that single parents felt that their children had the right to know about their positive HIV status. In this way, they are being honest and truthful in every way possible, for when the time comes when they pass away, but the children will know about the cause of parent's death. In addition to knowledge about HIV/AIDS that children learn from school, they felt it is also their duty as parents to educate their children about HIV and how in future they can behave and not be in the same situation; always practice safe sex and showing the importance of partner support.

Single parents must consider child's maturity if they will be able to understand what is happening when they are told about their parents' status. With regard to this objective the study had hoped that single parents must delay disclosure and only inform their children about their HIV status once they are older. Contrarily, younger children in this study are the ones who honestly understood, showed support to their parents compared to the older ones. The older children tend to be judgmental and discriminating towards their parents, hence, it was not easy for them to disclose their status, once they did, they were called names and told that they deserve it.

The researcher sought to assess the challenges facing parents and the ways on how they overcome challenges and maintain a healthy parent-child relationship. Challenges included depression, lack of proper houses for the family and the most importantly, high unemployment rates. However, these parents did not abandon their children, on every little penny they get, they make sure that their children are always a priority and they get food at least to eat and not sleep on an empty stomach.

This research provided a background and overview, conceptual clarification, legislation on HIV/AIDS disclosure that is practiced in the international arena, as well as the beliefs that our country South Africa holds. The researcher managed to identify and explore in detail the qualities of the HIV status disclosure, the importance of parental disclosure as well as its negative effects on the child, parents and family members.

Identifying the consequences, the reasons for HIV disclosure and the positioning of the researcher, made it easier to gain understanding of what to achieve by the end of the study.

This was also achieved through extensive readings and review of existing literature. It was important to explain the concerns and motivations of HIV disclosure, gender and societal norms since people in different settings of the world respond differently to the disclosure of an infected person concerning their positive HIV status. The researcher, hence, looked at the global, sub-Saharan as well as South African literature. Findings revealed that, the disclosure of a positive status is not always a good thing to do, especially if the child is too young to understand. In this instance, it is advisable to delay disclosure until the child is older. It was also found in this study that, there must be proper disclosure guidelines in place, as well as proper referral structures should the child and the parent face challenges and it affect them psychologically.

The research motive, arose to one from observations in the Vulindlela community concerning the HIV/AIDS, and how it has affected most households, hence, a study ought to be conducted to find more information from the objectives one had. The use of a theory in chapter three made the researcher achieve knowledge and explore the challenges that parents face with the use of a theory, as theories are important in the social science as well as the society, we live in. Therefore, the researcher explained the applicable perspective, the theoretical perspective in the study and why she chose to use the collective finger's theory to better under the study and its aims and objectives.

Furthermore, for any study to be conducted, it has certain methods that must be followed in order to be able to get the information that is required. The study sample and population made it possible for the researcher to gain an understanding on the research topic. Findings and analysis of the study revealed that, disclosure seemed to be a concept that need further exploration, the community of Vulindlela must know about its importance, challenges as well as solutions and mechanisms that should be applied when other parents decide to disclose their HIV status to their children. Children again must also be aware of this process and how they could respond towards it. In most countries, many households are child-headed due to HIV and the death of parents. However, when children are aware of their parent's status, they are in a position to assist parents adhere to medication and thus they live longer and a healthy life.

Lastly, this can be achieved if the community has support groups, ward counsellors that are interested in assisting the families who are affected, a community that does not discriminate and stigmatize HIV, health

care facilities who provide the best care to the people, and proper family structures and advanced education in schools on the social issues.

## **6.5 SUMMARY OF CHAPTER**

This study set out to generate exploratory evidence of single parents who are HIV infected responses to the lived experiences and challenges they face when disclosing their HIV status to their teenage children in the rural Vulindlela area. This has had both positive and negative impacts on both caregivers and the whole community. It can be concluded from the findings of this study that the positive aspects of the experiences outweighed the negative aspects in terms of the effects the disclosure process has brought between the parents and their children

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## APPENDICES

### Appendix A – Informed Consent



#### Informed Consent Form

#### Consent Form for Participation of Human Subjects in Research

#### University of Kwa-Zulu Natal

#### PROJECT TITLE:

*An investigation into the challenges facing single parents in disclosing their HIV/AIDS status to their teenage children. A case of the Vulindlela Area in the uMsunduzi Local Municipality.*

**RESEARCHER:** Bhengu Nomfundo

**Protocol Reference Number:** HSS/1431/018M

**STUDENT NUMBER:** 212530064

The Department of Sociology (Society and Social Change)

University of KwaZulu-Natal, Durban South Africa.

**DURATION:** Please note that the interview will require **sixty minutes** of your time.

**Dear Participant**

**INFORMED CONSENT**

My name is Nomfundo Bhengu student number, 212530064. I am a Master's student studying at the University of KwaZulu-Natal, Pietermaritzburg Campus. The title of my research is: ***An investigation into the challenges facing single parents in disclosing their HIV/AIDS status to their teenage children. A case of the Vulindlela Area in the uMshunduzi Local Municipality.*** This study aims at discovering the views and perceptions of the community members on challenges parents face in the disclosure process of mother-child transmission. Studies on the impact of HIV/AIDS infection disclosure to infected children are limited, therefore, it will be an advantage to the South African literature to write about who and how the challenges rural parents and children face affects one.

Please note that:

- The information that you provide will be used for scholarly research only.
- Your participation is entirely voluntary. You have a choice to participate, not to participate or stop participating in the research. You will not be penalized for taking such an action.
- Your views in this interview will be presented anonymously. Neither your name nor identity will be disclosed in any form in the study.
- The interview will take about *45 minutes long*.
- The record as well as other items associated with the interview will be held in a password-protected file accessible only to myself and my supervisors. After a period of 5 years, in line with the rules of the university, it will be disposed by shredding and burning.
- If you agree to participate please sign the declaration attached to this statement

I can be contacted at: School of Social Sciences, University of KwaZulu-Natal, Pietermaritzburg Campus, Email: 212530064@stu.ukzn.ac.za; Cell: 0748231846. My supervisor is Dr Mariam Seedat-Khan who is located at the School of Social Sciences. University of KwaZulu Natal. College of Humanities. Room F117, Memorial Tower Building. University of KwaZulu-Natal Howard College Campus. Tel: +27 (0) 31-2601056. Seedatm@ukzn.ac.za

Thank you for your contribution to this research.

DECLARATION

I \_\_\_\_\_ (full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participate in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire. I understand the intention of the research. I hereby agree to participate.

I consent to have this interview recorded.

**SIGNATURE** \_\_\_\_\_

**DATE** \_\_\_\_\_

## Appendix B Translated Informed Consent



Imvume Yokuba Yingxenywe Yocwaningo

iNyuvesi YaKwa-Zulu Natali

### ISIHLOKO SOCWANINGO:

*An investigation into the challenges facing single parents in disclosing their HIV/AIDS status to their teenage children. A case of the Vulindlela Area in the uMsunduzi Local Municipality.*

Sawbona,

Igama lami ngingu Nomfundo Bhengu, inombolo yokuba ngumfundi engu-212530064. Ngingumfundi wase Nyuvesi yaKwaZulu-Natali owenza izifundo zakhe ze – Masters ekolishi yase uMgungundlovu. Ngithanda ukwenza ucwaningo ngesihloko esicubulungula kabanzi ngemibono yamalunga omphakathi okumayelana nezinkinga abazali abahlangabezana nazo uma bechazela abantwana babo abazalwe negciwane iSandulela Ngculazi, Kanye nokukhubazeka kosikompilo kubantwana. Ucwanino lwaphambilini luveze ukuthi ukuxoxisana kwabazali nabantwana ngokutheleleka nesifo kuncane, ngakho ke, lolu cwaningo luzokwandisa isibalo sezocwaningo eNingizimu – Afrika mayelana nezinkinga ezihlangabezana nabazali Kanye nabantwana.

Ngicela wazi lokhu:

- Imininingwane yakho ozongipha yona izosetshenziswa kulolu cwaningo kuphela
- Uvumelekile ukuzikhethela ukuba yingxenywe yocwaningo. Kuyilungelo lakho ukuba ucele ukuhoxa uma uzizwa ungaphathekile kahle.
- Imibono yakho kanye nezimoendulo zizovezwa ngokufihlekile. Asilisebenzisi igama lakho okanye yemininingwane yakho.

- Ingxoxo yethu izothatha iskhashana esingango – 45 wamaminithi kuphela
- Amarekhodi engxoxo yethu yokugcinwa ephephile lapho kuzokwazi khona mina okanye isikole kuphela. Emva kweminyaka emihlanu, sizobe sesikushisa lokhu okuqoshiwe sesiqedile ukukusebenzisa.
- Uma ukukungele ukuba yingxemye yocwaningo, ngicela usayine ngezasi imvumo yakho

Ungaxhumana nami kwisikole sezeNhlalo Yomphakath, iNyuvesi yaKwaZulu-Natal, Pietermaritzburg ikiolishi, Email: 212530064@stu.ukzn.ac.za;

Inombolo yocingo: 0748231846

Umqeqehi wami kwezocwaningo uDkt. Mariam Seedat-Khan otholakala esikoleni Sezifundo NgezeNhlalo Zomophakathi eKolishi i-Howard eThekwini. Utholakala lapha: Ucingo: +27 (0) 31-2601056. Inombolo Yocingo+27 (0) 837879495. I – Email: Seedatm@ukzn.ac.za

Ngiyabonga ngegalelo lalo kulolu cwaningo.

### IMVUME

Mina\_\_\_\_\_ (amagama aphelele evolontiya) ngiyavuma ukuba ngichazekile futhi ngiyavuma ukuba yingxenye yalolu cwaningo.

Ngiyaqonda ukuba kuyilungelo lami ukuzikhethela ukungabi yingxenye yocwaningo uma ngingazizwa kahle. Ngiyaqonda izifiso zalolu cwaningo ngakho ngiyavuma ukuba ngibe kulolu cwaningo.

Ngiyavuma futhi ukuba ingxoxo yethu iqoshwe.

**ISIGNISHA**\_\_\_\_\_

**USUKU**\_\_\_\_\_

## Appendix C – Ethical Clearance Certificate



UNIVERSITY OF  
KWAZULU•NATAL  
INYUVESI  
YAKWAZULU.NATALI

4 February 2019

Ms Nomfundo P Bhengu 212530064  
School of Social Science  
Pietermaritzburg Campus

Dear Ms Bhengu,

Protocol reference number: HSS/1431/018M

Project title: An investigation into the challenges facing single parents in disclosing their HIV/ AIDS status to their teenage children. A case of the Vulindlela Area in the uMsunduzi Local Municipality.

In response to your application received 24 July 2018, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted FULL APPROVAL.

Full Approval— Full Committee Reviewed Protocol

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment [modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Shamila Naidoo'.

.....  
Dr Shamila Naidoo (Deputy Chair)  
Humanities & Social Sciences Research Ethics Committee

/pm

cc Supervisor: Dr Mariam Seedat-Khan cc Academic  
Leader Research: Prof Maheshvari Naidu cc School  
Administrator: Mrs Nancy Mudau

## Appendix D – DoH Approval Letter



Physical Address: 330 Langalibalele Street, Pietermaritzburg  
Postal Address: Private Bag X9051  
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782  
Email: [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)  
[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

DIRECTORATE:

Health Research & Knowledge  
Management

NHRD Ref: KZ 201902 001

Dear Ms N. Bhengu

UKZN

Approval of research

1. The research proposal titled 'An investigation into the challenges facing single parents in disclosing their HIV/AIDS status to their teenage children, A case Of the Vulindlela Area in the uMsunduzi Local Municipality' was reviewed by the KwaZulu-Natal Department of Health.

The proposal is hereby approved for research to be undertaken at Taylors' Halt, Songonzima and Mafakatini clinic.

2. You are requested to take note of the following:

- a. Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These included but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.
- b. Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.
- c. Provide an interim progress report and final report (electronic and hard copies) when your research is complete to HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200 and e-mail an electronic copy to [hrkm@kznhealth.gov.za](mailto:hrkm@kznhealth.gov.za)

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

 02/02/19

Dr E Lutge

Chairperson, Health Research Committee

Fighting Disease, Fighting poverty. Giving Hope



## Appendix E - Translated Interview Schedule



*“Izinsela ezihlangabezana nabazali ababodwana uma bechazela abantwana babo ngesimo sabo ngesifo i-Sanduleza Ngculazi. Ucwaningo lomphakathi wase Vulindlela ngaphansi kuka Maspala wendawo”.*

### **IMIINIGWANE YOMHLANGANYELI**

#### **IMNINIGWANE NGE NGCIWANE**

1. Yini eyenza ukuba uhlole igazi?
2. Wamelana kanjani nalesi simo?

#### **USIZO**

3. Wathola luphi usizo ngaleyo nkathi?
4. Udinga hlobo luni losizo zinsuku zonke?
5. Umndeni wakho kanye nomohakathi wase Vulindlela bakusiza kanjani?
6. Uthola sizo luni ku-Hulumeni?

#### **UKUVEZWA KWEGCIWANE**

7. Kwakuthatha isikhathi esingakanani usuwazi ukthi uphila nalesi sifo ukwazisa abantwana bakho, wabazisa bonke bakho ngaso?
8. Bebe neminyaka emingaki ngaleyo nkaithi?
9. Bayithatha kanjani abantwana?
10. Ngabe bayaqonda siyini lesi sifo nemthelela yaso empilweni yakho?
11. Yini eyaba nzima kakhulu uma ubazisa?
12. Ngabe yiziphi izinkinga ohlangabezana nazo mihla yonke okuba nzima ukuthi unakekele abantwana bakho?
13. Ubudlelwane phakathi kwakho nomntwana/abantwana bakho buhlukile?
14. Ngabe uyaludinga usizo kubantwana bakho?

#### **UMPHAKATHI WASE-VULINDLELA**

15. Ngabe uyaluthola usizo ngokwempilo? Ama gulubhu okuzwelana?
16. Imtholampilo iusiza kanjani?
17. Ngabe kukuphi lapho udinga khona usizo wena nomntwana/ abantwana bakho?

#### **Ngiyabonga ngesikhathi sakho**



## Appendix F - Turn it in Report

Document Viewer

### Turnitin Originality Report

Processed on: 18-Jun-2019 1:53 PM CAT  
ID: 1144878535  
Word Count: 41311  
Submitted: 1

HIV MASTERS By Nomfundo Bhengu

Similarity Index <b>6%</b>	Similarity by Source Internet Sources: 0% Publications: 0% Student Papers: 6%
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mode:  quickview (classic) report  Change mode

6% match (student papers from 17-Feb-2017)  
[Submitted to University of KwaZulu-Natal on 2017-02-17](#)

AN INVESTIGATION INTO THE CHALLENGES FACING SINGLE PARENTS IN DISCLOSING THEIR HIV/AIDS STATUS TO THEIR TEENAGE CHILDREN. A CASE OF THE VULINDELA AREA IN THE UMSUNDUZI LOCAL MUNICIPALITY. BY NOMFUNDO BHENGU 212530064 SUBMITTED IN FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE MASTERS IN SOCIOLOGY SCHOOL OF SOCIAL SCIENCE SUPERVISOR: DR M. SEEDAT KHAN 2019 **DECLARATION I, Nomfundo Precious Bhengu, declare that this study is my own work, it has not been submitted for any degree or examination at any other university. The sources that I have used have been fully acknowledged.** This study is submitted in fulfillment for the requirements for the degree of Masters in Sociology in the faculty of Humanities, School of Social Science, University of KwaZulu Natal, Howard College, Durban, South Africa. Signature: Student Number: 212530064 Date: DEDICATION I dedicate this work to God, for his has granted me the strength and opportunity to do this work. He is the God Almighty, without Him, none of this would have been achieved. Amen ACKNOWLEDGEMENTS A sincere thanks and appreciation to my Supervisor Professor Mariam Seedat-Khan for your support, co-operation and encouragement throughout this whole dissertation. I am solely indebted to you, as you were my pillar of strength during this whole process. In a time that I thought there was no hope you came to my rescue as being my supervisor. God, bless you and your family. To my parents, thanks for your encouragement and support, the community of Vulindlela as well the Clinic Operational Managers, none of this would have been accomplished without your support and participation during my studies.

LIST OF TABLES Table 4.3.1: uMsunduzi Municipality..... Error! Bookmark not defined.  
Table 4.3.2: Gender..... Error! Bookmark not defined.  
Figure 5.6.1: Respondents Demographics ..... Error! Bookmark not defined.  
LIST OF FIGURES  
Figure 5.6.2: Reasons why respondents got tested ..... Error! Bookmark not defined.  
Figure 5.6.3: Dealing with the situation .....

## Appendix G – Parents and Children

SEX	AGE	NUMBER OF CHILDREN	AGE OF CHILDREN
1.Female	35	1	16
2. Female	48	2	16 and 19
3.Female	50	1	19
4.Male	43	1	12
5. Male	50	1	19
6. Male	46	2	18 and 14
7. Male	43	1	12
8.Female	39	1	14
9.Female	32	1	13
10.Female	35	1	18
11.Female	35	1	23
12.Female	57	3	19, 13 and 11
13.Female	56	1	17
14.Female	57	2	15 and 24
15.Male	40	2	15 and 17
16.Male	31	2	12 and 4
17.Male	47	2	21 and 24
18.Male	39	19	19
19.Male	39	13	13
20.Male	43	10	10

## Appendix H – Transcripts

**When parents were asked about what made them decide to get tested?**

**Respondent A** replied, *“I got sick, really got sick then I decided to go to the clinic”.*

**Respondent B** responded *“I had flu, it had been going on for quite some time. I decided to go to the clinic for an injection, but sometimes I would go and leave the clinic without any help”.*

**Respondent C** too shy to respond, felt that *“I was concerned about my health, after some time I had not been feeling well. I decided to go test at the clinic”.*

**Respondent D** proudly responded, *“I wanted to be sure of my status, that’s why I tested”.*

**Respondent E** sadly responded, *“I was sexually assaulted, that is when I had to get tested for HIV and found out that I am HIV positive”.*

**Respondent F** without hesitation, *“I was just going to the clinic for my regular check-ups, one day I found out that I am HIV positive”.*

**Respondent G** similarly to respondent A and B responded, *“I was very ill, that is why I decided to come to the clinic. I got tested for HIV”.*

**Respondent H** responded *“I wanted to test for HIV, I was okay. Not that I was not feeling well. So, I found out I am HIV positive”.*

**Respondent I** similarly to responded A, B, G responded *“I was not feeling well, I was weak for some time and I had lost weight. My mother suggested that I get tested for HIV, then I did”.*

**Respondent J** similarly to A, B, G, I responded *“I was ill, in such that way that my immune system was very weak. I had to be hospitalized because my inner body was becoming “rotten” I had sore. Then I got tested for HIV, when it got severe, I had sores around my mouth as well”.*

**Respondent K** similarly to A, B, G, I, J responded *“I was sick most of the time. I decided to get tested”.*

**Respondent L** Likewise, felt that *“I was sick at that time, I had TB but then the HIV counsellor suggested that I also do an HIV test”.*

**Respondent M** contrary responded *“It was more of I wanted to know my status. One day I decided to go get tested, and I was diagnosed with HIV”.*

**Respondent N** calmly with a sad face responded, *“I was sick then I decided to get tested”.*

**Respondent O** contrary to all respondents responded *“I wanted to ensure if I am still HIV negative and wanted to make sure that I also keep my partner healthy. But then again, I had to make sure if I already am infected, I need to take proper measures to keep up healthy”.*

**Respondent P** likewise felt that *“I was sick, then I decided to go to the clinic. They suggested that I do an HIV test. That is when I discovered that I am HIV positive”.*

	<p><b>Respondent Q</b> responded, <i>“I was sick, and I was not sure of what was wrong with me”</i>.</p> <p><b>Respondent R</b> differently felt that <i>“It had been some days that I had a runny stomach and also suffered a terrible headache, I decided to get tested”</i>.</p> <p><b>Respondent S</b> responded, <i>“I was not feeling well, I decide to get tested”</i>.</p> <p><b>Respondent T</b> with enthusiasm and looking forward to answer, responded <i>“I was suspecting that I am infected already, looking at the things that I have done and the sexual partners that I had had before. I just wanted to be sure and take treatment from there.”</i></p>
<p><b>When respondents were asked about how they dealt with the status results</b></p>	<p><b>Respondent A</b> responded, <i>“When I found out I was sick, there was not much I could do, it was easy for me to accept that I am infected”</i>.</p> <p><b>Respondent B</b> Calmly responded, <i>“It was not that hard, because I have seen few people from my family who were infected already, and I saw that they live longer it was easy for me to accept.”</i></p> <p><b>Respondent C</b> similarly to respondent A and B responded, <i>“It was easy for me to accept. Because I know that being HIV positive is not a death sentence”</i>.</p> <p><b>Respondent D</b> responded, <i>“It was not easy for me, I was somehow confused, but eventually accepted the condition”</i>.</p> <p><b>Respondent E</b> strongly felt that, <i>“It was not hard because most people in my family were already infected. It was easy for me to accept. Being sexually violated was the only trauma I had encountered.”</i></p> <p><b>Respondent F</b> contrary felt that <i>“I was shocked, because my husband had passed away a long time ago. But, learnt to accept as time passed by”</i>.</p> <p><b>Respondent G</b> gladly responded, <i>“It was easy for me to accept, but I did not know how I got infected.”</i></p> <p><b>Respondent H</b> with a smiley face, responded, <i>“I tested positive, then I attended regular checkups it was not hard for me to accept, I met kind people we were able to share our results and made peace with our similar statuses”</i>.</p> <p><b>Respondent I</b> felt <i>“It was not easy, but I did accept as time went by, because I have seen it and I know that infected people do live longer so long as they keep healthy and adhere to their medication”</i>.</p> <p><b>Respondent J</b> responded, <i>“It was easy for me to accept. Because I wanted to get better.”</i></p> <p><b>Respondent K</b> responded, <i>“It was hard for me to accept, I don’t want to lie. Because I knew that I am well behaved. But then, I had to accept”</i>.</p> <p><b>Respondent L</b> felt <i>“It was hard, but as time went by, I became used to it and I accepted.”</i></p> <p><b>Respondent M</b> <i>“Well, I found out in a very strange way. My partner is the one who got ill first, I found his HIV status results at home where he had hidden them. This is when I confronted him and told him that we need to go to the clinic and get tested together. This is when he also started his medication. It was hard to accept but eventually I did”</i>.</p>

	<p><b>Respondent N</b> felt <i>“It was easy for me to accept it because I know people who are HIV infected and they have lived for quite a long time”</i>.</p> <p><b>Respondent O</b> hyperactively replied <i>“It was easy to accept, because I had been previously diagnosed with TB. And since the disease is no longer shameful, I even hear on radio even celebrities live longer those who are HIV positive. I made peace with myself.”</i></p> <p><b>Respondent P</b> <i>“It was hard to accept, but then because I received the best counselling from a counsellor, she made it easy for me accept.”</i></p> <p><b>Respondent Q explained</b> <i>“Before, I had TB, so it was easy for me to accept because even with TB I managed to take my medication until I finished. And on radio, they also educate people that TB is one of the opportunistic diseases to HIV, I was not that surprised”</i>.</p> <p><b>Respondent R responded,</b> <i>“I accepted, because I know that it does not mean I will die so long as I take my medication”</i>.</p> <p><b>Respondent S</b> quick to respond, responded, <i>“I was shocked, I wasn’t expecting it. But with proper counselling I accepted.”</i></p> <p><b>Respondent T lastly, felt</b> <i>“It was difficult to accept I must say. But as time went by, I managed to accept”</i>.</p> <p><i>Respondents A, B, C, F, G, H, J, N, O, Q, R felt it was easy to accept the results of their HIV status, contrary respondents D, E, I, K, L, M, P, S, T felt it was hard and shocking to accept.</i></p>
<p><b>When respondents were asked about the support that was available to them at the time</b></p>	<p><b>Respondent A</b> responded, <i>“after the HIV test tested positive, the clinic facility further tested me for Tuberculosis (TB), from there I did so many blood tests on HIV”</i>.</p> <p><b>Respondent B</b> responded, <i>“I can say my family is very supportive, and also the clinic counsellor initiated me free medication”</i>.</p> <p><b>Respondent C</b> similarly to respondent A and B responded, <i>“I got counselling and started treatment same day I was diagnosed with HIV”</i></p> <p><b>Respondent D</b> similarly to respondent A, B, C responded <i>“I was initiated to medication same day I was diagnosed with HIV”</i></p> <p><b>Respondent E</b> similarly to respondent A, B, C, D responded <i>“I received my medication, went for therapy classes regularly.”</i></p> <p><b>Respondent F</b> similarly to respondent A, B, C, D, E responded <i>“I received counselling and my first medication, and further was referred to a doctor in hospital.”</i></p> <p><b>Respondent G</b> responded <i>“As I am a traditional healer, and in most cases I assist my patients without gloves, I suspected this is how I got infected. The nurse told me to about the procedures from the day, and I started with treatment immediately. Now, I know that I always have to use gloves when assisting my patients.”</i></p> <p><b>Respondent H</b> similarly to respondent A, B, C, D, E, F responded <i>“I think I am well supported when I come for medication every month.”</i></p> <p><b>Respondent I</b> similarly to respondent A, B, C, D, E, F, G, H responded <i>“I received counselling from the nurses, I did not experience any sort of discrimination.”</i></p>



	<p><b>Respondent J</b> similarly to respondent A, B, C, D, E, F, G, I responded “I cannot recall properly, because I was very ill at the time. But I do believe that I received the best support as I am a better person now, I am taking my medication.”</p> <p><b>Respondent K</b> hyperactively responded, “I got counselling, it was made clear to me that it does not mean that you were sexually active to be infected with HIV/AIDS.”</p> <p><b>Respondent L</b> calmly responded “I realized that I have a very supportive family. And at the clinic, I received pre and post counselling and I a chance to ask questions of what was unfamiliar to me at the time.”</p> <p><b>Respondent M</b> also felt that, “After I had my CD4 count tests, the nurses told me that I should also start with my medication same day. And then I was introduced to a class, where we learn more about HIV”.</p> <p><b>Respondent N</b> similarly responded, “I started a class and began with my medication intake immediately.”</p> <p><b>Respondent O</b> also felt that “I was brave enough that I could not even wait to disclose my status to my family. I received counselling at the clinic.”</p> <p><b>Respondent P</b> with pride responded, “I trusted a counsellor at the clinic that I am also friends with, she told me she is also HV positive and life is the same so long as I take care of myself.”</p> <p><b>Respondent Q</b> positively responded, “I got courage through the counselling that I received, I informed my family which is why I am living a healthy lifestyle.”</p> <p><b>Respondent R</b> similarly responded, “I got tested and received my medication same day, at night I had my first tablet. The next morning, I was feeling better”.</p> <p><b>Respondent S</b> with confidence responded, “Finding out that I am HIV positive, because if I didn’t go get tested, I wouldn’t know even today that I am HIV positive.”</p> <p><b>Respondent T</b> felt that, “I was encouraged to keep healthy and eat healthy food. I also learnt the importance of being faithful and having one sexual partner.”</p>
<p><b>When respondents were asked about the support they require on a daily basis</b></p>	<p><b>Respondent A</b> responded “Ei (sigh), I’m not sure. But I think I would really appreciate getting healthy fruits and vegetables to maintain a healthy and balanced diet”.</p> <p><b>Respondent B</b> sadly responded, “I need my children to remind every day when I have to take my medication intake so that I live longer”.</p> <p><b>Respondent C</b> similarly to respondent A responded, “I need food, since I am unemployed, I sometimes take my medication without food, I then suffer throughout the day with the medication side effects”.</p> <p><b>Respondent D</b> contrary responded, “I am not sure of what I require every day, because I am as healthy as a person who is HIV negative”.</p> <p><b>Respondent E</b> similarly to A, B, C responded, “I need to have my medication every day in order to live a healthy and long life.”</p>



	<p><b>Respondent F</b> similarly to A, B, C, E responded, <i>“I only require assistance in relation to my medication intake”.</i></p> <p><b>Respondent G</b> contrary responded <i>“I need emotional support more than anything in my life. Because, I am old, hence sometimes it is too hard to understand how I got infected. But then, only God knows”</i></p> <p><b>Respondent H</b> similarly to A, B, C, E, F responded, <i>“For now, my medication is important thing I require on a daily basis”.</i></p> <p><b>Respondent I</b> similarly responded, <i>“I rely on my mother, and food if I could get enough healthy food on a daily basis, in that way I will not be suffering as much from the side effects of the medication.”</i></p> <p><b>Respondent J</b> sadly responded, <i>“If we can have a campaign that would deliver us the medication at home, instead of going to the clinic. We live far from the clinic, and the car hire is expensive since I am not working”.</i></p> <p><b>Respondent K</b> responded, <i>“I believe I need to be stress free. I am trying my all means to avoid being depressed and live a happy life.”</i></p> <p><b>Respondent L</b> sadly responded, <i>“I wish that the residents of the Vulindlela community will accept me as I am, I am still a human being like everyone else. There are rich people in this community, I would really appreciate it if one can offer me a job as a domestic worker in their home”.</i></p> <p><b>Respondent M</b> responded, <i>“It is important to attend classes in the clinics, because this where I also learnt that I can fall pregnant and my baby will not be infected so long as I follow proper procedure given to me”.</i></p> <p><b>Respondent N</b> similarly responded, <i>“Nothing much, besides my medication and some emotional support from the people I am close with”.</i></p> <p><b>Respondent O</b> felt that <i>“I normally require assistant when I must take my medication, as well as bath time I also need assistance on that because sometimes I am too weak to bath myself”.</i></p> <p><b>Respondent P</b> responded, <i>“I wish I can have someone to remind every day to take my medication I forget sometimes”.</i></p> <p><b>Respondent Q</b> similarly responded, <i>“I need to have something to eat every day before I take my medication, it’s hard to take medication on an empty stomach. I get sick more often because I cannot afford to maintain my basic need, food”.</i></p> <p><b>Respondent R</b> felt otherwise <i>“I have a young child, unfortunately she also got infected as well. But with her, it’s a different procedure because she is deaf. I need help on that, if there could be an easier way to communicate with her, maybe social workers might assist”.</i></p> <p><b>Respondent S</b> felt <i>“I do not need any support, I can say I am doing well”.</i></p> <p><b>Respondent T</b> responded <i>“I need emotional support. I also wish that, those of us who are too ill to go to the clinic, receive medication in their homes. It is hard to get to the clinic in my state.”</i></p>
<p><b>When respondents were asked about the support they receive from their</b></p>	<p><b>Respondent A</b> responded <i>“I can say that I do everything for myself I receive no support from anyone. Also, the community does not support me because they do not know about my HIV status”.</i></p>

**families and the community of Vulindlela**

**Respondent B** responded, *“My family is always there for me. Our community does not support us. We are on our own, I can say.”*

**Respondent C** similarly to respondent **A** responded, *“I receive no support from my family and the community”.*

**Respondent D** full of pride, responded, *“I am independent. I do not rely on anyone for support.”*

**Respondent E** sadly responded, *“I do not have a family. Some families in the community do support me by giving me piece jobs and do cleaning in their homes as I am unemployed. In that way, I get something to eat every day and I survive”.*

**Respondent F** similarly to respondent **B** felt that, *“My family accepted my condition and is very supportive in terms of taking care of my kids and their basic needs. The Vulindlela community is not aware, I receive no support from them”.*

**Respondent G** similarly to respondent **B** and **F** *“My daughter supports me, every morning I wake up to a nice warm porridge prepared for me, as for the community no, I receive no support from them”.*

**Respondent H** similarly to respondent **B, F, G** *“My family is supportive emotionally, the community of Vulindlela is not aware of my status.”*

**Respondent I** contrary felt that, *“We have a good relationship. My family supports me, and my friends from the community for instance, if I need money to go to the clinic, they do lend me”.*

**Respondent J** similarly to respondent **A, C** and **D** *“I am supporting myself. Fortunately, I still have some funds in my name from the accident that I had years ago.”*

**Respondent K** similarly to respondent **B, F, G, H, I** responded *“My family supports me with adhering to my medication, as for the community no, they do not support me”.*

**Respondent L** similarly to respondent **J** *“My family reminds of the dates when I have to go to the clinic and collect my medication, as well the time every day they remind me it is consistent. Vulindlela community encourages me to live healthily, and that this is not a death sentence, I will live longer”.*

**Respondent M** similarity to respondent **B, F, G, H, I** *“My family is supportive, we don’t discriminate against each other.” the community does not offer support.*

**Respondent N** similarly to respondent **C, and D** *“I come from a poor family, they do not offer me any support. Same applies as the community, I receive no support from them”*

**Respondent O** felt that, *“Both the community and my family support me emotionally. They are aware of my condition”.*

**Respondent P** similarly to respondent **J, L** responded *“The community members are very supportive, those who have vegetables at home they do offer me food to eat. My family, they also offer the same support”.*

**Respondent Q** similarly felt that, *“When I wake every morning, I have warm water waiting for me to bath, my family is very supportive and at*

	<p><i>night, they always remind me to take medication when its time. As for the community, some are very supportive emotionally, well a few of them know my status”.</i></p> <p><b>Respondent R</b> contrarily felt that, <i>“I receive no support from both structures.”</i></p> <p><b>Respondent S</b> similarly to respondent J, Land P responded, <i>“My family is supportive emotionally. The community of Vulindlela is not aware of my status”.</i></p> <p><b>Respondent T</b> <i>“My family make sure that I have something to eat daily, and they do my laundry. I receive no support from the community”.</i></p> <p>Seven respondents felt that they only receive support from their families. Four respondents receive no support from their families and the community of Vulindlela. Lastly, nine respondents felt that they do receive support from both structures.</p>
<p><b>When respondents were asked about the support they receive from Government departments</b></p>	<p><b>Respondent A</b> responded, <i>“The Government does not support me besides with the assistance of getting free medication.”</i></p> <p><b>Respondent B</b> contrary responded <i>“I can say that government support me through free medication that is vital to me at this stage.”</i></p> <p><b>Respondent C</b> similarly to respondent B <i>“I get free medication from the Government departments.”</i></p> <p><b>Respondent D</b> similarly to respondent A <i>“I receive no support from the government, I am unemployed as we speak.”</i></p> <p><b>Respondent E</b> similarly to respondent A and D, believed that <i>“There is no direct support I get from the government departments.”</i></p> <p><b>Respondent F</b> similarity to respondent A, D and E respondent calmly, <i>“None.”</i></p> <p><b>Respondent G</b> different to other respondents, responded <i>“The government provides with a grant for being HIV infected.”</i></p> <p><b>Respondent H</b> similarly to respondent B and C responded, <i>“The free medication that I collect in this clinic.”</i></p> <p><b>Respondent I</b> similarity to respondent A, D, E and F <i>“I receive free medication.”</i></p> <p><b>Respondent J</b> similarly to respondent G, responded, <i>“I am in receipt of a grant, as I am HIV positive.”</i></p> <p><b>Respondent K</b> similarity to respondent A, D, E, F and I, responded <i>“I receive nothing from the government departments.”</i></p> <p><b>Respondent L</b> similarly responded, <i>“I receive nothing from the Government departments.”</i></p> <p><b>Respondent M</b> similarly to respondent B, C and H responded, <i>“Free medication”</i></p> <p><b>Respondent N</b> similarity to respondent A, D, E, F and I, felt that he receives <i>“None”</i></p> <p><b>Respondent O</b> similarly to respondent B, C, H and M responded, <i>“I receive free medication.”</i></p>

	<p><b>Respondent P</b> contrary felt that <i>“There is this new program whereby we have an option to collect our medication in desirable facilities, like Clicks, if I am afraid to go to local clinics.”</i></p> <p><b>Respondent Q</b> similarly to respondent B, C, H, M and P <i>“I get free medication.”</i></p> <p><b>Respondent R</b> similarity to respondent A, D, E, F, I and N felt that <i>“Nothing as well, no support.”</i></p> <p><b>Respondent S</b> similarly to respondent B, C, H, M, P and Q responded, <i>“I get free medication.”</i></p> <p><b>Respondent T</b> lastly, also felt that he receives <i>“Free medication from Government Departments”.</i></p>
<p><b>When respondents were asked how long after they had become aware of their status did they disclose to their children</b></p>	<p><b>Respondent A</b> <i>“I have a new sexual partner, she is aware of my HIV status and I know hers. It’s been 2 years since we disclosed to each other. My family and my son are aware of my HIV status as well.”</i></p> <p><b>Respondent B</b> with pride, openly responded, <i>“It had been not so long, it took me only 3 months.”</i></p> <p><b>Respondent C</b> <i>“After 4 years, if I remember correctly.”</i></p> <p><b>Respondent D</b> <i>“It had been after 6 years. I don’t have children of my own, I look after my sister’s children. Hence, I did disclose my status to them because I take them as my own.”</i></p> <p><b>Respondent E</b> trying to think back, responded <i>“It took me years to disclose my status. I can’t remember how many years.”</i></p> <p><b>Respondent F</b> <i>“It took me some time, after 11 years, yes I did disclose to my children.”</i></p> <p><b>Respondent G</b> <i>“It was after 5 years, my daughter was married already when I disclosed to her.”</i></p> <p><b>Respondent H</b> <i>“After 9 years, I did disclose to both my children.”</i></p> <p><b>Respondent I</b> similarly to respondent C responded, <i>“It took me 4 years. I did disclose to all my children.”</i></p> <p><b>Respondent J</b> similarly to respondent G, responded, <i>“I disclosed to my children after 5 years.”</i></p> <p><b>Respondent K</b> similarly to respondent A responded, <i>“It took me 2 years, but they were aware even before because they are the reason why I am infected today.”</i></p> <p><b>Respondent L</b> <i>“It was 11 years later. Yes, they are all aware I did disclose my status to them.”</i></p> <p><b>Respondent M</b> <i>“It was after 7 years. I disclosed to them.”</i></p> <p><b>Respondent N</b> similarly to responded A and K responded, <i>“After 2 years.”</i></p> <p><b>Respondent O</b> <i>“It took me 8 years, yes all of them.”</i></p> <p><b>Respondent P</b> <i>“It took me 10 years.”</i></p> <p><b>Respondent Q</b> <i>“I disclosed my status after 8 years, all my children know.”</i></p> <p><b>Respondent R</b> <i>“it took me 5, I disclosed to my children.”</i></p> <p><b>Respondent S</b> <i>“3 years, yes I did.”</i></p> <p><b>Respondent T</b> similarly to respondent M responded, <i>“I disclosed after 7 years. Yes, they all know.”</i></p>

<p><b>When respondents were asked how old their children were at the time of disclosure were</b></p>	<p><b>Respondent A</b> <i>"I only have one child, who was 12 years of age."</i></p> <p><b>Respondent B</b> <i>"My child was 16 years at that time, he knows very well what I am going through."</i></p> <p><b>Respondent C</b> <i>"The oldest was 21, and the other one was 17 years of age."</i></p> <p><b>Respondent D</b> <i>"One was 18, the other was 14 years."</i></p> <p><b>Respondent E</b> <i>"The daughter was 16, my son was 19 years."</i></p> <p><b>Respondent F</b> <i>"My oldest daughter was 19. They younger one was too young to understand."</i></p> <p><b>Respondent G</b> <i>"Just above 20, I also disclosed to her kids, my grandchildren."</i></p> <p><b>Respondent H</b> <i>"My first born was 14 years old at the time."</i></p> <p><b>Respondent I</b> <i>"My old son was 13 years old."</i></p> <p><b>Respondent J</b> <i>"He was 18 years old."</i></p> <p><b>Respondent K</b> <i>"One was almost 23 years."</i></p> <p><b>Respondent L</b> <i>"My first child was 19, two others were 13 and 11 years of age."</i></p> <p><b>Respondent M</b> <i>"My older son was 16 years old."</i></p> <p><b>Respondent N</b> <i>"One was 15 years at the time. Others are older, they live elsewhere."</i></p> <p><b>Respondent O</b> <i>"They were 15 and 17 years of age."</i></p> <p><b>Respondent P</b> <i>"My children were very young, I had to wait until they reached age 12 and 14 to finally get a chance to disclose my status to them. They were able to understand."</i></p> <p><b>Respondent Q</b> <i>"They were 21 and 24."</i></p> <p><b>Respondent R</b> <i>"My son was 19 years old."</i></p> <p><b>Respondent S</b> <i>"My first born was 13 years old."</i></p> <p><b>Respondent T</b> <i>"The firstborn was 10 years at that time."</i></p>
<p><b>When respondents were asked how the children responded</b></p>	<p><b>Respondent A</b> <i>"I struggled to inform him, because he lives with his mother. His mother and I are not in good speaking terms. I thought my son is too young to understand what my illness is, but he is a brave young man he understood and accepted"</i></p> <p><b>Respondent B</b> <i>"After I had disclosed to him, it was hard for him to accept it, he would not eat at times, but he then understood that I am not going to be around for long and learnt to accept."</i></p> <p><b>Respondent C</b> <i>"They accepted, because I made sure that I disclose to them in a way that they understand it. I made it clear that I did not choose to be infected, but it happened."</i></p> <p><b>Respondent D</b> <i>"They accepted it, because it is no longer shameful to be infected with HIV."</i></p> <p><b>Respondent E</b> <i>"They did not judge me. I am their mother, I guess they felt sorry for me."</i></p>



	<p><b>Respondent F</b> <i>"They were hurt at first and it was hard for them to believe. But then, fortunately there is HIV education in schools, my children are well educated about HIV/AIDS."</i></p> <p><b>Respondent G</b> <i>"It was not hard they all accepted. Then my youngest grandchild reminds me all the time if it's 8 o'clock in the evening to take my medication."</i></p> <p><b>Respondent H</b> <i>"It was okay for the first born because he is older, the younger one is only 5 years old."</i></p> <p><b>Respondent I</b> <i>"He was shocked. But now I am sure he has learnt to accept."</i></p> <p><b>Respondent J</b> <i>"Well, he did not seem to have a problem because he is also HIV positive. He was here yesterday to collect his medication."</i></p> <p><b>Respondent K</b> <i>"It came as a shock to them, but they eventually accepted because I got infected whilst assisting them as a parent."</i></p> <p><b>Respondent L</b> <i>"They are hurt for quite some time they could not accept, but when they learnt that the disease is not a death sentence, they were able to accept it."</i></p> <p><b>Respondent M</b> <i>"It was hard for my kids, although I saw that they are brave. They tried to make feel special."</i></p> <p><b>Respondent N</b> <i>"I can say it was easy for them to accept, because "Sunshine" my daughter I sometimes send her to fetch my medication for me."</i></p> <p><b>Respondent O</b> <i>"They found it easy to accept. They are by my side every time."</i></p> <p><b>Respondent P</b> <i>"They were happy that I was honest, and I trusted them."</i></p> <p><b>Respondent Q</b> <i>"They were supportive and encouraged me to take my medication as instructed."</i></p> <p><b>Respondent R</b> <i>"He is also HIV positive, he accepted."</i></p> <p><b>Respondent S</b> <i>"My family helped me through the disclosure process. We sat with my child and explained to him, he accepted easily."</i></p> <p><b>Respondent T</b> <i>"He understood and learnt to accept."</i></p>
<p><b>When respondents were asked if the children understand what HIV is and the outcome it will have on your life and health:</b></p>	<p><b>Respondent A</b> <i>"No. I don't stay with him."</i></p> <p><b>Respondent B</b> <i>"Yes, he does, he is a smart child."</i></p> <p><b>Respondent C</b> <i>"Yes, they do."</i></p> <p><b>Respondent D</b> <i>"Yes, they do understand because they did not tell anyone else about it."</i></p> <p><b>Respondent E</b> <i>"Yes, they are more informed about HIV/AIDS, more than me actually."</i></p> <p><b>Respondent F</b> <i>"Yes, they are quite well informed."</i></p> <p><b>Respondent G</b> <i>"Yes, and they are grateful that I did disclose my HIV status."</i></p> <p><b>Respondent H</b> <i>"Yes, the older one does understand."</i></p> <p><b>Respondent I</b> <i>"Yes, he does understand. I had a chat with the older one since I believe that the 8-year-old does not understand yet."</i></p> <p><b>Respondent J</b> <i>"Yes, he understands very well."</i></p>

	<p><b>Respondent K</b> <i>"Yes, they do."</i></p> <p><b>Respondent L</b> <i>"Yes, they all do."</i></p> <p><b>Respondent M</b> <i>"Yes, they do. Even the 17-year-old one."</i></p> <p><b>Respondent N</b> <i>"Yes, they do."</i></p> <p><b>Respondent O</b> <i>"Yes, they do understand. Because one of them is also HIV positive I believe he made others aware and accepted us as we are."</i></p> <p><b>Respondent P</b> <i>"Yes, they do. I made it easy for them to understand. And I encouraged them not to engage in unprotected sex once they are older."</i></p> <p><b>Respondent Q</b> <i>"Yes, they do. One of them is also HIV positive."</i></p> <p><b>Respondent R</b> <i>"Yes, they do understand."</i></p> <p><b>Respondent S</b> <i>"Yes, he did understand."</i></p> <p><b>Respondent T</b> <i>"Yes, he does understand."</i></p>
<p><b>When respondents were asked about the challenges they faced when disclosing their status to their children</b></p>	<p><b>Respondent A</b> responded, <i>"I can say my child is too young to understand, also he does not live with me which makes it hard for me to make him understand my sickness."</i></p> <p><b>Respondent B</b> responded, <i>"I was also worried about the confusion this was going to have to my child, and that maybe he has questions to ask that I cannot even have answers to."</i></p> <p><b>Respondent C</b> responded, <i>"For me it was easy for them to understand, because of the older one. In that way, I did not encounter any challenges when disclosing my status."</i></p> <p><b>Respondent D</b> responded, <i>"At first, I did not want to be sorry about it, I struggled with deciding whether to tell them or not."</i></p> <p><b>Respondent E</b> with eyes filled with tears, responded, <i>"My son did not seem to be supportive, at first. It was like I got what I wanted."</i></p> <p><b>Respondent F</b> responded, <i>"The younger one is too young to understand. I will inform her when she is older."</i></p> <p><b>Respondent G</b> responded, <i>"Sometimes I am too ill, I struggled, I did not have the right words or the correct manner to disclose my status to my children."</i></p> <p><b>Respondent H</b> responded, <i>"I did not know where to begin, and most importantly, I was more worried about the younger one. But I am taking my medication, he will grow up and I will disclose to him as well."</i></p> <p><b>Respondent I</b> responded, <i>"Besides the age difference between them, there are no challenges that I faced."</i></p> <p><b>Respondent J</b> felt that <i>"I was afraid the older will judge me. Which is why I decided to disclose only to the young one."</i></p> <p><b>Respondent K</b> angrily responded, <i>"I sometimes blame them, especially when I am depressed. because I got infected through them, I was so angry and frustrated even during the time of disclosure."</i></p> <p><b>Respondent L</b> similarly to respondent I, responded, <i>"It was not easy for me detect whether they did understand when I disclosed to them concerning their age. But after some time, I realized that they did understand through the constant support and reminder they give me every day."</i></p>

	<p><b>Respondent M</b> responded with a smile, <i>“No challenges, the 17-year-old one is smart even if I cough, he tells me not to cough with my mouth wide open I need to cover it.”</i></p> <p><b>Respondent N</b> responded, <i>“I first thought of keeping it a secret and not disclose to my children, because I was afraid to even take my medication when they are around. I later realized that I am doing no favour to anyone. I later decided to disclose, and my children accepted it.”</i></p> <p><b>Respondent O</b> responded, <i>“I thought they are too young to understand. I guess it’s how they reacted, they just kept quiet and the other one cried.”</i></p> <p><b>Respondent P</b> responded, <i>“At first, I was not sure if telling them was the right thing to do.”</i></p> <p><b>Respondent Q</b> responded, <i>“I was afraid of how they would respond, as a result I delayed for so long.”</i></p> <p><b>Respondent R</b> responded, <i>“I did not experience any challenges, because as I’ve said my son is HIV positive.”</i></p> <p><b>Respondent S</b> gladly responded, <i>“I did not encounter any challenges, I had my family at the time of disclosure.”</i></p> <p><b>Respondent T</b> responded, <i>“I was afraid that he will not take it well, and eventually underperform in school.”</i></p>
<p><b>When respondents were asked about the challenges that they encounter daily in relation to caring for their children</b></p>	<p><b>Respondent A</b> responded, <i>“Challenges? No, besides the “baby mama” drama.”</i></p> <p><b>Respondent B</b> similarly to respondent A <i>“I can say that there are no challenges that we face, besides the confusion that I thought it would bring to him, but I managed it as well.”</i></p> <p><b>Respondent C</b> similarly to respondent A and B <i>“So far, I don’t have any challenges.”</i></p> <p><b>Respondent D</b> similarly to A, B, and C <i>“Since I was able to accept that I am living with the disease, life is not hard for me, I live a healthy life without any worries. I am making sure that I come across no challenges in life but maintain my health and live longer with the little that I have.”</i></p> <p><b>Respondent E</b> felt otherwise <i>“I am stressed and depressed most of the time. I feel like the world is coming to an end.”</i></p> <p><b>Respondent F</b> contrarily to respondent E <i>“For the younger one, sometimes I get so moody and not give attention to her. I think that affects her. I need to deal with my emotions properly.”</i></p> <p><b>Respondent G</b> similarly to respondent A, B, C and D responded, <i>“None, besides the money issue. I need more money to take care of my children.”</i></p> <p><b>Respondent H</b> similarly to respondent A, B, C, D and G responded, <i>“None.”</i></p> <p><b>Respondent I</b> responded, <i>“I believe I am living a healthy lifestyle, and my mother is here to support not only me but my children as well.”</i></p> <p><b>Respondent J</b> contrarily felt that <i>“There was a time where became very ill from taking my medication. I struggled to do anything in the house. But as time went on, I got used to it.”</i></p>



	<p><b>Respondent K</b> similarity to respondent E and F <i>"The fact that I got infected from this old one, make me angry at times. But then, I had to disclose to him. I pray that I manage to manage my anger one day."</i></p> <p><b>Respondent L</b> felt otherwise <i>"Sometimes I do not have money to give them to carry at school."</i></p> <p><b>Respondent M</b> felt otherwise <i>"Sometimes I fear that the young one will go out and his friends when they play games or at school, and maybe other kids will discriminate him and later affects his school performance."</i></p> <p><b>Respondent N</b> similarly to A, B, C, D, G and H <i>"There are no challenges."</i></p> <p><b>Respondent O</b> felt otherwise <i>"Sometimes as a man, I do not even know what to do and how to approach my children. It takes guts to disclose your status to your children as a man. I think it is easy for women to disclose than men."</i></p> <p><b>Respondent P</b> <i>"I must make sure that we are always happy within the family, I encounter no challenges in relation to taking care of my children"</i></p> <p><b>Respondent Q</b> similarly to respondent A, B, C, D, G, H and N <i>"No challenges"</i></p> <p><b>Respondent R</b> similarly to respondent A, B, C, D, G, H, N, and Q <i>"I only have challenges with the one who is deaf."</i></p> <p><b>Respondent S</b> similarly to A, B, C, D, G, H, N, Q, and R responded <i>"No challenges"</i></p> <p><b>Respondent T</b> felt otherwise <i>"My son does not stay with me anymore."</i></p>
<p>When respondents were asked how has the relationship between them and their child/children changed</p>	<p><b>Respondent A</b> responded, <i>"We have a very healthy relationship with my son, if I were to disclose my status to him, I do not know how he will feel about it."</i></p> <p><b>Respondent B</b> responded, <i>"We have a good relationship, because he respects me."</i></p> <p><b>Respondent C</b> responded <i>"No, our relationship is still the same we live a healthy life."</i></p> <p><b>Respondent D</b> responded, <i>"Our relationship is still the same, we are family and we look after each other."</i></p> <p><b>Respondent E</b> responded <i>"It did not change. They are supportive."</i></p> <p><b>Respondent F</b> responded <i>"No, I am still the mother they respect."</i></p> <p><b>Respondent G</b> responded <i>"No, in fact we have a great bond within the family."</i></p> <p><b>Respondent H</b> responded <i>"No, it has not changed."</i></p> <p><b>Respondent I</b> responded <i>"No, they still love me as their mother."</i></p> <p><b>Respondent J</b> felt otherwise <i>"My child does not care much, I think maybe it's because I am old, and he is also infected he cannot say much about it. He just focuses on his treatment, I do the same because I do not know how he got infected."</i></p> <p><b>Respondent K</b> sadly responded, <i>"Everyone minds their own business. It's just a relationship, I don't know how to explain it."</i></p> <p><b>Respondent L</b> responded <i>No, it's the same they are very supportive."</i></p> <p><b>Respondent M</b> responded <i>"It is the same. They are very supportive."</i></p>

	<p><b>Respondent N</b> responded <i>“We have a good relationship. Nothing has changed.”</i></p> <p><b>Respondent O</b> responded, <i>“No, it has not changed. They respect me, and they give me money when I need to take care of something.”</i></p> <p><b>Respondent P</b> responded, <i>“We have a good relationship.”</i></p> <p><b>Respondent Q</b> responded <i>“The relationship has not changed. We are a happy family.”</i></p> <p><b>Respondent R</b> responded <i>“No, no one discriminated against me.”</i></p> <p><b>Respondent S</b> responded, <i>“We have a good relationship.”</i></p> <p><b>Respondent T</b> responded, <i>“We have a good relationship.”</i></p> <p>Most respondents responded that they have good/healthy relationships with their children. Except for respondent J and K who felt otherwise.</p>
<p><b>When the respondents were asked if they rely on their children for assistance</b></p>	<p><b>Respondent A</b> responded <i>“Yes, I believe my child must be able to support me emotionally.”</i></p> <p><b>Respondent B</b> responded, <i>“A lot, I need him be there for me and support me all the way.”</i></p> <p><b>Respondent C</b> responded <i>“Yes, we need to support each other emotionally, as they are also unemployed, they cannot do much for me. I just need them to remind me as they do, with my medication daily.”</i></p> <p><b>Respondent D</b> responded, <i>“I need them to support me emotionally, and when I am too ill to collect my medication from the clinic, they shall be able to do so for me.”</i></p> <p><b>Respondent E</b> responded, <i>“I need food, sometimes I am too weak to cook for us.”</i></p> <p><b>Respondent F</b> responded <i>“I am self-employed. Sometimes I do not make enough money to support my family, I need them to stand by my side, always.”</i></p> <p><b>Respondent G</b> responded <i>“Yes, my daughter as she is taking care of me. I hope that she does until time comes that I pass on.”</i></p> <p><b>Respondent H</b> felt otherwise <i>“No, for now I am still able to do everything by myself. Emotional support maybe.”</i></p> <p><b>Respondent I</b> responded, <i>“My children are supportive, I cannot say I rely on them as compared to the way I rely to my mother for assistance.”</i></p> <p><b>Respondent J</b> similarly to respondent H felt otherwise <i>“No, I am doing well on my own.”</i></p> <p><b>Respondent K</b> similarly to respondent H and J felt otherwise <i>“No, not really.”</i></p> <p><b>Respondent L</b> responded <i>“Yes, I rely on them to support me especially whenever I am no longer able to do things on my own for myself.”</i></p> <p><b>Respondent M</b> responded <i>“My children are young. The older ones that I could rely on for assistance I left them at home, since I am now staying with this new partner. And I only have young children with him.”</i></p> <p><b>Respondent N</b> responded, <i>“I think I do, especially from my daughter whom I usually send to collect my medication for me.”</i></p>

	<p><b>Respondent O</b> responded “Yes, I do need them to remind me to take my medication.”</p> <p><b>Respondent P</b> responded, “I only need them to support me and never a day must I feel lonely.”</p> <p><b>Respondent Q</b> responded, “Sometimes I need money from, they always make a plan and give me some.”</p> <p><b>Respondent R</b> responded “If we can stick together as a family, and not abandon each other especially since we are both sick me and my son. We need to adhere to medication.”</p> <p><b>Respondent S</b> responded, “My child could help me with reminding me to take my medication every day.”</p> <p><b>Respondent T</b> responded, “I need to be loved and taken care of emotionally.”</p>
<p><b>When respondents were asked if they are part of any community support groups</b></p>	<p><b>Respondent A</b> responded, “No, we do not have support groups in Vulindlela.”</p> <p><b>Respondent B</b> responded, “No, we do not have support groups on our community.”</p> <p><b>Respondent C</b> responded, “No, we do not have support groups.”</p> <p><b>Respondent D</b> responded, “No, we do not have support groups.”</p> <p><b>Respondent E</b> responded, “No, we do not have support groups in Vulindlela.”</p> <p><b>Respondent F</b> responded, “No, we do not have support groups.”</p> <p><b>Respondent G</b> responded, “No, we do not have support groups.”</p> <p><b>Respondent H</b> responded, “No, we do not have support groups in Vulindlela.”</p> <p><b>Respondent I</b> responded, “My children are supportive, I cannot say I rely on them as compared to the way I rely to my mother for assistance.”</p> <p><b>Respondent J</b> felt otherwise “We usually meet at some crèche in the area. We have a support group called ‘Siyathuthuka’, where we discuss our challenges and possible solutions to those challenges.”</p> <p><b>Respondent K</b> responded, “We used to have them, but not today. They are no longer there.”</p> <p><b>Respondent L</b> responded, “We do not have support groups.”</p> <p><b>Respondent M</b> contrary responded, “Yes, we do. They teach us how to grow crops for instance in our homes because vegetables are healthy.”</p> <p><b>Respondent N</b> responded, “No, we do not have support groups. There used to be one years ago at Santi clinic. But then it closed.”</p> <p><b>Respondent O</b> responded, “No, we do not have support groups.”</p> <p><b>Respondent P</b> responded, “No, we do not have support groups.”</p> <p><b>Respondent Q</b> responded, “No, we do not have support groups.”</p> <p><b>Respondent R</b> responded, “No, we do not have support groups.”</p> <p><b>Respondent S</b> responded, “No, we do not have support groups.”</p> <p><b>Respondent T</b> responded, “No, we don’t have support groups.”</p>

<p><b>When respondents were asked how clinic facilities assist them</b></p>	<p><b>Respondent A</b> responded <i>“They provide us with our medication, antiretroviral therapy (ARV)s.”</i></p> <p><b>Respondent B</b> responded, <i>“In clinics, we get counselling and free medication.”</i></p> <p><b>Respondent C</b> responded, <i>“I get my medication free of charge.”</i></p> <p><b>Respondent D</b> responded, <i>“Clinics assist with providing us with medication.”</i></p> <p><b>Respondent E</b> responded, <i>“I receive my medication and get the best attention that I require from the clinic staff.”</i></p> <p><b>Respondent F</b> responded, <i>“The clinic assists me with other related infections like TB or persistent coughing, not just HIV.”</i></p> <p><b>Respondent G</b> responded <i>“We used to get some porridge, I need it. As well as the medication that I get as treatment.”</i></p> <p><b>Respondent H</b> responded, <i>“The clinic assists with free medication.”</i></p> <p><b>Respondent I</b> responded, <i>“I receive treatment, and they always remind me and encourage me to take my medication according to their instructions.”</i></p> <p><b>Respondent J</b> responded very thrilled about the whole research purpose, responded <i>“It helps to go to the clinic whenever I am not feeling well. And also, to get such opportunities as this one where our educated children do research amongst their own community, meaning they do care about us - “spoke about me the researcher”</i></p> <p><b>Respondent K</b> responded, <i>“We used to get porridge, it was helpful when it comes to taking medication.”</i></p> <p><b>Respondent L</b> responded, <i>“Provision of medication, and the messages they send us before time that we have to come for medication on a specific date.”</i></p> <p><b>Respondent M</b> responded <i>“I am grateful for the medication that they provide us with. And the messages they send us for dates to collect our medication.”</i></p> <p><b>Respondent N</b> contrary felt that <i>“Besides the free medication that we receive, I wish that our local councillors could do something about us poor families. And provide us with food and shelter as well.”</i></p> <p><b>Respondent O</b> responded, <i>“Even if I have flu, they do assist me not only in terms of my HIV condition only.”</i></p> <p><b>Respondent P</b> responded, <i>“They give us medication on time.”</i></p> <p><b>Respondent Q</b> responded, <i>“I get free medication.”</i></p> <p><b>Respondent R</b> responded, <i>“I get free medication.”</i></p> <p><b>Respondent S</b> responded, <i>“We get free medication.”</i></p> <p><b>Respondent T</b> responded <i>“Free medication, and I always get it, we do not run out of medication.”</i></p>
<p><b>When respondents were asked what are the main areas that they require assistance</b></p>	<p><b>Respondent A</b> responded <i>“Mmmmm, I will speak to my partner and hear from her side of view where we require assistance. I think we both need assistance.”</i></p>

<p><b>with in relation to their children</b></p>	<p><b>Respondent B</b> felt that <i>“I need assurance that my child will be taken care of, and that he receives the best education when I die.”</i></p> <p><b>Respondent C</b> similarly to respondent B responded, <i>“I need my younger child to focus on school, me disclosing to them must not affect him and his performance in school.”</i></p> <p><b>Respondent D</b> contrary felt that <i>“I wish that my children will take accountability of their actions. They need to be orientated, be responsible and learn to practice safe sex.”</i></p> <p><b>Respondent E</b> responded <i>“Nothing, I am okay for now.”</i></p> <p><b>Respondent F</b> contrary felt otherwise <i>“If the government can assist with family support grant, I would really appreciate that.”</i></p> <p><b>Respondent G</b> hopefully responded, <i>“I wish that he can build me proper house, I would really appreciate it if I could see it before I die and be assured that my children have a home.”</i></p> <p><b>Respondent H</b> responded <i>“For now, I can say I am going strong. I do not rely on my children for any assistance.”</i></p> <p><b>Respondent I</b> responded <i>“Uhm...what can I say, I think for now my biggest worry is my children. But then again, my mother is my hope, she will take care of my children when I am no more in this world.”</i></p> <p><b>Respondent J</b> responded <i>“To keep busy, I would really appreciate if the community councillors can assist us with plants and crops to grow in the yard. Just to keep busy and have something on the table and not sleep on an empty stomach. My son will also be taken care of in that way. He might also be able to tell some to the community.”</i></p> <p><b>Respondent K</b> similarly to respondent F <i>“Government assistance through family support grant, would be highly appreciated.”</i></p> <p><b>Respondent L</b> similarly to respondent G <i>“I wish that we could maintain a healthy relationship amongst each other. We need help in terms of shelter, I would really love to see my children living in a proper house before I leave this world when death comes.”</i></p> <p><b>Respondent M</b> similarly to respondent D felt that <i>“I wish for my children to be well educated about the disease and that they take care of themselves and make sure that they do not fall in the same trap of being HIV infected.”</i></p> <p><b>Respondent N</b> responded <i>“I am unemployed, I sometimes find it hard to provide for my children. Even the grown ones they are also unemployed.”</i></p> <p><b>Respondent O</b> responded, <i>“I think I am fine for now.”</i></p> <p><b>Respondent P</b> similarly to respondent F and K responded, <i>“I wish our ward councillor could give us some grant as most of us are unemployed and unable to take good care of our children.”</i></p> <p><b>Respondent Q</b> with pride, responded, <i>“They are old, they can take care of themselves.”</i></p> <p><b>Respondent R</b> sadly responded, <i>“I wish that my child can be taken to school for the deaf. So that she will have a brighter future.”</i></p> <p><b>Respondent S</b> similarly to respondent F, K and P <i>“I need social support grant, because I am not working and be able to feed my child.”</i></p> <p><b>Respondent T</b> responded <i>“Nothing. We are fine for now.”</i></p>
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