THE CHALLENGES THAT SINGLE MOTHERS EXPERIENCE WITH REGARD TO THE DISCLOSURE OF THEIR HIV STATUS

by

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ABSTRACT

The researcher observed that stigma and discrimination among other things associated with HIV and AIDS makes it difficult for single mothers living with HIV and those with AIDS to disclose their status, as they often experience feelings of rejection, blame, and ambivalence together with fear of death. These reasons often lead to single mothers choosing not to share any information concerning their HIV positive status. In reaction to the above, the researcher conducted a study to explore the challenges that single mothers experience with regard to the disclosure of their HIV status. The objectives were to report how the single mothers experienced disclosing their status with regard to their families, community and the workplace; that includes their quality of life, and to establish the kind of support they would expect from their families, the community and the workplace in order for them to be able to disclose their status with ease. In addition, the eco-systematic approach, which is the theoretical framework of this study, brings an understanding of the various ways a person may adapt to an ever-changing environment in order to cope and survive as a family system. Thus, by following the eco-systematic approach, in this study researcher explored single mother’s experiences with all the systems in the community to which they are connected and the way the systems create challenges for them during the disclosure of their HIV status.

Investigation into existing literature has revealed that insufficient previous studies have been conducted on the care of patients or preventative work regarding the impact of HIV and AIDS on households, specifically in the South African context, and even fewer pertaining to the challenges single mothers specifically experience with regard to the disclosure of their HIV positive status. Therefore, two literature studies form the knowledge base of the study, where the first one investigates single motherhood as a phenomenon. The causes of single mothers, the challenges they face and their strengths were discussed. For the second literature study, the effects of HIV and AIDS on human beings was investigated and attention was given to the process of disclosure where multiple factors affecting disclosure was discussed. To determine whether or not the goal of this study was reached, the qualitative explorative research design was deemed appropriate for this study.

The sample comprised nine single mothers who are HIV positive and who voluntarily came to the office of the Staff Wellness of University of Technology and disclosed their HIV status in order to receive emotional support. In-depth interviews were conducted with the participants; the
questions in the interview schedule were in line with the objectives of the study. Information emanating from the data was analysed qualitatively using the process of thematic analysis.

The empirical findings of this study suggest that participants experience challenges regarding disclosure in all identified sectors, namely in the family, in the community, and in the workplace. The challenges manifest themselves as: judgmental attitudes, gossip, humiliation, and criticism. The empirical findings further revealed that the behaviours displayed by the stakeholders in question affect the quality of life of the single mothers to the extent that they become stressed and depressed, among others. The results also inform us that the single mothers are prepared to disclose their status, albeit under certain conditions. It was proven that on the basis of these findings, strategies for facilitating disclosure and emotional concerns of single HIV mothers were espoused; that includes creating a positive environment for facilitating disclosure.

This study contains an in-depth literature review, followed by the empirical findings that answer the research question. The last objective of the study will be to draw a conclusion and make recommendations regarding the establishment of the kind of support that single mothers would expect from their families, the community and the workplace in order for them to be able to disclose their HIV status with ease.

KEY CONCEPTS

- Challenges
- Single mother
- HIV
- AIDS
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CHAPTER 1

INTRODUCTION, BACKGROUND, DEFINITION OF RELEVANT CONCEPTS AND STATEMENT OF THE PROBLEM

1.1 INTRODUCTION

In this chapter attention will be focused on the manner in which the research has been conducted, with reference to the motivation for the choice of topic, the goal of the study, statement of the problem, the pilot test, research design, ethical concerns, definition of key concepts, and the division of the project report.

This study investigates the challenges single mothers experience regarding the disclosure of their human immunodeficiency virus (HIV) status. Kruger (2006:196) postulates that it is important to understand the meaning of motherhood in order to be able to deal effectively with the issue of closure or concealment in the case of women living with HIV and those with acquired immune deficiency syndrome (AIDS). According to Kruger (2006:196), the discourse on motherhood is much more complex than simply describing mothering practices as fulfilling or successful, difficult or problematic, as the historical, socio-cultural and economic context of the women who are doing the mothering largely influence these. Thus, the intention of this study is to understand the different challenges single mothers living with HIV and those with AIDS may experience during the disclosure of their HIV status.

An estimated 6.4 million people in 2015 are living with HIV in South Africa; more than in any other country (UNAIDS, 2012a). The rising mortality rate has serious consequences for children. Although the Department of Health (DoH) has broadened government support to regional clinics and hospitals, these facilities are still hard to reach for most people living in rural areas (African Solutions to African Problems, 2013:1). This disease has produced panic, fear, guilt, blames, severe suffering and always, in the end, death. Generally, people diagnosed with HIV are stigmatised. Often, they are labelled as having poor moral standards and values, especially in African communities, and this creates a situation where people living with HIV (PLWH) and those with AIDS (Acquired Immune Deficiency Syndrome) are scared to disclose their HIV status to anyone, as they fear rejection. In the case of single mothers, this may be more intense in nature.
According to UNAIDS (2011:11) and Van Dyk (2001: 4-5) HIV is an acronym for the human immunodeficiency virus, which is a virus that causes AIDS. AIDS is an abbreviation for acquired immune deficiency syndrome (UNAIDS, 2011:11). UNAIDS (2011:4) also view AIDS as an epidemiological definition based on marks and warning signs. It is caused by HIV, the immunodeficiency virus. The end-stage of AIDS is a pattern of diseases, which may result from that infection. Santrock (2000:543) and Van Dyk (2001:4-5) describes AIDS as a sexually transmitted disease caused by HIV, which destroys the body’s immune system.

The 2009 AIDS epidemic update by the Joint United Nations Programme on HIV and AIDS and the World Health Organization (WHO), states that in South Africa HIV affect women more than men (UNAIDS& WHO, 2009:21-22). This means that with national prevalence rate done by UNAIDS women in antenatal clinics were HIV positive. For instance, in 2005 the national prevalence rates at antenatal clinics in Swaziland was 23%, while in 2015 it was estimated that it will reach 41, 1% by the end of 2015 (Ministry of Health, 2010:21). Single mothers face the additional challenges of when and how to disclose their HIV status to their children, extended family members, friends and colleagues (Moloi, 2013; Mochadibane, 2013; Murphy & Marelich, 2008:2). In this instance, the term challenges is understood as defined by the Oxford Advanced Learners Dictionary (2005:231) as “difficulties that test your ability”. Relating to this study, these difficulties include how culture and stigma, poor economic conditions, social relationships, psychological fear, and religion influence single mothers’ experiences during the disclosure of their HIV status. The Collins English Dictionary (2015)defines a single mother as a female who is bringing up a child or children on her own, because the other parent is not living with her; or a person with a dependent child or children, who is widowed, divorced or unmarried.

Sub-Saharan Africa has one of the highest global prevalence rates of HIV and AIDS, with an estimated 22.5 million people; representing 68% of the global HIV burden, which continues to affect women and children excessively (UNAIDS, 2013a). Furthermore, South Africa has one of the biggest seropositive populations, where some 5.6 million people are living with HIV and furthermore it is estimated that approximately 1.3 million Africans died of AIDS in 2013. These figures remain staggering and it therefore comes as no surprise that the impact and effect of HIV and AIDS are no longer limited to mortality rates and illnesses, but are actually widespread and influence all aspects of our everyday lives. In particular, this study will focus on the challenges single mothers experience regarding the disclosure of their HIV status.
1.2 BACKGROUND

“Although the subject of HIV and AIDS remains taboo in some communities in South Africa”, many people are infected, stigmatised, and marginalised from their communities and society, or dying of related diseases (Heartbeat, 2002:1). According to research undertaken by the International Labour Office (ILO, 2010:3), people with HIV and those with AIDS, together with their families, often face hostility and isolation, with profoundly altered social shame rather than support. In this regard, Mutwa (2000:14) highlights the problems and blames the media for the examples they set with TV shows, which imply that promiscuity is acceptable; the government for concentrating too much on the development of resources to deal with HIV and AIDS at the expense of other chronic diseases which display higher mortality rates, such as diabetes, hypertension and cancer; and the community, which stigmatises HIV-infected people. The researcher has observed, in the company where she is employed currently, that the communities of families infected and affected by HIV and AIDS have labelled them negatively, which creates new and greater challenges for them when they have to disclose their HIV positive status. These challenges are discussed below.

1.2.1 Culture and Stigma

Stigma is attached to a person who is discredited within a certain culture or setting for contravening community norms (Parker & Aggleton, 2002:8). HIV and AIDS create a stigma and isolation amongst families and communities with feelings of rejection and humiliation that prevent the sufferers from telling their families of their HIV-positive status, preferring instead to continue to engage in unprotected sexual activities (Parker & Aggleton, 2002:4). Discrimination is directed towards both PLWH and those with AIDS and their family members who are often not infected. Sometimes children from these families have difficulty understanding why people treat them in a degrading way and they often feel different from other children, which may lead to avoidance and isolation.

In a study carried out in South Africa by Notshe (2007) which focuses mainly on issues of sick parents’ disclosure of their own HIV status to their own children, the cultural influence was found to play a very important role in preventing them from disclosing their status. She defines stigma as internal and external; the former being a personal feeling of guilt and shame, the latter being a reaction. This concurs with a study done in Zimbabwe by Mucheto, Chadambuka, Shambira,
Tshimanga, Notion and Nyamayaro (2009), which indicated that most rural women do not want to disclose their HIV status for fear of the stigma and this often resulted in a divorce. According to these authors, this fear emanates from the African belief that generally anything sexual is blamed on the women, and it is therefore considered taboo or disrespectful for men to be blamed. These authors also point out that an HIV-positive test is associated with promiscuity and multiple sexual partners (Mucheto et al., 2009).

Research by Maleka (2006:62) found that the lowest strata employees at a motorcar factory, who were HIV positive, were stigmatised by words such as:

- Koloi ya Elijah (Chariots that were used by the Prophet Elijah)
- Lekhwekhwe (Leprosy)
- Sephamola (Snatcher)

These words were used figuratively to refer to these employees in what Ngwenya (2000) refers to as “the AIDS phase”, which is derogatory and destructive for an infected employee’s self-esteem and morale.

1.2.2 Poor Economic Conditions

HIV infection manifests itself in impoverished environments and is, in itself, one of the most prevalent causes of the outcomes of poverty (Ssengozi, 2009:311). Households in which people are ill because of HIV have a higher expenditure due to medical costs, experience a reduced income through loss of earnings and also often, when the breadwinner dies and the family’s resources are further divided as a result of funeral expenses, the loss of property. A vicious cycle of poverty and increased vulnerability in the family system may perpetuate the AIDS epidemic (Whiteside & Sunter, 2000:91). It is significant for this study to take note that people who are dying of AIDS are not only parents, but for the most part employees, consumers and taxpayers. According to Madrid International Plan of Action on Ageing (2008), Bork & Johnson(2008:2) Kimuna & Makiwane (2007:97) grandparents often spend their latter years struggling to raise a large number of children on a state pension. Although it is not clear that AIDS is a disease of poverty, it helps to drive the epidemic (Whiteside & Sunter, 2000:91).
1.2.3 Parental Illness

Parental illness causes major stress to the family system and, therefore, impacts negatively on the parent’s relationships, parenting skills, household management, work responsibilities and social relationships (AIDS Foundation South Africa, 2007; UNAIDS 2012b; Bock & Johnston 2008:2). Long-term parental illness may impose new dynamics of power and control within the family and has, therefore, a traumatic effect on the upbringing of children. This may lead to continuing stress in a family; the family has to adapt to a context in which role reversal takes place when the sick parent becomes the child, and the school age or adolescent child has to fulfil the role of a parent. Botha (1996:16) addresses an example of this situation by outlining a scenario in Uganda in which an 18 year old child kept his dead father’s land in production in order to take care of himself and his younger sister and brother. According to De Wagt & Connolly (2004:3), parental HIV illness invariably affects children’s physical and psychological well-being, whether or not they are themselves infected.

1.2.4 Fear of Death

With little prediction of a cure, HIV infections are increasing in number and people are dying of AIDS-related diseases such as pneumonia, tuberculosis, oral thrush and herpes simplex (Msomi, 2000:8). In her recent study of HIV positive women living in Khayelitsha, Cape Town, Soskolne (2003) noticed that these women’s social construction of HIV was framed as a death sentence for a sick person. Njoko (2000:3) refers to the following quotations of a mother diagnosed with HIV, as a way of confirming her concerns regarding death:

- “I wondered what will happen to my son after my death.”
- “I wondered how people would treat him once I had left for the new place.”
- “I was thinking how he is going to face life without me?”
- “His grandmother would be there but he also needed me.”

The psychosocial needs of people dying from AIDS related diseases should not be overlooked; parents sometimes suffer from anxiety regarding what will happen to their children after their death, as most become too ill to work and feel helpless to provide their children with any kind of prospective vision for their future. Sufferers are not aware that the consequences of AIDS affect children’s lives even before the parent dies and as a result many children have to leave school...
to take care of their ill parents and the siblings in the family system (Atilola, 2014; Ssemakuwa, 2006:46-48).

### 1.2.5 Social Relationships and Religious Influence

Hazard Vallerand, Hough, Pittiglio & Marvicsin (2005) opine that the fear parents experience plays an important role in the disclosure process of their HIV status. The parents rather withhold information in order to maintain good relationships with family members. Khathidi (2003) confirms that the issue of guilt plays an important part in the disclosure process and that some parents may feel that their families need to be protected from the bad news, especially their children. Parents face additional worries, such as whether the child is old enough to understand or able to keep the information confidential. Another perspective on HIV is that it is considered as God’s punishment for bad behaviour, such as adultery or sex outside marriage (Khathidi, 2003). Talking about sex in the home and in the context of the church is still, for many people, an unacceptable subject. Khathidi (2003) argues that this factor makes it more difficult for single mothers to disclose their HIV status, as they have to talk about an issue related to sexuality.

As limited research has been conducted on the single mother who is infected with HIV and those with AIDS, the researcher was forced to review literature that predominantly focused on ‘parents’ or women who are infected, rather than only on the single mother.

### 1.3 THEORETICAL FRAMEWORK

A theory is defined by Rubin and Babbie (2008: 57) as a systematic set of interrelated statements intended to explain some aspects of social life or enrich our sense of how people conduct and find meaning in their daily lives. It contributes to the development of social work research as well as social work practice in that it assists social workers in identifying and making sense of patterns and observations (Rubin & Babbie, 2008:56-57). This study was undertaken within a framework of the eco-systematic approach, according to which the person and his/her environment are dependent on one another as they are in interaction with the systems that surround them (Shearfor & Horesji, 2008:40). This theory brings an understanding of the various ways a person may adapt to an ever-changing environment in order to cope and survive as a family system (Shearfor & Horesji, 2008:40). The eco-systematic approach argues
that the behaviour of an individual occurs within a particular environment and context. This is also important in the context of this study, as other systems will influence the single mother.

According to the eco-systematic approach, the action of an individual or a group has an effect on other persons and groups in society, and vice versa (Shearfor & Horesji, 2008:50). This can also be linked to the phenomenon of single mothers whose HIV status affects not only them, but also their children, other people surrounding them, and society as a whole. Individuals, in general, as human beings who are developing within complex system of relationships, are affected by multiple levels of the surrounding environment (Berk, 2009:26). This includes the attitudes, beliefs and perceptions of the HIV-positive mother towards her family members and other significant people in the community.

Thus, by following the eco-systematic approach, in this study the researcher explored single mother’s experiences with all the systems in the community to which they are connected and the way the systems create challenges for them during the disclosure of their HIV status.

1.4 RATIONALE AND PROBLEM STATEMENT

Leedy and Ormrod (2013:31) state that transforming an interesting idea into a feasible, researchable problem is one of the first activities in conducting a research project. The idea for this study came as a result of observations made by the researcher as a social worker, while working in the field of HIV and AIDS. The researcher observed that stigma and discrimination, among other things, associated with HIV and AIDS make it difficult for single mothers living with HIV and those with AIDS to disclose their status, as they often experience feelings of rejection and blame, ambivalence together with the fear of death. These reasons often lead to single mothers choosing not to share any information concerning their HIV positive status.

While working at the Department of Social Development, as well as at non-governmental organisations (NGOs), the researcher observed that little research has been carried out on the care of patients or preventative work, regarding the impact of HIV and AIDS on households, specifically in the South African context. Moreover, little has been published on the challenges single mothers specifically experience with regard to the disclosure of their HIV positive status (Makin, Forsyth, Visser, Sikkemma, Neufeld & Jeffrey, 2008:1). The outcome of the proposed study may support professionals who are working in the field of HIV and AIDS and assist them
in becoming aware of the challenges that single mothers experience regarding the disclosure of their HIV positive status. This can also support social workers in determining which intervention and counselling services are needed most to support these mothers. The research question in an exploratory study should present a general overview to the reader regarding the area of inquiry (Fouché & Delport, 2011:108).

Single mothers seem to experience challenges with regard to the disclosure of their HIV status. In view of the above problem statement the following research question needs to be answered: “What are the challenges that single mothers experience with regard to the disclosure of their HIV status?”

1.5 GOALS AND OBJECTIVES

Fouché and De Vos (2011: 94) indicate that the goal of a research study refers to what a researcher plans to do. The goal of this study was to explore the challenges single mothers experience with regard to the disclosure of their HIV status.

1.5.1 Objectives of the Study

Fouché and De Vos (2011:94) define objectives as the practical steps taken to achieve the aim of the research. The key objectives for this study were:

- To explore factors preventing disclosure in relation to the family, community and workplace.
- To determine factors that may affect the social functioning and quality of life of single mothers.
- To identify factors that will help single mothers to disclose their status in the family, community and workplace.

1.6 RESEARCH METHODOLOGY

Leedy and Ormrod (2013:76) state that a research design is the plan of how the research will be conducted. Terre Blanche and Durrheim (2002:29) explain that a research design acts as a link between the research question and the actual implementation of the research. “In this study, the
research method that was followed is qualitative in nature”. The researcher used interviews to obtain ‘rich data’ in order to understand and describe the phenomenon from the participant’s point of view (Fouché & Delport, 2011:64-65). This approach was used in this study as it explored the narrative descriptions of the experiences of the single mothers regarding the disclosure of their HIV status.

The basic goal of this research study was to contribution to knowledge and an understanding in the field of HIV and AIDS about challenges single mothers experience with regard to the disclosure of their HIV status.

“The objectives of the research were exploratory in nature (Fouché & De Vos, 2011:95) in that it had been conducted to gain insight into the phenomenon of single parent motherhood in exploring the challenges single mothers may experience when they have to disclose their HIV positive status”. The problem relates to the challenges experienced by single mothers and the disclosure of their HIV positive status. Terre Blanche and Durrheim (2002:39) state that exploratory studies are used to investigate unknown areas of research by using an open and flexible approach.

Qualitative research design of a combination descriptive (Babbie, 2010:93), explorative (Babbie, 2010: 92) and contextual (Fouché & Delport, 2011:64) type was utilised as the researcher wished to afford participants to describe their experiences with exposing what is unknown about the plight of participants. In the current study, explorative research entailed through listening and the building of an understanding from what was said and this is especially helpful when a problem is generally not well understood (Creswell, 2009:26).

As descriptive study, the intention of this study was to note and describe features of the problem before writing it up (Polit & Berk, 2008:274).Fouché and De Vos (2011:95,96) hold that thorough details are provided in a description, while exploration aims to gain insight into the subject studied. It was the researcher’s belief that describing the data gathered and observed during data collection would provide more knowledge and a better understanding of the challenges that single mothers experience with regard to the disclosure of their HIV status (Babbie, 2010:93).The study transpired at the Vaal University of Technology in Vanderbijlpark, Gauteng, South Africa and thus within the natural context of the participants, therefore the design was also contextual (Creswell, 2009: 175).
This study followed the eco-systematic approach as a framework for exploring the challenges single mothers experience regarding the disclosure of their HIV status.

Applied research was utilized as the researcher wished to apply and tailor knowledge to address a certain problem. The problem relates to the challenges experienced by single mothers when they have to disclose their HIV status.

Babbie (2010:92) mentions that qualitative research makes use of unique methods and procedures to collect data. Data was collected with the use of a semi-structured interview schedule. A semi-structured interview schedule can be defined as a questionnaire that has open-ended questions (Bryman, 2012:314). One of the advantages of using the semi-structured interview schedule was that it allowed the researcher to probe for more clarity. Furthermore, it allowed for the individual meanings and understandings of each individual to be brought to the fore (Greeff, 2011: 342).

This data gathering method was also used to better understand how culture and stigma, poor economic conditions, social relationships, psychological fear, and religious influences create challenges for single mothers living with HIV and those with AIDS. By interviewing the single mothers, the researcher elicited the meaning of their experience attached to their everyday life (Fouché & Delport, 2011:64). It also allowed for the open discovery and documentation of participant’s personal experiences and views (Creswell, 2003: 90).

A case study design was used in this study, which is described by Fouché and Schurink (2011:307) and Nieuwenhuis (2007:75-76) as the researcher becoming engaged in the activities of the participants in order to “gain intimate familiarity with their social world and to look for patterns in the participant’s lives”. Babbie (2010:92) further states that case studies are used to answer descriptive and exploratory questions. Case studies were used as the researcher was interested in the subjective meaning the participants gave to their experiences regarding the disclosure of their HIV positive status. A case could be people or a programme. The Single mothers employed by the Vaal University of Technology were used as a case study their challenges they experience when they have to disclose their HIV status.

As part of the data analysis, tape recordings were transcribed and analysed in conjunction with the field notes analysed to further assist data analysis. Various categories such as notes,
names, titles, dates, context and attendance were colour coded to identify similarities and differences (Schurink, Fouché & De Vos, 2011:404). The researcher then identified themes and sub-themes.

Qualitative data was analysed in a circular fashion by means of preparing data, transcribing the interviews, classifying the data into codes, interpreting results and then representing the data in writing and in tabular form (Strydom & Delport, 2014:404, Creswell, 2013:183-187).

The semi-structured interview schedule was piloted. The rationale of piloting the semi-structured interview schedule was that it assisted the researcher in finding out which questions were relevant for this study and which were not. The researcher piloted the semi-structured interview schedule by interviewing one of the single parent mother who was diagnosed with HIV infection and had referred herself to the staff wellness office for emotional support. The data gathered from such an interview did not form part of the findings.

Throughout the data collection process, the researcher had to abide by the research ethics. Ethical considerations were guided by the researcher’s profession as a social worker who adheres to the South African Council for Social Service Professions’ (SACSSP) code of ethics. Ethical considerations, as set out by Whittaker (2009:110) and Welman, Kruger and Mitchell (2005:11), were a core feature from the start of the research in terms of the research process, selection of participants, interviewing, and data analysis.

1.7 DEFINITION OF KEY CONCEPTS

The following key concepts can be defined in the context of this study:

1.7.1 Challenges

Single mothers face the additional challenge of when and how to disclose their HIV status to their children, extended family members, friends and colleagues (Moloi, 2013; Mochadibane, 2013; Murphy & Marelich, 2008:2). In this instance, the term challenge is understood as defined by the Oxford Advanced Learners Dictionary (2005:231) as “difficulties that test your ability”. Relating to this study, these difficulties include how culture and stigma, poor economic
conditions, social relationships, psychological fear and religion influence single mothers’ experiences during the disclosure of their HIV positive status.

1.7.2 Single Mother

The *Collins English Dictionary* (2015) defines a single mother as a ‘female’ who is bringing up a child or children on her own, because the other parent is not living with her; or a person with a dependent child or children, who is widowed, divorced or unmarried. Single motherhood refers to a woman who has at least one dependent child under the age of 15 and is without a partner (Clark & Cotton, 2013). For the purpose of this study a single mother will refer to an HIV positive female in the employment of VUT and is bringing up at least a dependent child or children on her own.

1.7.3 HIV

According to Marcus (2006:6) and UNAIDS(2011:12) HIV is an acronym for the human immunodeficiency virus, which is the virus that causes AIDS. It is a virus which is a pathogen or germ that reproduces itself inside a living cell. It infects humans by weakening the immune system, which is an important system in the body for fighting off infections and illnesses (Louw & Louw, 2014:417). HIV leads to a weakened immune system, making a person with HIV vulnerable to a group of illnesses called opportunistic infections (Nattrass, 2009; Caribbean Food and Nutrition Institute, 2002:2-4).

1.7.4 AIDS

Santrock (2000:543) describes AIDS as a sexually transmitted disease caused by HIV, which destroys the body's immune system. AIDS is an abbreviation for acquired immune deficiency syndrome (Ngwenya, 2000: 98; Louw & Louw, 2014: 417). AIDS is an epidemiological definition based on signs and symptoms. It is caused by HIV, the immunodeficiency virus (UNAIDS 2011:4).

1.8 CHAPTER OUTLINE

The outline of this report will be as follows:
Chapter 1: Introduction and problem setting

The focus was on matters such as background of the study, statement of the problem, rationale of the study, theoretical framework, research question and study objectives, limitations of the study, research ethics and definition of key concepts.

Chapter 2: single motherhood

This chapter presents reviewed literature on single motherhood phenomena and discusses in relation to its causes, the challenges of single mothers, myths on single motherhood and the strengths of single mothers.

Chapter 3: The effects of HIV and AIDS on human beings

Chapter 3 will briefly present information on the effects of HIV and AIDS on human beings as a disease, the nature of HIV and AIDS as a disease, and the routes of transmission of HIV and AIDS. Chapter 3 will also discuss the process of disclosure in terms of multiple factors influencing HIV positive status disclosure. The literature review serves as the basis for the research.

Chapter 4: The Empirical process

This chapter will describe the methods applied in this study to collect data in the study. Such methods will include sampling, sampling methods, data collection methods used as well as research ethics.

Chapter 5: Data Analysis and discussion of research findings

Chapter 5 will record the research findings followed with discussions.

Chapter 6: Conclusion and recommendations
Chapter 6 will constitute the brief summary of the research findings and conclusion drawn from the research and recommendations informed by the study for future research in the field. In this chapter the researcher will list reasonable recommendations. The limitations of the study will also be acknowledged.

1.9 CONCLUSION

In conclusion, Chapter 1 provided an introduction and background to the study, describing the problem statement, goals and objectives of the study. Furthermore, it provided a summary of the research methodology that was utilized in this study. The following chapter will focus on single motherhood as a phenomenon.
CHAPTER 2

LITERATURE REVIEW: SINGLE MOTHERS

2.1 INTRODUCTION
Chapter two presents reviewed literature on single motherhood phenomena and discusses in relation to its causes, the challenges of single mothers, myths on single motherhood and the strengths of single mothers.

The traditional concept of a family – a husband, wife and child or children – is facing challenges. Worldwide, most families are undergoing drastic changes from two-parent families to one-parent ones, thus creating the emergence of and an increase in the number of single-parent families. The result is that single mothers are not an exceptional occurrence (Lauer & Lauer, 2012:29; Clark & Cotton, 2013). Single motherhood refers to a woman who has at least one dependent child under the age of 15 and is without a partner (Clark & Cotton, 2013). Both in developing and developed countries, single mothers amount to 7, 9 million which means that approximately 70% of women are single parents (Clark & Haplova, 2013; Lauer & Lauer, 2012:29). This may be a temporary family form that lasts a few months or a few years until a remarriage transforms it into a stepfamily. The rise in single mother families in countries such as Zimbabwe, Swaziland, Lesotho and South Africa is increasing (Moyo & Kawewe, 2009). A study by Dlamini (2006) indicates that in Zimbabwe 26.3% of mothers are single parents, whereas South Africa had the highest number with 34.4%. In a research study conducted by Myers (2012) it was found that in Liberia 95% of women in the country are single mothers.

Single mothers live everywhere – in large cities, small towns, and rural areas. They are found amongst all ethnic groups, religious backgrounds, and educational and income levels. According to Tijani and Ogunbanwo (2010) single motherhood, which is a fast-growing primary global trend, also affects Nigeria. For instance some celebrities, including Monalisa Chinda, Shan George and Grace Amar, have been listed amongst the single mothers in Nigeria.
2.2 CAUSES FOR SINGLE MOTHERS

The reasons for single motherhood differ across nations, starting from personal choices to situations beyond their control (Lauer & Lauer, 2012:122). Single-motherhood families develop mainly because of the three reasons discussed below.

2.2.1 Separation from a Spouse / Divorce

According to a report by the South African Migration Projects (SAMP, 2005), divorce or separation is the most common cause of single-parent households. Several studies have observed an increase in the number of divorce cases in sub-Saharan Africa (Takyi & Gymiah, 2007). For instance in Nigeria, an estimated 10% of married women have been divorced previously. The report by SAMP (2005) mentions that during the past couple of years Southern African countries are reported as the countries with the highest rates of divorce. These include Zimbabwe and South Africa. The Urban Institute (2006) confirms this with a report that, according to the Human Sciences Research Council, over 51% of cases where children are growing up in single-mother families is due to divorce.

2.2.2 Death of a Husband / Widowhood

Single-parenthood, contrary to general belief, does not only happen as a result of the choice to get a divorce or separate. Women could become single mothers following the death of a husband. In Southern Africa, the situation appears to be worsening in countries that are the hardest hit by the AIDS epidemic (Moyo & Kawewe, 2009).

2.2.3 Single Motherhood by Choice

One of the reasons to become a single mother is when a woman chooses not to get married, but still wants to have children. Such a choice is easier than it was in the past, as single parenthood is less stigmatised (Lauer & Lauer, 2012:29). Women who choose to be single mothers range from young teenage mothers to older women. SAMP (2005) mentions that single motherhood in countries such as Zimbabwe and Swaziland is a common and accepted phenomenon, because almost 10% of never-married women aged 15 to 24 have given birth. Similarly, comparing countries in Southern Africa, Lauer and Lauer (2012:29) found that through
premarital childbearing never-married women in South Africa contribute nearly 50% of all births to women aged between 12 and 26.

Single people provide a number of reasons for not getting married (Straus, 2006:84-92). In a study that was done in Nigeria (Alaefule, 2011), it became clear in order for single mothers to remain single, they needed money and education. In support of the above statement, the researcher fully agrees that the issue of women’s empowerment, either through education, economic means or both, has also increased the phenomenon of single mothers worldwide (Straus, 2006:84-92). The researcher further argues that, even though education is regarded as the main cause of single mothers, the above statement does not refer to uneducated single mothers and those who reside in the rural areas, because these mothers are still young with poor education. They are less likely to be part of the labour force and more likely to be dependent on welfare assistance, as the literature already indicated. Desire for personal growth has been cited as another reason for women to remain single mothers, because marriage is seen as another aspect that may interfere with their educational aspirations (Lauer & Lauer, 2012:122). Maintaining personal freedom is another reason to become a single mother, as it gives the woman the freedom to travel. Yet another reason is the belief that single people have a better sex life than married people (Straus, 2006:84-92).

2.3 CHALLENGES OF SINGLE MOTHERS

According to Olson & Defrain (2006:23), complete family systems have and still experience challenges. In the case of single-parent families, the situation is not different from other families. Thus, parenthood is challenging and difficult even when there are two parents in the home (Lauer & Lauer, 2012:30). Although literature has identified single motherhood as fast becoming a regular family type, studies have also shown that such families are associated with negative impacts, not only on the parents and children, but also on society as a whole (Kalil, DeLeire, Jayakody & Chin, 2001).

The main concern is that single motherhood seems to be associated with poverty and negative outcomes for children (Kalil et al., 2001; Louw & Louw, 2014:400). Single mother families share three kinds of challenges, namely financial, social and emotional challenges (Lauer & Lauer, 2012:30).
2.3.1 Financial Challenges of Single Mothers and their Children

Amato (2005) contends that never-married mothers are by far the poorest group of single parents. They are also the youngest single-parent group with the lowest educational qualifications, the least likely to be in the labour force, and the most likely to be dependent on welfare assistance. Several studies have revealed that a divorce process is associated with a quick decline in household income for women and this may have negative effects on a child and on the household (Amato, 2005). These single mothers often engage in high levels of risky sexual behaviours by resorting to sex work, either by formally entering into prostitution or by maintaining several sexual partnerships with men who are expected to provide financial assistance (Kabiru, Beguy, Undie, Zulu & Ezeh, 2010). This often leads to unwanted pregnancies after which children are born out of wedlock. Fotso, Ezeh and Essendi (2009) indicated that of the women who are living in the slums of Nairobi, 31% admitted that their pregnancies were unwanted.

In the literature it was mentioned that single mothers are by far the poorest and youngest group of single parents, with either no education or a low level of education (Ellwood & Jencks, 2002). Unmarried mothers who live with their parents or other relatives face fewer economic problems than mothers who live on their own (Ellwood & Jencks, 2002). Women who live on their own experience high levels of stress in providing for themselves and their offspring, as they earn little income and have to cope without the support of relatives and/or government. As a result, their children often have a poor health status and they suffer from malnutrition. According to the United Nations Children’s Fund (UNICEF, 2010b), a Zimbabwean National Nutrition Survey in 2010 revealed that more than one third of Zimbabwe’s children under the age of five live in single motherhood families and suffer from a condition of serious malnutrition resulting in stunted growth, while 12 000 die each year due to malnutrition-related illnesses. Most of the single mothers in Zimbabwe are unemployed (Moyo & Kawewe, 2009) and the fact that there is no child support grants offered in Zimbabwe, Swaziland and Lesotho worsen the lives of single-parent families. A high proportion of single mothers in these countries are not formally educated, which reduces their chances of acquiring good employment with good salaries and further aggravates the situation.

Children who come from single-mother homes tend to perform less well in school and as a result are more likely to have a lower level of educational attainment than children who come...
from a two-parent family. Children raised in one-parent families have an increased risk of poor academic achievement, as they complete fewer years at school and are at a higher risk of not graduating from high school, which results in unemployment and poverty (Van Ewijk & Sleegers, 2010). De Lange, Dronkers and Wolbers (2014) confirm the latter when they mention that single mothers have fewer resources at home and as a result, are more exposed to poor or even a lack of education.

2.3.2 Social Challenges

Single mothers are likely to face the challenge of both caring for and supporting their children on their own. Myers (2012) contends that parenting is hard, thus single mothering is harder as it involves one person playing two roles. This could have some negative impact on the development of children, especially where there is more than one child (Myers, 2012). Single mothers lack the necessary support of a husband that can support her in nurturing duties. It is usually the case that after a divorce or separation, the quality and quantity of parental involvement decreases as parents experience a high level of stress and anxiety after the disruptions caused by the break-up of the family unit (Myers, 2012).

As single parents have to divide their time between work and home, they may end up devoting less time to their children as compared to two-parent families. For instance if the parent is employed full-time outside the home as well as having to take care of the children and managing the household, he or she is likely to feel overwhelmed by the entire number of tasks that need to be done (Kending & Bianchi, 2008). According to Kim (2011), these children often display behaviour that is more deviant and may experience cognitive developmental problems as well as behavioural maladjustment.

Kimano, Kombo and University (2010:14) mention that 71% of high school dropouts in South Africa come from single mother families. Garriga (2010) found that children from single-parent families are more often late for school and they perform worse at school than children from two-parent families. This is because of the decrease in educational support they receive from the single parent (Park, Byun & Kim, 2011).

Studies have revealed that female children from single mother families are more likely to be single mothers themselves in future (McLanahan & Percheski, 2008). This is confirmed by the
studies that were conducted by the South African Demographics and Health Survey in 1998, which shows that more than 50% of the women that were interviewed had their first child when they were still unmarried adolescents between the ages of 12 and 19 years (McLanahan & Percheski, 2008). It is also reported that single mothers often exercise less supervision over their daughters’ dating habits, which in turn lead to earlier sexual activities and possible premarital births (McLanahan & Percheski, 2008). These children are furthermore likely to become victims of abuse and become addicted to substances (Magnuson & Berger, 2009).

Coumarelos, Macourt, People, McDonald, Wei, Iriana and Ramsey (2012) revealed that single mothers are vulnerable to legal problems and these legal problems have a negative impact on their living circumstances. The same authors mention that in many cases single mothers often face serious difficulties to resolve their legal problems and if they do, they achieve poor results because they do not involve the formal justice system, which could be due to their financial problems and the difficulty they have in affording legal fees. According to Coumarelos et al. (2012) the legal problems that single mothers often experience include:

• Family/rights problems
• Financial problem

2.3.3 Emotional Challenges

Divorce on its own or in conjunction with the reduction of parental involvement may lead to emotional and other related problems that can contribute to poor school performance among children as compared to children from two-parent families. Park et al. (2011) confirm the latter when they found in their research that loss of parental involvement affects children’s educational outcomes.

De Lange et al. (2014) mention that there is a possibility that after divorce or separation community ties might not form or might disintegrate due to a possible move to another neighbourhood or town. The social network of divorced parents will decrease, causing the parent to have less information about the child’s education and school and they will be unfamiliar with extracurricular activities, which will result in a negative influence on the children’s educational performance.
2.4 MYTHS ABOUT SINGLE MOTHERS

While single parent families have become more socially acceptable over the years, single parents and their children often have to face stigma, violence and social problems based on a number of myths, prejudice, half-truth said stereotypes levelled against single parenting.

The following myths exist regarding single mothers:

- **They are broken families.**
  
  Even today, the unjust stereotype is still sometimes raised: a single parent manages a broken home that creates troubled children. The idea that the home is broken simply because the parents are divorced or were never married to begin with is unreasonable and, in some cases, completely biased and this may cause the single parent homes to doubt their adequacy and confidence as parents. The truth is many single parent homes are now complete. It is not the number of parents in a family, but the quality of parenting a child receives that matters most. The single parent home can be just as happy, healthy and stable as any two-parent home and sometimes even more so. A home is only “broken” when healthy family interaction breaks down. The home was broken while the single parent lived in a marriage that was unhappy and abusive. Many single parents have escaped an abusive situations, or were thrust into single parenthood, due to their spouse having dropped the parental responsibilities. The fighting, yelling, cold silences and other things that occurred in those homes were more destructive to the child’s upbringing than living in a peaceful and calm home with one parent.

  Many single parents who divorced or did not marry made the healthiest choice in creating a peaceful and stable home for their family. Many well-researched studies have documented a number of positive outcomes in single parent families. For instance, single parents often find themselves better able to care for their children because they are now happy and no longer concerned about what might happen when their spouse arrives home. Secondly, single parenting develops the parent’s independence and ability to handle a number of situations. Thirdly, children benefit from increased levels of responsibility and, lastly, parental and child health outcomes were related to larger networks of social support and good communication within the single parent family (Cullen, 2011).
• The parents lack parenting, organisational and determination skills.

If children do not receive adequate love, attention and mental stimulation, they are likely to suffer from all kinds of problems. The reality is that such conditions can exist in any home, regardless of family structure. Being raised in a single parent situation does not, in itself, create any danger of being disturbed or ineffective as an adult. Positive outcomes in single-parent families are not uncommon and single parents are often more independent and multi-tasking and their children actually learn to handle greater responsibility. The outcome of single parent families actually depends on social networks and support to the family and good communication within the family. Children of single parent homes can be as healthy and as well-settled as other children while they even enjoy greater stability and happiness. Those divorcees who happen to get remarried are more able to adjust and concentrate more on keeping their families whole and happy. In a study conducted by the University of Michigan, over 6,000 adults had surprisingly positive conclusions for children from divorced homes. The results showed that adult children from divorced homes were just as likely to be happily married as someone who grew up in a two-parent home. Perhaps confronting the reality of the fragility of marriage, the adult children of divorce were more than twice as likely to be worried about the health of their marriage. In addition single parents, because they have no parent partner with whom to share the daily child raising load, must absorb additional family demands and support additional responsibility.

However, by rising to this challenge, single parents develop important strength that merit recognition and appreciation. For instance, single parent homes are highly committed – taking their family responsibilities very seriously. Single parents vote with their actions, doing more as parents now that they are parenting alone, thereby increasing dedication to the welfare of their children. Secondly, single parents are clear communicators – with much to talk about and limited time to talk, their busy schedule causes single parents to speak directly and to the point and not hesitate to speak up when difficult issues need to be addressed. Thirdly, single parents are firm decision-makers. Accepting that parenting often requires taking a stand against what children want, single parents are not afraid to make harsh and unpopular ground rules. Fourthly, single parents are well-organised. With so much to do and only one parent to do it, single parents create efficient systems to manage so much responsibility. Lastly, single parents manage various family
functions. Parenting alone, single parents expand their traditional role to include family tasks the absent parent used to do (Pickhardt, 2013).

- The parents neglect their children when they are working.
  Single parents have limited time and number of single parent would attest to that. However, their children are their first priority and they make sure to spend time with their children and give them plenty of attention and love. Having home two parents in a home does not automatically make for a happy and healthy child. Two parents in a home does not equal more attention either. In fact, if you ask many single parents why they left is that the other parent was essentially absent from the home, paying no attention to either spouse or children. Plus, when you no longer have to devote time to trying to save a degrading relationship, you have more time to devote to your children.

- The society always supports the single-parent family and these families experience intensive family problems.
  Along the same line of thinking that single parent households are poor households, many people believe that most single parents receive some kind of welfare assistance and that are supported by the tax payers. In fact, this is actually a false concept. In a study conducted by the United States Census Bureau's in 2006 regarding the facts about single parenting, out of all single mothers only 22% collect medical aid, 23, 5% receive food rations, 12% are on some kind of housing subsidy program and 5% are enrolled in Temporary Assistance for Needy Families (TANF). According to Cullen (2011) the emphasis on self-sufficiency often produces unnecessary shame and guilt in parents who are emotionally and financially challenged, including the single parents. Meaning one has to learn to be interdependent; give and receive; taking our own responsibilities and asking for healthy support; and requesting professional help, when needed. Parents should not become too dependent on their children for social and psychological support; rather children should receive support from their parents. Parents should also join support groups in order to have their needs for emotional support met, for instance a social outlet, childcare and fun, as well as volunteering within the community. Parents should also learn the balance between nurturing and being nurtured so that each family member may become more mature and independent (Cullen, 2011; Pickhardt, 2013).
Both parents and children are not able to thrive in such situation.
The common belief is that children in single-parent families cannot receive good care in their families and only those in families with two parents receive care (Clark & Cotton, 2013; Carter & McGoldrick, 2005). It is also believed that children in these families are always worse off than children living with both parents. However, this is not always the case. Being raised in a single parent situation does not, in itself, create any danger of being maladjusted or ineffective as an adult. In fact, the opposite could be claimed, based on studies that have found many children from single parent families to be especially resilient, independent and emotionally stable; possibly due to the heightened level of responsibility they may have carried within the family unit. Furthermore, there is an assumption that these children raised from single parent families are almost always poor and because of that, they grow up feeling inferior to peers raised in two-parent homes with adequate incomes. As mentioned in the Census statistics of 2006, this theory does not really state the truth when faced by the facts about single parenting, since not all or even most of single parent households are underprivileged. There are too many factors that contribute to low self-esteem and thus it cannot be solely attributed to growing up in single parent household. For instance, children’s self-esteem is linked mostly to the income level of the family. Since single parent families also only have a single provider, they are often low-income households and thus children’s self-esteem tend to be lower too, similar to children of low-income two-parent homes (Cullen, 2011). Parents can teach resilience and self-esteem skills to their children by being a model to them, boosting their self-respect and self-nurturance and helping them to realise that their possessions do not determine what they are (Cullen, 2011; Pickhardt, 2013).

2.5 STRENGTH OF SINGLE MOTHERS

Despite the number of challenges single-parent families’ experience, they are still able to cope with their hectic lifestyles (Louw & Louw, 2014:400). Although children of single mothers are dependent on the characteristics of the mothers, such as their financial background and age, Lombe, Sefadi and Newransky (2011) agree that single mothers are more likely to have positive aspirations for the welfare of their children and are prepared to make sacrifices to ensure that their children have the best in life (Lombe et al., 2011). They tend to support their children in whatever ways or means they can.
A single-parent family may have greater flexibility in planning for their children. Single parents are not distracted by the expectations or time demands of another adult. With fewer schedules to negotiate, there may be greater flexibility to spend time with each child and this may foster an interdependent, working-together approach to problem solving and daily living. Single parents depend more heavily on the voluntary cooperation of their children. This cooperation is often encouraged by holding family meetings in which children are directly involved in making decisions and solving problems. When children are thus involved, they are more likely to help carry out the decisions. Single parenting provides many opportunities for growth and sharing and single parents often need to develop new skills and obtain additional education.

2.6 RELIGION, CULTURE AND SINGLE MOTHERS

The role of a single mother can be very different from that of a married mother as these mothers often have to cope with highly stressful lives. They often use their religious beliefs and practices as a mechanism to cope with these circumstances (Sullivan, 2008). Having social supportive relationships within their religious faith would be an asset to single mothers. Sullivan (2008) indicated that seven out of 10 American adults find purpose and meaning in life because of their religious faith. Studies show that being invested deeply in religion improves the mental health of adult women.

In response to economic, social and psychological challenges faced by single mothers, some turn to faith as a way to deal with stress. Sullivan (2006:106) mentions that single mothers found their faith to be a powerful tool in helping them to calm down and deal productively with rude customers or difficult bosses or co-workers.

In a survey done by Myers (2012) in Nigeria, it was revealed that both culturally and within the religious circles, single mothers are often seen as promiscuous and as a result they are often stigmatised as a morally ruined member of the community that deserves no respect. However, not all single mothers are promiscuous. It was believed that a woman could not live alone; either she had to reside with her husband or her parents. In the near past it was unacceptable for a woman in Nigeria to choose to remain a single parent or to become pregnant outside of marriage. Songs existed that were prepared in the open by the public in order to belittle these single mothers. The only acceptable reason to be single at that time was the death of a husband or life partner, or a divorce (Olurounbi, 2010). Divorce was a less-desirable option since after
the death of a spouse, the widows were quickly provided with another partner as a way to maintain balance in the society and earn respect. Nyoro (2004) highlighted that there are still many church organisations that discriminate against single mothers by preventing them from participating in church activities.

This also happens with positions relating to the job market where the employers will give the position to married mothers rather than the single mothers, who in many instances are young and lack experience. Single mothers who may still wish to get married find it hard to get married, especially when the man has difficulty accepting marriage to a woman with children fathered by another man (Alaefule, 2011).

2.7 CONCLUSION

In conclusion, Chapter 2 provided an explanation into the phenomena of single motherhood in relation to its causes, the challenges of single mothers, myths about single motherhood as well as the strengths of single mothers. The following chapter will focus on the effects of HIV and AIDS on human beings as well as the process of disclosure.
CHAPTER 3

LITERATURE REVIEW: THE EFFECTS OF HIV AND AIDS ON HUMAN BEINGS

3.1 INTRODUCTION

No country in Africa has escaped the HIV and AIDS infection. Research conducted by UNAIDS (2012a) confirms that sub-Saharan Africa is the hardest hit by HIV/AIDS, and is home to 67% of the most infected and affected people worldwide. About 40 million people in the world are living with HIV of whom 29,4 million are in Africa (Andrews, Skinner & Zuma, 2006:269-276; UNAIDS, 2013a). Globally there has never been an epidemic that matches the devastating effects that HIV has. HIV infection rates have spiralled out of control in Sub-Saharan Africa and the ripple effects will undoubtedly still be felt for years to come (Motsukunyane, 2009:14). The epidemic incidences differ from country to country, as do national responses to this complex state of emergency. As of 2011, the most severely hit African countries include Botswana, Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia, Zimbabwe and South Africa, the latter currently estimated to have an HIV prevalence for adults aged 15 to 49 with a total number of 12, 2% infected with HIV in 2014 (Statistics South Africa, 2011; Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Labadarios & Onoya, 2014). This is the fourth highest national prevalence globally, and the highest number of people living with HIV and of any country (Shisana, Rehle, Simbayi, Zuma, Jooste, Pillay-van Wyk, Mbelle, Van Zyl, Parker, Zungu & Pezi, 2009; UNAIDS, 2012a).

According to Motsukunyane (2009:14), HIV and its effects have been known to the general public since the 1980s. South Africa is currently experiencing one of the most severe HIV and AIDS epidemics in the world. HIV is a dilemma that is growing by the minute. Not only does it have profound effects on the South African economy, but also on the social wellbeing of the country (Motsukunyane, 2009: 14). HIV and AIDS pose a major threat to social development, as most infections occur in young economically active adults. The principal age group infected by this disease falls between the ages of 20 and 49 years and research has indicated that of all the AIDS related deaths in South Africa, 70% of those deaths are people between the ages of 24 and 45 (Shisana, Rehle, Simbayi &Mobile, 2005). In South Africa HIV and AIDS, like tuberculosis, were declared a national priority in 1998. AIDS is a chronic disease that makes demands on a variety of services, and to make matters worse, the regions are faced with
decreased life expectancy, rising infant mortality, and an increase in the number of AIDS orphans (Avert organization, 2010:1). The mortality rates due to the virus are on the increase; statistics show that in the past 15 years over 1.9 million South Africans have died of AIDS related illnesses and it is further estimated that by 2015 over 5 million South Africans would have died of because of AIDS. It is further stated that the cumulative number of AIDS deaths is expected to rise to a total of 9.31 million by 2020 (Motsukunyane, 2009:46).

In 2015, an estimated 6, 4 million South Africans were HIV positive and 1 million die every year due to AIDS, according to Statistics South Africa (StatsSA, 2011; Shisana et al., 2014; UNAIDS, 2012b). The number of AIDS-related deaths reported in South Africa in 2011 exceeded 800 000 (Bradshaw, Johnson, Schneider, Bourne & Dorrington, 2002:48).

There is a lower prevalence rate in countries in North Africa, as their population typically engages in fewer high-risk cultural patterns that have been implicated in the spread of the virus in sub-Saharan Africa (UNAIDS, 2012c; UNAIDS & WHO, 2013).

South Africa remains the worst affected by the HIV and AIDS epidemic and it is a major public health concern and cause of death in many parts of Africa. Although the continent is home to about 15.2% of the world’s population, sub-Saharan Africa alone accounted for an estimated 70% of all HIV infections, and 70% of all AIDS deaths in 2011 reported was 270,000, with 1 600 infected each day (UNAIDS, 2012b).

A survey published in 2004 found that South Africans spent more time at funerals than they did having leisure time, such as getting haircuts, shopping or having barbecues. It was also found that more than twice as many people had been to a funeral in the previous month than those who had been to a wedding (UNAIDS, 2004).

In Botswana the number of newly infected people per year has declined by 67%, from 27 000 in 2009 to 9 000 in 2011. In 2009 about 37% of the adult population in Botswana were infected, however the number decreased to 23, 4% in 2011 (Owusu-Ampomah, Naysmith & Rubincam 2009:40). Beside AIDS, the epidemic was aggravated by the outbreak of tuberculosis and malaria (Avert Organization, 2008:1). In a study conducted by World Initiative for Soy in Human Health (WISHH, 2010:2), children orphaned by HIV and AIDS were experiencing malnutrition as well as nutrition-related problems in both urban and rural areas of Botswana (WISHH, 2010:2).
The AIDS epidemic in Lesotho has had a distressing impact on the country. Poverty and the AIDS epidemic have caused life expectancy to drop to 40 years for both men and women. A household survey analysis conducted in 2008 showed that orphan hood does not exceed 5% in most countries, whereas in Lesotho over 20% of children are orphans (UNICEF, 2008:1). These children become family heads when older family members are unable to work because of sickness and thus unable to provide food and care for their children (Avert Organization, 2009:1).

The following table (UNAIDS, 2012b) illustrates the number and percentages of population per country that were living with HIV, who have died from HIV related illnesses, including new infections and adult prevalence ages of those between 15-49 during the year 2011.

Table 3.1 Number of people infected by HIV and AIDS globally in 2011

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of people living with HIV</th>
<th>AIDS deaths</th>
<th>New HIV infected</th>
<th>Adult prevalence ages 15-49</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year</td>
<td>2011</td>
<td>2011</td>
<td>2011</td>
<td>2011</td>
</tr>
<tr>
<td>Botswana</td>
<td>300,000</td>
<td>4,200</td>
<td>9,000</td>
<td>23.4%</td>
</tr>
<tr>
<td>Lesotho</td>
<td>320,000</td>
<td>14,000</td>
<td>26,000</td>
<td>23.3%</td>
</tr>
<tr>
<td>Malawi</td>
<td>910,000</td>
<td>44,000</td>
<td>46,000</td>
<td>10.0%</td>
</tr>
<tr>
<td>Mozambique</td>
<td>1,400,000</td>
<td>74,000</td>
<td>130,000</td>
<td>11.3%</td>
</tr>
<tr>
<td>Namibia</td>
<td>190,000</td>
<td>5,200</td>
<td>8,800</td>
<td>13.4%</td>
</tr>
<tr>
<td>South Africa</td>
<td>5,600,000</td>
<td>270,000</td>
<td>396,000</td>
<td>17.3%</td>
</tr>
<tr>
<td>Swaziland</td>
<td>190,000</td>
<td>6,800</td>
<td>13,000</td>
<td>26.0%</td>
</tr>
<tr>
<td>Zambia</td>
<td>970,000</td>
<td>31,000</td>
<td>51,000</td>
<td>12.5%</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>1,200,000</td>
<td>58,000</td>
<td>74,000</td>
<td>14.9%</td>
</tr>
</tbody>
</table>

(Source: Adapted from UNAIDS Report on the global HIV/AIDS Epidemic, 2012b)
Within Africa, Swaziland is the smallest country but has the highest prevalence of HIV and AIDS (UNICEF, 2012). Swaziland is one of the countries that have been most severely impacted by the HIV and AIDS crisis in the world. As of 2011, the HIV prevalence rate in Swaziland was the highest in the world at 26% of persons aged 15 to 49 (UNICEF, 2013). In 2015 national prevalence rates at antenatal clinics in Swaziland were estimated to reach 41.1% (Ministry of Health, 2010: 21). The United Nations Development Programme wrote in 2005 that the immense scale of AIDS-related illness and death will have serious consequences on food, security, economic growth and human development. AIDS undermines the capacities of individuals, families, communities and the state to fulfil their roles and responsibilities in society. If current trends are not reversed, the long-term survival of Swaziland as a country will be seriously threatened (UNICEF 2013).

The HIV epidemic in Swaziland has reduced life expectancy at birth to 49 for men and 51 for women (based on 2009 data) (UNAIDS & WHO, 2009b). Life expectancy in 2009 was 59 for men and 62 for women (UNAIDS & WHO, 2009b). Based on 2011 data, Swaziland’s approximate death rate of 6 800 per year was the third highest in the world, just behind Lesotho (UNAIDS & WHO, 2009).

Additionally, the number of AIDS-related deaths in 2011 in both Africa as a whole, and sub-Saharan Africa, was 33% less than the number in 2005 (UNAIDS, 2012a). The number of new HIV infections in Africa in 2011 was also 33% less than the number in 2008, with a 24% reduction in new infections among children from 2009 to 2011 (UNAIDS, 2012c). According to Statistics South Africa, 2011 this increased from an estimated 4.10 million in 2008, to 5.6 million in 2014.

Table 3.1 confirms that there is a high incidence of HIV and AIDS infection in sub-Saharan Africa, with South Africa as the worst affected region having the highest number of HIV and AIDS infections at 6.4 million and deaths at 270 000, which both appear to be rapidly increasing. It is evident that if no cure or vaccine is found South Africa will face a crisis of increasing numbers of HIV and AIDS infections and deaths, with a marked decline in the total population, which will result in an orphan generation (UNAIDS, 2012a). This statement is in agreement with Cluver, Gardner & Operario (2008:414) with their estimation that by 2020, HIV and AIDS will orphan an estimated 2.3 million children in South Africa, while 19% are already affected.
It should be noted that these figures are mere estimates, which do not reflect reality, because many cases remain unknown due to the silence enforced on the HIV status of clients.

3.2 THE NATURE OF HIV AND AIDS AS A DISEASE

3.2.1 The Historical background of AIDS and the Origins of HIV

For many years, scientists have theorised about the origins of HIV and the way it first appeared in the human population. Between 1979 and 1980, Robert Gallo and Luc Montagnier discovered in France a new illness called the human immunodeficiency virus (HIV) (Bradshaw et al., 2002:45; Whiteside & Sunter, 2000:1). Many researchers believe that HIV originated in primates. Of the many theories and myths about the origin of HIV, the most likely explanation is that HIV was introduced to humans by monkeys. HIV probably originated in a remote tribe in Africa, inter alia western central Africa, in the 1920s or 1930s. HIV-1 is known to be a strain of the virus that has existed for many years in chimpanzees, without harming them. It is the virus responsible for the global AIDS pandemic. In Africa HIV-1 is very common, whereas it is rare in America and Europe. Thus, HIV spread from Africa to other parts of the world (Ahluwalia & Ahluwalia, 2005:1).

Another uncommon strain, subtype HIV-2, came from black monkeys. According to Ahluwalia and Ahluwalia (2005:1), at some point a group of Haitian labourers who went to Africa to work on a project as hunters brought AIDS with them. The virus likely moved from primates to humans when the hunters were exposed to the blood of infected primates. The hypothesis is that someone with a cut on his/her hand was preparing monkey meat for the pot (Ahluwalia & Ahluwalia, 2005:1). The hunters then became infected with HIV and passed on the disease to other humans through body fluid contamination. This theory is known as the bush meat theory (Sharp, Shaw & Hann, 2005). Although the literature offers different opinions as to where and when HIV originated, authors are in agreement that the first case was diagnosed in 1981 in homosexual men and the fact remains that HIV and its effects affect every country in the world.

3.2.2 The Definition of HIV and AIDS

Many people do not really understand how HIV and AIDS are related, even though they often hear the two words being uttered together. Many people also refer to HIV as the AIDS virus. When HIV and AIDS and the effects thereof are being explained, it is important to have in mind
the two classifications of the disease according to the WHO and the Centre for Disease Control (CDC) (Robertson, 2008). Since the WHO system has four stages, as it will be discussed later in this chapter, the definition of HIV and AIDS will be based on the contents provided by the WHO and CDC.

Furthermore, HIV and AIDS do not kill instantly. According to Mzobe (2000:13), the classification of the disease is divided into two groups of PLWH and those with AIDS, namely:

- **Group 1 refers to people who test HIV-positive, but show no signs and symptoms of the disease**

During this period, the infected individual feels healthy, with a healthy life lasting an average of seven years. People who are infected by the virus may have many years to live a productive and normal life. This is a dangerous stage due to the myths and misconceptions about the existence of the disease. It is associated with a lack of safe sex practices and the spreading of the HIV infection to others. This is based on the classification of the WHO, who mentioned that in the first stage an HIV infection is asymptomatic and not classified as AIDS. According to the WHO (2006), Robertson (2008) and Ngwenya (2000:98), a person infected with HIV goes through several phases before reaching the AIDS phase. The first phase occurs shortly after contracting HIV. This stage of infection lasts for a few weeks and is often accompanied by a short flu-like illness. Apart from these mild flu-like symptoms, the host displays no other significant symptoms. In up to about 20% of people the symptoms are serious enough to consult a doctor, but often it is not diagnosed as HIV because the infected person may not yet have produced anti-bodies against HIV (Ngwenya, 2000:98).

HIV is a virus that causes AIDS (Andrews et al., 2006:269-276). It is a virus that cannot survive outside of a human cell, but reproduces itself inside a living cell. HIV must be transmitted directly from one person to another through body fluids that contain HIV-infected cells, such as semen, vaginal secretions, breast milk or blood. It infects humans by weakening the immune system, which is an important system in the body for fighting off infections and illnesses. HIV leads to a weakened immune system, making a person with HIV vulnerable to a group of illnesses called opportunistic infections. Healthy people
are not so easily affected by these infections (Di Pentima, 2005; Caribbean Food and Nutrition Institute, 2002:2-4).

People who are HIV positive have been tested and found to have signs of HIV in their blood system. HIV lives in blood and other body fluids such as semen or vaginal secretions that contain blood or white blood cells (Ferri, 2006:2; Ahluwalia & Ahluwalia, 2005:5; Di Pentima, 2005). Ahluwalia and Ahluwalia (2005:2) describe HIV as a virus (an agent, which may cause different types of ailments) and as a piece of free-floating genetic material contained in a protective protein called a capsid. A virus is not a cell and is not alive, but it only replicates. Any virus can replicate through genetic material, *inter alia* single-stranded RNA, single-stranded DNA, double-stranded DNA, and a particular RNA virus called retrovirus. Once a virus enters a body, it will find a host cell. Subsequently it can pierce the host cell membrane with a spike, which is combined in the capsid, or it can use an enzyme to break down the cell membrane to enter it. Once inside the cell, the virus will use the host cell’s machinery for duplication. Sometimes after entering the cell, the virus may go into dormancy and the virus may remain hidden. When HIV enters a human body, the individual will test positive for antibodies to the virus even though the individual does not have the condition of AIDS. However, testing HIV positive implies that the person has the risk factor for reaching the condition of AIDS. A number of studies found that many people who test HIV positive may not reach the AIDS condition, as their strong immune system is able to immediately destroy the invader (Ahluwalia & Ahluwalia, 2005:4).

According to Marcus (2006:6), HIV is an acronym for the human immunodeficiency virus, and AIDS is an acronym for acquired deficiency syndrome. When HIV gets into the blood stream, the body responds by producing antibodies for the infection. This forms part of the immune response. Often an infection can be counteracted by the production of antibodies. However, HIV is a retrovirus, which sets out to destroy the immune system itself. At first the body may respond successfully, but gradually the ability of the body to fight off infection is reduced and this is because HIV and AIDS is characterised by a long incubation period and a gradual increase in morbidity from opportunistic infections. That is why people who have been infected with HIV often develop one or more of a whole range of diseases, collectively known as AIDS. The immune system in the body is therefore no longer able to resist the infection.
• **Group 2 refers to people in the second phase of the HIV and AIDS cycle known as full-blown AIDS**

AIDS is the advanced stage of HIV and causes a profound suppression of the immune system, also known as cell-mediated immunity. The immune system deteriorates very fast. This is the last and terminal stage of the disease. In this group, the disease shows the clinical manifestations of various opportunistic infections, which appear frequently and usually cause death (Farham, 2002b:104).

HIV is the virus that causes AIDS, and people with HIV are infected. Some of these people will develop AIDS as a result of their HIV infection. To be diagnosed as having AIDS, a person has to show certain opportunistic infections such as HIV wasting syndrome or Kaposi sarcoma. Once the person is diagnosed with AIDS, he/she cannot return to a stage of HIV (WHO, 2006; Robertson, 2008). Only when patients enter the final phase of HIV infection can they be said to have full-blown AIDS.

AIDS is caused by HIV, which weakens the human immunity system against diseases (Burgess, Bijlsma & Ismael, 2009:199). Santrock (2000:543) describes AIDS as a sexually transmitted disease caused by HIV, which destroys the body’s immune system and is characterised by opportunistic infections or HIV-related cancers, or both. This means that a person who has contracted HIV is vulnerable to germs that a normal immune system could destroy. Although the incidence of HIV and AIDS is a worldwide concern, it is of particular significance in sub-Saharan Africa.

According to Wild’s (2001:3) clinical findings, the initial stage of the infection is represented by HIV seropositivity, which is the detectable presence of antibodies to HIV in serum. He continues to say that although the incubation period from exposure to HIV and development of seropositivity may range from months to years, many, if not most, patients who are seropositive will develop AIDS. This last phase occurs when an infected person’s counting cells, also known as the T-helper cells (CD4+) cells, are decreasing rapidly and medical scientists measure this illness by looking at a person’s number of CD4+ cells in the blood (Farham, 2002b:104). According to the CDC, people who are in the AIDS phase mostly lie in bed, patients become infected by relatively rare and unusual organisms that do not respond to antibiotics and their CD4+ count is less
than 200 cells/mm$^3$ (Evian, 2000:26; WHO, 2006; Robertson, 2008). In general, a healthy person has a “CD4+ cells count of between 500-600 cells/mm$^3$” (Evian, 2000:26). The following figure gives a graphic illustration of the progression of HIV phase and AIDS in years.

**Figure 3.1 Phases of HIV infection**

(HIV infection → No Symptoms → Minor Symptoms → AIDS)


Once an individual is infected with HIV, he/she should understand the progression of the disease from the initial infection, which is between one and three years. After the initial infection comes, the latency period that lasts between four and six years in which people living with HIV do not show symptoms.

The full-blown stage occurs between seven and nine years; people become ill and develop symptoms of AIDS. The infected individual will then usually die of AIDS related complications. Many countries, particularly in Africa, are already in the AIDS stage (Farham, 2002b:104). The course of untreated HIV is not known, but may go on for 10 years or longer in many people.
3.3 ROUTES OF TRANSMISSION OF HIV AND AIDS

AIDS was at first regarded as a disease of gay men and drug addicts, but in Africa it took off among the general population (Pisane, 2011; Shisana et al., 2009). Elof (1998:6) mentions that initially it was thought that the disease originated from Haiti, due to the fact that a larger number of the first cases reported were from Haiti. Haiti is also a favourite holiday destination for homosexual men. It is believed that these homosexual men contracted the virus and brought the disease back to the USA. However, even if it came through the homosexual community, it is not regarded as a homosexual disease (Ahluwalia & Ahluwalia, 2005:1).

HIV has been found to be present in the blood, semen, vaginal fluids and breast milk of infected persons. HIV is also found in the cerebrospinal fluids (which bathes the brain and spinal cord), synovial fluids (which occupies the narrow space between the lungs and the chest wall), and amniotic fluid (which surrounds the foetus) of infected persons (Ahluwalia & Ahluwalia, 2005:5). HIV may be passed from one person to another when infected blood, semen or vaginal secretions come into contact with an uninfected person’s broken skin or mucous membranes. A mucous membrane is wet thin tissue found in certain openings to the human body. These can include the openings of the penis, rectum, vagina, nose, eyes and mouth (UNICEF, 2001:8). The transmission of HIV in human beings is mainly possible through three ways:

- Sexual contact, either homosexual or heterosexual sexual intercourse (heterosexual is the leading means of HIV transmission in the world).
- Contact with blood or other bodily fluids, blood products or tissues of an infected person.
- Transfer of the virus from an infected mother to her infant before or during birth, or shortly after birth through breastfeeding (Ahluwalia & Ahluwalia, 2005:5; Mah & Halperin, 2010).

3.3.1 Sexual Transmission

In Africa, HIV is transmitted predominantly when people engage in unprotected or unsafe sexual intercourse. In high-income countries, such as the USA and Western Europe, unsafe sexual behaviour was also referred to as a major contributing factor to HIV transmission (Ahluwalia & Ahluwalia, 2005; UNAIDS, 2010a).
Ahluwalia and Ahluwalia (2005:6) and Shisana et al. (2009) confirmed in their studies that the sexual transmission of HIV is believed to account for 90% of AIDS cases globally, where it is either transmitted through heterosexual or homosexual sex. However, the majority of the infections are transmitted through heterosexual sex (sexual intercourse between male and female). The authors reported that the risk of HIV transmission from an infected male to an uninfected female through unprotected vaginal intercourse is about one per 100 sexual contacts. However, the risk of female-to-male is lower with a rate of one per 1000 infected women. This means that out of 1000 couples having vaginal intercourse, where the woman is HIV positive and the man is HIV negative, one case of transmission will occur. That is why the higher rate of male-female transmission is believed to be the reason why women outnumber men in cases of infection due to heterosexual transmission.

The rates mentioned above differ due to a number of factors, which may alter an individual’s susceptibility to HIV infection. Some of these factors are (Ahluwalia & Ahluwalia, 2005:7):

- Infection through anal intercourse (anal intercourse easily causes tears in the rectal lining that results in direct contact between the infected semen and the blood of the receptive partner).
- When a man has sexual intercourse with a woman during her menstrual period (during a woman’s menstrual period the rectum lining is thin and contains many lymphocytes, macrophases and other cells that HIV can infect).
- During outbreaks of genital sores or cuts (caused by herpes and other sexually transmitted infections such as syphilis and herpes, which can increase the risk of transmission).
- An increase in sexual transmission if one of the partners has acute HIV infection or advanced HIV disease (AIDS).

### 3.3.2 Blood and Needle Sharing

Even with HIV programmes in countries, blood transfusion accounted for a large number of HIV transmission in the developing countries. For instance, in Nigeria blood transfusion has been cited as the major source contributing to HIV transmission in children. However, this is very different in the developed countries (Ahmad, 2004:38). Unsafe health practices may also occur in the traditional health sector and these include activities such as male circumcision, ear piercing, and tattooing. (Ahluwalia & Ahluwalia, 2005:8; UNAIDS, 2010b). In some of the rural
areas in South Africa, such as in Kwa-Zulu Natal, HIV can also be transmitted when indigenous tribal rituals require cuts to be performed on a person, for example during circumcision. It is claimed that the people perform these operations often use HIV contaminated razor blades or other sharp instruments (Van Dyk, 2001:25-26). The operations are also often conducted under unsterile conditions in non-medical settings, such as in the bush initiation school or in the mountains (Shisana et al., 2009).

3.3.3 Mother-to-Child Transmission

According to UNAIDS (2013b), pregnant women who are HIV positive can also pass HIV to their babies through the placenta before birth (during pregnancy), during labour or delivery, or through breastfeeding. In developing countries, it is estimated that one in every three children born to an HIV positive mother, are infected with HIV. In developed countries like the USA, less than one child out of 50 born to an HIV mother will be infected due to good health practices, which include caesarean delivery, treatment with antiretroviral drugs, and safe alternatives to breastfeeding (Shisana et al., 2009; UNAIDS, 2013b).

The above concurs with a study done in South Africa by the Medical Research Council (MRC) of South Africa and the Department of Health (DoH), in which it was found that HIV transmission from mother to child was reduced from 3.5% in 2010 to 2.7% in 2011 (Pillay, Dinh, Goga & Jackson, 2012).

A child may be suspected of having HIV infection if it is born to a woman who is known to be HIV positive or if the child becomes ill. However, it is difficult to interpret HIV tests in children under the age of 18 months. Children born to HIV positive women have HIV antibodies from their mothers in their blood until they are about 18 months old; these are called maternal antibodies. In a very few cases, these maternal antibodies are found in the blood of children older than 18 months. The tests, however, are very expensive and not widely available in developing countries. One of the tests used is the deoxyribonucleic acid (DNA) polymerase chain reaction (PCR). In the USA, children born to HIV positive mothers receive PCR tests at birth and again at one to two months, as well as at the age of four to six months. Two positive tests can confirm if a child is HIV infected or not (UNAIDS, 2009; UNICEF, 2013).
A number of studies have concluded that HIV cannot be transmitted by any of the following (Ahluwalia & Ahluwalia, 2005:6, 8; UNAIDS, 2004:19-39; UNAIDS, 2013a; Van Dyk, 2001: 32-33):

- Through casual contact like hugging or kissing.
- Sharing of eating utensils, etc. or lunch rooms (that is, where no blood or body fluids are involved).
- Touching computers or telephones in the workplace.

### 3.3.4 Other Secondary Factors that can contribute to the Spreading of HIV

Many people know about HIV transmission and prevention, but the problem is that they do not act upon it and that is why the HIV prevalence still remains high in some regions (Louw & Louw, 2014: 418; UNAIDS, 2012c); The following are factors that are necessary to include when discussing the transmission of HIV:

- **Non-injection drugs and HIV transmission**

  The use of alcohol and other drugs increases the risk of acquiring or transmitting HIV infection. Because of the use of these substances, individuals’ judgement may be so affected that it can increase the probability of engaging in unsafe sexual behaviour, which may lead to sexually transmitted infections (STIs) like syphilis. This can thus lead to a higher risk of acquiring HIV infection through sexual contact (Ahluwalia & Ahluwalia, 2005:8; Parry, Rehm, Poznyak, & Room, 2009).

- **HIV campaigns**

  Many campaigns that people are exposed to in South Africa as well as in other countries, prove that people tend not to adhere to safe sexual behaviour. This is because people are not interested in hearing more about a disease that they have already heard about (UNAIDS, 2013a).
• Behavioural Factors

High-risk behavioural patterns have been cited as the main contributing factor to the spread of HIV and AIDS in Sub-Saharan Africa. Among these are the traditionally liberal attitudes adopted by many communities to have multiple sexual partners (WHO, 2006). HIV transmission is most likely in the first few weeks after infection and can increase when people have more than one sexual partner in a short time period. It is relatively common in other Black African cultural groups, such as the Zulus, for both men and women to have sexual relations with more than one person, which promotes HIV transmission (Pisane, 2011; Sax, Cohen & Kuritzkes, 2011).

• Migration

Kunene (2000:5) agrees that migration is a contributing factor to the spread of the HIV infection. Some researchers believe that a possible reason is the high number of immigrants coming into South Africa from surrounding countries. For instance, migrant labourers, including men and women, stay away from home for long periods and others engage in sexual activities with sex workers who may be HIV infected and this contributes to HIV transmission. Migrant labourers often return home when they fall ill and continue spreading the HIV virus (SADC, 2006).

• Religious Factors

Pressure from both Christian and Muslim religious leaders has resulted in the banning of a number of safe-sex campaigns, including condom-promoting advertisements; an activity Kenya has banned (Schoof, 2013).

• Regional Prevalence

Patterns of sexual behaviour, including the attitude towards premarital and extra-marital sexual conduct, and female infidelity within marriages are also considered as another important factor that may lead to the spreading of HIV (Ahmad, 2004:36). This includes practices such as multiple sexual partners and unprotected sex.
• Patriarchy

Another factor in South Africa that encourages the transmission of HIV is patriarchy. Patriarchy is defined as the dependency of females on males, which implies that some women do not have the right to make decisions or question the decisions or statements made by their male partners (Marshall, 1998:485). The researcher does not agree with the statement above, because this happens in some cultures and it is not true for all. For instance according to Delius and Glaser (2002:33), in the Pedi culture, which is an ethnic group in Limpopo Province, men often make all the decisions on when and how to have sexual intercourse. As a result, the women involved in this, either are not or were not empowered to suggest safe sex, which would protect both partners from HIV infection (Bujra, 2000:13).

• Socio-Economic Factors

According to Baingana, Thomas and Comblain (2006:7; UNAIDS, 2013b), the AIDS pandemic is worsening in South Africa due to the high rate of poverty. Poor nutrition, insignificant housing, a lack of health care, water and sanitation, together with myths about the cure for HIV and AIDS also encourage the spread of the virus.

The DoH (2007:11) considers the low social status of women as one of the major causes that are contributing to the HIV and AIDS epidemic in South Africa. For example, during the 1940s in South Africa women were excluded from work as lowest strata employees of the working class. The majority of black women worked as domestic or farm workers; they had little power to negotiate about sex and earned very low wages (Bozzoli, 1983:137). In recent years, to make ends meet, unemployed black women often resort to commercial sex work, which makes them susceptible to HIV infection (Delius & Glaser, 2002:44; UNAIDS & WHO, 2013). The nature of their jobs puts their health at risk because they have unsafe sexual intercourse with people whose health status is unknown to them (Gilgen, 2000:134).

In informal settlements, some poverty-stricken black women often have different sexual partners who fulfil their financial needs in exchange for unsafe sex (Hunter, 2002:111; Mah & Halperin, 2010). Since commercial sex workers (CSWs) depend on their clients to
offer them payment, they might lose a client if they for example insist on the use of condoms (Gilgen, 2000:164). Thus, the environment contributes to the fact that these women can become vulnerable enough to choose unhealthy methods to generate income. Rightfully, research in South Africa shows that especially black females are infected with HIV because they are predominantly not financially independent (Shisana & Simbayi, 2002:3-4). Furthermore, trust is another factor that prevents black people from wearing condoms (LeClere-Mandala, 2002:28). In a study conducted in Mandeni in the Kwa-Zulu Natal province, it was discovered that males view the use of condoms as a confirmation of a lack of trust and love (Hunter, 2002:109). Therefore, black male participants were reported to be reluctant to use condoms (Levine & Ross, 2002:109). Both LeClere-Mandala (2002:28) and Hunter (2002:109) found that the rejection of condom usage leaves females in a difficult situation as they eventually engage in unprotected and unsafe sex, which may lead to contracting of HIV.

3.4 THE EFFECT OF HIV AND AIDS ON HUMAN BEINGS AS A DISEASE

The impact of HIV and AIDS cannot be overestimated as this epidemic is on the increase in all parts of the world, particularly in under-developed countries. According to Motsukunyane (2009:14), the situation is getting worse day by day, because HIV infection rates have spiralled out of control in sub-Saharan Africa and the ripple effects will definitely still be felt in the years to come. Globally, there has never been an epidemic that matches the devastating effects that HIV has. This concurs with the study done in 2005 in South Africa, which indicated that the incidences of HIV and AIDS will increase internationally. It is estimated that about 45 million new infections will take place by 2020 (Ahluwalia & Ahluwalia, 2005). It is further stated that the cumulative number of AIDS deaths is expected to rise to a total of 9.31 million by 2020 (Motsukunyane, 2009:46).

Avert Organization (2010) indicated that HIV has caused immense human suffering and death on the African continent. A study by the WHO in 2006 found that AIDS-related illnesses remain the leading cause of death for men aged 25 to 44. In fact, AIDS is regarded as the third major cause of death in the world (Ahluwalia & Ahluwalia, 2005). Even though AIDS-related illnesses is the major cause of deaths in South Africa, the impact is not confined to households, the health sector and workplaces alone; economies have also been badly affected. The impact of HIV and AIDS can be best described in terms of the aspects discussed below.
3.4.1 Effects on Individuals, Families and Communities

The HIV and AIDS epidemic in South Africa started worsening at the end of 2006, and an estimated 5.5 million people out of a population of 47.4 million were found to be HIV positive (Akinboade, 2008:857; UNAIDS & WHO, 2009:32).

The toll of HIV and AIDS on households can be severe. It is often the poorest sectors of society that are most vulnerable. In many cases, AIDS causes the family unit to disintegrate, and as parents die children are sent to relatives for care and upbringing. However, before this disintegration occurs, other things happen since AIDS strips families of their assets and income earners, further impoverishing the poor (UNAIDS, 2003a).

The vulnerability of children with HIV positive infected parents increases long before the deaths of the parents or guardians. Not only are family members lost, but these vulnerable children are also subjected to an increased prevalence of malnutrition, inadequate access to education, inadequate access to health care services (Ssemakuwa, 2006:46). Without sufficient care and support, many children are exposed to exploitative child labour because parents and other family members become ill and children have to take on the responsibility to earn an income, produce food and care for family members. Due to the death of the parents, most orphan children lack support and guidance from family and the community (Ssemakuwa, 2006:46-48), as well as education that is necessary for normal growth and wellbeing later in life. Therefore, under these circumstances, the orphaned children are themselves exposed to being infected with HIV (Ssemakuwa, 2006:46).

3.4.2 Health and Support Services

A number of factors hamper the consistent care and support that HIV positive women need, namely the lack of appropriate medical services (Shinn, 2008). Women who are HIV positive often have trouble sharing the trauma they experience. In particular, the support services available in rural areas are insufficient and sometimes it is not possible for HIV infected women to visit them due to their location.
3.4.3 Effects on Health Sectors

The DoH (2007:10) emphasises the devastating impact HIV and AIDS have on households in South Africa. In fact, the high maternal death rate related to HIV and AIDS in the country has already threatened the achievement of the eight millennium development goals, one of which is the comprehensive care, support and treatment of HIV infected people by 2015.

In an attempt to address both the direct and indirect impact of HIV and AIDS on the health of a nation, as well as the health care system of a nation (UNAIDS, 2004), an initiative was formed to accelerate efforts by heads of state and the government to implement their commitment for the fight against HIV and AIDS, and to mobilise the required national and international resources. This initiative was formed at the Abuja African Union summit on HIV and AIDS in April 2001, when the heads of state of Botswana, Ethiopia, Kenya, Mali, Nigeria, Rwanda, South Africa and Uganda established the AIDS Watch Africa (AWA) advocacy platform. In January 2012, the AWA was revitalised to include all of Africa and its objectives were broadened to include malaria and tuberculosis (Setswe & Zuma, 2013; UNAIDS, 2004).

3.4.4 Effects of HIV and AIDS on the Economy and the Workplace

The AIDS pandemic in Southern Africa is not only a major public health crisis, but also a threat to the economic development of the country (Natrrass, 2004:13). One of the impacts of HIV and AIDS is the premature deaths of parents of young children, resulting in orphanhood (UNAIDS, 2012a).

It is important to remember that the people who are dying of HIV and AIDS are not only parents, but are for the most part also consumers, workers and taxpayers. In 2013, AIDS killed almost 1, 34 million people worldwide while nearly 35.3 million became infected, bringing the number to 39.5 million people living with the virus. Almost 25 million of these people live in Sub-Saharan Africa (UNAIDS, 2013a). Their passing not only presents the state with a bill for medical expenses and another one for child maintenance, but it deprives the state of a source of revenue to meet these costs. Often when family members get sick with HIV or other related illnesses, family members end up selling most of their belongings in order to provide health care for the sick individual (Shinn, 2008). For this reason in the 1980s the United Kingdom (UK) and USA warned employers about the expenditure they would have to face if employees became ill.
because of HIV (Adkins, 2002:3). Since then, research has been conducted with the specific aim of identifying the employee strata most vulnerable to HIV infection and prevalence. In a study in South Africa conducted by Maleka (2006) during the period 2000-2001, it was found that HIV prevalence among skilled workers (technicians managers and engineers) was 6.7% and 17.7% amongst semi-skilled workers (car assemblers, truck drivers and mineworkers) (Maleka, 2006:1). Although the author did not indicate which racial group comprised semiskilled employees, the majority of this strata are black males who “are relegated to the lowest strata” of workplaces (Evian, 2004:129).

When the lowest strata employees are infected with HIV, workplaces in SA are less able to compete with their global competitors (USAID, 2001:37). This was also noted in Abidjan in the Ivory Coast during 1999, where production targets were lost through fatigued lowest strata employees being forced to work long hours, as HIV-infected employees were either on sick leave or unable to cope with their daily tasks (Aventin & Huard, 1999:5).

According to UNAIDS and the WHO, HIV predominantly infects people between the age of 15 and 49, who should form part of a workforce in a country (UNAIDS & WHO, 2013:3).

The following table summarises the effects that HIV and AIDS may have on the workplace. The following table also shows how HIV progresses from the initial stage to the next impacting on the workplace.
Table 3.2: Progression of AIDS in the workplace

<table>
<thead>
<tr>
<th>Progression of HIV/AIDS in the workplace</th>
<th>Economic impact on individual person</th>
<th>Economic impact on workplace</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employee becomes infected with HIV</td>
<td>No costs to company at this stage</td>
<td>No costs to company at this stage</td>
</tr>
</tbody>
</table>
| HIV/AIDS-related morbidity begins       | • Sick leave and other absenteeism increase  
• Work performance decline due to employee’s illness  
• Overtime and contractor’s wages increase to compensate for absenteeism  
• Use of company’s on-site health clinic increases  
• Pay outs from medical aid schemes increase  
• Employee requires attention of human resources and employee assistance personnel | • Overall productivity of workforce declines  
• Overall labour costs increase  
• Additional use of medical aid benefits causes premiums to increase  
• Additional medical staff may need to be hired at the company  
• Managers begin to spend time and resources on HIV/AIDS related issues  
• HIV/AIDS interventions are designed and implemented |
| Employee leaves workforce due to death, medical boarding, or voluntary resignation | • Pay outs from death benefit or life insurance scheme is claimed  
• Pension benefits are claimed by employee or dependants  
• Other employees are absent to attend funeral  
• Funeral expenses  
• Company loans to employee are not repaid | • Pay outs from pension fund cause employer and/or employee contributions to increase  
• Returns on investment in training are reduced  
• Morale, discipline, and concentration of other employees are disrupted by frequent deaths of colleagues |
Co-workers are demoralised by loss of a colleague

Company recruits a replacement employee
- Company incurs recruitment costs
- Position is vacant until new employee is hired
- Cost of overtime wages increases to compensate for vacant positions
- Additional recruiting staff and resources must be brought in
- Wages for employees increase as labour markets respond to the loss of workers

Company trains the new employee
- Company incurs the cost of pre-employment training
- Company incurs the costs of in-service training to bring new employee up to level of old one
- Salary is paid to employee during training
- Additional training staff and resources must be brought in

New employee joins the workforce
- Performance is low while new employee comes up to speed
- Other employees spend time providing on-the-job training
- There is an overall reduction in the experience, skill, institutional memory and performance of the workforce
- Work unit productivity is disrupted as labour turnover rates increase

(Source: UNAIDS, 2003b; ILO, 2010).

As indicated in Table 3.2 above, the impact of the progression of HIV in the workplace, how it influences individual wellbeing and work productivity.

The elements mentioned above in Table 3.2 are by no means far-reaching, but they are aimed at emphasising some of the major effects that countries will experience as a result of the growing AIDS epidemic. As a developing country, South Africa is not immune to these effects.
Recent reports in the financial publications have indicated that South Africa specifically is losing millions of capital in productivity every year due to employees who are always sick as a result of HIV related diseases (USAID, 2001:37). In light of the increasing infections each year, this situation is not about to get better.

As mentioned earlier literature indicates that of the adults who AIDS will affect, over 90% will be between the key productive ages of 20 and 50 years (Motsukunyane, 2009:56; UNAIDS & WHO 2004:3).

Absenteeism due to HIV is the main cost that organisations will have to deal with, as there have been an increasing number of employees infected with the virus. Costs emanating from factors such as funeral attendance and burials should not be incurred by organisations, but in reality they are and they also contribute to decreasing productivity levels due to shortage of staff (Motsukunyane, 2009:60).

How HIV is viewed in the workplace can be looked at from the employees and employers’ viewpoints; in some areas their needs overlap and in others they diverge. Thus a case in point would be the employees’ need for medical care, sick leave benefits, death in service, and pension benefits, while employers will be concerned about decreased productivity, increased medical costs, and the need to limit expenditure. As a result of this, organisations and employees are faced with serious risks because of the increased impact of the epidemic within the workplace.

Employers are faced with particularly hard challenges because HIV and AIDS do not only cause illness, disability and death for employees and severe economic and emotional disruption for their families, but it also increases the cost of doing business (Motsukunyane, 2009:58-59). According to UNAIDS (2012a), for employers and managers in sectors with high HIV and AIDS prevalence, the following risks can be expected:

- Increased absenteeism due to ill health, looking after relatives and attending funerals.
- Increased deaths among the workforce at all levels.
- Increasing costs of occupational benefits such as sick leave and compassionate leave, life insurance and health care.
• Higher costs of recruitment, training and retraining as a result of reduced investment in human resources.
• Higher staff turnover, loss of skills, experience and institutional memory.
• Lowered morale, reduced efficiency and output.
• Increased strain on personnel staff

To understand the full effect of HIV and AIDS on the workplace, the following table can highlight certain important aspects in this regard.
Increased costs

HIV/AIDS in the workplace

Increased absenteeism
Increased staff turnover
Loss of skills
Loss of tacit knowledge
Declining morale

Insurance cover
Retirement funds
Health and safety
Medical assistance
Testing and counselling

Increased demands for and recruitment

HIV/AIDS in the community
Declining markets, labour pool and supplies

Funeral costs

INCREASED COSTS
Declining re-investment
Declining reliability
DECLINING PRODUCTIVITY

DECLINING PROFITS

DECLINING PROFITS
Figure 3.2 indicates that the economic impact of HIV and AIDS on organisations is tremendous. It is estimated that in the next 10 years, HIV will be the single biggest challenge, facing organisations in South Africa (Motsukunyane, 2009:58-59). Apart from the anticipated direct costs to be incurred by organisations, there are also indirect costs that will heavily burden organisations. Indirect costs such as absenteeism, morbidity on the job, and drainage of management resources, will also have an adverse effect on how organisations function. Production costs will also increase because of the higher costs of group life insurance, pensions and medical aids (Barker, 2002).

The insurance industry is said to be the one industry that will feel the effects of the epidemic. Insurance companies are increasingly exposed to liabilities on existing policies and as such, insurers are forced to increase premiums. This invariably has an adverse effect on the economy as it means less disposable income to insurance holders and consequently less expenditure (Barker, 2002). It is estimated that with the labour force continuing to grow, job creation will become an imperative in this country. AIDS will result in an increase in mortality in the 25-40 year age group and this will negatively affect the dependency ratio as it will result in a large number of orphans and the elderly will lose their adult children and thus their support structure (Bock & Johnson, 2008:2). Poverty will also have a significant impact on communities. Many households will face financial difficulty as income earners fall ill and die and household incomes are diverted to care for PLWH and those with AIDS.

### 3.4.5 Malnutrition amongst People Living with HIV and their Affected Families

Malnutrition is a state in which a deficiency, excess or imbalance of energy, protein and other nutrients causes adverse effects on body form, function and clinical outcome (Ahmed & Haboubi, 2010:208; Valentini & Schulzke, 2011:13). Faber and Wenhold (2007:393) and Vorster (2010:240) have indicated that South Africa has a quadruple burden of disease. This means that malnutrition, linked with underdevelopment and chronic diseases related to unhealthy lifestyles, as well as HIV and AIDS are prevalent.

Globally the HIV epidemic continues to have a devastating impact on health, nutrition, food security and overall socio-economic development in the countries that have been affected by the disease. Nutrition plays an important role in the holistic care, support and treatment of HIV infected people (Ahmed & Haboubi, 2010:208; Valentini & Schulzke, 2011:13). There is
supported evidence that specific nutritional deficiency, such as Vitamin A, may accelerate disease progression and speed up the onset of AIDS and death, because this will reduce the body’s ability to fight the infection. For instance, the lack of Vitamin A may cause the problem of cervical cancer in women and genital ulcers in men who are living with HIV and those with AIDS.

Nutrition and immunity in HIV positive individuals interact in two ways, therefore the relationship between malnutrition and HIV and AIDS is more complicated and results in a vicious cycle of immune dysfunction and infectious and opportunistic diseases, such as tuberculosis (TB), diarrhoea, herpes simplex and malnutrition (Piwoz & Preble, 2002; Fawzi, 2003), as shown in Figure 3.3.

Figure 3.3 illustrates the summary of the causes of malnutrition as discussed, as it shows the relationship between malnutrition amongst people living with HIV and their affected families.

**Figure 3.3: The cycle of nutrition and HIV and AIDS**

(Source: Food and Agriculture Organization of the United Nations & WHO, 2002:5; Faber & Wenhold, 2007:393)
The anti-retrovirals (ARVs) increase the appetite of HIV infected individuals, and result in other members of the household having to consume less food, thereby worsening an already difficult situation.

Women and girls from households in which food insecurity is prevalent, become more vulnerable to infection. They often engage in illicit sexual activities to generate money to purchase food for household members (Population Council, 2007; UNICEF, 2013). According to Mochadibane (2013), women living with HIV, need to maintain their health and it is necessary to prevent re-infection with HIV as it increases the viral load and could therefore further weaken an HIV infected person’s immune system.

3.4.6 Psychosocial Stress and Trauma of Parents living with HIV and their Children

The diagnosis and disclosure of HIV status itself, is a major source of stress for any person. The prospect of death is an emotional, psychological and social trauma to the individual and the family, and the thought of leaving orphans behind with no one responsible for their wellbeing leads to severe depression, especially when both parents are terminally ill (Day, 2003:668). In a study done by Maleka (2006:12), one fearful miner indicated "you think about death, have no plans for the future and everything comes to a stop" (Day, 2003:668). The study also found that the fear of knowing your HIV positive results brought feelings of hopelessness, as there is no cure for HIV and AIDS (Day,2003:668).

In their study, Enriquez, Lackey and Witt (2008:40) refer to depression as the continuous emotional battle in the minds of women living with HIV. This concurs with a study carried out in South Africa by Thompson (2011:64), which focuses on the healthy literacy needs of women living with HIV and AIDS and their wellness clinic attendance. Thompson (2011:64) mentions that the participants explained that HIV and AIDS is a disease of the whole body which affects every aspect of a person, including the mind. They indicate that it is important to maintain a healthy frame of mind to manage HIV effectively. In the same study, one of the participants explained the adverse psychological impact that a negative attitude can have on a person living with HIV and those with AIDS. "And we must stop complaining that ‘I will die soon and leave my children behind’ because the more you complain, the earlier you will die".
Another result of this study indicated that a lowered self-esteem has a negative impact on the psychological health of a woman living with HIV and those with AIDS. This supports the significance of addressing the psychological health and wellbeing of women living with HIV and those with AIDS. Thompson (2011:64) as well as Van Dyk (2011:7), found a positive relationship between the perceived body image and weight changes, and the quality of life of a person living with HIV and those with AIDS.

A lack of commitment by other family members, the refusal to perform some care-giving activities, such as mouth cleaning, dressing of wounds and administering injections, and the fear of contracting the infection, lead to severe stress for the individuals who are infected with HIV.

3.4.7 The Effects of HIV and AIDS on the Elderly as Caregivers of the Orphans

According to Statistics South Africa (2011) and UNAIDS (2012b), the total number of people living with HIV in South Africa is estimated at 6,4 million, which creates a severe problem for elderly people, as they are left with no or little resources to care for their grandchildren, and this may also have a negative effect on their health.

An estimation was made during 2015 that some 5 700 000 children under the age of 18 years would have lost at least one parent or both parents to AIDS, while some 3100 000 children under 18 years would be maternal orphans and 4700 000 would be paternal orphans, according to the Medical Research Council in 2002 (UNAIDS, UNICEF & USAID 2004:1). Nearly 80% live in sub-Saharan Africa (UNAIDS, 2013a) whilst 3 million were in South Africa (Shisana et al., 2009). Most of these children are being taken care of by extended families and communities. As these families were already very poor, they were placed in even greater need of external support. In addition to orphaned children, the HIV and AIDS epidemics is viewed as one of the major challenges that threatens the development of children and the realisation of children’s rights in South Africa (Department of Social Development, 2013; UNICEF 2007). The African perspective on health care was linked to the family, which provides most of the care for its sick and elderly population. Because of the HIV and AIDS pandemic, taking care of family members as a family system changed dramatically. Many elderly people are now the ones who have to take care of their sick adults and children and at the same time have to raise their orphaned grandchildren (StatisticsSA, 2011).
In South Africa, the extended families and elderly grandparents are caring for orphaned children. Cluver and Gardner (2007) highlight that AIDS orphans are exposed to multiple stressors, which compound and complicate the negative impact of HIV and AIDS.

By 2020 an estimated 2.3 million children in South Africa will be orphaned; 19% are already affected, and most of them showed a higher level of psychological problems due to the AIDS-related deaths of family members (Cluver et al., 2008:414; UNAIDS 2012a).

The worst effects are seen in deeply impoverished households, due to the illness and death of breadwinners and working adults. HIV and AIDS-affected orphans lose not only their parents, but also their families, as they are separated from caregivers and siblings or siblings are sent to stay with other relatives or carers. They also lose their social networks, due to the fact that they may become separated from their childhood friends (UNAIDS, 2012a).

Orphans are considered to be at risk of HIV because of their vulnerability. They are at risk of being forced into sex or have sex in exchange for support or even to become sexually active earlier than their peers (Population Council, 2007).

Therefore, elderly people are now playing a key role in the upbringing of children – the future workforce. They also find themselves providing physical, emotional and social support to their ill children, and hence have less time to engage in income-generating opportunities to sustain their living (Tavengwa-Nhongo, 2004). A recent study conducted in Thailand, Zimbabwe and Uganda found that over two-thirds of elderly participants were the main caregivers of ill adults or orphans whose parents had died of AIDS (Knodel & Zimmer, 2007:13; UNICEF, 2007).

3.5 PROCESS OF DISCLOSURE

HIV infected individuals often experience difficulty in telling others about their HIV positive status. A number of studies conducted on the disclosure process indicated that many factors influence this process (Mucheto et al., 2009). Some of these factors are:

- permanency of close and unfamiliar relationships
- fear for abandonment
- discrimination
- social factors (support)
• illness severity and the length of time since diagnosis
• age
• socio-economic status
• level of education
• marital status
• social relations
• knowledge

Mucheto et al. (2009) found in their research that young people with a low socio-economic status, as well as a low education level, are less likely to disclose their HIV status. People living with HIV disclose their status to family and relatives rather than to their friends, and to long-term partners rather than to casual partners (Obermeyer, Baijal & Pegurri, 2011:1011-1023). Serovich (2000:823-832) found that PLWH found more comfort in disclosing their HIV positive status to their mothers as a way of receiving emotional support and care.

Hult, Wrubel, Branstrom, Acree and Moskowitz (2012:181-190) indicate that although there is no clear indication regarding the response on the disclosure of one’s HIV status, the positive reactions to disclosure “outweigh” the negative ones. Negative responses mostly include rejection, abuse, violence, stigma and discrimination, while positive responses include more quality social support, stronger family cohesion and relationships, a decrease in anxiety and depression, and the improvements in physical health.

Many factors are necessary to include when discussing the disclosure of a person’s HIV positive status. These factors will be discussed in detail to indicate the way these multiple factors interact with each other and how they may lead to the disclosure of the HIV status of a person.

The following figure indicates the multiple factors that may influence the disclosure of a person’s HIV positive status.
3.5.1 Discrimination, Stigma and Rejection

The disclosure of an HIV positive status is a complex, difficult and very personal matter that entails communication about a potentially life-threatening, stigmatised and transmissible illness to someone (Chaudoir, Fisher & Simoni, 2011:1618-29). Disclosure of an HIV positive status can be an extremely difficult process because it makes one vulnerable to the perceived stigma of friends, family and/or the community (Paxton, 2002). The stigma and discrimination
associated with HIV makes it difficult for PLWH to be identified, to be open about their status, and/or to disclose their HIV positive status (Rohleder & Gibson, 2005; UNAIDS, 2013a).

HIV-related stigma has been documented as a barrier to health care and social support by several studies on the disclosure of HIV status (Norman, Chopra & Kadiyala, 2007). Non-disclosure may lead to non-adherence as a way to conceal the disease from others (Arnold, Rice, Flannery & Rotheram-Borus, 2008:80-92), as well as disadvantaging the people from receiving the care and support they need when living with HIV and those with AIDS (Sebitloane & Mhlanga, 2008:492). A factor that could prevent people living with HIV from disclosing their HIV status, as compared to other chronic illnesses such as cancer, is fear of being stigmatised and discriminated against (Fesko, 2001:3). Though mass media awareness campaigns have been effective in increasing people’s awareness and knowledge of HIV in South Africa, some of the initial campaigns revealed AIDS as devastating. According to the WHO (2008a:12), the main obstruction in disclosure is fear of rejection and discrimination by family, friends, and in the community and workplace.

In a study conducted by Thompson (2011:86) in South Africa on the health literacy needs of women living with HIV and those with AIDS who attend the wellness clinic at the Jubilee Hospital in Hammanskraal, one participant recounted her experience of rejection and discrimination when she was chased from her home by her mother after disclosing her HIV positive status. The participant mentioned that wanting to save relationships with their families is the reason people diagnosed with HIV do not disclose their status. Furthermore, according to Obermeyer et al. (2011:1011-23), disclosure can lead to disrupted relationships with families and communities, rejection by close friends and close ties, separation from partners, abuse, criticism and isolation.

Similarly, in a study conducted by Core-Felton, Koopman, Power, Israelski, Duran & Porter (2008:83-98) the authors agree that cultural norms specific to different communities, may dictate different responsibilities towards disclosure. For example, in their studies with the Asian communities they cited that the norm of collectivism dictates that disclosure of one’s HIV-status affects not only the individual but also their families. Therefore, the road of non-disclosure could be taken as a way to avoid embarrassing the entire family and the community.
HIV-infected parents face the problem of when and how to disclose their own HIV status to their family members and children and often fear that when disclosed, children will feel stigmatised by their mother’s illness (Madiba 2013:50; Qiao, Li & Stanton, 2013). Although health care officials often encourage parents diagnosed with HIV to disclose their HIV status to their families and children, many parents delay this because they fear negative consequences. Parents are concerned that the psychological burden of shock, fear and stigma will be more than family members, especially children, can handle. Indeed, parents believe that they are protecting their children by not disclosing their HIV status (Madiba, 2013:50). Mothers fear that others will reject their children or family if their HIV status is known (Hazard Vallerand, Hough, Pittglio and Marvicsin, 2005).

PLWH and those with AIDS and their families are often subjected to social isolation (Mochadibane, 2013). The author mentions that other employers do reject PLWH and those with AIDS. Mochadibane (2013) mentions that women who are living with HIV and those with AIDS rather prefer and often opt not to disclose their HIV status in their workplace, as they believe that they may be discriminated against. They further believe that they do not need to disclose their status, as they do not endanger their fellow colleagues. Studies show that employees or people who have feelings of rejection and humiliation might not tell their co-workers or families of their HIV-infected status, and could continue breastfeeding babies and engaging in unprotected sexual intercourse (Parker & Aggleton, 2002:4).

The WHO (2008a:39) warns that stigma and discrimination undermine the human rights of PLWH and those with AIDS. People infected with the disease are still stigmatised and marginalised from their communities and societies as a whole (Heartbeat, 2002:1).

In a study done by the International Labour Office (ILO, 2010:3), it was found that people with HIV and those with AIDS and their families often face hostility and ostracism rather than support. According to Grodeck (2003:188), discrimination happens all the time to people living with HIV as other members of the community do not want to be in contact with PLWH and those with AIDS (Caribbean Food and Nutrition Institute, 2002:63-71). Within a social climate where HIV positive people are stigmatised, women are not prepared to disclose their HIV status (Moore, 2009) as they fear to be identified as HIV positive, which may lead to malicious gossip in their communities (Gilbert & Walker, 2010). Therefore, fear of rejection and social discrimination force women to try and conceal their HIV status.
In Africa, different human rights violations have been reported as having been perpetrated on HIV-positive women and these include sexual abuse and coercion, discrimination in terms of access to health information, discrimination in property inheritance, rape and labour exploitation (ILO, 2010:3). For a prominent example of such a story, the researcher refers to Mpho Motloung, who was murdered by her husband, after which he placed a sign on her grave that read “HIV-positive AIDS” (Skinner & Mfecane, 2015).

3.5.2 Beliefs

Grodeck (2003:66) mentions that there are different reasons for the disclosure of one’s HIV status, which will differ from one person to the other. This may include:

- the right for others to know;
- the need for emotional support from others and access to medical resources or services;
- the need for intimacy; and
- Integrity.

On an individual level, people living with HIV and those with AIDS tend to conceal their stigmatised identities as far as possible to sustain the rewards of a normal identity, especially in a society with a high HIV prevalence. Such rewards may include:

- sexual freedom;
- avoidance of discrimination;
- avoidance of family or community rejection;
- prevention of the loss of sexual partner; and
- Avoidance of emotional, social and physical isolation and avoidance of being blamed for others’ illness (Niekirk & Kopelman, 2005).

Not only is disclosure important for the HIV positive individual, but also for those around them. For instance, children who are unaware of their mother’s HIV status can often perceive something is wrong and thus become distressed when they are unable to express their feelings (Kennedy, Cowgill, Bogart, Corona, Ryan, Murphy, Nguyen & Schuster, 2010:1095-105; Murphy, Armistead, Marelich, Payne, Herbeck, 2011:203-14).
3.5.3 Cultural Beliefs

The cultural beliefs of different societies shed a different light on the right way of truthful disclosure. In a study conducted in Tanzania by Braddock (2008), it was found that according to the traditional beliefs of the Navajo tribe and other cultures, speaking about the treatment of HIV is unacceptable and tantamount to inviting problems. These types of belief systems could cause people to withhold truthful information about their HIV status, as they would be in fear of inviting negative and harmful effects into their lives (Braddock, 2008). According to Mbonu, Bome and De Vries (2006:3), some societies still associate specific indicators with the HIV and AIDS disease. Thus if infected persons do not show any signs commonly linked with HIV and AIDS, such as weight loss, the community may not believe that they are infected with the disease. Other societies associate HIV with witchcraft, which would also discourage disclosure. This concurs with a study done in Zimbabwe (Duffy, 2005) which reveals that traditional healers often tell people that HIV is not a virus, but bad luck caused by unhappy spirits. Therefore, a diagnosis of unhappy ancestors or bewitching leads to non-disclosure by the infected person regarding his/her HIV positive status. In addition to the above discussion, parents must cope not only with their physical problems, but also with their religious beliefs, which is considered a cultural aspect that plays an important role in the disclosure of parents’ HIV status. For instance, religion shapes an individual’s outlook on living with HIV and it is also used as a coping mechanism by PLWH and those with AIDS, as it provides a sense of hope and peace through prayers and faith in God (Mbonu et al., 2006; Zou, Tamanaka, John, Watt, Ostermann & Thielman, 2009). Lugalla, Yoder, Sigalla and Mahidi (2011) argue that this factor also makes it difficult for PLWH and those with Aids to disclose their HIV status.

3.5.4 Physical Violence

Women are often the primary caregivers in families and remain central in maintaining the relationships that hold the family unit together. Despite a world-renowned constitution and legislative overhaul that supposedly safeguards women’s rights, South Africa still has high levels of violence against women (UNICEF, 2009). Kaminer and Eagle’ (2010:17) reported in 2002 that the Western Cape presented the highest rates of gender-based violence in South Africa. In the case of physically abusive relationships, the disclosure of a woman’s HIV status to her violent partner can often increase the likelihood of him using physical and/or sexual violence against her. According to the Health Canada (1998) report entitled HIV and Sexual Violence
against Women, women living with HIV face additional fear and threat of rejection or emotional, physical and/or sexual violence from men who are closest to them, including husbands, lovers, family members and co-workers. Mochadibane (2013) mentions that often, society treats women as the carriers of the disease and the HIV positive women may feel they have no right to be functioning beings. As a result, other family members and the community remain the decision-makers on behalf of these women for their health, emotional well-being and life choices (family planning), as well as when to start treatment.

3.5.5 How to Disclose an HIV Positive Status

This concept refers to the knowledge that parents need to have to disclose their HIV positive status. In many situations parents take a lot of time to disclose of their HIV status to children or avoid disclosure altogether, because some believe that they do not know how to disclose this information or how much information they should disclose (Kennedy et al., 2010). Rwemisisi, Wolff, Coutinho, Grosskurth and Whitworth (2008) previously reported similar findings, namely that Ugandan parents often delay testing and disclosure of their HIV positive status to their children, not because of a lack of willingness or concern, but because of a lack of skills and guidance about how to approach such a sensitive topic. Parents may be hesitant to disclose their HIV status to their children because they do not know how to bring up the discussion on the issue of the HIV transmission, more especially because sex and sexuality are not topics that parents often discuss with their children in Sub-Saharan Africa (Moore, Kalanzi & Amey, 2008). According to Ostrom, Serovich, Lim and Mason (2006), explaining to children about the mode of infection, especially in these situations where mothers were infected through heterosexual HIV transmission, can be very difficult. In an effort to avoid such situations, mothers may decide to conceal their HIV positive status.

3.5.6 Gender Relations

There is currently a debate on whether disclosure differs due to gender, especially because the gender of the child has been shown to influence a mother’s disclosure. A number of studies which investigated this phenomenon suggest that daughters are more likely to be informed of their parent’s HIV status than their male siblings (Tompkins, 2007). The literature further shows that not only is disclosure made to female children more often than to male children, but female children are the targets of earlier disclosures. Mothers may discuss their health status more
thoroughly with daughters than with sons, and give more detailed information to female children (Lee & Rotheram-Borus, 2002). Researchers have hypothesised that this pattern may be driven by an expectation that girls assume household responsibilities as mothers become unable to do so due to ill health (Armistead, Tannenbaum, Forehand, Morse & Morse, 2001).

3.5.7 Attitude towards disclosure

Many HIV infected persons have negative attitudes towards disclosure of their HIV status because they fear that the community will discover their HIV status. A study in Nigeria about the attitudes of patients on the disclosure of their HIV sero-positive status revealed that people living with HIV fear the negative outcomes of disclosure and rejection due to stigma, discrimination, social withdrawal and being disgraced by their families (Denue, Jacks, Bello, Akawu, Hussaini & Adebayo, 2012:32). Similarly, in another study Zou et al. (2009:8) highlight that religious beliefs on HIV help to shape attitudes towards HIV status disclosure. This includes religious teachings, which inform people that HIV and AIDS is a punishment from God and makes an individual feel guilty, hence it increases the likelihood of non-disclosure for fear of being blamed for unfaithfulness and adultery.

3.6 CONCLUSION

In this chapter, the researcher has discussed the effects of HIV and AIDS as a disease on human beings. The nature, historical background and origins of HIV as well as the way the disease progresses from HIV to AIDS over years, was also highlighted. Furthermore, this chapter focuses also on the way how HIV is transmitted, how secondary factors encourage the spread of HIV, how HIV and AIDS affect human beings as a disease, the process of disclosure as well as the multiple factors that may influence the disclosure of a person’s HIV positive status.

The research methodology will be discussed in the next chapter.
CHAPTER 4

THE EMPIRICAL PROCESS

4.1 INTRODUCTION

Chapter 3 provided a detailed picture of the effects of HIV and AIDS on human beings. Amongst the issues discussed, were the disclosure process and multiple factors that may influence this process. In this chapter the research methods that have been utilized for this study, will be discussed in detail as well as the empirical process which was based on the goal and the objectives of the study.

4.2 RESEARCH APPROACH

By nature, the topic of this study necessitated the use of applied research. While working in the field of HIV and AIDS as a social worker, the researcher observed that stigma and discrimination, amongst other things, associated with HIV and AIDS make it difficult for single mothers living with HIV and AIDS to disclose their HIV status, as they often experience feelings of rejection and blame, together with the fear of death. While working at the Department of Social Development, as well as at NGOs, the researcher also observed that little research has been carried out on the care of patients or preventative work regarding the impact of HIV and AIDS on households, specifically in the South African context. Moreover, little has been published on the challenges single mothers specifically experience with regard to the disclosure of their HIV status. In light of this information, the researcher wished to explore these various experiences in order to determine which intervention and counselling services are needed most to support these mothers, as well as the professionals who are working in the field of HIV and AIDS, to assist them in becoming aware of the challenges that single mothers experience regarding the disclosure of their HIV status.

In order to gain a comprehensive understanding of the single mothers’ experiences regarding the disclosure of their HIV status, the individual voices of single mothers had to be explored and this could be achieved by asking them in person to elaborate on their personal experiences regarding the disclosure of their HIV status.
The primary goal of the qualitative study is to describe and understand, rather than explain human behaviour (Babbie & Mouton, 2012:270). Another goal of qualitative is to explore an area where very little is known about experiences of HIV positive single mothers. The researcher sought to achieve both goals and thus opted for to combine two types of qualitative research methods; the descriptive and the exploratory. Qualitative methods provide richer detail for exploring viewpoints which allow the researcher to gain a better initial understanding of issues. The subjects were analysed as individuals and as a group of HIV positive single mothers. The case study design was deemed appropriate for this study. The rationale for its use was based on the fact that this design uses multiple cases to explore current, real-life issues in order to arrive at a detailed and comprehensive understanding of the phenomenon under study (Creswell, 2013:97-98; Fouché & Schurink, 2011:321; Neuman, 2011:42).

4.3 RESEARCH TYPE

The goal of the research is not to determine the quantity of challenges that single mothers experience regarding the disclosure of their HIV status, but rather the specific challenges that single mothers experience regarding the disclosure of their HIV status, which makes a qualitative approach more important.

4.4 RESEARCH DESIGN

According to Leedy and Ormrod (2013:76), a research design refers to a strategy for solving a research problem. A research design provides the researcher with direction regarding what procedure to follow, the data to be collected, and the data analysis is to be conducted. On the other hand, Creswell (2009:54) agrees that a research design refers to a plan for selecting subjects, research sites, and data collection procedures to answer the research question. The selection of a research design for a study depends on which individuals will be studied, where, when and under which circumstances they will be studied, the nature of the study, and what needs to be achieved. Furthermore, it is a game plan that the researcher spells out in detail before data collection commences and ensures that the evidence obtained enables the researcher to answer the initial question as unambiguously as possible (Gray, Williamson, Karp & Dalphin, 2007:358). This study focused on individual experiences rather than on processes, activities or events (Fouché & Schurink, 2011:321). A qualitative design is the use of narratives to represent the findings of a study. The research design indicates the plan of action; the road
map towards accomplishing the aims and the objectives of the study. The qualitative research design was deemed appropriate for this study based on reasons stipulated in the research approach (see 4.2 paragraph 2).

4.4.1 Study Population

According to Strydom (2011b:228) a population is defined as the totality of persons...with which the research question is concerned, meaning, where will data be obtained and secondly how will it be obtained. Since it is almost impossible, as submitted by Maxfield and Babbie (2005: 107), to study all members of the population that interest us, the population consisted of 10 single mothers employed by the Vaal University of Technology (VUT), who were diagnosed with HIV and had referred themselves to the office of the Staff Wellness to receive emotional support, were studied. Since it would be impossible to study all staff members who attended the VUT Wellness Section the researcher had to study a sample. The sample is chosen from the population and is used to represent the population (Moleko, 2012:43; Strydom and Delport, 2011: 390; Unrau, Gabor & Grnnel in Strydom, 2011b:228). Unfortunately nine single mothers presented themselves at the Staff Wellness Section; due to limited number that population had to be used as sample of the study. In essence in this study no specific sampling strategy nor a specific sampling method was used by the researcher. The whole population was used with the following characteristics:

- single mothers who are employees of the Vaal University of Technology;
- single mothers who are diagnosed with HIV; and
- single mothers who voluntarily came to the office of the Staff Wellness of University of Technology and disclosed their HIV status to receive emotional support.

4.5 DATA COLLECTION

Single mothers who are HIV positive were identified as sources of data for this study. The researcher opted for semi-structured interviews as the most appropriate data collection method which was also supported by a semi-structured interview schedule.

4.5.1 Interview
Leedy & Ormrod (2013:155) state that one way to find out about a phenomenon, is to question the people who are involved in it in some particular way. Interviewing involves asking another person or people questions with the aim of gathering information from them. The respondent is able to provide information in their own way and the interviewer is able to glean rich and potentially useful information in this way. As with all methods, interviews have both advantages and disadvantages. The researcher’s choice of an interview was made on the basis that interviews eliminate unknown answers and give the researcher an opportunity to probe for more answers. The above statement is in agreement with Hofstee’s (2006:122) statement namely that events cannot be understood unless one understands how these events are understood and interpreted by people who participate in them. One of the disadvantages of interviews is that interviewers may motivate respondents to provide socially ‘desirable’ or ‘expected’ answers (Berends & Zottola, 2009:93). The researcher tried to avoid this shortfall by being neutral. According to Greeff (2011:342), there are many types of interviews, ranging from highly structured, formal interviews to informal conversations. Out of these, Leedy & Ormrod (2013:153) indicates that the researcher may choose one suitable for the study, as they allow for probing and collecting in-depth data.

As indicated already, the researcher required detailed accounts of single mothers about their experiences regarding the disclosure of their HIV status. Of the existing types of interview, a one-on-one interview method was chosen as it allows for the individual meaning and understanding of each individual to be brought to the fore (Creswell, 2013:173; Greeff, 2011:342) and, as Greeff (2011:351-352) mentions, it allows the researcher to explore the participant’s views, opinions, attitudes and beliefs about certain events and phenomena. One-on-one interviews have the important advantage of allowing the researcher to build a relationship with potential participants and, as a result, gain their cooperation through the establishment of a rapport (Leedy & Ormrod, 2013:196).

The themes of the interview schedule were as follows:

- Factors that may hinder the participants from disclosing their HIV status in the workplace.
- Factors that may hinder the participants from disclosing their HIV status in the family.
- Factors that may hinder the participants from disclosing their HIV status in the community.
- The way different factors affect participant’s social functioning and quality of life.
- Factors that may support the participants to disclose their HIV status in the workplace, family and community.
Originally the researcher planned to interview 10 single mothers for this study. However, only nine participants were interviewed as the other participant withdrew at the last stage. The discussions were conducted in the communal language, namely Sesotho and Setswana, to facilitate better understanding during the process.

The interview process was facilitated by means of Seidman’s (1998:11) guidelines in an attempt to ensure informative interviews. Seidman (1998:11) suggests five guidelines to facilitating the process namely:

- Ask clear, brief and easy to understand questions.
- Let the participants do most of the talking when answering the questions, with few interruptions.
- Ask one question at a time to avoid confusion.
- Avoid sensitive questions.
- Repeat the key questions throughout the interview.

To ensure trustworthiness during the study, the researcher checked the accuracy of the responses which were received from the interviewees on the spot by paraphrasing questions and probing when clarity was needed. This ensured a “depth, detailed and rich” interrogation of issues or experiences of single mothers regarding the disclosure of their HIV status (Rubin & Rubin, 2005:129). At the conclusion of each interview, a review of the key points of the discussion was given to provide a sense of completion and allow each individual participant to clarify and correct as required.

Richards and Morse (2007: 109) agree that the quality of data is influenced by the cooperation between the researcher and the participants during data collection. Despite the apparent casual, friendly and conversational style of qualitative interviews, preparation is important to ensure successful data collection (Polit & Beck, 2008:399). The individual interviews were conducted from 13 to 17 July 2015. Before commencement of interviews, the purpose of the study, the objectives and interview process were once again explained to the individual single mothers in Setswana or Sesotho- depending on their preferred language and the researcher obtained written consent from each of the individual single mothers before they were interviewed (refer to Appendix E). It was decided beforehand that the interviewing process would be stopped if the participants became uncomfortable or emotional; such interruptions occurred with only one
participant who was then referred for debriefing to the Campus Health Promoter. The interview room was prepared in advance which was situated within the Human Resources Department. The researcher ensured that the door could close properly to ensure privacy and limit external noise. Two comfortable chairs were placed facing each other at a comfortable position. Permission was also requested from participants to record the interviews by using a tape recorder, as advised by Bryman (2012:314). Refer to (Appendix E). The use of the tape recorder made it possible for the researcher to reflect on what the participants actually said and to think more deeply about their responses. As soon as possible after each interview has been terminated, the researcher should check that no technical problems have prevented recordings. There were no time limits set to the interviews, they lasted between 40 and 50 minutes and were conducted during working hours from 11:00-16:00. The researcher thanked each participant for taking the time to be interviewed and for their contributions. No reward or incentives were given to the participants. The recorded interviews were later transcribed for deeper analysis.

4.5.2 Pilot Testing

A pilot testing is conducted to test the appropriateness and the effectiveness of the interview schedule (Strydom & Delport, 2011:394-395). For example, Strydom and Delport (2011:394-395) argue that piloting a questionnaire ensures that any integral errors are corrected before the main study. This principle applies also to the interview schedule. The pilot testing led to one important change. It revealed the need to refine the quality of the questions, with particular reference to the sequence of the questions. In order to address this issue the interview schedule was adapted accordingly and the researcher changed the format of the questions to a friendlier format. Having refined the data gathering instruments through a pilot, the main data gathering was embarked on.

4.6 DATA ANALYSIS

According to Saldana (2009:122), data analysis is a process that requires the researcher to capture an understanding of the data in writing. Data analysis is also the heart of qualitative research and the process that most distinguishes qualitative from quantitative research (Ary, Jacobs, Razavieh & Sorensen, 2009:465). This is the most important role of the researcher since he/she has to search, arrange and rearrange the collected data in such a way that it can
be clearly understood and presented. “The above statement confirms with Leedy and Ormond’s
(2013:161) assertion that “analysis in qualitative research is a systematic process of selecting,
categorising, comparing and synthesizing and interpreting data to provide explanations of the
single phenomenon of interest”. Data analysis has taken the form of reviewing the interview
data, identifying issues, and reporting these as main themes in terms of the research questions.
The process of qualitative data analysis involves moving back and forth between the steps of
the analysis (Spencer, Ritchie & O’ Connor, 2005: 213; Mouton, 2006:111). Data is also
analysed so that it can be presented in a “more meaningful way” (Liamputtong, 2013: 241).
Mouton (2006:111) is of the opinion that we analyse data by identifying patterns and themes in
the data and drawing conclusions from them. In this study, for the data analysis process the
researcher utilized the data analysis method as proposed by Schurink et al., (2011:404) and
Creswell’s spiral process, which suggests that the process of data analysis is flexible and
circular rather than fixed and linear (Creswell, 2013:401).The following are the four major steps
that the researcher followed in this study:

- **Transcription**

  According to Siedman (2007:281), transcribing “…is a critical step, since there are
possibilities for great loss of data, misrepresentation and decrease of complexity”. Therefore, the transcription of the conversation should commence as soon as possible. As far as interviews are concerned, the audio- taped interviews were transcribed verbatim for analysis. To avoid the loss of valuable data, the researcher personally transcribed the tape immediately after each and every interview. At that stage, the interview setting was still fresh in the researchers mind and the body language and other gestures of the interview were also clearly remembered. This ensured that detail was recorded. The first step involved listening to the tape recordings several times and getting to understand the data before transcribing the entire interviews. Once the interviews had been conducted they were transcribed and organised into electronic files (Leedy & Ormrod 2013:161; Creswell, 2013:183), separately for each interviewee. The researcher then read and re-read the transcriptions in order to familiarise herself with the data content and made sense of the responses of the participants (Creswell, 2013:183). Knowing the data well, gave the researcher insight into what the participants were saying. This was informed by Leedy & Ormrod (2013:161), who suggest that reading, reading and reading once more through the data forces the researcher to become
familiar with the data in an intimate way. For instance some notes were made in the margin, which formed the basis for the classification process to follow. These notes were in the format of ideas or key concepts (Creswell, 2013:183). This helped the researcher to recall the body language, facial expressions and other gestures of the participants.

• Classification

Qualitative data requires logical reasoning, organising data into categories and identifying patterns and relationships among the categories, making specific observations and then drawing inferences about larger and more general phenomenon (Ritchie, Spencer & O’Connor, 2003:228;Leedy & Ormrod 2013:161). In order to manage the data in analytical approaches, the themes or concepts under which the data is labelled, sorted and compared have to be decided upon. Following this, emerging common words and topics discussed by participants were colour coded and these codes were aggregated into specific themes and sub-themes for interpretation (Creswell, 2013:184-186). Recurring themes were identified and labelled by the use of a marker or different colour pens. This proved helpful since through these codes the researcher managed to work out commonalities and differences in the participants’ responses with regard to their experiences regarding the disclosure of their HIV status. To Creswell (2013:186-187), "data analysis requires that the researcher be comfortable with developing categories and making comparisons and contrasts”. Finally, themes which focused and supported the experiences of single mothers regarding the disclosure of their HIV status were summarised, interpreted and regarded as the findings of this study.

For this study, the interpretation of the findings was presented in a narrative form, with direct quotations supporting the interpretations. The relevant quotes for each theme and sub-theme were translated from Setswana and Sotho to English.

• Interpretation

A good start in interpreting the data is to develop a list of key points, as suggested by Leedy & Ormrod (2013:161). In this study, in order to interpret the data, the researcher used available literature as well as personal experience from practice as a social worker (Creswell, 2013:186-187). This assisted the researcher in examining the data within the context of the research issue.
• Data representation

Interpreted data was presented in text and in visual format as themes and sub-themes with accompanying discussions on findings.

The themes and relevant comments are presented in Chapter 5.

4.6.1 Ethical considerations

In research, ethical considerations are crucial, especially when a researcher is working with human subjects. Equally important is the honest reporting of data gathered and the results generated. The researcher acknowledges the unique experiences involved when dealing with single mothers who are HIV positive and for the purpose of this study all necessary ethical considerations were followed (Rubin & Babbie, 2008:290-291; Strydom, 2011a:129; Louw & Louw, 2014:48).

• Permission to conduct the study

Louw and Louw (2014:48) suggest that before researchers can collect any data it is important to follow the correct channels. For instance, they must negotiate for permission to collect data with the person in charge of the institution or settings where he/she wants to collect data. Informed by this, the study proposal was submitted to the ethics Committee of the University of Pretoria which approved this study. (refer to Appendix A). A written request to seek permission to conduct the research project within the Vaal University of Technology (VUT) was made by following the required guidelines, procedures and processes of the Human Resource Department of the Vaal University of Technology. The researcher is of the opinion that while the granting of permission by the relevant authority is important, it also let people on the ground know what the study seeks to accomplish. Informed by this, the researcher included an explanation about herself as the researcher and the possible uses to which the data or conclusions might be put (Foster, 2008:79). Once ethical approval had been obtained from the Research Ethics Committee, permission to collect data from the participants of interest was granted by the Executive Director of Human Resources Department (HRD) of VUT (refer to Appendix D). The data that was collected by means of a tape recorder was kept in a
safe place before and after it was transcribed. As per the ethical requirements of the University of Pretoria, it will be stored for minimum of 15 years for archiving purposes. Informed consent will be sought for use in further research when a need arises.

• **Avoidance of harm and debriefing**

This was one of the main ethical considerations in this study, specifically due to the sensitivity of the study. In research studies, harm can occur in physical or emotional manner (Strydom, 2011a:115). The researcher conducted the interviews in a professional manner and ensured that the single mothers are not unnecessarily emotionally exposed during the research process. Only one single mother cried during the interview and this was addressed with the campus clinic health promoter afterwards. In this case, the researcher informed the health promoter of this participant in order to provide her with the necessary support.

The researcher also provided a debriefing time after each interview, during which the participants could ask the researcher questions or voice any concerns they may have regarding the research. This period was also used by the researcher to ensure that no miscommunication or misunderstandings existed on the side of the participants.

• **Voluntary participation and informed consent**

Louw and Louw (2014:48) maintain that “all human behaviour is subjected to ethical principles and rules and that research practice is no exception”. One of the most important principles for ethical acceptability is informed consent (Louw & Louw, 2014:49). Participants should be informed beforehand about the objective and the benefit of the research. For the purpose of this study, the participants were informed that their participation was voluntary and that they may withdraw from the study at any time without providing reason(s) for their decision (Babbie, 2008:67). The researcher made it clear to the participants that they are not forced to take part in the research and that no negative consequences would occur if they chose not to be involved in the study. This was also addressed in the content of the informed consent letter, which participants were required to read and sign prior to the interviews (Waynberg, Schroeder & Chennels,
The participants were made aware of the type of information needed, why the information is needed, the procedures involved, and the duration of the study. They were provided opportunities to ask any questions they may have regarding the research before the interviews started. Informed consent to make use of the tape recorder was also requested from the participants.

- **Deception of subjects**

  Deception of participants is unethical. In this study the researcher did not deceive the participants in any way. The participants were informed about the purpose of the study and what procedures will be followed during the study. The data obtained was used to determine the challenges of the participants regarding the disclosure of their HIV status.

- **Violation of privacy/confidentiality/anonymity**

  According to Bryman (2009:31), privacy and confidentiality are two ethical issues that are crucial. Qualitative research is more likely to be personally insensitive than quantitative. The researcher requested that the participants share their experiences regarding the disclosure of their HIV status. For the purpose of this study, all the participants were informed that information provided in the interview would remain confidential, only be used for the purpose of this study, and would not be discussed with others except the research supervisor. This aspect was also addressed within the informed consent letter. Full anonymity could not be assured, as the participants names were known to the researcher. However, participants were guaranteed anonymity in any recorded or published material.

- **Actions and competence of the researcher**

  The researcher was competent to undertake this study, as she completed a mini-dissertation during her undergraduate studies in social work, as well as a postgraduate research module in sociology and a postgraduate course in research methodology at the University of Pretoria. It should be noted that the researcher is a registered social worker who is currently working in this specialised field with 18 years’ work experience. In agreement with Dintwe (2009:20), correct referencing techniques were applied to avoid
plagiarism. In each case where the researcher made reference to any existing work, necessary credit was given through acknowledgement of sources.

- **Release or publication of the findings**

  Both the participants and the Vaal University of Technology (VUT) Human Resources Department were informed that the research report will be published. Upon release, the VUT Human Resources Department will be provided with a copy of the research report. The researcher explained to the participants and the Human Resources Department that the final report will remain the property of the University of Pretoria.

  From the above it can be seen that all the ethical considerations were attended to throughout the research process and no ethical violations took place. In conclusion, when conducting the study that deals with HIV, it is important that the researcher adheres to the ethics of research because it is an illness that requires a sensitive and careful approach.

4.7 **CONCLUSION**

This chapter presented the process through which data was collected during this study. The specific methodology and all the ethical considerations that were utilised, were discussed in detail. The next chapter will focus on the analysis and discussion of the data collected throughout this process.
CHAPTER 5

PRESENTATION AND DISCUSSION OF EMPIRICAL FINDINGS

5.1 INTRODUCTION

In this chapter the researcher will present the data collected pertaining to the challenges single mothers experience regarding the disclosure of their HIV status. In this study the researcher employed the qualitative research approach. The objectives of the study were to explore factors preventing disclosure in relation to the family, community and workplace; the quality of life of single mothers, as they are HIV positive; and finally factors that will help them to disclose their HIV status to the family, community and workplace. An interview schedule was used to collect data from nine participants through the means of face-to-face semi-structured interviews. In order to analyse the gathered information, the researcher coded the data by using the process of thematic analysis. Themes that formed part of the interview schedule, were formulated to facilitate the data gathering process. The behavioural observations of the participants were also integrated into the analysis. The use of themes and quotes together enabled the researcher to explore, describe, and give an explanation and exposition of the challenges single mothers experience regarding disclosure of their HIV status. In this chapter the findings will be presented as they were given by the participants and they will be presented under the different themes that were identified in the coding process. The responses from the participants will be indented and in italics.

In order to understand the situation of these single mothers who are HIV positive, their background was provided in Table 5.1

5.2 BIOGRAPHIC DETAIL OF PARTICIPANTS

Table 5.1 indicates the backgrounds of participants.
Table 5.1: Background of participants

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age group*</th>
<th>Type of area*</th>
<th>Do you live in your own house?*</th>
<th>Number of occupants in house*</th>
<th>Do you own the house?*</th>
<th>Type of house*</th>
<th>Type of employment*</th>
<th>Length of employment*</th>
<th>Total income*</th>
<th>Educational level*</th>
<th>Race</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>45 – 58</td>
<td>Township</td>
<td>Yes</td>
<td>4</td>
<td>Own</td>
<td>Clay</td>
<td>Permanent</td>
<td>14 years</td>
<td>R2500&gt;</td>
<td>Grade 1 - 3</td>
<td>Black</td>
</tr>
<tr>
<td>B</td>
<td>34 – 44</td>
<td>Township</td>
<td>Yes</td>
<td>3</td>
<td>Own</td>
<td>Clay</td>
<td>Permanent</td>
<td>3 years</td>
<td>R2500&gt;</td>
<td>Grade 7 - 9</td>
<td>Black</td>
</tr>
<tr>
<td>C</td>
<td>34 – 44</td>
<td>Township</td>
<td>No</td>
<td>5</td>
<td>Own</td>
<td>Zinc</td>
<td>Permanent</td>
<td>5 years</td>
<td>R2500&gt;</td>
<td>Grade 7 - 9</td>
<td>Black</td>
</tr>
<tr>
<td>D</td>
<td>34 – 44</td>
<td>Township</td>
<td>No</td>
<td>6</td>
<td>Stay with parents</td>
<td>Zinc</td>
<td>Contract</td>
<td>2 years</td>
<td>R1501 – R2000</td>
<td>Never been to school</td>
<td>Black</td>
</tr>
<tr>
<td>E</td>
<td>34 – 44</td>
<td>Township</td>
<td>No</td>
<td>4</td>
<td>Rent</td>
<td>Clay</td>
<td>Permanent</td>
<td>6 years</td>
<td>R2001 – R2500</td>
<td>Grade 4 - 6</td>
<td>Black</td>
</tr>
<tr>
<td>F</td>
<td>34 – 44</td>
<td>Township</td>
<td>No</td>
<td>5</td>
<td>Stay with parents</td>
<td>Zinc</td>
<td>Contract</td>
<td>2 years</td>
<td>R1501 – R2000</td>
<td>Never been to school</td>
<td>Black</td>
</tr>
<tr>
<td>G</td>
<td>34 – 44</td>
<td>Township</td>
<td>No</td>
<td>4</td>
<td>Stay with parents</td>
<td>Clay</td>
<td>Contract</td>
<td>3 years</td>
<td>R1501 – R2000</td>
<td>Grade 10 – 12</td>
<td>Black</td>
</tr>
<tr>
<td>H</td>
<td>34 – 44</td>
<td>Township</td>
<td>No</td>
<td>3</td>
<td>Stay with parents</td>
<td>Zinc</td>
<td>Contract</td>
<td>3 years</td>
<td>R1501 – R2000</td>
<td>Never been to school</td>
<td>Black</td>
</tr>
<tr>
<td>I</td>
<td>45 – 58</td>
<td>Township</td>
<td>Yes</td>
<td>3</td>
<td>Stay with boyfriend</td>
<td>Clay</td>
<td>Contract</td>
<td>3 years</td>
<td>R1501 – R2000</td>
<td>Never been to school</td>
<td>Black</td>
</tr>
</tbody>
</table>

Note*: At the time of the interview July 2015.
5.2.1 Discussion of the content of the table

The participants in this study were 9 black, single mothers whose ages ranged between 34 and 58. “They all lived in a township and only three own houses”. The number of occupants in the houses range between three and six. Four of the nine participants live with their parents. One participant who owns her own house lives with her boyfriend. Four of the participants have permanent employment, while five are on contract. The duration of employment ranged from two to 10 years, and the income bracket ranged between R1500 and R5000. The educational level of the participants ranged from Grade 1 to 12. One participant fell in the category Grade 10 to Grade 12. Two participants fell in the category educational Grade 7 to Grade 9, one in the category Grade 4 to Grade 6, and one fell in the category Grade 1 to Grade 3. Four participants have never been to school. As Table 1 shows, it can be concluded that the participants come from a poor socio-economic background and that they have a low level of literacy.

5.3 DISCUSSION OF THE DATA THAT WAS GATHERED DURING THE RESEARCH PROCESS

In this section, the researcher will discuss the data that was gathered by means of the interviews and according to the different themes of the interview schedule. “The themes and sub-themes are presented in a table followed by a discussion”.

Table 5.2: List of Themes and Sub-themes

<table>
<thead>
<tr>
<th>THEME 1</th>
<th>SUB-THEME 1</th>
<th>CODE</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Factors that may hinder the participants from disclosing their HIV status in the workplace, family and community</td>
<td>• Judgemental attitudes</td>
<td>JA</td>
</tr>
<tr>
<td>SUB-THEME 2</td>
<td>• Lack of trust</td>
<td>LT</td>
</tr>
<tr>
<td>SUB-THEME 3</td>
<td>• Gossip by family, community members and colleagues about single mothers’ HIV status.</td>
<td>G</td>
</tr>
<tr>
<td>SUB-THEME 4</td>
<td>• Humiliation and criticism</td>
<td>HC</td>
</tr>
<tr>
<td>SUB-THEME 5</td>
<td>• Fear of hurting loved ones</td>
<td>F</td>
</tr>
<tr>
<td>SUB-THEME 6</td>
<td>• Discrimination</td>
<td>D</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>THEME 2</th>
<th>SUB-THEME 1</th>
<th>CODE</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The way different factors affect participant’s social functioning and quality of life</td>
<td>• Stress</td>
<td>S</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>THEME 3</th>
<th>SUB-THEME 1</th>
<th>CODE</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Factors that may support participants to disclose their HIV status in the workplace, family and community</td>
<td>• Support and support groups</td>
<td>SSG</td>
</tr>
<tr>
<td>SUB-THEME 2</td>
<td>• Educating those who gossip and judge</td>
<td>EGJ</td>
</tr>
<tr>
<td>SUB-THEME3</td>
<td>• Having role models who will disclose.</td>
<td>RM</td>
</tr>
<tr>
<td>SUB-THEME 4</td>
<td>• Trust</td>
<td>T</td>
</tr>
</tbody>
</table>
5.3.1 Theme 1: Factors that may hinder the participants from disclosing their HIV status in the workplace, family and community.

The environment we live in is comprised of multiple levels as according to the eco-system theory spelt out in chapter one. These levels depend on each other, affect each other and can affect us positively or negatively; thus facilitate or hinder the disclosure of HIV status by infected person particularly single mothers. Table 5.2 has displayed a theme and sub-themes of various factors that may hinder the participants from disclosing their status at various levels; these are discussed below.

5.3.1.1 Sub-theme 1: Judgmental attitudes

In Table 5.2 the participants indicated that they are exposed to family members, the community and colleagues who act judgmentally towards their HIV Status. An observation was made by some of them that some family members, community members, and colleagues have a tendency to judge people who are HIV positive. One participant commented as follows about her family:

“After they know about my HIV positive status I realised that my other family members, such as my brothers and sisters, were becoming judgmental towards me.”

In addition to judging them, some (community members) go to the extent of using derogatory words to refer to the participants. Some pertinent comments about community members:

“They [community members] are also judgmental when you are HIV positive. When you are HIV positive, they see you as rubbish or are loose/ have no morals.”

“When you meet them [community members] and they are speaking about someone who has HIV, or even if they aren’t positive, but see them sick and weak and losing weight, they’ll say that that person is positive...”

Moreover, colleagues are perceived to be judgmental to the extent of destroying potential intimate relationships. The following extracts illustrate this:

“...they [at work] judge you even when they don’t know your lifestyle.”
“They [at work] say... maybe if there is someone whom they want to be their girlfriend or wife, you'll hear one of them say ‘No, don’t approach that one because they are positive’. It’s sad because that person might love that woman, and when they hear that she is positive they might have chosen to love them just as they are”.

Participants find it difficult to disclose their HIV status due to a variety of reasons besides not knowing how or when, or which skills to use. The judgmental attitude of the family, the community, and colleagues is among the factors that surfaced. These groups of individuals use degrading words when referring to HIV positive people. These include terms that label them as rubbish, loose persons, or persons without morals. Using derogatory names to refer to people who are HIV positive is not new in this era. As early as 2005, Maleka (2006:61-63) found that lowest strata employees at a motorcar factory were labelled by words such as Koloi ya Elijah (Chariots that were used by the Prophet Elijah), Lekhwekhwe (Leprosy), and Sephamola (Snatcher). For example, when one is referred to as Elijah’s chariot it simply means you are on your way to disappearing into heaven through death because your condition is irreversible and incurable, like leprosy. The level of judgment from the community is such that any sick person is assumed to have contracted the virus. It must be noted that the participants of the study were also employees of the lowest strata, as background information indicated.

This judgmental and stigmatising attitude is not surprising, as Mucheto et al. (2009) have already intimated that a positive HIV test is associated with promiscuity and multiple sexual partners. The fact that contracting the virus is associated with promiscuity and multiple sexual partners is an indication that some people are ignorant of the fact that sexual intimacy is not the only mode of transmitting the virus.

5.3.1.2 Sub-theme 2: Lack of trust

Being HIV positive is not a pleasant experience and is a very emotional issue. When one is at breaking point, one needs to confide in someone who can keep a secret. Such people are hard to find in the family, community, or at work. HIV positive single mothers even doubt the ability of their children to be entrusted with confidential information. This observation is supported by the assertions of Gachanja, Burkholder and Ferraro (2014:11) namely that parents face additional worries, such as whether the child is old enough to understand or able to keep the information confidential. The family is portrayed as an institution that cannot be trusted with sensitive information. This is exemplified by the following comments:
“When it comes to telling the family, you have to tell those that you know you can trust”.

Another one uttered comments to this effect about the issue of trust and co-workers:

“If they are with someone that you trust [at work], you are able to speak freely.”

At times even if one can be selective in terms of disclosing one’s status, one gets disappointed by the fact that those one considers confidants (at work, for example) breach confidentiality, as one respondent stated:

“Sometimes you need to talk to someone [at work] because you feel that you are close to them, but at the end of the day you find that there’s no one that does not know”.

Qualitative findings have revealed that some family members and the community cannot be trusted with one’s HIV status. This fundamentally means that HIV positive single mothers have to be selective when choosing a confidant. This situation reduces chances of future disclosure. The judgmental attitude of those already mentioned as portrayed by participants is a concern, considering the fact that the issue of HIV and AIDS has been prominent in the country for more than 20 years, before the dawn of democracy in the country. In the workplace, HIV raises many very serious issues. One of those issues is the way in which HIV positive workers are viewed and treated by their colleagues. Traditional perceptions and belief systems have very much informed people’s attitudes still continue to shape their responses towards PLWH and those with AIDS (Motsukunyane, 2009:58). In addition, there have been number of campaigns to educate the country about HIV and AIDS, not excluding issues of disclosure to infected and affected. Many of the HIV prevention awareness campaigns have utilised mass media, including television, newspapers, and billboards. HIV and AIDS awareness campaigns are used to helping people grasp how HIV is transmitted. For example, during awareness campaigns cheap cassette recorders are purchased, especially for employees with a low literacy level, such as those working in manufacturing workplaces and cleaning services. Tape recordings and DVDs are made of well-known or influential people informing employees about how HIV is transmitted. At Telkom SA, pamphlets are available at the office of the HIV and AIDS coordinator (Nxasana, 2002:21).

Furthermore, much of the preventative campaigns around HIV in South Africa have hinged on condom use and condom distribution as being the most useful tool against fighting HIV transmission, because condoms are highly effective in preventing HIV transmission from one
partner to another during sexual intercourse. Condoms have been around for a long time. In the past they were used as a birth control method only, but with the introduction of HIV their use shifted towards being used for the prevention of sexually transmitted diseases (Motsukunyane, 2009:52). Added to the above, condoms are distributed in different sections of the workplace. For instance at Telkom SA and the Vaal University of Technology (VUT), condoms are placed in the vending machines, in the toilets and the clocking in and out areas (Nxasana, 2002:20). The positive side of condom distribution is that employees in the workplace do not have to buy them. In addition, peer educators are also employed to educate their co-workers about HIV transmission. Peer educators spread relevant information about HIV in the language that their peers understand. Maleka (2006:8) mentioned that during communication with peers, peer educators share the knowledge that they have acquired at the training they have attended. After training peer educators are expected to encourage co-workers to make use of different HIV preventative methods, including condoms. To motivate employees to use condoms, BMW SA and VUT use well-known HIV positive employees to distribute condoms (Researcher, 2015; Maleka, 2006:14). Another way of addressing HIV and AIDS is through Voluntary Counselling and Testing (VCT). Testing is one of the strategies aimed at preventing new infections and slowing the transmission of HIV in the general population (Adedimaji, 2010:16). The benefits of attending VCT for those who are HIV negative is that they get a chance to be educated about ways to stay HIV negative. For those who are HIV positive the benefits include HIV medication and support (Day, 2003:665). Positive talking can be useful to encourage employees to go for VCT; this can involve getting a person who is HIV positive to talk about his or her experience of HIV.

5.3.1.3 Sub-theme 3: Gossip

Table 5.2 depicts that the participants have overheard or witnessed situations where someone’s HIV status was the subject of gossip. This happened even when they suspected that an individual is HIV positive. This observation resulted in them keeping their HIV status confidential. A noteworthy comment related to family gossip reveals how a participant felt about her family’s gossiping tendency:

“I don't trust them [family]. They talk too much; even when we have discussed something, it will resurface outside the home. They aren't people that I can confide in, because they will slip up and tell someone else. When we explicitly say that this is family business, you will hear about it from someone else outside the home.”

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Community members add to the group of gossips. The fear felt by participants regarding what that community would say if they disclose their HIV status is attested by the following accounts:

“Gossip would also be a reason [in the community], as people would come up to you and gossip about someone else. That also prevents people from talking”.

“I was afraid they’d [the community] gossip about me. I just wasn’t ready to tell them that this is what is going on with me”.

“They [at work] are the same as the community, because everyone who is positive where I work is being gossiped about… Nothing will stop them from talking about me as well; that’s why I won’t tell them”.

Findings reveal that the workplace also stifles disclosure, as it seems to be the main centre of gossip – the capital city, if you will. This disheartening situation is corroborated by the following assertions: “When you meet them [colleagues] and they are speaking about someone who has HIV, or even if they aren’t positive but see them sick and weak and losing weight, they’ll say that person is positive. I think it’s not good for me to speak about my status in the community”.

“…people [at work] gossip a lot. And when you tell someone your status and they tell someone else, you feel hurt because you needed to heal on the inside in your heart, so when you hear someone else talk about your business you feel hurt”.

“People [at work] undermine others, they speak badly of people who are HIV positive. When they find out that someone is positive, they’ll say HIV positive people are like this, they have this shape, they are like this, and this make you look down on yourself and keep quiet because they speak badly of you, you see… people gossiping about them…”

“They [at work] speak about you if they know you have it. That’s what prevents me from telling them”.

Gossip impacts negatively on any individual, more so if one has a life-threatening condition. It undermines one’s integrity and strips one’s dignity (Mills, 2004:8). The participant’s responses indicated that people infected by the virus become the subject of discussion in their homes, the community, and the family. Women are seen as the ones who bring the
A study by WHO found that when men are diagnosed with HIV they receive full support, including treatment without questioning, whilst women on the other hand are questioned and interrogated, suspected of promiscuous sexual behaviour, and given less support in their treatment (WHO, 2003a). In a study by Rhine (2013:1-20), it is stated that if a woman is HIV positive she is blamed for infecting the men. This happens behind their backs, but sometimes remarks about the status of their health are uttered in their presence. It is surprising from the findings that although gossip seems take centre stage in terms of being a prevention to disclosure, the family, though mentioned, seemed not to be such a huge problem. Some families are probably driven by the urge not to wash their dirty linen in public and to protect the infected children and the family name. It is not surprising that the community and the workplace were portrayed as places were frequent gossip about people who are HIV positive took place; the main reason might be that they are not blood relatives. Based on the above, the levels at which sensitivity statements are made about HIV infected individuals [HIV positive single mothers] have come to the fore. Stigma against people living with HIV is widespread and severe. Colleagues have been revealed to be the worst gossipers, thus inhibiting disclosure at work. PLWH and those with AIDS and their families are often subjected to social isolation (Mochadibane, 2013). The same author mentioned that other employers and colleagues do reject PLWH and those with AIDS. Mochadibane (2013) mentions further that women who are living with HIV prefer and often opt not to disclose their HIV status in their workplace, as they believe that they may be discriminated against. Studies show that employees or people who feel rejected and humiliated might not tell their co-workers about their HIV infected status and could continue engaging in unprotected sexual intercourse (Parker & Aggleton, 2002:4).

Socially, AIDS is a disease of stigma and shame; those who are infected with the disease are treated as outcasts that deserve no place in the communities. In African countries this situation is made worse by the misperception which associates HIV with promiscuity. In the workplace, HIV and AIDS raise many very severe issues. One of those issues is the manner in which HIV positive workers are seen and treated by their colleagues. Traditional perceptions and belief systems have very much informed people’s attitudes and continue to shape their responses towards people who are living with HIV and those with AIDS. This is confirmed by a study conducted by Motsukunyane (2009:76) where it was found that people [participants] who hear about HIV and AIDS from other people often paint a very worrying picture about HIV and AIDS. Motsukunyane (2009:76) mentions that more often than not, information acquired from those who have little knowledge about HIV leads to the recipients of the information getting inaccurate information. In her study, Motsukunyane (2009:76) found that some of the participants who heard about HIV and AIDS from ordinary people on
the street often had erroneous information about HIV and AIDS. A typical response from someone who has heard about AIDS from other people would sound thus: “I heard from a lot of people that AIDS kills people who sleep around with many women. So I think that means AIDS affects those who have many partners”. Most people have a distorted view of HIV and its sufferers; to them AIDS kills promiscuous people who engage in unprotected sex with many partners. This view is often held by many members of society, because that is how AIDS sufferers have been portrayed. They have been portrayed as shameless people who have been promiscuous and deserve everything that is coming to them. However, there are often personal stories to be told by AIDS victims and they paint a totally different picture than the one often presented.

5.3.1.4 Sub-theme 4: Humiliation and criticism

In Table 5.2 data reveals that HIV positive individuals are humiliated and made a laughing stock by the family, community members and co-workers. They are even condemned to die. As a result of these actions, they would rather refrain from disclosing their HIV status. The following extracts reveal how respondents felt:

“Family speaks in a nasty way. If you find out that… they speak terrible things, like that you are going to die”.

“People don’t tell people in their community, because they fear being laughed at by community. They think ‘If I tell my neighbour, they will laugh at me, or think that I will die’.”

“At work, people laugh at each other – ‘this one is sick’. Even when I’m angry, you’ll hear someone say ‘they’re this irritable because of the pills they are drinking’.”

It is worrisome that years later (in 2015), people’s (the family, community and co-workers) social construction of HIV and AIDS is still death, even at the time when HIV positive sufferers have access to antiretroviral medication and a lot of health-promoting education and initiatives. This, in essence, suggests that they have not grasped that an HIV positive person does not die of the virus or AIDS, but of AIDS-related diseases.

In most societies, especially in black societies, HIV and AIDS is still a very difficult and a sensitive topic to discuss, more especially when the discussion centres on one’s HIV positive status. Again HIV and AIDS still carries stigma and thus talking about being HIV positive is not an easy task in the community, especially when it includes family members (Seid, Wasie
& Admassu, 2012:103). Perhaps one can attribute this difficulty to the fact that in general sexual matters are regarded as taboo and they are never discussed openly. They are only discussed in reaction to something that has happened or as a response to a comment. It can perhaps be said that people do not talk freely about HIV because of the fear of being judged or ridiculed. Whatever the case may be, there is not enough talk when it comes to HIV and AIDS.

There has been considerable attention given to AIDS by the media in South Africa and across the globe. Though mass media awareness campaigns have been effective in increasing people’s awareness and knowledge of HIV in South Africa, some of the initial campaigns revealed AIDS as devastating, frightening and related to death. The fear that HIV means death and dying continues today. The way in which AIDS has been portrayed has in fact horrified and at the same time puzzled a lot of people, because the message that has been sent to the general population is that AIDS is nothing but a disease that kills. This would mean that the minute a person contracts HIV, that person has received a death sentence. Not enough attention has been paid to ordinary people who have managed to live positively despite the burden of the disease in their lives. People only perpetuate this one message from the media – that AIDS means death. The message that has been dispensed therefore borders on negativity instead of hope. The high level of negativity has thus meant people are afraid of talking about AIDS and they are also very wary of any future prospects when one is infected with the virus. For instance, with little prediction of a cure HIV infections are increasing in number and people are dying of AIDS-related diseases such as pneumonia, tuberculosis, oral thrush and herpes simplex (Msomi, 2000:8). Therefore, the fear of death and dying still plays a central role. HIV infected people and their families experience many fears. The families of people living with HIV are particularly fearful of being isolated, stigmatised and rejected. Fear may also be the result of not knowing enough about HIV infections and how the illness can be handled. Infected individuals often do not disclose their medical condition for fear of being sentenced to an isolated death (Van Dyk, 2001:256-259).

Myths regarding the transmission of HIV still exist, which contribute to the stigma surrounding the disease. These myths spread because of the fear people harbour about HIV. HIV has a great stigma attached to it; one reason being the method of transmission. The media and the AIDS-related stigma literature in South Africa often quote accounts of people who have disclosed their HIV positive status openly and as a result have experienced some form of HIV and AIDS-related discrimination (Almeleh, 2006:3-4). For a prominent example of such a story, the researcher refers to Mpho Motloung who was murdered along
with her family by her husband who then placed a sign on her grave that read “HIV-positive AIDS” (Skinner & Mfecane, 2015). These stories are constantly broadcast openly in public through the media and they highlight some of the very negative social contexts faced by people living with HIV in South Africa. However, it is important not to generalise too quickly from these highly publicised events about the level of stigma in society. As LeClere-Mandala (2001:38) reminds us that “AIDS is more than a simple biomedical entity, it is also a cultural construction heavily loaded with meanings that shift, expand and change as the epidemic grows.” Women are considered as the main caregivers in many cultures and communities. It therefore implies that if a mother in a family is infected with HIV, she will be unable to care for any other family member who may also become ill after being infected with HIV because of her own illness (Erhardt, Sawires, McGovern, Peacock & Weston, 2009:100). Even though they are knowledgeable and educated about HIV, they have difficulty in shifting their mind-set to accommodate new information about HIV-related issues. The social construction of HIV and AIDS by the family, the community and co-workers makes those who are infected lose hope and thus not see a need for disclosing their HIV status.

Humiliation affects one’s self-esteem. As early as the year 2000 Njoko (2000:3), in a study of HIV positive women living in Khayelisha, noted that their social construction of HIV and AIDS was framed as being a death sentence for a sick person. In a study done by Maleka (2006:12), one fearful miner indicated “you think about death, have no plans for the future and everything comes to a stop” (Day, 2003:668). From the above, the researcher surmises that HIV infected single mothers do not want to be humiliated and condemned to death. The very fact that they have raised the concern about being condemned to death means their thinking and social construction of their HIV status is ‘life’, not death. To them, people who condemn them to death and humiliate them are the reason they do not disclose. It is interesting to note that the environment which is supposed to embrace the single mothers in their plight humiliates them. This action deviates from the principles of the eco-systematic theory which stipulates among other things that “the person and his/her environment are dependent on one another as they are in interaction with the systems that surround them (Shearfor & Horesji, 2008:40).”

5.3.1.5 Sub-theme 5: Fear of hurting loved ones

Single mothers face challenges regarding when and how to disclose their HIV status to their children, extended family members, friends and colleagues (Moloi, 2013; Mochadibane, 2013; Murphy & Marelich, 2008:2). A participant in Thompson’s (2011:86) study mentioned that wanting to save relationships with their families and to protect children (Corona et al., 2006) is the reason people diagnosed with HIV do not disclose their status. That is another
issue apart from that of protecting the family from imminent hurt. Furthermore, disclosure can lead to disrupted relationships within families and communities, as Obermeyer et al. (2011:1011-23) have documented. They often feel guilty about the behaviour that may have led to the infection. There is also guilt about the sorrow that the illness will inflict on loved ones and families, especially children (Van Dyk, 2001:256-259).

Mothers fear that others will reject their children or family if their HIV status is known (Hazard Vallerand et al., 2005). The results have revealed that people who are HIV positive withhold disclosing their status to loved ones for fear of hurting them, especially children and elderly family members. This situation is confirmed by the following statements:

“When it comes to my family, I found that I could not talk to my children because they were young and I thought the news would affect them”.

“As a single mother, I think of my children and that they have no father, and if I tell them that I am positive… If I tell them that I am positive, I think they will feel hurt and think that their mom will die”.

“I was afraid of hurting my mother, since she has a heart condition. In 2011 the elders believed that it was a deadly disease, so I was afraid to disclose to my parents because they were old... A friend of mine is afraid and ashamed to tell her family due to the same reasons... Her mother was old”.

According to the findings, children are deprived of the privilege to know about the status of their parents because they will be emotionally affected, as the condition is associated with death. This, in essence, means that once the children know, they will be devastated, bearing in mind that they are children of single parents. This to participants will mean that if their parents passes on they will be left destitute, as their source of support and income will be gone. On the other hand, children who are aware of their mother’s status will understand when something is wrong and provide support. In many situations, parents take a lot of time to disclose their HIV status to children or avoid disclosure altogether, because some believe that they do not know how to disclose this information or how much information they should disclose (Kennedy et al., 2010). They also lack the skills and guidance about how to approach such a sensitive topic (Rwemisisi et al., 2008). Additionally, infected parents are deprived of disclosure because of the age of their own parents. The explanation to this may be that aging is associated with ill-health and fragility. Individuals who are HIV positive might be scared that upon hearing the news, the aged parents might be in a state of shock and die.
as result of that. In the participants’ opinion, the main reason sick parents fail to disclose their HIV status to their children is culture (WHO, 2004a:18). However, the researcher is of the opinion that the main reason is the desire of the infected parent to protect their family, especially the children and the elderly, which does not differ from other recent studies (WHO, 2004b:12). Some medical personnel discourage those infected from disclosing their status to their children, basing their reasons on the assumption that the children’s’ emotional well-being will be affected. The situation is vividly captured by the following statement:

“The doctor I went to told me not to let her children know as it would disturb them mentally as they were still attending school. Because they knew that the disease was deadly … even today they still don’t know”.

It is worth noting from the findings that some people who are HIV positive are prevented from disclosing their status to children by medical doctors; that is an unfortunate situation. The responsibility of medical practitioners is to guide and support the patient. Their other responsibility is to maximise the patient’s quality of life, and not to dictate to the patient whether or not to disclose their status. What some of these doctors do may be considered as a violation of the ethical code of disclosure.

In addition to the above, the researcher has observed that the ease of reporting about ones condition of ill-health to loved ones depends on the perception people have about the disease and the impact the disease will make loved ones. For example, when one discloses that one has Influenza (flu) to loved ones, the recipients of the message take the condition lightly, as flu is hardly associated with death. These news can be released even if there is a sick, elderly person or children, for that matter. The situation is different when it comes to chronic diseases such as cancer and HIV and AIDS. For example, they tend to be at pains to disclose their status, taking into consideration the health, the age, and the circumstance of others whom they consider vulnerable. Non-disclosure may lead to non-adherence as a way to conceal the disease from others (Arnold, Rice, Flannery & Rotheram-Borus, 2008:80-92), as well as disadvantaging the people from receiving the care and support they need when living with HIV (Sebitloane & Mhlanga, 2008:492) and placing their sexual partners at risk of contracting the virus (Kebede, Woldemichael, Wonderfrash, Halle & Amberbir, 2008:81).

5.3.1.6 Sub-theme 6: Discrimination
Table 5.2 shows that discrimination still prevails against HIV positive people. This is clearly expressed by one participant.
“You also don’t want to be around other people, because they might think that I’ll make them sick or that as I have my cup of tea and offer them some, they’ll recoil and not want to drink from my cup, you see? People will be afraid to share utensils with you.”

Disclosure of a positive HIV status can be an extremely difficult process, because it makes one vulnerable to discrimination, as one infected single parent has shown. These findings are in accord with research (Rohleder & Gibson, 2005; UNAIDS, 2013a). Discrimination involves more than people not wanting to share utensils with those infected. In a study conducted by Thompson (2011:86), one participant recounted her experience of rejection and discrimination when she was chased from her home by her mother after disclosing her HIV positive status. Stigma and discrimination prevent PLWH and those with AIDS from disclosing their status (Sebitloane & Mhlanga, 2008:492) and from receiving the care and support they need when living with HIV. According to the eco-systematic approach, the action of an individual or a group has an effect on other persons and groups in society, and vice versa (Shearfor & Horesji, 2008:50); this assertion relates to the participants. The discriminatory action of family members and significant others does not only affect the infected mothers but also their children, other people surrounding them, and society as a whole (Berk, 2009:26). The results have not only revealed how difficult disclosure is for infected single mothers, but have also supported what the theoretical frame-work has stipulated.

5.3.2 Theme 2: The way different factors affect the participant’s social functioning and quality of life.

The type of feelings which single mothers go through will determine whether they are coping with their condition or not.

5.3.2.1 Sub-theme 1: Stress

Table 5.2 depicts that the quality of life of single mothers who are HIV positive is characterised by both negative and positive feelings, the dominating feelings being negative. The prominent negative feelings are stress, feeling even sicker, feeling isolated and neglected, discomfort, fear, hurt, and anger. Pertinent comments of participants in relation to stress were:

“They would affect me, because I would always suffer from stress caused by being afraid that someone told will tell someone else.”
“I would always suffer from stress caused by being afraid that someone I told will tell someone else”.

“I’d stress a lot. I’d argue with other people; it makes you feel sick”.

As early as the year 1998, literature (RSA, 1998:89) had already documented that infected people experience considerable psychological stress, which is aggravated by social stigma and discrimination. The diagnosis and disclosure of an HIV status itself is a major source of stress for any person. In this research, the main source of stress seems to originate from mistrust regarding disclosure and confidentiality, and arguments (most probably about their health status). Stress in HIV persons is aggravated by the attitude, utterances and behaviour of those who claim not to be infected. For example, finding about factors that prevent disclosure have already revealed that some family members, the community and colleagues humiliate and gossip about them (RSA, 1998:89). Van Dyk (2001:256-259) has identified other variables that have the potential to cause stress to HIV infected persons. These is a lack of commitment by other family members, refusal to perform some care-giving activities such as mouth cleaning, dressing of wounds, and administering injections, and the fear of contracting the infection. All of this leads to severe stress for the individuals who are infected with HIV.

One respondent elaborated on a range of other negative feelings she went through and related the following:

“I feel hurt. I ask myself why we, as human beings, can’t be compassionate towards one another. It is very painful when someone speaks about you; you wonder whether they know their status. I also get filled with anger, to the extent that I will go up to the person and say ‘I know what you are saying about so-and-so. Do you know your status?’”

Negative feelings breed a negative attitude, and thus an unhealthy frame of mind. But positive feelings indicate gaining strength, accepting the situation, and moving on with life. Two noteworthy responses relating to positive feelings clearly indicate how each respondent maximised quality of life:

“Before, I used to be affected, but now the more they talk, the more they make me strong… because the more hurt you are on the inside, the more you sink”.

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“I don’t feel affected at all, because…. I am just happy that I know my status, because I know that I am positive. As long as I know that I don’t have high blood, diabetes or any other disease; that’s the only one I have”.

The results showed that most participants are preoccupied with negative feelings. This is exemplified by what was observed in one participant. She uttered the word “Eish” and played with her keys. Her facial expression changed and she became sad. This may indicate that she feels alone, especially since she has not told anyone and it is her secret. It is not unusual for infected people to display negative feelings, as indicated in Chapter 2. The feelings identified were depression (Day, 2003; Enriquez et al., 2008), fear, guilt, (Van Dyk, 2001) and anxiety (Msomi, 2000:8). Literature (Van Dyk, 2001:256-259) has further indicated that HIV infected people’s fears are related and include the fears of being isolated, stigmatised and rejected, and sentenced to an isolated death due to their medical condition. Fear has also been seen to be related to the loss of their ability to care for themselves and their families, loss of their jobs, and loss of their friends and family. They fear the loss of control, autonomy, ambitions, their physical attractiveness, sexual relationships, status and respect in the community, financial stability, and independence. It is worth noting that some participants (two) resorted to adopting positive feelings, as findings have indicated. The two participants exemplified that positive feelings can also be adopted in an unfortunate situation. This suggests the fact that they have realised that the more they dwell on the negative aspects of their condition, the more their health status will deteriorate. This situation points to the fact that for some people prolonged hurt due to a debilitating condition can lead to resilience, especially if one has the responsibility of parenting.

It is important, therefore, for HIV positive people to maintain a healthy frame of mind in order to manage HIV and AIDS effectively, as HIV is a disease that affects every aspect of a person, including the mind (Thompson, 2011:64). In this study (Thompson, 2011:64), one of the participants explained the adverse psychological impact that a negative attitude can have on a person living with HIV: “And we must stop complaining that ‘I will die soon and leave my children behind’ because the more you complain, the earlier you will die”. It is a known fact that psychosocial factors affect social functioning; that includes relationships with the family. For example, a stressed parent or worker becomes a stressor to people around him or her. A stressed worker also becomes unproductive at work. Finally, HIV positive single mothers who have a supportive environment for disclosure will be less stressed.
5.3.3 Theme 3: Factors that may support participants to disclose their HIV status in the workplace, family and community.

Disclosing one’s HIV status is voluntary. The ideal is that HIV positive persons disclose their status in order not to re-infect themselves and others. This important action can only occur when certain conditions are created.

5.3.3.1 Sub-theme 1: Support and support groups

An HIV positive person requires an environment that will enable them to disclose. The environment must include everybody (family and friends, including those who are positive), which would make them feel they are not alone. A pertinent comment about support was:

“When people receive support from family and friends, and others that you know, and those that are positive, then you know that you are not alone”.

Participants felt that there should be empathetic support, which is free from all types of hurt that may prevent disclosure. This was confirmed by the following responses:

“If a lot of people can disclose their status and they are given support and not judged, because at work being judged and gossiped about is prevalent”.

“If you know that you have a problem, you should have an opportunity to connect with others. For instance, counsellors in the community, you can go to them…”

The respondents further endorsed support groups as structures that will make them feel accepted, as the structure will involve those they identify with. Comments to this effect were:

“… that we [community] should have support group in order to support each other, help each other. Each person would know that on a certain day we will support each other, help each other”.

“Support groups - we’ll meet, go out to see other people, speak to people, and so on”.

Chapter 1 referred to the fact that Cawyer and Smith-Dupre (1995: 243) found that people with HIV and AIDS, together with their families, often face hostility and isolation, with
profoundly altered social shame rather than support. This essentially means that the greatest need of single parents who are infected would be a supportive environment free from hostility, judgment and discrimination, among other things. Participants seem to understand the concept of support groups and how these would facilitate disclosure. Disclosure of HIV status contributes to the general well-being of PLWH and those with AIDS. The statement here is in agreement with Enriquez et al. (2008:40) namely that women considered social support important in surviving with HIV and Van Dyk’s (2011:7) findings which stress the importance of family support, community and colleagues for people living with HIV. This is stressed by one participant who mentioned the following: “I went there [to the clinic] and then I was sick and she [the sister] asked me, ‘Have you tested?’ I said, ‘Yes’ and she asked: ‘What are the results?’ and I said: ‘Positive’... then she talked to me and tell me this is not the end and you must accept it. And then, ah, it was easy for me even at home”. A thorny issue in both labour and business circles has been the issue of disclosure by those who are HIV positive. Thus a major challenge for employees living with the virus has been to deal with colleagues that are not fully informed about the virus and as such are discriminatory against them. Since the employer has a duty to protect the employees in his/her service, one would assert therefore that employers have a duty to ensure that these employees are not stigmatised within the workplace and that they receive all the necessary support. Support could make people, whether at home or at the workplace, unashamed of taking ARVs. In his research, Maleka (2006:15) shows that one participant who was supported by a family member claimed the following: “My husband...gives me encouragement to take medication, but if he does not say anything, I forget”.

5.3.3.2 Sub-theme 2: Educating those who gossip and judge

Educating those who are ignorant about the condition, be it family, the community or colleagues, and about how to treat people who are infected seems to be a factor that will encourage the participants to disclose their status. Comments to this effect were:

“When [family members] speaking to someone who has HIV, leave them with comforting words, not those that will hurt them. From there, don’t gossip about them after leaving them. Don’t talk about them”.

“It’s this issue that they [colleagues at work] gossip about others... I desire to speak to them so that they know that they should not talk about others, because they themselves, as long as they have not tested, they are positive. So they shouldn’t go around pointing fingers at people”.

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“I wish I could go to that person [community] and say ‘You know what, child of God, HIV doesn’t kill. You’ll be killed by stress’.

Educating individuals about HIV and AIDS can be done through mediums such as campaigns that are related to HIV-specific issues, such the importance of condom use. This was also highlighted by one respondent:

“When there are campaigns, we go out on e.g. AIDS Day, Condom Week… They [colleagues] will be able to see that we have this disease and we can advise them… You just have to talk and be open”.

What is implied in the comments of respondents is that maybe some people treat them unfairly to the extent that they fail to disclose their status because of a lack of knowledge about the condition. In addition, these individuals might be ignorant about the damage they cause to HIV positive persons due to a lack of knowledge. Education through campaigns, among other things, might even maximise HIV testing by others who have not tested, resulting in an understanding of what a person goes through before and after disclosure. Furthermore, educating significant others is an important reason for disclosure amongst mothers living with HIV. This is attributed to the fact that people living with HIV may want to change the popular misunderstanding about HIV and AIDS which people still have and to protect their loved ones from possible infection (Almeleh, 2004:25-26).

5.3.3.3 Sub-theme 3: Having role models who will disclose

Participants are of the view that having role models that are HIV positive and that are willing to disclose, would encourage disclosure. Comments to this effect were:

“When friends reveal that they are positive, then I will be free to reveal my own status”.

“If I find others [in the community] who have it, we could talk about my status…”

“I’m not ready to talk about it. (Long pause). Maybe if there were others [at work] who are also positive I’d speak up, but not if there’s someone who is not”.

“If they speak freely [others who are infected], then I will be able to speak about my status”.
The participants further endorsed support groups as structures that will encourage disclosure. Their wishes are expressed as follows:

“…that we [community] should have support group in order to support each other, help each other. Each person would know that on a certain day we will support each other, help each other”.

These findings suggest that the main strength of HIV positive single mothers are those who are similar to them, because they will identify with their plight. The 2009 AIDS Epidemic Update (UNAIDS & WHO, 2009:9) identifies a need for HIV prevention programmes specifically designed for people living with HIV. It suggests that people living with HIV should be involved in programmes and be included in efforts to prevent HIV infection. In a study by Seung, Bitalabeho, Buzaalirwa, Diggle, Downing, Bhatt Shah, Tumwebaze and Gove (2008:1206) during an evaluation of a training programme in which HIV infected persons were actively involved in contributing towards the improvement of healthcare for people living with HIV, people living with HIV portrayed their illness to healthcare workers in order to train the latter in skills vital to the chronic management of HIV. This approach was considered to be an effective and useful practice since it involved persons with first-hand experience of living with HIV (Seung et al., 2008:1206). Furthermore, the study correlates with the UNAIDS and WHO recommendation to involve people living with HIV in programmes related to HIV (UNAIDS & WHO, 2009:9). It was also determined that people who took part in this training programme were excited to contribute to the training of healthcare workers in a meaningful way; they felt empowered and had a more positive attitude towards their HIV positive status (Seung et al., 2008:1207). Goudge, Ngoma, Manderson and Schneider (2009:103) found in their study that HIV infected people who fulfilled a meaningful social role were more likely to resist stigma and redeem their self-esteem.

5.3.3.4 Sub-theme 4: Trust

Infected single women do not trust anybody with their status; this includes relatives. They do not see relatives as being able to keep secrets. This has resulted in them being selective when disclosing their status. Serovich (2000:823-832) found that PLWH found more comfort in disclosing their HIV positive status to their mothers as a way of receiving emotional support and care. Respondents do not mind extending their willingness to disclose to other members of the family and colleagues, provided they could keep a secret. Pertinent comments to this effect were:
“If they are able to keep what I say confidential; they can’t keep a secret, my aunts, uncles…”

“…with someone that you trust [at work], you are able to speak freely”.

“I told those that I was close to someone at work. What led me to telling them freely was because I attended a class in my community... After attending that class, I started understanding more about the disease...”

What can be deduced from this is that participants are willing to disclose their status, subject to certain conditions being met. It should be a close person that can be trusted with confidential information and the person should also be knowledgeable about the condition. Being knowledgeable about the condition includes, among others, knowing why, when, how you should disclose, how some people will react and, finally, how to deal with criticism. To this end, Hult et al. (2012:181-190) have indicated that although there is no clear indication regarding the response on the disclosure of one’s HIV status, the positive reactions to disclosure “outweigh” the negative ones. Positive responses include more quality social support, stronger family cohesion and relationships, a decrease in anxiety and depression, and improvements in physical health. Based on the findings and assertions by the author, one may say that they chose to disclose where there is support, because they are hoping for genuine support from all stakeholders (family, the community and co-workers) and stronger family cohesion that is free from gossip, judgment, discrimination, humiliation and criticism, and characterised by the ability to keep the status a secret. By disclosing their status in a supportive environment, single mothers infected by the virus will have a better quality of life free from depression, stress, fear, anger and other psychological effects associated with not disclosing. Factors that maintain disclosure, such as support groups, counselling, campaigns, education, and being given a platform to educate others were identified by participants as being helpful to them disclosing their status.

Counselling encourages the infected persons to disclose their HIV positive status to others, thus HIV counselling promotes the disclosure of one’s HIV status. Counselling, which according to UNAIDS (2011:6)it is an interpersonal dynamic communication process between a client and a trained counsellor who is bound by a code of ethics and practice, to resolve personal, social and or psychological problems, can be done during pre-test and post-test counselling sessions or during routine clinic visits for care and treatment programmes. A number of studies conducted on counselling revealed that clients who receive ongoing counselling are more likely to disclose their HIV status and this is because counselling is coupled with a discussion on the advantages of disclosure, which is important for HIV care and prevention (Seid, Wasie & Admassu, 2012:97). Counselling also helps
mothers living with HIV to share their feelings and concerns about having HIV and other life issues, and this can reduce distress and depression. Counselling is also important to help the mothers deal with ongoing anxieties about disclosure and stigma (Reif, Whetten, Ostermann & Raper, 2006). For instance, in a study done in South Africa by Maleka (2006:8) on the HIV/AIDS-related needs of lowest strata employees, provision is made for lowest strata employees in their HIV awareness campaigns at the end of a shift to speak to an HIV and AIDS counsellor about how to deal with situations in which they fear they have transmitted or contracted HIV (Forbes, 2003:43).

5.4 CONCLUSION

This chapter has examined the challenges single mothers experience regarding the disclosure of their HIV status, and has presented and interpreted the data collected by means of an interview schedule. From this source (the interview schedule) the conclusion was reached that single HIV infected mothers face numerous challenges regarding disclosing their HIV status. These factors are located in the family, the community and the workplace. This in turn affects their quality of life. Another conclusion arrived at was that HIV positive single mothers are prepared to disclose, albeit under certain conditions. The findings also led to a conclusion that in times of adversity especially with regard to being a victim of a pandemic such as HIV and AIDS the eco-system theory principles are discarded or ignored. The final chapter (Chapter 6) will constitute the brief summary of the research findings, conclusions based on the data collected and presented data, as well as recommendations resulting from the findings. The limitations of the study will also be outlined.
CHAPTER 6

THE RECOMMENDATIONS AND CONCLUSIONS OF THE STUDY

6.1 INTRODUCTION

Any research intends to arrive at certain findings and conclusions. These findings are directly derived from the data presented by sources of data in that particular research. The previous chapter tabled and discussed results. This chapter constitutes the brief summary of the research goals and objectives of the study, discussions of the key themes that emerged from the empirical findings as discussed in Chapter 5, the value of the study, and its limitations. This chapter will reflect on recommendations with the view of improving the problems highlighted earlier in the statement of the problem in Chapter 1. The chapter also captures recommendations for further research and conclusions based on the data collected.

While working at the Department of Social Development, as well as at NGOs, the researcher observed that little research has been carried out on the care of patients or preventative work regarding the impact of HIV and AIDS on households, specifically in the South African context. Moreover, little has been published on the challenges single mothers specifically experience with regard to the disclosure of their HIV positive status (Makin et al., 2008:1).

The rationale for this study develops as a result of observations made by the researcher as a social worker while working in the field of HIV and AIDS. The researcher observed that the stigma and discrimination, among other, associated with HIV and AIDS, make it difficult for single mothers living with HIV and those with AIDS to disclose their status, as they often experience feelings of rejection and blame, ambivalence, and a fear of death. These reasons often lead to single mothers choosing not to share any information concerning their HIV positive status and preferring instead to continue engaging in unprotected sexual activities (Parker & Aggleton, 2002:8). The outcome of the study will support professionals who are working in the field of HIV and AIDS and assist them in becoming aware of the challenges that single mothers experience regarding the disclosure of their HIV status. Furthermore, in order to establish which intervention and counselling services are needed most to support these mothers in disclosing their HIV status, social workers would need to know more about their challenges. This will be done through an accurate reference to the research question
which forms the basis of this research. More specifically the study intended to answer the following question:

“What are the challenges that single mothers experience with regard to the disclosure of their HIV status?”

The goals and objectives of the study were attained in order to answer the research question: “What are the challenges that single mothers experience with regard to the disclosure of their HIV status?”

6.2 GOAL AND OBJECTIVES OF THE STUDY

The goal of this study was: To explore the challenges that single mothers experience regarding the disclosure of their HIV status. The researcher reports that this goal was achieved and important information regarding the challenges that single mothers experience regarding the disclosure of their HIV status was obtained and presented in this study.

In order for the researcher to achieve the above goal, the following objectives were developed and operationalised:

- To explore factors preventing disclosure in relation to the family, community and workplace

The objective to explore factors preventing disclosure in relation to the family, community and workplace was reached by conducting a comprehensive literature research. Consequently, this objective was met as the researcher conducted an extensive literature study of all literature pertaining to challenges experienced by single mothers regarding the disclosure of their HIV status. However, as limited research has been conducted on single mothers who are infected with HIV and those with AIDS, the researcher was forced to review literature that predominantly focused on ‘parents’ or women who are infected, rather than only on single mothers. Relevant books, internet resources, articles and media reporting with regard to challenges that single mothers experience regarding the disclosure of their HIV status were accessed. In addition professionals and lay persons working in the field of HIV were consulted. Furthermore, using the information obtained in the literature review the researcher developed a semi-structured interview schedule that guided the researcher when conducting the interviews with the participants.
• To determine factors that may affect the social functioning and quality of life of single mothers

The objective to determine factors that may affect the social functioning and quality of life of single mothers was reached by interviewing the single mothers who were diagnosed with HIV and had referred themselves to the office of the Staff Wellness to receive emotional support. Subsequently, this objective was definitely met as the participants were interviewed using the semi-structured interview schedule as a basis for conducting the interviews. In addition the researcher obtained written permission from the participants to digitally record their responses. After a comprehensive data analysis of the transcribed interviews the researcher interpreted the data as explained in Chapter 5, in order to present the factors that may affect the social functioning and quality of life of single mothers.

• To identify factors that will help single mothers to disclose their status in the family, community and workplace

The objective to identify factors that will help single mothers to disclose their status in the family, community and workplace was met in that a number of recommendations were formulated in correlation with the extensive literature review and the empirical findings from the interviews that were conducted with the research participants. This leads the researcher to discuss the specified key findings that were identified within the empirical study.

6.3 DISCUSSION OF KEY THEMES THAT EMERGED FROM THE EMPIRICAL FINDINGS

Key findings on challenges that single mothers experience regarding the disclosure of their HIV status were as follows: judgemental attitudes; lack of trust; gossip by family, community members and colleagues about single mothers’ HIV status; humiliation and criticism; fear of hurting loved ones; and discrimination. In addition the key themes and sub-themes that the researcher identified in this study substantiate the empirical findings as discussed below.
6.3.1 Theme 1: Factors that may hinder the participants from disclosing their HIV status in the workplace, family, and community

In Chapter 5 a detailed discussion focusing on various factors that may hinder the participants from disclosing their HIV status in the workplace, in the family, and in the community was given. These factors include judgemental attitude; lack of trust; gossip by family, community members and colleagues about single mothers' HIV status; humiliation and criticism; fear of hurting loved ones; and discrimination. Regarding factors that prevent single HIV positive mothers from disclosing their status, it emerged from the study that stigma and discrimination still persist in the lives of women living with HIV and those with AIDS despite government initiatives to create HIV and AIDS awareness. The literature review in Chapter 3 in correlation with the empirical findings of this study confirmed stigma and discrimination as challenges that participant’s experience, which prevent them from disclosing their HIV status. These challenges were also supported by literature from the United State Agency for International Development (USAID) / Synergy (2004), which argues that perceived negative reactions discourage people from disclosing their HIV positive status. The empirical findings of this study in correlation with the literature review clearly indicate that discrimination and stigma, as reported by other studies, were experienced by the study participants and still persist as barriers to disclosure. PLWH and those with AIDS find it difficult to disclose their HIV status, because they fear rejection and being victimised by family members, the community and colleagues. For a prominent example of such a story, the researcher refers to Mpho Motloung who was murdered with her family by her husband who then placed a sign on her grave that read “HIV-positive AIDS” (Skinner & Mfecane, 2015). Another theme that emerged in this study was the way the different factors may affect the participant’s social functioning and quality of life.

6.3.2 Theme 2: The way the different factors may affect the participant’s social functioning and quality of life

In this theme the researcher found that as far as the social functioning and quality of life of participants is concerned, it emerged that the single mothers experience challenges from family members, the community and colleagues that affect not only their social life, but also their quality of life. The results have shown that their quality of life is affected by a lot of negative feelings, the prominent one being stress. The literature review conducted in Chapter 3 together with the empirical findings of this study correlate and show that the diagnosis and disclosure of an HIV positive status itself is a major source of stress. In this research, the main source of stress seems to originate from mistrust regarding disclosure,
confidentiality and arguments (most probably about their health status). Stress in HIV persons is aggravated by the attitude, utterances and behaviour of those who claim not to be infected. All the other negative feelings, for example feeling isolated and neglected, discomfort, and fear, are a manifestation of the underlying stress. Furthermore, the researcher concluded in Chapter 5 after the empirical findings were analysed that as a result of stress, the infected single mothers feel sicker and become hurt and angry about their status. The findings suggest that it is important for HIV positive people to maintain a healthy frame of mind in order to manage HIV and AIDS effectively, as HIV is a disease that affects every aspect of a person, including the mind (Thompson, 2011:64). As explained in Chapter 3, dwelling on negative feelings has the potential to affect one’s health and affects the quality life of HIV positive mothers. One of the participants elaborated on a range of other negative feelings she went through and related the following:

*I feel hurt, I ask myself why we, as human beings, can’t be compassionate towards one another. It is very painful when someone speaks about you; you wonder whether they know their status. I also get filled with anger, to the extent that I will go up to the person and say ‘I know what you are saying about so-and-so. Do you know your status?*

In the contrary, the results have displayed that for some people prolonged hurt due to a debilitating condition, can lead to resilience. This in essence suggests that adversity can equip the victims various ways of adapting to the ever-changing environment. These findings are accord with eco-systematic approach/theory in that they have brought an understanding of the various ways a person may adapt to an ever-changing environment in order to cope and survive as a family system as explained in Chapter 1. This includes coping with the community and the workplace.

6.3.3 Theme 3: Factors that may support the participants to disclose their HIV status in the workplace, family and community

In this theme the researcher found that concerning factors that may support the participant to disclose their HIV status in the workplace, family and community, support groups emerged as the favoured option. Generally, the picture elicited by this study is that the concept of support groups needed to be implemented and developed in order to facilitate disclosure, whether at home or at the workplace, and to facilitate acceptance of an HIV positive status. In addition, role models who have disclosed their status have been found to be useful in facilitating disclosure. Through role models, the workplace can create an environment where negative talking is discouraged and instead, employees who are HIV positive can be
encouraged to disclose their HIV status. The researcher would therefore recommend that professionals working in the field of HIV need to become aware of which intervention and counselling services are needed by single mothers who are HIV positive in order to disclose their HIV status. This leads the researcher to the value of this type of study with regard to the challenges that single mothers experience regarding the disclosure of their HIV status in South Africa.

6.4 VALUE OF THIS STUDY

It is the researcher's opinion that this study has made a contribution with regards to the knowledge of the challenges that single mothers experience regarding the disclosure of their HIV status. In addition this study will assist all professionals working in the field of HIV and AIDS. Although the sample was small, professionals working in the field of HIV and AIDS would be able to draw information from this study in order to better assist the single mothers living with HIV and those with AIDS when they have to disclose their HIV status.

Based on the limited literature that is available, further research that explores the challenges that single mothers experience regarding the disclosure of their HIV status is needed. This leads to the researcher to discuss the limitations of this study.

6.5 LIMITATIONS OF THIS STUDY

The study in question provides important findings to the literature, yet there are some limitations to the study as well. No research is perfect (Holloway & Wheeler, 2010:42) meaning that there are aspects that might restrain the study. The following were identified as limitations:

- There was a limit in relation to communication. Some of the HIV positive single mothers were not able to respond to the questions without being emotional and declared that they were still coming to terms with their status. This might have further limited the quality of responses.
- Another limitation is the nature of the sample itself. The study focused on one group of people, namely black single mothers. Therefore the generalisation of findings should be cautioned.
- The findings of this study would have been more informative if single fathers and married mothers were also interviewed, as well as women from other racial groups.
Yet the results are important, because mothers are the ones faced with the huge responsibility of looking after families.

- A further limit was that the study was conducted on non-academic female employees who come from a poor socio-economic background and whose level of literacy is also low; this could result in biased findings.

However, regardless of these limitations, the study managed to gather useful information about the plight of single mothers who are HIV positive and who are employed at the institution regarding disclosing their HIV status.

6.6 RECOMMENDATIONS

The main intention of any research is to identify a particular problem, investigate the problem, and establish the possible remedial measures. According to Hofstee (2006:159), these recommendations are also called suggestions for the application of research and must be realistic to implement and clearly be valuable. Based on the empirical findings of this study and on the literature review, the following needs for further research and to be taken note of by professionals in this field, were identified:

- Alert the Vaal University of Technology to the issues surrounding issue of HIV and disclosure – The HIV and AIDS campaigns should include the theme of disclosure, as a way of showing how significant disclosure is. Such programs should in fact not only attempt to provide information about HIV, but they also need to take into consideration the public communication networks that influence how information is received. Indeed the programs should also be challenging the mind-sets and stereotypes that people still have towards HIV and AIDS.
- Reveal conditions that might facilitate disclosure – In order to facilitate disclosure, families, communities and employment sectors should be educated about their roles and responsibilities in creating an atmosphere that embraces the culture of disclosure.
- Sensitise the university to the needs of HIV positive single mothers – Those who have already disclosed their status should be used as ambassadors in disclosure campaigns as a way of encouraging others to disclose and also as a way of educating all stakeholders that they (people who are HIV positive) need a supportive environment that is non-judgmental in order to disclose their status.
- Support groups should be established, as they have been found to assist in encouraging the acceptance of an HIV positive status and disclosure to others.
• Education plays an important role in the fight against HIV – Educational awareness should be provided to the entire community and these should be more on HIV counselling and testing so that communities can be encouraged to learn more about the aspects of living with HIV.

• Expose the quality of life of single mothers infected by the HIV virus – Educational awareness related to issues of healthy living and managing emotions by people living with HIV and those with AIDS should be put in place so as to assist them to maintain a healthy frame of mind in order to manage HIV and AIDS effectively and to maximize their quality of life.

• Add knowledge to the field of HIV and AIDS, health and social development – Social workers and other HIV specialists need to provide on-going support to mothers living with HIV and those with AIDS in the form of support programmes which include counselling and educational awareness. These also need to play a key role in facilitating programmes that encourage disclosure from women living with the HIV virus.

The researcher in her capacity as a Social worker and a staff-member in the Wellness Section will take a leading role in ensuring that most of the recommendations are implemented. This will be done in consultation with the university and other relevant stakeholders of the university such as policy makers and the Institutional HIV and AIDS Unit (IHAU) in this way the plight of participants will receive the attention it deserves.

6.7 RECOMMENDATIONS FOR FURTHER RESEARCH

The literature review clearly indicates that other researchers and writers have researched on the care of patients or preventative work regarding the impact of HIV and AIDS on households, specifically in the South African context. Moreover, little has been published on the challenges single mothers specifically experience with regard to the disclosure of their HIV status and therefore the following are seen as the avenues for further research:

• More research needs to be conducted to explore the experiences of people living with HIV regarding the disclosure of their HIV status, particularly married mothers from different races.

• Another study can be conducted on experiences of single fathers in disclosing their HIV status.
• A comparative study can be done on the challenges experienced by males and females who are HIV positive in disclosing their status.
• A comparative study can be done on the challenges experienced by single, HIV positive mothers whose level of education is high as compared to those whose level of education is low regarding disclosure.
• A study can be done on the effect the age of family members has on disclosing one’s HIV status.

6.8 CONCLUSIONS

Stigma and discrimination, among other, associated with HIV and AIDS make it difficult for single mothers living with HIV and those with AIDS to disclose their status, as they often experience feelings of rejection and blame, and ambivalence to mention few. Hopefully this study will motivate and encourage continued research in order to explore effective ways of assisting the single mothers, in allowing the single mothers to share their experiences as a way to facilitate and encourage disclosure. There is a paucity of research in regard to the challenges that single mothers experience regarding the disclosure of their HIV status and this matter needs to be urgently addressed. There is a need to play a key role in facilitating programmes that will encourage disclosure from women living with HIV and those with AIDS. Stigma and discrimination prevent PLWH and those with AIDS from disclosing their status and from receiving the care and support they need when living with HIV. In the light of the results of this study the researcher would advocate for effective intervention. Social workers and other specialists who are working in this field of HIV and AIDS need to provide on-going support to mothers living with HIV and those with AIDS. This study reports an in-depth qualitative understanding of the challenges that single mothers experience regarding the disclosure of their HIV status. Furthermore, the empirical findings of this study emphasise the challenges that single mothers are experiencing regarding the disclosure of their HIV status, factors that hinder them from disclosing their HIV status in the community, family and workplace, and recommendations for further research in this area of study. In addition, it is the researcher’s opinion that the empirical findings and recommendations of this study will motivate and encourage continued research in order to explore effective intervention of assisting the single mothers who are living with the HI virus and have to disclose their status.
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Appendix A: Ethics Approval

1 April 2014

Dear Prof Lombard

Project: The challenges parent single mothers experience regarding the disclosure of their HIV status
Researcher: QM Mogamisi
Supervisor: Prof GM Spies
Department: Social Work and Criminology
Reference numbers: 27445292

Thank you for the application that was submitted for ethical review.

I am pleased to inform you that the above application was approved by the Research Ethics Committee on 27 March 2014. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof Karen Harris
Acting Chair: Postgraduate Committee & Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:karen.harris@up.ac.za

Research Ethics Committee Members: Dr L Blokland, Prof Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris (Acting Chair); Ms H Kruiper; Dr C Pareibocone-Warns; Dr Charles Puttergill, Prof GM Spies; Dr Y Spies; Prof E Taljaard; Dr P Wood
Appendix B: Ethical clearance

FACULTY OF HUMANITIES
RESEARCH ETHICS COMMITTEE

APPLICATION FOR ETHICAL CLEARANCE

PLEASE NOTE:

1. Researchers using HUMAN respondents as sources of information for data capturing, must complete ALL the sections
2. Researchers using OTHER sources of information for data capturing do not have to complete sections 4.1 and 5 to 9
3. An application is only considered once approval is granted by the Departmental Research Committee and all required documentation is provided
4. An electronic copy of this form is available from [link]

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2. OBJECTIVES OF THE RESEARCH - Please list.

The goal of this research study is to explore the challenges single mothers experience with regard to the disclosure of their HIV status.

The objectives of the prospective study are:
- To explore factors preventing disclosure in relation to the family, community and workplace
- To determine factors that may affect the social functioning and quality of life of single mothers
- To identify factors that will help single mothers to disclose their status in the family, community and workplace

3. SUMMARY OF THE RESEARCH

Please provide a brief overview of the planned research (maximum 250 - 300 words)

The intention of this study is to explore the challenges single mothers experience regarding the disclosure of their HIV status.

The theoretical framework that will guide the researcher is the eco-systematic approach and thus by following the eco-systematic approach, in this study the researcher will explore single mothers experiences with all the systems in the community to which they are connected and the way the systems create challenges for them during the disclosure of their HIV status.

A qualitative approach will be followed in this research. The researcher is interested in exploring the cultural, religious, economic and emotional challenges that single parent mothers are experiencing regarding the disclosure of their HIV status in the community in which they live.

The most suitable data collection method for the research will be semi-structured interviews, supported with an interview schedule. The interview schedule will contain certain themes, and will serve as a guideline to ensure that the necessary information is obtained, while the interview will remain flexible. Open-ended questions, constructed on the basis of each theme, will be developed to guide the researcher during the interviews and will be used to elicit information from the interviewee.
The researcher will make use of a pilot test in order to ensure that this open-ended question provides adequate opportunity for the participants to respond. This pilot study will test whether themes from the participants’ responses from the open-ended question can be accumulated.

Audio recordings will be made during the interviews and each interview will be transcribed. During the data-analysis phase categories, themes and patterns will be highlighted for the database and coded together. The researcher will present the data, during the final phase of the data-analysis in a complete research report. Conclusions and recommendations will be based on the outcome of the study and knowledge that can support professionals who are working in the field of HIV and AIDS, and assist them in becoming aware of the challenges that single mothers experience regarding the disclosure of their HIV status. This can also support social workers in determining which intervention and counselling services are needed most to support these mothers.

4. SOURCES OF INFORMATION AND/OR DATA

4.1 HUMAN PARTICIPANTS

4.1.1 Where and how are participants selected?

In the proposed study there will be no sample and sampling methods as the researcher will use the whole population.

The criteria for selection of participants for this study are the following:

- Single mothers who are employees of the Vaal University of Technology.
- Single mothers who are diagnosed with HIV.
- Single mothers who voluntarily came to the office of the Staff Wellness of University of Technology and disclosed their HIV status to receive emotional support.

4.1.2 If participants are asked to volunteer, who are being asked to volunteer and how are they selected?

Not applicable

4.1.3 Will any incentives be offered to persuade the subject to participate?

Yes ☐  No ☐ x

If Yes, please specify.

4.1.4 If records of participants are to be used, specify the nature of these records and indicate how they will be selected.
4.1.5 Has permission been obtained to study and report on these records?
Yes ☐ No ☐ Not applicable ☑
*If Yes, letters must be attached.*

4.1.6 Characteristics of participants:

- Number: 12-15
- Gender: Female ☑ Male ☐
- Age range: Between 23 and 58 years

Characteristics: Participants must be single mothers, who voluntarily came to the office of the Staff Wellness of University of Technology and disclosed their HIV status to receive emotional support.

4.1.7 Has permission of the relevant authorities (e.g. school, hospital, clinic) been obtained to conduct research within that organization/ institution?
Yes ☑ No ☐ Not applicable ☐
*If Yes, letters must be attached.*

4.1.8 Indicate data collection methods to be carried out with participants to obtain data required by marking the applicable box(es):

- ☐ Record review
- ☑ Interview schedule (*Attach if available. If not, submit at a later stage, together with initial approval of Ethics Committee.*)
- ☐ Questionnaire (*Attach if available. If not, submit at a later stage, together with initial approval of Ethics Committee.*)
- ☐ Clinical assessment (e.g. tests)
- ☐ Procedures (e.g. therapy). *Please describe.*
- ☐ Other *Please specify.*

As the researcher regards in-depth interviewing as the most appropriate form of data collection for this proposed research study, the theme for the interview will centre on the following open-ended question that will be directed at the participants:

“What are your experiences and views regarding the challenges that you are facing to the disclosure of your HIV status?”

4.1.9 If professional evaluation/assessment and treatment procedures are to be used, is the researcher registered to carry out such procedures? *Please specify*

Not applicable
4.1.10 If the researcher will not personally carry out the procedure, state name and position of person who will.

Not applicable

4.1.11 Is a life history used as information source?
   Yes □  No □  x

   Is permission required for the disclosure of the source?
   Yes □  No □  Not applicable □x

   If Yes, has permission been obtained? (Attach proof)

   If No, explain

4.1.12 Are the opinions of experts obtained?
   Yes □  No □  x

   Is permission required for the disclosure of the source?
   Yes □  No □  Not applicable □x

   If Yes, has permission been obtained? (Attach proof.)

   If No, explain.

4.2 OTHER SOURCES OF INFORMATION AND/OR DATA

4.2.1 Document Analysis
   Yes □  No □  Not applicable □x

4.2.2 Are the documents in the public domain?
   Yes □  No □  Not applicable □x

   If Yes, please disclose.

   If No, has permission been obtained to study the documents?
   Yes □  No □  Not applicable □x

   If Yes, attach approval.

5. INFORMED CONSENT

5.1 Attach copy of consent form(s) printed on the official letterhead of the Department within which the research resides.

Please find a copy of the consent form attached as Annexure A

© University of Pretoria
5.2 If participants are under 18, or mentally and/or legally incompetent to consent to participation, how is their assent obtained and from whom is proxy consent obtained? Please specify.

Not applicable

5.3 If participants are under 18, or mentally or legally incompetent, how will it be made clear to the participants that they may withdraw from the study at any time? Please specify.

Not applicable

5.4 If the researcher is not competent in the mother tongue of the participants, how will you ensure the participant's full comprehension of the content of the consent form? Please specify.

Not applicable

6. RISKS AND POSSIBLE DISADVANTAGES TO THE PARTICIPANTS

6.1 Do participants risk any potential harm (e.g. physical, psychological, legal, social) by participating in the research?

Yes □ x No □ If Yes, answer 6.2.

6.2 What safeguards will be taken to reduce the risks? Please specify

The researcher will create an opportunity for emotional support directly after each interview to identify and address potential psychological harm of the participants or any misinterpretation pertaining to the study. Although the researcher will be available to attend to the participants regarding the content and goal of the study, they will also be referred to the Health Promoter of the Campus Clinic at Vaal University of Technology for counseling if any emotional or psychological distress is identified. The Health Promoter is informed of the nature and goal of the study.

6.3 Will participation or non-participation disadvantage the participants in any way?

Yes □ No □ x If Yes, explain.

7. DECEPTION OF PARTICIPANTS

Are there any aspects of the research about which the participants are not to be informed?

Yes □ No □ x
If Yes, please justify.

8. BENEFITS TO THE PARTICIPANTS

Will participation benefit the participants?

Yes ☑️ No ☐

*If Yes, please describe briefly.*

I am aware that there are no direct benefits for participating in this study. However, participation in this study might contribute to a better understanding of the challenges that single mothers experience regarding the disclosure of their HIV status. This may contribute to more effective service rendering to single mothers who are diagnosed with HIV, and who have to disclose their HIV status. This study is intended to assist HIV and AIDS organizations in providing this population group with appropriate and needed services.

9. CONFIDENTIALITY/ ANONIMITY

9.1 Will anonymity of participant(s) be protected?

Yes ☐ No ☑️ Not applicable ☑️

*If Yes, describe how.*

Full anonymity of the participants cannot be assured as the identity of the participants will be known to the researcher.

9.2 How will the confidentiality of information be assured? *Please describe.*

Only the researcher will be familiar with the identity of the participants. Audio recordings will be utilised as part of the data-collection method and the informed consent of the participants will be obtained in writing (see appendixE). The participants’ names and personal detail will never be disclosed, neither on the recordings, the transcriptions nor in the research report or to any other person, except to the Health Promoter if the participants request support and counselling themselves.

10. DISSEMINATION OF RESEARCH RESULTS

10.1 To whom will results be made available?

The results will be made available to the internal and external supervisors of the researcher and also in the research report.

10.2 In which format do you expect results to be made available?

Please mark those applicable:

☐ Doctoral thesis ☐ x Masters Dissertation ☐ Honours Research Report

☐ x scientific article ☐ conference papers ☐ book

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11. STORAGE OF RESEARCH DATA

11.1 Please note that according to the University of Pretoria policy, data must be securely stored for a minimum of 15 years. Where and in what format will the data be stored? Please specify.

The data will be safely kept in the format of transcripts for a period of 15 years according to the stipulation of policy of the University of Pretoria in the Department of Social Work and Criminology. This will be explained to the participants.

11.2 For what uses will data be stored? Please mark those applicable:
- [ ] research
- [ ] teaching
- [ ] public performance
- [x] archiving

11.3 If data is to be used for further research, how will participants' permission be obtained?
- [x] Informed consent form
- [ ] Other Please specify.

11.4 Have the above issues been addressed in the letter of informed consent?
- [x] Yes
- [ ] No

12. OTHER INFORMATION

Please describe any other information that may be of value to the Committee when reviewing your application.

Not applicable

13. CHECKLIST OF ATTACHMENTS

COMPULSORY:
- [ ] Research Proposal

If appropriate:
- [x] Letter(s) of Informed Consent (on University of Pretoria Letterhead) with an explanation of the intent of the research
☐ x Permission from relevant authorities (on the institution's letterhead and/or with their stamp) for study to be conducted

☐ Questionnaire

☐ Interview Schedule
14. SUBMISSION DETAILS

RESEARCHER / APPLICANT

Name in capital letters: ……………………………………………………………………..

Signature: ........................................... DATE: .........................................

STUDY SUPERVISOR

I am of the opinion that the proposed research project is ethically acceptable

Ethical Implications □ No ethical implications □

Name in capital letters: ……………………………………………………………………..

Signature: ........................................... DATE: .........................................

CHAIR: DEPARTMENTAL RESEARCH COMMITTEE

Name in capital letters: ……………………………………………………………………..

Signature: ........................................... DATE: .........................................

HEAD OF DEPARTMENT

Name in capital letters: PROFESSOR ANTOINETTE LOMBARD

Signature: ........................................... DATE: .........................................

CHAIR: FACULTY RESEARCH ETHICS COMMITTEE

Name in capital letters: PROFESSOR JOHN SHARP

Signature: ........................................... DATE: .........................................

With acknowledgement to Harvarthrd University 1999-2000, and the University

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Appendix C: Declaration of own work

UNIVERSITY OF PRETORIA
FACULTY OF HUMANITIES
RESEARCH PROPOSAL & ETHICS COMMITTEE

DECLARATION

Full name: Queen Mphonyana Mogamisi

Student number: 27445292

Degree/Qualification: MSW (Play therapy)

Title of mini-dissertation: The challenges that single mothers experience with regard to the disclosure of their HIV status.

I declare that this mini-dissertation is my own original work. Where secondary material is used, this has been carefully acknowledged and referenced in accordance with university requirements.

I understand what plagiarism is and am aware of university policy and implications in this regards.

SIGNATURE........       DATE........
Appendix D: Permission from VUT (HR Department) to do research

17 October 2013

Attention: Mrs Queen Mogamisi: Staff Number (2010239)

RESEARCH: VAAL UNIVERSITY OF TECHNOLOGY (HR DEPARTMENT)

Be informed that permission is granted to do research at VUT.

CSM Phatudi
EXECUTIVE DIRECTOR: HUMAN RESOURCES DEPARTMENT
Appendix E: Informed consent from the participants

INFORMED CONSENT
OF THE RESEARCH PARTICIPANT

Researcher: Ms Q.M. Mogamisi

Name of institution: University of Pretoria

Name of participant: _______________________

Date: _______________________

I, the undersigned, confirm that I have been informed of the following information regarding the research study.

1. Title of the study:

   *The challenges that single mothers experience with regard to the disclosure of their HIV status.*

2. Purpose of the study:

   The purpose of this study is to explore the challenges single mothers experience regarding the disclosure of their HIV status.
3. Procedures:

The researcher will conduct an in-depth interview with me as the participant and the interview will be guided by the following question:

*What are the challenges that I experience as a single mother with regard to the disclosure of my HIV status?*

The length of interview will be approximately one to two hours.

4. Risks and discomfort:

To my knowledge, there are no known risks or discomfort associated with this research study. I will inform the researcher if I experience any distress because of the content of the interview. I will be free to withdraw myself from the interview/study at any time. Debriefing will be available to me directly after the interview, and should further support be requested by me, the researcher will refer me for counselling to the Health Promoter of the Campus Clinic at Vaal University of Technology.

5. Benefits:

I am aware that there are no direct benefits for participating in this study. However, participation in this study might contribute to a better understanding of the challenges that single mothers experience regarding the disclosure of their HIV status. This may contribute to more effective service rendering to single mothers who are diagnosed with HIV, and who have to disclose their HIV status. This study is intended to assist HIV and AIDS organisations in providing this population group with appropriate and needed services.

6. Financial compensation:

I understand that I will not gain financially, or in any other way, from this study.

7. Confidentiality:

I am aware that the interview will be audio-recorded to verify my responses, and notes will be taken during the interview to ensure the precision of data that will be collected. All
information will be viewed as confidential, and my personal identity will not be disclosed to any person or in any document. As the results of this study will be published in professional journals, or presented at professional conferences, my identity as a participant will be protected at all times. The data obtained from this interview may also be used for future research purposes.

Transcripts will be made of the interview and the data will be kept at the University of Pretoria in the Social Work and Criminology Department for a period of 15 years.

8. Questions:

Should I have any concerns or questions regarding this research study, I can call the researcher Ms Queen Mphonyana Mogamisi at: 016 950 9382 or 083 559 2939.

I hereby give my informed consent to participate in this research study. I am aware I will receive a signed copy of this consent form.

Respondent’s signature...........    Researcher’s signature...........
Appendix F: SEMI-STRUCTURED INTERVIEW SCHEDULE

INTERVIEWING QUESTIONS

1. Factors that may hinder the participants to disclose their HIV status in the workplace.
2. Factors that may hinder the participants to disclose their HIV status in the family system.
3. Factors that may hinder the participants to disclose their HIV status in the community.
4. The way these different factors affect the participant’s social functioning and quality of life.
5. Factors that may support the participants to disclose their HIV status in the
   5.1. work place
   5.2. family
   5.3. community
Appendix G: Socio – Demographic Questionnaire

PERSONAL INFORMATION

Age group in years: 28-33, 34-44 and 45-58

Accommodation and Family Composition

Where do you live?

<table>
<thead>
<tr>
<th>urban</th>
<th>township</th>
<th>Farm</th>
<th>Other, specify...</th>
</tr>
</thead>
</table>

Do you live in your house?

Yes ☐
No ☐

How many people are living in the house?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

In which type of house are you staying?

<table>
<thead>
<tr>
<th>Brick</th>
<th>Clay</th>
<th>Shack</th>
<th>Flat</th>
<th>Zinc</th>
<th>Other, specify...</th>
</tr>
</thead>
</table>

Do you?

Rent ☐
Own ☐
Staying with parents ☐
Other, specify... ☐

WORK STATUS AND INCOME

Are you employed?

<table>
<thead>
<tr>
<th>Permanent</th>
<th>Contract</th>
</tr>
</thead>
</table>

How long have you been employed? ______________

What is the total income in the household per month?

EDUCATION LEVEL

What is the highest qualification you have?

<table>
<thead>
<tr>
<th>Never been to school</th>
<th>Grade 1-3</th>
<th>Grade 4-6</th>
<th>Grade 7-9</th>
<th>Grade 1-12</th>
</tr>
</thead>
</table>

Race: African ☐ white ☐ Black ☐ Coloured ☐ other ☐

Thank you for your co-operation and time.

Researcher: Queen Mogamisi
016 950 9382
083 559 2939