

**THE EXPERIENCES OF WOMEN LIVING WITH HIV AND AIDS IN CENTURION,
GAUTENG PROVINCE**

by

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submitted in accordance with the requirements for
the degree of

MASTER OF PUBLIC HEALTH

at the

UNIVERSITY OF SOUTH AFRICA

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JUNE 2014

DEDICATION

To my parents, who always stood behind me and knew I would succeed. Gone now but never forgotten. Your words of inspiration and encouragement in pursuit of excellence still linger on.

DECLARATION

I declare that **THE EXPERIENCES OF WOMEN LIVING WITH HIV AND AIDS IN CENTURION, GAUTENG PROVINCE** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before any other degree at any other institution.

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ACKNOWLEDGEMENTS

I would like to express my sincere gratitude and appreciation to the following people:

- Ms. Habedi and Professor Mgutshini, my thesis supervisors, for their teaching, guidance and advice throughout the course of this research,
- The participants, for sharing their time, feelings and experiences with me,
- My husband, Noble, for his constant encouragement and belief in me,
- My son, Panashe, for his understanding and patience the time I had to be away to concentrate on my study,
- Mr. Maseko, for his critical reading and editing of this research and
- Finally, to the Almighty God for giving me the opportunity and the brains, I would not have achieved this far without his mercy.

ABSTRACT

This qualitative study aimed to explore and describe the experiences of women living with HIV and Aids in Centurion, Gauteng Province. The study was conducted at Lyttleton clinic and 12 women living with HIV and Aids were selected for the study using a non-probability, purposive sampling technique. In-depth, individual semi-structured interviews were used during data collection. A thematic content approach in data analysis yielded the following main themes: experience of being diagnosed HIV positive, disclosure of an HIV positive status, physical signs and symptoms of HIV and Aids, stigma/ emotional stress well experiences in services rendered. The study highlighted the need for a well-established health system, assisting women living with HIV and Aids on how to cope and to raise awareness on HIV and Aids.

KEY CONCEPTS

Experiences, HIV and Aids, women living with HIV and Aids, Centurion, Gauteng Province, thematic content analysis.

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LIST OF ABBREVIATIONS

AIDS	Acquired immune – deficiency syndrome
CDC	Center for disease control
HIV	Human immune-deficiency virus
PLHIV	People living with HIV and Aids
ART	Anti-retroviral treatment
LP	Lyttleton participant

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CHAPTER 1: ORIENTATION TO THE STUDY

1.1 INTRODUCTION

HIV and Aids is a global pandemic that affects individuals, families and communities around the world. Although some progress has been made in preventing new HIV infections and lowering the annual number of Aids related deaths, Aids continues to constitute a major global health priority as the number of HIV infected individuals continues to increase. Globally, young women aged 15-24 are most vulnerable to HIV and the disparity is most pronounced in Sub-Saharan Africa where 3.1% of young women are living with HI virus compared to 1.3% of young men (UNAIDS 2012:8).

HIV and Aids in South Africa has become a prominent health concern. South Africa has been reported to have the highest prevalence of HIV and Aids compared to any other country in the world with a reported number of 6.4 million people living with HIV and Aids in 2012 (HSRC 2014:25). Although adult prevalence has stabilized at about 17%, the absolute number of people living with HIV (PLHIV) is on a steep increase of approximately 100 000 additional PLHIV each year (UNAIDS 2012:51). The Human Sciences Research Council (HSRC) reported that HIV incidence in South Africa indicated that 469 000 new HIV infections occurred in the population 2 years and older in 2012 (HSRC 2014:37).

The impact of HIV and Aids is multidimensional. According to UNAIDS (2012:33), HIV and Aids affects both the individual and society. HIV and Aids has caused much suffering, confusion, uncertainty, and hopelessness in humanity. In addition, on the individual level, the effects of this syndrome do not only cause damage at a biological level but also at psychological, social, spiritual, and financial levels.

In South Africa, HIV prevalence varies according to provinces with some provinces more severely affected than others. The provincial HIV prevalence for 2012 was as follows: Eastern Cape = 11.6%; Free State = 14.0%; Gauteng = 12.4%; Kwazulu Natal

= 16.9%; Limpopo = 9.2%; Mpumalanga = 14.1%; North West = 13.3%; Northern Cape = 7.4% and Western Cape = 5.0% (HSRC, 2012: XXIV).

The City of Tshwane Metropolitan Municipality (CTMM) has a population of approximately 2.1 million people which translates to 911 536 households according to the 2011 census (City of Tshwane Draft IDP Review 2013:11). The HIV infection rate in CTMM in 2010 was reported to be 26.1%. According to the report on the state of HIV and Aids response in the CTMM, the total number of adults older than 15 years of age in need of ART was estimated to be 80 134 whilst those in need of anti-retroviral initiation were 25 595 in 2011 (The state of HIV and Aids services response in the City of Tshwane 2011:12). This study was conducted at Lyttleton Clinic in Centurion, which also falls under CTMM. According to the 2011 census, the total population of Centurion was estimated at 236 580. According to the monthly statistics at Lyttleton clinic, 169 women visited the clinic's ART site and got tested for HIV and Aids, and 29 of them tested HIV positive.

With regard to the above statistics, recommendations that can improve policy making about women living with HIV and Aids have not yet been made. This research therefore aimed to describe the experiences of women living with HIV and Aids. Women between the ages of 18-49 years were interviewed. The researcher chose this age group because in South Africa, most data or statistics on HIV prevalence considers the ages 15-49 as the reproductive age population (HSRC 2014:43). This is also the most sexually active and child bearing age group that visits the clinic often for HIV and Aids services. The researcher, however in this study chose to study participants from the age of 18 rather than 15 as these were capable of giving their own consent to participate in the study.

1.2 BACKGROUND AND RATIONALE OF THE RESEARCH STUDY

Globally, women make up half of all people living with HIV and Aids. Women experience the effects of the epidemic in many ways, whether HIV positive themselves or as

primary caregivers in families and communities affected by HIV and Aids (Khana 2010:7). The Centre for Disease Control (CDC) estimates reported that there are nearly 300 000 women living with HIV in the United States. Over the past 30 years the epidemic's toll on women has worsened and now appears to have stalled at a stubbornly high level. The CDC further contends that in 1985, women presented 8% of HIV infections each year in the US and by 2006 that had more than tripled to 27% (CDC 2006:23).

According to Rohleder (2009:37), the HIV prevalence rate among women is generally higher than that of men. A survey conducted by the HSRC of South Africa suggests that the incidence rates among females remain a concern. In 2012 the number of new infections among adults 15-49 years was 1.7 times higher in females than in men. The HIV incidence rate among females in youth aged 15-24 was over four times higher than the incidence rate found in males of the same age group (HSRC 2014:37). In 2008, the adult HIV positive female population in South Africa (15 years+) was 3 230 000. In the Tshwane district of Gauteng province, the HIV prevalence among ante-natal women remained constant at 26.1% from 2008 to 2010. Countrywide, 30.2% of pregnant women aged 15-49 were living with HIV/AIDS in South Africa in the year 2010 (HIV and Syphilis Prevalence Survey 2010:58).

Invariably, women carry the burden of HIV and Aids as a disease. Upon a family member becoming ill, it is the role of women as carers, income-earners and housekeepers which is stepped up. Women are often forced to step into roles outside their homes, for example; some women may be forced to turn into prostitution and others end up moving into the traditionally male-dominated industries like the carpentry industry as a way of finding extra income as well as cover medical fees (Congressional Research Service Report 2006:12).

In Sub-Saharan Africa, the HIV and Aids epidemic has historically concentrated in urban areas, where significantly higher prevalence rates have been recorded than in rural areas (Van Donk 2006:157). Although official statistics based on antenatal surveys do

not disaggregate HIV prevalence in urban and rural areas in South Africa, closer scrutiny revealed that prevalence rate in urban areas is often higher compared to rural areas. This could be due to the fact that urban areas are centres of employment and income generating opportunities as a result many young adults migrate to urban areas in search of economic security. In addition, urban areas generally have higher levels of public services such as housing, education, health care and welfare facilities and this attracts people. Migration, therefore, as a livelihood strategy is associated with higher levels of risk of HIV infection (Mutinta 2012:101). The above points under 1.2 where the reasons behind the rationale of this study and why the researcher particularly focused on women in an urban setting.

1.3 STATEMENT OF THE RESEARCH PROBLEM

UNAIDS (2011:14) contends that women must be equal and valued partners in decision making if sexual transmission of HIV and Aids is to be reduced by 50% and prevalence by 75% by 2015, in accordance to millennium development goal 6 and target 7. However, according to its report, almost thirty years since the onset of HIV epidemic, there has been failure to meaningfully engage women living HIV as leaders in prevention efforts.

In South Africa, pregnant women are often encouraged to test their HIV status during their ante-natal clinic routine visits. This makes the group central to a statistical analysis of HIV prevalence in the country. During 2009, HIV amongst pregnant women in South Africa was estimated at 29.4% (Department of Health 2010: 41). Being the first member of the family to be tested during ante-natal care, women tend to be blamed for bringing HIV into the family and are therefore exposed to a number of experiences in the family and in the community.

As reported by the UNAIDS (2011:24), women and girls continue to be affected disproportionately by HIV as they are twice more likely to acquire HIV from an infected

partner during unprotected heterosexual sex than men. Furthermore, women generally have greater physiological susceptibility to contracting the HIV virus than men. In addition, in the traditional African society men are more powerful. Women's vulnerability to HIV and Aids in many cultures is due to their positions in society and therefore at an increased risk of contracting HIV. The UNAIDS report goes further and states that most cultural expectations of masculinity encourage men to assume the patriarchal attitude that wives, partners and daughters are the possessions of men and most husbands demand their conjugal rights.

Women living with HIV and Aids are faced with difficult circumstances and their lives are affected in different ways. Little exploration of this has been carried out particularly in South Africa. Seemingly, it is not clear what should be done to support and improve the lives of women living with HIV and Aids. A successful rights based response to HIV prevention requires the involvement of women living with HIV and Aids, especially young women at all levels in the design and implementation of policies and programmes (UNAIDS 2011:17).

The above mentioned information on 1.3 motivated the researcher to conduct this study as the aim of this research is to describe the experiences of women living with HIV and Aids. This might help in making policy recommendations with regard to the effects of HIV and Aids for strategy formulation purposes (Horton 2006:213).

1.4 AIM OF THE STUDY

The aim of this study is to investigate the experiences of women living with HIV and Aids. The study sought to answer the research questions below.

1.4.1 Research questions

- What are the experiences of women living with HIV and Aids?
- Which recommendations can improve policy making with regards to women living with HIV and Aids?

1.4.2 Research objectives

- To describe the experiences of women living with HIV and Aids.
- To make recommendations for policy makers to support women living with HIV and Aids.

1.5 SIGNIFICANCE OF THE STUDY

It is hoped that by addressing the experiences of women living with HIV and Aids, the outcome of the study will:

- To enable the development of guidelines and recommendations to policy makers that would assist in the healthcare of women living with HIV and Aids.
- Also contribute to the already existing knowledge on experiences of women living with HIV and Aids in the Tshwane district and Gauteng province.

1.6 DEFINITION OF TERMS

HIV: HIV is an abbreviation for Human Immunodeficiency Virus. It is known as a transmissible retrovirus that causes Aids in humans. It comes in two forms that are now recognized as HIV-1 and HIV-2 (Kartikeyan, Bharmal, Tiwari and Bisen 2007:3).

Aids: AIDS is the abbreviation for Acquired Immune Deficiency Syndrome. It is called 'acquired' because it is not a disease that is inherited but caused by the virus that enters the body from outside. AIDS is a collection of many different conditions that manifest in

the body. It is known as a syndrome of opportunistic diseases, infections and certain cancers — each or all of which has the ability to kill the infected person in the final stages of the diseases (Dyk 2008:4).

Experiences: experiences are defined as knowledge resulting from what one has undergone. It refers to a practical acquaintance with facts or events. In this study, the term experiences refers to knowledge, facts or events that the study participants have undergone as a result of living with HIV and Aids (Shorter Oxford English Dictionary 2007:899)

Woman: refers to an adult female human being (Shorter Oxford English Dictionary 2007: 3 675). In this particular research, woman refers to an adult female being who is being regarded as the study participant, who is between the ages 18–49 years and living with HIV and Aids.

Counselling: According to UNAIDS (2011:6), it is defined as an interpersonal, dynamic communication process between a client and a trained counsellor, who is bound by code of ethics and practice to resolve personal, social, or psychological problems and difficulties.

Disclosure: refers to the process in which one partner shares his or her HIV status with another partner or any other person after learning about their HIV test results alone (WHO 2012:9).

1.7 FOUNDATIONS OF THE STUDY

1.7.1 Research paradigm

The study is of a pure generic qualitative tradition. Qualitative research is research that aims to generate data that comprises words and pictures. It is focused on words and experiences in order to understand and explain behaviour (Moule and Goodman 2009:171). The scholars further contend that qualitative research looks at questions around life experiences, beliefs, motivation, actions and perceptions.

Fox and Bayat (2007:30) state that there are three common aims of research which are: exploration, description and explanation. Exploratory research involves exploring a topic in order to gain some preliminary insights into the key issues to help shape future research because there is not much in existence. It seeks to investigate an under-researched aspect of life. Descriptive research involves describing situations and events. The interest is in understanding participants' experiences (Fox and Bayat 2007:30). This investigation is qualitative in nature as it used in-depth individual semi-structured interviews to explore and provide a thick description of the experiences of women living with HIV and Aids.

According to Moule and Goodman (2009:206), qualitative research is most commonly part of inductive reasoning. The authors explain that inductive reasoning is a process of starting with details of an experience, or our observations or something and using these to develop a general understanding of phenomenon. In addition, there is interaction with participants. The researcher in this study used an inductive approach to investigate the experiences of women living with HIV and Aids. The researcher made use of a person-centred approach and hence, considered participants as whole human beings and not a collection of physical parts.

1.8 RESEARCH DESIGN

A non-experimental, exploratory and descriptive research design based on qualitative approach was applied in this study. The purpose of an exploratory research design is to enhance the researcher's comprehension of a phenomenon (Babbie 2007:95). The researcher seeks to understand the experiences of women living with HIV and Aids.

An exploratory research is often used when there is limited knowledge and understanding of the subject being studied. The researcher attempted, during data collection, to gather new information and gain insight into this subject by exploring the experiences of women living with HIV and Aids.

A descriptive research presents a picture of the specific details of the specific situation, social setting or relationship, and focuses on 'how' and 'why' questions (Kreuger and Newman 2006:23). Furthermore, a descriptive research assisted the researcher to obtain a better understanding of the experiences of women living with HIV and Aids.

In this study, the experiences of women living with HIV and Aids were investigated in order to have a detailed picture of the extent of the problem and to contribute to the body of knowledge in this important area of public health (Joubert 2007:78). Data for this qualitative research was presented in a descriptive form mainly in the words of the study participants.

1.9 RESEARCH METHODS

1.9.1 Research setting

The research was conducted at Lyttleton Clinic in Centurion. The researcher chose this health facility because it is the most convenient and accessible site to the researcher since the researcher stays in the same area. The researcher used facilities at this clinic occasionally and came across a number of women receiving HIV and Aids treatment at this facility. This sparked the researcher's interests to find more about the experiences of women living with HIV and Aids. Moreover, the clinic has a well-established ART site which serves many women living with HIV and Aids.

Below is an aerial view map showing Lyttelton Clinic in Lyttelton, Centurion, Gauteng.



Fig 1.1: Aerial map showing Lyttelton Clinic, Centurion, Gauteng

1.9.2 Research population

According to Joubert (2007:94), the study population is the group which the researcher intends to gather information and draw conclusion from. Gerish and Lacey (2010:142) state that the whole total population that forms the focus for the study is known as the target population. In this study, all HIV and Aids positive women attending Lyttelton Clinic constituted the research population during the time of data collection. A sample was drawn as it was not possible to study the entire population of women living with HIV and Aids.

1.9.3 Sample and sampling technique

The research engaged a non-probability technique, purposive sampling. This type of sampling method is used when the researcher specifies the characteristics of interest and then locates individuals who match the needed research study. The researcher in this case chose a sample of HIV-positive women between the ages of 18 and 49 years, who attend, get help and treatment at the clinic (Larry, Johnson and Turner 2011:159). This is a qualitative study and no statistics were used to draw the sample.

The researcher chose purposive sampling for this study because it allows for selection of key individuals from the spectrum in which the researcher is interested (Joubert 2007:101). Purposive sampling includes intensity sampling which focuses on examples of the phenomenon. Samples are small and rich in information. In this study, 12 participants were selected for intensive exploration on the experiences of HIV-positive women. The few informed participants chosen gave insightful and reality based perspectives and information on the experiences of women living with HIV and Aids (Ulin, Robinson, and Tolley 2005:57).

1.9.4 Sample size

A small sample size was chosen and interviewed as suggested by (Terre Blanche, Durrheim and Painter 2006:50). The small sample size chosen assisted in avoiding generating mountains of interview data Brown in (Terre Blanche et al 2006:50). However, the final number of 12 participants interviewed was determined by the criterion called saturation of information. This is the point in the study where the researcher begins to hear the same information repeatedly being reported and she no longer learns anything new (Babie 2007: 305-306). The interviews lasted for 30 minutes to an hour. Terre Blanche et al. (2006:300) are of the idea that people find it difficult to concentrate in an interview lasting beyond an hour and a half.

1.9.5 Inclusion criteria

The research participants were chosen based on the following characteristics:

- Only HIV-positive women.
- Females aged 18-49 years. The researcher chose this age group because it is the most affected and sexually active group, the so called producers and providers. Younger women are particularly vulnerable and can have sex in exchange for goods or money (Tallis 2012:105).
- Only women seeking help at Lyttleton Clinic in Centurion.
- Only those who were willing to participate. Participation in the study was voluntary.

1.9.6 Exclusion criteria

- Women who had never been tested and who were not aware of their HIV status were not included in the study.
- HIV and Aids-positive women who were mentally disturbed could not participate in the study as they could not be able to give sound, meaningful answers.
- Women aged below 18 years and above 50 years were not considered for the study. These are not considered as mostly sexually active and in addition those below 18 were not in a position to give consent on their own without their parents' permission.

1.10 DATA COLLECTION

The researcher made use of in-depth individual semi-structured interviews as a means of data collection. Green and Thorogood (2009:94) state that in depth interviews allow the interviewees enough time to develop their own accounts of the issues important to them. The in-depth interviews allowed the respondents to express their experiences of living with HIV and Aids. The researcher took the position of a facilitator to help

respondents talk freely. Open questions to seek clarification, illustration and further exploration were used (Balls 2009:3).

A pilot study was conducted one week prior to the main study. The purpose of the pilot study was to find out if participants would understand the purpose of the study, the interview questions, and if there were any changes to be made prior to the data collection process. A pilot study is a dress rehearsal for all members of the field team in a mock venue with characteristics of the actual research setting (Ullin, Robinson and Tolley 2005:123). Two trial respondents with the same inclusion characteristics were interviewed at the research setting, Littleton Clinic. The same participants were not included in the real study. During the pilot study, the same interview guide that was used in the real main study was used. Interviews were recorded by a digital voice recorder exactly the same way it was done in the main study. A trial run of data management and analysis was also conducted by the researcher to check the need for further revision on the interview guide, instruments and data collection process (Ullin et al 2005:124).

After conducting the pilot study, the researcher then conducted the main study. Although the researcher made use of pre-planned questions on a face to face encounter, the researcher allowed questions to flow naturally based on the information provided by the respondents. The flow of the conversation mainly dictated the questions asked and those omitted. Follow-up prompts based on the initial response were used to generate further discussion.

The interviews were conducted in a flexible and open-minded inquiry. The researcher took some field notes and at the same time recorded the interviews to refer to later during data analysis. Field notes were taken in English, the same language used during the interviews. Data records were kept in a locked cabinet to which only the researcher had access.

1.11 DATA ANALYSIS

Data analysis is the description of what is done with data during and after data collection to obtain a clearer picture of what the information conveys to us (McNee and McCabe 2008:33). The researcher used a thematic content analysis approach for data analysis. The process involved searching through data about the experiences of women living with HIV and Aids as given by the study participants to identify any recurrent patterns. This process was done through data coding. Data coding is a process that involves reading, thinking about and labelling every piece of data in order find it easily later in analysis. Coding is undertaken so that portions of data about similar topics, ideas, actions or communication can be easily identified and compared (Griffiths 2009:137).

1.12 SCOPE AND LIMITATIONS OF THE STUDY

No attempt was made to generalise the findings of this study to a larger population as the research was limited to HIV-positive women only. The study is also about the experiences of women living with HIV and Aids in Centurion and only limited to Lyttleton Clinic. The findings were not be generalised to the whole of Gauteng province nor whole of Centurion.

In addition, due to the complexity of a positive status, not every participant managed to give detailed information as some participants withheld information which was sensitive to them.

1.13 STRUCTURE OF DISSERTATION

Chapter 1: Introduces the problem under study and the motivation for the study.

Chapter 2: Presents the literature review related to this study.

Chapter 3: Describes the research design and methodology.

Chapter 4: Describes the analysis, presentation and description of the research findings.

Chapter 5: Presents the summary, conclusions and makes recommendations for further study.

1.14 CONCLUSION

This chapter discussed the background and rationale for the study, problem statement, research questions, purpose and objectives of the study, as well as the paradigmatic perspective on which the study was based. The research design and methodology were also briefly discussed. The next chapter, chapter 2, will present the literature review related to this study.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 1 introduced the problem under study and the motivation of the study. This chapter reviews literature related to this study. Booth, Papaioannov and Sutton (2012:2), define literature review as a systematic, explicit and reproducible method of identifying, evaluating and synthesizing the existing body of completed and recorded work by researchers, scholars and practitioners. Literature review aims at giving background of current knowledge on a topic and highlights the necessity for new studies. It provides essential background knowledge about similarities and differences between the present study and prior research studies done which are relevant to a particular topic (Burns and Groove 2007: 137).

Booth et al (2012:3) are of the idea that one of the aims of literature review is to learn whether findings are consistent across multiple studies, since disagreements among findings are valuable whilst conflicts, on the other hand, provide more knowledge. The authors further explain that this helps in identifying settings in which a particular social policy might succeed, under what circumstances an educational program might work best or what dose of drug is most effective. In addition, literature review aims to highlight weaknesses in evidence to argue for further research and to offer a valuable aid to decision making.

In summary, the purposes of literature review are highlighted in the following table:

Table 2.1: Purposes of Literature Review

Purposes of literature review according to Booth et al (2012:4)

- To place each work in the context of how it contributes to an understanding of the subject under review.
- To describe how each work relates to others under consideration.
- To identify new ways to interpret and shed light on gaps in previous research.
- To identify and resolve conflicts across seemingly contradictory previous studies.
- To identify what has been covered by previous scholars to prevent needlessly duplicating their efforts.
- To signpost the way forward for further research.
- To locate the authors original work within existing literature.

Literature review in this study aims to produce extensive reference to research related to the experiences of women living with HIV and Aids in order to set the research in context, to explain some of the key work conducted previously and to show how the current research topic builds up on that (Oliver 2012:131). In order to meet the aims of this literature review, the researcher sought answers to the following questions:

1. What are the experiences of women living with HIV and Aids?
2. What kind of treatment do HIV positive women face from their health providers in health care settings?
3. Which recommendations can improve policy making with regards to women living with HIV and Aids?

2.2 PRE-REVIEW CONSIDERATIONS

The researcher felt that, the research topic, 'Experiences of women living with HIV and AIDS' was unique in its own way. Factors surrounding HIV and Aids are very complex since the epidemic is spreading throughout the world. Disclosure of HIV status has

rendered women especially vulnerable to rejection by partners and family and even subjects them to violence (Cloete, Strebels, Simbayi, van Wyk, Henda and Nqeketo 2010: 1). Literature review on this topic assisted in the exploration on experiences of women living with HIV and Aids, enabling the researcher to appropriately position the research amongst the sources consulted and to set the research context. Furthermore, literature review on this topic provided a framework in evaluating policy recommendations about the kind of support given to women living with HIV and Aids.

2.3 DATA SEARCH STRATEGY

The researcher consulted with the research librarian at UNISA to help search for studies that met the eligibility criteria. The search included browsing through several electronic data bases including Pub med, med forum, med Line, EBSCO, CINAHL and Pro Quest. In addition, websites such as Google and Google Scholar were also used.

The researcher consulted both national and international literature related to the experiences of women living with HIV and Aids. When conducting the searches each phrase was used independently or sometimes combined with other key terms using the Boolean operator. The words “AND” and “OR” were placed between two or more search terms. The key phrases that were used to search from the above databases were:

- Experiences of HIV positive women
- Women AND HIV and Aids
- HIV and Aids AND experiences
- Social experiences AND HIV, OR women
- HIV/AIDS affecting women
- Women and HIV in South Africa
- HIV/AIDS in Gauteng Province
- Religion AND HIV positive women
- HIV positive AND culture

The initial search from the search term “experiences of HIV positive women” yielded 2 293 articles. The table 2.2 below gives an outline of how the researcher went through the process of refining the literature search conducted:

Table 2.2: Refining of Literature Search

Total identified n = 2 293	
Databases:	<i>Pub med-293</i> <i>med forum-307</i> <i>med Line-54</i> <i>EBSCO-594</i> <i>CINAHL-594</i> <i>Pro Quest-374</i> <i>Psychinfo -156</i>
Articles requiring title review n = 2 293	
Excluded	= 2 193
<i>Process of refining search:</i>	
<ul style="list-style-type: none">▪ <i>Firstly, the EBSCO data base was used. To narrow down the search results, the use of ‘controlled vocabulary’ was utilized by the researcher that is the researcher made use of the vocabulary that appeared automatically on the search results page under each article title in the left column under "Subjects." The location of ‘controlled vocabulary’ varied from data base to data base.</i>▪ <i>For the Pro Quest database, on the results page, controlled vocabulary appeared above the search results and in the lower right column, under headings including "Subject,"</i>▪ <i>Secondly, the researcher limited the search results according to the language, only English articles were selected.</i>▪ <i>A timeline of 2006 to present was also selected to limit the search results.</i>▪ <i>The researcher made use of the phrase ‘HIV/AIDS and Women’ to select studies that particularly focused on only women.</i>	
Articles requiring title and abstract review: 100	

Excluded: 79

Process of refining search:

- *The researcher made use of quotation marks around search phrases.*

Reason: Since databases do not recognize context inherent in phrases. They understand words as individual, unrelated items. So quotation marks around search phrases force the database to search for the phrase as a whole, not just the words here and there. Example: "Women AND HIV and Aids"

- *The researcher looked at the study titles and study population, only studies that were conducted on 'HIV positive Women' were selected*

Articles requiring full text review = 21

Data extraction n=21

2.4 ELIGIBILITY CRITERIA FOR INCLUSION OF STUDIES WITHIN THE REVIEW

- Types of participants - Only those studies that used women who are HIV positive as study participants were considered. Most importantly, studies that looked into experiences of HIV positive women and the treatment they received from their health care providers were also considered for inclusion within the review.
- Only studies which were published in English were included in the review.
- Studies that specifically focused on HIV positive women and evaluation of the treatment they received were included in the literature review.
- Only studies that were conducted from 2006 to present were selected for literature review.

2.5 REVIEW REMIT

The preliminary literature search yielded a great number of studies and most of them were not adequately relevant to the research topic. Some were older than seven years and others did not discuss 'HIV positive women' but rather included studies on men who have sex with other men. Most studies did not meet the inclusion criteria and were excluded due to some of the following reasons:

- Studies which made use of quantitative methods of data collection.
- Studies not focusing on women in particular regarding their experiences of living with HIV and Aids.
- Studies which were vague in terms of methodology utilized by the researchers.
- Internet articles such as newspaper articles and reports which were not research articles.

Table 2.3: A Summary of Studies Analysed in the Review

Author and Study title	Summary of the study	Primary findings
Rochon (2012:55-67): HIV positive and Pregnant: Defying the Social Order.	A qualitative study on HIV positive pregnant women. Purposive sampling was used to choose the study participants and in depth interviews were used for data collection.	The study participants revealed experiences of both negative unsupportive attitudes whilst on the other hand some participants reported on having received positive attitudes from family and health care workers. Lack of confidence and understanding of HIV and Aids information from health providers as well as judgmental attitudes from health care providers.
Iwelunmor and Airhihenbuwa (2012:134-149): Cultural implications of death and loss from HIV and Aids among women in South Africa	The study recruited 110 women from three communities in Cape Town. Focus group methodology was used to explore participants' perceptions surrounding death and loss from HIV. Out of the 110 participants, 67 were females from families with HIV positive women and 43 were HIV positive women.	The study findings revealed that participants experienced fear of death from HIV and Aids and viewed HIV and Aids as a death sentence. However, some of the participants revealed a positive attitude in accepting their sero positive status and in believing that HIV and Aids is a disease like any other disease and that if treatment was taken one would survive. The cultural belief in life after death also kept some participants going.
Rohleder and Gibson (2006:25-40): We are	The purpose of the study was to explore how women experienced	In the study themes such as stigma emerged and some felt they were

<p>not fresh: HIV positive women talk of their experience of living with their 'spoiled identity.'</p>	<p>and dealt with AIDS stigma under conditions where they had little formal support. In depth narrative interviews were conducted with ten HIV positive women living in a poor black township in Cape town.</p>	<p>living with a 'spoiled' identity. Experiences of some social discourses of HIV emerged such as HIV positive people being viewed as dangerous, dirty and contagious.</p>
<p>Duplessis (2011:465-476): Individual responsibilities for health and HIV infection: A critical investigation of the lived experiences of HIV positive women.</p>	<p>Multiple in depth interviews were conducted over a period of two years with ten women at public health care clinics in Gauteng to examine their uptake of prescriptions. Transcription narratives were analysed using qualitative coding of emergent themes. Interviews were conducted on how these women struggled with their spoiled identity as women living with HIV and Aids.</p>	<p>The study findings demonstrated how material deprivation, dependence on the state and stigma contoured the lived experiences of these women. HIV positive women were faced with having to deal with stigma, forging an identity as a woman living with HIV and Aids, being fearful of losing relationships and support due to disclosure of HIV status.</p>
<p>Tshabalala and Visser (2011:20-37): Developing a cognitive behavioural therapy model to assist women deal with HIV and Stigma.</p>	<p>A cognitive behavioural therapy was developed, implemented and assessed to assist women deal with internalized stigma. A mixed method, in depth interviews and focus group discussions were conducted. Aims of the study were to gather information about women's beliefs that influence their emotional reaction to HIV and how they cope, to develop an understanding of how they experience HIV, people's reaction towards them and how they cope with stigma.</p>	<p>The study revealed that being HIV positive and trying to cope with stigma involves diverse experiences. Participants experienced feelings of worthlessness, guilt and anger, fear about the future, anticipated being stigmatized and had behaviour detrimental to their own health.</p>
<p>Richardson</p>	<p>An observational and longitudinal</p>	<p>According to the study findings, pain</p>

<p>(2009:503-6510): Experience of Pain among Women with advanced HIV disease.</p>	<p>six centre cohort study was carried out to evaluate pain frequency and severity among HIV positive women. 339 women were enrolled in the women's interagency HIV study (WIHS). Data was collected over a period of two years. Face to face interviews were conducted for data collection. A five point analogue scale was used to describe/ rate pain severity.</p>	<p>frequency was not associated with age, education, ethnicity or current therapy or location. Pain frequency and severity was related to lower CD4 count, higher depression with a history or longer duration of drug use such as Marijuana or smoking. The primary study finding was that pain is frequent and often severe among women with HIV requiring medical management.</p>
<p>Melton (2011:300-310): Sex, Lies and Stereotypes: HIV Positive Black Women's Perspectives on HIV Stigma and The Need for Public Policy. Prevention Intervention, Race, Gender and Class</p>	<p>Interview data was drawn from 30 HIV positive black women in an inner city in Florida, America to study HIV positive black women's perspectives on HIV stigma and the need for public policy.</p>	<p>The main findings of the study suggests that in addition to gender, race, and class oppression, stigma stereotypes and ineffective public policies shape HIV prevention efforts. In addition, HIV and Aids were found as a leading cause of death among women of ages 25-34 years in African Americans.</p>
<p>Ross, Sawatphanit, Draucker and Suwansujarid (2007:730-742): The lived experiences of HIV-positive women in Thailand.</p>	<p>The purpose of the study was to examine the lived experiences of ten pregnant women in Thailand following HIV diagnosis. In depth interviews with open ended questions were conducted during 2000-2001. Each participant was interviewed 5-12 times.</p>	<p>Struggle was the main theme that emerged in the study findings from the participant's lived experiences. Struggling alone, sharing one's struggle, struggling for the baby and struggling through ups and downs were some of the study participant's lived experiences.</p>

Themes that emerged during the literature search were outlined as follows: physical experiences of women living with HIV and Aids, social, emotional, spiritual and cultural experiences for HIV positive women. These themes are discussed in detail below.

2.6 PHYSICAL EXPERIENCES OF WOMEN LIVING WITH HIV AND AIDS

Most research has indicated that women living with HIV and Aids are exposed to a number of physical experiences and amongst them the following were reviewed by the researcher: violence forced or coerced sterilization and physical pain. These experiences are discussed in detail below.

2.6.1 Violence

According to UNAIDS (2010:134), gender inequality and violence against women constitute one of the key drivers of the HIV epidemic. Violence against women is a persistent and devastating manifestation of gender-based discrimination. South Africa continues to experience a major HIV epidemic within a context of persistent and high levels of violence against women.

A study conducted on rural women living with HIV and Aids in South Africa by the Amnesty International asserts that most women continue to experience oppression in their relationships with male partners, within families and in the wider community as a result of their HIV status. The study findings established that women tend to be the first members of the family to be tested for HIV through ante-natal testing and are subsequently blamed for bringing HIV into the family. This can result in rejection or violence towards women from their spouses or in-laws (Amnesty International, 2008:44). A research done by the International Community of Women with HIV and Aids (ICW) on women and girls living with AIDS in South Africa reveals the same notion of violence in that some women in abusive relationships find it difficult to test for HIV as they fear they might die in their partner's hands or have their confidence and self-esteem flushed down the drain (Engender Health 2006:22).

The same experiences were also reported in one study conducted in the United Kingdom (UK), in which a certain participant reported that she was too scared to tell her

partner because it was too much, she was scared that he would leave her and being pregnant, she could not deal with it (PozFem UK 2008:4).

The above findings are consistent with the findings on a qualitative study conducted on challenges faced by people living with HIV and Aids (PLWHA) in Cape Town. The study findings revealed that HIV and Aids related stigma is still pervasive in local communities. This was associated with difficulty of disclosure of their HIV - positive status to spouses and family members as they were subjected to violence. This was particularly problematic where the women were financially dependent on the male partner. Disclosure often rendered women, especially, vulnerable to rejection and violence. This is further supported by a woman who reported that:

“When my partner discovered that he is also HIV positive, he wanted to kill us both, he was devastated” (Cloete et al 2010:5).

It is clear from the above that HIV positive women tend to experience some violence and are faced with difficulty when it comes to disclosing their HIV status. These findings confirm the need for issues of disclosure to be a central component of intervention for people living with HIV and Aids.

2.6.2 Forced or coerced sterilisation

Forced sterilisation is when a woman undergoes the procedure without her knowledge. Coerced sterilisation occurs when a woman is made to sign a consent form while in labour, under distress or without proper information and explanation. She is made to feel like she does not have a choice and that sterilisation is her only option (Turley 2012:1). Some HIV positive women in South Africa are being sterilized without their consent. They become victims of forced or coerced sterilisation. A qualitative study conducted by Strode, Mthembu and Essack (2012:65-66) on 22 HIV positive women’s experiences of involuntary sterilization in two South African Provinces brought out evidence of the practice of forced sterilization. In the study, some of the women reported being sterilized

without their informed consent. According to the study findings, it appears that HIV positive women were not seen as fit mothers who could live long and productive lives. Maputle and Jali (2008:45-51) argue that for interventions to be effective, every individual woman, more so those of child bearing age, needs to be empowered and updated with knowledge concerning HIV infection, the associated risks of transmission to their babies and the available options that might help them deal with the risks of infecting their babies with HIV.

Similarly, the ICW has documented cases in Namibia where HIV-positive women, minutes from giving birth, were encouraged to sign consent forms to prevent them from having more children. They were made to sign whilst they were in pain, not knowing what it was and thinking it was part of their HIV treatment. None of them knew what sterilisation was, including those from urban areas, because it was never explained to them. These women were therefore forced to do things that they were unaware of and without their consent (ICW 2006:44).

2.6.3 Physical pain

It has been established that women living with HIV and Aids have experiences of intense and persistent physical pain. This is supported in a study by Richardson (2009:506) on “Experience of Pain among Women with Advanced HIV Disease” which studied 339 HIV positive women. In the study, women suffering from HIV and Aids experience various types of pain which include abdominal pain, chest pains, headaches, muscular pains and others such as kidney and bladder. Furthermore it indicated that pain is a significant problem both in terms of intensity and persistence among women living with HIV and Aids (Richardson 2009:506).

In the study mentioned above by Richardson, lower CD4 as well as diagnosis and duration of clinical AIDS was highly correlated with increased pain severity. However, one limitation to this study could be the fact that the study was conducted at a time

when protease inhibitors were being introduced and Highly Active Antiretroviral Therapy (HAART) has changed dramatically since this data was collected. The study of pain mentioned above by Richardson was hampered by subjective measurement biases that are inherent in large clinical cohort studies. Due to the above limitations, the researcher therefore felt the need to explore more on the experiences of HIV positive women to generate more knowledge (Richardson 2009:506).

While examining the issue of pain among HIV positive women, the manifestations of the Aids as a disease can disturb other aspects of life functions such as mobility, social interactions and fear of uncertain future (Richardson 2009:507).

2.7 SOCIAL EXPERIENCES

On a social level, women have to deal with issues around stigmatization, social exclusion and disintegration of family structure and social support networks. Women living with HIV and Aids can sometimes be faced with a judgemental attitude from the health care providers leading them to stop seeking assistance from the health facilities (Ross 2007:40).

2.7.1 Stigma

Stigma manifests itself externally and internally and has different effects. External stigma refers to the actual experience of discrimination. This includes the experience of domination, oppression and exclusion. Internal stigma is the fear of being discriminated. It can be a mechanism of protecting oneself from external stigma and can result in the refusal or reluctance to disclose one's HIV positive status or the denial of HIV and Aids (Ross 2007:741).

People of mixed race have different mentality when it comes to HIV and Aids. They view people with HIV and Aids are still being viewed as having led a promiscuous life with

some believing that it is a black or gay disease. In addition, they tend to distance themselves from HIV giving it other names. They do not talk openly about it hence fostering stigma. In the Western Cape province of South Africa HIV and Aids is called “Ulwazi” which means “that thing” suggesting that it is a stigmatized illness that cannot be referred to by name (Cloete et al 2010:3).

Aids related stigma for women is reinforced or consolidated by their subordinate role in society. Women are forced to breastfeed their babies due to the societal belief that if a woman gives a baby formula feed brand it means she is HIV positive hence exposing her status. The author goes on further to show how HIV stigma and discrimination is escalating as HIV positive people are being discriminated against in their own home. One is expected to buy gloves and wear them when cooking and has to use her own cutlery (Cloete et al 2010:4).

HIV positive women only revealed their status to their spouses and family but not to friends and neighbours because of their fears of stigmatisation and discrimination. Sharing one’s struggle was always performed selectively. HIV and Aids related stigma has often been identified as a primary barrier to HIV prevention as well as the provision of treatment, care and support. This is because of the belief that HIV and Aids is somehow associated with the disgrace and shame that leads to further discrimination (Ross 2007:741).

2.7.2 Disintegration of family and support system

In a study that was conducted in Cape Town by Rohleder and Gibson (2006:33-40) on “We are not fresh” HIV positive women spoke of their experiences of living with their “spoiled identity”. The purpose of the study was to explore how women experience and deal with AIDS stigma under conditions where they have little formal support. In the study, HIV positive women seemed to capture an internalized sense of themselves as dirty, dangerous and contagious. Some women narrated giving up the possibility of

having sex with their partners and being viewed as dangerous even when preparing food (Rohleder and Gibson 2006:33-40).

Family structures and social support networks are being broken and family compositions changing as a result of HIV and Aids. This is evidenced by a significant finding on a study conducted in Uganda on the socio-economic impact of HIV on rural households which revealed that there are more women who have lost their husbands to HIV and Aids compared to men who have lost their wives. Female as well as child headed households are increasing in a number of African countries and family compositions are shaking with more and more women living with HIV and Aids having to live as single deserted women (Madhu 2013: 2).

Disintegration of family support system and networks continues to be one of the challenges experienced by PLWHA. Ndlovu, Ion and Carvalhal (2010:218) indicated that most women found disclosure of their status to their children and spouses very stressful and are faced with the guilt of keeping quite. This also complicated the children's questions regarding their deceased father's HIV status and subsequent shift in their perception of him.

2.7.3 Constraints on adhering to treatment

A study was conducted on women and girls living with HIV and Aids in rural South Africa where women living with HIV and Aids faced judgmental attitudes from health workers who believed that they should not have children because of the risk that HIV could be passed on to the infant during child birth or breastfeeding, or out of concern for the child if the parents die prematurely from AIDS (Esplen 2006:17).

Women living with HIV and Aids at times may be deterred from returning to health clinics by the judgmental attitudes of health workers who sometimes deny them their right to privacy and treat them with disrespect. Poor quality of services, when combined

with having to deal with bureaucracy and long queues, being at the mercy of everyone from a receptionist to ambulance drivers, doctors and pharmacists, means accessing and adhering to treatment can be an exhaustion, humiliating and traumatic process (Esplen 2007:10).

2.8 EMOTIONAL EXPERIENCES

Iwuagwu studied sexual and reproductive decisions and experiences of women living with HIV and Aids in Abuja, Nigeria. The purpose of the study was to explore the sexual and reproductive decisions and experiences of women in Abuja, who became pregnant and had a child after knowing their positive HIV status. In the study, most women said that they had difficulty in getting pregnant and this was often associated with lower CD4 count. Repeated miscarriages, preterm delivery, and infant death were common painful experiences for most of the women. One woman reported she had seven infants' deaths and another had four miscarriages (Iwuagwu 2009:123).

A similar study was conducted by Rochon (2012:66) on HIV positive women who were pregnant. The purpose of the study was to attend to challenging circumstances faced by women living with HIV and Aids and to assess the psychosocial and emotional treatment that they received from their health care providers. One of the major findings was that of the stress involved in the thought of infecting their children. Most women in the study found the HIV positive status emotionally trying, wondering what they had done and how to handle it if their children were to be born HIV positive. This is further supported by Maboko (2005:39) who studied the experiences of African women diagnosed with both HIV and cervical cancer. In the study it is indicated that HIV positive women experience denial and anger with most women taking a long time to accept the diagnosis of HIV and Aids. Some of them reported they did take the diagnosis seriously as they had not seen the symptoms by the time of the diagnosis.

It is important for women living with HIV to have clear and accurate information on reproductive health and links with HIV. Women living with HIV are often afraid to seek pre-natal care because of possible condemnation from health professionals who disapprove of their pregnancy. Stigma and discrimination sometimes manifested through forced or coerced sterilisation (Satande 2010:7).

To reach the target of eliminating new child HIV infections and keeping their mothers alive, it is critical to protect the sexual and reproductive health and rights of all women living with HIV. These include their right to access voluntary and confidential HIV counselling, accurate and non-judgmental information, quality treatment and to bear children in an environment free of stigma and discrimination (UNAIDS 2011:29)

2.9 SPIRITUAL EXPERIENCES

In a study conducted in the Democratic Republic of Congo on 'The Role of Religion in HIV positive Women's Disclosure Experiences and Coping Strategies in Kinshasa,' women's faith played an important role in their long term coping strategies. Conceptualising their infection as a path chosen by God and believing that God has the power to cure their infection comforted women and provided them with hope. The women used prayer to overcome the initial shock, sadness and anger of learning their HIV diagnosis (Marman, Cathcart, Burkhard and Behets 2009:965).

In addition, Ironson and Ironson (2006:11) further demonstrated the importance of spirituality in the lives of HIV positive women. One African American woman who had been diagnosed with HIV ten years before the time of the study described that she was touched by the Holy Spirit during an intense prayer for her by her people at church. This dramatic spiritual experience led her back to God and helped her to stop drugs and to accept her disease as a plan of God.

Women living with HIV describe how a profound spiritual experience can initiate a quantum change of spiritual transformation, which leads to an extensive change in behaviour, attitudes, beliefs and one's view of the world and the self, and may contribute to the discovery of a new meaning in living with HIV and Aids (Plante and Thoresen 2007:179).

Even after the onset of antiretroviral treatment, most women living with HIV often relied on religiousness and spirituality to cope with their disease. Several investigations have shown that spiritual well-being is associated with less depressive symptoms (Ironson and Ironson 2007:180). The authors further contend that spiritual beliefs that were described as helpful were those that viewed God as loving and forgiving, the belief in life after death, and the belief of being selected by God or a Higher Power to have HIV. Spirituality or religiousness can transform the challenge of living with HIV to a life with higher quality, with a greater sense of peace, love and connectedness to life. The central role of spirituality in coping and bringing a sense of meaning and purpose in living with HIV and Aids as a chronic illness has been emphasized in several qualitative research and research studies (Ironson and Ironson 2007:181).

In a study conducted by Plante and Thoresen (2007:181) on how the spiritual mind fuels physical wellness. According to the study, spirituality is linked to slower disease progression and better quality of life, directly and indirectly via finding meaning, benefit and purpose in life which in turn links them to less depressive symptoms and preserving an optimistic outlook. The diagram below illustrates how a spiritual mind is linked to physical wellness and a better quality of life.

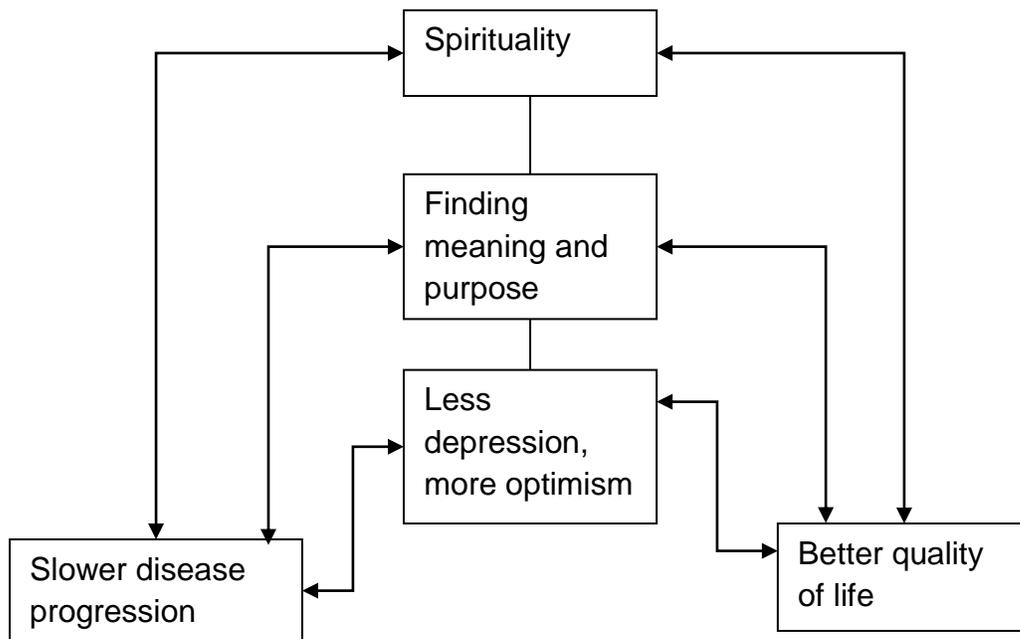


Figure 2.1: Spiritual Mind Linked to Better Quality of Life

However, further studies have revealed that church does not always come as a support system or coping strategy to some HIV positive women. In a study conducted by Melton (2011:309) on HIV positive black women's perspectives on HIV stigma, one participant, an old mother and grandmother, who defined herself as an educator, reported that she ran a support group and fed a complete meal to HIV positive women. She further mentioned that nobody from her church with the virus attended this support group. Historically, the black church was seen as a mecca for fighting oppression, a place where African American women could sustain one another spiritually, mentally and physically yet the HIV and Aids stigma has destroyed these women centred networks. Women with the HIV virus in this church did not attend these meetings or disclose their status.

2.10 CULTURAL

In a study by Melton (2011:303) on HIV positive women's perspectives on HIV stigma, HIV and Aids stigma divided Americans and portrayed positive people as outcasts. According to the study stigma for black women is coupled with historical negative images of African American women as sexually loose. One participant in this study reported that deviant behaviour such as doing drugs was frequently considered as the cause of HIV infection in her economically challenged neighbourhood.

Due to this negative historical image of HIV positive women, Melton (2011:308) states that many HIV positive black women remain silent to avoid stigma rather than openly seek education, treatment or prevention. These women would rather die in silence than have their status become public knowledge and risk losing their relationships and support systems (Melton 2011:308). In this study it is clear that stigma and stereotypes together with ineffective public policies shape HIV prevention efforts. This calls for a more holistic social and structural prevention intervention to HIV and Aids.

Contrary to the above study by Melton, a study conducted by Iwelunmor and Airhihenbuwa (2012:142) on cultural implications of death and loss from AIDS among women in South Africa, Cape Town reveals that death is taken in a positive way. In the study, even when HIV was associated with death, the belief in the persistence of life was a common theme generated from focus group discussions. This belief is also consistent with the African notion of life after death. For one participant in the study, the reality of living with knowledge of a sero-positive status was tied to the belief that there is life after death, in this case life after discovering that one is HIV positive. Furthermore, this notion was also supported by a strong sense of being reborn as one participant remarked that believing that HIV sero-positive status was the end of one's life, she accepted her HIV sero-positive status and that it was like a new life she had to start, that is, it was like she was reborn again (Iwelunmor and Airhihenbuwa 2012:142).

As much as HIV positive women may want to practice safer sex in order to avoid re-infection, the reality is that they may not be in a position to do so. One woman reported that as much as they were having counselling and information about the necessity to practice safer sex, her husband forced her into having unprotected sex because of the fact that she was his wife and that he had paid *lobola* for her (Personal testimony, South African positive young woman, 2003). Many health programmes fall short of helping HIV positive women, especially young ones, to acquire the knowledge, negotiating skills, assertive behaviours or the ability to say 'no' to unprotected sex (ICW 2003:4).

On the other hand a study conducted by Iwuagwu on sexual and reproductive decisions and experiences of women living with HIV and Aids in Abuja, Nigeria reveals the issue of culture in terms of cultural beliefs that are associated with breastfeeding. The purpose of the study was to explore the sexual and reproductive decisions and experiences of women in Abuja, who became pregnant and had a child after knowing their positive HIV status. In the study, most women reported that their culture valued breastfeeding and that every woman is expected to breastfeed her child hence a popular saying, "every animal feeds its own". There are some beliefs that if children are fed cow milk, they will act like an animal. For this reason, measures such as herbs to stimulate the flow of breast milk or the use of a wet nurse when the child's mother dies are implemented. Hence women were faced with having to balance cultural expectations and pressure to breastfeed against their need to prevent infecting their babies. One woman expressed fear that her baby might not bond with her or recognize her if she did not breast feed (Iwuagwu 2009:125).

2.11 OTHER EXPERIENCES

2.11.1 Death

The possibility of a shortened survival time amplifies the HIV positive women's anxiety. In a study conducted by Maboko on the experience of African women diagnosed with

both HIV and Aids and cervical cancer, HIV positive women experienced fear of death and its consequences, particularly about what would happen to their children when they die (Maboko 2005:43)..

Iwelunmor and Airhihenbuwa (2009:140) studied cultural implications of death and loss from AIDS among women in Cape Town, South Africa. The study participants included 110 women recruited from three communities of South Africa, out of them, 67 were female family members living with HIV positive women while 43 of them were women living with HIV and Aids. Focus group interviews were used to explore the participants' perceptions surrounding death and loss from HIV. The study findings revealed that there were negative and positive perceptions related to how women cope and respond to death and loss from HIV.

In the study, the belief that HIV and Aids was a death sentence was evident in the participants' perspectives. Some participants believed that living with HIV and Aids signalled the end of everything particularly as it becomes difficult to continue with life. One participant reported she believed she was going to die irrespective of what she was going to do and that death was the only thing she could wait for (Iwelunmor and Airhihenbuwa 2012:145).

On the contrary, some participants in the same study revealed that people living with HIV and Aids should not consider HIV and Aids a death sentence because there is treatment. Some participants reported that treatment allowed people with HIV and Aids to cope well with the disease. In the study the participants revealed that every disease kills because death is for everybody, however, the potential for surviving any disease such as HIV and Aids involves taking one's treatment because doing so enables people living with HIV and Aids (PLWHA) to live a long life. One participant stated that HIV is like living with a cold. There was a sense that HIV was like a chronic disease such as high blood pressure and therefore treatable when one takes treatment as required. According to the study participants, when one takes treatment as required, one will live

for a long time until they die as they have to since death is for everybody (Iwelunmor and Airhihenbuwa 2012:141).

Acceptance of one's sero-positive status was amongst the themes that emerged in the study findings by Iwelunmor and Airhihenbuwa (2012:140). In the study it was revealed that notions of hope are pivotal in coping with negative experiences of living with HIV and Aids. Acceptance of one's sero-positive status was expressed in terms of living day by day with HIV, rather than thinking that you are going to die in 10-15 years. As one woman living with HIV and Aids explained that even if she had the virus, she accepted it and is treating it the way it is supposed to be treated.

However, Niehaus (2007:854) argues that the representation of persons living with HIV and Aids as being 'dead before dying' is more likely the main source of stigma often experienced by people living with HIV and Aids as well as their family and community members.

2.11.2 Psychological stress and feelings of powerlessness

Ross (2007:732) maintains that women diagnosed with HIV in both developing and developed countries often manifest psychological distress, including low self-esteem, fear, anxiety, depression and suicidal ideas. He further asserts that depression, shame and suicidal ideas are common among sero-positive mothers of young children. Struggling alone during the earliest phase of HIV acknowledgement seemed to be the hardest time for all women. While struggling alone, they experienced feelings of shock, fear, anxiety and depression. Half of the women thought about ending their lives (Ross 2007:741).

Due to the perception that HIV is a result of deviant behaviour, some women feel and speak of their HIV infection as being a kind of punishment and taking it as a death sentence (Rohleder and Gibson 2006:35).

According to Tshabalala, Jan, Visser and Maretha (2011:20), HIV-positive women tend to experience irrational thoughts of failure, powerlessness and worthlessness. One woman expressed these feelings in an interview:

“My confidence has been lowered because I sometimes do not regard myself as a person.”

The scholars further contend that women tend to pity, isolate and neglect themselves and develop destructive behavioural patterns. They often feel uncomfortable when other people talk about HIV as if there is something that tells them that people know about their status and therefore pass remarks to make them feel bad. The research therefore shows the necessity of exploring the cognitive behavioural therapy model with HIV positive clients in the development of intervention strategies (Tshabalala et al 2011:20).

2.12 CONCLUSION

The literature presented in this chapter largely focused and explored the experiences of HIV positive women as reported in other studies done. Some physical experiences such violence, sterilization and physical pain were identified in various studies analysed. Also social experiences characterized by stigma, family disintegration and constraints in adhering to treatment were some of the challenges that were faced by study participants from the reviewed studies. In addition to physical and social experiences were also emotional and spiritual experiences were also discussed. It came out that spirituality plays a role in decision making process of women living with HIV and Aids. Some cultural experiences and breastfeeding challenges were some of the experiences encountered from studies reviewed above. From the literature discussed it can be concluded that emotional experiences of women with HIV are largely affected by the misconception that HIV is a death sentence and that the internalization of the stigmatisation attitudes result in the expectation of being socially isolated and rejected.

The next chapter, chapter 3, will discuss in detail the research design and methodology used in this study.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

The previous chapter presented the literature related to this study. This chapter discusses the research design and methodology including measures to ensure trustworthiness.

3.2 RESEARCH DESIGN

A non-experimental qualitative research design that is explorative and descriptive is employed in this study.

3.2.1 Exploratory design

The purpose of an exploratory research design is to enhance the researcher's comprehension of a phenomenon (Babbie 2010:95). An exploratory research is often used when there is limited knowledge and understanding about the subject being studied. Therefore, this design is used to explore the experiences of women living with HIV and Aids.

3.2.2 Descriptive design

The goal of descriptive research is to describe the phenomenon under study. A descriptive research presents a picture of the specific details of the specific situation, social setting or relationship, and focuses on 'how' and 'why' questions (Kreuger and Newman 2006:23). Data for this qualitative research is presented in descriptive terms mainly in the words of the study participants. In this study, the experiences of women living with HIV and Aids are described so as to have a detailed picture of the extent of

the problem and to contribute to the body of knowledge in this important area of public health (Joubert 2007:78).

3.3 RESEARCH METHOD

In order to explore the experiences of women living with HIV and Aids, the researcher used the research methods outlined below.

3.3.1 Sampling

Sampling is known as a process of choosing people or organisations that represent a range of characteristics based on what is known about the population and the aims of the study (Griffiths 2009:198). A non-probability method of sampling, purposive sampling technique was used in this study. Non-probability sampling is defined as the selection of sampling units or participants from a population using non-random procedures (Polit and Beck 2008: 759). According to Gerish and Lacey (2010: 144), non-probability sampling schemes are widely used in qualitative research to study the population of interest and to ensure that the research samples reach sources of data that generate in-depth conceptual and theoretical understanding.

Purposive sampling was used in this study, that is, HIV positive women who had the characteristics of the population of interest were chosen for the study. Purposive sampling means selecting participants for their ability to provide rich information that reflects the purpose of the study (Ulin et al 2005: 57). The researcher, in this case conducted the study with females aged between 18-49 years who had been diagnosed with HIV and receiving services at Lyttleton Clinic. HIV positive women meeting the characteristics of the study population, who were present at the clinic at the time of data collection and who were willing to participate were interviewed. The characteristics described below were used for inclusion in the target population.

The study participants were females within the 18-49 age group, HIV positive and also receiving services at Lyttleton Clinic. The researcher targeted this age group because it is the most sexually active and the so called providers; hence they are highly exposed to HIV and Aids. The issue of language did not affect participation in this study. The study participants were interviewed in English as they all indicated that they were comfortable with the language, taking into account that the researcher was not fluent in the local language, Sotho. Place of residence did not affect participation in this study. Participation in this study was voluntary. The researcher only interviewed participants who were willing to take part in this study.

3.3.2 Population

In this study, the target population consisted of only HIV positive women who were attending voluntary counselling and testing and collecting their antiretroviral treatment (ART) at Lyttleton Clinic in Centurion. The researcher also targeted only women who were aged between 18-49 years. The researcher was assisted by the nurse to identify those women who are HIV positive as these women were already in a separate queue for check-up and receive treatment. The researcher did not access the participant's files or records to respect their confidentiality.

3.3.3 Ethical issues related to sampling

3.3.3.1 Institutional permission to conduct the study at the study site

Before commencing with the research, the researcher first obtained ethical clearance from the ethics review committee to respect the rights and dignity of participants as human beings, for the institution, UNISA. The researcher then secured permission from the Gauteng Provincial Health Department, District Health services support, Tshwane research committee, to conduct research at Lyttleton clinic. A letter explaining the purpose of this study and seeking for permission to conduct research was submitted (see Annexure A).

3.3.3.2 Voluntary decision

After obtaining permission to conduct research at the study site, the researcher made it clear to the potential participants that participation in the research study was voluntary. Participants were informed that they were free to withdraw from this research study, or may withdraw participation at any point without penalty. The decision whether or not to participate in this research study did not influence the way they received treatment at Lyttleton Clinic.

3.3.3.3 Beneficence

Beneficence was also taken into consideration in this study to ensure that there was no physical or mental distress, harm or any danger to the study participants. Beneficence is the principle of doing well to both the research participants and society. Research is expected to benefit both the individual participants and society in general for a positive contribution towards the welfare of people (Moule and Goodman 2009: 57).

3.3.3.4 Non-maleficence

The principle of non-maleficence was also considered by the researcher. According to the Policy on Research Ethics Unisa (2007:9) research should not cause harm to the research participants in particular or to people in general. Non-maleficence is a duty wherever possible to prevent physical, psychological, emotional, social and economic harms. There is also a duty to protect the weak, vulnerable and incompetent by adopting procedures and processes to take into account their vulnerabilities (Moule and Goodman 2009: 57).

3.3.3.5 Justice

The researcher also applied the principle of justice. According to Moule and Goodman (2009: 57), the principle of justice is about being fair to participants and not giving preference, or being discriminatory with some participants over others.

3.3.4 Sample

The researcher targeted 12 participants for interviews at the research site. The sample size chosen allowed an in-depth investigation of the experiences of HIV positive women at Lyttleton Clinic (Terre Blanche et al 2006: 50).

3.3.5 Data collection

In-depth semi-structured individual interviews were used for data collection. Green and Thorogood (2009: 94) state that in-depth interviews allow the interviewee enough time to develop their own accounts of the issues important to them. The researcher's role was that of a facilitator to help respondents talk freely. The selected interview questions sought clarification, illustration and further exploration (Balls 2009: 3). The researcher made use of open questions such as:

What are your experiences as an HIV positive woman?

3.3.4.1 Data collection approach and method

In-depth, semi structured individual interviews were conducted. Follow up prompts were also used based on the initial response to generate further discussion. The interviews were conducted in a flexible and open minded inquiry. The researcher adopted a curious and facilitative stance. This interviewing technique allowed the researcher to explore the challenges faced by women who are living an HIV positive life. Responses were written down in the form of field notes and the interviews were also recorded by a digital voice recorder.

3.3.4.2 Development and testing of the data collection instrument

The researcher made use of an interview guide. It was piloted using a small sample of two individuals selected from the target population to check if participants understood the questions. The very same participants were excluded from the real study. The

researcher met with the women living with HIV and Aids at the clinic and conducted the interviews with them on a face to face encounter. The interviews were conducted after the women had signed the consent forms. Follow-up prompts were used based on the initial response to generate further discussion. The interviews were conducted in a flexible and open-minded inquiry. Data records were kept in a safe cabinet to which only the researcher had access.

3.3.4.3 Characteristics of the data collection instrument

The researcher used in-depth semi structured individual interviews as a means of data collection. The research questions were worded in such a manner that respondents could not simply answer yes or no but rather provided elaborate answers.

Although the researcher had some pre-planned questions during the interview, the researcher also allowed questions to flow naturally based on information provided by the respondents. The flow of the conversation dictated the questions asked and those omitted. The researcher tried to interpret the participant's responses and sought clarity and deeper understanding from the respondents throughout the interview.

3.3.4.4 Data collection process

The researcher first explained to the potential study participants on the study topic, "The experiences of women living with HIV and Aids". The participants were also informed on the approximate time for an interview which was between 30 minutes to an hour to encourage high concentration among the study participants (Terre Blanche *et al* 2006: 300).

The study participants who were willing to participate were requested to sign a consent form. After obtaining consent from the study participants, the researcher commenced the interview with an opening question:

What are your experiences as an HIV positive woman?

During the interviews, the researcher utilised facilitative communication techniques such as probing, clarifying, silence, minimal verbal response and summarising in order to encourage participants to elicit further information about their experiences as women living with HIV and Aids as suggested by (Polit and Beck 2010: 484). The transcripts were typed for manual analysis.

The in-depth interviews were conducted in English and recorded by a digital voice recorder and transcribed by the researcher. Each interview record was labelled with an assigned code, LP and numbered 1-12 according to the occurrence of the interview. Soon after finishing the interviews, the researcher listened to the recordings and transcribed audio recordings into 'verbatim' reports. The researcher ensured that the digital recorder functioned well and that spare batteries were available. The interview setting was as free as possible from background noise and interruption.

3.3.4.5 Ethical considerations related to data collection

Prior to the interview taking place, participants were allowed time to read the information form and to decide on participation. The participants then signed a consent form. Apart from obtaining the consent signature, the researcher also educated the potential participants on the aspects discussed below.

3.3.4.5.1 Disclosure of information

The researcher, with the assistance of a nurse from the clinic, discussed the details of the research study to the potential participants. This discussion included the purpose of the research, the procedures to be followed, the risks and discomforts as well as potential benefits associated with participation, the purpose of the research and its benefits to the community and the public health system as a whole. The researcher used English while the nurse used the participants' own language to ensure understanding of the information.

3.3.4.5.2 Understanding

Discussions about the research topic and what it entails were clarified to the research participants. Technical and medical terminology was avoided or explained in 'lay' language. Non-English speaking subjects had information presented to them in a language they understand.

3.3.4.5.3 Confidentiality

The information provided for this study by participants was kept as confidential as possible. No individual identities were used in any reports or publications resulting from the study. Research information was kept in a secure place at all times. Only research personnel had access to the information.

3.3.4.5.4 Anonymity

Data provided by research participants was not identifiable to any participant. No names or any form of identity was gathered from research participants.

3.3.6 Data analysis

Data analysis is a description of what is done with data collected to obtain a clearer picture of what the information tells us (McNee and McCabe 2008: 33). In conducting data analysis, the researcher made use of simple thematic content analysis adopted from Krippendorf (1980:21). The researcher conducted the following steps:

- Analytic process

1. The data for analysis

The researcher transcribed all the data from the interviews on the experiences of women living with HIV and Aids into text.

2. Read the text , noting items of interest perform

- i. Initial reading of the text

An inductive approach to thematic analysis allows themes to emerge from the data, rather than searching for pre-defined themes.

ii. Re-read the text and annotate any thoughts in the margin

Examine the text closely line by line to facilitate a micro analysis of the data.

3. Sort items of interest into proto themes

This is where themes begin to emerge by organizing items relating to similar into categories. At this stage, keeping the themes as simple as possible assists flexibility in the categorization process.

4. Examine the proto-themes and attempt initial definitions. This is the phase of trawling back through the data to examine how information was assigned to each proto-theme in order to evaluate its current meaning. A provisional name should now be created for each emerging theme.

5. Re-examine the text carefully for relevant incidents of data for each proto- theme. This is the second process of trawling back through the data. It involves re-contextualisation whereby any data is now considered in terms of the categories developed through this analysis.

6. Construct the final form of each theme.

The name, definition and supporting data are re-examined for the final construction of each theme, using all the material relating to it. This stage focuses more closely upon the underlying meaning of each theme.

7. Report on each theme

Finalise the name of each theme, write its description and illustrate it with a few quotations from the original text to help communicate its meaning to the reader (Anderson 2007: 2-4).

3.4 MEASURES TO ENSURE TRUSTWORTHINESS OF THE STUDY

Trustworthiness is a term used in the appraisal of qualitative research when describing credibility, dependability and transferability. It is the degree of confidence that qualitative researchers have on their data (Moule and Goodman 2009:395). According to Polit and Beck (2008: 768), trustworthiness is assessed using the criteria of credibility, transferability, dependability and conformability.

3.4.1 Credibility

The truth value of this qualitative research was in the discovery of the experiences of women living with HIV and Aids. A qualitative study is credible when it presents confidence in the truth of the finding (Polit and Beck 2008: 539). In order to enhance credibility of the study, the researcher kept on conducting the in depth interviews until data saturation was reached. The participants were given enough time to share their experiences and their responses were recorded.

3.4.2 Dependability

Dependability evaluates whether the process of research is logical, traceable and clearly documented, particularly on the methods chosen and the decisions made by the researchers. Qualitative data cannot be seen as credible unless its dependability is known, that is its ability to stand the test of time (Moule and Goodman 2009: 189). To ensure dependability, the researcher engaged in prolonged engagement during data collection phase and continuously verified it till it was sufficiently gathered.

3.4.3 Confirmability

Conformability is an assessment criterion of trustworthiness for ensuring that the results reflect what the participants or respondents shared in the research. Here, the researcher took steps that helped to ensure as far as possible that the study findings were the result of the experiences of participants, rather than characteristics and preferences of the research (Shenton 2004: 72).

3.4.4 Transferability

Transferability refers to the applicability of the findings to other situations and other people. However, qualitative research is not designed for the purpose of making generalisations as quantitative aims to. Instead, qualitative research describes a phenomenon within a certain context (Tapen 2011: 160). The author further contends that qualitative researchers may make connections between their findings and those

from other studies, making careful comparisons across settings and people. To address transferability, the researcher provided a detailed description of the study, the study participants and the target group and background information to enable the readers to evaluate and compare the study findings with other studies or settings. In this particular research, the experiences of women living with HIV and Aids around the Sotho speaking or English speaking people and their culture, are likely to be transferable to similar contexts.

3.5 CONCLUSION

This chapter discussed the research design and methodology in detail together with measures to ensure trustworthiness. Chapter 4 will analyse, present and describe the research findings.

CHAPTER 4: ANALYSIS, PRESENTATION AND DESCRIPTION OF RESEARCH FINDINGS

4.1 INTRODUCTION

Chapter 3 gave a full description of the research design and methodology utilised in this study. This chapter presents results of the study. In order to arrive at the research findings, an explorative and descriptive qualitative research design was adopted. The purpose of this study was to investigate the experiences of women living with HIV and Aids. The objectives of the study were to answer the following research questions:

- What are the experiences of women living with HIV and Aids?
- Which recommendations can improve policy making with regards to women living with HIV and Aids?

A simple thematic content analysis approach to data analysis was employed. For the sake of confidentiality, the researcher did not ask for participants' names, the participants' interviews were labelled LP for Lyttleton participant and numbered 1-12 hence all study participants are referred to as LP-1 to LP-12. Four themes which are: Experience of Being Diagnosed with HIV and Aids, Disclosure, Physical Signs and Symptoms, Stigma or Emotional Stress including various categories under each theme were identified from the transcribed data.

4.2 FIELDWORK EXPERIENCE

Permission to conduct research was requested from the Gauteng Health Department, District Health Services Support, Tshwane Research Committee, as well as Lyttleton clinic. A clearance letter was issued (see Annexure A).

The researcher did not have any difficulty in accessing the research setting. Arrangements were made way on time with the sister in charge at the clinic who

informed the responsible nurses. The nurses working at the Voluntary and counselling section were aware of the research topic and the researcher's agenda with the patients on the first day of the interviews. The sister in charge was friendly and introduced the researcher to the nurses who welcomed the researcher. The researcher explained the purpose of the study to the two nurses. The nurses then assisted the researcher in addressing all the HIV positive patients who were present, on the purpose of the study and explained that participation was voluntary and that only females were expected to participate. The participants were included in the interview according to their eligibility as explained in chapter 3 of this study. The interview dates and times were arranged with the nurses working at the clinic prior to data collection process. The interviews were conducted between 0900hrs-1400hrs and each interview session lasted approximately between thirty minutes to an hour. It took the researcher three days to interview all the twelve participants.

The researcher was given a private room which was next to the nurses' consultation rooms to use for interviews with research participants. In depth, semi-structured individual interviews were conducted with the participants. The interviews were only conducted by the researcher and there was no research assistant used. The researcher felt that the study participants would open up more on their experiences in the presence of only one person, the researcher. Before commencing with the interviews, an information sheet that explained the nature and purpose of the study was given to those who expressed an interest in taking part in the research. The researcher also explained about the research verbally and answered questions that potential participants had. In addition, the researcher also explained to each participant individually on the purpose of the study, confidentiality and the right to consent. Those who agreed were asked to sign a consent form before participating in the study to ensure confidentiality of interviews and all data collected (Annexure D).

Data was collected by means of a digital voice recorder, treated with confidentiality and transcribed verbatim immediately by the researcher. Field notes were also taken by the

researcher as back up during the interviews. Texts from the voice recorder and field notes were typed into Ms Word processing document and saved as a pdf document. The document was then printed for manual coding.

4.3 DATA MANAGEMENT AND ANALYSIS

As explained above, Ms Word was used for efficient data storage. The data was saved and labelled according to each separate interview by indicating the participant and number, for example LP-1. Names and personal details were anonymised at the data collection stage therefore a specific participant could not be identified by name; only their label, LP and their number were identifiable. The researcher also took some field notes during the interviews as this saved as backup copies of the data collected. The same way of labelling was used in labelling and saving the fields notes. Data records were then kept in a locked cabinet at the researcher's home where only the researcher had access to.

The researcher used a simple thematic content analysis approach by Krippendorff (1980:21) in analysing the data collected. Content analysis consists of breaking down the messages in simple elements in order to code them according to thematic categories and to register their frequency. Furthermore, Krippendorff defines content analysis as a technique that draws valid and repeatable inferences from the data to their context. The following six phases of thematic analysis were applied by the researcher in this study in conducting data analysis:

1. Becoming familiar with the data.
2. Generating initial codes.
3. Searching for themes.
4. Reviewing themes.
5. Defining and naming themes.
6. Producing the report.

The data collected from the participants was carefully transcribed. An iterative process of close reading and re-reading of data led to the development of themes and categories. The researcher carefully read the transcribed data line by line, underlined words and phrases representative of participant's experiences of living with HIV and Aids and divided the data into meaning analytical units. After locating the meaning segments, category names were assigned. The researcher continued with the process until initial coding was completed on all data. Checking of themes on the experiences of women living with HIV and Aids as reported by the participants was then conducted. The researcher then went on to check if the themes were coherent, consistent and distinctive and then analysed them (Brown and Clarke 2006:76).

Brown and Clarke (2006:76) state that thematic analysis is a method of identifying, analysing and reporting patterns (themes) within data. Although the authors state that thematic analysis minimally organizes and describes data set in rich detail, they however argue that it frequently goes further and interprets various aspects of a research topic. The authors further contend that a theme captures something important about the data in relation to the research question and represent some level of patterned response or meaning within the data set (Brown and Clarke 2006:82).

4.4 SAMPLE CHARACTERISTICS

In this study, the sample was drawn purposively from women diagnosed with HIV and Aids who were present at Lyttleton clinic at the time of data collection. These women had come either for check-up or to receive treatment at Lyttleton Clinic in Centurion. The sample comprised of twelve women who volunteered for in-depth individual semi-structured interviews with the researcher. The researcher made use of an interview guide which included biographic information of the research participants such as age, marital status, educational level, number of children, language and area of residence and employment status.

4.4.1 Biographic information

All research participants were above twenty-six years with the most prevalent age groups being 34-41 and 42-49 respectively. The least presented age group was 26-33 with only two participants. Most of the participants were single that is five out of twelve. Three of participants were divorced, two married and the other two were widows. Amongst the participants, only one participant reported that she never attended school, one of them completed her tertiary education, three went up to Grade twelve while five participants attended at least Grade eight to ten. Only one participant had no child, while six participants had between one to three children and five participants having between four to six children. Although the language used with all the research participants was English, the home languages for the participants differed, half of the study sample which constituted the majority were of Tswana or Sotho speaking. Three participants reported Zulu as their mother language, two were Shona speaking and one participant spoke Shangaan. However all participants were able to speak in English and therefore the issue of language was not a barrier as all interviews were conducted in English.

The majority of the participants, eight out of twelve lived in Centurion while the remaining four lived outside Centurion. Likewise eight participants were employed and only four were unemployed two of them having lost their jobs due to illness related to HIV and Aids.

4.5 RESEARCH FINDINGS

The study participants raised many concepts in relation to their experiences of living with HIV and Aids. These concepts were grouped into themes and categories which are illustrated in table 4.1 below and discussed in detail afterwards. A theme represents a level of patterned response or meaning from the data that is related to the research questions at hand. It occurs numerous times across the data set eventually providing an

accurate understanding of the big picture. A category on the other hand is a general class of ideas or concepts which are closely linked in meaning. Categories which have similar meaning can be brought together into a theme (Brown and Clarke 2006:102).

Table 4.1: Themes and categories

Theme One: Experience of Being Diagnosed with HIV and Aids
<p>❖ Categories</p> <p>Fear of an HIV positive status</p> <p>Coping with an HIV positive status</p> <p>Acceptance or lack of acceptance of HIV and Aids</p>
Theme Two: Disclosure
<p>❖ Categories</p> <p>Selective disclosure</p> <p>Silence</p> <p>Living with partners of unknown HIV status</p>
Theme Three: Physical Signs and Symptoms of HIV and Aids
<p>❖ Categories</p> <p>Illness experienced by participants</p> <p>Alternating CD4 count</p>
Theme Four: Stigma/ Emotional Stress
<p>❖ Categories</p> <p>Fear of death</p> <p>Loss of employment</p> <p>Functional disturbance</p>
Theme Five: Experience in services rendered
<p>❖ Categories</p> <p>Long waiting period</p> <p>Inadequate information from counsellors</p>

4.5.1 Experience of being diagnosed with HIV and Aids

Data analysis revealed experience of being diagnosed with HIV and Aids as a first theme that emerged. Two categories namely: Fear of an HIV positive status and coping with an HIV positive status fell under this theme.

The news of being diagnosed HIV positive came with various stressful experiences. These stressful experiences ranged from the time of being tested for HIV and Aids in which participants awaited the outcome of their results. One participant narrated her experience as follows:

“When I discovered I was HIV positive in 2007 I was very depressed. I thought my life was ending....” (LP-2).

According to LP-2, discovering that she was HIV positive was more of a disruptive event in which she thought her life was coming to an end. She considered HIV as a threat to her life and viewed HIV as a death sentence.

4.5.1.1 Fear of an HIV positive status

The fear of having to be found HIV positive itself was stressful among participants as one participant indicated that:

“Since I was pregnant that time they tested me for HIV. Yoh! It was difficult. I had to wait outside for my results. I did not know what they were going to tell me” (LP-10).

Furthermore another participant reported having felt emotional disturbance and stressed upon realizing her HIV status to an extent that she was hit by a car due to confusion. The participant reported her experience as follows,

“...even on my way back to work I did not realize that there was a car on the road then it hit me, I was so stressed” (LP-3).

Two other participants went on and expressed that that they were hurt upon discovering that they were HIV positive:

“I was very hurt. Those days I was not feeling good and I was scared” (LP-11).

“.....that’s the time I was tested for HIV. I cried for a long time and thought I was going to die. Aids is not good for the people” (LP-9).

The participants interviewed had different reactions to the diagnosis of HIV and Aids. The news of being diagnosed HIV positive, or having Aids, was a traumatic event for the participants in this study. However, despite the disruption caused by HIV infection, the participants sought to put their lives together by applying different strategies in order to cope with the disease.

4.5.1.2 Coping with an HIV positive status

While participants had their different experiences and reactions upon the discovery of their HIV positive status with most of them getting stressful, one of the participants revealed that she was well informed about HIV and Aids. The participant reported that she looked after her late two brothers who were HIV positive. According to the participant, she had already discovered some developing rash on her private parts and suspected it could be HIV. The participant reported that she refused to be given medication and she asked to be tested for HIV and Aids first. The participant reported the following:

“I went to the clinic and they gave me some medicine that I had used before. I told them it wasn’t working so I asked them to test me for HIV. They told me I was HIV positive. I wasn’t surprised because I had seen it with my brothers so I did not put it in my mind. I live a normal life. I know if you treat yourself right you will survive” (LP-4).

The participant applied a more positive copying mechanism due to the fact that she had experienced and learnt more about HIV and Aids through her siblings who had also suffered from HIV and Aids. The participant learnt to accept that HIV and Aids is something that one can live with instead of thinking that they will die from it.

Some of the participants did not just merely cope but reported that their belief in God helped them to gain the courage and carry on with a positive mind regarding their HIV positive status.

LP-3 reported on the following:

“I believe that God will help me in my situation” (LP-3).

Similarly, another participant described her experience as follows:

“Coming to the clinic has made me more confident because we are a family and we are supporting each other. Believing in God has also assisted me so much” (LP-8).

More so participant LP-12 further supported the notion of believing in God regarding her HIV positive status by saying the following:

“I know when it is time I will die because everyone has their time. And God is helping me” (LP-12).

The participants believed that death was due to God and that everyone has their time to die. Some participants received support from their partners and family members including their children and this helped them cope with their status. One participant highlighted that her son who is seventeen years old often reminds her when it is time to take her antiretroviral treatment (ART). The participant’s exact words were,

“My oldest child encourages me to take my treatment as he gets information at school. He even sets the alarm and reminds me to take them so I have so much support” (LP-10).

Another participant highlighted the importance of disclosing status:

“I was taking my medication in private I did not want anyone to see me like this. However, I later told my aunt, my mother, my first born and my husband. They supported me very much” (LP-6).

As participants were open about their diagnosis of HIV and Aids, they received love, care and support from their family members. Support is particularly important in women living with HIV and Aids as it assists them in building a positive life

4.5.1.3 Acceptance or lack of acceptance of HIV and Aids

As some of the respondents gained knowledge of HIV and Aids, with time, through encouragement and the acquisition of more knowledge they later on accepted their status and viewed HIV and Aids as any other disease. LP-7 reported that she had accepted her status after revealing it to her sister. She indicated:

“I told my sister and not others and my sister said, ‘clever girl’. Now I have accepted it and there is no difference” (LP-7).

Participant LP-11 also showed her boldness and acceptance of her HIV status although initially she had struggled to accept. She went on and mentioned later in the interview how she was ready and willing to tell anyone about her HIV positive status and that she was at a stage of assisting other HIV positive people. She said:

“Right now I am very fine. I am alright. I can even tell everyone that I am HIV positive and can counsel people with HIV. I have accepted it and I am fine with it. Even if I can

see you there with HIV and Aids, I can tell you that this is HIV, I don't have a problem calling you and counsel you or tell you to go and get tested" (LP-11).

LP-11 managed to come to terms with her status and has embarked on a mission to aid others in a similar situation. The participant developed a sense of purpose in using her experience to help others.

However some participants revealed a sense of partial denial, not only during the initial stages of diagnosis, but also from time to time later on. They struggled to accept their HIV positive status. LP-8 reported on the following:

"I tested HIV positive in 2009. I did not take my treatment that time. I could not believe I was positive, it was very hard" (LP-8).

Later on in the interview, the same participant mentioned the following:

"I have been doing this for the sake of my children, I can't explain it. If it wasn't for them I wouldn't be doing it" (LP-8).

Initially, the participant reported that it was very hard for her to accept that she was HIV positive; the participant revealed that she could not take her treatment that time. This was a sign of denial. Although the participant later on decided to take her medication a year later after the diagnosis, she still felt she was doing it for her children and not for herself.

4.5.2 Disclosure

This theme mainly deals with the participants' decision to disclose their HIV status to their people. Almost all participants except for one, managed to disclose their HIV status

to at least one person or more. Some participants who managed to disclose were quoted as follows:

“I have known about my HIV status since November 2012. I told my husband immediately” (LP-1).

“I have told my boyfriend but he insists that he is negative...” (LP-2).

“However, I later told my aunt, my mother, my first born and my husband” (LP-6).

A high rate of disclosure in this study may be attributed to the presence of peer counsellors who encouraged disclosure and adherence to ART at the clinic. Selective disclosure, choosing to keep quiet and living with partners of unknown status were the categories that emerged under the theme ‘disclosure’ and these are discussed below.

4.5.2.1 Selective disclosure

Although almost all of the study participants managed to disclose their HIV status to at least one person or more, some of them were selective as to whom they told. Participant LP-5 reported that she told her mother and her mother’s reaction was not very encouraging:

“Yuuuuh! When I told my mother she said ‘oh you again! What’s wrong with my family? She said this because my sister had also died from HIV and Aids” (LP-5).

More so the same participant went on to say:

“I told my baby but she was scared to talk to me” (LP-5).

The above reactions, for example the gesture *“oh you again”* from the participant’s mother, which was a sign of disappointment, could be one of the reasons why HIV

positive people might decide not to share their status or being selective on who to share the information with due to the anticipated response from people around them.

Selective disclosure was also highlighted by the following participants:

“So I told my child who is 22 years and he is fine with it. My other children are so cheeky I cannot tell them” (LP-3).

“I only told my family members who I know they do not talk too much” (LP-4).

“You become selective regarding who to tell about your status and you are blamed about your status for something that you did not do as a woman” (LP-1).

The findings of this study reveal that participants had their reasons in deciding who to tell and one of them was largely to do with the fear of reactions from different people.

4.5.2.2 Silence

Out of the twelve study participants who were interviewed in this study, only one participant indicated that she had not told anyone about her HIV positive status. As the interview went on, the researcher discovered that the participant had lost most of her family members due to HIV and Aids as she reported that she was now alone at home.

“I am alone at home because most of my family members died of HIV. My sisters and my sister’s children all died of HIV” (LP-9).

However, the participant revealed that she was in a relationship and she still did not disclose her HIV status to her partner as she mentioned the following:

“I separated with my husband. My boyfriend does not know that I am HIV positive. We use a condom. It is my secret I don’t want to tell him. When I take my medication I tell him it is for high blood pressure” (LP-9).

Since the participant reported that she had lost most of her family members and was alone at home, she might have feared that disclosing her status to her partner might chase him away. The findings of this study suggest that women’s decisions related to disclosure are likely to be influenced by their evaluation of the consequences of disclosure. There is therefore a need for greater support for women undergoing voluntary counselling and testing (VCT) in encouraging individuals to disclose their HIV status and reducing the stigma associated with HIV.

4.5.2.3 Living with partners of unknown HIV status

The study findings also revealed that participants experienced having to live with their partners whose HIV status was unknown. Two participants reported that they were married and therefore revealed their status to their partners, they however both struggled with the fact that their partners refused to test for HIV. The participants reported that:

“I managed to tell my husband about my HIV status but the problem is my husband does not want to test” (LP-1).

And the other,

“They gave me a note at the clinic for him but he doesn’t want to test” (LP-10).

As women living with HIV and Aids, the participants were therefore faced with different challenges in living with partners whose HIV status was unknown. The situation presented additional anxiety and stress regarding exposure to re-infection hence affecting their progress with their anti-retroviral treatment.

4.5.3 Physical signs and symptoms of HIV and Aids

In this study participants reported to have experienced some physical signs and symptoms of HIV and Aids which include: TB related cough, loss of weight, vaginal rush and black spots, sweating, headaches, stomach pains, fever and tiredness. One participant in this study narrated the following:

“I suffered from headache, fever...” (LP-5).

Due to the above mentioned signs and symptoms, participants therefore fell ill from time to time. Illness therefore emerged as a category under this theme.

4.5.3.1 Illness

Some of the study participants experienced HIV and Aids related illnesses soon after testing HIV positive. One participant reported an experience of flulike symptoms:

“I only cough and often get flu which goes within 3-5 days” (LP-2).

Moreover, more participants highlighted on having fallen ill as seen in the quotations below:

“...I was sick and I was TB suspect so the man said I would spread TB to his family as I was coughing, having fever and tired” (LP-5).

“The first time I tested I had some rush down there. At times I do feel physical pain but when I am sick my boss takes me to the doctor” (LP-4).

“I am not feeling well. I feel dizzy. I suffer from stomach pains and headache” (LP-8).

Weight loss was also reported as one of the signs related to HIV and Aids illness. LP-8 and LP-11 reported on how they were losing weight which they believed was due to HIV and Aids:

“Currently I am losing weight” (LP-11).

“I have lost weight. I used to weigh 60 now I am 55kg” (LP-8).

4.5.4 Stigma or Emotional Stress

People living with HIV and Aids are inevitably affected by the symbolic meanings attached to the disease. The social stigma attached to HIV and Aids often presents obstacles to the lives of people living with HIV and Aids. The women interviewed indicated having experienced some stress at some stage because of an HIV positive status. Participants were faced with having to deal with stressful experiences which included the fear of death attached to HIV and Aids, loss of employment, and functional disturbances upon being diagnosed HIV positive. Another factor attributed to emotional stress was the delay in services rendered at the clinic.

4.5.4.1 Fear of death

One of the most likely sources of stigma of HIV and Aids is its association with death and it illuminates many people’s responses to HIV and Aids. According to some of the study participants, the possibility of dying came into their minds after discovering that they were HIV positive. Participant (LP-1) revealed her fear of death by the following statement:

“The problem is our husbands who do not want to test for HIV and we are scared of death” (LP-1).

Participant LP-12 associated HIV and Aids with death as she likened her situation to that of her sister who died of HIV and Aids:

“...but now there is a cure maybe I will not die like my sister” (LP-12).

“that time I was feeling like I was going to die” (LP-5).

As seen from the above assertions, the participants reacted as if they had been diagnosed with a fatal and untreatable disease. The participants in the study were faced with the reality of death and were scared that they would die. One participant related to death as something that happens to everyone, whether HIV positive or not. The participant was so confident and relaxed as she narrated the following:

“I know when it is time to die I will die because everyone has their time” (LP-13).

Although LP-13 seemed to accept the possibility of her own death, it is almost inconceivable for our unconscious to imagine an actual ending of our own life here on earth. People living with HIV and Aids tend to put this consideration aside or accept it as a natural occurrence in order to be able to get on with their lives. There is a need to emphasize that HIV is not necessarily an early life sentence. People with HIV and Aids can live normal lives if the resources to help are properly in place.

4.5.4.2 Loss of employment

Loss of employment was among some of the stressors faced by women living with HIV and Aids. One participant gave a narration of how she was employed, fell ill on and off until she was forced to leave work due to her illness:

“I was working but now I stopped. I did not tell my boss about this disease but I think she was suspecting because I was sick and I was TB suspect, her husband said I would spread TB to her family as I was coughing, having fever and tired. He complained and said I must leave work as I would spread my sickness to the family. Her wife said I must

leave for one month and come back. So I went back again and started working but that disease started again and I was sick. I lost my job” (LP-5).

Although some people living with HIV and Aids are likely to maintain their jobs until serious physical dysfunction occurs, their occupational abilities and performances maybe restricted by periodic crisis of symptoms and pain. Women living with HIV and Aids often encounter occupational difficulties due to ongoing challenges of adjustment to the illness and social stigma.

4.5.4.3 Functional disturbance

Participants in this study expressed having suffered some discomforts such as psychological distress, depression, hopelessness and confusion.

“From the day I realized I was positive I was touched by my status” (LP-1).

“I discovered I was HIV positive in 2007. I was very depressed. I thought my life was ending...” (LP-2).

From the above assertion, it is clear that HIV and Aids is perceived as destructive especially at the initial phase of diagnosis. The participants in this study were faced with the stress of finding out that they were HIV positive. In such a situation the anxiety of what will happen next is inevitable. Questions related to possibility of treatment, sickness, disclosure and the future of the affected people can run through one’s mind causing stress and a feeling of hopelessness.

“In our culture when they know you are HIV positive they start talking funny things behind your back these black people. Like last time that I was too sick they were talking funny things saying maybe she has HIV, what...what” (LP-12).

“Sometimes I fear that maybe when they look at me at work they can see that am HIV positive although I didn’t tell them. Sometimes someone can just ask me that am losing weight and I will tell them that am on diet” (LP-11).

Consistently worrying about what people might or are saying can mean a turnaround of the lives of women living with HIV and Aids. Participants in this study experienced a life full of social constructions around HIV and Aids.

4.5.5 Experience in services rendered

When asked about the services and treatment that they receive at Lyttleton clinic, most women indicated that they were happy and that the nurses treat them well. However, some women were not happy with the long waiting period they had to endure before getting into the consultation room. On the other hand, some expressed disappointment with the lack of information given regarding their medication.

4.5.5.1 Long waiting period

Some of the study participants reported that they would come to the clinic at 07H00 only to leave in the afternoon around 14H00. This meant an average of seven hours of waiting in the long queues to get assistance. One participant, LP-1 expressed her dissatisfaction as follows:

“There are a lot of delays but everything else is fine, the nurses are good” (LP-1).

The other participant went ahead and narrated:

“The nurses are too slow but they are very friendly” (LP-5).

One more participant further confirmed that waiting period was too long as she reported:

“Waiting time to get treatment is too long” (LP-3).

The above assertions show that participants wait for a long time in the queues to get treatment and this can be frustrating to them. In addition, they felt that the delays in receiving services could be due to the fact that they are HIV positive and hence may be regarded as less important than patients. This adds on the stress of living with HIV and Aids that they already endure. As gathered from the participants’ notions, getting time to visit the clinic while one is employed can be a problem. One participant reported that it was very difficult to get time from work to go to the clinic every month:

“Coming to the clinic every month is too much. If only they can give us at least medication to last us for two months. Having to ask for a day off every month to go to the clinic is too much, also I want to get enough information about my medication. I don’t understand why I have to take 5 tablets a day instead of 1 that the others are taking” (LP-10).

According to LP-10, being employed and being HIV positive is a challenge to her. Frequent visits to the clinic can be disruptive since one has to be absent from work.

4.5.5.2 Inadequate information from counsellors

It is also very necessary for health care providers to explain all the medication to be taken by their patients so that they understand the reasons why they are taking them. When asked about what information they needed from the voluntary testing and counselling section, one participant reported that she did not get enough information regarding her medication and the type of food to eat and avoid.

“I do not get enough information about my medication and how to take them. I want them to write down for me about the virus and immune system. When must we take the tablets, before or after meals? Which drinks must we take, whether it is ok to take coke or not” (LP-3).

Another participant, LP-4 replied to the researcher's question as follows:

"I need information and treatment. I suffer from heartburn but they do not want to give me tablets for heartburn, they just say am not eating the right food. But I tell you I eat healthy foods, vegetables and fruits. They must give me information on what foods to eat and which diet to follow" (LP-4).

Taking medication and following a good diet is one of the most important things to do when one is HIV positive and it is therefore necessary that health care providers take the issue of information giving as a serious matter.

4.6 DISCUSSION OF RESEARCH FINDINGS

This study has explored how women's experiences to the diagnosis and how finding out they have HIV infection affected their senses of self. The experience of being diagnosed with HIV and Aids comes with the fear of an HIV positive status, struggling to cope with the condition as well as a difficulty in acceptance of the disease. The findings of this study are similar to the findings reported by Evans and Becker (2009:94) who suggest that diagnosis represents the moment at which HIV and Aids is officially "named" which can produce a range of contradictory reactions. The writers further contend that many women describe their discovery of their HIV status as a traumatic experience that had a major impact on their emotional well-being and sense of identity.

However, on the contrary, study findings of a study conducted by Kajura (2010:37) maintains that accepting to be tested meant accepting everything that would come out. According to the author, people tend to feel better and at ease when told of their HIV positive status because at least they know the cause of their illnesses and hence freely accepting the results. Only one participant in this study felt at ease with the fact that she was HIV positive, the rest of the participants experienced some emotional stress and were disrupted upon finding out they were HIV positive.

Participants in this study reacted differently in terms of disclosing their HIV status. Some of them were selective regarding who to tell while the others decided to be silent about their status and not telling a single soul apart from the health care providers. Congruent study findings have been reported by Preau, Bouhnik, Roussiau, Lert and Spire (2008:521) who concluded that all individuals who learn about their HIV antibody status face an important decision regarding who they should share this information with. The decision of disclosure of one's HIV sero-positivity to others is often perceived as a double edged sword. According to the authors, opening up about one's status may open up the opportunity of receiving social support; however it may also lead to added stress due to stigmatisation, discrimination and disruption of interpersonal relationships.

Furthermore, Kajura (2010:46) asserts that most women fear that they would be rejected or detested by their family members if they realised that they were HIV positive. The author further contends that disclosing one's status would upset family members and lead to individuals being scorned by family members (Kajura 2010:47).

According to Patel, Baxi, Shringarpure, Bakshi, Modi, Cooner and Mehta (2012:132), although HIV disclosure offer benefits, there are several barriers for HIV positive individuals to disclosing which include being blamed for having HIV, fear of stigma and discrimination as well as potential disruption of relationships.

In addition, although some study participants managed to open up about their seropositive status even to their partners, they were still faced with a difficult situation of having to live with their partners who refused to test for HIV. The results of this study are in agreement with a study by Deribe, Woldemichael, Wondafrash, Haile and Amberbir (2008:78). In the study a significant proportion of the women interviewed did not know their partners' HIV statuses despite having disclosed their own statuses to their partners.

Physical signs and symptoms as well as HIV related illness was also amongst the themes that emerged in this study. Participants narrated their different experiences of HIV related illness which included headaches, stomach pains, fever, sweating and a lot more. A study by Willard, Holzemer and Wantland (2009:220) reveals the same findings that people living with HIV and Aids experience several common but controllable symptoms throughout their illness trajectory. The frequently reported physical symptoms in their study include pain, fatigue, drowsiness, headaches and fever to mention a few. Gonzale, Michael, Zvolensky, Parent, Grover and Hickey (2012: 156-7) recognized in their study that as a result of HIV and Aids, including medication regimens used, persons living with the disease often experience a wide range of bodily sensations and the common symptoms include fatigue, nausea, chills or sweats and dizziness.

Along with physical illness were traumatic conditions that came up such as depression and anxiety came up. Some women were scared that being diagnosed meant that death was around the corner, some lost their jobs while on the other hand some endured functional disturbances. Similar findings have been reported in a study conducted by (Rief 2011:153) on highly stressful and traumatic experiences among individuals with HIV and Aids in South Africa where study participants were also faced with stressful experiences, having to, deal with the loss of employment, stigma and functional disturbance after being diagnosed with HIV and Aids (Rief 2011:155).

4.7 CONCLUSION

This chapter presented a description of the study findings and provided a comparative summary of the study findings in relation to other studies conducted on experiences of women living HIV and Aids. The next chapter will present a conclusion of the research in relation to the research questions and also provides recommendations for future research in the same topic.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

Chapter 4 presented the analysis and description of the research findings, recommendations, limitations and conclusions drawn from the study are discussed in this chapter. The researcher investigated the experiences of women living with HIV and Aids. The study was conducted at Lyttleton clinic in Centurion, Gauteng Province of South Africa. The participants were HIV positive women aged between 18-49 years receiving health care services at Lyttleton clinic.

5.2 RESEARCH DESIGN AND METHOD

A pure qualitative research design was adopted in this research. A sample of twelve participants was interviewed and chosen through a purposive sampling technique, that is, only HIV positive women were chosen as they were the only participants who could provide rich and relevant information on the experiences of women living with HIV and Aids.

Information was collected through semi-structured individual interviews, however, the researcher also allowed information to flow naturally based on the information provided by the study participants. The data analysis process involved searching through data to identify recurring patterns. Themes and categories then emerged from the data with similar meanings. The researcher combined both the thematic and content analysis approaches. The researcher focused on the meaning of data collected giving a more discursive interpretation and at the same time, employed predefined mutually exclusive categories to count on the frequency of themes.

5.3 SUMMARY AND INTERPRETATION OF RESEARCH FINDINGS

The research described the experiences of women living with HIV and Aids. The researcher explored the women's initial experiences of being diagnosed with HIV and Aids, issues such as whether the women managed to disclose their status to their partners, families and friends, the physical signs and symptoms that they experience in living an HIV positive life, the stigma and emotional stress that they go through as well as their experiences of services rendered by their health care providers.

5.3.1 Experiences of being diagnosed with HIV and Aids

The study participants narrated various experiences after having tested for HIV and Aids. For some participants, experiencing the diagnosis of being HIV positive was a very negative and disrupting experience. The fear of an HIV positive status as well as coping with HIV and Aids were amongst the experiences that were reported by these women. Some participants felt as if their life ended after being diagnosed HIV positive. However, on the other hand, some participants who were well informed about HIV and Aids from their past experiences felt that being diagnosed with HIV and Aids was not different from being diagnosed with any other disease. The participants remarked that HIV positive women should not consider HIV and Aids as a death sentence as there is treatment for the disease. Participants noted that every disease kills and that death is for everybody. Hope and optimism about the future as well as acceptance of sero-positive status and a good diet was seen as an effective way of surviving with HIV and Aids.

Support from family members including children enabled the participants to live a positive life. On the other hand, some of the participants gained their strength from their belief that God will help them in their situation.

5.3.2 Disclosure

Almost all study participants managed to disclose their HIV positive status to at least a family member or their spouses for those who were in formal relationships. It is clear from the study participants that disclosure had a more positive effect as it resulted in participants receiving support from their family members. Although there is a high rate of disclosure, the participants are very selective regarding who they told about their HIV status. All the participants who disclosed found comfort in telling a family member rather than friends and neighbours. One of the participants chose to be silent about her status as she reported that she was all alone, had lost most of her family members and therefore had no one to talk to. However, the study participants who were in formal relationships had to live with partners with unknown HIV statuses as they all refused to be tested.

5.3.3 Physical signs and symptoms

TB related cough, loss of weight, vaginal rash and black spots, sweating, headaches, stomach pains, fever and tiredness were HIV and Aids related signs and symptoms highlighted by the participants in this study. Some of the women experienced some illness and this prompted them to test for HIV and Aids. At some stage, some of the participants reported having to stop working due to the on and off physical pain they experienced.

5.3.4 Stigma and emotional stress

Women living with HIV and Aids face not only illness and medical problems but also the symbolic meanings associated with the disease. HIV and Aids carry stigma and disclosing one's positive status may lead to negative labelling. One of initial responses highlighted by the women in this study, upon their HIV positive diagnoses, was the thought that they were going to die. This is not a reality but a misconception attached to

HIV and Aids. This increases the emotional stress that they have to go through. As one study carried out on the stigma of people living with HIV and Aids in Sub-Saharan Africa revealed that different languages are used to describe people living with HIV and Aids for example being referred to as, “a walking corpse”. People living with HIV and Aids tend to experience stigma throughout their lifetime (Ngozi, Mbonu, van den Borne and De Vries 2009:342).

In relation to the stigma associated with HIV and Aids were also stressful experiences from living with HIV and Aids. These among others included loss of employment due to the ongoing illness brought about by HIV and Aids. The periodic symptoms, illness and pain make it difficult for women living with HIV and Aids as it leads to their continuous absence from work making it difficult for them to deliver their maximum performance in the work place. This results in loss of income amongst other HIV positive women. The shock and signs of disappointment experienced by others at the time of disclosure also added on to the stress that already existed.

5.3.5 Experience of services rendered

Although most women interviewed reported that they were happy with the services they received at the clinic. Some of the women had complaints about the long waiting periods they endured before getting to the consulting rooms. Women receiving ART at Lyttleton clinic are expected to visit the clinic every month for their medication and this is a huge setback for working women as it is difficult for them to get a day off each and every month to visit the clinic. Adding to their grievances about the services, some women reported that they had no full information regarding their treatment. Some of these women reported that they found themselves having to take more than one type of medication and did not understand why as it was never explained to them.

5.4 CONCLUSIONS

The research revealed that the experiences of women living with HIV and Aids are to some extent related to the stigma that is associated with HIV and Aids which led to fear of being diagnosed HIV positive, fear of death as well as issues related to disclosure and who to trust with one's HIV positive status. However, apart from issues related to stigma, there was no discrimination experienced amongst those who revealed their statuses to their partners and family. The study actually showed the benefits of disclosure in that there was support and acceptance. However, illness was found inevitable at some stage in the life of living with HIV and Aids therefore as a result, highlighting the importance of a good health system in place with all the necessary medication available.

5.5 RECOMMENDATIONS FOR PRACTICE

- Educational, structured support groups for women living with HIV and Aids that is for those with no family should be implemented and developed to assist in facilitating acceptance of HIV positive status and disclosure to others.
- Testing of couples should be strengthened to avoid issues of living with a partner whose HIV status is unknown.
- HIV and Aids counsellors and health care providers are directly involved with patients on a day to day basis, this means they should be well educated and equipped with knowledge. Additional on the job training and workshops should be implemented so that they will be able to attend to patients in a more professional way, provide necessary information to women living with HIV and Aids and to be conversant with how to prescribe and dispense medication (ART) correctly.
- According to the research findings, interventions are needed in South Africa to reduce the Aids stigma and to assist women diagnosed with HIV and Aids to

make effective decisions on disclosure. Interventions could be in the form of awareness in different communities.

- There is a need to promote access to HIV and Aids healthcare resources such as introducing mobile clinics and more staff to reduce pressure on the already existing fixed facilities, clinics and hospitals.

5.6 RECOMMENDATIONS FOR FURTHER RESEARCH

- The study sample was only drawn from women getting services from Lyttleton clinic in Centurion. More research is therefore recommended to be conducted on a larger scale with women living with HIV and Aids from different settings such as both urban and rural areas to get experiences of women living with HIV and Aids from all walks of life.
- The issue of finding time from work every month to visit the clinic for medication was also highlighted in the study. The researcher recommends further research on how women living with HIV and Aids cope with the pressure of having to be at work and having to find time off to visit their health care providers for treatment and check up.
- A follow up study is recommended on the role of partners/ boyfriends/ husbands and workplace support amongst HIV positive women who are sole breadwinners in the household.

5.7 CONTRIBUTIONS OF THE STUDY

This qualitative research study on experiences of women living with HIV and Aids highlighted the need to focus on activities on 'how to cope' rather than 'how to prevent' amongst women living with HIV and Aids.

Moreover, the study has identified important issues raised by participants regarding the services they receive at the clinic and one of them being the long waiting period for one

to be attended to by a nurse. With a report back at the clinic on this note, it is hoped that measures will be put in place to shorten the amount of time spent at the clinic waiting for assistance.

5.8 LIMITATIONS OF THE STUDY

- The study focused only on women living with HIV and Aids receiving health care services at Lyttleton clinic in Centurion, therefore, the findings cannot be generalized to all women living with HIV and Aids in the whole of Gauteng Province.
- Possibility of sample bias due to the fact that the study participants were only women living in Centurion which is an urban setting that could not reflect experiences of women from a different setting such rural areas.
- The study participants chosen were HIV positive women who were only present at the time of data collection whose return date to the same clinic was unknown. This made it impossible for follow up interviews to be conducted to verify the research results. Due to this, the confirmability of the research findings was compromised to some extent. The researcher therefore recommends an audit trail of crucial examples provided in this research from the transcript which is under the research findings section of this research.

5.9 CONCLUDING REMARKS

According to the findings of this research, HIV and Aids has negatively affected women. Women living with HIV and Aids are still trying to find their way around coping positively in living with HIV and Aids.

Experiences such as on and off or ongoing illness, the difficulty and challenges faced in accepting the HIV positive status, experiences in services rendered such as long waiting periods and lack of adequate information experienced by some participants,

issues regarding disclosure as well as the stigma and emotional stress encountered have highlighted how coping is still a big challenge amongst women living with HIV and Aids. These findings have led the researcher in recommending structured and educational support groups, interventions and awareness campaigns on stigma and improved education and training amongst health care professionals in public health practice. The findings also prompted the need for further research on women living with HIV and Aids regarding how they cope at work having to find time off from work every now and then to visit clinics and hospitals.

Although this research was subject to some limitations such as lack of follow up on study participants and a study sample only chosen from one small geographic area, the study findings and recommendations would require consideration by the management of Tshwane Health District in order to improve overall health experience of women living with HIV and Aids in Centurion. If areas that need improvement could be strengthened and maintained, with everyone taking his or her responsibility, living with HIV and Aids will be more bearable and enhanced.

In order to disseminate knowledge gained from this research, the researcher is going to avail a copy of this research to Tshwane Health District of Gauteng Province. The researcher also plans to publish these research findings so that information obtained from this research can be made available and useful to stakeholders such as practitioners, patients and the public. The voices of women in this study are loud and clear. The need to assist them on coping positively in living with HIV and Aids will remain vital even beyond the conclusion of this study.

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7. LIST OF TABLES

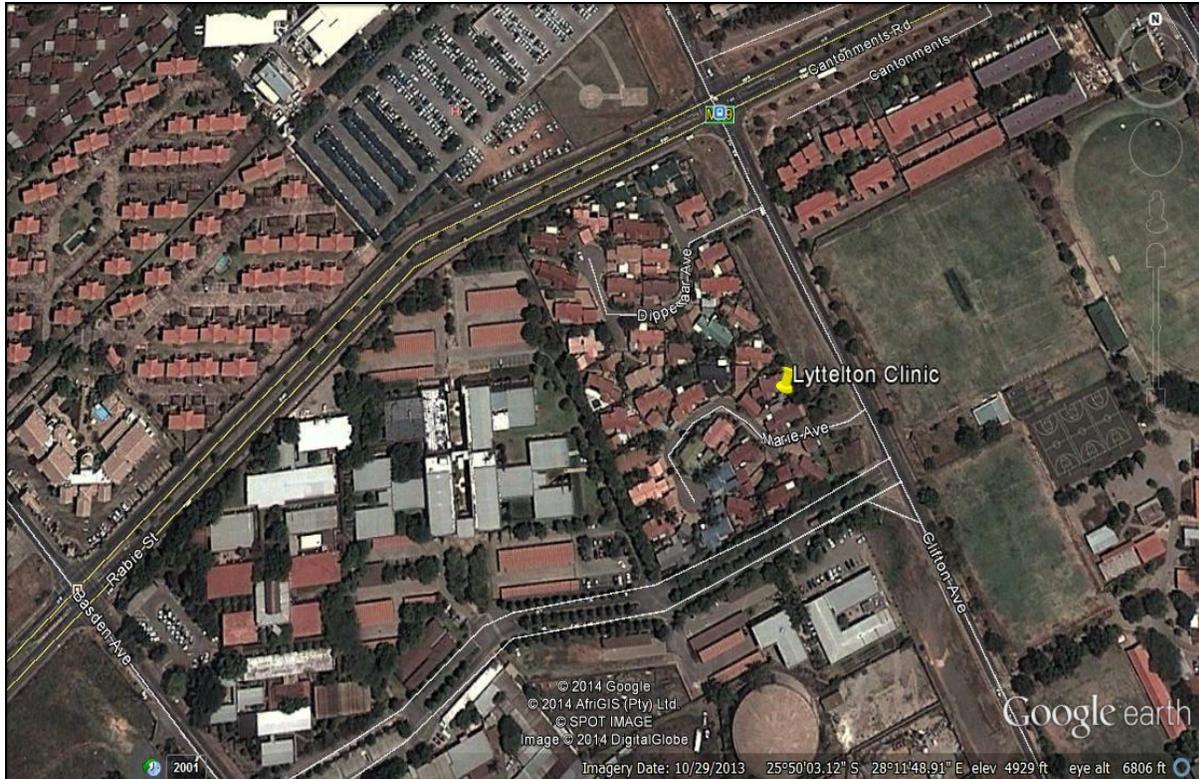
7.1: Biographical data of participants

Age	Number
18-25	0
26-33	2
34-41	5
42-49	5
Marital status	
Married	2
Widow	2
Single	5
Divorced	3
Educational level	
Never attended school	1
Up to Grade 7	1
Grade 8-10	5
Grade 11-12	3
Tertiary	2
Number of children	
0	1
1-3	6
4-6	5
Home language	
Zulu	3
Sotho/ Setswana	6
Shangaan	1
Shona	2

Area of residence	
Centurion	8
Outside Centurion	4
Employment status	
Employed	8
Unemployed	4

8. LIST OF FIGURES

8.1: Aerial map showing Lyttelton Clinic, Centurion, Gauteng



9. ANNEXES

9.1: Annex A: Letter Seeking Consent from the Department of Health: Gauteng Province

Tshwane District Health Services
The Fields Building
327 Hilda Street
Hatfield

Unit 28, Alto
Basden Avenue
Lyttleton
Centurion
0157

28 March 2013

Attention: The Management

RE: PERMISSION TO CONDUCT RESEARCH

I am a social worker at Pretoria Care for the Aged in Pretoria. I am a registered Masters student with the Health Department at the University of South Africa (UNISA).

I hereby apply for permission to carry out a study at your clinic on the experiences of women living with HIV and Aids in Centurion, Gauteng Province. The study aims to describe the experiences of women living with HIV and Aids in Centurion. The researcher wishes to conduct a minimum of fifteen interviews, however the final number of participants will be determined by data saturation.

During the interview, participants will be asked different questions about their experiences of living with HIV and Aids. (See the attached annexure which will be the

researcher's interview guide). Some of the questions going to be asked to the study participants maybe personal and sensitive and may lead to emotional stress.

The researcher therefore will seek permission from Lyttleton clinic's trained staff to offer free counselling if the need may arise due to some information they may have to disclose.

Participation in this study is voluntary. The interviews may each take approximately 30 minutes to an hour. The information provided will have to be recorded by a digital voice recorder for use by the researcher during data analysis and some notes will be taken as well. These notes and voice recorder will be kept in a locked cabinet that will only be accessed by the researcher. The information provided by the study participants will be labelled LP followed by the number of interview and not by the participant's name. Participants may withdraw from the study at any time and this will not affect their care at this clinic in any way. The information provided will be kept confidential. It will not include names or any other identifying information, and no one at the practice will see the answers.

Patients provide very insightful information about their experiences of living with particular diseases. It is hoped that by addressing the experiences of women living with HIV and Aids, the outcome of the study will assist:

- To improve recommendations to policy makers in assisting with the healthcare of women living with HIV and Aids.
- The outcome of the study will also contribute to the already existing knowledge in the Tshwane district and Gauteng province.

The researcher will provide the clinic with a copy of feedback/ research results on completion of the study.

I would really appreciate if you can grant me the permission to carry out the study at this clinic. Should you have any queries, please do not hesitate to contact me or my supervisor on the details provided below.

Yours Sincerely,

Tsitsi Makombe (Reseacher)

Phone (Work): 012 320 3577

Cell: 076 199 7055

Email: tsie.mak@gmail.com

Habedi DSK (Supervisor)

Phone 012 429 6180

9.2: Annex B: Clearance Certificate: Department of Health: Gauteng Province



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

*Kwinqeshwani! Gauteng Working Better
Kuyasheshwa! Gauteng Working Better*

427 Hilda Street, The Fields Building, Pretoria 0001 South Africa. Tel: +27 12 451 9000 Fax: +27 12 451 9125
Enquiries: Dr. K. E. Letebele-Hartell.
e-mail: Manei.Letebele@gauteng.gov.za

TSHWANE RESEARCH COMMITTEE

CLEARANCE CERTIFICATE

Meeting: N/A

PROJECT NUMBER: 30/2013

Title: The experiences of women living with HIV and AIDS in Centurion, Gauteng Province

Researcher: Tsitsi Makombe
Co-Researcher:
Supervisor: Ms D S K Habedi
Department: UNISA

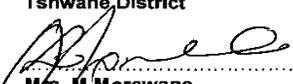
DECISION OF THE COMMITTEE

Approved

**NB: THIS OFFICE REQUESTED A FULL REPORT ON THE OUTCOME
OF THE RESEARCH DONE**

Date: 19th July 2013


.....
Dr. K.E Letebele-Hartell
Chairperson Tshwane Research Committee
Tshwane District


.....
Mrs. M Morewane
Acting Chief Director: District Health Services Support
Tshwane District

NOTE: Resubmission of the protocol by researcher(s) is required if there is departure from the protocol procedures as approved by the committee.

9.3: Annex C: Ethical Clearance Certificate from the University

UNISA  university of south africa

**UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE**

HS HDC / 128 / 2012

Date: 12 December 2012 Student No: 4701-841-0

Project Title: The experiences of women living with HIV and AIDS in Centurion, Gauteng Province

Researcher: Tsitsi Nyasha Makombe

Degree: Masters in Public Health Code: DLMPH95

Supervisor: Ms DSK Habedi
Qualification: MA in Public Health
Joint Supervisor: -

DECISION OF COMMITTEE

Approved Conditionally Approved

for 
Prof L. Roets
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE


Prof MM Moleki
ACTING ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

to **PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES**

Open Rubric

9.4: Annex D: Letter Seeking Consent from Participants

**College of Humanities and Social Sciences
Department of Health Studies
Information letter for Participants**

Principal investigator: Ms Tsitsi Makombe

Dear Research Participant

Title of the study: The Experiences of Women living with HIV and Aids in Centurion, Gauteng Province.

My name is Tsitsi Makombe. I am a social worker at Pretoria Care for the Aged. I am currently a registered student at University of South Africa (UNISA) studying Masters in Public Health.

I am kindly asking you to participate in the study that I am carrying out about the experiences of woman living with HIV/AIDS. The aim of the study is to describe the experiences of women living with HIV and Aids in Centurion. About fifteen women will participate in this study.

During the interview, you will be asked different questions about your experiences of living with HIV and Aids. Some of the questions you will be asked maybe personal and sensitive. However, free counselling will be available and arranged for you if you may need it due to some information you may have to disclose.

Participation in this study is voluntary. If you agree to participate in this study, the interview may take approximately 30-60 minutes. The information you provide will have to be recorded by a digital voice recorder for use by the researcher during data analysis and some notes will be taken as well. These notes and tape recorder will be kept in a

locked cabinet that will only be accessed by the researcher. The information you provide will be labelled according to the date of the interview and your name will not be attached to it. You may withdraw from the study at any time and this will not affect your care in any way. The information you provide will be kept confidential. It will not include your name or any other identifying information, and no one at the practice will see your answers.

Patients provide very insightful information about their experiences of living with particular diseases. With your help we can address some of these experiences that are being faced by women who are HIV positive to create a better environment for you and your community. If you would like more information about the research, please feel free to contact me or my supervisor on the given contact details below.

Your participation in this study will be highly appreciated.

Would you like to participate in this study?

YES	NO
-----	----

Yours sincerely,

Tsitsi Makombe (Researcher)

Phone (Work): 012 320 3577

Cell: 076 199 7055

Email: tsie.mak@gmail.com

Habedi DSK (Supervisor)

Phone 012 429 6180

9.5: Annex E: Letter of Consent from Participant

Informed consent form

I have read and understood the information form for this study. I do understand that the information discussed in this interview is strictly confidential and there will not be any disclosure of names and identity.

If at any time I have further questions, problems, or encounter adverse events, I can contact the researcher, Ms.Tsitsi Makombe on 00 27 76 199 7055 or her supervisor, Ms Habedi on 012 429 6180.

I agree to participate in the interview for this research project.

By my signature, I acknowledge that this form has been fully explained to me, and I have had a chance to ask questions, have no questions, or have received satisfactory answers.

Signature of Participant

Date

Investigator/ Signature

T. N. Makombe, (Social Worker).

9.6: Data Collection Instrument: Interview Questions and Responses

Date of interview: 23/09/2013 Time 11:40-12:36

BIOGRAPHICAL DATA

1. Age of Participant: 41

2. Ethnic group: Zulu

3. Home language: Zulu

4. Area of Residence: Lyttleton

5. Marital status: Divorced

6. Educational level: Grade 9

7. Employment Status: Employed (Domestic worker) _____

8. Number of children: 4

9. Any infant deaths/miscarriage/still birth? No _____

If yes, how many? N/A _____

10. Religion Christian _____

Researcher: What are your experiences of living with HIV and Aids?

Participant: I tested HIV positive in 2005. This is the story of my life. My husband had a girlfriend who was a school child. His sister told me about the affair. I didn't believe it because I loved him too much. This school girl passed away and I heard from his sister that this girl looked like she was HIV positive and had an affair with my husband so she told me to go and get tested.

On the same day I went to the clinic. When I got there I wasn't scared of anything. I told them I wanted to test for HIV. They asked me where my husband was and I told them I left him so I said I just wanted to be tested and get my results then I would talk to them later. I received counselling before I got my results.

I got my results and I was positive. I received counselling again. It was very painful and I didn't accept it. I suffered too much because before this my marriage was not good. I was not working at that time and we were struggling. My husband was unemployed as well. We were asking my mother and brother to assist us with money. Our love was normal before he got into this affair.

I told the nurses that we were suffering and I had children and my husband was unemployed. So they assisted me with a grant. I got a grant for a year. When I got home I didn't tell my husband about my status but I just I asked my husband that we must go and get tested. Immediately he said he didn't have AIDS. I told him that I also did not have AIDS but if he refused get tested we were going to divorce. He did not sleep that night he kept turning and turning. His brother was a doctor and he advised us to go and get tested. We spent a number of days without going to the clinic and it could show that there was something bothering him too much. Ever since I mentioned about being tested he was not ok. Finally he agreed to go to the clinic. We got in and went to the VCT. I told him I would give him space but he refused he asked why I was leaving him. So we got in together. He was tested first and he showed me his results. So I

asked him who was wrong between the two of us. I asked the nurses to test me as well and that they must give him my results as he was my husband.

When we went back home I asked why he rushed to say that he did not have AIDS the first day I asked we got tested. I told him it was because he knew something. I told him about the affair he had and he agreed.

As we stayed on he refused to use condoms and I told him I would not sleep with him if we did not use a condom. He fell sick several times and he was in and out of hospital. He was not taking his treatment every day. I explained to him that he must take his medication seriously but he said it was not a problem. I phoned his brother who knew about it that it had been a week without him taking his medication. I even went back to the clinic and I told them my husband was not following his treatment and asked if it was not going to affect me. The nurses told me if I used a condom with him I was going to be fine.

He suffered a lot of pimples and rushes.

I am now separated with my husband because he later cheated on me and had a child with another woman. He did not tell me about this I only heard from people. I was willing to forgive him if he sat down with me and told me but he did not bother telling me and I could see there was no love since he had a new girlfriend. So we separated.

Researcher: Ok, so how do you feel now about your HIV status?

Participant: Right now I am very fine. I am alright. I can even tell everyone that I am HIV positive and I can counsel people with HIV. I have accepted it and am fine with it. Even if I can see you there, when I see a person with signs and symptoms of HIV and Aids, I can tell that this is HIV and I don't have a problem calling you, I approach them and counsel them or tell them to go and tested. Because of this church badge (referring

to her ZCC badge) they always think that because am a church person I have seen it already so they don't get angry.

Researcher: So have you suffered any physical symptoms ever since you tested HIV positive?

Participant: Yes at one time I had some rush down there. But my problem is when I went home for a funeral I was very down feeling so low so after the funeral I went to the clinic and was tested for my CD4 count and it was 288 so they started giving me ARVs. But I am fine. I eat my vegetables and I can even counsel myself.

I know when it is time I will die because everyone has their time. And God is helping me.

I am very careful with my ARVs every time I go out of the house I always go with a 2ltr bottle so that when it is time to take my ARVs I don't get stuck, I take from my hand bag and I drink them. If it's 8 O'clock I make sure I take my pills and I always eat before. I don't have to go hungry.

Researcher: Tell me about your experiences of attending the VCT service at Lyttleton clinic.

Participant: Very good. The nurses are very friendly.

Researcher: What are the services that are there for you in Lyttleton clinic as a woman living with HIV and Aids?

Participant: Medication, counselling, treatment.

Researcher: What is your experience with the Health care that you receive at Lyttleton?

Participant: There are a lot of delays. But everything else is fine the nurses are good.

Researcher: What do you mean by a lot of delays?

Participant: We wait for a long time in the queue before being attended to, like you can come at 7 in the morning and leave at 2 in the afternoon. But I don't blame them maybe they do not have enough staff.

Researcher: What information do you need from VCT services in Lyttleton?

Participant: Diet and a good explanation on everything. I want information about my medication and how to take them.

Researcher: How can nurses and doctors at Lyttleton clinic assist you as a woman living with HIV and Aids?

Participant: Yes. If they can put tents outside on the streets in the location to give us services maybe some people can go to there and can get to know about this thing.

I also wish they can give me a return date on the days that am not working because I work Monday, Wednesday and Fridays. I can only come to the clinic Tuesdays and Thursdays.

(Silence)

Researcher: Is there anything more that you would like to talk about?

Participant: No I don't have anything more to say.

Researcher: Ok. Thank you very much for your willingness to participate in this study.