THE HEALTH LITERACY NEEDS OF WOMEN LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS OR ACQUIRED IMMUNE DEFICIENCY SYNDROME WHO ATTEND THE WELLNESS CLINIC AT THE JUBILEE HOSPITAL IN HAMMANSKRAAL

by

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DECLARATION

I hereby declare that this mini-dissertation *the health literacy needs of women living with human immunodeficiency virus or acquired immune deficiency syndrome who attend the Wellness Clinic at the Jubilee hospital in Hammanskraal* submitted to the University of Limpopo Medunsa Campus for the degree of Masters in Advanced Community Health Nursing Science has not been previously submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

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Initials & surname **Date**

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Student number

DEDICATION

I dedicate this study to all those affected by the HIV/AIDS epidemic

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My resources alone could not have realised this dream; God truly provides.

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ABSTRACT

South Africa continues to have the largest HIV infected population in the world. Bearing in mind the decrease in the global number of deaths related to HIV/AIDS as well as the fact that new HIV infections – specifically in sub-Saharan Africa – has shown a significant decline in recent years, the growing number of people living with HIV/AIDS presents healthcare workers caring for these people with new challenges.

Women constitute 60% of all people living with HIV/AIDS. Since oppression contributes to women's vulnerability to HIV infection, it is essential that they are empowered in the fight against HIV/AIDS.

This study focussed on the educational empowerment of women in the form of health literacy which referred to the acquirement of skills and competencies to understand, access, and utilise health related knowledge, and included the ability to read in order to obtain and apply health related materials.

Accordingly, the objectives of the study were to explore and describe the health literacy needs of women living with HIV/AIDS attending the Wellness Clinic at the Jubilee hospital in Hammanskraal, Gauteng, South Africa and to make recommendations for healthcare providers to address the health literacy needs of these women.

The study design was qualitative, explorative, descriptive and contextual, and purposive sampling was utilised. Data were collected by means of semi-structured face-to-face interviews and field notes. Interviews were transcribed and then analysed by means of coding.

The findings indicated the need of women living with HIV/AIDS to increase their health literacy about HIV/AIDS to *understand* the disease and to develop the knowledge and skills needed to *physically manage* HIV/AIDS effectively. The knowledge and skills needed ranged from basic HIV/AIDS pathophysiology and the impact of HIV/AIDS on reproductive health, to awareness of the modes of transmission of HIV, and methods of protecting others from getting infected. Women also needed knowledge about, and access to, resources available to women living with HIV/AIDS. Health literacy needs in terms of *psychosocial skills* were also identified as necessary for women living with

HIV/AIDS to manage relationships effectively. The findings further revealed *recommendations* made by women regarding the effective *acquisition of health literacy* on HIV/AIDS.

Recommendations, guided by the research findings, were made for healthcare providers to address the health literacy needs of women living with HIV/AIDS.

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CHAPTER 1: INTRODUCTION, BACKGROUND AND RATIONALE

1.1 INTRODUCTION

Dr J E Kwegyir-Aggrey, Ghanian intellectual, missionary and educationist, once said: "When you educate a woman, you educate a nation" (Nyamidie, 1991:Heading). It can be assumed that these profound words have inspired many campaigns to empower women around the world. In light of the South African human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) epidemic, this saying could be rephrased as: "An HIV educated woman, an HIV educated nation."

1.2 BACKGROUND AND RATIONALE

South Africa continues to have the largest HIV infected population in the world; 5.7 million according to the 2009 AIDS Epidemic Update (Joint United Nations Programme on HIV/AIDS [UNAIDS] & the World Health Organization [WHO], 2009:27). The 2009 AIDS Epidemic Update further estimates that 22.4 million people were living with HIV in sub-Saharan Africa in 2008, and that 72% of AIDS related deaths worldwide occurred in sub-Saharan Africa during the same year (UNAIDS & WHO, 2009:21). The United Nations Secretary-General, Mr Ban Ki-Moon, refers to the eight Millennium Development Goals set to be achieved by 2015 as "a blueprint for a better world" (United Nations, 2009:3). Incorporated as one of the Millennium Development Goals, the fight against this debilitating disease is therefore in the interest of an improved world.

Although the global number of AIDS related deaths was about 10% lower in 2008 than in 2004 (UNAIDS & WHO, 2009:8) and new HIV infections in the sub-Saharan African region specifically had also declined from 2.3 million in 2001 to 1.9 million in 2008 (UNAIDS & WHO, 2009:21), the growing number of people living with HIV presents its own new challenges. AIDS related illnesses are considered to have been among the leading causes of mortality in recent years and it is expected to be the main cause of premature deaths in the years to follow (WHO, 2008:29). Improved services to prevent HIV infections and treat HIV related illnesses could avoid new infections and reduce HIV/AIDS related deaths (WHO, 2008:13).

The 2009 AIDS Epidemic Update (UNAIDS & WHO, 2009:9) identifies a need for HIV prevention programmes specifically designed for people living with HIV/AIDS. It suggests that people living with HIV/AIDS should be involved in programmes and be included in efforts to prevent HIV infection. A study by Seung, Bitalabeho, Buzaalirwa, Diggle, Downing, Bhatt Shah, Tumwebaze and Gove (2008) evaluated a training programme in which HIV infected persons were actively involved in contributing towards the improvement of healthcare for people living with HIV/AIDS. In this programme people living with HIV/AIDS portrayed their illness to healthcare workers in order to train the latter in skills vital to the chronic management of HIV/AIDS. This approach was considered an effective practice since it involved persons with first-hand experience of living with HIV/AIDS (Seung et al., 2008:1206). It correlated with the UNAIDS and WHO recommendation to involve people living with HIV/AIDS in programmes related to HIV/AIDS (UNAIDS & WHO, 2009:9). It was also determined that the people who participated in this training programme were excited to contribute to the training of healthcare workers in a meaningful way; they felt liberated and had a more positive attitude towards their HIV serostatus (Seung et al., 2008:1207).

Goudge, Ngoma, Manderson & Schneider (2009:103) found that HIV infected people who fulfilled a meaningful social role were more likely to resist stigma and regain their self-esteem. This can be interpreted as the empowerment of HIV infected individuals based on Page and Czuba's (1999:Understanding empowerment, para.3) definition of 'empowerment' as "a multi-dimensional social process that helps people gain control over their lives". Page and Czuba (1999:Empowerment and PEP, para.3) further explain 'empowerment' as the harnessing of power, starting with an individual and progressing to the community, in order to take action in issues considered important to themselves.

Ehrhardt, Sawires, McGovern, Peacock and Weston (2009:97) are of the opinion that empowerment is crucial in countering the gender imbalances that allow the prosperity of HIV/AIDS. The 2009 AIDS Epidemic Update (UNAIDS & WHO, 2009:22) reports that 60% of people living with HIV in sub-Saharan Africa are women. This gender disproportion is significant and can be attributed to women's "greater physiological susceptibility to heterosexual transmission, but also to the severe social, legal and economic disadvantages they often confront" (UNAIDS & WHO, 2009:22). In its HIV and AIDS and STI Strategic Plan for South Africa 2007-2011, the Department of Health (DOH) (2007:34) refers to a study by Meyer-Weits, Reddy, Weijts, Van den Borne and Kok (1998) in which it is explained that patriarchal cultures deprive women of the freedom of choice, especially in sexual relationships. Thus, even if women in sexual relationships possess the knowledge to protect themselves from HIV infection they often do not have the cultural right to do so. The WHO (2003:Gender norms increase vulnerability to HIV infection, especially in young people, para.1) also states that gender norms increase women's risk of HIV infection as virility is associated with masculinity in some cultures, and early sexual debut is required in others. Furthermore, heterosexual HIV transmission rates are presumed to be higher in women as a larger portion of mucous membranes are exposed during sexual intercourse (WHO, 2003:Are there differences between women and men in rates of sexual transmission of HIV?, para.1). Poverty often forces women into commercial sex work which undoubtedly exposes them to HIV infection, and violence adds to the risk of HIV infection where women are forced to have sex or are raped or beaten because they want to practice safe sex (WHO, 2003:Violence is an important factor in the transmission of HIV, para.1).

The DOH (2007:11) considers the low social status of women as one of the major causes contributing to the HIV/AIDS epidemic in South Africa. This supposition supports the belief that the empowerment of women can benefit not only women but society as a whole in the fight against HIV/AIDS (Ehrhardt et al., 2009:97). Traditionally, women are responsible for the health needs of their families and make most of the decisions pertaining to the family's healthcare (Wittmann-Price, 2004:438). This implies therefore that women are most likely to care for those family members with HIV/AIDS (Erhardt et al., 2009:99). An UNAIDS study found that, while men were generally treated for HIV/AIDS without questioning, women, on the other hand, were interrogated, suspected of promiscuous sexual behaviour and given less support in their treatment (WHO, 2003:There are gender differences in the social and economic consequences of HIV, para.1). This type of behaviour together with the fact that women may feel inferior to men may inhibit them from getting treatment once they themselves become sick after having been infected with HIV (Erhardt et al., 2009:96). In fact, the biggest concern here is that the growing numbers of HIV infection among women may leave them unable to care effectively for their families once they themselves are debilitated by AIDS. Equally important, women are considered as the main caregivers in many cultures and communities. It thus stands to reason that if a mother or female caregiver in a family is infected with HIV, she will be unable to care for any other member in her family who may also become ill after contracting HIV because of her own illness – in other words, the HIV infected family member's chances of survival is also compromised (Erhardt et al., 2009:100).

The DOH (2007:10) emphasises the devastating impact HIV/AIDS has on households in South Africa; in fact, the high maternal and child mortality rates related to HIV/AIDS in the country threaten the achievement of the Millennium Development Goals by 2015. Clearly, the observed high incidence of HIV/AIDS among women makes it vital to recognise the significant role they can play if they are actively involved in the fight against HIV/AIDS (DOH, 2007:37). In support of such an outcome, Erhardt et al. (2009:102-103) propose four areas of empowerment for women: economic, educational, political and social empowerment.

This study focused on the educational empowerment of women in the form of health literacy, in the fight against HIV/AIDS (Erhardt et al., 2009:103). Although health literacy refers to the ability to read health related materials, it also entails the ability to obtain and apply information related to health matters (Finset & Lie 2010:1). Zarcadoolas, Pleasant and Greer (2005:196) expand the concept of 'health literacy' to the acquirement of a variety of skills and competencies to understand, access and utilise health knowledge towards a healthy life. It requires decision-making and efficiency in finding health information, and understanding and applying it as vital aspects in gaining entry to - and benefitting from - healthcare services (Jordan, Buchbinder & Osborne, 2010:41). These authors argue that health literacy is not an entity on its own; they concede that the improvement of health literacy is achieved through the individual, the society at large, and the healthcare system. This is relevant because improving the health literacy of women will not empower them if the healthcare system and the society hinder the attainment of health literacy (Jordan et al., 2010:41).

Health literacy influences health outcomes in three areas: access to healthcare, patient-healthcare provider interaction, and self-care (Paasche-Orlow & Wolf, 2007:21). For health literacy to be an asset, it must be developed so that individuals may wield authority over their health and in this way empower their decision-making in healthcare (Nutbeam, 2008:2074).

Zarcadoolas et al. (2005:197) define fundamental, scientific, civic and cultural domains of health literacy in describing its multidimensionality, while Nutbeam (2008:2075) simply explains that these different types of health literacy indicate progressive autonomy and empowerment in health decision-making: empowerment through improved health literacy results in a sense of self-efficacy which leads to better self-care in illness as well as improvements in other aspects of health (Aujoulat, D'Hoore & Deccache, 2007:18). Although there are many aspects to consider surrounding health literacy, it basically comes down to simplifying health related information so that it is easy to understand and accessible to all people (Baker, 2006:881).

In light of the educational empowerment needed as a response to the disproportionate incidence of HIV/AIDS in women, the Wittmann-Price theory of emancipated decision-making was considered a fitting theoretical framework for this study. The Wittmann-Price theory of emancipated decision-making proposes that women are oppressed in healthcare decisions (Wittmann-Price & Bhattacharya, 2008:225) and promotes free choice in women's healthcare related decision-making (Wittmann-Price, 2004:438). To promote free choice in healthcare related decisions in HIV/AIDS, the gaps in women's health literacy on HIV/AIDS should be identified to facilitate their educational empowerment.

Since statistics indicate that women are more likely to be affected by HIV/AIDS, whether directly as patients or indirectly as caregivers, they may be the most valuable sources of information regarding gaps in health literacy pertaining to HIV/AIDS. It was envisaged that the identification of these health literacy needs would enable the researcher to make recommendations for healthcare providers to address the health literacy needs of women living with HIV/AIDS.

1.3 PROBLEM STATEMENT

A rising number of people in sub-Saharan Africa are living with HIV and 60% of them are women (UNAIDS & WHO, 2009:21-22). Worldwide, South Africa has the highest number of people living with HIV at 5.7 million according to the 2009 AIDS Epidemic Update (UNAIDS & WHO, 2009:27).

In the researcher's experience as a primary healthcare nurse, many women living with HIV/AIDS lacked health literacy about living with this disease and it prevented them from receiving optimal healthcare. Osborn, Paasche-Orlow, Davis and Wolf (2007:376) describe the effect of poor health literacy on effective self-care in people living with HIV/AIDS. In order to facilitate emancipated decision-making and provide a flexible yet appropriate healthcare service for women living with HIV/AIDS, their specific health literacy needs should be identified. At the onset of the study it was unclear what the health literacy needs of women living with HIV/AIDS who attend the Wellness Clinic at the Jubilee hospital were.

1.4 RESEARCH QUESTION

In response to the problem, the following research question was posed:

- What are the health literacy needs of women living with HIV/AIDS who attend the Wellness Clinic at the Jubilee hospital in Hammanskraal?

1.5 PURPOSE OF THE STUDY

The purpose of this study was to establish the health literacy needs of women living with HIV/AIDS who attend the Wellness Clinic at the Jubilee hospital in Hammanskraal in order to assist them to care effectively for themselves.

1.6 OBJECTIVES

The objectives of the study were to:

- explore and describe the health literacy needs of women living with HIV/AIDS attending the Wellness Clinic at the Jubilee hospital in Hammanskraal
- and to make recommendations for healthcare providers to address the health literacy needs of these women.

1.7 THEORETICAL FRAMEWORK

For this study, the Wittmann-Price theory of emancipated decision-making served as a lens to bring some insight into the perspectives that shaped the research problem and the resultant question asked. It also fostered an understanding of the methods employed in studying the health literacy needs of women living with HIV/AIDS (Creswell, 2009:49, 62).

The Wittmann-Price theory of emancipated decision-making is based on assumptions from the critical social theory as well as the feminist theory (Wittmann-Price, 2004:440). Departing from a critical social theory perspective that environmental influences affect human behaviour and that society marginalises certain groups (Wittmann-Price, 2004:440), this study was driven by the perception that the healthcare system has imposed assumptions about the health literacy needs of women living with HIV/AIDS which may not match the actual health literacy needs of this marginalised group of women (Bloomberg & Volpe, 2008:9). This study explored the health literacy needs of women living with HIV/AIDS who attend the Wellness Clinic at the Jubilee hospital to identify their health literacy needs and make recommendations to healthcare providers to address these needs, thereby liberating this oppressed group of women from the constraints of health literacy needs imposed on them by the healthcare system.

This study's feminist interest was rooted in the perception that society constantly dominates over women and causes oppression and inequality that reach as deep as women's decision-making in healthcare (Wittmann-Price & Bhattacharya, 2008:228). Erhardt et al. (2009:96) confirm this with a statement that women's inferiority to men may inhibit them from getting the necessary treatment in healthcare.

Considering the overwhelming amount of health information available to consumers today (Wittmann-Price, 2006:377), emancipated decision-making is important to make satisfying healthcare choices, especially for women who may feel that their personal knowledge is inferior to generally accepted opinions and decisions (Wittmann-Price & Bhattacharya, 2008:226,228). Wittmann-Price (2004:442) describes the concept of 'emancipation' as a process of reaching a state where freedom of choice can be practiced once oppression has been recognised by referring specifically to the shift from physician-centred decision-making to shared decision-making in healthcare (Wittmann-Price, 2004:438).

Since oppression restricts choices by decreasing autonomy and self-esteem, Wittmann-Price (2004:441) maintains that oppression must be recognised before emancipation can begin. In healthcare, oppression occurs when a person is obligated to choose a socially acceptable option in healthcare instead of an option best suited for the individuals' situation (Wittmann-Price & Bhattacharya, 2008:225). Wittmann-Price (2004:441) believes emancipated decision-making can be facilitated where *reflection* is encouraged, *personal knowledge* is explored, *empowerment* and *awareness of social norms* are considered and where there is a *flexible environment*. Wittmann-Price (2004:441) describes these five concepts as the critical attributes of emancipated decision-making.

Reflection necessitates the deliberate consideration of all information and knowledge available to an individual in order to make a healthcare decision (Wittmann-Price, 2004:441). The act of reflection should be a conscious appraisal of what is known to the individual about the particular healthcare aspect. In the case of health literacy on HIV/AIDS, a woman should reflect on what she knows about the subject and be able to identify her needs. The commonly used method to facilitate reflection is dialogue (Wittmann-Price, 2004:441) as it enables the woman to explore what is known and unknown to her. In this study, the researcher encouraged dialogue through semi-structured, face-to-face interviews which encouraged unrestricted reflection of the health literacy needs of the participants.

Wittmann-Price (2004:441) considers the awareness that various personalised options in healthcare have been considered as the second attribute that must be present for emancipated decision-making. This self-awareness is labelled *personal knowledge* (Wittmann-Price, 2004:441) and nurtures the ability of the woman to know what is best for her personal health (Wittmann-Price, 2006:381). Because people are different, health literacy needs are very specific for every individual; this is also the case with HIV/AIDS health literacy. Consider, for example, infant feeding options: exclusive breastfeeding, mixed feeding, and formula feeding are presented as feeding options for infants of HIV positive women. The woman should consider the feasibility of each option in her situation before choosing the option that personally suits her best. It is therefore perceived that a woman's personal knowledge plays a vital role in her making emancipated decisions concerning her healthcare.

Empowerment, as a third attribute of the Wittmann-Price theory of emancipated decision-making (Wittmann-Price, 2004:441), is described as the information and resources provided to women about healthcare alternatives. By making recommendations to health professionals about the participants' HIV/AIDS health literacy needs, the women may contribute to improving the healthcare they receive, ultimately empowering women to effectively take care of themselves. The importance of empowerment through information given by healthcare providers was confirmed in Wittmann-Price's follow-up publication (Wittmann-Price, 2006:381) in which it was affirmed that improved knowledge facilitated autonomy and independence in healthcare decision-making.

Awareness of social norms addresses the recognition that society has a preference for certain alternatives (Wittmann-Price, 2004:442). Although social norms are often established by finding the best practice based on evidence, the researcher agrees with

Wittmann-Price and Bhattacharya's (2008:227) view that these norms can be oppressive when they do not allow for the use of personal knowledge. Translated to health literacy, awareness of social norms is portrayed by the standard health education and information available to women living with HIV/AIDS in the form of pamphlets, posters, and other communication media such as television and radio programmes, as well as knowledge obtained during consultation with healthcare professionals. The woman may therefore be aware of what is socially accepted and recommended, but may decide to choose an alternative that suits her personal needs. In emancipated decision-making, women should be aware of these social norms but, at the same time, be empowered to make health decisions that are appropriate for themselves.

The last attribute of emancipated decision-making is a *flexible environment* which Wittmann-Price (2004:442) describes as an environment where a woman is allowed to carry out her chosen option without opposition. Because the current healthcare environment is more receptive to active decision-making by the healthcare user (Wittmann-Price, 2006:378), a flexible environment is considered vital in emancipated decision-making - especially when there is a discrepancy between the woman's personal knowledge and the social norms (Wittmann-Price & Bhattacharya, 2008:226). Satisfaction with choice was added as an outcome of emancipated decision-making (Wittmann-Price & Bhattacharya, 2008:231). It was found that a flexible environment was one of the attributes that contributed most to emancipated decision-making and greatly contributed to the women's satisfaction with the healthcare decision they made (Wittmann-Price & Bhattacharya, 2008:232). It is therefore essential for health professionals to create an environment where women are allowed to obtain personalised health literacy in order to attain emancipated decision-making.

The outcome of emancipatory decision-making is free choice without consequences for the woman; a sense of liberation and awareness that the best choice was made for her circumstances (Wittmann-Price, 2004:442). In exploring the health literacy needs of women living with HIV/AIDS, this study supported the theory of emancipated decision-making.

Next, specific concepts used in this study are defined to clarify their application throughout the study.

1.8 OPERATIONAL DEFINITION OF CONCEPTS

The following definitions are presented for the concepts used in this study:

1.8.1 **Health literacy needs:** Stemming from the WHO (1998:10) definition of health literacy, this study referred to ‘health literacy needs’ as the women’s lack of skills and knowledge to facilitate informed decision-making in healthcare with regard to HIV/AIDS as well as their inability to obtain and apply health related information pertaining to the disease.

1.8.2 **Women living with HIV/AIDS:** For the purpose of this study, this concept referred to women 18 years and older who presented with a positive HIV antibody test (WHO, 2007:8) or who met the clinical criteria for diagnosis of advanced HIV according to national policies and guidelines (WHO, 2007:8) and who attended the Wellness Clinic at the Jubilee hospital in Hammanskraal for health monitoring during the time of the study.

1.8.3 **Wellness Clinic:** For the purpose of this study, it referred to the site at the Jubilee hospital in Hammanskraal where women living with HIV/AIDS were seen and antiretroviral therapy (ART) was administered in accordance with South African protocols and guidelines.

1.9 RESEARCH DESIGN

The study ventured to establish the health literacy needs of women living with HIV/AIDS by means of a qualitative (Creswell, 2009:176), descriptive (Babbie, 2010:93), explorative (Babbie, 2010:92), and contextual (Babbie & Mouton, 2003:272; Fouché & Delport, 2011:64) research design. This design allowed for the in-depth exploration of the health literacy needs of the participants and afforded the researcher the opportunity to give detailed descriptions of these needs. Chapter 2 presents a comprehensive discussion of the research design used in the study.

1.10 RESEARCH METHOD

In this study a qualitative, descriptive, explorative and contextual research design was implemented through specific methods which included the careful selection of a study sample through a purposive sampling technique (Creswell, 2009:178). The Wellness Clinic at the Jubilee hospital in Hammanskraal was selected as the research setting because of its richness in potential participants for the study (Creswell, 2009:178). To collect data a semi-structured face-to-face interview schedule (Polit & Beck, 2008:424; Richards & Morse, 2007:111) was compiled from recommendations made by the WHO (2008:vi) as well as recommendations from two previous studies conducted on the health literacy needs of people living with HIV/AIDS: Nokes, Kendrew, Rappaport, Jordan and Rivera (1997:49) and Maneesriwongul, Panutat, Putwatana, Srirapo-ngam, Ounprasertpong and Williams (2004:35). The semi-structured interview schedule was administered by the researcher and interpreted into Setswana when necessary by a translator who was proficient in Setswana. Interviews were transcribed and thereafter analysed following guidelines described by Tesch in Creswell (2009:186) in collaboration with an independent coder. A detailed discussion of the research methodology is presented in Chapter 2.

1.11 ETHICAL CONSIDERATIONS

To ensure that the study complied with ethical standards, the study proposal was reviewed and approved by the following three ethics committees: the School of Health Care Sciences (SREC) and Medunsa Research Ethics Committee (MREC) of the University of Limpopo, Medunsa campus as well as the Tshwane Metsweding region research ethics committee.

The researcher adhered to the professional code of conduct and was guided by the principles of ethics which consider the right of the participant to self-determination and autonomy, privacy, full disclosure, confidentiality and protection from harm and discomfort (Burns & Grove, 2009:190-199). Because of the stigma associated with, and the discrimination against, people with HIV/AIDS, the main considerations were protection from harm and discomfort, and maintaining the confidentiality of the participants. The researcher respected these rights by recruiting participants from a site where every person present was affected by - or infected with - HIV. Participants remained anonymous and the interviews were conducted in a private room, thus adhering to the principle of confidentiality. The ethical considerations for this study are discussed in detail in Chapter 2.

1.12 TRUSTWORTHINESS

Rigour shows a study's integrity and competence and involves ethical as well as political matters (Tobin & Begley, 2004:390). Ongoing debates about the appropriateness of the term ‘rigour’ in qualitative research inspired the use of the term ‘trustworthiness’ instead. The term was more appropriate to the aims of qualitative research, namely to be subjective and creative, yet scientific (Tobin & Begley, 2004:390). Trustworthiness is also concerned with the methodological soundness and adequacy of a study (Holloway & Wheeler, 2010:302) and therefore Lincoln & Guba’s (1985) measures of credibility, dependability, confirmability, transferability and authenticity were used to address the trustworthiness of this study (Tobin & Begley, 2004:391).

Measures employed to satisfy the question of the study’s truth, methodological soundness and adequacy of this study (Holloway & Wheeler, 2010:302) included bracketing, triangulation, peer review, thick descriptions, an audit trail, and the establishment of the researcher’s authority and prolonged engagement in the research field. These are discussed in depth in Chapter 2.

1.13 STUDY OUTLINE

The outline of the study is as follows:

Chapter 1: Introduction, background and rationale
Chapter 2: Research methodology
Chapter 3: Discussion of findings and literature control
Chapter 4: Conclusion of findings, limitations and recommendations

1.14 SUMMARY

Chapter 1 introduced the study and discussed the background and rationale that led to the problem statement and question. The purpose of this study was expressed and the objectives aimed to achieve were set. This chapter also presented the theoretical orientation of the study and defined specific concepts used in this study. A brief overview of the research design and methods, ethical considerations and trustworthiness was given before the study was outlined. In Chapter 2 the methodological aspects are discussed.

CHAPTER 2: RESEARCH METHODOLOGY

2.1 INTRODUCTION

In this chapter, the research design as well as the methods used to collect and analyse the data are discussed, and the appropriateness of the methods employed is argued.

2.2 RESEARCH DESIGN

This study followed a qualitative (Creswell, 2009:176), descriptive (Babbie, 2010:93), explorative (Babbie, 2010:92) and contextual (Babbie & Mouton, 2003:272; Fouché & Delport, 2011:64) research design.

To obtain an understanding of the health literacy needs of women living with HIV/AIDS, the researcher had to merge various pieces of information to form a complete understanding of this phenomenon (Polit & Beck, 2008:219). A qualitative design best served this purpose because of its inductive properties (Burns & Grove, 2009:51; Creswell, 2009:4).

Creswell (2009:175) describes qualitative research as characteristically occurring in the natural setting where the problem is experienced, where the researcher is the key instrument in data collection, and multiple forms of data are collected. Reporting multiple perspectives and any details related to the problem provides a holistic account of the problem and facilitates an in-depth understanding thereof (Creswell, 2009:176). Burns and Grove (2009:51) further describe the qualitative design as giving significance to life experiences based on its belief that reality is dynamic, personal, diverse and subjective. A qualitative study also orientates its reader on its theoretical perspective (Creswell, 2009:176); the current study's emancipatory perspective was proclaimed throughout its course. Featuring all of these characteristics, this study was considered *qualitative*.

The research design for this study also had a *descriptive* (Babbie, 2010:93), *explorative* (Babbie, 2010:92) and *contextual* (Babbie & Mouton, 2003:272; Fouché & Delport, 2011:64) focus: As a *descriptive* study, the intention of this study was to note and describe features of the problem before writing it up (Polit & Beck, 2008:274). In the current study, e*xplorative* research entailed thorough listening and the building of an understanding from what was said – this is especially helpful when a problem is generally not well understood (Creswell, 2009:26). Fouché and De Vos (2011:95, 96) hold that meticulous details are provided in a description, whilst exploration aspires to gain insight into the subject studied. It was the researcher's belief that describing the data gathered and observed during data collection would provide more knowledge and a better understanding of the health literacy needs of women living with HIV/AIDS (Babbie, 2010:93).

The study transpired at the Wellness Clinic at the Jubilee hospital in Hammanskraal, Gauteng, South Africa, and thus within the natural context of the participants, therefore the design was also *contextual* (Creswell, 2009:175). The participants' natural language was used when they were uncomfortable with English – the assistance of a translator who was proficient in Setswana was used in these cases. This served to gain an in-depth understanding of the HIV/AIDS related health literacy needs of the participants (Fouché & Delport, 2011:66). Collecting data in the participants' natural context also allowed the researcher access to the women's contextual perceptions and experiences of living with HIV/AIDS, thus promoting a thorough understanding of their health literacy needs.

This specific research design permitted the researcher to engage with the target population and the study participants; it allowed her to concentrate on the particular meaning and significance of their situation (Creswell, 2009:4) which was, in this case, their health literacy needs as women living with HIV/AIDS. Reaching this understanding allowed the researcher to make recommendations aimed at contributing to the existing body of knowledge regarding HIV/AIDS specific care (Burns & Grove, 2009:51).

2.3 RESEARCH SETTING

In accordance with Polit and Beck's (2008:221) perspective on characteristically qualitative data collection, this study took place in an actual, real life setting. At the Wellness Clinic at the Jubilee hospital in Hammanskraal, healthcare was provided to people with HIV/AIDS. Therefore, it was selected as the study setting based on the nature of information needed to address the research problem (Polit & Beck, 2008:57), as well as the likelihood that the researcher would encounter participants at this site who would be able to provide such information (Creswell, 2009:178). The site of data collection was natural as opposed to experimental since nothing was manipulated in the environment where the data was collected (Burns & Grove, 2009:363; Curry, Nembhard & Bradley, 2009:1442).

Situated on the grounds of the Jubilee hospital on the periphery of the Hammanskraal district, the Wellness Clinic serves mainly people who live in Hammanskraal. Housing structures in the Hammanskraal community vary between fixed houses and informal dwellings and municipal services (water, sanitation and electricity) are mostly available (Plan Associates, 2005:n.p.). The people of Hammanskraal speak predominantly Setswana, have little or no formal education, and about half of the population is unemployed (Plan Associates, 2005:n.p.).

The Wellness Clinic is sponsored by the United States Agency for International Development (USAID), the President's Program for AIDS Relief (PEPFAR) and the Gauteng Department of Health (GDOH). At the time of the study, it employed a professional nurse as a unit manager, three professional nurses with training in HIV/AIDS care and ART, three staff nurses, four medical doctors, a dietician, and a social worker. The number of healthcare users utilising the clinic services increase daily, but at the end of December 2011 the Wellness Clinic served 9768 clients of which 6340 were women.

Although appointments are scheduled for healthcare users on specific days, those who are ill or have problems are attended to on any day. At the time this study was conducted, Mondays were reserved for healthcare users who visited the clinic for the first time as well as those who came for their second visit. On Tuesdays children, single parents and pregnant women were scheduled for consultation. On Wednesdays, Thursdays and Fridays all other clients on ART were attended to. Once healthcare users were stable and had been compliant on ART for three months and had no problems or long-term complications that needed constant monitoring, they were referred to one of three down-referral sites that were more accessible to them for chronic treatment and care.

The healthcare users who attended the Wellness Clinic at the time the study was conducted were composed from the diverse population that live in the Hammanskraal area, and their input provided rich information relevant to this study (Fouché & Delport, 2011:66; Polit & Beck, 2008:354).

2.4 POPULATION

In research, the term ‘population’ is generally considered as the group of people the researcher wants to study (Babbie, 2010:199). According to Burns and Grove (2009:43), the term ‘population’ pertains to all who meet the criteria for inclusion in a study. In the view of Polit and Beck (2008:337), a ‘population’ is a collection of cases that interests the researcher.

The *target* population, namely all women living with HIV/AIDS, was not accessible to the researcher. The *accessible* population for this study was all the women living with HIV/AIDS who attended the Wellness Clinic at the Jubilee hospital in Hammanskraal, Gauteng, South Africa, on the specific days that data were collected. Therefore, healthcare users who were easily available to the researcher and who met the specified criteria (Polit & Beck, 2008:338) composed the study sample.

2.5 SAMPLE

A research sample refers to the section of the population chosen to participate in the study (Burns & Grove, 2009:42). In qualitative research it is particularly important to select a sample that will be of most value to the study (Polit & Beck, 2008:355) so that the researcher obtains trustworthy information. Purposive sampling was used to select the sample for this study. The sample consisted of females who were healthcare users at the Wellness Clinic at the Jubilee hospital in Hammanskraal, who were interested in participating in the study and who met the specified sampling criteria.

2.5.1 Sampling procedure

Burns and Grove (2009:343) describe sampling as a process of selecting study participants. The researcher used a non-probability sampling method because the total population of women living with HIV/AIDS was unknown; consequently, they were inaccessible to the researcher and could not be included in the sample (Babbie, 2010:192; Burns & Grove, 2009:353).

Purposive sampling was chosen as the sampling method for this study, for two reasons: Firstly, the applicable nature of the study setting as a clinic providing healthcare specifically for people living with HIV/AIDS, and, secondly, the researcher’s acquaintance with the population of the setting and belief that, as individuals, they could contribute valuable information towards understanding the health literacy needs of women living with HIV/AIDS (Babbie, 2010:193; Creswell, 2009:178). This type of sampling is said to aid qualitative research in obtaining an extensive understanding of a specific subject (Burns & Grove, 2009:355).

Participants were recruited by addressing the whole group of healthcare users present at the clinic on the days of data collection. As the healthcare users were seated in the waiting area awaiting consultation, the researcher introduced herself, the study and its purpose as well as what was expected of participants (Burns & Grove 2009:364). The healthcare users were addressed in English, but the information was also conveyed in Setswana by a translator proficient in both Setswana and English. The women were then invited to meet the researcher in a specified interview room if they were interested in participating in the study.

As explained, the Wellness Clinic reserves specific days of the week for certain healthcare users and, in an attempt to include a variety of participants (Burns & Grove, 2009:355), the researcher conducted interviews on different days of the week during the data collection period.

2.5.2 Sampling criteria

This concept, also referred to as eligibility criteria, refers to attributes a participant needs in order to become part of the study sample (Polit & Beck, 2008:338). These authors also state that exclusion criteria refer to those characteristics that can exclude a person from the sample. The criteria for this study were drawn from the research problem, the purpose of the study, the design, the definitions of concepts as well as from aspects encountered in literature (Burns & Grove, 2009:344). The sampling criteria also influenced the interpretation of the findings (Polit & Beck, 2008:339) as the findings related only to this specific sample.

2.5.2.1 Inclusion criteria

Because of the large proportion of females attending the Wellness Clinic, the researcher decided to focus on women. For participants to be included in this study, they had to meet the following sampling criteria: all participants had to be female and 18 years or older, had to have had a positive HIV antibody test, or had to meet the clinical criteria for diagnosis of advanced HIV according to the national policies and guidelines (WHO, 2007:8), and had to attend the Wellness Clinic at the Jubilee hospital. Participation was voluntary. At least half of the sample had to be on antiretroviral therapy (ART) at the time when their interviews were conducted in order to provide information about items on the interview schedule that were related to ART as well as the antiretroviral (ARV) medicines themselves. No timeframe was set for the period on ART. Participants who met these criteria were most likely to give information relevant to the research problem (Burns & Grove, 2009:345).

2.5.2.2 Exclusion criteria

These criteria aimed to eliminate those women who would not be mentally or physically capable to participate meaningfully in an interview (Burns & Grove, 2009:345). Consequently, the women living with HIV/AIDS who presented with clinical criteria for diagnosis of advanced HIV according to national policies and guidelines (WHO, 2007:8) and were too ill to participate were excluded as participants. And in keep with ethical conduct, women with mental health problems who were not able to sign informed consent to participate in the study were also excluded as participants in the study.

The exclusion of participants was guided by the researcher’s practical experience and professional understanding of the limitations of physically and mentally debilitated patients. In this study no participants were excluded from participation.

2.5.3 Sample size

The sample size was determined by theoretical saturation (Curry et al., 2009:1445). The semi-structured, face-to-face interviews were conducted until no new information came forward and information started replicating (Curry et al., 2009:1445). Evidenced by the repetition of themes in data, saturation was declared once the researcher, supervisors and independent coder agreed that saturation of the data had been achieved (Burns & Grove, 2009:361).

2.6 DATA COLLECTION PROCESS

Polit and Beck (2008:367) proclaim that effective data collection is imperative to ensure high quality data are obtained that can be translated into meaningful conclusions. By using flexible strategies to obtain the data, the researcher had the freedom to adapt the trend of enquiry during the research process to get the most prolific data towards a holistic understanding of the phenomenon (Polit & Beck, 2008:383).

For the purpose of this study, semi-structured face-to-face interviews were used to collect data. In addition to the interviews, qualitative observations in the form of field notes were useful in recording participant behaviour and other observations not covered by the interview itself (Creswell, 2009:181). The interviews were piloted on two participants and thereafter some adjustments were made to achieve more efficient data collection.

2.6.1 Gaining entry

The research proposal was reviewed and approved by the School of Health Care Sciences (SREC) and the Medunsa Research Ethics Committee (MREC) of the University of Limpopo, Medunsa campus to ensure the ethical soundness of the proposed study before it commenced. The Tshwane Metsweding region research ethics committee also reviewed the research proposal and the researcher received ethical clearance certificates from Medunsa as well as the Tshwane Metsweding region. (Refer to Annexure A and Annexure B). Verbal consent was also obtained from the Jubilee hospital management as well as the unit manager of the Wellness Clinic to gain access to potential study participants.

Before data collection started, the researcher spent time at the Wellness Clinic to familiarise herself with the set-up, organisation and staff. This allowed her to refine the sampling procedure, identify an interview room and establish rapport with the clinic employees.

2.6.2 Structure of the interview schedule

Interviews are considered one of the primary sources of data collection in qualitative studies (Curry et al., 2009:1445) because self-reported data such as interviews, as advocated by Polit and Beck (2008:399), best assist the researcher to understand the participants' realities.

Polit and Beck (2008:424) explain that participants are more likely to open up and describe their experiences, feelings and emotions in face-to-face interviews. Curry et al. (2009:1445) support this view, explaining that the privacy of one-on-one interaction may give the participant the confidence to disclose sensitive information and explore the issue at hand in depth. Face-to-face interviews also allow for the inclusion of people who cannot read or write; it further enables the researcher to ensure that questions are correctly interpreted and, finally, during face-to-face interviews the researcher can make notes of additional observations which add authenticity to the data collected (Polit & Beck, 2008:424-425). Therefore, the researcher decided to use face-to-face interviews as data collection instrument for this study.

Because of the vastness of the topic under discussion, semi-structured face-to-face interviews guided the discussion of the women's health literacy needs pertaining to HIV/AIDS. In attempt to identify topics for inclusion in the semi-structured, face-to-face interviews and in preparing the interview schedule, the researcher reviewed studies conducted by Nokes et al. (1997), by Maneesriwongul et al. (2004), as well as the recommendations for prevention and care interventions regarding the quality of life of persons infected with HIV by the WHO (2008: vi).

Richards and Morse (2007:111) explain that semi-structured interviews are constructed of open-ended questions, and that prepared probes are often developed in advance. The open-ended questions used in the interviews in this study were inspired by Nokes et al. (1997) who developed an HIV Educational Needs Assessment Tool (HENAT) to assess HIV positive persons' learning needs regarding issues relevant to living with HIV/AIDS. HENAT examines learning needs under specific headings, namely: *treatments, entitlements, relationships, preventing infections, social support* and *working* (Nokes et al., 1997:49). Learning needs pertaining to *treatments* explore aspects such as the need for treatment, the correct use of treatments, the expected side-effects, the individual's current health status, and the need to understand laboratory test results. *Entitlements* enquire about governmental programmes and support available to the individual as well as their healthcare rights, while *relationships* address disclosure of one's status to family and friends. *Preventing infections* is concerned with learning needs about general hygiene, preventing transmission of HIV, confidentiality of one's status and awareness of development in HIV care. *Social support* learning needs discuss support groups, and *working* focuses on the impact of the disease on the individual's working ability (Nokes et al., 1997:49).

Maneesriwongul et al. (2004) evaluated the health educational needs of caregivers of HIV infected persons in a study conducted in Thailand. They concluded that healthcare professionals needed to educate caregivers on the *course of the disease*, provide them with the necessary *resources and skills to manage minor ailments,* and advise them on the norms of *preventing transmission*. They also felt that caregivers needed to know the *outcomes of good care* as well as the *support and resources available* to them (Maneesriwongul et al., 2004:35).

In 2008 the WHO (2008:vi) also made recommendations for interventions to improve the quality of life of persons infected with HIV which pertained to *psychosocial treatment* and *support*, *disclosure* of one's status, *notifying partners*, *counselling and testing* of persons at risk, and *cotrimoxazole prophylaxis*. It further addressed the prevention and management of *TB/HIV co-infection*, how to *prevent fungal*, *sexually transmitted* and other *reproductive tract infections, family planning,* and the *prevention of mother-to-child transmission of HIV.* In addition, it related to *preventing malaria* and selected *vaccine preventable diseases* such as hepatitis B, pneumococcal disease, influenza and yellow fever. *Nutrition, safe water, sanitation* and *general hygiene* also needed to be addressed. The WHO further suggested drug rehabilitation programmes and education on safe needle and syringe use where indicated.

For the purpose of this study, questions were arranged in a logical, flowing, conversational manner while sensitive topics, such as relationships, were addressed later in each individual interview and once the participant was more comfortable with the researcher (Babbie, 2010:318). The interview schedule served mainly to guide the participant to explore the specified topics and did not dictate the interview (Greeff, 2011:352). As Babbie (2010:320) states, the qualitative researcher may have a set of topics that need to be covered during the interview. (Refer to Annexure C for the interview schedule).

The interview schedule was piloted to ensure its acceptability as a reliable data collection tool (Burns & Grove, 2009:44). This also allowed the researcher time to practice interviewing skills and identify problems with the interview guide before the main study was commenced.

2.6.3 Pilot of the interview schedule

As a trial run to pilot the interview schedule, and also to give the researcher an opportunity to practice interviewing skills (Burns & Grove, 2009:510), the interview schedule was piloted to test its effectiveness in collecting the data necessary to answer the research question.

The interview schedule was put to test in a simulated interview and evaluated by peers and supervisors. It was determined that the questions in combination with the prepared probing questions were too focused and this made it difficult for the participant to answer when the question was not applicable to the participant. Therefore, the researcher decided to ask broader, more open-ended questions to facilitate a better exploration of health literacy needs and to avoid objectified answers.

The modified interview schedule was then piloted at the Wellness Clinic with actual participants. A Setswana speaking participant as well as an English speaking participant was individually interviewed. The interviews were then roughly transcribed and discussed with the supervisors. The interviews seemed very superficial at first because the researcher moved through questions too quickly, missing opportunities to probe (Greeff, 2011:346). The researcher was reminded to probe more to improve the depth of data obtained during the interviews. Some of the questions were difficult for participants to understand and had to be rephrased for clarity, for example, the question: *"What is important to know about HIV/AIDS as a condition?"* was rephrased as: *"What do you think people need to know about HIV/AIDS?"* Also, questions about methods of addressing health literacy needs were moved to the end of the interview to aid the flow of the interview.

In addition, the pilot study reassured the researcher that the method for participant recruitment was satisfactory (Polit & Beck, 2008:214). It also showed that relevant, in-depth data could be obtained in 45 minutes and reminded the researcher that certain interviewer qualities and communication skills were more effective than others when conducting interviews.

2.6.4 Interviewer qualities and communication skills

Richards and Morse (2007:109) state the quality of data is influenced by the collaboration between the researcher and the participant during data collection.

Despite the apparent casual, friendly and conversational trend of qualitative interviews, preparation and reflection are important to ensure successful data collection (Polit & Beck, 2008:399). In preparation for the interviews the researcher reviewed knowledge on interviewing and communication skills by reading and practicing. She also attended a workshop to further develop effective interviewing skills.

As a professional nurse, the researcher applied communication skills learnt during psychiatric training to facilitate effective interpersonal communication and establish therapeutic relationships with the participants. The communication skills applied by the researcher promoted a safe, consistent and trustworthy relationship and included listening, responding, the use of appropriate language and terminologies, assertiveness and self-awareness (Uys, 2010:176).

Listening and responding are vital to the communication process. Uys (2010:177) states listening often implies a passive role on the part of the researcher, and responding entails the accurate conveyance of understanding to the participant (Uys, 2010:178). During all of the face-to-face interviews conducted in the course of this study, the researcher applied communication techniques to indicate to the participants that she was not only listening, but also understood what they said. Verbal responses were kept to a minimum, but participants' responses were acknowledged by, for example, the researcher nodding her head. The researcher further acknowledged participants by paraphrasing what they had said, clarifying information they had divulged, and reflecting on certain aspects during the course of each individual interview. Participants were also encouraged to add detail about their health literacy needs in aspects where they were vague and the researcher reflectively summarised what had been said (Greeff, 2011:345).

The language and terminologies used were appropriate to the level of education, intellect and culture of the participants (Uys, 2010:179). The researcher demonstrated assertive behaviour by being confident and by not being influenced by participants, for example, the researcher refocused the interview when participants got side tracked (Uys, 2010:182). The researcher fostered an awareness of her personal hopes, fears, anxieties, expectations, needs and values and consciously bracketed them in order to concentrate on the participants (Uys, 2010:184). Bracketing was achieved through self-reflection in a reflective diary (Hamill & Sinclair, 2010:19).

The researcher further studied the interview schedule to ensure familiarity with its contents. This aided in the flow of the interviews and ensured that the participants answered questions satisfactorily without being led (Babbie, 2010:276).

While spending time in the research setting, the researcher observed that the healthcare users and the nursing staff had positive relationships. The healthcare users seemed to trust the nurses with their concerns and problems and, as witnessed in some cases, even with issues that would naturally elicit confrontation - such as poor adherence to ART and inconsistent condom use during intercourse. Considering the fact that participants would probably be more comfortable and familiar with a nurse than with a researcher, it was recognised that the latter could be an unfamiliar concept to the population of Hammanskraal. The researcher decided that rapport with participants would best be established if she presented herself to participants as a nurse instead of a researcher (Polit & Beck, 2008:399). In order to avoid communication barriers related to rank, the researcher did not wear epaulettes during the interviews.

2.6.5 Data collection

The individual interviews were conducted on certain days between 19 July 2010 and 21 August 2010. Since the Wellness Clinic is an exclusive HIV/ART clinic and, at any time, all those present utilise the clinic's HIV/AIDS healthcare services, the recruitment of participants did not lead to involuntary disclosure of HIV status.

Women who were 18 years or older and who were interested in participating in the study were screened one by one for eligibility. The purpose of the study, the objectives and interview process were once again explained to the individual women in English or Setswana – depending on their preferred language. If they chose to participate, they were given a participant information leaflet in either English or Setswana (refer to Annexure D) and the researcher then obtained written, informed consent from each of the individual women before they were interviewed (refer to Annexure E). Those who chose not to participate in the study returned to the waiting area.

The women who consented to participate were interviewed while awaiting consultation. This was done in order to prevent prolonging their waiting time at the clinic. It was decided beforehand that the interviewing process would be stopped if the participant became uncomfortable or was called for consultation; but such interruptions did not occur during any of the individual interviews. The researcher found that a lively, friendly invitation recruited more participants than a reserved formal approach (Polit & Beck, 2008:208).

The interview room was prepared in advance. The researcher ensured that the door could close properly to ensure privacy and limit external noise. Two comfortable chairs were placed facing each other at a comfortable angle. All interviews were audio-recorded (Curry et al., 2009:1448). Each participant was informed of the recording before the interview commenced (refer to the participant information leaflet, Annexure D) and was requested to sign a consent form allowing the researcher to record the interview (refer to Annexure E). The Dictaphone was placed on a table between the participant and the researcher to ensure quality voice recording. The researcher tested the Dictaphone before each interview, checked that there was sufficient recording memory and battery power, and ensured that there were interview schedules and sufficient supplies for taking notes.

Participants who were comfortable with English were interviewed by the researcher while interviews in Setswana were facilitated with the help of a Setswana speaking colleague who was experienced in research and interviewing. Audio-recordings of these translated interviews were translated verbatim to ensure that the participant's true affective meaning and expression was incorporated in the data analysis.

Basic demographic data was collected to allow for a detailed description of the sample (Burns & Grove, 2009:179) and interviews were numbered consecutively from 01, starting with the pilot study interviews. An interview schedule (refer to Annexure C) was used to probe participants to explore their health literacy needs under specific topics (Polit & Beck, 2008:394). At first broad, open-ended questions were posed and the participant was given time to answer. The researcher used spontaneous probing to extract more information from participants where exploration of the topics was insufficient or statements had to be clarified (Burns & Grove, 2009:405; Richards & Morse, 2007:111). Probing increased the depth and quality of the data (Greeff, 2011:345). The researcher made notes of the participants' responses (Creswell, 2009:183) and added field notes next to relevant questions in the space provided on the interview schedule.

The researcher anticipated that the following problems could arise during interviewing: Interruptions such as participants' cellular telephones ringing, their small children or babies becoming agitated, participants being called out for consultation as well as performance anxiety once the participant became aware that she was being recorded, or if she felt violated by the direct and personal nature of questions. Failure of the researcher to establish rapport with the participant or talkative participants that kept wandering off the subject (Burns & Grove, 2009:511) was also considered.

Difficulties that were in fact encountered included participants' cellular telephones ringing during their interviews. This, however, did not distract any of them from their purpose in answering the questions and, despite recurrent telephone calls during one specific interview, the participant wanted to continue with the interview. Another participant refused audio-recording of her interview but was eager to participate in the research, so the researcher summarised the participant's answers and wrote them down. Although no quotations could be used with regard to this participant's interview, valuable data was collected which repeated itself in further interviews.

One unexpected problem encountered was a very noisy environment which could not be controlled because of the large numbers of healthcare users passing by the interview room. No other rooms were available for interviews but, regardless of noisy recordings, the interview conversations could be distinguished from the background noises.

2.6.6 Field notes

Field notes were kept as an aid to record observations made during the data collection process (Creswell, 2009:182). The purpose of field notes is to render significant additional information, and its importance is realised only when recognising that the researcher is a multifaceted tool that perceives, experiences, reflects, bonds and records observations to retrieve and analyse later (Burns & Grove, 2009:508). As recommended by Creswell (2009:181), the researcher used a dedicated space for field notes on the interview guide (refer to Annexure C). The researcher made unstructured observations pertaining to the surroundings, the participants' behaviours, and the feelings she felt and experienced during the data collection – this allowed for some unobtrusive spontaneous reflection (Burns & Grove, 2009:508).

Polit and Beck (2008:406) distinguish between observational notes and reflective notes. In this study, observational notes extensively described observations about the setting and the participant in order to achieve a thick description for data analysis. Reflective notes, which recorded the researcher's personal observations and feelings, served to clarify some descriptive observations (Polit & Beck, 2008:406), but also served as methodological notes that reflected on the method of observation. They were useful as reference for the researcher to identify effective and less effective methods used during the interviews. Theoretical notes guided the researcher towards understanding observations in context and personal notes simply documented the researcher's feelings during the data collection process. The field notes were paired with the correlating interview transcriptions by means of tabulation (refer to Annexure F) and recorded emerging themes and ideas which allowed for a comprehensive data analysis (Holloway & Wheeler, 2010:117).

2.7 DATA ANALYSIS

The purpose of analysing data is to get structure and purpose from raw data (Polit & Beck, 2008:507). Polit and Beck (2008:219) state data analysis occurs continuously to determine the completion of fieldwork. Schurink, Fouché and De Vos (2011:405) explain that this continuous analysis occurs firstly at the research site and secondly away from the research site. Since the researcher was the main tool in data collection, the data were reviewed during data collection and during the periods between data collection, thus the data collection and analysis were made inseparable.

2.7.1 Preparation for data analysis

Data analysis began when the data which had been collected through audio-recordings (Burns & Grove, 2009:507) were transcribed verbatim and systematically organised together with the field notes to identify emerging themes.

Transcription is vital in the preparation of data for analysis and must be concise and accurate as transcription errors could jeopardise the reliability of research findings (Polit & Beck, 2008:509). For this reason, experienced transcribers were enlisted for the transcription of the interviews in this study. Interviews in Setswana were transcribed in the original language and then translated into English.

The transcriptions were considered as the raw data (Burns & Grove, 2009:520) and were simplified and focused to identify the characteristics of data through the process of coding (Richards & Morse, 2007:133).

2.7.2 Coding

As suggested by Creswell (2009:175), an inductive reasoning process was applied for the qualitative data analysis in this study. The opinions, views and perceptions of the participants in the study were analysed to construct a complete understanding of their health literacy needs. The participants' interpretations regarding their health literacy needs were pursued and not the researcher's perception thereof.

Coding was used to facilitate inductive reasoning; this process aided in the simplification of data and focused on certain characteristics of the data. It also entailed the organisation of data into categories to bring meaning to the information collected (Creswell, 2009:186; Richards & Morse, 2007:133), but the numerical conversion of the data was omitted, true to qualitative research (Babbie, 2010:394).

An independent, experienced coder with a postgraduate degree in nursing and who was proficient in English and Setswana was employed to assist with the coding of the data to ensure the credibility of the study. The coder checked the correctness of the Setswana translations and met with the researcher to reach consensus about the categories, themes and sub-categories derived from the data.

Richards and Morse (2007:145) stress that there is no single step-by-step summary of the qualitative coding process; therefore the coding process of Tesch, as suggested by Creswell (2009:185), was followed. Since there were some predetermined topics, coding was done under - but not limited to - these topics. Questions that addressed predetermined topics were tabulated by the independent coder and mind-mapped by the researcher. The responses of the participants to these questions – depicted in their own words - were then recorded in the independent coder's table and the researcher's mind-map and these led to *descriptive codes* (Burns & Grove, 2009:522).

The data were studied as a whole to develop an overall impression and this led to some broad ideas regarding the information gathered (Creswell, 2009:185). The *descriptive codes* were then re-read and, as the researcher became more familiar with the data and attached underlying meaning to the participants' phrases, *interpretive codes* were formed which identified general categories (Burns & Grove, 2009:522). Finally, *explanatory codes* depicted conclusions about the data (Burns & Grove, 2009:522) and allowed the researcher to name categories and assemble data belonging to each category (Creswell, 2009:186). To illustrate, the category '*Knowledge needed by women living with HIV/AIDS in order to understand the disease'* was derived from questions pertaining to the participants' perception of health literacy needs in areas such as the information they considered important for others to know about HIV and its effects on the body. Important data under this category was then highlighted as sub-categories: *'Knowledge about the pathophysiology and disease progression of HIV/AIDS'* and *'Knowledge about the modes of HIV transmission and prevention of HIV transmission'*.

The reconstruction of the data allowed for the identification of general concepts and connected categories (Holloway & Wheeler, 2010:180; Schurink et al., 2011:413) which were finally interpreted to determine the health literacy needs of women living with HIV/AIDS (Creswell, 2009:189).

In motivation of the legitimacy of the study and its findings the researcher applied specific methods to establish trustworthiness (Richards & Morse, 2007:189).

2.8 TRUSTWORTHINESS

Trustworthiness refers to the accuracy and adequacy of qualitative methods and is considered the equivalence of quantitative rigour (Holloway & Wheeler, 2010:298,302). This important research concept gives an indication of the value of the study results and is considered on the basis of openness in the study, its significance to the body of knowledge, methodological congruence, thoroughness in data collection and processing, and the researcher's self-understanding (Burns & Grove, 2009:54).

Holloway and Wheeler (2010:302) hold that in 1985 Lincoln and Guba revolutionised the mind-set of researchers by introducing distinct criteria for determining the trustworthiness of qualitative research. They established *credibility, dependability, confirmability, transferability* and *authenticity* as measures of trustworthiness.

Credibility pertains to the accuracy of the data and its interpretation (Polit & Beck, 2008:539). In this study the accuracy of the data was achieved by the researcher's prolonged engagement in the research field - from visiting the study setting to building relationships with employees of the Wellness Clinic to be present at the research setting throughout the data collection process (Bloomberg & Volpe, 2008:77). Considering that the researcher was the main tool in the data collection, the accuracy of the data collected was largely influenced by the authority of the researcher (Krefting, 1991:220). The authority of the researcher was also established by the fact that she had had two years of practical experience in working with women living with HIV/AIDS during which she encountered various problems directly related to their lack of health literacy. In addition, the researcher had experience in psychiatric nursing where interviewing and communication skills were acquired; these skills were refreshed during a workshop on interviewing skills and coaching from peers and persons with experience in interviewing. The researcher was also supervised throughout the research process, adding to the accuracy of the data collected as well as to the interpretation thereof.

The fact that peer debriefing can verify the credibility of the study (Murphy & Yielder, 2010:65) motivated the researcher to periodically discuss the progress of the study with peers and supervisors for critique. The researcher also met with an independent coder to reach consensus concerning the saturation of the data as well as the accurate interpretation of the collected data.

Credibility in this study was further enhanced through triangulation, in other words, by collecting information from multiple participants and through various methods such as observations and audio recordings (Creswell, 2009:191). Triangulation included taking field notes, using an independent coder during data analysis and comparing the findings with previously published data (Murphy & Yielder, 2010:65). These authors further consider the process of member-checking essential to increase the credibility of a study. In this study, the researcher validated findings immediately after each individual interview by summarising what the participant had said during her interview and by checking whether her summaries and interpretations correlated with the views of the particular participant.

Reflexivity is concerned with the critical reflection of the researcher's preconceived ideas and views. According to Hamill and Sinclair (2010:19), bracketing plays an important role in reflexivity and is vital in establishing the trustworthiness of a study. Bracketing is discussed in detail in section 2.9 under BIAS (page 32). The researcher also took field notes, thereby constantly considering her own feelings and reactions to the responses and views of the participants (Holloway & Wheeler, 2010:331).

Dependability pertains to the stability of data throughout the research process (Polit & Beck, 2008:539). Well-kept documentation and transparency in the methodology, data analysis and conclusions (Murphy & Yielder, 2010:65) that could be audited by an external reviewer (Creswell, 2009:192; Polit & Beck, 2008:539) ensured dependability in this study. A clear audit trail assisted the independent coder and the supervisors to follow the researcher's methods of data collection and analysis, the decisions she made, and the conclusions she drew (Holloway & Wheeler, 2010:303). It was possible that the consistency and accuracy of the findings could have been influenced by the involvement of a translator. The researcher minimised this threat by involving a translator that was experienced and understood the purpose of the study.

Confirmability has to do with the objectivity of the data to such a point that independent people will agree with the accuracy, relevance and meaning of the data (Polit & Beck, 2008:539). Bracketing is vital in achieving confirmability (Murphy & Yielder, 2010:65) based on the fact that the findings and conclusions of a study achieves its aims without the influence of the researcher's assumptions or preconceptions (Holloway & Wheeler, 2010:303; Polit & Beck, 2008:539). Systematic documentation or a confirmability audit trail would allow an independent auditor to come to the same conclusions as the researcher (Polit & Beck, 2008:539). The use of an independent coder corroborated that findings were clearly derived from the data and not from the researcher's assumptions or preconceptions, and therefore served to increase the study's confirmability (Murphy & Yielder, 2010:65).

As result of a qualitative design of this study, the research findings were not generalisable; however, it could be transferred to similar populations in which the knowledge obtained from this study would be relevant to a study in a similar context (Holloway & Wheeler, 2010:303). The possibility for *transferability* of the data was ensured by thick detailed descriptions of the research methods, research setting, and portrayal of the composition of the sample (Polit & Beck, 2008:539). Transferability was furthered by the data shared in interviews, quotations from interviews, and field notes (Murphy & Yielder, 2010:65).

Authenticity is concerned with the practical implications of the research and ensures that participant's views are reported accurately throughout the strategies employed in the research process (Holloway & Wheeler, 2010:304). Reflexivity and bracketing played an important role in this study's authenticity but it was also achieved by fairness towards the participants, the participants' acceptance of the researcher, continuously obtaining participants' informed consent, and the fair portrayal of the participants' views (Holloway & Wheeler, 2010:304). The study strived for ontological authenticity by increasing the readers' as well as the participants' understanding of the health literacy needs of women living with HIV/AIDS, and facilitating an appreciation of different perspectives (educational authenticity). Catalytic and tactical authenticity was verified by influencing a change in the health literacy of women living with HIV/AIDS through recommendations to healthcare providers (Holloway & Wheeler, 2010:304; Tobin & Begley, 2004:392).

The methods employed and described to increase the trustworthiness of this study were triangulation, peer review, an audit trail, thick descriptions, reflexivity and bracketing, establishing the researcher's authority, and member-checking.

2.9 BIAS

Polit and Beck (2008:197) describe bias as an influence that alters study results and renders it fallacious or of poor quality. They suggest that bias must be identified early in the research process and Burns and Grove (2009:220) suggest that bias is avoided or eliminated as it might influence the research findings. Therefore, the clarification of bias also played an important role in supporting the credibility of this study (Bloomberg & Volpe, 2008:77). Qualitative researchers acknowledge bias to avoid its negative impact on the trustworthiness of the study. In identifying bias, the researcher considered the following factors that could influence the data collection process in this study: personal beliefs, prior knowledge, and the role of the researcher.

Mehra (2002:Deciding what to do research on – beginning of bias, para.1) explains that, more often than not, the researcher has personal beliefs about the research topic that ultimately introduce bias into a study. With regard to this study, the researcher, as a practitioner, had experienced cases where HIV infected women were uninformed on many issues regarding HIV/AIDS. Consequently, it was the researcher's expectation to find these same issues in other settings where HIV infected women were treated such as the Wellness Clinic at the Jubilee hospital. To prevent this bias from interfering with the research findings, an interview schedule was used to ensure that the researcher only probed for answers and did not guide the participant towards expected responses.

Equally important, Mehra (2002:Specific questions about bias, para.16) states that the researcher is an integral part of the research process that can be controlled up to point, but not separated from the process – the interaction between the researcher and the participants generates knowledge and therefore researcher bias remains part of the equation. Babbie (2010:260) notes that even the wording of questions may have an impact on the answers of participants. To prevent questions from influencing participants' answers in this study, the researcher kept questions open and impartial and bracketed her personal perceptions. All the interviews were also audio-recorded, transcribed by independent transcribers, and analysed in collaboration with an independent coder to maintain objectivity.

In order for a researcher to be receptive to new information regarding a phenomenon, prior knowledge surrounding the phenomenon must be put aside (Richards & Morse, 2007:51). This is labelled bracketing and was used to reduce bias and increase the trustworthiness in this study. The virtues of a researcher that brackets presuppositions are: firstly, to be aware of one's own values and their influence on the research process; secondly, to question one's own understanding of the phenomenon as described by participants and, thirdly, to be precise in the meaning assigned to words, phrases or terms. Finally, one should be willing to check with participants to ensure one's understanding of their input is correct (Hamill & Sinclair, 2010:18).

The researcher experienced a level of role conflict as predicted by Burns and Grove (2009:445). Despite the fact that the researcher experienced the feeling of being caught between the role of researcher and interviewer and that of being the clinician or counsellor offering advice to the participant (Jack, 2008:58), bracketing urged the researcher to maintain the role of an objective researcher. Hamill and Sinclair (2010:20) suggest the identification and recording of preconceptions and revision of these preconceptions throughout the research process to ensure that objectivity is maintained and that the views of participants are not influenced by the researcher's preconceptions. In this study, role conflict was controlled through bracketing.

In reducing bias in this study, the researcher ensured an audit trail and made use of supervisor support, an independent coder as well as peer review to confirm that results were found in the raw data and not from her own preconceived ideas. Ethical research was conducted to protect participants from harm and risk (Holloway & Wheeler, 2010:53) and the following was considered in attainment thereof.

2.10 ETHICAL CONSIDERATIONS

The study proposal was submitted to the School of Health Care Sciences (SREC) and the Medunsa Research Ethics Committee (MREC) of the University of Limpopo, Medunsa campus. Once ethical clearance had been obtained from them, the regional director of the Gauteng Department of Health (GDOH) granted the researcher permission to conduct the study at the intended site after the research proposal had been reviewed and approved by the Tshwane Metsweding region research ethics committee. The chief executive officer (CEO) of the Jubilee Hospital and the unit manager of the Wellness Clinic were also involved in obtaining permission to conduct this research at the Wellness Clinic (refer to Annexure A and Annexure B for proof of ethical clearance and permission to conduct research at the Wellness Clinic at the Jubilee hospital in Hammanskraal).

Participants, like all healthcare users, have the right to self-determination, privacy, autonomy, confidentiality, full disclosure about the study, and protection from discomfort and harm (Burns & Grove, 2009:190-199). The researcher introduced the study and its purpose with minimal disruption to the site's organisation, and interviewed participants while they waited to be seen – making the data collection process in which they were involved, minimally time-consuming for the participants. The researcher also ensured that participants did not lose their place in the queue. No one was coerced in any way to participate in this study and there were no foreseen risks involved in their participation. Although interviews are not considered threatening to participants, Burns and Grove (2009:511) warn that interviews can influence participants emotionally – therefore counselling was available if participants in this study needed such an intervention after their interview. Participants were required to sign informed consent before participating in the study.

A participant information leaflet (refer to Annexure D) accompanied the consent form and specified the researcher as contact person. Her contact number was also provided on the leaflet for any enquiries related to the study. Furthermore, the participant information leaflet provided an outline of the method for participant selection and the purpose of the study. Participants were informed that interviews would be audio-recorded, given an explanation of the research process and what was expected of them, and assured that confidentiality would be maintained throughout the study. They were also informed that they would have the right to voluntary withdraw from the study at any stage of the process without prejudice (Sarantakos as cited in Creswell, 2009:89). The researcher was available to answer any questions related to the study at all times during the data collection period.

Recruitment occurred at the Wellness Clinic at the Jubilee hospital in Hammanskraal, Gauteng, South Africa, where potential participants were receiving treatment for HIV/AIDS. It was verified that participants were in fact receiving treatment for HIV/AIDS by the clinic personnel as well as through healthcare user records. As mentioned before, there was no involuntary disclosure of the participants' HIV status as all present at the time of recruitment were at the clinic to access HIV/AIDS healthcare services. The researcher refrained from using the names of the participants during the individual interviews to protect their anonymity. Audio-taped recordings were kept secure in an undisclosed location after data collection for the remainder of the research process, and will be destroyed after it has fulfilled its purpose. Sieber (as cited in Creswell, 2009:91) recommends that these records be kept for 5 to 10 years. Transcriptions were done in a private location, transcribers and translators signed confidentiality agreements to treat participant names or confidential data that emerged from the audio-recordings, as well as the actual audio-recordings as completely confidential and to refrain from sharing any of these. The researcher did not submit demographic data for transcription and translation to minimise breach of confidentiality.

The researcher's presentation of the research results was unprejudiced and original. It recognised all references and gave due credit to those who contributed to the study. Findings were made available to interested participants, the Wellness Clinic personnel, and any other interested persons (Sarantakos as cited in Creswell, 2009:89).

2.11 SUMMARY

This chapter described the technical aspects of research as they were applied to this particular study. The study design was discussed and the setting, population, sample and sampling characteristics were reviewed. The data collection process was presented in terms of the interview guide, the pilot study and interview implementation which also addressed finer details such as communication strategies, while the data preparation and coding concluded the data analysis portion of the research methodology. The trustworthiness of the study was ensured, bracketing was debated as a method of reducing bias and, finally, the ethical aspects were thoroughly examined. Chapter 3 discusses the biographic composition of the sample, identifies the health literacy needs of participants, and compares these findings with literature.

CHAPTER 3: DISCUSSION OF FINDINGS AND LITERATURE CONTROL

3.1 INTRODUCTION

This study set out to identify the health literacy needs of women living with HIV/AIDS and to make recommendations for healthcare providers to address the health literacy needs of women living with HIV/AIDS.

In this chapter the findings of the study are discussed under four main categories identified during the process of data analysis as described in Chapter 2. The first section describes the sample and the second addresses the health literacy needs of women living with HIV/AIDS. The findings are also discussed in relation to literature on the health literacy needs of women living with HIV/AIDS.

3.2 BIOGRAPHIC DESCRIPTION OF SAMPLE

The sample was obtained from a population of women living with HIV/AIDS who attended the Wellness Clinic at the Jubilee hospital in Hammanskraal, Gauteng, South Africa and who met the sampling criteria set out in Chapter 2. The sample size consisted of eight women as determined by saturation of the data.

The ages of participants ranged between 21 and 45, with five of the eight participants in their thirties. It was noteworthy that the oldest participant (45 years) had been living with HIV since 2002 and had only started taking ART in 2009. Table 3.1 indicates the year during which each participant was diagnosed with HIV and the year she started taking ART.

Table 3.1 Year of HIV diagnosis and ART initiation

Participant	01	02	03	04	05	06	07	08
Year diagnosed with HIV	2005	2009	2008	2009	2007	2004	2002	2009
Year started taking ART	2006	Not yet	2008	2010	Not yet	2010	2009	2010

Six of the eight participants were already on ART at the time of their interviews and the other two participants, although not on ART themselves, had babies on ART. Therefore all participants were knowledgeable about the use of ARV medication. Two of the participants who were already on ART were also pregnant at the time of their interviews. Three of the participants were Setswana speaking, two spoke Tsonga, one spoke Sepedi, one Sotho and one was Xhosa speaking.

Although English was not the first language of any of the participants, five of them were proficient in English and indicated they were comfortable to be interviewed in English. Two participants were interviewed in Setswana and the remaining one in a mixture of English, Setswana and Sotho with the assistance of a translator who was competent in all three of these languages.

Two of the participants had no school education at all and were also the participants who were interviewed in Setswana. One participant attended school until the end of Grade 7, another Grade 9 and the other one received schooling up until Grade 10. The participant who had completed Grade 10 followed apprentice training in hairdressing. The three participants who had matriculated also developed further skills: one studied commercial business but did not complete her studies due to financial constraints, another did general administration courses and the third did some courses in HIV counselling.

Four of the participants were unemployed, but one of them volunteered as an HIV counsellor at another community institution. Of the four who were employed, one worked as a meat packer, one as a caregiver at an old age home, one as a hairdresser and the fourth as a housekeeper. The respective employers of the participant who worked as a meat packer and the one who worked as a housekeeper were aware of their employees' HIV status.

The above description of the sample indicates that, apart from adhering to the sampling criteria, the sample was diverse which allowed the researcher to obtain a rich description of the health literacy needs of women living with HIV/AIDS.

3.3 DESCRIPTION OF FINDINGS AND LITERATURE CONTROL

The analysis of the data revealed four categories. These categories corresponded with the health literacy needs of women living with HIV/AIDS and are summarized in Table 3.2. The categories and sub-categories were explored and the logic that led to their formulation are explained and supported by quotes from interviews and references to literature on the health literacy needs of women living with HIV/AIDS.

Table 3.2 Summary of categories and sub-categories in the health literacy needs of women living with HIV/AIDS

Category	Sub-categories
3.3.1 Knowledge needed by women living with HIV/AIDS in order to **understand the disease**	3.3.1.1 Knowledge about the **pathophysiology** and **disease progression** of HIV/AIDS 3.3.1.2 Knowledge about the **modes of HIV transmission** and **prevention of HIV transmission**
3.3.2 Knowledge and skills needed by women living with HIV/AIDS regarding the **physical management** of HIV/AIDS	3.3.2.1 Knowledge and skills concerning effective **self-care** 3.3.2.2 Knowledge and skills related to the effective use of **antiretroviral therapy (ART)** 3.3.2.3 Knowledge and skills regarding **reproductive health**
3.3.3 **Psychosocial skills** needed by women living with HIV/AIDS	3.3.3.1 Achieving **acceptance** of HIV diagnosis and life as a HIV positive woman 3.3.3.2 Effective management of **relationships** with reference to: • disclosure of HIV status • increasing community awareness 3.3.3.3 Accessing **resources** available to women living with HIV/AIDS 3.3.3.4 Entitlements in **employment issues**
3.3.4 **Recommendations** made by women living with HIV/AIDS for the **effective acquisition of health literacy**	3.3.4.1 Recommendations about **who** should provide health literacy 3.3.4.2 Recommendations about **how** health literacy should be improved 3.3.4.3 Recommendations about **where** health literacy should be provided 3.3.4.4 Recommendations about **when** health literacy should be addressed

The **central theme** throughout the data was concerned with the needs of women to increase their knowledge about HIV/AIDS in order to **understand the disease** and develop knowledge and skills needed to **physically manage** HIV/AIDS effectively. Knowledge and skills identified as necessary for women living with HIV/AIDS constituted basic HIV/AIDS pathophysiology and the impact of HIV/AIDS on reproductive health. An awareness of the modes of transmission of HIV and the methods of protecting others from being infected was also raised in this category. Furthermore, the need was also identified for women living with HIV/AIDS to know about the resources available to aid them to cope with HIV/AIDS and for them to have access to these resources. Other health literacy needs that emerged focused on **psychosocial skills**. These needs indicated that women living with HIV/AIDS required information on how to maintain relationships with their partners, families, friends, and the community, with specific references to acceptance and dealing with the disclosure of their HIV status. They also needed to be aware of entitlements in terms of employment issues. Finally, the participants made recommendations about the **effective acquisition of health literacy** on HIV/AIDS with reference to 'who', 'how', 'where' and 'when' health literacy should be addressed.

3.3.1 KNOWLEDGE NEEDED BY WOMEN LIVING WITH HIV/AIDS IN ORDER TO UNDERSTAND THE DISEASE

This category of health literacy needs addressed the fact that women living with HIV/AIDS needed knowledge about certain aspects of HIV/AIDS to understand the disease. These aspects included understanding the **pathophysiology** and **disease progression** of HIV/AIDS, awareness of the **modes** through which **HIV** can be **transmitted** as well as knowledge about the **prevention of HIV transmission** to other persons.

3.3.1.1 Knowledge about the pathophysiology and disease progression of HIV/AIDS

The participants described the need to be more knowledgeable about the **pathophysiology** and **disease progression** of HIV/AIDS in order to understand the disease better. They agreed that this knowledge would help women realise that having HIV *"is not the end of the world"* as one participant stated. The participants were of the opinion that knowledge about the pathophysiology and disease progression of HIV/AIDS would give them hope for their lives ahead and would inspire them to live a quality life despite their HIV positive status. This view is reflected in the words of a participant who said:

"It's a virus and then not knowing how it infects you and when you are infected, how must you keep yourself and you know, healthy, living longer. I think what will encourage

people, is when people know that HIV doesn't kill. I think that will be more [very][1] *helpful to people."*

In the participants' view knowledge about the **pathophysiology** of HIV/AIDS needed to include information about:

- CD4 count
- viral load
- interrelation of CD4 and viral load

In their individual interviews, the participants specifically referred to the fact that, to understand the pathophysiology of HIV/AIDS, more knowledge about the CD4 count and viral load was needed. Their clear references and detailed descriptions about the interrelation between the CD4 count and the viral load indicated how important they believed these aspects were as health literacy needs. The participants wanted other women living with HIV/AIDS to know and understand that an increased CD4 count meant a better health status. They explained that it was important to know that HIV weakens the body's immune system and renders it vulnerable to opportunistic infections. The following quotes support this:

"It is important that people should know about their CD4 count because once your CD4 count is low, you may get sick [and] *some people start showing symptoms of HIV."*

"By the CD4 count they need to know that when you are HIV positive there is a CD4 count and the viral load. When the viral level goes up, the CD4 count goes down..."

One participant seemed baffled by the terms 'CD4' and 'viral load', knowing only that it relayed information about her adherence to ART. When probed, she admitted that she was unsure about what these terms meant or indicated in terms of her health status; yet she knew it was important that women living with HIV/AIDS should understand them since it obviously played a significant role in determining their health status. This participant commented:

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[1] Words in brackets are the researcher's words added for clarification

"The CD4? And the viral load? The only thing that I know about, they said before it shows how much you are taking – if you are taking your medication all right... . It's necessary [to tell women about the CD4 count and the viral load] *because some of them don't understand what is the CD4. The viral load too, they don't understand."*

Petroll, Hare and Pinkerton (2008:232) explain that the CD4 count and the viral load are the two most prognostic indicators of a person's HIV status. Kalichman, Benotsch, Suarez, Catz, Miller and Rompa (2000) conducted the test of the functional health literacy in adults (TOFHLA) on a group of people living with HIV/AIDS and made comparisons between lower health literacy and higher health literacy groups. The study determined that people with a higher level of health literacy were twice as likely to report fully understanding the meaning of their CD4 count and three times more likely to report fully understanding their viral load results (Kalichman et al., 2000:329). In a study by Nokes et al. (1997:49) it was found that there was a need for people with HIV/AIDS to know exactly what their HIV diagnosis meant, while a nurse-delivered HIV treatment adherence intervention conducted by Kalichman, Cherry and Cain (2005) indicated the necessity for people with HIV/AIDS to have an improved knowledge about HIV/AIDS and enhanced self-efficacy for more successful adherence to ART (Kalichman et al., 2005:14). The intervention included two intervention sessions of which the first addressed the disease progression of HIV/AIDS with reference to the CD4 count and viral load and an illustration of the impact of HIV on the immune system and the second session focused on skills to improve adherence to treatment (Kalichman et al., 2005:9). The aforementioned sources support the finding of this study in that the participants felt it was necessary for women living with HIV/AIDS to understand the pathophysiology of the disease with reference to detail about the CD4 count and viral load. If not explained in detail and correctly to these women, the significant roles of the CD4 count and viral load could be missed or misunderstood by the woman living with HIV/AIDS.

In the current study, two participants did associate the CD4 count with the blood tests done at the Wellness Clinic, but they linked these tests to follow-up care and not directly with the understanding of the pathophysiology of HIV/AIDS:

"It's very important that they [women living with HIV/AIDS] *must know their CD4 counts. When I went to the clinic I take blood, taken from my CD4 count, then go and take the result...they say no you are still okay, come back after six months..."*

"...when you come to the clinic your CD4 will be tested and you will know how you are progressing..."

Nokes et al. (1997:49) found that participants wanted to know about the different tests done on a person with HIV/AIDS and they also wanted to be informed of the results of such tests and what it meant with regard to their health. Kalichman et al. (2000:328) further found that people with higher health literacy were more likely to report an undetectable viral load. Laboratory tests are important in monitoring viral and immune responses in HIV/AIDS (Petroll et al., 2008:232). It stands to argue then that women with HIV/AIDS should be educated about the meaning of the CD4 count and the viral load as well as the implications of these test results on their health status. This literature supports the inclusion of education about the different tests done on a person with HIV/AIDS as a health literacy need for women living with HIV/AIDS to understand the pathophysiology of the disease.

The participants in this study also reflected on the physical changes that take place when one is living with HIV/AIDS. It was important for them that women should know that certain changes are expected to occur and do occur in the body as the **disease progresses**. They spoke about the physical changes they had observed in themselves as well as in others. Some of the changes they mentioned included losing or gaining weight, developing acne, sores that do not heal properly, or experiencing changes in one's complexion.

"There are many signs [of HIV/AIDS] *some they lose weight, some get sick, some don't eat...there are many signs, but some they even gain weight."*

"...like some other people, they are just like spot-spot...some people they are just black and their skin is just [indicated pimples]*, you see?"*

"...when a person is HIV positive, it is easy to be attacked by all sorts of diseases. People suffer from a lot of illnesses and they don't know it is happening because they are HIV positive...there are many symptoms of HIV."

"Some people get very sick when they have HIV, their colour changes and their face changes. They should know how HIV works and why these changes happen."

It was important to the participants for women to know that a person with HIV/AIDS can not necessarily be told apart from one who does not have the disease by just looking at the person's physical appearance or noting the person's apparent health. In other words, a woman can not decide whether or not she has HIV/AIDS by the way she *looks* and/or *feels.* One participant related her own story of refusing HIV testing because she *felt* healthy:

"...I wasn't sick and the father wasn't sick too. But we only realised that we were HIV positive because of the baby..."

A study conducted by Enriquez, Lackey and Witt (2008:39,40) found that women wanted to know whether symptoms they experienced were due to HIV/AIDS or if they could be ascribed to the normal ageing process. Maneesriwongul et al. (2004:35) add that is vital for healthcare providers to discuss and explain the change in a person's appearance, for example losing weight, and other physical changes that may occur as HIV progresses. Moreover, they should include the changes to be expected as HIV progresses to AIDS according to the WHO stages used to classify HIV infection in their explanation. In another study conducted by Corless, Nicholas, McGibbon and Wilson (2004:295) a positive correlation was found between the ideal weight and body image and the quality of life of people living with HIV/AIDS. The authors maintain that people living with HIV/AIDS should be acquainted with the course of the disease; they thus suggest that knowledge concerning the changes in the immune function, changes in the viral load, and the possible opportunistic infections incidental with HIV/AIDS should be integrated. According to them, such integration of knowledge could help women living with HIV/AIDS to understand the effects of HIV and its progression to AIDS.

The current study showed a definite need for women living with HIV/AIDS to understand the pathophysiology and progress of HIV/AIDS in detail.

It must be noted that the need to understand the pathophysiology and progress of HIV/AIDS serves as an introduction and is linked to self-care in the management of HIV/AIDS as discussed in sub-section 3.3.2.1 Knowledge and skills concerning effective self-care (page 50).

Equally important to understanding the disease progression and pathophysiology of HIV/AIDS, the participants in this study voiced that there was a need for knowledge about the spread of HIV and how to protect others from being infected with HIV.

3.3.1.2 Knowledge about the modes of HIV transmission and prevention of HIV transmission

The data analysis revealed that the participants felt women needed to be educated on the **modes of transmission** of HIV to understand which actions put themselves as well as others at risk of being infected with HIV. The participants knew that HIV is sexually transmitted and not by touching or kissing as evidenced by the following two quotes:

"...and they [women living with HIV/AIDS] *should also know that it* [HIV] *is not transmitted through touching or kissing, but through sexual intercourse."*

"You can not be infected by kissing a person but you can only be infected when you have sex and you don't use condoms."

Some referred to alternative ways in which HIV can be transmitted. One participant mentioned:

"...by touching someone's blood and using somebody's needle..."

Another used a car accident as an example to illustrate the transmission of HIV through direct contact with blood:

"To be transmitted there must be an entry and an exit point where the virus could get in and then from me where the virus could go out and get into you,… . Like, blood, let's say I am involved in a car accident and again...but I am not hurt…the blood is not there. If I don't have any entry points I won't be infected, but if I have any entry point it is then that I am going be infected."

One other participant felt strongly about expanding the health literacy of pregnant women living with HIV/AIDS. She wanted women to understand that their breast milk contains the virus and can serve as a mode of transmission to infants. She stated:

"...they [HIV positive mothers] *will just take them and breastfeed their children whereas the breast milk has the virus."*

Another participant suggested that women living with HIV/AIDS should be educated about the specific body fluids that host HIV in order to increase their understanding of the transmission of HIV:

"... there are these body fluids, they [women] *don't know which one carries the high viral load and which one carries the low viral load..."*

Blood, semen, vaginal fluids and breast milk are the specific body fluids that transmit HIV. Activities that promote the exchange of these fluids are needle stick injuries and needle sharing, breastfeeding, not using a condom during sexual intercourse, and during labour when the infant is exposed to blood or vaginal fluids (Petroll et al., 2008:229). The transmission of HIV from mother to child occurs not only through breastfeeding, but also during pregnancy, labour and delivery (WHO, 2010:11). The transmission of HIV also depends on the viral load in the specific body fluid; since ART reduces the viral load, it also decreases the likelihood of HIV transmission through these fluids (Petroll et al., 2008:229). These authors posit that knowledge of these aspects can significantly influence the behaviour of an HIV infected person to reduce the transmission of HIV. Kalichman et al. (2005:7) explain the transmission of HIV through sexual intercourse and drug use behaviours in their nurse-delivered HIV treatment adherence intervention and, as mentioned earlier, they found the intervention proved effective in increasing the knowledge about HIV of the participants in their study.

The participants in the study by Nokes et al. (1997:49) were very concerned about protecting their sexual partners, family and friends from infection with HIV; similarly, women in the current study expressed the importance of **preventing** caregivers and loved ones from being **infected with HIV**. The participants in the current study wanted other women to know how they could protect those they come in contact with from being infected with HIV. Matters that arose in the interviews pertaining to the prevention of HIV infection to others were:

- making caregivers and loved ones aware of the *"health hazards"* - as one participant described those situations that put others at risk of HIV infection;

- teaching caregivers and loved ones measures to prevent infection with HIV when dealing with an HIV infected person; and
- the protection of sexual partners.

The discussion of *"health hazards"* revealed the need for knowledge about alternative modes of transmission of HIV. It was essential to the participants in the current study that women living with HIV/AIDS should understand that it is very much their responsibility to prevent infecting other persons with HIV. Women should be aware of potentially risky situations and should inform their caregivers and loved ones of these risks. One *"health hazard"* mentioned by the participants was direct contact with the blood or body fluid of a person living with HIV/AIDS as portrayed by the following quotes:

"To be careful, especially if you are bleeding, they [caregivers and loved ones] *have to be careful not to touch the blood...I will have to tell them if I am bleeding, just to wear gloves...to protect themselves."*

"I cook a lot but I don't cut veggies, at home they know they have to cut, but potatoes I can peel, but pumpkin - things that are harder - I don't do that. Because I'm afraid I can cut myself, the blood will be there."

Some participants referred to the discrimination they sometimes experienced; they thought that discrimination would become less if caregivers and loved ones know that many daily actions do not allow for the transmission of HIV:

"And they should also know that it [HIV] *is not transmitted through touching or kissing, but through sexual intercourse."*

"Most people are discriminated against by their own families. They are told to use their own utensils; they don't share anything with them..."
Another participant described the discrimination she experienced as follows:

"…they take you aside, and they discriminate against you. No that one, they don't want to touch you or talk to you, sit next to you, eat with you; you know, they have that kind of attitude."

She added:

"I think they must, you know if there was possible they can do the awareness campaign, teach people and then how to live a positive life when you are HIV positive."

Making communities, and especially people close to the HIV infected woman such as caregivers and family members, knowledgeable about the actions and situations that may or may not increase their risk of HIV infection can help them to have a better understanding of the modes of HIV transmission. However, it is also essential to increase their health literacy on measures that can be employed to prevent the transmission of HIV. One such measure, as the next quote shows, is to wear gloves when coming in contact with the body fluids of a person with HIV/AIDS:

"These are the people who should know about your status [friends and family]. *Because you might get sick one day and they should help you. They have to put gloves and if they don't know your status they might help you just like that* [without gloves]*."*

"Because when I'm sick maybe I can't take care of myself and I need to be cleaned and washed, maybe I poef [pass stool] *in my room whatever, maybe I'm bleeding, I've got sores somewhere. They need to know they have to use gloves..."*

The nurses who participated in the study conducted by Maneesriwongul et al. (2004:31) proposed that improved knowledge about HIV/AIDS care could overcome the fear caregivers could have to contract the 'scary, dangerous and communicable' disease that is HIV when caring for an HIV positive person. These nurses as well as the caregivers of people living with HIV/AIDS suggested that demonstrations and opportunities to practise skills in caring for persons with HIV/AIDS would improve their confidence in caring activities (Maneesriwongul et al., 2004:34).

The participants in the current study noted that the protection of the sexual partners of women living with HIV/AIDS was just as important as protecting others close to them. They expressed the importance of this health literacy need with reference to education about sexual practices that put partners at risk of infection with HIV:

"...in the bedroom we have condoms and we do everything that any partner can do but we don't [have] *oral sex, we don't do things like that."*

A second participant stated because she was concerned about the safety of her partner she shared the risks with him and therefore they used condoms:

"...because I want him [my sexual partner] *to know all the health hazards, how things should be done. For him to be safe and me to be safe as well..."*

The participants further referred to the importance of understanding the transmission of HIV from mother to infant both intrapartum and postpartum in order to prevent HIV transmission from mother to child as far as possible. They expressed that women who understood this aspect of HIV transmission could then make informed decisions about becoming pregnant; they would be aware of the possible consequences such as HIV transmission to the infant and weakening of their own immune systems, as evidenced by the following quote:

"Yes it can be possible [to become pregnant]*, but after the baby's birth, will you be healthy enough to take care of the baby or will you die or will you or the baby be healthy?"*

Knowledge about the transmission of HIV in the perinatal period would also allow women to make informed decisions about the pregnancy care needed to minimise the possible risks of pregnancy when living with HIV/AIDS, for example, the use of ART during pregnancy and infant feeding options which are discussed as reproductive issues in women living with HIV/AIDS under sub-section 3.3.2.3 Knowledge and skills regarding reproductive health (page 61).

The participants in the study by Nokes et al. (1997:49) expressed the need to know how to protect their sexual partners, family and friends from being infected with HIV when interacting with them. Caregivers need information with regard to protecting themselves from infection with HIV during the course of caring for those infected with HIV; they also need clear guidelines on how to protect themselves (Maneesriwongul et al., 2004:35). The WHO (2008:12) recommends that, once diagnosed with HIV, a person should take responsibility to protect his or her own health as well as the health and well-being of others regarding HIV infection Kalichman et al. (2000:329) report it was found in their study that people with lower health literacy believed that, once on ART, they had a smaller chance of transmitting HIV to their sexual partners and considered it safe to practice unprotected sex once their viral load was undetectable. The particular concern is that misconceptions such as this can lead to HIV infection of uninfected partners (Kalichman et al., 2000:330). Although this particular misconception was not mentioned by participants in the current study, it is important to realise that false views exist about the modes of HIV transmission. To prevent re-infection and new cases of HIV infection, women living with HIV/AIDS need to be fully informed about the modes of transmission. They must be aware and understand the actions and situations that could put them as well as others at risk of being infected with HIV.

Empowering women living with HIV/AIDS with knowledge about the disease will provide them with a better understanding of it, but it is equally important for them to be equipped with skills in order to manage the disease.

3.3.2 KNOWLEDGE AND SKILLS NEEDED BY WOMEN LIVING WITH HIV/AIDS REGARDING THE PHYSICAL MANAGEMENT OF HIV/AIDS

The second category of health literacy needs required by women living with HIV/AIDS was to acquire knowledge as well as skills to enhance the physical management of HIV/AIDS through effective **self-care**, the **use of anti-retroviral treatment (ART)**, and making informed choices about **reproductive healthcare**.

3.3.2.1 Knowledge and skills concerning effective self-care

The foremost health literacy need to **manage HIV/AIDS effectively** was indicated by the participants in this study to be **self-care**. The participants wanted other women living with HIV/AIDS to know that health outcomes are related to the way they live; how they take care of themselves both physically and psychologically. The health literacy needs surrounding **self-care** were related to the following topics:

- maintenance of a healthy lifestyle with reference to diet, exercise, general hygiene and psychological health;
- preventing re-infection with HIV;
- going for follow-up visits; and
- understanding the causes and management of conditions related to HIV.

With regard to self-care, the participants wanted women living with HIV/AIDS to understand the details of a healthy lifestyle. They communicated that information such as what a healthy diet entails guidance about affordable and practical dietary choices, the importance and benefits of exercise, avoiding alcohol abuse, and ceasing smoking habits needed to be conveyed. The participants explained that knowledge and skills in these lifestyle aspects would enable a woman to take good care of herself. The following quotes from three participants reflect this view:

"...and then by not leading a healthy lifestyle, drinking too much alcohol, smoking, not using protection and things like that they take down your CD4 count and then the viral level goes up..."

"...exercising, even if you are not HIV positive, your body needs to be exercised."

"I think we need to eat a lot of vegetables and fruits... . We should at least have one fruit a day in order to boost our immune system and be strong."

A participant wanted women to learn that food should be prepared in ways that preserve the nutrients. She explained that vegetables should be washed properly before it is prepared and should not be overcooked in order to preserve their nutritional value:

"And even the preparation of food you know, like veggies, we blacks eat a lot of veggies but the way we cook them...we cook them so that we cook the vitamins away. Even the food, the diet, they need to know. Sometimes I eat raw ones because the vitamins are stronger them."

In its recommendations for interventions to improve the quality of life of people living with HIV/AIDS, one of the important aspects mentioned by the WHO (2008:35) is nutrition; weight loss and wasting are considered by this organisation as independent risk factors in the progression of HIV/AIDS and mortality related to HIV/AIDS. It is essential for women living with HIV/AIDS to have access to nutritious food because they have increased energy needs but a decreased appetite (WHO, 2008:35). Symptoms of HIV or conditions related to HIV/AIDS can cause, amongst other problems, difficulty in swallowing – which aggravates anorexia – and the malabsorption of nutrients (WHO, 2008:35).

Sebitloane and Mhlanga (2008:495) additionally state that nutritional deficiencies are common in women living with HIV/AIDS; it is associated with impaired immune functioning and therefore the risks of opportunistic and other infections are much higher than in people who are not infected with HIV/AIDS. Studies have shown that people living with HIV/AIDS have specific nutritional requirements (WHO, 2008:36), but there is no agreement of what specific diet is recommended for them. Anabwani and Navario (2005:98) stress the importance of protein and calorie intake as well as vitamins and trace elements to maintain the defence mechanisms of the person infected with HIV. They recommend the nutritional assessment and screening of people living with HIV/AIDS followed by appropriate interventions and monitoring. Nutritional education is therefore considered as an extremely important aspect of self-care in the physical management of HIV/AIDS.

Because of the higher risk for opportunistic infections in a person who is HIV positive, participants also felt that it was vital for women living with HIV/AIDS to keep their bodies healthy:

"...and it's still important to keep your body warm. If you keep your body warm there won't be these things like coughing, flu, blocking noses, things like that. These germs, bacteria, they won't be there if you keep your body clean."

The participants also believed that details about hygienic living conditions and safe food preparations were essential for self-care. In their views, hygienic living conditions included keeping healthy, regular hand washing, proper cleansing of the body, and washing clothes often. The importance of the safe storage of foods such as meat was also mentioned as an important health literacy need. Because the incorrect storage of foods can lead to the degradation thereof, it can have grave implications for people living with HIV/AIDS because of their weakened immune systems; their weakened immune systems can result in them contracting opportunistic infections such as diarrhoea very quickly and very often. The participants therefore wanted women living with HIV/AIDS to know that the implementation of these activities is necessary in protecting themselves from opportunistic infections and keeping them healthy. This is reflected in one of the participants' statement:

"...healthy and a clean environment because when the place is clean, the bacterias are less... . Hand wash and things like that, they need to wash carefully and the way they store their food..."

The WHO (2008:50) stresses the importance of good hygiene to prevent especially diarrhoea in people living with HIV/AIDS. Since people with HIV/AIDS are twice as likely to develop diarrhoeal diseases (WHO, 2008:50), it is vital to promote hand washing after using the toilet or handling human or animal waste and also before handling or consuming food. However, merely educating is not considered enough motivation for people with HIV/AIDS to wash their hands regularly, therefore, the WHO (2008:50) encourages the re-enforcement of hand washing behaviour through focused clinic- and home-based programmes. These programmes should include demonstrations of effective hand washing techniques, the distribution of soap to those without sufficient income to buy soap and also provide opportunities for persons to practice hand washing (WHO, 2008:50).

Tufts, Wessell and Kearney's (2010:42) stance is that dietary changes are a minor consideration with regard to self-care. Their main focus is on emotional aspects such as religion, supportive surroundings, and disclosing of one's HIV status. The participants in the current study explained that HIV/AIDS is a disease of the whole body which affects every aspect of a person, including one's mind. They mentioned the importance of a healthy frame of mind in managing HIV/AIDS effectively. One participant explained the adverse psychological impact that a negative attitude can have on a person living with HIV/AIDS:

"And we must stop complaining that I will die soon and leave my children behind because the more you complain, the earlier you will die."

In their study Enriquez et al. (2008:40) discuss the constant emotional battle raging in the minds of women living with HIV – living with HIV versus dying from the disease. They recommend a more intense level of emotional healthcare for women living with HIV/AIDS (Enriquez et al., 2008:43). Psychological support and addressing and caring for their mental health also form part of the WHO (2008:8) recommendations for prevention and care in people living with HIV/AIDS. In fact, specific reference is made to the value and importance of adapting and tailoring psychological programmes and interventions to address the emotional and mental needs of people living with HIV/AIDS. In the current study, one participant made it clear that a lowered self-esteem has a negative impact on the psychological health of a woman living with HIV/AIDS:

"...they [women with HIV/AIDS] *mustn't look down on themselves, they mustn't think they that they've been bad enough* [to get HIV] *because once you have that mentality you lower your self-esteem and if you don't respect yourself, accept yourself as you are then nobody will accept you..."*

This quote supports the importance of addressing the psychological health and well-being in the health literacy of women living with HIV/AIDS. Corless et al. (2004:296) found a positive relationship between the perceived body image and weight changes and the quality of life of a person living with HIV/AIDS. They suggest the monitoring of these perceptions in addressing the quality of life op people living with HIV/AIDS. Additionally, Van Dyk (2011:7) also found positive attitudes, and therefore better psychological health, in participants who were maintaining behaviour changes related to HIV/AIDS.

It was clear that all the participants in the current study believed in the importance of a healthy lifestyle to keep their bodies healthy and fit to fight against HIV/AIDS. They reflected that, to maintain their health, it was necessary to prevent re-infection with HIV. They explained that re-infection increases the viral load and could thus further weaken an HIV-infected person's immune system:

"When you are HIV positive you need to always use condoms when you have sex. But if you don't use condoms you will be re-infected."

"Because when you start having sex, the sperms go up [into the vagina] *and the virus multiplies, and then you start to be* [get] *weak. But if you use condoms, you will live healthy like I am."*

To date, prevention programmes have mainly focussed on the prevention of HIV transmission to HIV negative persons, but UNAIDS as cited in Anand, Shiraishi, Bunnell, Jacobs, Solehdin, Abdul-Quader, Marum, Muttunga, Kamoto, Aberle-Grasse and Diaz (2009:1566) suggest the scale-up of efforts to prevent transmission of HIV between HIV positive persons. The most important consideration found in preventing re-infection was condom usage during sexual intercourse. An understanding of its function in preventing re-infection seemed to encourage constant compliance in condom use among participants in the study by Anand et al. (2009:1566). Although recommendations by the WHO (2008:10) regarding the importance of condom use in preventing re-infection with HIV were poorly supported by evidence, the participants in the current study felt that this was an important fact for women with HIV/AIDS to know. A particularly adamant participant insisted on condom use should she ever have a sexual relationship again. Referring to a possible future male sexual partner, she firmly stated:

"…if she [he][2] *don't like* [to use a condom]*, she* [he] *must go."*

The female condom was considered by some of the participants as an effective way in which a woman can take control in preventing re-infection with HIV whenever a male partner refuses to use a male condom. This alternative empowered participants in taking responsibility for their sexual health, an area where they often have little or no input.

"And if their men don't like to use condoms there are women's condoms...because if my man doesn't like it [using male condoms] *I will use it myself and he won't know."*

Welbourn (2006:35) also found that women felt in control of sexual relations when they use the female condom, adding that the female condom also protects the outer parts of the clitoris and labia from being infected with or re-exposed to herpes which commonly occurs among HIV positive persons (Welbourn, 2006:39) .

Another important aspect in self-care that participants felt strongly about was the importance of keeping follow-up visits. The participants stressed the value of follow-up visits to not only monitor the success of ART through blood tests, but to also learn about HIV/AIDS and discuss problems with healthcare workers and fellow healthcare users. Follow-up visits to the clinic were also considered essential by the participants for

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[2] The participant was Sepedi speaking and during her interview in English she used the pronouns 'her' and 'she' when referring to males throughout her interview

women who are not yet on ART because they felt that women should keep apprised of their health status and constantly gain more knowledge about living with HIV/AIDS:

"They [women with HIV] *have to come to the clinic just to have their treatment on time, just to talk..."*

"...when you come to the clinic your CD4 will be tested and you will know how you are progressing, and they will tell you if it is time for treatment or not. So it is important to come for check-up visits even if you're not sick or taking ARVs."

Follow-up visits to the clinic are identified as a crucial part of self-care by various sources. Tufts et al. (2010:42) incorporate follow-up visits in the framework for self-care in living with HIV/AIDS, stating that women should seek care and medical advice as necessary. Petroll et al. (2008:232) also mention the importance of follow-up visits, especially for people already on ART, to monitor adherence to treatment, evaluate the effects of ART, and check immune response to treatment. Although the WHO (2008:13) explicitly mentions the benefits of Cotrimoxazole prophylaxis in reducing morbidity and mortality in HIV positive healthcare users with a CD4 count below 200 cells/ɥL, participants did not mention the importance of Cotrimoxazole prophylaxis in the period before starting ART. This anomaly indicated that more emphasis should be put on the usefulness of Cotrimoxazole prophylaxis, especially in light of evidence that this prophylaxis can change the spectrum of opportunistic infections that may affect women living with HIV/AIDS (WHO, 2008:15).

During discussions of self-care and the effects of HIV on the body, the participants spoke about problems such as constant diarrhoea, recurrent vaginal sores and susceptibility to colds and influenzas ('flu'). This, and the physical changes such as weight loss or gain, or skin changes to be expected as HIV progresses, led to the conclusion that women living with HIV/AIDS need knowledge about common HIV related conditions as well as knowledge and skills on the management of these conditions to avoid serious complications to their already weakened immune systems. One participant explained that the advice women needed in managing these HIV-related conditions should be affordable and practical. She gave as an example the sterilisation of water by boiling it for use in wound care or for drinking and cooking purposes when water supply was unsafe:

"They need to know they have to use gloves, sterilise the water, everything must be clean. Not to say they must go and buy bundles and bundles of sterilised water. Let them cook the water, put it there cooled, it's fine, it's sterilised..."

The participants felt that it was important to pay attention to their bodies and to be aware of changes that might indicate an illness or the need to seek healthcare. A participant explained that a woman living with HIV/AIDS must pay attention to warning signs associated with changes in her body:

"You must know, for you it's not small because your body is warning you, it's already weak because you're carrying the virus, so every change in your body will be an alert."

Sebitloane and Mhlanga (2008:494) are of the opinion that HIV positive women (specifically pregnant HIV positive women) are not screened for opportunistic infections which then present as acute emergencies. It is therefore suggested that women are screened for opportunistic infections to receive early and appropriate care. The WHO (2008:16,20,23) recommends specifically addressing fungal infections in people living with HIV, as well as TB/HIV co-infection with the emphasis on symptoms, risks and management of these conditions. Nokes et al. (1997:49) found that people living with HIV wanted to know how to prevent new infections in general. The current study's participants also expressed the need to know about infections that occur with HIV/AIDS, and their inquiries led to the conclusion that women living with HIV/AIDS should not only be aware of these problems, but should also have the skills to identify and manage infections up to the point where they can seek professional healthcare. Women in another study also spoke of their susceptibility to infections and the need to take additional care with seemingly minor health problems as these problems are easily augmented in women who are HIV positive (Enriquez et al., 2008:40).

In managing HIV/AIDS, ART plays an integral part and requires adherence in order to be effective in managing the disease.

3.3.2.2 Knowledge and skills related to the effective use of ART

The participants in this study emphasised the importance of health literacy concerning ART and explained that a woman living with HIV/AIDS who takes her treatment regularly and as prescribed, will have a decreased viral load and an increased CD4 count and will therefore look and feel healthy – this view again linked to the fact that it was crucial to the participants that the reasons for, and results of, blood tests are understood by women living with HIV/AIDS. The importance for women living with HIV/AIDS to understand the blood tests done in HIV/AIDS care is reiterated in the following quote:

"...the more they know about the ARVs the more they learn about their health, their CD4 count and viral load. Because they learn that, if I'm taking my ARVs properly, automatically my CD4 count is going to be getting higher and higher, and the higher it grows the healthier you become..."

In a study by Van Dyk (2011:6) participants who adhered to treatment explained the role of ART in increasing their quality of life. In the same study it was also found that those participants who did not adhere to their treatment were more concerned with the physical health achieved by using ART as well as its role in preventing death. Although these participants had different reasons for using ART they agreed that improved health made it easier to adhere to ART (Van Dyk, 2011:6). Knowledge and skills related to the **effective use of ART** included:

- the correct use of treatment, including adherence; and
- knowing the effects and the side-effects of the treatment.

It was regarded as very important by the participants in the current study that women had to know that the correct use of, and strict adherence to, ART will have a positive impact on their CD4 count as well as a lowered viral load. They emphasised the importance of adherence and wished to convey to women living with HIV/AIDS that poor adherence diminishes the effectiveness of ART and causes a resistance to treatment which, in turn, makes it harder to bring the viral load to an undetectable level:

"...they [healthcare providers] *told me... if I don't take them* [the ARV medicines] *it will be like, and do things that they* [healthcare providers] *tell me not to, I will get sick and I will then end in hospital and my body will reject the medicine. They* [the ARV medicines] *won't help me anymore."*

"...as I understand, the service of the ARVs in our body, its fourteen hours. So if its fourteen hours per day then these twenty-eight hours I don't take, you see there's a gap, there's nothing of those ARVs in my body. For those fourteen hours it [the ARV medication] *stops* [working] *and then it starts again."*

Van Dyk (2011:7) found that proper education on ARV medication and adherence counselling made it easier for participants to adhere to ART. Another participant in the current study also expressed it was important for her to know the names of her treatment to ensure adherence should she need to obtain treatment from a facility or healthcare professional other than the ones she usually consulted. She explained as follows:

"I would like to know the names of the tablets I am taking. Because you might find yourself involved in an accident or get sick when you are travelling and you don't have them or you only took a few...which tablets are they going to give you if you don't know the names?"

An assessment of ART adherence in India revealed that less than half of the participants knew the names of the ARV medications they were taking. It was further noted that those who knew the names of their medications were more likely to adhere to treatment regimens (Sarna & Weiss, 2007:14). This supports the finding in the current study, namely that knowing the names of the ARV medications is a health literacy need for women living with HIV/AIDS.

The interaction of other medications with the effectiveness of ART was also considered an important health literacy need for women living with HIV/AIDS and the participants insisted that women consult with healthcare professionals before taking any supplements with their ART or when considering any alternatives to ART. As one participant explained:

"So they need to know okay its fine, I'm taking the traditional stuff and all that, but...they also have to do some research, is it possible for them to use the ARVs with that? Because some they feel traditional medicine is the best. Most of us actually, because I'm black, they believe that."

Not only traditional medicines interact with ART, often prescribed medicines to treat infections or conditions related to HIV/AIDS can interact with ART (Anabwani & Navario, 2005:98). In fact, Van Dyk (2011:8) identified alternative medicines as a barrier in adherence to ART since the participants expressed they became confused when they had to choose which treatment regime to follow (Van Dyk, 2011:8). It is essential that not only healthcare providers know about the interactions of ARV medicines with other treatment, but for the women on ART to be aware of such possible interactions as well in order for them to consult with healthcare providers about the use of additional treatment in conjunction with ART.

Although the participants regarded knowledge about the possible side-effects of ART as important, their greatest concern was, however, to convey the positive effects the treatment has. The following encouraging statement regarding ART was made by a participant in the current study:

"Look at how I gained weight. If I can tell you when I was diagnosed, you will not believe me. I don't use traditional herbs because the tablets I am taking cannot be used together with traditional medicines. You must drink things and say you are cleaning yourself? You have to take these tablets only."

The WHO (2010:20) states the use of ART is considered the most effective intervention in maintaining the health of a woman with HIV/AIDS. Sebitloane and Mhlanga (2008:494) are of opinion that the availability and accessibility to lifesaving ART would defer women from the thought that HIV is a death sentence. The findings by Nokes et al. (1997:49) are in accord with the view of the participants in the current study in that they wanted detailed information about ARV medication, ranging from the purpose of each medication to the side-effects they could expect when taking ART. In another study, participants indicated that not understanding ART made it hard for them to adhere to the treatment (Van Dyk, 2011:8).

Sarna and Weiss (2007:8) describe the aspects that need to be addressed in ART education: knowing how to take medication, the importance of adherence to prescribed regimens, side-effects and the management thereof, and accessing ART services. Kalichman et al. (2005:9) extensively discuss the various aspects of ART in their nurse-delivered HIV treatment adherence intervention which comprised of two intervention sessions and one booster session. The influence of ART on the progression of

HIV/AIDS was explained during the first session and the second session focused on skills to improve adherence to treatment. The booster session addressed the problems experienced with ART adherence; the results of these interventions were improved knowledge of HIV/AIDS as well as improved adherence to treatment. Van Dyk (2011:7) also found that comparing the advantages and disadvantages of ART increased participants' acceptability thereof. These studies support the health literacy need to have knowledge about ART in order to manage HIV/AIDS effectively.

Reproductive health was another prominent sub-category which emerged in the health literacy needs of women living with HIV/AIDS.

3.3.2.3 Knowledge and skills regarding reproductive health

In managing HIV/AIDS, it is extremely important for a woman to consider the implications of the disease on her reproductive health with reference to:

- the importance of Pap smears;
- an awareness of pregnancy prevention options; and
- pregnancy care.

One participant shared her view regarding the significance of educating women living with HIV/AIDS about having regular Pap smears to identify opportunistic infections in the female reproductive system which may include sexually transmitted infections:

"I think to have a Pap smear is important. To my knowledge, a Pap smear they take [to check] *that you don't have any of the diseases inside your womb...because there is much opportunistic disease...too many diseases in your body causes syndrome, then those syndromes will affect you CD4 count and then they take it* [CD4 count] *down. So, for HIV positive women it's very important to do the Pap smear to check even those diseases inside* [the womb]*."*

Women in the study by Enriquez et al. (2008:40) expressed the desire for frequent healthcare visits and screening tests such as mammograms and Pap smears because of their perception that they were at a higher risk for infections and cancers than women who were HIV negative. They wanted to make sure that they were in good physical health despite their HIV status.

The importance of identification and management of sexually transmitted and reproductive tract infections is stressed by the WHO (2008:23) because the occurrence of these infections in women with HIV/AIDS can result in health complications and increased HIV transmission. Regular cervical cancer screening is also encouraged by the WHO (2008:27). Massad, Evans, Wilson, Goderre, Hessol, Henry, Colie, Strickler, Levine, Watts & Weber (2010:70) maintain that women with HIV may participate in regular cervical cancer screening when they understand their risk for cervical cancer, the course of the human papillomavirus, and the prevention thereof. Although educational interventions have shown improvements in adherence to regular cervical cancer screening in other populations, such interventions have not been tested in women with HIV, and it is recommended to guide effective interventions in this matter (Massad et al., 2010:71). The above literature indicates it is crucial to educate women with HIV/AIDS about the importance of Pap smears in managing HIV/AIDS.

The participants in this study furthermore expressed their concern about being pregnant while having HIV. Inquiries about the recommended method of contraception revealed that the participants were content with using condoms as protection against re-infection with HIV as well as preventing pregnancy – as one participant said:

"I don't think it's important for people living with HIV to know about family planning and pregnancy. When you are HIV positive, you should use condoms all the time..."

Women with HIV/AIDS have unique contraceptive needs to prevent unintended pregnancies and also to prevent the transmission of HIV to an infant or partner. They therefore need access to and information about a broad range of contraceptive choices, including condom use (WHO, 2008:38). While the WHO (2008:10) recommends the use of condoms in preventing pregnancy, its importance in preventing sexually transmitted infections is also stressed. In fact, one of the participants in the current study formulated her view as follows:

"It is important [to use condoms] *because they* [sexual partners] *won't infect you with any virus. It's not only HIV, STD also."*

However, when asked about alternative methods of contraception that women living with HIV/AIDS should be informed of, only one participant felt women should be educated on the use of injectable prevention methods. On the opposite extreme of prevention options, another participant suggested that women who are HIV positive should be sterilised because the risks of pregnancy in a woman who has HIV are too great for both the mother and the infant:

"I don't know if I'm wrong, but I feel HIV positive people shouldn't get pregnant. They should just get sterilised because this could be risky to both the parent and the child..."

According to the WHO (2010:26), the use of contraception to prevent unintended pregnancy should be stressed during the times healthcare is rendered to women living with HIV/AIDS; it is especially crucial to empower them with this knowledge in their reproductive years. In the opinion of Sebitloane and Mhlanga (2008:492), the main objective of contraception is to prevent unintended pregnancies. McCall and Vicol (2010:3) concede with Sebitloane and Mhlanga, adding the significance of contraception and pre-conception planning lies in the complexity of ART regimes and their possible negative effects on foetal development if pregnancies are unplanned. Meanwhile, Ezeanolue, Stumpf, Soliman, Fernandez and Jack (2010:4) conclude that the introduction of ART, which brought with it the realisation and understanding that maternal treatment could reduce the transmission of HIV from mother to infant, may have been the reason fewer women in their study chose sterilisation as method of contraception. Women living with HIV/AIDS should receive effective and appropriate health literacy on all the pregnancy prevention options available to them, with special consideration for possible interaction of ART with hormonal contraceptives which may render contraceptives less effective (WHO, 2010:26).

McCall and Vicol (2010:6) are of the opinion that healthcare professionals should enlighten women about the options available for prevention of pregnancy, and the protection of their sexual partners and infants from HIV infection. Condom use, hormonal contraceptives, and intrauterine devices are considered as contraceptive options for women living with HIV/AIDS (McCall & Vicol, 2010:3-6). They name intrauterine devices as the optimal method of contraception for women living with HIV/AIDS, but at the same time emphasise the importance of condom use in the prevention of HIV transmission (McCall & Vicol, 2010:6).

A study by Hoffman, Martinson, Powers, Chilongozi, Msiska, Kachipapa, Mphande, Hosseinipour, Chanza, Stephenson and Tsui (2008:479) found an increase in the use of contraception in women diagnosed with HIV; there was an increased use of condoms with a decreased intention of pregnancy. Anand et al. (2009:1567) found that contraceptive use among HIV positive Malawian and Kenyan women was low despite the fact that they expressed they did not want to have more children. These researchers further identified a need for temporary as well as permanent contraceptive methods in women with HIV/AIDS and therefore stressed the need for barrier contraceptives in preventing pregnancy as well as HIV transmission and sexually transmitted infections (Anand et al., 2009:1571). The importance of contraceptive services in preventing HIV transmission stems from its concern with the outcomes of sexual relationships (Askew & Berer, 2003:56), and can contribute to HIV knowledge by addressing methods to prevent HIV transmission to both a sexual partner by condom use and an infant by preventing the mother from becoming pregnant.

Women should be able to make informed decisions about their sexual and reproductive lives (WHO, 2008:39). To make such decisions, they must have access and knowledge regarding adequate information to maintain their health and reduce the transmission of HIV to partners, but also to infants if they were to become pregnant (Sanders, 2009:67) or termination of pregnancy when required (Sebitloane & Mhlanga, 2008:493).

The following quotes from the participants in the current study reflect their views about a woman with HIV/AIDS and pregnancy:

"I think you must first go to the doctor and check your immune system, you viral load, you[r] body, how strong it is. Can it be possible [to become pregnant]*? Yes it can be possible, but after the baby's birth will you be healthy enough to take care of the baby or will you die or will you or will the baby be healthy? Especially your health, the mother, the important one for the baby as well because if I can have the baby now and be weak and die tomorrow, what about my baby?"*

"The only thing most of the people, like me, we keep on asking ourselves whether the baby is going to get infected or not. We get worried about that."

"If your CD4 count is high, you can be able to fall pregnant. And if you want a child, there are ways that can help you conceive. But if it [the CD4 count] *is low, it's a risky situation for you. One can loose a lot of blood during birth and you can die..."*

For the participants of this study, the risks of pregnancy were primarily associated with the well-being of the infant, the chances of the infant being infected with HIV, having to grow up without a mother, and not being cared for appropriately if the mother should die. It was therefore deducted that women should be well informed about the risks involved in becoming pregnant while being HIV positive as this would assist them to make an educated choice about pregnancy or the prevention thereof.

Sanders (2009:67) explored the sexual behaviour and practices of women living with HIV/AIDS and discovered that women who desired a pregnancy took sexual risks to become pregnant. Sanders (2009:67) therefore promotes firstly assessing whether the woman living with HIV/AIDS has the intention of becoming pregnant and, if she does, to assist her to plan a healthy pregnancy and prevent HIV transmission to the infant through education and informed decision making. Despite increased contraceptive use and reports of not intending further pregnancies, Hoffman et al. (2008:480) found incidences of unintended pregnancy among women living with HIV/AIDS. Therefore, another health literacy need is knowledge and skills about HIV/AIDS with regard to pregnancy care. This includes knowledge about the specific antenatal care for women who are HIV positive and methods to prevent mother-to-child transmission of HIV, for example, prophylactic ARV use during pregnancy, infant feeding options as well as testing the infant for HIV in the postnatal period. The need for health literacy on these issues was evidenced by the following remark of one of the participants in the current study:

"I think each and every woman who is pregnant should go and test [for HIV]*. This will help save the baby. You can remain positive but the baby can be born negative...the sooner you go for testing, the better. The baby will come normal and healthy like any other babies."*

Literature stress the significance of educating women living with HIV/AIDS, also when they become pregnant, about the risk factors involved. These include infant infection with HIV, the potential drug toxicity for mother and infant, and the prevention of sexually transmitted infections (WHO, 2010:27). The stance of the WHO (2010:2) is that the use of ART throughout pregnancy and breastfeeding, and also thereafter, is most effective in maintaining maternal health and reducing HIV transmission to the infant, thus preventing infant death. The WHO (2010:2) further advocates the initiation of ART in pregnant women as soon as their health requires it, irrespective of the gestational age.

Mercey and De Ruiter (2008:76) discuss the association of a low viral load with a decreased risk of HIV transmission to infants during pregnancy and also during delivery. Although the appropriate use of ART, pre-labour caesarean section, and avoidance of breastfeeding were previously identified as interventions to reduce the risk of HIV transmission from mother to infant, Mercey and De Ruiter (2008:78) argue that the actual suppression of the viral load with ART in pregnant women may have made this intervention the most effective in preventing mother-to-child transmission of HIV. Sebitloane and Mhlanga (2008:494) are also of the opinion that vaginal delivery should be encouraged in pregnant women who are HIV positive since Caesarean sections are associated with high maternal mortality rates.

With specific reference to infant feeding options, the WHO (2010:11) maintains that alternatives to prolonged breastfeeding can greatly reduce the risk of mother-to-child transmission of HIV in the postnatal period as long as it is practised safely and is enhanced by extensive support and nutritional counselling. A participant discussed infant feeding options and felt that other women need to know more details about the advantages, disadvantages and considerations for each feeding option. The feeding options that were discussed were exclusive breastfeeding or exclusive bottle feeding as well as mixed feeding:

“But what I want people to know mostly, is for pregnant women. They must know that after giving birth to their babies what routine they must take if they breastfeed and then what they must do to take care of their children.”

Regardless of the infant feeding option, a short duration of antiretroviral prophylaxis is indicated for infants born to HIV positive women who use ART to further minimise the risk of HIV transmission peripartum and postpartum (WHO, 2010:27). Braun, Kabue, McCollum, Ahmed, Kim, Aertker, Chirwa, Eliya, Mofolo, Hoffman, Kazembe, Van der Horst, Kline and Hosseinipour (2010:1) explain that the inadequate use of HIV services result in unidentified HIV exposed and HIV infected infants. They therefore suggest the pairing of mothers and infants in order to ensure access and utilisation of HIV services as delayed infant testing and diagnosis and enrolment in ART programmes lead to increased infant mortality (Braun et al., 2010:6). Combining HIV education and ART adherence with the enrolment of mothers in HIV services, could lead to earlier infant participation in HIV services (Braun et al., 2010:6). Educating mothers about the importance of early infant testing for HIV and the importance of early enrolment in ART for positive infants will empower women to insist on the appropriate care for their infants after delivery.

In literature the issue of reproductive health in HIV/AIDS is compartmentalised as evidenced in the recommendations made by the WHO in 2008 (WHO, 2008:vi) where prevention of sexually transmitted infections and reproductive tract infections, contraception and prevention of mother-to-child transmission of HIV are discussed as separate areas. Results from the present study indicated that a holistic approach on reproductive health specifically would give women living with HIV/AIDS a way to connect all the issues related to women's reproductive health. Askew and Berer (2003:52) refer to an unpublished WHO Reproductive Health and Research Department strategy document when listing five elements considered key in sexual and reproductive health. The five elements are: contraceptive choice and safety, improved maternal and newborn health, reduced sexually transmitted and reproductive tract infections, elimination of unsafe abortions and the promotion of healthy sexuality which include screening and treatment of reproductive tract cancers, managing menstrual disorders, and preventing and treating infertility. Askew and Berer (2003:54-56) consider these elements essential in HIV/AIDS care because women utilise one of these services at one point or another, thus enabling healthcare providers to equip women with the necessary HIV/AIDS information related to reproductive health. These researchers therefore advocate for the integration of these elements in HIV/AIDS care. Sebitloane and Mhlanga (2008:493) also maintain that contraception is often neglected when women seek other medical care in managing HIV/AIDS. This integration is also supported by Myer, Rabkin, Abrams, Rosenfield and El-Sadr (2005:142) who state that reproductive services should be linked with HIV care and treatment and include as far as possible every aspect related to reproductive health. This includes a range of contraceptive options including male and female condoms, screening and treatment of sexually transmitted infections, cervical cancer screening, and the termination of pregnancy. The findings of the current study strongly support the integration of all these elements in the healthcare of women living with HIV/AIDS.

Apart from the important aspects regarding the physical management and understanding of HIV/AIDS, participants also mentioned and discussed the psychosocial aspects vital to the holistic well-being of a woman living with HIV/AIDS.

3.3.3 PSYCHOSOCIAL SKILLS NEEDED BY WOMEN LIVING WITH HIV/AIDS

The analysis of the interviews showed that the participants in this study relied on support gained from relationships in the different aspects of their lives as women living with HIV/AIDS. The relationships explored included relationships with themselves, their loved ones, communities and friends, as well as relationships with their employers and the resources available to them. Considering the participants' experiences, **psychosocial skills** as part of their health literacy could greatly benefit women living with HIV/AIDS in managing relationships in the different aspects of their lives.

3.3.3.1 Achieving acceptance of HIV diagnosis and life as an HIV positive woman

Participants revealed that **acceptance** of their HIV diagnosis and of the self was an important step towards taking responsibility to live with HIV. One participant admitted that she wanted to commit suicide when she learned that she was HIV positive, another withdrew from society and perceived that life as she knew it had ended. Only once these participants had come to terms with their HIV diagnosis and had taken responsibility for their lives, they learned that life could continue normally. The following quotes portray the experiences of some of the participants in this study:

"It wasn't easy then, but eventually I was going to get used to it [HIV diagnosis]. *Like now, it* [the fear] *has passed. I live a normal life. I go to parties and weddings, I am fine and I live like any other person."*

"Ah it [counselling] *helped me even with many things. It is just that when I found out I was HIV positive, I nearly killed myself about this because I have four children...because of those four children I have something to live for."*

"I said to her [the person who told me I am HIV positive] *I am going to die. Firstly I will leave my children behind, and they are still very young...I cried. I used to stay away*

from people. I am much better now; I am able to talk to other people. I used to lock myself in the house..."

The participants also explained aspects that aided in their acceptance of themselves as well as their HIV positive diagnosis as:

- a better understanding of HIV;
- knowledge that there were others living with HIV;
- physically meeting and talking to others living with HIV/AIDS; and
- the support they received from friends and/or families once they had disclosed their HIV status.

As discussed previously, the participants strongly believed that women living with HIV/AIDS should have knowledge about the disease to understand its progress and implications. Understanding that HIV was like any other disease in that it could be managed seemed to bring peace of mind to some of the participants and helped them to accept their diagnosis:

"I told myself I was going to die...the counselling helped me because they told me that being HIV positive doesn't not mean I am going to die. If I can take my medication I will not die anytime soon. I can live much longer than I think. I said to myself these people think I am a fool, I see a lot of people dying every day… I said to God, 'You are the one who knows all the things. If I am going to die, then it means it will be my time to die. If I am going to succeed on this, still it was meant to be like that…' "

"You have to tell people how HIV is just like other sicknesses, like hypertension as sister already said, and sugar diabetes...like people they think maybe if you are having HIV you already dead, you have to accept it, just like other sicknesses."

Van Dyk (2011:7) found that acceptance of HIV/AIDS as well as its treatment was prominent in people with HIV/AIDS who adhered to their ARV treatment. As one participant pondered her situation, explaining that HIV should, in her opinion, be considered the same as other chronic conditions, she suddenly seized upon the idea of hope that a cure will be found for HIV/AIDS. Saying that she will take the treatment in the meantime, but she hoped *"to see us all* [people with HIV] *cured one day"*. Learning that she was not alone in her fight against HIV/AIDS brought her, as well as others, to a mental state where they could accept themselves as being HIV positive:

"...if they just tell me it's not you [only] *more people have HIV... So I accept, I see more people when I come here* [to the Wellness Clinic] *I see more people and we talk and talk and talk, so I accept* [that I am not the only one that has HIV].*"*

The value of sharing their experiences with others living with HIV/AIDS and learning from each other was pointed out by some of the participants; it helped them towards accepting their HIV status. It was therefore considered essential by them that women living with HIV/AIDS should be made aware that talking to each other, sharing their worries, fears and individual experiences with others who find themselves in similar circumstances can aid them on their own journey with HIV/AIDS:

"They [women living with HIV/AIDS] *have to come to the clinic just to have their treatment on time, just to talk. You see, today I come, I get you, you* [teach] *me something...they must come to the clinic they get different things you see."*

The notion that women living with HIV/AIDS provide support for each other is verified by the experiences of women who participated in the study conducted by Enriquez et al. (2008:42). They conveyed that interaction with other women living with HIV/AIDS was a significant source of support for them.

In addition, knowing that friends and family accepted them unconditionally and are willing to support them in their journey were very important to participants in acceptance of themselves as well as their HIV status:

*"...like now I've started the ARVs, they all know at home that 8 o'clock is the time *respondent and her child is taking their medication...they see the time is twenty to eight then they'll call me...I think support it's needed in our families."*

"Most people die because they are stressed, they don't die because they are HIV positive. If they can be shown love, they can live like any other person. The person who starts feeling isolated and different from other people, if that person is given support, he can live happy and be healthy again."

Enriquez et al. (2008:40) also found that women considered social support vital in surviving with HIV/AIDS and Van Dyk's (2011:7) findings emphasised the importance of family support for people living with HIV/AIDS. In the current study, dealing with the issues surrounding acceptance was of prominence for participants in their emancipated healthcare related decision-making as women living with HIV/AIDS. A participant stated that people who tested positive for HIV often did not live healthy because *"they have told themselves they are dying".* Therefore, it was considered vital to address acceptance of one's HIV status as a health literacy need. A participant shared how support and understanding from a healthcare worker assisted her to psychologically accept that she was living with HIV/AIDS:

"I went there [to the clinic] *and then I was sick and she* [the sister] *asked me, 'Have you tested?' I said, 'Yes' and she asked: 'What are the results?' and I said: 'Positive'…then she talked to me and tell me this is not the end and you must accept it. And then, ah, it was easy for me even at home."*

Another difficult aspect encountered by participants in the current study concerning the development of their psychosocial skills, was whether or not to disclose their HIV status to others, including their partners, and how to then still maintain those relationships effectively.

3.3.3.2 Effective management of relationships

The participants explained that **relationships** were their main support system and that they had to manage these relationships effectively to keep their support system intact. One participant shared that she had discovered a family member who was also HIV positive but had not shared their HIV status with anybody else in the family:

"I found out that my aunt was HIV positive because she was taking the same medication as mine. I asked her about this and I told her my status too. I told her we both have the same issue and we are scared to let people know about this."

The WHO (2008:8) agrees that friends and relatives are sources of strength and social support to those living with HIV/AIDS. Another study also found that family support made it easier for people with HIV to take their ART (Van Dyk, 2011:7). The participants in the current study perceived that the best way to maintain these relationships was by being honest about their HIV status. They reflected it was easier to disclose their status once they were better informed about the disease and, in reciprocity, disclosure often aided participants in the acceptance of their HIV status. Therefore, the importance of effectively managing relationships was considered as a health literacy need and addressed two aspects, namely:

- disclosure of HIV status; and
- increasing community awareness.

The disclosure of HIV status as a health literacy need pertains to sharing one's HIV status with relatives and close friends in order to gain their support, acceptance and understanding in the course of living with HIV/AIDS. This is evidenced by the following quote:

"Yeah, once I'm HIV positive and I don't accept the problem particularly the people around you [me] *will be worse than me* [in accepting the HIV diagnosis]*, but if I tell them okay I am HIV but I am fine, they will be okay."*

The participants considered informing their sexual partners of their (the participants') HIV status an integral part of disclosure of status. They reasoned that this would, in the first instance, encourage those partners who might have been unaware of their HIV status to be tested for HIV and, secondly, it would provide their partners with the opportunity to receive counselling on measures to be taken to prevent them from being infected with HIV. A participant reflected on the necessity for constant condom use:

"When I get another boyfriend, I just have to tell him...I am HIV positive and in my life we have to use condoms everyday..."

Sharing one's HIV status would also allow for open conversations about HIV/AIDS – thereby effectively managing the relationship between the woman living with HIV/AIDS and her sexual partner. A participant explained sharing her HIV status with her partner as follows:

"...and what he likes is that I didn't hide it from him. Because I love him, I want him to be safe and sometimes we talk, like now he wants me to stay with him and I feel one day I

am getting sick. I told him...you know, I think I will go look at the hospice...because one day I am going to be sick and don't be afraid to take me to a hospice..."

Sebitloane and Mhlanga (2008:492) agree that disclosing her HIV status assists in giving a woman living with HIV/AIDS hope; it also paves the way for support from her partner, friends and family. The WHO (2008:11) recommendations further support the belief of participants in the current study that disclosure is important – not only to access care and support, but also to prevent further transmission of HIV.

According to the WHO (2008:12), the main obstruction in disclosure is fear of rejection and discrimination by family and friends and also in the community and workplace, yet women in the study by Tufts et al. (2010:43) commended the healing nature of disclosure.

Unfortunately not all relationships are open and mature and the participants also wanted women to be prepared for possible hostile situations and for partners that may be unreceptive to the idea of being HIV positive or being with a woman who has HIV/AIDS. Two participants described such situations as follows:

"Once you get tested they explain to you that you should start using condoms. And before you could do that, you need to discuss this with your partner...your partner might say you brought it [HIV] *to the house, then you start having confusion as to whether you should tell him or not...I know this woman who tested positive and she told her husband about it, she was thrown out of the house..."*

"Some of the time its not, he's not positive, and you tell him, he gets cross and so on but he doesn't accepts [accept it]*, but at least I have told him, but he doesn't accept it most of the time."*

As Askew and Berer (2003:62) point out, success in reducing the HIV/AIDS epidemic has come from multiple strategies that do not solely address individual behaviour, but implies that both the woman and her partner should be involved in preventing the transmission of HIV. Expectations that mere counselling will empower a woman to disclose her status to her partner and negotiate safe sexual practices are unrealistic, which is why Askew and Berer (2003:62) encourage the development of communication skills during counselling to equip the woman to disclose her HIV status to her sexual partner.

The participants in the current study repeatedly mentioned how much simpler it would have been for them to maintain relationships if the general community had had a better awareness and understanding of HIV/AIDS. Stigma and discrimination prevent people living with HIV/AIDS from disclosing their status (Sebitloane & Mhlanga, 2008:492) and from receiving the care and support they need when living with HIV/AIDS (Maneesriwongul et al., 2004:31). As an example, a participant spoke of her situation where her mother rejected her brother for being HIV positive. Up to the time she participated in this study, she had kept her own HIV status from her mother simply to maintain their relationship and avoid being banned from her mother's home. The participant expressed her wish for a better informed society:

"The only thing that a person living with HIV needs is love. That is the most important thing you can give to that particular person. Most people are discriminated against by their own families, they are told to use their own utensils, they don't share with them anything. And if people can change and show these people love, support and accept them as they are."

The WHO (2008:8) proposes comprehensive interventions which should include individual as well as family counselling regarding various aspects of living with HIV/AIDS. The participants in the current study felt that women living with HIV/AIDS should understand the importance of disseminating their knowledge about the disease not only to other women living with HIV/AIDS, but also to the wider community. They also considered it a health literacy need to educate others about HIV/AIDS as evidenced by the next quote:

"You know, I am very strong physically and emotionally. I feel I can help other people who are HIV positive so that they can accept..."

One participant used her own situation as an example of the importance of increasing awareness and understanding of HIV/AIDS in the community. She wanted to share her HIV status with her sister, but she knew that her sister had a very negative attitude towards people living with HIV/AIDS. Fortunately, she had the opportunity to invite her sister to a workshop about HIV/AIDS. Once the sister had gained more knowledge about HIV/AIDS, her attitude towards those infected with HIV changed significantly:

"I just knew that she [her sister] *needed more information* [about HIV] *before I could tell her* [that I am HIV positive]*, yes, so she was taught and then she asked questions and then after that, that's when I asked her if you can go and test and find out that you are positive, are you still going to kill yourself? She said no, now I know what I must do and how I must treat people that are living with HIV and AIDS."*

A community survey conducted in Zambia (Sarna & Weiss, 2007:13) also indicated a need to increase community awareness about HIV/AIDS. In addition, the WHO (2008:12) mentions the responsibility people with HIV/AIDS have in protecting others from HIV infection through education. Women should be aware of the resources available to them and should be able to access these resources should they need them.

3.3.3.3 Accessing resources available to women living with HIV/AIDS

Drawing on their own experiences of living with HIV/AIDS, the participants assessed that other women living with HIV/AIDS should be made aware of the different sources of support and resources available and accessible to help them cope with the disease. This led to the conclusion that the following psychosocial skills were needed by women living with HIV/AIDS:

- emotional support and resources; and
- physical support and resources.

One participant mentioned how much she valued the emotional support and encouragement she received from sharing her feelings and experiences with fellow HIV infected people when she visited the Wellness Clinic (sub-section 3.3.3.1 Achieving acceptance of HIV diagnosis and life as an HIV positive woman, page 68) Another participant formed an emotional bond with her aunt after she had discovered that the latter was also HIV positive. Some participants said they gained useful advice and emotional support from support groups, hospices and social workers and wanted women living with HIV/AIDS to be aware of and utilise such resources in their area:

"I received support from the Carousel hospice. They helped me a lot, if I ask them to come to my house, they do come to my house...they are the ones who have been giving me support, even now, when I need them, I go there. They also provide people with healthy food which are rich in vitamins."

Participants in the study by Van Dyk (2011:7) also mentioned the benefits of the understanding and assistance they had received from support groups, treatment counsellors and healthcare providers. Similarly, Nokes et al. (1997:49) report participants in their study also wanted access to support groups to help them cope with HIV/AIDS. Despite the importance of emotional support, the participants in the current study felt financial and physical aid in the form of grants and/or food will also greatly benefit women living with HIV/AIDS who cannot provide for themselves. The participants wanted these women to know that they should seek employment while they were healthy enough to work but, at the same time, the participants wanted them to be informed of the resources available if they are too ill to work or cannot make ends meet. They felt women living with HIV/AIDS have to be assured that physical support in the form of food or money is available and accessible if they cannot provide for themselves. The following quotes validate this finding:

"Maybe if I just have some, like food for my baby to give her what she needs, good food. Even me, you see?"

"I don't want that money long, I want it just for now because when I'm already okay, I'm going to stop the grant when I go to work but now I need to attend clinic and my mother is old and I didn't want to be a burden for the family..."

The WHO (2008:35) explains that lack of resources or inability to access food contributes to poor nutritional status and resultant poor health and recommends supply or assistance where feasible. Nokes at al. (1997:49) also identified a need among people living with HIV/AIDS to be informed about governmental programmes; they needed to be assured that financial support would be available to them if they need it. The participants in the current study were adamant in their belief that women living with HIV/AIDS should continue working while they were healthy enough to do so. Though some of them had encountered some problems with regard to employment, they nevertheless urged women living with HIV/AIDS to continue working and discouraged the latter from living off the social grants provided by government if at all possible:

"...people who are not working I can say have to get grant, but those who are working, they have to keep working. They don't have to stop the treatment so the CD4 must go down to get the grant..."

3.3.3.4 Entitlements in employment issues

The participants' feedback regarding employers ranged from receptive employers to those who completely rejected them because of their HIV status. In fact, some of the participants in the current study said they did not want to risk discrimination and opted not to disclose their HIV status at their workplace because they felt they were not endangering anyone. The participants emphasised the need for more awareness of HIV/AIDS in communities and also in the work environment as reflected in the following statement:

"I think if, especially as you say those who are working, our companies, I think they must do some teachings there so they know. To the managers or staff members to teach them, because other companies when people are HIV positive they just dismiss you."

It was clear that the participants in this study wanted employment and did not expect to be treated as disabled in order to receive financial grants just because of their HIV diagnosis. They wanted to work for as long as they were able to work and thus, to them, employment issues were another important aspect in psychosocial skills needed when living with HIV/AIDS:

"We are human and they have to treat us with dignity. They must not segregate us, they don't want to give us grants, and then they should give us work...I feel healthy and fit to can work, so they should just give me a job and I will work..."

The WHO (2008:39) warns that stigma and discrimination undermines the human rights of people living with HIV/AIDS – moreover, it insists that the human rights of these people are safeguarded. Equally important, the stance of the International Labour Office (ILO) (2010:3) is that there should be no discrimination against people with HIV/AIDS in their workplace or when seeking employment. In other words, women living with HIV/AIDS cannot be discriminated against in any workplace if their HIV status becomes known. Their employment can neither be terminated nor can they be refused employment on the basis of their HIV status. The ILO (2010:7) encourages accessible dispute resolution procedures to redress people with HIV/AIDS where their rights have been violated. Nokes et al. (1997:49) found that the participants in their study also wanted assistance with legal problems. Therefore, women living with HIV/AIDS should be educated on their human rights, and be knowledgeable about the employment equity acts. Knowledge about employment issues will make them more confident; it will enable them to know what they are entitled to and will empower them to make sure they are treated fairly in the workplace. The following statement made by a participant in the current study clearly shows that such health literacy could have benefitted her in the situation she encountered when she was seeking employment:

"They [the future employers] *tested me and I tested positive* [for HIV]. *If you are positive you are not allowed to enter inside the firm. Because of my status I was not employed..."*

3.3.4 RECOMMENDATIONS MADE BY WOMEN LIVING WITH HIV/AIDS FOR THE EFFECTIVE ACQUISITION OF HEALTH LITERACY

The participants made some recommendations on the ways in which health literacy could be disseminated to best achieve its purpose of reaching women living with HIV/AIDS and thereby empowering them with the necessary health literacy.

3.3.4.1 Recommendations about who should provide health literacy

Six of the participants believed that women who are already living with HIV/AIDS have more knowledge and experience regarding the disease than those not living with HIV/AIDS. They therefore felt that the former should play a more prominent role in the provision of health literacy simply because they are deeply involved in the day-to-day living with HIV/AIDS. One participant explained that a person who travels a road often eventually comes to know its twists and turns; such a person is obviously more familiar with the road than a person who does not travel the road at all. For this reason she felt that a person living with HIV/AIDS who knows the problems and difficulties that have to be faced on a daily basis as well as some of those that may still lie ahead, is equipped and qualified because of first-hand experience to address the health literacy needs of women living with HIV/AIDS.

"Who can tell me? [about HIV] *I'd say people who are already infected. They can tell us how they live and how they experienced the treatment, so it's better if somebody can tell you they already went through all this experience so they can tell you from experience."*

This recommendation is in accordance with the premise that inspired a study by Seung et al. (2008:1206) as well as the UNAIDS and WHO (2009:9) recommendation to enlist people with HIV/AIDS in programmes and efforts that address HIV/AIDS. This is a logical and sensible view when considering that, according to Sebitloane and Mhlanga (2008:493), healthcare providers are often uncomfortable in discussing HIV/AIDS with healthcare users. In addition the Treatment Action Campaign (TAC) in South Africa as well as The AIDS Support Organization (TASO) in Uganda both employ people living with HIV/AIDS in their HIV education efforts (Sarna & Weiss, 2007:16-17), while participants in the study conducted by Nokes et al. (1997:49) stated they wanted to know how other people living with HIV/AIDS deal with their disease.

Another participant in the current study was of the opinion that authority figures such as preachers or pastors and parents are best suited for this task because they are trusted and respected figures in the community and would have the greatest success in meeting the health literacy needs of women living with HIV/AIDS:

"I think because when he is preaching we are having more concentration on him. Even when he will be teaching is concerning HIV and AIDS, we have more concentration than other people when they teach us because he is our pastor and you'll take it from there that he knows what he is talking about, yes."

Only one participant felt that health professionals should satisfy the health literacy needs of people living with HIV/AIDS because, in her opinion, they were best trained to provide medically sound input. Another participant who felt strongly that women living with HIV/AIDS should provide the health literacy on HIV/AIDS, agreed however that medical professionals sometimes had medical knowledge to add and could be approached where a lay person's knowledge fell short.

3.3.4.2 Recommendations about how health literacy should be improved

Various opinions were aired about the medium through which HIV/AIDS information could be disseminated, but the mass media such as television and newspapers were the most popular choices. One participant felt strongly about the effectiveness of awareness campaigns and workshops and another felt that dramas would be very effective in getting information across - not only to those already living with HIV/AIDS, but also to society at large:

"You know like, especially families, communities, friends you know, because when I am HIV positive sometimes I am afraid to tell my friends...the fact is they must know. I think if there is awareness or something like that, you know, people can be gathered and be taught that living with HIV and AIDS is not the end of the world."

An evaluation of programmes in Uganda and South Africa showed the effectiveness of implementing a diversity of media methods, such as talk shows and radio programmes, to spread the message about HIV/AIDS (Sarna & Weiss, 2007:16). Caregivers in the study by Maneesriwongul et al. (2004:31) reflected that the media plays an important role in the portrayal of the disease. Still, the participants in the current study agreed that word of mouth was the best way to educate people about HIV/AIDS. A participant reasoned that, although informative pamphlets are often distributed, there is no one available to answer questions the reader may have or to give explanations about its contents. She therefore believed it would be more meaningful and positive to have an actual person addressing health literacy needs and answer questions women might have about living with HIV/AIDS.

"I would say who are already infected. They can tell us how they live and how they experienced the treatment... so they can tell you from experience. To talk, and if we have to ask question [we can ask them]*."*

Another important aspect of the method by which health literacy needs should be addressed was that participants wanted a hopeful message about HIV/AIDS to be spread. They explained that, although women needed to realise the severity of the disease, it was profoundly important for them to also understand that HIV/AIDS can be managed effectively; in fact, they stressed that a person living with HIV/AIDS can still live a normal and healthy life. Petroll et al. (2008:228) explain that HIV/AIDS has become a manageable chronic disease in the eyes of those who live with it because of advances in HIV/AIDS treatments. One way in which the participants in this study felt HIV/AIDS could be addressed was by conveying it as a chronic condition, comparable to other chronic conditions such as hypertension and diabetes. A participant explained:

"I feel it's like any sickness...just take your friends who get ill and sugar diabetes it kills, high blood it kills. Yes, they say when you take your treatment as they have told you, you will not get sick and I don't think I will die because of AIDS because I take my medicines."

The health literacy need applicable in this instance was to understand HIV/AIDS as a chronic condition that, although not curable, is treatable and, if neglected or left untreated just as with any other chronic condition, could lead to death. Two participants also linked the commonality of HIV/AIDS to that of influenza and did not want women to hide the fact that they were HIV positive. They wanted women to be open and honest about their HIV status and seek treatment for HIV/AIDS as freely as they would seek treatment for influenza. This is evidenced in the following words:

"Not to be private [not to keep your HIV status to yourself]*, these days it is not private because you are going to die* [if you keep your status to yourself]*. More people don't want to go to hospital; more people don't want to tell somebody. When they tell them you have HIV, must tell then as if you have flu..."*

Findings by Maneesriwongul et al. (2004:33) also suggest that positive information about HIV/AIDS will encourage people with HIV/AIDS as well as their families to live a meaningful life despite the presence of HIV/AIDS.

3.3.4.3 Recommendations about where health literacy should provided

Presently most information on HIV/AIDS is provided at healthcare institutions. Although the participants in the current study accepted that it was essential for health literacy to be disseminated at these sites, they also recommended the expansion of locations to include schools, places of work, malls and churches. They pointed out that by addressing HIV/AIDS everywhere would not only have educational value for people living with HIV/AIDS, but also create a greater awareness of HIV/AIDS in the public. In support, Sarna and Weiss (2007:16) describe the success achieved in Uganda by the

Treatment Action Campaign's (TAC) "Project Ulwazi" during which health literacy on HIV/AIDS were addressed at a variety of sites such as schools, workplaces, shopping centres, churches and public sector health clinics. In the current study, a participant's remark on where health literacy on HIV/AIDS should be provided was as follows:

"If ever you think there are other ways people can be taught about HIV, use them. No matter how they feel this thing has been preached for a very long time, continue preaching it, one day they will understand. I would also appreciate if HIV was taught in schools; I feel it's very important for people to be told about HIV."

3.3.4.4 Recommendations about when health literacy should be addressed

The participants shared their experiences regarding the time they themselves were diagnosed with HIV. They said that they could not remember what had been said to them during post-test counselling. But, above all else, they remember the need to be comforted. They said they needed encouragement during the post-test period and explained that too much detail about HIV/AIDS at that point in time was overwhelming. The participants suggested that health literacy about HIV/AIDS should instead be addressed over a period of time after the initial diagnosis. Furthermore, as the needs arise, women must be able to access the information they personally and individually need during scheduled follow-up visits at the clinic or hospital. The participants also mentioned that the availability and accessibility of an out-of-hospital service such as a hospice or a social worker would be of significant value to women living with HIV/AIDS if health literacy is needed in periods between clinic or hospital visits. A participant noted that being given all the information on HIV/AIDS at once could be overwhelming:

"I can teach them little by little because if I can try to explain in one time, it will be difficult [for them to understand]*."*

Maneesriwongul et al. (2004:33) note that nurses in their study were also of the opinion that information on HIV/AIDS should be given little by little because people, especially if they find themselves in a difficult or traumatic situation such as being diagnosed with HIV/AIDS, forget details if they are overwhelmed with too much information at once.

A particular participant in the current study had one simple recommendation in delivering health literacy about HIV/AIDS - a request that should inspire every person who works with women living with HIV/AIDS to inspire them with hope, to instil in them the courage and determination to find purpose and meaning in their lives:

"Just one thing, to tell me something good about HIV..."

3.4 SUMMARY

This chapter discussed the composition of the study sample as well as the findings gathered from the eight semi-structured interviews.

The health literacy needs identified by the participants of this study ranged from the desire to increase knowledge about the pathophysiology and disease progression of HIV/AIDS to managing the disease effectively when considering the impact of HIV/AIDS on a woman's reproductive health. It included applying effective self-care and using ARV treatment correctly as well as enhancing the psychosocial skills of the women living with HIV/AIDS to effectively manage relationships. The recommendations made by participants for the effective dissemination of health literacy on HIV/AIDS were also discussed in this chapter.

The findings of the study were correlated with health literacy needs identified in literature.

Chapter 4 will discuss the limitations of the study and make recommendations for healthcare providers to address the health literacy needs of women living with HIV/AIDS.

CHAPTER 4: CONCLUSION OF FINDINGS, LIMITATIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

This final chapter gives a brief conclusion of the study's findings, an overview of its limitations and makes recommendations for future research. The second objective of the study is addressed by making recommendations for healthcare providers to address the health literacy needs of women living with HIV/AIDS based on the findings of the study. Recommendations are also made for education in nursing.

4.2 CONCLUSION OF FINDINGS

This study's enquiry into the health literacy needs of women living with HIV/AIDS identified four main categories of health literacy needs specific to women living with HIV/AIDS. These categories addressed knowledge needed to understand HIV/AIDS, knowledge and skills needed to physically manage HIV/AIDS, psychosocial skills needed by women living with HIV/AIDS, and recommendations made by the participants regarding the acquisition of health literacy.

The participants spoke about the need to understand the concepts 'CD4 count' and 'viral load', their interrelation as well as the influence of the CD4 count and viral load on the health status of a woman living with HIV/AIDS. Women also included the need to understand the results of blood tests, the implications it has on a person's HIV/AIDS status, and the ways by which the disease is spread. From this it became clear that there was a health literacy need among women living with HIV/AIDS to know about the disease processes, the progression of HIV/AIDS as well as the modes by which HIV is transmitted in order for them to have a better understanding of the disease. Not only did the participants want to understand the different ways in which HIV is transmitted, they also wanted knowledge about the prevention of HIV transmission to caregivers, loved ones and sexual partners. They further wanted knowledge and a better understanding of specifically the use of barrier methods during sexual activities and avoiding contact with body fluids that carry the virus; in other words, broadening the scope of the health literacy need to understand HIV/AIDS to include an understanding of the prevention thereof.

The participants reflected on the importance of maintaining a healthy and quality life when living with HIV/AIDS with reference to the importance of a healthy diet and exercise, and indicated a need to understand the application of dietary and exercise advice towards healthy living. Some mentioned that women should avoid alcohol use and smoking to keep healthy. This showed that knowledge and skills in self-care were needed to manage HIV/AIDS effectively. Self-care related aspects in health literacy further entailed the prevention of re-infection with HIV, follow-up visits, and knowing about conditions that commonly occur together with HIV/AIDS. Women also needed to know how to manage conditions associated with HIV/AIDS infection effectively and should know when to seek professional healthcare. These aspects indicated the importance of health literacy needed to physically manage HIV/AIDS.

Adherence to ART was another prominent feature in interviews and the participants spoke of the importance of this treatment in managing the disease – this was over and above stressing how essential it was to know about the effects and side-effects related to the treatment. The participants also stressed the importance of adhering to ART, the correct use of ARV medicines and knowing the names of ARV medicines they were taking – indicating the prominent role ART plays in the management of HIV/AIDS and in the health literacy needed by women living with HIV/AIDS.

Guided by references to knowledge needed in matters related to reproductive health, health literacy on reproductive health was identified as a unique health literacy need for women living with HIV/AIDS. Specific knowledge and skills needed in reproductive health comprised of a variety of interrelated aspects such as the importance of regular Pap smears and using contraception, pregnancy care, prevention of mother-to-child transmission of HIV as well as care of an infant born to a mother with HIV/AIDS. The fact that some of the participants did not offer more information or suggestions about the relationships between aspects such as the prevention of mother-to-child transmission of HIV and pregnancy care, could be attributed to them not being fully informed or knowledgeable about these aspects. It was thus concluded that their silence indicated a need to address health literacy about reproductive health holistically in the management of HIV/AIDS.

Psychosocial skills identified as health literacy needs for women living with HIV/AIDS pertained to the acceptance and disclosure of HIV diagnosis. The participants spoke about the problems they had encountered before accepting their HIV status and disclosing it. They described how acceptance and disclosure assisted them in achieving and maintaining their psychological health. Assertiveness in maintaining functional relationships with society in terms of employment issues and the access to resources available to women living with HIV/AIDS were also addressed during interviews. It was apparent that women needed health literacy on their human rights in employment matters and in gaining access to resources available to women living with HIV/AIDS.

Finally, the participants made recommendations about the methods by which health literacy could be disseminated to women living with HIV/AIDS. The most significant recommendation was that a woman living with HIV/AIDS should disseminate health literacy about HIV/AIDS because she would be able to empathise with women living with the disease. A variety of venues were listed for the dissemination of health literacy, but in essence participants explained that health literacy related to HIV/AIDS should be disseminated wherever possible and by any means possible. The participants emphasised how crucial it was that a message of hope must be given to women living with HIV/AIDS when health literacy about HIV/AIDS was shared. An example of such an encouraging message mentioned by the participants was that HIV/AIDS should be related to in the same way as other chronic conditions such as hypertension or diabetes mellitus. In fact, it was important to the participants that other women living with HIV/AIDS should know and accept that HIV/AIDS is just as treatable as a cold or influenza.

Literature reviewed on the knowledge and health literacy of people living with HIV/ AIDS did not discuss the health literacy needs of women living with HIV/AIDS as a holistic concept. However, the findings of this study corresponded with literature on the health literacy of women living with HIV/AIDS which added to the credibility of the study.

4.3 LIMITATIONS

Limitations are those aspects of a study that restrain the study (Holloway & Wheeler, 2010:42) and the following discussion of the limitations of this study demonstrates the researcher’s understanding that no research design is perfect in reality (Marshall & Rossman, 2011:76).

A qualitative research design and a purposive sampling method may be viewed by some researchers as limitations to a study since it does not allow the results to be generalised (Sandelowski, 2008:193). It is the stance of Marshall and Rossman (2011:76) that, in qualitative research, the trustworthiness of the results lie in the transferability of the findings. This was achieved in the current study by making detailed recordings of the demographics of the sample, the research process, and the findings so that the study can be transferred to a similar context should the need arise. By ensuring the transferability of the study through these measures, this possible limitation of the research design was overcome. It should, however, be noted that the findings of this study are applicable only to this group of women living with HIV/AIDS in the Hammanskraal area who share similar socioeconomic backgrounds. The results may be different in a group with a different socioeconomic background or culture. Furthermore, the current study focused on the health literacy needs of women living with HIV/AIDS, whereas the health literacy needs of men living with HIV/AIDS may be different from those of women.

There was evidence of a language barrier throughout interviews. Even though some of the participants had chosen to be interviewed in English, they still lacked the language proficiency to express their thoughts clearly and completely in English. The translated interviews were particularly difficult despite the presence and assistance of a translator.

The researcher realised during the verbatim transcription and translation of the two Setswana interviews and the one English, Setswana and Sotho combined interview that probing opportunities were missed during these interview sessions. This could be ascribed to the fact that the researcher had to take notes while the translator interviewed and translated information at the same time. The result of this was that the researcher and the translator had to recapture and clarify what exactly had been said by the participant, many times leading to prolonged interview times. Therefore, the use of a translator was also deemed as a limitation in this study.

4.4 RECOMMENDATIONS

Experiences in conducting the research brought about some recommendations for future research and the findings of the study allowed the researcher to make recommendations for healthcare providers who work with women living with HIV/AIDS and also for nursing education.

4.4.1 Recommendations for future research

There is limited recent data available about the health literacy and health literacy needs of people with HIV/AIDS in the South African context, and it is recommended that further studies are done on the health literacy and health literacy needs of people living with HIV/AIDS in South Africa.

Although the researcher's intent was to gain an in-depth understanding of the health literacy needs of women living with HIV/AIDS through semi-structured interviews, valuable data could also be obtained from a structured data collection tool such as the one used by Nokes et al. (1997) where a quantitative research approach was utilised. A quantitative approach may encourage study participation by people who are not comfortable in discussing their HIV/AIDS concerns due to poor language proficiency. With a quantitative approach data from larger samples could be collected through questionnaires and would be less time-consuming than face-to-face interviews.

The researcher also recommends that future research include men in exploring health literacy needs as men at the research setting also showed an interest in sharing their health literacy needs. It is often overlooked that men are also oppressed by the patriarchal health system which promotes standardised rather than individualised healthcare.

Interviews should preferably be conducted in the natural language of the participant as this will allow participants to express their thoughts comfortably and completely. Removing a translator from the research process will limit the opportunity for messages to be wrongly interpreted. Furthermore, the use of experienced interviewers could assist in faster and more focused collection of data, and more accurate recognition of opportunities to probe.

Future research is recommended into the role of especially South African cultures in the perception of HIV/AIDS as well as the influence of culture on the use of and adherence to ART. Research is also needed to determine the specific nutritional requirements of people living with HIV/AIDS towards the development of an ideal diet for people living with HIV/AIDS.

Once a programme is developed to address the health literacy of women living with HIV/AIDS, future research is also necessary to evaluate the effectiveness of HIV/AIDS specific health literacy in promoting emancipated decision-making in the healthcare of women living with HIV/AIDS.

4.4.2 Recommendations for healthcare providers

Freedman, Bess, Tucker, Boyd, Tuchman and Wallston (2009:446) explain that health literacy is concerned with the increase of communication and skills to maintain health so that healthcare users may make informed decisions related to their health and adhere to medical regimens. They also reason that health literacy strengthens the patient-healthcare provider relationship. In meeting the second objective set for the study, the following recommendations were made for healthcare providers to address the health literacy needs of women living with HIV/AIDS.

Recommendations were made based on the principles of the Wittmann-Price theory of emancipated decision-making (2004) to improve the health literacy and decision-making in the healthcare of women living with HIV/AIDS by considering the four categories of health literacy needs identified in the study: (i) knowledge needed by women living with HIV/AIDS in order to **understand the disease;** (ii) knowledge and skills needed by them regarding the **physical management** of HIV/AIDS; (iii) **psychosocial skills** needed by women living with HIV/AIDS, and (iv) **recommendations** made by women living with HIV/AIDS for the **effective acquisition of health literacy.**

When addressing knowledge needed by women living with HIV/AIDS in order to understand HIV/AIDS, healthcare providers should focus on increasing knowledge about the pathophysiology and disease progression of HIV/AIDS with special reference to the role of the CD4 count and the viral load as well as the interrelation of these aspects in the progression of the disease and the physical changes that can be expected as the HIV infection progresses. Women should also be educated on the progression of HIV to AIDS and the course expected thereafter as in the stages used to classify HIV/AIDS. Kalichman et al. (2005:9) addressed the progression of HIV/AIDS and found increased HIV/AIDS related knowledge and self-efficacy among participants (Kalichman et al., 2005:14). Increasing the knowledge of women with HIV/AIDS empowers them (Wittmann-Price, 2004:442) and forms a cornerstone in the foundation towards emancipated decision-making in healthcare.

Another important aspect in empowering women towards emancipated decision-making in healthcare (Wittmann-Price, 2004:442) is fostering an understanding of the modes through which HIV can be transmitted. Although study findings indicated a common understanding that HIV is transmitted sexually, it is recommended that women are educated about the specific body fluids that contain HIV. Petroll et al. (2008:229) support this recommendation by reasoning that the behaviour of a person with HIV/AIDS would be influenced by such knowledge. In conjunction with the knowledge of modes of transmission, the researcher recommends that healthcare providers address methods to prevent infection of others with HIV such as condom use with sexual partners and the use of gloves by caregivers. As Petroll et al. (2008:229) explains, detailed knowledge about the modes of transmission will increase awareness of methods of prevention – inspiring reflection and personal knowledge (Wittmann-Price, 2004:441) in the preparation for emancipated decision-making in healthcare. It is also important for women to understand that HIV cannot be transmitted by mere physical contact and the sharing of household furnishes, for example utensils, toilets, baths, and showers.

For some aspects in health literacy about HIV/AIDS, women should be equipped with knowledge as well as skills in order to manage the disease effectively. Healthcare providers should distinguish between knowledge and skills. It is beyond the scope of this study to argue the difference between knowledge and skills but, in short, the transference of knowledge requires the communication of information whilst skills entail the physical ability to perform tasks with confidence; transferring and communicating skills require demonstration and practice. The study revealed that knowledge and skills are needed in self-care, ART use, and reproductive health for women to manage HIV/AIDS effectively.

Self-care pertains to a general healthy lifestyle and the participants expressed the need to know what a healthy lifestyle entails, but also needed to be equipped with the skills to maintain a healthy lifestyle. It is recommended that healthcare providers explain aspects of a healthy diet and exercise regime and refer to the benefits of these aspects in managing HIV/AIDS; they should give practical guidelines and advice to achieve a healthy diet and exercise regime such as examples of healthy meals and practical exercises. The WHO (2008:35) also stresses the importance of healthy nutrition in people living with HIV/AIDS. The researcher further considers it essential that healthcare providers explain general cleanliness and everyday aspects of hygiene, such as hand washing and food preparation, to women living with HIV/AIDS to empower them to make informed decisions towards a healthier lifestyle. This may require demonstration to ensure effective practice in agreement with the WHO (2008:50) recommendations. Finally, with HIV/AIDS being a whole body disease, psychological health is also an important aspect in self-care. Women need skills in behaviour changes (Van Dyk, 2011:7) and personalised psychological aspects (WHO, 2008:8) to maintain sound mental health.

In maintaining a healthy self, women should also be educated on the concept of re-infection with HIV and the prevention thereof through condom use. Women need skills in negotiating safe sexual intercourse, and knowledge about re-infection will empower them to consider alternatives in maintaining health (Wittmann-Price, 2004:442). Healthcare providers should explain the benefits of adhering to follow-up clinic visits, even if women are not on ARV medication, with reference to the importance of Cotrimoxazole in women who qualify for this prophylaxis (WHO, 2008:13) and blood tests done to monitor CD4 count and viral load – yet again empowering them to make emancipated decisions related to their healthcare.

Based on the findings of this study, the researcher recommends that women are equipped with knowledge and skills to identify and manage conditions that commonly occur in HIV positive people. One such example would be to recognise and manage diarrhoea. Healthcare providers can demonstrate to women how oral rehydration solutions can be prepared at home, educate them on foods to avoid when having diarrhoea, and teach women when diarrhoea needs professional medical care. Providing women with such knowledge and skills could decrease unnecessary visits to the clinic and serious complications due to HIV/AIDS as they will be empowered to treat the minor problems and identify those problems that need professional medical care.

The effective use of ART is vital in order to get maximum results from treatment and the participants indicated the need to understand the importance of the correct use of this treatment. Healthcare providers should ensure that women living with HIV/AIDS are familiar with the names of their medications, that women understand how and when to take medication, and that they are aware of the side-effects as well as the positive effects of medication, and, finally, they should know of the interactions of ART with other medications or supplements. Skills healthcare providers can develop among women are the correct identification and dosage of treatment as implemented by Kalichman et al. (2005:9).

Reproductive health is another set of knowledge and skills needed by women living with HIV/AIDS. It is the researcher's recommendation that this issue is addressed holistically by including information on the importance of Pap smears, contraception and pregnancy care as well as postnatal care of the mother and infant. This holistic approach is supported by Askew and Berer (2003:55-56). Women should be educated on the various contraceptive methods available to them and should be made aware of the risks of pregnancy to both mother and child to allow for informed decision-making in contraception and pregnancy. Women should also be educated on the pregnancy care of women with HIV/AIDS irrespective of their pregnancy status as this will encourage early booking in the case of pregnancy to allow optimal care during pregnancy. Skills needed for women to manage HIV/AIDS effectively with reference to reproductive health are mainly concerned with assertiveness in negotiating preferred methods of contraception, knowing when Pap smears are indicated, and insisting on appropriate antenatal and postnatal care. This will also include skills in preventing mother-to-child transmission of HIV where demonstrations will assist in the correct preparation of formula feeds, water sterilisation and breast care.

According to Wittmann-Price (2004:441-442), reflection and awareness of social norms form an integral part of emancipated decision-making in healthcare. Health literacy on self-care, reproductive health and ARV use will not only increase the personal knowledge (Wittmann-Price, 2004:441) of women living with HIV/AIDS, it will allow them to think critically when considering healthcare choices – especially when choices may conflict with social norms.

The researcher further recommends that healthcare providers equip women with psychosocial skills to empower them in the acceptance of their HIV positive diagnosis and in managing relationships effectively by disclosing HIV status to their family, friends and the community. Van Dyk (2011:7) points out that acceptance is vital in enhancing good self-care in people living with HIV/AIDS. Van Dyk (2011:7) and the WHO (2008:8) further agree that the value of support systems for people living with HIV/AIDS cannot be underestimated, and disclosure is a way of managing these relationships effectively to avoid losing a support system. Communication skills are central to disclosing their HIV status, and assistance in accessing support groups where issues such as acceptance and disclosure are often dealt with would greatly benefit women living with HIV/AIDS. Askew and Berer (2003:62) also encourage the development of communication skills in disclosing HIV status.

Psychosocial skills entail the interaction a person has with other people as well as the environment; therefore specific attention should be paid to the resources available to women living with HIV/AIDS and their ability to access these resources. Resources can include support groups and social services that could assist these women with physical support such as food or money. The skills required in this instance can be as basic as teaching a woman to use a telephone, or complete a form to gain access to the available resources. Healthcare providers should therefore be aware of resources available to women in their immediate community. Women with HIV/AIDS should also be educated on their human rights in order to address and manage situations in which they are discriminated against because of their HIV status – including situations with employers. Psychosocial skills play a very important part in emancipated decision-making for women in healthcare, but also in other aspects of their lives related to their health status. The Wittmann-Price (2004:441) sub-concepts for emancipated decision-making are prominent in this health literacy need where reflection, empowerment, awareness of social norms, and personal knowledge all play an important role.

The final set of recommendations is concerned with the dispersal of health literacy and, in essence, the creation of a flexible environment (Wittmann-Price, 2004:442) as the final ingredient towards emancipated decision-making in healthcare for women living with HIV/AIDS. Study findings suggest that health literacy is better received by women living with HIV/AIDS when it is conveyed by a person who is living with HIV/AIDS. This implies that healthcare providers make use of people living with HIV/AIDS to teach women about the disease. Although the participants respected the input of healthcare professionals, they felt they could relate better to a person who shared their experiences; therefore, it is recommended that healthcare providers should make themselves available to answer questions, but should entrust the education of the healthcare users to a person that lives with HIV/AIDS as recommended by Seung et al. (2008:1206) and the UNAIDS and WHO (2009:9). This recommendation also entails the need for women to hear positive aspects about life when living with HIV/AIDS. By approaching HIV/AIDS as similar to other chronic conditions such as hypertension or diabetes mellitus in terms of the need for treatment compliance and follow-up visits, a message of hope is spread. Petroll et al. (2008:228) explain that HIV/AIDS has become a manageable chronic disease because of advances in HIV/AIDS treatments.

It is recommended that health literacy is provided mainly through speech with written media such as pamphlets and posters used as supportive measures, and that health literacy is advocated in as many as possible venues including schools, places of work and shopping malls through methods as broad as dramas and plays, newspaper articles and television shows to reach an audience as wide as possible. Kalichman et al. (2005:9) used illustrations effectively in increasing knowledge about HIV/AIDS and Sarna and Weiss (2007:16) also found that a variety of methods were useful in disseminating knowledge about HIV/AIDS.

Finally, the researcher recommends that the health literacy of women living with HIV/AIDS is improved gradually. This will avoid overloading these women with information and minimise the risk that they will retain little or none of the information given. A handout like a booklet, pamphlet or DVD could also prove helpful as a reference to take home. Health literacy needs should be addressed according to each woman’s specific needs, prioritising needs that could have an immediate impact on her condition and addressing other aspects of health literacy over time as participants in Maneesriwongul et al. (2004:33) also concluded.

4.4.3 Recommendations for education in nursing

It is recognised that nurses need to be literate about HIV/AIDS in order to provide women with adequate knowledge and skills in living with HIV/AIDS. The researcher therefore recommends that nurses are educated about the health literacy needs of women living with HIV/AIDS as set out by the results of this study, and that nurses are equipped with the specific knowledge and skills pertaining to the understanding of HIV/AIDS, the physical management thereof, and the psychological skills needed in living with HIV/AIDS in order to convey the necessary knowledge and skills to women living with HIV/AIDS. Nursing education should be continuously adapted as new knowledge is constantly gained in the fast changing area of HIV/AIDS care.

4.5 SUMMARY

This chapter concluded the findings of the study and discussed the limitations of the study. Recommendations were made for future research in the replication of the study as well as for further exploration of the subject and related subjects. And, in meeting the second objective of the study, recommendations were made to healthcare providers to address the health literacy needs of women living with HIV/AIDS. Recommendations were also made for education in nursing.

The knowledge and insight I gained from this study guide my everyday practice in working with people living with HIV/AIDS. But most of my interaction with this group of people evolves around one participant's plea:

"Just one thing, to tell me something good about HIV..."

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ANNEXURE A

MEDUNSA RESEARCH & ETHICS COMMITTEE CLEARANCE CERTIFICATE

UNIVERSITY OF LIMPOPO
Medunsa Campus

P O Medunsa
Medunsa
0204
SOUTH AFRICA

Tel: 012 - 521 4000
Fax: 012 - 560 0086

MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

MEETING: 05/2010

PROJECT NUMBER: MREC/H/102/2010: PG

PROJECT :

Title: The Health Literacy needs of women living with Human Immunodeficiency Virus or Acquired Immuno Deficiency Syndrome who attend the wellness clinic at Jubilee Hospital

Researcher: Mrs J Thompson
Supervisor: Mrs S Naude
Co-supervisor: Mrs Y Havenga
Hospital Superintendent: Mrs D Magano (CEO Jubilee Hospital)
Dr Senkubuge (Regional Director)
Other Involved HOD: LJV Aswegen
Department: Nursing Sciences
School: Health Care Sciences
Degree: MPH

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: 09 June 2010

PROF GA OGUNBANJO
CHAIRPERSON MREC

Note:
i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
ii) The budget for the research will be considered separately from the protocol.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

ANNEXURE B

TSHWANE METSWEDING REGION RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

Umnyango wezempilo no Kuthuthukiswa Komphakathi
Lefapha la Maphelo le Tshebeletso le Ntshetsopele ya Sechaba
Department of Health and Social Development
Departement van Gesondheid en Maatskaplike Ontwikkeling

TSHWANE/METSWEDING REGION
Enquiries: Ms M Mosito
+27725602528
Email:Motlalepule.Mosito@gauteng.gov.za

TSHWANE METSWEDING REGION RESEARCH ETHICS COMMITTEE

CLEARANCE CERTIFICATE

Meeting: 02/2010

PROJECT NUMBER: TMREC 2010/52

PROJECT:

Title:	The health literacy needs of women living with Human Immunodeficiency Virus or Acquired Immune Deficiency Syndrome who attend the Wellness Clinic at Jubilee hospital in Hammanskraal
Researcher:	Mrs. J Thompson
Supervisor:	Ms S Naude
Department:	Department of Medicine (Medunsa)
Degree:	MCur

DECISION OF THE COMMITTEE

Approved

Date: 27 July 2010

....
Mr S Silwimba
Chairperson Tshwane Metsweding Research Ethics Committee
Tshwane Metsweding Region

Maduna
....
Dr PMH Maduna
Chief Director: District Health Services
Tshwane Metsweding Region

NOTE: Resubmission of the protocol by researcher(s) is required if there is departure from the protocol procedure as approved by the committee.
ALL CORRESPONDANCE TO INCLUDE PROTOCOL NUMBER

The Fields Building, 427 Hilda Street, 0028, Pretoria

ANNEXURE C

INTERVIEW SCHEDULE

INTERVIEW SCHEDULE FOR THE STUDY
The health literacy needs of women living with HIV/AIDS

Date: **Interviewer's name:** **Interview number:**

Participant's Demographic Data

Age:
Level of education:
Employment:
HIV diagnosed:

Race:
Language:
Religion:
ART initiated:

Field notes

1. What questions did you have when you were newly diagnosed with HIV/AIDS?

2. What do you think people need to know about HIV/AIDS?
Explore on transmission, pathophysiology and prevention

3. What information do you think people need about living with HIV/AIDS?

4. Before starting ARVs, what can we tell people about what happens at the follow-up clinic visits?
Explore CD4 counts & prophylactic treatment

5. What is important to know about the ARV medication you receive?
Explore side-effects, effects and interactions as well as religious/cultural practices used to treat HIV/AIDS

Field notes

6. What do people need to know about taking care of themselves?
Explore on hygiene, lifestyle and minor ailments

7. What do we need to tell people about how HIV/AIDS affects your body?

8. What do people need to know about how living with HIV/AIDS affects your relationship with family and friends?

9. What does a person need to know about how living with HIV/AIDS affects your relationship with your partner?

Field notes

10. What do you think would help people to disclose their status to family/friends/the community?

11. What is important for a person living with HIV/AIDS to know about family planning and pregnancy?
Explore on effects on baby and effects of breastfeeding

12. What does a person need to know about how living with HIV/AIDS affects your work?
Explore ability to work

13. What kind of support/help do you think a person living with HIV/AIDS needs?

14. Who do you think would be the best to give information about HIV/AIDS?

15. What would be the best way to give this information?	**Field notes**
16. When would you like this information about HIV/AIDS to be given?	
17. Where should this information be given?	
18. Is there anything else that you think a person needs to know about living with HIV/AIDS?	

ANNEXURE D

PARTICIPANT INFORMATION LEAFLET

(ENGLISH AND SETSWANA)

PARTICIPANT INFORMATION LEAFLET FOR THE STUDY ON

The health literacy needs of women living with HIV/AIDS who attend the Wellness Clinic at Jubilee hospital in Hammanskraal

Dear prospective participant,

Thank you for considering participating in this study. My name is Judy Thompson. I am a Registered Professional Nurse pursuing my Master's Degree in Primary Health Care at the University of Limpopo, Medunsa Campus under the supervision of Mrs. S. Naudé and Mrs. Y. Havenga.

I experienced that some patients living with HIV and AIDS have some very basic unanswered questions about HIV and AIDS and I realised that we need a programme to help people living with HIV/AIDS to better understand the disease and give them some basic skills and knowledge to live as healthy as possible with HIV/AIDS.

I decided, first of all, to find out what those questions are so that I can put them all together and make some suggestions for the development of a programme or workshop for people living with HIV and AIDS.

I also decided to speak with women to find out about these problems because women need to take care of their own health and also the health of their families, and sometimes women care for other sick people with HIV/AIDS. Women might also have other concerns that men may not think about. I feel that women will be the best ones to talk about their needs, and especially women that have experience in what it is like living with HIV/AIDS. Therefore the name of my study is "**The health literacy needs of women living with HIV/AIDS who attend the Wellness Clinic at Jubilee hospital in Hammanskraal**".

In order for me to collect the information I need for this project, I will need to speak to you alone for about 30 minutes during which I want you tell me everything you think is important to know about HIV and AIDS, what you think other people need to know about HIV and AIDS and what you would like to know about HIV and AIDS. I will speak to you while you wait to be seen at the clinic – we will keep your place in the queue, and allow you to go if you are called in during our interview.

I will be writing down some of the things you say to me, but to save time and to make sure I get exactly what you tell me, I will also be making an audio-tape recording of our conversation. These recordings will be kept in a safe place and destroyed once I wrote down the information you gave me. Everything you say to me will be kept private, and your name will not be used in any discussions of the information I find.

If you feel uncomfortable at any stage during the conversation and you do not want to take part in the study anymore, you are welcome to leave and we will discard any information you gave us. You will not be forced to take part in this project.

There will be someone available to talk to if you feel the study or questions upset you, and I will be available to answer any questions you have after the interview.

I am looking forward to talking with you,
Judy Thompson. Contact number (for any enquiries): 082 404 4720

Dumela Motsayakarolo

Ke leboga go ithaopa ga gago go tsaya karolo mo patlisisong e.
Leina la me ke Judy Thompson, ke mooki ke ithutela dithuto tsa godimo kwa unibesiting ya Limpopo (Medunsa Campus), mogolo wa me ke Ms. S. Naude mo porejekeng ya UNEDSA.

Kwa tirong ya me ke lemogile gore bangwe ba balwetse ba ba nang le HIV le AIDS le dipotso mabapi le HIV le AIDS. Ka jalo ka lemoga gore go batlega porokereme ya go thusa batho ba ba tshelang ka HIV/AIDS, gore ba utlwisise bolwetse jo le go ba abela kitso le bokgoni go dira gore ba tshele ba itekanetse le ge ba na le HIV/AIDS.

Santlha ke tsere tshwetso go batlisisa ge go na le batho mo mafeleng a mangwe ba ba nang le dipotso malebana le go tshela le HIV/AIDS. Ke batla go itse gore dipotso tseo ke dife gore ke kgone go di kgobokanya go dira dikakanyo tsa go tsweletsa porokereme ya batho ba ba tshelang ka HIV/AIDS.

Ke tsere gape tshwetso go buisana le basadi go batlisisa ka mathata a, gonne basadi ba tshwanetse go ba ba na le ditlhotlho ka boimana le thibelo ya pelegi tse e leng gore ke dilo tse banna ba sa akanyeng ka tsona. Ke akanye gore basadi e tla ba bona ba ba siameng go bua ka ditlhotlho tse, segolo thata ba na nang le maitemogelo a go tshela ka HIV/AIDS.

Ka jalo leina le patlisiso ya me ke: **“Go batlisisa tse di ka rutwang ka ditlhotlho tsa maphelo tsa basadi ba ba tshelang ka HIV/AIDS ba ba yang tliliniking ya Wellness kwa sepetleleng sa Jubilee, Hammanskraal”.**

Go ntetla go kgobokanya tshedimoso e, ke e tlhokang mo projekeng e, ke tlile go tlhoka go buisana le wena metsotso e le 30 mo ke tla beng ke batla gore o mpolelele tsotlhe tse o batlang go di itse ka HIV/AIDS. Le se o akanyang gore batho bangwe ba batla go se itse ka HIV/AIDS. Ke tla bua le wena fa o santse o emetse go ka bonwa ko tliliniking re tla go beela phatla mo moleng, go go letlelela ge ba go bitsa. Ge e le gore o kgona go bua Sekgowa/Seafrikanse ke tla buisana le wena, go seng jalo modirammogo le nna o tla go thusa ka Setswana. Re tlile go kwala dingwe tsa tse o re bolelelang tsona, fela go boloka nako le ge tlhomamisa gore re fitlhela se o re bolelelang sona re tlile go gatisa puisano ya rona. Re ka se dirise leina la gago go go sireletsa.

Ge o ikutlwa o sa lokologa mo tsamaong ya puisano, e bile o batla go ikgogela morago mo patlisisong, o ka tsamaya, tshedimoso yotlhe e e tswang go wena e tla latlhwa. O ka se gapelediwe go tsaya karolo mo porojekeng e.

Ke tla itumelela go dira le wena.
Mmatlisisi, Judy Thompson
Nomoro ya sellathekeng (go botsa sengwe) 082 404 4720

ANNEXURE E

INFORMED CONSENT FORM

(ENGLISH AND SETSWANA)

UNIVERSITY OF LIMPOPO (Medunsa Campus) ENGLISH CONSENT FORM

Statement concerning participation in a research project.

Name of study: **The health literacy needs of women living with HIV/AIDS who attend the Wellness Clinic at Jubilee hospital in Hammanskraal**.

I have read the information on the study/heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurised to participate in any way.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this study has been approved by the Medunsa Research and Ethics Committee (MREC), University of Limpopo (Medunsa Campus) / Dr George Mukhari Hospital. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this study.

....	....
Name of patient/volunteer	Signature of patient/guardian
....	....
Place	Date

Statement by the researcher

I provided verbal and written information regarding this study.

I agree to answer any future questions concerning the study as best as I am able.

I will adhere to the approved protocol.

....	....	....	...............................….
Name of researcher	Signature	Date	Place

UNIVERSITY OF LIMPOPO (Medunsa Campus) SETSWANA CONSENT FORM

Seteitemente se se ka ga go tsaya karolo mo Porojeke ya Patlisiso.

Leina la Porojeke Patlisiso: **Go batlisisa tse di ka rutwang ka ditlhotlho tsa maphelo tsa basadi ba ba tshelang ka HIV/AIDS ba ba yang tliliniking ya Wellness kwa sepetleleng sa Jubilee, Hammanskraal .**

Ke buisitse tshedimosetso mo/ke utlwile maitlhomo le maikemisetso a patlisiso e e tshitshintsweng mme ke filwe tšhono ya go botsa dipotso le go fiwa nako e e lekaneng ya go akanya gape ka ntlha e. Maitlhomo le maikemisetso a patlisiso e a tlhaloganyega sentle. Ga ke a patelediwa ke ope ka tsela epe go tsaya karolo.

Ke tlhaloganya gore go tsaya karolo mo Patlisiso ke boithaopo le gore nka ikgogela morago mo go yona ka nako nngwe le nngwe kwa ntle ga go neela mabaka. Se ga se kitla se nna le seabe sepe mo kalafong ya me ya go le gale ya bolwetsi jo ke nang le jona e bile ga se kitla se nna le tlhotlheletso epe mo tlhokomelong e ke e amogelang mo ngakeng ya me ya go le gale.

Ke a itse gore Patlisiso e e rebotswe ke Patlisiso le Molao wa Maitsholo tsa ya Medunsa (MREC), Yunibesithi ya Limpopo (Khampase ya Medunsa) / Bookelo jwa Ngaka George Mukhari. Ke itse ka botlalo gore dipholo tsa Patlisiso di tla dirisetswa mabaka a saentifiki e bile di ka nna tsa phasaladiwa. Ke dumelana le seno, fa fela go netefadiwa gore se e tla nna khupamarama.

Fano ke neela tumelelo ya go tsaya karolo mo Patlisiso e.

....

Leina ka molwetse/moithaopi Tshaeno ya molwetse kgotsa motlamedi.

....

Lefelo. Letlha.

Seteitemente ka Mmatlisisi

Ke tlametse tshedimosetso ka molomo le/kgotsa e e kwadilweng malebana le Patlisiso e. Ke dumela go araba dipotso dingwe le dingwe mo nakong e e tlang tse di amanang le Patlisiso ka moo nka kgonang ka teng. Ke tla tshegetsa porotokolo e e rebotsweng.

....…… ....

Leina la Mmatlisisi Tshaeno Letlha Lefelo

ANNEXURE F

TRANSCRIBED INTERVIEW

TRANSCRIPTION OF INTERVIEW 06

I - Interviewer
P- Participant

Line no.	Person	Dialogue	Field notes
1	I	Let's think back a little bit to that time when you just found out that you have HIV. **What questions did you have on that day?** Can you remember?	**Observational notes:** This lady is a volunteer HIV counsellor and recently went to a HIV course sponsored by Soul City where she learnt a lot about HIV and how it works – she wants others to know about these details.
2	P	Firstly it was “why me?” and then “what am I going to do” and “how am I going to tell my boyfriend, my mother? Am I going to live long or what? Am I going to die as they say?” Too many questions.	**Theoretical notes:** Fear of discrimination, uncertainty of what the future holds.
3	I	How did you manage all those questions?	
4	P	Ahh, I think at the clinic, because there was the other sister, I went there and then I was sick and she asked me “have you tested?” I said “yes” and she asked “what are the results?” I said “positive” then she talked to me, and tell me “this is not the end and you must accept it”. And then, ah, it was easy for me even at home. Firstly I was afraid to tell my mother but then when I told her she was, you know, more supportive, she didn't take me otherwise, but the problem was my boyfriend. When I told him, he just refuses; “Me I’m not, my blood doesn't get that HIV”. You know that kind of saying, they say? [Ja] But at least that kept me going you know, support from my mom and they gave me a little bit more information day by day.	**Observational note:** Proper counselling seemed to have helped with the acceptance of HIV, which in turn seems to make disclosure easier. Support motivates her to continue with life, despite her boyfriend’s obvious denial.
5	I	So it was a long journey.	
6	P	Yes it was, it really was. You know sometimes I just say no maybe they made a mistake, I'm not positive, things like that.	**Observational notes:** She thinks they may have made a mistake because she feels healthy
7	I	I can imagine, but you've come far. **So what do you think people need to know about HIV?**	

8	P	Firstly I think people must know that when you are HIV positive, it's not the end of the world because some people, especially where I am staying, they think when you are positive you don't socialise with other people, they take you aside, and they discriminate against you. No that one, they don't want to touch you or talk to you, sit next to you, eat with you; you know, they have that kind of attitude. I think they must, you know, if there was possible they can do the awareness campaign, teach people and then how to live a positive life when you are HIV positive. But what I want people to know mostly is for pregnant women, they must know that after giving birth to their babies what routine they must take if they breastfeed and then what they must do to take care of their children. You know there was this, we were taught this way, expressive breastfeeding, [umm hmm] ja, they must know if like we have our gogos at home, they don't know that thing. Maybe I am breastfeeding, I'm HIV positive, I leave the baby with her. She is going to take water and give that baby you know porridge, because she doesn't know [ja], but when I come back I will ask did you give this child water or what? So I must know just take out the milk from my breast and heat it to the maximum temperature fifty eight or sixty degrees for ten minutes then cook it and I can give it to my baby because I think the way I was taught that virus is dead. It's destroyed, ja, so many people don't know.	**Theoretical notes:** HIV doesn't make you contagious, or end your life – you can live a long and healthy life with it. Increasing awareness and knowledge about HIV might increase acceptance from society. Pregnant women should be knowledgeable about feeding options.
9	I	So you think it's very important?	
10	P	It's very, very, very important.	
11	I	Especially for the women who are having the babies who are HIV positive?	
12	P	Yes because they don't know, they are just going to leave their babies. When they come back they will just take them and breastfeed their children whereas the breast milk has the virus.	

13	I	So we should tell people why they must not mix the feeds?	
14	P	Ah hey, ja and then tell them how long they must breastfeed.	
15	I	So you said you went to this course where they taught you about all these things, like the breastfeeding. What other things did they tell you about HIV that you can remember?	
16	P	Okay, I was taught again that HIV, firstly before you get infected you are being exposed to HIV for seventy two hours. So let's say maybe I am positive, I have a boyfriend who is negative, then we are using a condom, then that condom bursts. So we can go to the clinic and explain that and then that can be reversed, but he is negative, I am positive. But I think firstly they will test him, then if he is positive, it means if it doesn't happen by that time at which the condom burst [ja]. So if he is negative I think they are going to give him a PEP Prophylaxis, something like that.	**Theoretical notes:** Window period, prophylactic treatment.
17	I	Yes...	
18	P	Yes, so to reverse so that he mustn't be infected, but after seventy two hours that is when the infection takes place and then the HIV cell goes to the CD4 cell and then they get in by the receptors. If your cell doesn't have receptors it's not easy for you to get infected.	**Theoretical notes:** How HIV works and what it does in your body.
19	I	Do you think it's important that people know those small things about HIV?	
20	P	Yes.	
21	I	You don't think that they will say:”Ag, this thing it's making me ... I don't understand it?”	
22	P	You know it's important because I've got my two, my younger sister and my younger brother, but this, the younger brother was ok but this younger sister has that attitude, so I took her there to the training courses you know and the volunteering, all this things you know, because she was negative, negative about people who are HIV positive. [Is it?]. Yes, and I didn't tell her at the	**Observational notes:** People who are knowledgeable about HIV are more likely to support those living with HIV.

22 (Cont)		time. Because I knew when I tell she's going to, she's going to be confused. I just knew that she needed more information before I could tell her [ja] yes, so she was taught and then she asked questions and then after that that's when I asked her if you can go and test and find then you find out that you are positive are you still going to kill yourself? She said no, now I know what I must do and how I must treat people that are living with HIV and AIDS.	
23	I	So you think that if people know more about HIV they will have a different attitude?	
24	P	Yes.	
25	I	That's wonderful that you took her. It made it easier for you also. **What do you think we need to tell people about living with HIV?** Like how you live with HIV. What should we tell them about that?	
26	P	Uh, I think, if I understand you, people must be taught how to live with HIV and AIDS. I don't know how can I put this.	
27	I	Just try, it's fine	
28	P	Okay. You know like, especially families, communities, friends you know, because when I am HIV positive sometimes I am afraid to tell my friends because they are going to go back and they will say you know this ... but they must know, the fact is they must know. I think if there is awareness or something like that, you know, people can be gathered and be taught that living with HIV and AIDS is not the end of the world. It's just living normally, like any other person, it's a change of lifestyle only and then you will live.	**Theoretical notes:** Living with HIV is a change in lifestyle and you need support to live normally with it.
29	I	So what changes in lifestyle should we tell people about?	
30	P	Okay change of lifestyle means exercising, eating healthy foods, protection as in protection with condoms or abstinence, I can't say being faithful, nowadays there's no	**Theoretical note:** People should understand the details of healthy lifestyle.

		being faithful nowadays. Things like that, taking medication if needed.	
31	I	So it's important that they understand those things.	
32	P	Yes	
33	I	**Before you started with the ARVs, you went to the clinic a lot of times, what should we tell people about those visits to the clinic?**	
34	P	It's very important that they must know their CD4 counts. When I went to the clinic I took blood, taken from my CD4 count, then go and take the result, then come back. They say no you are still okay come back after six months. After six months I went there. It is very important to go to those clinic visits when you are HIV positive and then again for the women to do Pap smear. It is very much important.	**Theoretical notes:** The role of CD4 count in care and its impact in determining when ARVs should be initiated.
35	I	What do you think we should tell people about the CD4 count? What do you think they need to know about it?	
36	P	By the CD4 count they need to know that when you are HIV positive there is a CD4 count and the viral load. When the viral level goes up the CD4 count goes down and then by not leading a healthy lifestyle, drinking too much alcohol, smoking, not using protection and things like that they take down your CD4 count and then the viral level goes up. That's the thing they must know.	**Theoretical notes:** Role of CD4 and viral load in HIV care.
37	I	Why do you think it's important to have a Pap smear?	
38	P	I think to have a Pap smear is important, to my knowledge a Pap smear they take that you don't have any of the diseases inside your womb. So it's too much important. I can’t sit (and wait). Most people they do that. You will find some people say my womb is too aching, you know I can't walk, but not going to the clinic, not knowing what's happening inside you. So when you go to the clinic taking your Pap smear you know I think you	**Theoretical notes:** Pap smears to detect changes accelerated by HIV, sometimes these changes are not obvious.

		are up to date.	
39	I	Why do you think it's more important for women with HIV to have a Pap smear?	
40	P	Because there is much opportunistic disease and from what I've been taught is that HIV doesn't kill. It's this opportunistic disease, too many diseases in your body causes syndrome, then those syndromes will affect your CD4 count and then they take it down. So for HIV positive women it's very important to do the Pap smear to check even those diseases inside.	**Theoretical notes:** Types of opportunistic infections and effect on body
41	I	It sounds like you learned a lot from that course. It must have been very nice.	
42	P	Yes it was!	
43	I	Did you know a lot of the things that they told you at the course or did you learn more?	
44	P	Some I knew but some ... it was actually 50/50. Some I knew and then some I didn't know, I just knew that when you are positive, like breastfeeding. You mustn't breastfeed. When you are breastfeeding you know you are infecting your baby. I didn't know much more detail.	
45	I	And you felt that they gave you nice details?	**Observational notes:** This participant is very knowledgeable – she might give information much more detailed than other participants because of the detailed course she took.
46	P	Yes.	
47	I	And those details they helped you to understand better.	
48	P	Yes, and I teach other people.	
49	I	Teach other people, that is also very important, ne? [yes] **And this ARV medication that you are getting, what should we tell people about that medicine?**	

50	P	You know that medicine ARVs, when you are taking it, firstly you must be more punctual because you take them by time and then eat more healthy foods, drink much water. Yes.	**Theoretical notes:** Correct use of treatment and importance of healthy lifestyle with taking these medications.
51	I	Why do you think it's important for the healthy food and the water together with the medicine? (Respondent hesitates). Ah, it's not to test you it's just to know what do you think, should we tell that to people? Do you think they would want to know why it is important to take the food and the water with the medicine?	
52	P	Yes because water you know, now I'm lost, [no its ok, its ok]... if I remember a little bit, these pills need more water to work, to do their work inside the body and then healthy food because if you don't eat you are going to get weaker. Your immune system will become complicated. So it needs water, you need water and healthy foods.	**Theoretical notes:** Understanding the logic of healthy diet in taking ARVs might encourage compliance.
53	I	That's fine. Do you think we should tell people about it, that they must know why they must take the water and the food? It mustn't just be taught you must take water and food, they must know why?	
54	P	By explaining to them why, yes.	
55	I	Are there certain effects that this medicine has on you that you think we should tell people about?	
56	P	Ja, [Like which ones?] like vomiting firstly, most of it, vomiting like this baby of mine once started the ARV. Yo, I was, you know so stressed [Ja]. After giving him medication and then he vomits, all of it, all. Then I waited maybe five, ten minutes giving him back again, then he vomit. I didn't know what to do and then I came back here and I said "No this is not working". They said we told you that you must give him another. I said still he is vomiting. They said no relax nothing is going to happen. He will get used to the medication and when time goes on after giving him medicine I will then keep him for one hour not giving him anything to eat or water to drink and	**Theoretical notes:** Information on effects and side-effects of medications to ensure compliance.

56 (cont.)		the more he drinks this the more he wants water. After drinking he said "mama metsi!" - I want water, so I just take him and take a stroll, let him stroll with me to forget at least for one hour. I then come back give him some small amounts of food, small amounts food. And then some, you know, they have rash and then a runny stomach and so, that is the side-effect I know and then sometimes they have horrible dreams.	
57	I	Is it?	
58	R	Yes. It happened to me.	
59	I	Really? That is interesting...	
60	P	Ja, horrible dreams, you know sometimes you'll dream people are attacking you and you are running and running and when they are about to get you then you wake up, or dreaming going inside a deep hole and not getting to the end of that and saying YO!!!!... yes it's sort of a nightmare.	
61	I	So people should know about these side effects of the ARV medicines?	
62	P	People should know and then they must know that even though it happens but they must continue with the medication.	
63	I	And do you think in your culture as in Tsonga or even in your church, are there special things that affects how you see HIV - in your culture or in your church that affects the medicine that you take?	
64	P	Ja... you can say, especially in my church you know even our pastor don't allow that condoms must be there in our church he [he is very strict] yes, he says no I know it means I'm encouraging young people to go and sleep around [ok], yeah, so even teaching, especially my culture, teaching people with HIV and AIDS it's like, you know it's not common to talk about sleeping to each other, using condoms with other people, it's like we are not used to it. Ja.	**Theoretical notes:** Religion could have an impact on compliance. Religious leaders should be more knowledgeable about HIV to give appropriate guidance regarding this issue.

65	I	Hmmm. Do you think it will help if those leaders in the cultures and the churches if they knew more about it do you think it will change things?	
66	P	Yes I think it will because when a person can stand there in front of us and start teaching us that you must know that when you go and sleep around without using condoms you will be infected and after infection there will be this and this and this. I think because when he is preaching we are having more concentration on him. Even when he will be teaching us concerning HIV and AIDS we have more concentration than other people when they teach us because he is your pastor and you'll take it from there that he knows what he is talking about, yes.	
67	I	You already talked a little bit about taking care of yourself, but **what other things do you think we need to tell people about taking care of their bodies when they have HIV?** (hesitation and interviewer clarifies). Like we already spoke about the Pap smears and going to the clinic but what else at home? Are there special things that you need to do to take care of yourself?	
68	P	Ja, I think at home you must keep your body clean, warm, you know things like that, exercising.	
69	I	Why do you think those things are important?	
70	P	I think they are important because firstly I can say exercising, even if you are not HIV positive, your body needs to be exercised and it's still important to keep your body warm. If you keep your body warm there won't be these things like coughing, flu, blocking noses, things like that. These germs, bacteria, they won't be there if you keep your body clean. And the foods that you eat, be hygienic. Ja, I think.	
71	I	Would you say that it is different for a person who has HIV or is the same for the person who doesn't have HIV in taking care of yourself?	

72	P	I think it's the same whether the person be HIV negative and positive. Actually all of us must take care of our selves [hmmm].	**Theoretical notes:** Personal care is just the same as for a person who does not have HIV.
73	I	So you are saying that self-care shouldn't be different for a person who has HIV. What do we need to tell people - okay we already spoke about how it affects your body - you said like with the medication sometimes you get dreams and that, but we start with the medication what did HIV do to your body? Was there anything that you felt was different for your body than for somebody who doesn't have HIV?	
74	P	No, not at all.	
75	I	Nothing at all. It's a good thing to know. People must know it's not that different.	
76	P	Yes.	
77	I	**Okay what do people need to know about living with HIV and how it affects your relationship with your family?** You already said that your mother was very nice and she was the one who carried you [Yes]. What other things should we tell people about that relationship?	
78	R	I think supporting each other is more important because, when I say supporting each other then taking care of each other. Like now I've started the ARVs, they all know at home that 8 o'clock is the time *respondent and her child is taking their medication, even though I'm busy cooking, they'll say “Sis *respondent it's 8 o'clock. Then I leave, someone will come and take over and then go and drink medication, then I come back. I think it is important. Sometimes maybe I went to the shop and then maybe I'm not coming, they see the time is twenty to eight then they’ll call me, come back it's already 8 o'clock and I come. You know I think that support it's needed in our families [definitely I agree],ja, ja.	**Theoretical notes:** Family support can help a person cope with HIV, and makes a person feel needed.
79	I	**And with a relationship and a partner, how does it affect a relationship with a partner?** Like a sexual partner, a boyfriend or a husband?	

80	P	You know, it was difficult,	
81	I	Why was it difficult?	
82	P	Because by the time I was pregnant, I was almost nine months pregnant when I found out, yes. So, I told him that I have been to the clinic, tested; you know I'm HIV positive. He said “Ja it's you, it's you, you know my blood doesn't carry that thing. I know that I'm negative, I know.” I said “How do you know that your blood doesn't carry HIV? Firstly go and test then after you’ll come and tell me that it's not you, it is me then I’ll agree.” Then you know it started, there is friction between us, not communicating, just sitting and not saying anything to each other. Sometimes not attending to each other you see and then after, I think it was one year six months he was involved in a car accident that Friday, then he went to Klerksdorp hospital and then when I got there I met with his doctor and he told me that your boyfriend has TB and HIV positive. I said that I know, HIV positive, I know but he refused, I told him but he refused but I didn't know it is TB. So that is where he started admitting that I'm HIV positive really and then he started seeing things differently. Then I started explaining things that I know of and then we took it from there but I think he is not serious any more.	**Observational notes:** Denial is big problem when disclosing. **Theoretical notes:** Information should be given on rights and on how to manage reactions like these. Open communication about HIV can increase each other’s knowledge and adjust behaviour.
83	I	Is it? Are you still together at this stage?	
84	P	We are still together but you know...	
85	I	But you feel it is not...	
86	P	He was the one who started taking ARVs. It was 2006... 2005 or six, somewhere there that he started taking ARVs. Then by the time I was working he was coming here alone, I didn't have that much information like now. So the other day when I came from work he said to me; now I'm okay, the doctor stopped me from taking ARVs they said my CD4 count is right, I said wow, congratulations because I didn't know anything but when I get information then I even asked my	**Personal notes:** I sense the participant’s frustration with her partner; wanting so badly for him to take care of himself and yet not knowing how to get him to do that.

86 (cont.)		facilitator that because you are saying ARVs are for life why did they stop you? When you take the medication they stop you and say no your CD 4 count is up, he said if really they stopped him, let him take them to court but if he doesn't take them to court then he was lying to you. Then I went back and asked him. “You said they stopped you there at Wellness?” He said “Yes.” “Do you know the person who stopped you?” He said “Yes” and then I laughed and said “You are lying to me. If I can say take that person to court will you?” He said “Why are you saying that?” I said “I know that you are lying.” But at the time I didn't know. I was told that ARVs are for life. It's your life time partner, the ARV. Then he laughed and I said to him “No you are not serious, you are not doing yourself any favours, you are just killing yourself.” He said “Okay I'll go back, I’ll go back”... he didn’t even.	
87	I	Ai. So it's important for one to know something so that they can help the other one.	
88	P	Yes I think it's very, very, very important.	
89	I	What helped you to talk to other people about having HIV?	
90	P	It's like, you know getting much information, because firstly we knew about when you are HIV positive it means you know, you just go sleeping around with many, so I was afraid and said if they can know that I am positive they’ll take me otherwise now, like that *respondent likes much men [umm, ja]. Ja, but so when I go around and get information that you know, firstly it wasn't my fault and it wasn't my choice [Ja]. Ja, so it's then that I get much stronger and to tell people but firstly I look first that honestly, you know what to tell other people, you know. First I look at you, it is then that I can disclose to you [umm]. Ja.	**Theoretical notes:** Increased knowledge increases confidence to disclose to people you trust.
91	I	If you look at somebody what do you look for before you will tell them?	

92	P	It's these who have too much to say you know. I know that we black people like too much to say and then you know, sit in groups there and they will be looking at others and laugh and I definitely know no this is not the one. If I can tell her or him who will be sitting with others who will be saying: “Ooo, you know *respondent is like this, you know” then no. I firstly look at the character of a person [Ja] before I tell him, but it helped me this information, it helped me a lot because now it’s like I’m having flu [hmmm] Ja, it is like that.	
93	I	What do you mean if you say it's like flu?	
94	P	It's like you know, I mean at first it was habit to me, not accepting, thinking too much but now because I know how to take care of myself and then how to prevent re-infecting myself, how to teach other people of this, it's not habit for me anymore. It's no problem for me now.	
95	I	So, it’s more common now [yes], you understand it better so you know more about it. It really does help.	
96	P	It does.	
97	I	And did you say you are working or you're a volunteer?	
98	P	Yes.	
99	I	**How would you say that having HIV is affecting your work as a volunteer?**	
100	P	You know sometimes you do door- to-door campaigns so you find that others are afraid to disclose and others when they disclose they know this is too painful when a person tells you that you know I'm alone, maybe he's gone and my family doesn't want me any more because I'm infected. I don't know what to do, things like that. It affects me because I've been there but thankfully I know what to do now.	**Observational notes:** Because of the personal nature of her work, her status helps her to understand her work better. **Theoretical notes:** Personal experience can assist others struggling with the problems you experienced at a time.
101	I	So what do you do?	
102	P	No I just encourage the person and then I tell her or him to go to the clinic	

102 (Cont.)		and then at the clinic they find the counsellor and the talk and then, you know, check his CD 4 count or whatever or find support groups, there our places it unifies us at the support group, I will there refer her to that support group [Ok, umm]. So you find people who are like you, who encourage people who know what your feelings are.	
103	I	It's important for them to know they're not alone.	
104	P	Yes.	
105	I	**What other help or support do you think we need to give to people that have HIV?**	
106	P	I think if, especially as you say those who are working, our companies, I think they must do some teachings there so they know, to the managers or staff members to teach them because other companies when people are HIV positive they just dismiss you. That's the support that I think you can give people who are positive, those who are working and then take teachings to that organisation, you know something like that.	**Theoretical notes:** Knowledgeable employers to allow people living with HIV to work for them. Rights.
107	I	Is there any kind of help that you think we can give them?	
108	P	Hmmm umm, those that I've said.	
109	I	You think those are sufficient, I also think you've given me a lot already. Now you spoke a little bit about the preacher and maybe when you're talking to him about HIV and also people at work but **who do you think would be the best kind of people to talk about HIV?**	
110	P	If I can say at home, our parents, I think it would be more helpful if they talk to us, the children who have got HIV/AIDS. Even though I know it's hard for them to talk to us but if they can talk to us and our teachers at school, I think they are, you know young people who will get information quickly.	**Theoretical notes:** Authority figures, such as parents to teach children from a young age so that awareness is increased.

111	I	Yes I also think I agree with that one and so **where would be the good places to talk?** You already said the church and the work, maybe schools. What other places do you think we can talk at?	
112	P	Like at the malls, doing the awareness campaign. There are more people there.	
113	I	I think that's a good idea and in **what way do you think we should do that?** Should we just talk to people or what other ways can we use to inform people?	
114	P	Like dramas, songs then, I mean to get more concentration, there must be like entertainment. People can then come, come and then let them see a small drama. Then they'll start asking themselves questions and after that maybe somebody can present to them, we are here because of this and this. Any questions, you can ask.	
115	I	So it must be interesting for people.	
116	P	Yes, because boring you won't get anybody near.	
117	I	No it's very true. And when you found out about the HIV there was so much you had learn about the HIV, **when would be a good time to me about all those things?**	
118	P	Sorry, come again?	
119	I	All this information about HIV, like you went on a course. If you could find this information that you have now, would you like to find out just when find you have HIV or this information...?	
120	P	I think before yes.	
121	I	Before you have HIV you want to know everything?	
122	P	Yes and I think if I get it before I think I won't be infected. [Laughter, background conversation 0:37:10.0] Because I will know everything, how to	**Personal notes:** Despite being well adjusted and seemingly accepting life with HIV, it is clear that this lady desperately would have wanted to avoid HIV infection. She stresses prevention,

122 (Cont.)		protect myself and yeah. I think people should know before, like starting at schools, young children, they should know this information to keep themselves safe.	especially in young people.
123	I	**Are there any other things you think we must tell people about HIV and living with HIV?** Anything that you haven't talked about yet.	
124	P	I think people don't know like ... there are these body fluids, they don't know which one carries the high viral load and which one carries the low viral load. I think people should know how to get infected is by blood, semen and then what people should know, I think most people don't know that sperm doesn't carry the virus, even I didn't know.	**Theoretical notes:** Transmission.
125	I	Umm, the sperm doesn't carry the virus?	
126	P	They say the sperm doesn't carry the virus that's why a positive woman can give birth to a negative baby but you know when I'm positive and I'm being pregnant my baby is negative because I'm positive and then my antibodies know this virus, they are going to protect my baby. So when I give birth I must get Nevirapine to protect mother to child transmission. If I say the sperm doesn't have the virus, when I have that Nevirapine it's just a protection for the cuts and those things and the blood only, but he doesn't think the virus is inside you because it's the sperm. So people don't know, I didn't know myself but through that lectures I was going to I understand that now, that the sperm doesn't carry a virus.	
127	I	And you say it was a Soul City course? [Ja, Soul City and (unclear)]. Ok, and do you think it would be nice for everybody who has HIV positive to have a course like that?	
128	P	Yes I think it would be very, very helpful because like if I think mostly they are positive but they don’t have that much information [umm], ja some are still saying no shame; you know that's what I heard. I don't want	**Observational notes:** The participant accepts responsibility for her status.

128 (Cont.)		someone to feel pity for me.	
129	I	Is it?	
130	P	No I don't want that. I think people have that, those trainings and then to have information. Do you know last time I was talking to another girl; we met here and took her number. She brought her sister's child, her sister is dead. So they didn't know how to tell that child that you are HIV positive. Already he is ten years old. I said no I think it's simple if you know information because I'm going take that child and sit him down and say "My boy in life is like this and this, you know HIV and AIDS, you know HIV is..." and then explain everything to that child. I don't think I'm going to have a problem with that child yes, because his brother knows, even at school when they get homework, he say "Mama, you know much about HIV and AIDS, come and help me."	**Theoretical notes:** Being knowledgable makes it easier to talk about HIV and will make it easier to discuss with children.
131	I	Wow, okay.	
132	P	Yes, yes. It is very important because people don't know, all that information and that's why some die quickly.	
133	I	I agree. I also just feel sometimes we talk about HIV but we don't give information. We just say it's a virus, it's a virus.	
134	P	It's a virus and then not knowing how it infects you and when you are infected how must you keep yourself and you know healthy living, longer. I think what will encourage people is when people know that HIV doesn't kill. I think that will be more helpful to people.	**Theoretical notes:** The course of HIV.
135	I	Is there anything else that you can think of? You've given me so much.	
136	P	I don't know if I forgot something but...	
137	I	No no, it's just if you think there's anything else.	
138	P	Okay like exposure I talk about it, transmission, ja let me say transmission. To be transmitted there must be an entry and an exit point	

138 (Cont.)		where the virus could get in and then from me where the virus could go out and get into you, something like that. Yes that's transmission. Like, blood, let's say I am involved in a car accident and again... Ok no, let me finish this. I am involved in a car accident, but I am not hurt but the blood is not there. If I don't have any entry points I won't be infected, but if I have any entry point it is then that I am going be infected. Then the other thing is that you know first we were taught the virus like if I can spill blood there, HIV positive for maybe five minutes the virus is dead, no it was wrong, the virus doesn't die. It can be many days or months but whenever it gets warm, maybe warm water or something to keep it warm, then it rises again, yes we didn't know that.	
139	I	We should tell people these little things [Ja, ja]. Thank you so much. You've really given me a lot of...	

ANNEXURE G

PROTOCOL TO CODER

Dr. Temane

Thank you for taking the time to assist me with the analysis and coding of the data I collected.

As discussed, you will find 8 transcribed interviews in the attached document, they are numbered 01 through to 08. Interview number 06 was not audio recorded as the participant felt uncomfortable in doing this, but notes were made as extensively as possible. Field notes also accompany the transcripts for additional information.

Interviews were recorded and transcribed in Setswana and then translated by a translator – I have included both the Setswana and English versions for you to consider in the analysis of data.

The aim in analysing the data is to identify the health literacy needs of women living with HIV/AIDS. Broad categories were identified in the compilation of the interview schedule which is discussed in the attached research proposal. The semi-structured interviews addressed the identified categories and these specific questions are bolded in the attached transcripts to aid in data analysis.

I would like to follow the process of Tesch, as described in Creswell (2009:185), in coding the data under the specific categories, but additional categories identified will be valuable in describing the health literacy needs of these women living with HIV/AIDS.

We will be in touch to discuss the analysis process.
Regards
Judy Thompson

ANNEXURE H

LETTER FROM LANGUAGE EDITOR

18 September 2011

TO WHOM IT MAY CONCERN

I, Suzette Marié Swart (ID 5211190101087), confirm that I have edited the following MINI-DISSERTATION:

Name of student:

JUDY THOMPSON

Title:

THE HEALTH LITERACY NEEDS OF WOMEN LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS OR ACQUIRED IMMUNE DEFICIENCY SYNDROME WHO ATTEND THE WELLNESS CLINIC AT THE JUBILEE HOSPITAL IN HAMMANSKRAAL

Thank you

Suzette M Swart* *(not signed – sent electronically)*
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LANGUAGE PRACTITIONER/EDITOR:
The Consortium for Language and Dimensional Dynamics (CLDD)
University of Pretoria (UP)
Tshwane University of Technology (TUT)
University of Johannesburg (UJ)
University of South Africa (UNISA)
Milpark business school

*Member of *The Professional Editors' Group*

The edit included the following:

- Spelling
- UK vs USA English
- Vocabulary
- Punctuation
- Grammar (tenses; pronoun matches; word choice etc.)
- Language tips
- Correct acronyms (please supply list)
- Consistency in terminology, italisation etc.
- Sentence construction
- Suggestions for text with unclear meaning
- Basic references (consistency in text and against bibliography)
- Basic layout, font, numbering etc.
- Logic, relevance, clarity, consistency

The edit excluded:

- Correctness of crediting another's work – PLAGIARISM.
- Content
- Correctness or truth of information (unless obvious)
- Correctness/spelling of specific technical terms and words (unless obvious)
- Correctness/spelling of unfamiliar names and proper nouns (unless obvious)
- Correctness of specific formulae or symbols, or illustrations
- Style
- Professional formatting

Suzette M Swart