

**GUIDELINES FOR THE ASSESSMENT OF ABUSE IN WOMEN LIVING WITH
HUMAN IMMUNE DEFICIENCY VIRUS AND ACQUIRED IMMUNE
DEFICIENCY SYNDROME IN MALAWI**

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DECLARATION

I declare that this work has been completed by the author at the University of Pretoria. It is my original work and has not been submitted for the award of any degree at any other institution. Due reference and acknowledgement has been made for the sources and quotations used.

WINNIE CHILEMBA

DATE

DEDICATION

The work is dedicated to the following people who supported me during my studies:

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ABSTRACT

Title: Guidelines for the assessment of abuse of women living with Human Immune Deficiency Virus and Acquired Immune Deficiency Syndrome in Malawi

Abuse negatively affects women living with HIV and AIDS. It can be a hindrance to living positively with the disease. Little is known about the essence of living with HIV, AIDS and abuse among women. The purpose of this study was to develop and refine guidelines for assessment of abuse in women living with HIV and AIDS. The objectives were to explore and describe the experiences of the women in Lilongwe, Malawi and to develop and refine guidelines for assessment of abuse in the women. In phase 1 of the study, descriptive phenomenology as espoused in life world research was used. Data were gathered using unstructured interviews from a purposefully selected sample of 12 women living with HIV and AIDS who had encountered abuse. The data were analysed using qualitative methods. The women's experiences were characterized by humiliation from partners, families, neighbours and friends; hopelessness and blame. Harm emanated from being beaten, stress suffered from the abuse, interrupted antiretroviral drugs and possible re-infection with HIV due to unprotected sex. Abandonment of the women by their husbands and families was a common occurrence. Phase 2 of the study was the development of guidelines that can be used with women who experience abuse while living with HIV and AIDS. The guidelines were based on discussion of the findings of phase 1 in the context of an extensive literature review on the constituents. Modified Delphi technique was utilized to refine the draft guidelines. Two rounds were used to finalize the guidelines by a panel of ten experts who were purposefully selected based on their involvement in issues of gender-based violence, HIV and AIDS. The study findings though applicable to the context of the study, can be transferable to similar contexts. Recommendations made include validating the assessment guidelines and testing them in practice to evaluate the applicability and feasibility of using the guidelines.

Keywords

HIV and AIDS, abuse, women, lived experiences, phenomenology, bracketing, essence, Malawi

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Abuse is a multidimensional concept that can be physical, emotional, economical or sexual in nature (Ellsberg & Heise 2005: 90; Shefer, Boonzaier & Kiguwa 2006: 135). Physical abuse includes any physical contact aimed at causing pain - from merely pushing, to shoving, slapping, kicking, dragging, choking, burning on purpose and severe beating (Garcia-Moreno *et al.* 2005: 28). Emotional or psychological abuse entails being yelled at, insulted, humiliated, intimidated, threatened and made to feel bad about oneself. It has been determined that emotional abuse causes fear, anxiety or distress, which can lead to feelings of inadequacy and guilt, or to loss of self-confidence and self-esteem (Garcia-Moreno *et al.* 2006: 1235). Economic abuse refers to inconsiderate control of the finances that belong to the family, whereby the woman has no influence over decisions relating to how money is used (Fawole 2008: 168). It also includes cases of property grabbing and deprivation of basic needs (Ministry of Women and Child Development [Malawi] 2008: 2). Sexual abuse is manifested as a sex act or an attempt to have sex, without mutual consent, including unwanted sexual advances, comments and other forms of coerced sex (Garcia-Moreno *et al.* 2005: 35; the World Health Organization [WHO] 2002: 149). It should be noted that sexual violence usually encompasses the physical and emotional aspects of abuse when threats and manipulation are involved (Kathewera-Banda *et al.* 2005: 651). When a woman resists sexual advances she faces coercion in the form of physical, emotional or economic consequences (Ellsberg & Heise 2005: 17).

Abuse in all its forms can be perpetrated by intimate partners, family or the community. In addition, institutions and organisations, such as the state, that fail women through lack of social, economic, legal and political structures to offer protection, perpetrate violence (Ellsberg 2006 a: 326). Where the general population is concerned, intimate partner violence is a well-documented and

common phenomenon (Svavarsdottir & Orlygsdottir 2009: 1452; Zolotor, Denham & Weil 2009: 847). Women usually report to have been beaten for reasons such as refusing to have sex with a partner and in cases where alcohol has been used (Strebel *et al.* 2006: 522). Women living with Human Immune Deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) are likely to experience abuse from their intimate partners (Emusu *et al.* 2009: 1365), their family or community (Dlamini *et al.* 2007: 390). Being HIV-positive has been cited as one of the risk factors for intimate partner violence among women and more so during pregnancy (Shamu *et al.* 2011: 1). Intimate partner violence has been associated with development of general health problems such as chronic pain and stress, which could result in hypertension and headaches. It has also been associated with the worsening of any existing health problems that the victim may have, due to stress and partner controlling behaviours that affect health seeking and self-care, compromising overall quality of life in the process (Thomas *et al.* 2008: 1266).

The terms violence against women (VAW) and gender-based violence are used interchangeably to refer to the full range of abuses, as recognised by the United Nations Declaration of 1993 (Ellsberg & Heise 2005: 11). It is generally agreed that abuse of women and girls should be regarded as gender-based violence, regardless of where or under what circumstances it occurs. The WHO (2005: 3) estimates that one in five women encounters some form of violence during her lifetime, with the WHO Multi-Country Study of 2000-2003 indicating that lifetime prevalence of acts of physical and sexual violence against women experienced from a partner, ranges between 15 and 71 per cent, varying from region to region (Garcia-Moreno *et al.* 2006: 1260). In South Africa, which is one of the countries in sub-Saharan Africa with a high prevalence of intimate partner violence, the rate is reported to be between 25 and 55 per cent (Gass *et al.* 2011: 2778). Similar trends are reported in Malawi, where the rate of physical violence against women ranges between 19 and 45 per cent (Malawi National Statistics Office [NSO] 2011: 240). In referring to the causes or contributing factors of abuse, it has been noted that this can mainly be attributed to women's subordinate status in society, in contrast to that of men (Ehrhardt *et al.* 2009: S98) The subordinate status is entrenched in expectations of behaviour that is socially constructed according to gender. As such, it is the power inequality in

relationships between men and women which leads to violence (Jewkes & Morrell 2010: 1). It is for this reason that understanding gender roles in relationships is of key importance when addressing the HIV epidemic (Greig *et al.* 2008: S35).

In this study experiences of abuse among women living with HIV and AIDS (WLWHA) in Lilongwe, Malawi have been explored, and this exploration was followed by the development and refinement of assessment guidelines, based on the women's experiences. Applicable guidelines can assist nurses and other healthcare professionals to identify and address abuse of WLWHA in a timely manner.

1.2 BACKGROUND

1.2.1 The HIV and AIDS situation

The HIV and AIDS epidemic is one of the greatest challenges facing the world today. HIV and AIDS have become a serious health and developmental problem in many countries around the world, particularly in sub-Saharan Africa. Globally, 33 million people currently live with the virus, of which, 30.8 million are adults and 2.2 million are children (Joint United Nations Programme on HIV/AIDS [UNAIDS] 2008: 4). The worst affected region is sub-Saharan Africa, with 22 million people (adults and children) living with HIV and AIDS. At the end of 2007, women accounted for 50% of all adults living with HIV worldwide, of which 59% were in sub-Saharan Africa (UNAIDS 2008: 4).

Among these affected countries in sub-Saharan Africa, South Africa registered an adult HIV prevalence estimated at 17% in the year 2010, with an estimated total number of about 5.2 million people living with HIV (Statistics South Africa 2010: 3). In Malawi, the adult prevalence rate of HIV was estimated to be 11%. About one million people, including children under the age of 15, were living with HIV and AIDS in the year 2007 as reported in the Malawi Demographic and Health Survey. Women constituted an estimated 60% of this number (UNAIDS 2008: 4; NSO 2011: 196).

1.2.2 Women's vulnerability to HIV

HIV is transmitted mainly through heterosexual contact (Bradley-Springer 2007: 1). According to the vulnerability paradigm, which addresses the disproportionate HIV infection rates in women compared to men (Higgins, Hoffman, & Dworkin 2010: 435), high infection rates among women could be due to a combination of factors, including the biological susceptibility which makes young women and girls more prone to infections (Lin, McElmurry, & Christiansen 2007: 689). Women have a large surface area that may be in contact with the virus during heterosexual intercourse and they may experience bruising, especially in the case of forced sex, which can provide a ready entry for HIV. In addition, the developing cervix in young girls is a recognised risk factor that increases susceptibility to infection with HIV, putting them at greater risk (Higgins *et al.* 2010: 437; Chersich & Rees 2008: S30). The practice of using foreign products to tighten, clean, warm or dry the vagina by women in southern Africa, which is believed to enhance the sexual experience for men, has been associated with bacterial vaginosis. This increases the risk for HIV infection (Chersich & Rees 2008: S30) because HIV transmission thrives in the presence of inflammation, as may occur in the presence of other sexually transmitted infections such as chlamydia.

However, it is gender role, rather than sex, that has been found to be the most influential factor in the risk of HIV transmission for women (Jewkes & Morrell 2010: 2). This is because when men enact a hegemonic gender role, they assume power over women, who are supposed to be submissive. The men may indulge in risky behaviours, such as having multiple and concurrent sex partners, in fulfilling the expected gender roles. The women become exposed to the risk when they assume the role that is expected of them, by accepting the men's behaviours as normal or by not being successful in challenging such practices (Jewkes & Morell 2010: 2).

Another aspect of the vulnerability paradigm is the high poverty level, which has forced women to exchange sex for money in order to survive, putting themselves at risk of acquiring infections (Andersson, Cockcroft, & Shea 2008: S77). It is asserted that due to the power imbalances between men and women,

men influence how and when sex takes place and that they have access to, and control of, resources such as land, credit and income (Kim *et al.* 2008: S57). Thus, women's economic dependence on men, their low social status within the society as well as various cultural expectations, make it difficult to negotiate for safer sex (Kaufman *et al.* 2008: 435). Women are unable to refuse sex or insist on the use of condoms when having sex, even when the partners are known to be involved in extramarital activities (Moreno 2007: 350; Whetten *et al.* 2008: 534). Thus, poverty is a factor that may lead women to partake in behaviours that are risky, including transactional and trans-generational sex leading to HIV infection (Greener & Sarkar 2010: S3).

Women have an early sexual debut compared to men and they tend to marry men several years their senior. This discrepancy in age increases their risk of infection. As such men are likely to be infected already with the virus from multiple and previous sex partners (Higgins *et al.* 2010: 436). These risk factors may explain the large differences in HIV prevalence between girls and boys aged 15-24 (Ehrhardt *et al.* 2009: S96). Girls were found to be more than three times likely to be infected with HIV than boys of the same age (USAID 2006: 1). This high prevalence in women is particularly true for sub-Saharan Africa, where it is highest in the late teens (Jewkes & Morrell 2010: 1).

1.2.3 The intersection of abuse and HIV

Gender-based violence and HIV are often linked in a complex relationship, where one gives rise to the other (van Rensburg 2007: 696). This relationship is commonly referred to as the intersection of gender-based violence and HIV. It has been shown that women who are in abusive relationships are more likely to be HIV-positive, while being HIV-positive increases the likelihood of being abused (Ramachandran *et al.* 2010: 1536). Men are largely the perpetrators of gender-based violence, while women are disproportionately affected by both gender-based violence and HIV infection (Campbell *et al.* 2008: 221).

Studies conducted in South Africa have found that men who are perpetrators of gender-based violence are more likely to engage in behaviours that are risky for acquiring HIV infection, such as having multiple and concurrent sexual partners

(Jewkes & Morrell 2010: 2). Furthermore, women who are HIV-positive, are more likely to be in a violent relationship compared to women who are HIV negative (Campbell *et al.* 2008: 223). This information suggests that intimate partner violence may act as an indicator of the greater likelihood that a perpetrator will have HIV. Similarly, women who have abusive partners have a greater likelihood of having an HIV infection (Decker *et al.* 2009: 593). In addition, disclosure of a positive HIV status may result in physical and/or emotional abuse (Medley *et al.* 2009: 1745; Strebel, Cloete & Simbayi 2009: 11; Christofides & Jewkes 2010: 280). Other consequences include shunning and abandonment (Smith & Niedermeyer 2009: 462).

Abuse of WLWHA may be perpetrated as part of the stigmatisation process (Holzemer *et al.* 2007: 546). Stigmatisation and discrimination against people living with HIV, is contrary to their human rights as they are often rejected and abused (Kohi *et al.* 2006: 405) and at the same time, may be denied access to care and support (Leiter *et al.* 2006: 89). Stigmatizing attitudes may be reflected in physical isolation and receiving no support from the community (Ndinda *et al.* 2007: 94; Wingood *et al.* 2007: 111).

Women are often blamed for bringing HIV into the family (Ndinda *et al.* 2007: 93), particularly if they are the ones who have been tested for HIV first, usually through antenatal clinics and/or the prevention of mother-to-child transmission programmes. Similarly, according to Makoae *et al.* (2008: 140), the stigmatizing of WLWHA includes different forms of abuse. The report of Liu *et al.* (2006: 139) indicates avoidance and non-supportiveness as some of the manifestations of public stigma. In support of these findings Shamos, Hartwig and Zindela (2009: 1678) have found that women living with HIV in Swaziland were experiencing more discrimination, as they were not assisted by their family and friends in the same manner as the men living with HIV.

1.2.4 Effects of abuse

There is compelling evidence of physical and non-physical abuse or acts of violence committed against women resulting in increased health problems (Svavarsdottir & Orlygsdottir (2008: 780). These health problems include

injuries such as bruises, cuts, fractures (Decker *et al.* 2009: 598) and gynaecological disorders such as abortion and cervical cancer (Coker *et al.* 2009: 1180). Mental health problems such as anxiety, sleep disturbance, post-traumatic stress disorder and depression have been associated with incidences of abuse (Ellsberg & Heise 2005: 18; Wijma *et al.* 2007: 569). Thus, it is undisputable that violence can increase women's risk of poor health (Ellsberg 2006 b: 2). Abuse of WLWHA may have an even greater impact when taking into consideration the physical and psychological demands the condition (HIV and AIDS) already exerts on the body.

Being diagnosed with HIV is a traumatic event that involves great emotional distress as well as a physical threat to an individual's life (Theuninck, Lake & Gibson 2010: 485). Thus, in the general context of living with HIV and AIDS, women are already affected physically, socially and psychologically (Mohammadpour *et al.* 2009: 249). They are required to make decisions pertaining to sexuality and health sustaining issues, such as adherence to antiretroviral drugs and dietary change. Concerns about drug side effects and the care of children in relation to the women's own mortality are some of the issues they grapple with. As noted by Kagee and Martin (2010: 162), psychological problems can substantially impact on the quality of life of people living with HIV and AIDS. WLWHA encounter these challenges in everyday life. Symptoms range from extreme exhaustion as a result of the illness, to mood and behavioural changes and may affect overall performance in daily activities.

These challenges can be compounded by abuse that may be experienced from intimate partners, the extended family and the community at large. Acts of violence or abuse are associated with emotional and physical health effects for the women (Ehrhardt *et al.* 2009: S96; Humphreys 2007: 122). In order to capture the dimensions of violence against women living with HIV and AIDS the following definition was specially proposed within the international community of women living with HIV:

“Violence against HIV positive women is any act, structure, process in which power is exerted in such a way to cause physical, sexual, psychological, financial and legal harm to women living with HIV”.

(Hale & Vasquez 2011: 13.)

1.2.5 Legislation and public services relating to gender issues

The United Nations General Assembly adopted the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) in 1979. It defines discrimination as “any exclusion or restriction made on the basis of sex which has the effect of impairing the recognition, enjoyment or exercise by women of their human rights and fundamental freedoms in the political and economical or cultural field” (Office of the High Commission for Human Rights 2007: 1). This is a fundamental convention that commits governments or states to embrace the principle of equality of men and women and to take action to end any discrimination. This convention was followed by the Declaration for the Elimination of Violence against Women in 1993 (WHO 2005: 3). These declarations have been put in place in recognition of the fact that violence against women is a threat to global social and economic development and that it is a violation of human rights. In the year 2000, United Nations General Assembly made the Millennium Declaration that adopted eight goals that were recognised as major concerns for sustainable development for the international community. These are referred to as the Millennium Development Goals (MDGs). The MDGs provide an avenue to focus interventions that address gender-based violence. They include:

Goal 1 - Eradication of extreme poverty and hunger.

(The majority among the poor are women).

Goal 2 - Achievement of universal primary education.

(The majority among the uneducated are women).

Goal 3 - Promotion of gender equality and empowerment of women.

(Women suffer gender inequality in issues such as employment, land and other asset possession and credit opportunities).

Goal 4 - Reduction of child mortality.

(Children of poor and uneducated women suffer more from morbidity and mortality).

Goal 5 - Improvement in maternal health.

(Childbearing results in high morbidity and mortality rates among women).

Goal 6 - Combating HIV/AIDS, malaria and other diseases.

(Women being disproportionately affected by HIV, particularly in sub-Saharan Africa, may not access services in a timely manner for other illnesses, due to competing demands in their lives).

Goal 7 - Ensuring environmental sustainability.

(Women are most immediately affected by environmental degradation, which may affect availability of resources such as water and firewood).

Goal 8 - Developing a global partnership for development.

(Women are at the core of developmental activities).

(United Nations Development Programme [UNDP] 2003: 1).

As indicated above, goal number three is strategic, as it is a cross cutting issue that has an impact on all the other goals. It is well documented that gender inequality exacerbates poverty among women who are already inadvertently affected, compared to men. It is also true that women are often less educated than men, as communities prefer to invest more in men than in women. Unfortunately, as it is, it is the illiterate and the least educated women who often suffer ill health for themselves and their children, and women are more affected by HIV than men (UN 2003: 3). Since violence against women is a consequence of inequality, it can be concluded that goal number three should be considered to be the key to achieving all the other MDGs (WHO 2005: 5).

One of the main strategies to achieve the Millennium development goals is to eliminate violence against women (Ellsberg 2006 a: 326). However, realisation of these goals can be a challenging task, especially in the face of widespread abuse in many communities. These sentiments were echoed by Kofi Annan, former Secretary General of the United Nations, who said “There is no time to lose if we are to reach the Millennium Development Goals by the target date of 2015. Only by investing in the world of women can we expect to get there...” (UN 2003: 6).

The Government of Malawi is a signatory to many of the international conventions and declarations such as the Elimination of all forms of violence against women and the Southern Africa Development Community Protocol on gender and development. This reflects an indication of its political will to address the existing gender disparities. Recognizing the severe impact of gender-based violence on poverty reduction, among other important targets, the Malawi Government passed the Prevention of Domestic Violence Act of 2006 (Ministry of Women and Child Development 2008: 1). The Act, developed by the Ministry of Gender, Child Welfare and Community Services, in consultation with stakeholders, covers spousal as well as other family relationships.

The Prevention of Domestic Violence Act follows the development and launch of the National Gender Policy of 2000, which advocates gender equality. In addition, the Malawi National HIV/AIDS Policy of 2003 addresses issues of gender and age, as they affect the HIV epidemic. The policy integrates the promotion of human rights and vulnerability in its guiding principles and policy statements (National AIDS Commission of Malawi 2003: 2). Although these conventions and policies are available, their implementation has not been effectively monitored.

Women (and men) who experience violence that is physical and sexual in nature are encouraged to report to the Police Victim Support Unit where the perpetrator is charged with an offence. The Ministry of Gender, Child Welfare and Community Services in Malawi has developed plans to build shelters for abuse victims in the near future (US Department of State 2006: 9).

1.2.6 Studies on abuse, HIV and AIDS in general

Many studies have explored abuse and intimate partner violence in general, but not specifically the experiences of abuse endured by WLWHA. Clark *et al.* (2009: 144-151) conducted a study that explored the role of the extended family in women's risk of IPV in Jordan. In the study, it was established that women's and men's exposure to violence in their lives as children in their respective families was a risk factor for the women to experience violence in adulthood and for the men to be perpetrators of the same. The authors concluded that further examination would be necessary to identify factors that promote supportive and protective families which could be used to reinforce programs that assist in nurturing families.

Horn (2009: 160-168) explored responses to intimate partner violence in Kakuma refugee camp and found that women experiencing violence did not receive adequate protection, and that response from humanitarian agencies was not forthcoming. The problem was attributed to the lack of reporting among the women. Another study to establish the efficacy of a psycho-behaviour intervention to reduce IPV in pregnancy was conducted in the USA among African American women, in a controlled randomised trial by Kiely *et al.* (2010: 273-283). Overall, the results indicated that the intervention reduced IPV in pregnancy and improved pregnancy outcomes in women who participated.

Alio *et al.* (2009: 35-38) examined the association between IPV and contraceptive use among women in six sub-Saharan African countries. The results showed that women who were exposed to IPV were more likely to use contraceptives. The authors recommended screening for IPV and improving accessibility to services, including female controlled methods for those more likely to experience violence.

Amuyunzu-Nyamongo *et al.* (2007: S29) found that women with HIV and AIDS were sexually abused and abandoned. Similarly, Emusu *et al.* (2009: 1365), in a study on sexual violence among discordant partners, found that all the participants experienced violence from their male partners, who wanted to have sexual intercourse against the women's will. This occurred irrespective of

whether it was the woman or the man who was HIV-positive. Even fewer studies on sexual violence in sub-Saharan Africa have focused on the experiences of the women.

1.2.7 Studies on abuse, HIV and AIDS in Malawi

The abuse of WLWHA needs further exploration based on the experiences of the women themselves (Lin, McElmurry & Christiansen 2007: 688). The researcher describes some studies that have been conducted in Malawi in relation to HIV/AIDS and abuse. Among these studies, the MDHS of 2004 first describe the national situation on domestic violence. A follow-up MDHS conducted in 2010 provides more comprehensive information about domestic violence in terms of the extent, factors influencing its occurrence and the impact of the problem in Malawi. The two studies provide valuable information regarding domestic violence but do not address the occurrence of violence against WLWHA in particular and make no reference to the assessment of these women.

Kathewera-Banda *et al.* (2005: 649-660) focussed their study on sexual violence and women's vulnerability to HIV transmission. In this study, conducted in Nkhonkhotakota district, the researchers made use of semi-structured interviews, focus group discussions with men, women and youth, as well as document analysis. From these discussions it was found that women trading in the fish business in the district partook in transactional sex to receive favours from traders and fishermen in order to buy the fish. The authors concluded that these practices were a product of exploitation of the women, due to their lack of economic autonomy, which rendered them powerless to protect themselves or to negotiate terms for sex, thereby perpetuating unequal gender power relations between men and women.

Mkandawire-Valhmu and Stevens (2010: 684-696) explored the use of focus group discussions with women living with HIV to analyse gender issues. In the study, 72 women attending ARV clinics (one urban and three rural) in the southern part of Malawi, participated in the discussions. The women were able to share their personal stories of painful experiences such as assault and abandonment. Their experiences were validated when other women in the group

expressed similar encounters and they were able to come up with solutions to address their problems in one sitting. The authors concluded that focus group discussions offered an opportunity to combine data collection and generate answers in a participatory manner within the affected groups. The focus group discussions were viewed to have had a therapeutic effect on the participating group members.

The studies discussed contribute significant knowledge on aspects of the situation of abuse, HIV, and AIDS in relation to women in the country. However, there is still paucity of information on experiences of abuse among WLWHA which needs to be investigated as it remains unidentified and therefore not always addressed.

1.3 RESEARCH PROBLEM

According to the World Health Organization estimate (2005: 3), one in five women encounter some form of violence during her lifetime. This number indicates that violence is of great concern worldwide and it is not acceptable. Gender-based violence and HIV are considered to be overlapping epidemics whereby one impacts on the other (WHO 2006: 2). Women who are in violent relationships are at greater risk of becoming HIV-positive, while women who are HIV-positive are more likely to experience abuse.

The majority of women endure abuse in silence (Ellsberg & Heise 2005: 5). They are not encouraged to tell health workers or any other person about their experiences. As a result of the silence that surrounds violence in women's lives, nurses and other health workers who care for women living with HIV and AIDS may not be aware that the women are encountering abuse.

Living with HIV and AIDS can impact on the general well-being of individuals (Abel, Hopson & Delville 2006: 537). In addition, abuse as a stressor can lead to further compromise in the physical, emotional and social health status and overall quality of life of women living with HIV and AIDS. Abuse may interfere with a woman's independence in accessing health services and her ability to adhere to the prescription of treatment with ARV medication.

A study to describe the experiences of women living with HIV and AIDS in Malawi, who are or have been exposed to abuse and how the abuse affects their lives, according to their own self reports, is important in order to highlight the challenges that are experienced by the women. Currently, there are no assessment guidelines in Malawi which are based on the experiences of the women. The assessment guidelines are required to ensure that abuse is identified and addressed in a timely manner by nurses and other health workers, who are sensitized about the problem and its impact. As previously stated, WLWHA can experience abuse from intimate partners, their family and/or the community at large.

1.4 RESEARCH QUESTION

The main research questions in this study were:

- What are the experiences of women living with HIV and AIDS who are exposed to abuse?
- What assessment is needed to identify abuse among women living with HIV and AIDS?

1.5 PURPOSE OF THE STUDY

The purpose of this study was to develop and refine guidelines for the assessment of abuse of women living with HIV and AIDS. The study explored the experiences of women in Lilongwe, Malawi, in order to gain insight into living with HIV and AIDS and abuse.

1.6 OBJECTIVES OF THE STUDY

The objectives of the study were to:

- Explore and describe the experiences of WLWHA in Lilongwe, Malawi, who are or have been exposed to abuse.
- Develop and refine guidelines for assessment of WLWHA in Lilongwe, Malawi, who are or have been exposed to abuse.

1.7 SIGNIFICANCE OF THE STUDY

The study is significant as it brings to light the experiences of women living with HIV and AIDS, who are or have been exposed to abuse. Considering that abuse and gender-based violence are of public health concern (Henttonen *et al.* 2008: 122), it can pose a hindrance to living positively with HIV and AIDS. Consequently, the study adds to the body of knowledge of nursing regarding the experiences of abuse among WLWHA.

The study highlights the necessity of having assessment guidelines that can be used for women living with HIV and AIDS, who are exposed to abuse. Such assessment guidelines could be beneficial, as they could have policy implications for the management of WLWHA in Malawi. The assessment guidelines could be used to identify abuse of the women in a timely manner for proper management, thereby contributing to an improvement in overall well-being.

1.8 ASSUMPTIONS

Assumptions are beliefs that are taken for granted without being verified (Holloway & Wheeler 2010: 337). Burns and Grove (2009: 40) refer to assumptions as 'statements that are considered to be true even though they have not been scientifically tested'. The authors state that assumptions can be made from the philosophical and theoretical underpinnings of a study as well as universally recognised truths. This study was conducted guided by qualitative methodology.

According to Polit and Beck (2008: 15) qualitative research is a form of naturalistic inquiry. The naturalistic paradigm has four major assumptions: related to the nature of reality (ontological), the relationship of the inquirer to those being researched (epistemological), the role that values play in the inquiry (axiological) and the manner of best obtaining evidence or methodological (Creswell, 2009: 17). The ontological assumption is that there is multiple and subjective reality which is mentally constructed by individuals. This is reflected in the perspective provided by the study participants of their own reality, based on each person's experiences and context. The epistemological assumption is that research findings are based on the interactive process between the inquirer and the research participants. In this study the researcher's role was to facilitate the process of the participants telling their own stories (Dahlberg, Dahlberg & Nyström 2008: 184). On methodological assumption, the process was focused on the subjective, in-depth and holistic descriptions of the phenomenon of abuse, grounded in the participants' experiences. Hence, the axiological lens, which stipulates that subjectivity and values are both desirable and unavoidable, was consciously taken into consideration. By utilizing the concept of bracketing throughout the research process, the researcher's values and biases were kept in check in order to bring out reality, as based on the participants' experiences.

Reports indicate that WLWHA in Malawi experience abuse from their partners, their family members and the community (US Department of State 2006: 9). The study uncovered reality based on personal experiences. The abuse negatively impacts on their physical, psychological and sexual well-being; thus, on their quality of life. Finding out about the abuse of the women has led to the development of assessment guidelines that would assist nurses to identify and address abuse of women living with HIV and AIDS, in order to meet their health care needs.

1.9 CLARIFICATION OF CONCEPTS

Abuse

The Oxford Advanced Learner's Dictionary (2007: 6) defines 'abuse' as: "the use of something in a way that is wrong or harmful; unfair, cruel or violent

treatment of somebody; rude or offensive remarks to or about somebody.” Similarly, the Blackwell’s Nursing Dictionary (2005: 5) describes abuse as ‘to treat without compassion and usually in a hurtful manner’. Pozgar (1996: 108) describes abuse as the mistreatment or neglect of other individuals.

In the study, ‘abuse’ refers to any behaviour/act that is physical, sexual, psychological or economic in nature that is hurtful, unfair or cruel to a woman living with HIV and AIDS. The terms abuse of women, violence against women and gender-related violence are used interchangeably in research. This is because the terms refer to the same acts perpetrated against women (Ellsberg & Heise 2005: 11). For this study, the term abuse will be used.

Assessment

According to Blackwell’s Nursing dictionary (2005: 56) assessment involves “gathering information from and about a patient identifying his or her health care problem and needs and stating these in terms that relate to the particular problem.” Potter and Perry (2009: 231) describe the process of assessment as a deliberate and systematic gathering of information about a client’s current and past health and functional status, to determine coping patterns of the client. Similarly, Allender and Spradley (2005: 45) define assessment as ‘gathering and analysing information that will affect the health of the people to be served’. In this study, assessment refers to the systematic gathering of information in order to identify health care problems and needs.

Guidelines

A guideline is defined as “something that can be used to help you make a decision or form an opinion” (Oxford Advanced Learner’s Dictionary 2010: 667). Potter and Perry (2009: 281) refer to guidelines as documents that guide decisions and interventions for specific conditions or situations, while the World Health Organization (2003: 2) defines guidelines as “systematically developed evidence-based statements which assist providers, recipients and other stakeholders to make informed decisions about health interventions.” They are

said to be formal advisory statements, robust enough to meet the specific circumstances of situations which they are applied to.

Thus, the guidelines for assessment have been used in this study as a tool to guide in the gathering of information from women living with HIV and AIDS who are or have been exposed to abuse, in order to identify their health care problems and needs.

1.10 RESEARCH METHODOLOGY

The study was conducted in two phases. The first phase focussed on exploring and describing the experiences of WLWHA, who were exposed or had been exposed to abuse to provide a comprehensive description of the women's experiences, using a phenomenological approach. The second phase was the development and refinement of assessment guidelines for WLWHA, based on the findings of Phase 1. Refer to figure 1.1 for a diagrammatic representation of the two phases of the study.

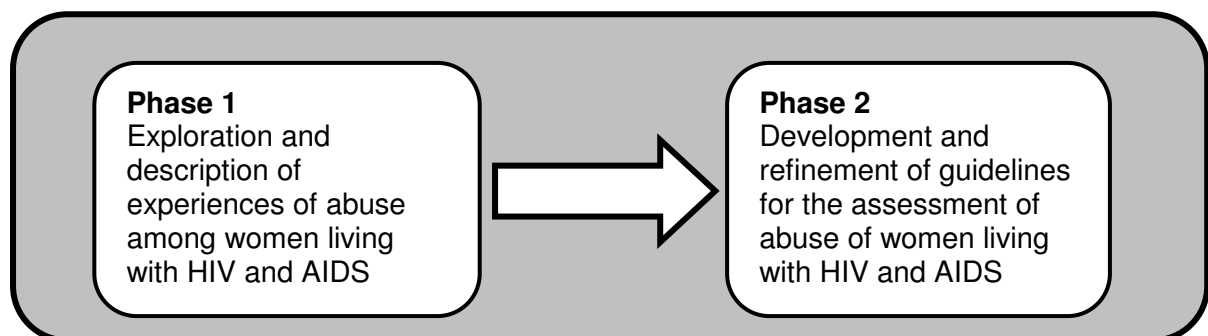


Figure 1.1 Two phases of the research

1.10.1 PHASE 1: EXPLORING AND DESCRIBING THE PHENOMENON

Phase 1 of the research explored and described the lived experiences of women living with HIV and AIDS who were or had been exposed to abuse. A brief overview of the process that was followed is provided with a comprehensive discussion following in chapter 2.

Research design

The researcher used a qualitative research design in phase 1 of this study following a phenomenological research approach. The chosen design and approach allowed the participants to communicate their experiences of abuse once their status of HIV and AIDS had been revealed (Polit & Beck 2008: 227).

Setting

The study was conducted in both rural and urban settings of Lilongwe district in Malawi. Malawi is a country situated in the south eastern part of Africa and lies between 13 57.5' and 33 42'. It is within the sub-Saharan region. It has a population of about 13 million people, of which 51% are women (National Statistics Office 2008: 2). Lilongwe is the capital city of Malawi where many programmes for people living with HIV and AIDS have been implemented.

In order to gain access to the setting, the researcher sought permission through the District Health Officer. Two health facilities, identified in consultation with the district health office, were used for recruiting participants for the study. These facilities, one in a rural and the other in an urban setting, provide HCT as well as ART services and hosted support groups for meetings for WLWHA.

Population and sample

The population in this study was women living with HIV and AIDS in the Lilongwe district, who were experiencing or had experienced abuse. Purposive sampling was used to select participants who were capable of providing the required information. Women who were living with HIV and AIDS, while also having been exposed to any form of abuse and who were attending the child and adult ARV Clinics at the health facility were invited to participate in the study. The women were those who were willing to provide information based on personal knowledge of HIV and AIDS and encounters with abuse. A sample size of 12 was adequate to provide a comprehensive description of their experiences for the study.

Inclusion criteria

The inclusion criteria were women from the age of 18 years. The women should have been in a relationship (current or past) and should have experienced living with HIV and AIDS for at least one year. The women were those who admitted to have encountered any form of abuse and were willing to describe their experiences. The experiences were from interaction with partners, families and the community.

Data collection

Access to the study participants was obtained through nurses working at antiretroviral clinics. Staff working with the women approached the potential participants. They asked women attending the clinic on that particular day, individually, whether they were being exposed to or had previously encountered any form of abuse. Those who indicated that they were experiencing or had experienced abuse, were informed about the study and those that showed interest to participate were referred to the researcher. The researcher then gave a detailed description of the study to the women who were interested, in order for them to make an informed decision of whether to participate in the study or not.

The researcher conducted the interviews on a one-on-one basis in a separate and private room. The participants were reassured that other people would not hear the conversation taking place and that their names would not be recorded anywhere. All information and records obtained were treated as private and confidential. Data was collected using unstructured interviews conducted in the local language (Chichewa). The invitation statement during the interview was:

"Tell me about your experiences as a woman living with HIV and AIDS who has been exposed to abuse".

This was a general opening statement before the specific issues of abuse were explored. Probing was used as and when necessary. In addition, paraphrasing was used as an interviewing technique. The interviews were audio taped with the

permission of the participants. Detailed notes were taken during and soon after the interview as back-up. The interviews were conducted at the health facility, which was the preferred place of the participants. Data collection and initial data analysis were done concurrently.

Data analysis

The recorded interviews were transcribed verbatim after each interview. The transcribed data was translated into English. Peers conversant in both Chichewa and English were consulted in the process of translation. The data analysis was guided by the process as described by Collaizi (cited in Streubert Speziale & Rinaldi Carpenter 2007: 83; Holloway & Wheeler 2010: 223) and that advocated by Dahlberg, Dahlberg and Nyström (2008: 240) in order to distinguish the essence and its constituents of the experience of abuse for WLWHA.

Trustworthiness

In this study, aspects of the following criteria were observed to ensure trustworthiness and rigour: confirmability, credibility, transferability and dependability (Lincoln & Guba 1985: 289). In addition, authenticity was observed as a means of ensuring rigour (Polit & Beck 2008: 544).

1.10.2 PHASE 2: DEVELOPMENT AND REFINEMENT OF GUIDELINES FOR ASSESSMENT OF ABUSE OF WOMEN LIVING WITH HIV AND AIDS

Phase 2 of the study focused on the development and refinement of guidelines for the assessment of abuse of women living with HIV and AIDS. A brief overview is provided with a detailed discussion following in chapter 5.

Development of the draft assessment guidelines

A follow-up on phase 1 was the development of guidelines for the assessment of abuse that can be used with WLWHA. The researcher formulated the draft guidelines based on findings from the data analysis conducted in phase 1, which

focused on the experiences of WLWHA, who were being or had been exposed to abuse. The various themes that were identified from the data analysis formed the initial contents of the draft assessment guidelines. A literature review was used to operationalise the themes accordingly and to change it into guidelines for the assessment of WLWHA, who are exposed to abuse.

Refinement of the draft guidelines for assessment

The researcher compiled the operationalized themes as presented in the draft assessment guidelines and utilized the Delphi technique to have it refined by experts working in the field of HIV, AIDS and gender-based violence.

Method

The Delphi method was used to reach consensus on the assessment guidelines. The Delphi technique is a multistage approach using a series of data collection rounds or stages, with each one building on the results of the previous stages (McKenna 1994: 1221). The first step allows for broad comments on a subject area (Efstathiou, Ameen & Coll 2008: 363). Subsequent rounds are developed from summarized responses and are fed back to the panel of experts for reconsideration in light of the new information (Crisp *et al.* 1997: 5). The process is repeated in several rounds until consensus is reached (Polit & Beck 2008: 327). Two rounds were used to reach consensus on the assessment guidelines.

Population and sample

Experts from Malawi, South Africa and Botswana participated in the Delphi process by means of electronic mail. The researcher contacted experts in the field of HIV, AIDS and gender-based violence. A list of names was compiled of people working at clinical, research and academic institutions. A purposive sample of ten experts, based on interest and knowledge on the subject was identified (Hasson, Keeney & McKenna 2000: 1010). The contact addresses were obtained from the research supervisors and contact made by the researcher.

Validity

The use of experts who are knowledgeable about the topic contributed to the validity of the results of the Delphi process. Studies have used different consensus cut-off points, depending on the importance of the topic under scrutiny. In this study the 60% consensus on any given item adopted, as this assumes that more than half the participants agree with the issue (McKenna 1994: 1222). The use of multiple rounds also contributed to the validity of the data that lead to the final assessment guidelines (Hasson, Keeney & McKenna 2000: 1013). An audit trail, documenting all decisions made during the Delphi process, was kept in a journal which is available for review (Skulmoski, Hartman & Krahn 2007:11).

1.11 ORGANISATION OF THE STUDY CHAPTERS

The chapters of the study have been organized as follows:

Chapter 1: Orientation to the study

Chapter 2: Paradigmatic and methodological grounding of phase 1 of the research study

Chapter 3: Presentation of findings for phase 1 of the study

Chapter 4: Discussion of findings of phase 1 of the study for the development of guidelines for assessment

Chapter 5: Phase 2 of the study: Development and refinement of guidelines for assessment of abuse of women living with HIV and AIDS

Chapter 6: The guidelines, recommendations, implications, limitations and conclusions

1.12 SUMMARY

This chapter has provided an overview of the study on guidelines for the assessment of abuse of women living with HIV and AIDS in Lilongwe, Malawi. It has discussed the intersection between gender-based violence and HIV/AIDS to provide a background for the research problem and its significance. The research methodology concerning the two phases of the study has been described in brief. Phase 1, which focussed on the experiences of abuse of women living with HIV and AIDS, utilised phenomenology to provide a comprehensive description of the women's experiences, while phase 2 utilised the Delphi process to refine the assessment guidelines (developed from the information discussed in phase 1). In chapter 2, which follows, is a presentation of a detailed description of the philosophical and methodological assumptions of phenomenology and its application as a research method. The processes completed to conduct the study are discussed in detail.

CHAPTER 2

PARADIGMATIC AND METHODOLOGICAL GROUNDING OF PHASE 1 OF THE RESEARCH STUDY

2.1 INTRODUCTION

Phase 1 of the research on guidelines for the assessment of abuse of women living with HIV and AIDS was conducted within the naturalistic research paradigm. The aim of this phase was to describe the experiences of abuse among women living with HIV and AIDS. Phase 2 of the study focuses on the development and refinement of guidelines for the assessment of abuse of women living with HIV and AIDS. According to de Vos *et al.* (2010: 261), it is necessary to outline the paradigm that underpins a particular study, as this is the frame of reference that is used to organize one's reasoning and observations. A paradigm is a way of viewing the world, and how knowledge is gained about the world (Babbie 2010: 42). Paradigms are fundamental orientations, perspectives, world views that are often not questioned (de Vos *et al.* 2010: 261).

A research paradigm has four major assumptions. According to Creswell (2007: 74), a research paradigm is based on assumptions that: relate to the nature of reality or existence (ontology), the relationship of the researcher and what is being researched or how knowledge is developed (epistemology), the role of the values in research (axiology) and the manner or process of best obtaining research evidence (methodology). A paradigm provides a variety of views and it influences how one conceptualizes the research process (de Vos *et al.* 2010: 261).

The ontological assumption is that there is multiple and subjective reality, which is mentally constructed by individuals (Creswell 2009: 17; Polit & Beck 2012: 13). Thus, the study participants provided a perspective of their own reality, based on each person's experiences and context. The epistemological assumption is that research findings are based on the interactive process

between the inquirer and the research participants (Creswell 2007: 17; Polit & Beck 2012: 13). In this study, the researcher's role was to facilitate the process of the participants telling their stories and to describe the experiences, as conveyed by the participants. On methodological assumption, it was in keeping with the qualitative design, whereby the focus is on the subjective, in-depth and holistic descriptions of the phenomenon of abuse that is grounded in the participant's experiences. However, the axiological lens, which stipulates that subjectivity and values are both desirable and unavoidable (Creswell 2007: 17; Polit & Beck 2012: 13), was consciously taken into consideration. By utilizing the concept of bridling throughout the research process, the researcher's values and biases were reflected upon, in order to distinguish reality, based on the participants' experiences (Dahlberg *et al.* 2008: 130).

2.2 META-THEORETICAL ASSUMPTIONS

Philosophies, models and theories of a discipline are the theoretical structures that address the central concepts of a discipline (Aligood 2010: 48). The meta-theoretical assumptions of a discipline describe the concepts and themes chosen as its focus (Cody 2006: 27). These concepts are the ones that differentiate it from other disciplines and reflect shared values and beliefs about the discipline (Cody 2006: 27).

The meta-paradigm of nursing is agreed to be composed of four concepts. These are: person, environment/society, nursing and health (Chinn & Kramer 2011: 54). They are the most abstract set of central concepts for the discipline of nursing and when defined within each of the conceptual models, provide a context to understand their interrelationship in contemporary nursing science (Aligood 2010: 48; Cody 2006: 27). Thus, nursing as a discipline subscribes to common values and beliefs that specify the scope of concern for the profession. The meta-paradigm does not guide practice, but provides boundaries, while definition of the concepts gives the desired direction (Aligood 2010: 80).

The meta-theoretical assumptions are clarified in this study to reflect the context in which the researcher conducted the study. Nursing is viewed as a helping process, with a primary focus on interpersonal interaction in preserving or

restoring health and wholeness (Chinn & Kramer 2011: 55). Nurses recognize the dignity, equality and wholeness of man as a unique, dynamic, bio-psychosocial and spiritual being who responds to life experiences. He/she is an individual, a member of a family and a community (Chinn & Kramer 2011: 55). Society or environment is a social structure of individuals and groups, whose interaction results in the transmission of values and cultural beliefs that impact on behaviours and perceptions that have implications on health. It could be said then, that society and culture are critical interacting concepts that shape an individual (Chinn & Kramer 2011: 56).

It is the researcher's belief that women living with HIV and AIDS should be treated with dignity and respect, just as all human beings and that they should live in a society that is free of abuse. It is therefore, the responsibility of the people that practise the discipline of nursing to support women who experience abuse. Promoting health is the goal of nursing actions and it exists independently of illness or disease. It is a dynamic process that changes with time and varies with life circumstances and experiences (Chinn & Kramer 2011: 55). Health is considered to be holistic, addressing the physical, mental and social status of individuals according to the level of wellness or illness experienced (Leech & Van Wyk 2011: 5). Optimum health of an individual is determined by the ability to cope with stressful situations in the internal and external environment. Abuse and living with HIV are both stressful situations that can compromise a person's health status.

2.3 QUALITATIVE RESEARCH

Qualitative research, or the naturalistic paradigm, uses the participants' language in order to clearly understand their world (Holloway & Wheeler 2010: 3). It is conducted when the researcher is interested in understanding and describing how individuals or groups perceive social phenomena. Thus, it is used to explore what lies at the core of the people's lives by exploring their behaviour, experiences and feelings. The foundation of qualitative research lies in the description of lived experience as it relates to human beings (Polit & Beck 2012: 14).

The emergent design of qualitative research is flexible and evolves throughout the research process (Creswell 2009: 175). The theoretical framework is not predetermined, but derived from the data. The focus is on the emic view, which seeks the perspectives and meaning of those involved in the research. This stance is valuable because it is believed that individuals are the ones who can best describe their experiences and feelings using their own words. Hence, participants are those who have experienced the phenomenon of interest and then describe it (Starks & Trinidad 2007: 1373). The relationship between the researcher and the participants is close, and the researcher is considered to be a key instrument (Creswell 2009: 175). The researcher uses reflexivity to consciously acknowledge his/her role and involvement in the research process and attempts to report the standpoint and account of the experience of those interviewed (Barkaway 2001: 191).

The researcher is immersed in the world of the participants through questioning, listening and observing. This process is possible because qualitative research is conducted in natural setting, which is an environment that is not controlled (Creswell 2009: 175). It involves thick description, presenting the individuals' accounts in a detailed and vivid manner (Polit & Beck 2008: 69). Burns and Grove (2007: 62) indicate that a qualitative research design is a systematic, subjective approach that yields in-depth information from the participants (Polit & Beck 2008: 17). This research design was suitable for phase 1 of examining the topic under investigation, as the researcher being a key instrument in the data collection, obtained a holistic and comprehensive account through, a qualitative inquiry, with participants expressing themselves in describing their experiences of abuse to the researcher to gain understanding.

2.4 PHENOMENOLOGY: A SUB-DISCIPLINE OF PHILOSOPHY APPLIED TO RESEARCH

Historically, phenomenology can be traced to the preparatory phase of Franz Brentano and Carl Stumpf, the German phase of Husserl and Heidegger, and the French phase of Gabriel Marcel, Maurice Merleau-Ponty and Jean-Paul Sartre. Similarly, Hans-George Gadamer (1900-2002) investigated human interpretation. Edmund Husserl (1859-1938), a German philosopher and

mathematician, is the founder of phenomenology (Honderich 1999: 211). Phenomenology is considered a sub-discipline of philosophy (Smith & Smith 1995: 9). It was defined by Husserl as “the study of the essence of conscious experience and especially of intentional experience” (Smith & Smith 1995: 9). The term ‘phenomenology’ is reported to have also been used by the philosopher, Emmanuel Kant. Kant, just like Descartes, provides the closest approach to a correct method of rigorous science: that we can only have direct knowledge of a phenomenal world of things as they appear to us and cannot know with certainty the nature of things as they are in themselves (West 2004: 89).

However, Husserl was not satisfied with Kant’s epistemological premise, whose subject of experience is still an abstract and unknowable ‘unity of apperception’. Instead, Husserl, throughout his philosophical career, investigated the relationship between the subjectivity of knowing and the objectivity of the content known (West 2004: 89). He presented phenomenology as a “rigorous science committed to knowledge that is fully justified” (Zahavi 2003: 44). “It is the attempt to describe our experience directly, as it is, separated from its origins and development independently of the causal explanations...” (The Penguin Dictionary of Philosophy 2005: 464).

Husserl believed that knowledge came from experience that was properly understood and that it was through consciousness that man was able to access the world (Solomon & Higgins 1996: 249). He considered philosophy as a “singular rigorous science, and was dedicated to the development of phenomenology as a method that would find and guarantee truth” (Solomon & Higgins 1996: 251; Zahavi 2003: 44). Husserl provided an alternative view to that of positivism and the scientific objective view, which stated that the only valid knowledge was from scientific inquiry and the affirmation of theories formulated using scientific method (Cogswell 2008: 85).

Phenomenon is a Greek word which means ‘appearance’ or ‘that which shows itself’ (Solomon & Higgins 1996: 251), in light of this it could be concluded that phenomenology should be about a faithful description of that which appears (Zahavi 2003: 14). Husserl, cited in Solomon and Higgins (1996: 251), defined

phenomenology as “the scientific study of the essential structures of consciousness”. It is the study of phenomena as they appear in experience that is conscious (Smith & Smith 1995: 9). Thus, it is the description of consciousness and its structural analysis as it is experienced (Zahavi 2003: 44). According to Smith and Smith (1995: 10), Husserl stressed consciousness as being ‘pure mental activity that is rational’. In other words, consciousness is the source of certain or reliable knowledge (West 2004: 89).

According to Cogswell (2008: 85), knowledge of objective phenomena is based on subjective experience and it is the subjective experience that is an important source and regarded as the most reliable ultimately. It is through phenomenology that consciousness is considered intentional, thus “consciousness is consciousness of something, and it is directed towards an object” (Smith & Smith 1995: 11). Consciousness and experience mirror each other, as consciousness travels towards bodily experiences and bodily experiences in turn are reflected back to consciousness. According to West (2004: 92), it is through phenomenological activity that we can distinguish that which is in the consciousness from what is normally assumed having a natural attitude or everyday standpoint. Phase 1 of this study concerns itself with women’s experiences of abuse, which can be better understood through phenomenology. It is not known with certainty what these experiences entail. Thus, the researcher describes the experiences as lived by the WLWHA.

Being part of the world is characterized by the natural attitude which refers to one’s everyday viewpoint of and immersion into one’s existence, from which perspective, the way things are perceived is taken for granted (Solomon & Higgins 1996: 251). This state is illustrated well by the expression “we are in the world and the world is in us” (Higgs & Smith 2006: 55). The natural attitude lacks critical reflection on our actions and response to the world around us. As such, perceptions formed in context of the natural attitude should not be taken at face value, as this is philosophically unacceptable (Zahavi 2003: 44). Research participants’ report their experiences from the perspective of a natural attitude when they describe what happened, while the researcher changes the natural attitude through a disciplinary view (nursing) to a scientific attitude, called the phenomenological attitude.

Phenomenology encourages us to explore, look and reflect on the everyday experience and to not take it for granted because human experience is a mixture of feeling, awareness and consciousness (Higgs & Smith 2006: 55). It requires of us to put aside all theories, prejudices and ideologies and to look more closely at what is actually happening in the now, which is the most real moment currently being experienced, unlike the past or future (Higgs & Smith 2006: 56). 'To the things themselves' means a return to the sources themselves, but the state of going back to the things, as such, cannot be achieved in our naive natural attitude. It requires bracketing and eidetic reduction. The latter refers to an active and planned process (research) during which rigour is ensured to provide trustworthy findings (Cogswell 2008: 86). Similarly, before the study, the researcher assumed a naive and natural attitude, which lacked critical reflection towards WLWHA and their experiences of abuse. During the execution of the research process the researcher had to step back and allow the phenomenon of abuse of WLWHA to reveal itself through the women's descriptions. Through phenomenology an attempt is made to penetrate illusion, so that reality underlying the illusion is uncovered (Higgs & Smith 2006: 55).

2.4.1 Bracketing

Bracketing (also called phenomenological reduction) is a practice in which one suspends the judgment of whether one's interpretation of experience is true (Cogswell 2008: 86). Husserl calls for casting aside all the systems and preconceptions that perceptions filter through and looking directly at the phenomena themselves, the concrete and actual data of experience (Cogswell 2008: 86). In examining consciousness as it appears, or as pure phenomena, all assumptions about the existence of physical objects in the world, to which thoughts normally take to, should be rigorously avoided (West 2004: 92). Through bracketing, basic rules are understood, whereby consciousness knows the world (Solomon & Higgins 1996: 251). In other words, bracketing is achieved using phenomenological reduction, through which, aspects of experience are removed from consideration (Solomon & Higgins 1996: 251).

On a regular basis, the researcher is in contact with issues of abuse of WLWHA through the media, literature and in the line of duty. It is necessary not to let

this prior knowledge influence a new understanding of abuse in terms of WLWHA. The women themselves had to shape the direction of the study. This stance was achieved through bracketing the researcher's own preconceptions about WLWHA as a group of vulnerable women. In phenomenological studies, bracketing allows the researcher to examine his/her own prejudices in order to allow the inclusion of the views of the participants (Dowling 2005: 136). These preconceived ideas have been formulated by reading about the issues of abuse and WLWHA. This notwithstanding, the women's descriptions of their experiences are the basis for the outcome of the study.

Phenomenological reduction means 'bracketing' of the natural attitude and suspending all assumptions about causality that exist in the natural, scientific and common sense explanations of the world (Honderich 1999: 214). Therefore, the phenomenological reduction, or epoche, espoused by Husserl, leads to the abandonment of the natural attitude (which takes the world for granted), in order to attain a transcendental attitude of consciousness, as given from the inside (Zahavi 2003: 45). Epoche is the term for the abrupt suspension of a naïve metaphysical attitude, entailing a change of attitude towards reality and not the exclusion of reality (Zahavi 2003: 46). Epoche is not effected to "deny, doubt, neglect, abandon or exclude reality" (Zahavi 2003: 90). Husserl used the term epoche to indicate the suspension or bracketing of 'all questions of truth or reality' in order to describe the contents of consciousness. It must be stated that bracketing is not an easy exercise, considering that our everyday understanding of issues is informed by our own and other people's experiences, which is embedded within the natural attitude. When an object is perceived, it does not appear in its totality, but is always transcended from the limited perspective that it is given (Zahavi 2008: 16).

2.4.2 Eidetic reduction

Eidetic reduction refers to an approach to the world in a way that concentrates on the essential components of phenomenon. It is a kind of conceptual analysis where the object is imagined being different from how it is currently, also referred to as 'imaginative variation' (Zahavi 2008: 39). Eidetic reduction is achieved by eliminating contents of consciousness that are empirical, to focus on

features that are essential: the meanings of consciousness (Solomon & Higgins 1996: 252; Smith & Smith 1995: 10). The eidetic reduction leads from particulars to general essences (Hintikka 1995: 79). In this study, the process of data analysis unfolds the particulars and the general essences that are revealed through the comprehensive description of the women's experiences of abuse.

2.4.3 Intuition

An important consideration in phenomenology is the concept of essence, or what makes an object a specific object. These are structures or essential properties that make the object into what it is (Zahavi: 2003: 39), for example, what makes a table a table. In the same manner, mental phenomena do not have an existence but an essence, which cannot be observed. The essence can be intuited or grasped and described. Consciousness can be intuited and the analysis of consciousness is the method of phenomenology (Smith & Smith 1995: 9). Husserl referred to going to "the things themselves". This is to be understood as the things of consciousness or phenomena, or our conscious ideas of things and not natural objects (Solomon & Higgins 1996: 251). Similarly, the phenomenon of abuse has an essence that can be intuited. Having no direct access to the emotional and mental life of others, the researcher relies on the women's descriptions of abuse to identify its essence for WLWHA. Therefore, although being excluded from other people's private experience, there is the possibility of understanding that experience.

According to Husserl, as cited by Solomon and Higgins (1996:252), 'the things perceived by consciousness are not merely objects of consciousness but the 'things themselves'. Furthermore, that one object or another is directed at by acts of consciousness. According to Solomon and Higgins (1996:251), a key principle of Husserlian phenomenology is that, "consciousness is intentional, that one can describe the nature of the intentional acts of consciousness and the intentional objects of consciousness which are defined through the content of consciousness". Thus, the contents of consciousness and not the things of the natural world, is the interest of phenomenology (Solomon and Higgins 1996: 251). The state of consciousness directs the mind towards objects which are physical or abstract as long as they can be reflected upon (Rapport & Wainwright

2006: 229). Phenomenology as a philosophy lacks specific articulated methods for its application in phenomenological research (Caelli 2001: 276). Therefore, in conducting research based on phenomenology, the philosophical principles are applied in a scientific manner, thereby differentiating between phenomenological philosophy and scientific phenomenology (Giorgi 1997: 4).

2.5 PHENOMENOLOGY: RESEARCH METHODOLOGICAL ASSUMPTIONS

Streubert Speziale and Rinaldi Carpenter (2007: 75) state that: "...phenomenological approach is a rigorous, critical and systematic method of investigation applicable to the study of phenomena important to the discipline of nursing because professional nursing is enmeshed in people's life experiences". It refers to those lived experiences belonging to a person (Giorgi 1997: 236). Experience refers to the relationship one has with the world (Dahlberg *et al.* 2008: 32).

The goal of phenomenological research is to describe lived experience (Streubert Speziale & Rinaldi Carpenter 2007: 7; Polit & Beck 2008: 227). Similarly, Lobiondo-Wood and Haber (2006: 154) describe a phenomenological method as a process of constructing meaning out of human experience. It is a process through which the lifeworld is clarified and not taken for granted (Todres & Wheeler 2001: 3). Essentially a first person experience, phenomenology can be applied to studying the experiences of other people (Barkaway 2001: 192). This process is done through intensive dialogue with the people living the experience, which has meaning for them.

It should be noted that there are major differences in the application of phenomenology between those who follow Husserlian or Heideggerian tradition in nursing research and even those who claim to follow Husserl (Paley 1997: 187). These differences include description versus interpretation, if and when bracketing should be applied as well as data analysis methods. However, phenomenological research is about fully understanding the lived experience. It is lived experience that presents truth and reality in an individual's life (Streubert Speziale & Rinaldi Carpenter 2007: 77). In this study, it was important to capture the women's own experiences of abuse in order to give a

comprehensive understanding. The researcher provides an objective description of situations which were subjectively experienced (Giorgi 2000: 14). Phenomenology “offers a way to engage in dialogue with others and to extract contextual and nuanced descriptions of their emotions” (Thomas 2005: 65). This is a descriptive phenomenological study where first-person experiences of WLWHA are described by the researcher.

As stated earlier, being part of the world is characterized by the natural attitude, which refers to one’s everyday immersion into one’s existence, where the way things are perceived is taken for granted, (Dahlberg *et al.* 2008: 98). The natural attitude lacks critical reflection on our actions and response to the world around and is not suitable as a framework for research. This natural attitude requires bracketing (epoche) in order to set aside anything that is taken for granted (Crotty 1996: 151). Bracketing as the suspension of all assumptions about existence and causality, means identifying and putting aside any preconceived ideas or biases related to the topic of study (Polit & Beck 2008: 228; Chamberlain 2009: 52).

Bracketing can be problematic if deliberate attempts are not made to cast away understanding, because the natural attitude draws on presuppositions (McNamara 2005: 703). Phenomenological reduction allows the suspension of the researcher’s ‘interpretations and meanings in order to enter into the world of a unique person who was interviewed’ (Giorgi 2006: 309). In contrast to the natural attitude, the scientific attitude is described as a phenomenological attitude of openness (Dahlberg *et al.* 2008: 97). In order for the phenomena to show themselves, lifeworld research demands openness from the researcher. Openness or sensitivity to the things, means seeing the world in a new way by making oneself available to the world to see phenomena in that new way (Dahlberg *et al.* 2008: 97). In the study, the researcher used sensitivity and openness with WLWHA to allow them to express themselves on the subject of their experiences of abuse, so that the phenomenon of abuse could reveal itself.

The open attitude is considered to be a criterion for objectivity, as it is marked by a discovering attitude and willingness to see, listen, and understand with sensitivity and respect, allowing the phenomenon to reveal itself (Dahlberg *et al.*

2008: 97). Openness promotes trust and a level of nearness that facilitate participants' self-disclosure. This nearness is referred to as intersubjective openness between the researcher and the participants (Dahlberg *et al.* 2008: 97). While remaining open and immersed in the phenomenon, the researcher must maintain a reflective distance, thus moving back and forth between immediacy and distance (Dahlberg *et al.* 2008: 103). This approach leads to openness to meanings and essences, which allows a deeper level of understanding evolving from the researcher, and the participants of the phenomenon.

The essence of mental phenomena or 'eidos' in Greek, can be grasped and adequately determined (Dahlberg *et al.* 2008: 103). Mental phenomena have no existence but only an essence or core, which can be intuited if not observed. Intuition grasps the essence as essential; it therefore allows the researcher to know more concerning the described phenomena from participants. This process occurs by being open to what the data could mean according to the participants (Streubert Speziale & Rinaldi Carpenter 2007:79; Polit & Beck 2008: 228).

Identifying a phenomenon's essence is based on the data obtained. The researcher needs to be immersed in the data to attain the full engagement required in the analytic process to ensure an accurate description (Streubert Speziale & Rinaldi Carpenter 2007: 86). The researcher engaged openness during the interaction with the study participants and the data analysis process in order to distinguish the essence of abuse from the women's descriptions of their experiences. A study that is espoused to phenomenology should describe the methodological keywords, the investigated phenomena and how an open attitude was maintained throughout the study (Norlyk & Harder 2010: 429).

Dahlberg *et al.* (2008: 96) state that a more rigorous understanding of the lifeworld is not made available to us; therefore, genuine philosophy must supply that rigorous understanding, thereby bridging the gulf between science and lifeworld. Husserl argued that to understand phenomena, one must go "to the things themselves" which means doing justice to the lived experience (Dahlberg *et al.* 2008: 180). The researcher should be in such a situation, so that the

things would reveal themselves. Similarly, in this study, the essence of abuse had to reveal itself through comprehensive description.

In order to understand experience, one needs to be part of the world, which is the intrinsic relatedness of one to another: 'to be' or sociality. By being in the world, humans relate and interact with the world, perceiving, understanding and being aware of it. Humans have access to the world through their bodies. Knowledge of the world is therefore said to be embodied, whereas our connectedness as humans is to the lifeworld, or 'flesh' (Dahlberg *et al.* 2008: 95). The lifeworld is made meaningful through intersubjectivity, which provides a dimension of the total horizon for one's understanding. Thus, in communicating with others, we form a common understanding of the world (Dahlberg *et al.* 2008: 95). From women's descriptions of abuse, a common understanding of the phenomenon is revealed through bridling.

2.5.1 An approach of bridling

Bridling refers to having an attitude of attention, an open and alert attitude of actively waiting for the phenomenon to show itself (Dahlberg *et al.* 2008: 130). It is a term that these authors borrowed upon having realized that 'bracketing was somewhat over-used' (Dahlberg *et al.* 2008: 130). The term was originally used to describe an art of horse riding where there is a disciplined, sensitive interaction and communication between the horse rider and the horse. Thus, the term bridling encompasses bracketing. Bridling allows the researcher to avoid making 'definite what is indefinite', as experience does have a certain definiteness in addition to the appresented, which is indefinite (Dahlberg & Dahlberg 2000: 37). Therefore, lifeworld researchers use bridling in order to understand a phenomenon and to describe its meaning by questioning the presupposed assumptions embedded within the natural attitude, where one assumes that what one sees is the way it is (Dahlberg *et al.* 2008: 132).

Considering that it may not be possible to bracket all pre-understanding of the lifeworld, it becomes possible to bridle the event of understanding not to happen without one's awareness. By using reflection and openness, the lifeworld of experience presents itself, in its complexity, for the researcher to see what may

be well known in a new light and the invisible aspects become visible (Dahlberg *et al.* 2008: 132). In other words, openness is explained by the bridling approach. Through the process of bridling, the researcher was able to allow the women's description of their experiences to evolve into a common understanding.

2.6 THEORETICAL ASSUMPTIONS

In keeping with a phenomenological investigation, the researcher approached the field without any preconceived framework. The literature control was conducted after the description of the essence of the experiences of abuse among women living with HIV and AIDS and the constituents that substantiate the essence.

2.7 METHODOLOGY OF THE RESEARCH

Qualitative research was used in this study. In this qualitative inquiry, the researcher used the phenomenological research approach for phase 1 of the study, in order to allow the participants to communicate their experiences of abuse to provide a comprehensive description of the women's experiences (Polit & Beck 2008: 227). WLWHA were interviewed to describe their experiences of abuse. The interviews were audiotaped with the permission of the participants, transcribed verbatim and analysed using the process described in Dahlberg *et al.* (2008: 236), in combination with the method of Colaizzi 1978 (cited in Streubert Speziale & Rinaldi Carpenter 2007: 83). The researcher used bridling to ensure that preconceived ideas were kept in check throughout the research process. The following section describes the research setting, population and sample, data collection, data analysis and ethical considerations of the study in detail.

2.7.1 The research setting

Setting denotes a physical location where data collection for the study takes place (Polit & Beck 2008: 57). The study was conducted in Lilongwe district in Malawi. A brief description of Malawi and the health care delivery system is

presented to provide a context of where the study was conducted. A map of Malawi is supplied (Refer to figure 1).

Figure 2.1: Map of Malawi



Country background

Malawi is a country situated in the south eastern part of Africa and lies between 13 57.5' and 33 42'. It is within the sub-Saharan region. It has a population of about 13 million people of which 51% are women (National Statistics Office 2008: 2). It shares its borders with the United Republic of Tanzania to the north and north east, the People's Republic of Mozambique to the east, south and southwest and the Republic of Zambia to the west and northwest. The country is divided into three regions namely north, central and south and it has a total of

28 districts. The districts are further subdivided into traditional authorities, each covering several villages. A village constitutes the smallest administrative unit in the country (NSO 2011: 1).

The study was conducted in both rural and urban settings in the Lilongwe district in Malawi, in order to obtain experiences of participants from different locations. Lilongwe is the capital city of Malawi where many programmes for people living with HIV and AIDS have been implemented by both government and non-governmental organizations. These programmes include HIV testing and counselling (HCT), treatment and support, including home-based care and support groups.

Like in many other African countries, women in Malawi bear the burden of HIV and AIDS more than their male counterparts. The reason for this largely remains the gender inequalities between men and women (Ministry of Women and Child Development [Malawi] 2005: 4). Women in Malawi have little access to productive resources such as income, assets and education. The lack of resources places them in an economically dependent situation, which influences their decision-making ability, to the effect that they may engage in risky behaviours such as transactional and unprotected sex (Kathewera-Banda *et al.* 2005: 649). Thus, for women, inequality in income is a major driving force behind the HIV infection (Feldacker, Ennet & Speizer 2011: 723). Consequently, unequal power relations lead to abuse of the women's human rights, through which violence is perpetuated and the risk of HIV transmission is increased.

Malawian society, to a large extent, condones gender norms that are permissive of multiple and concurrent partners for men (Ministry of Women and Child Development [Malawi]: 2005: 4). These norms are rooted in a culture of gender inequality that results in exploitation of women by tolerating and perpetuating gender-based violence (Ministry of Women and Child Development [Malawi]: 2005: 4). Low education of girls is the effect of gender barriers that impact negatively on the women, such as early marriages and pregnancy. The Malawi Demographic and Health Survey (MDHS) indicates that low education is a risk factor for gender-based violence, so is ever having been married, considering

that the most common perpetrators of violence reported by women, are their partners (NSO 2011: 240).

Malawi is a low income country characterised by a heavy burden of communicable, parasitic diseases and high levels of child and adult mortality, with non-communicable diseases on the increase (Zere *et al.* 2007: 3). The recent health indicators in Malawi show some improvements, though they still remain among the poorest in sub-Saharan Africa, with low life expectancy (44) and an adult HIV prevalence rate of 11%. The key indicators are summarised in table 2.1.

Indicator	Value
Life expectancy at birth	44 years
Total fertility rate	5.7 children per woman
Contraceptive prevalence	46%
Infant mortality rate	66 per 1,000 live birth
Under-five mortality rate	112 per 1,000 live birth
Maternal mortality ratio	675 per 100,000 live births
HIV prevalence rate	11% adults 15 - 49 years old (8% men 15 - 49 years old) (13% women 15 - 49 years old)

Table 2.1 Malawi health indicators

Source: (NSO 2011; WHO 2011).

Health care delivery system

The health care delivery system is organised around Primary Health Care (PHC), which the Government of Malawi has endorsed as the main health service delivery strategy. PHC aims to improve the health status of the population by focusing on essential health care that is cost-effective and accessible to the general population as a human right, through intersectorial collaboration and community participation (Muller 2009: 88). Primary health care reduces social disparities by ensuring that there is universal access to basic services for all on the basis of need (Setswe, Naude & Zungu 2011: 6).

There are three agencies that provide most of the formal health services in Malawi. These include the government (Malawi's Ministry of Health and Population and Ministry of Local Government) - approximately 50%; Christian Health Association of Malawi (CHAM) - about 40%; and private for profit practitioners and companies - 10% (Department for International Development 2008: 4). Services provided by the Ministry of Health are free to the user while those of CHAM and private practitioners are charged for. However, the Government of Malawi has a service agreement with the CHAM hospitals, which provide some services to the general population for free, on the understanding that the government reimburses the costs incurred. The services that qualify for reimbursement address maternal health, child health, tuberculosis and antiretroviral treatment (Department for International Development 2008: 12).

Eighty per cent of the population is estimated to live within eight kilometres of a health facility, although not all services are available at every facility. Provision of health services is divided into three levels: primary, secondary and tertiary. Interventions at the primary level focus on preventive and basic curative services for common and uncomplicated conditions, such as Malaria, through clinics and health centres. At the secondary level are district hospitals, community hospitals and some of the CHAM hospitals, which provide a range of preventive, curative and rehabilitative services. These also act as back-up, receiving referrals from the primary level facilities. Tertiary level hospitals provide services similar to district hospitals, including a range of specialist interventions and receive referrals from the secondary level. These are provided through central hospitals and a few private hospitals. Medical insurance is not available to all persons in the country. There are some people, albeit very few, who are mostly employed by companies, who benefit from membership to medical aid schemes (WHO 2011: 1; Ministry of Health [Malawi] 2005: 1; Department for International Development 2008: 4).

In Malawi, like most sub-Saharan African countries, there is a critical shortage of health workers, particularly doctors and nurses. The doctor/patient ratio is 1: 100,000 population while that of nurses is 34: 100,000 (Department for International Development 2008: 12). The bulk of health care services are provided by nurses, clinical officers, medical assistants and health surveillance

assistants. Clinical officers are a cadre of health workers that was trained to deal with the shortage of medical doctors. They undergo four years' training and provide needed health care to the population, including the carrying out of diagnostic and clinical interventions that are medical, surgical and obstetrical in nature, in the place of medical doctors (Mullan & Frehywot 2007: 2158). The medical assistants undergo two years' training and man most of the health centres that are located in the rural areas. Health surveillance assistants are community health workers who undergo ten weeks' training and provide mostly preventive services, including health education, growth monitoring, immunizations, hygiene and sanitation in the community. However, following the expanded task-shifting that has occurred in the country due to shortage of qualified personnel, this cadre has been trained to provide TB microscopy, TB treatment, and HTC services, among their other services (Philips, Zachariah & Venis 2008: 682). The district health officer, usually a medical doctor, is responsible for the overall administration of all the health facilities in a district. It should be noted that the services provided by the government, CHAM and private institutions may overlap, depending on the size of the facility and the health personnel available. Nurses form the backbone of the health care services in Malawi.

The Malawi government has scaled up HIV and AIDS services to improve access to its people. Government, CHAM and private hospitals and clinics provide such services. The majority of the people have access to HIV counselling and testing (HCT) services as well as treatment through public institutions, as these are provided free of charge to the patient, with support from Global Fund (WHO & MOHP 2005: 15). The HCT services are offered daily during weekdays while antiretroviral clinics are conducted on a weekly basis. However, in order to attend to illnesses and other emergencies, the clinics are open daily.

The contact persons at these clinics are mainly nurses, clinical officers, medical assistants and health surveillance assistants. After testing positive for HIV, individuals are encouraged to join support groups in their communities. Such organizations include the National Association for People Living with HIV and AIDS in Malawi (NAPHAM), which is open to everyone living with HIV. Its mission is to promote and advocate quality care, support and prevention services in

order to enhance positive living and to reduce HIV transmission for all people infected and affected by the pandemic in Malawi (NAPHAM 2011: 1).

In order to gain access to the setting, the researcher sought permission through the Lilongwe District Health Officer to collect data at two clinics, one rural and one urban, which were used for recruiting participants for the study.

2.7.2 Population and Sample

Gravetter and Forzano (2009: 128) noted that a population is the large group that a researcher is interested in. According to Burns and Grove (2009: 42), the researcher determines a study population based on eligibility and accessibility of the aggregate that meets specified criteria. Similarly, de Vos *et al.* (2010: 193) state that population 'sets the boundaries on the study units'. The population in this study was women living in the Lilongwe district, who were living with HIV and AIDS and who have experienced, or were experiencing abuse. This is the group that was able to provide the information sought by the study.

Sample refers to a part of the population which is selected to participate in a study (Polit & Beck 2008: 339). It is a subset of the population for study (Macnee & McCabe 2008: 116). The process of selecting that portion of a population is called sampling (Brink 2009: 124). Sampling is necessary as it is not always feasible to deal with a whole population in most research studies (de Vos *et al.* 2010: 194). This study utilized purposive sampling, a method that is used to select participants on the basis that they will be the most informative, by virtue of their personal knowledge of a subject (Streubert Speziale & Rinaldi Carpenter 2007: 94).

Women attending the child and adult HIV clinics, who were experiencing or had experienced any form of abuse, were invited to participate in the study. From among the women who volunteered to participate in the study, purposive sampling allowed the selection of women who would provide information based on personal knowledge of HIV and AIDS and abuse. A sample size of 12 participants was adequate for this study to provide in-depth information on abuse from their own personal experiences. This sample size was sufficient as

the purpose of the study was not to generalize the findings to apply to the whole population. The goal was to describe the participants' experiences of abuse from the perspective of women living with HIV and AIDS.

Recruitment process

After obtaining written permission from the District Health Officer (See Annexure B) the researcher presented the letter to the person in charge of the health facility and asked permission and assistance to meet with the persons who were working directly with women living with HIV and AIDS. The person in charge of the health facility introduced the researcher to the nurses responsible for conducting the child HIV clinic and those responsible for the adult HIV clinic at the health facility where most women living with HIV and their children come for services. Access to the study participants was obtained through the nurses and those in charge of the clinics at the health facilities mentioned above.

The staff concerned approached the potential participants who were in attendance on that particular day and asked the women, individually and in private, whether they had encountered any form of abuse from partners, family, friends and other members of the community since their HIV or AIDS status had been made known. Those who indicated that they had experienced abuse were informed of the study and those who showed interest and willingness to participate in the study were referred to the researcher. The researcher then gave a detailed description of the study to each of the women, in order for them to make an informed decision as to whether or not to participate in the study. This was done to obtain informed consent from the participants (See participant information leaflet: Annexure C).

Inclusion criteria

The inclusion criteria were: women aged 18 years and older, who had been in a relationship (current or past), who had been known to be living with HIV and AIDS for at least one year. The participating women were those who reported to have encountered any form of abuse, at the same time as being known to be HIV-positive and who were willing to describe their experiences to the

researcher. Women who were sick and those who had difficulties communicating were excluded from the study.

2.7.3 Pre-testing

Two women were interviewed as part of pre-testing. These women were recruited from a different service provider and were not included in the sample. The purpose of conducting the pre-test was to get a feel of what could be expected during the interviews and whether it would be necessary to vary the approach of interviewing (de Vos *et al.* 2010: 294). The question that was asked to the participants was the same, however, the technique for obtaining information varied from participant to participant. This variation was due to the fact that some participants in the main study needed more probing to give information than others, who told their stories more readily.

2.7.4 Data collection

Data collection is the process of obtaining information from participants in order to answer the research question (Burns & Grove 2007: 536). Interviews were conducted at the health facility, which was the venue preferred by the participants. The researcher conducted the interviews in a separate and private room at the clinic. The participants were assured that other people would not hear the conversation that would take place and that their names would not be mentioned or recorded anywhere. All information obtained would be private and confidential. Data was collected over a period of one month. The interviews were audiotaped to capture data in its entirety, with permission from the participants. Conducting the interviews took an average of 45 minutes per interview.

Data was collected using unstructured interviews conducted in the local language, Chichewa. Unstructured interviews do not have a predetermined plan regarding the flow and content of the information to be gathered from participants (Polit & Beck 2008: 769). The participants were encouraged to describe their experiences fully without it being a question-and-answer session (See Annexure G). The individual interviews were conducted one on one, assisting the development of rapport with the participants, in order for them to

be at ease during the interview. This allowed for open communication to take place. The participants were invited to share their experience:

"Tell me about your experiences as a woman living with HIV and AIDS who has been exposed to abuse".

This statement was an open, general invitation before the specific issues of abuse were explored. The formulation of the invitation statement was arrived at following consultations with the research supervisors. It was agreed that one statement was sufficient as a prompt to enable the women to freely describe their experiences, without being given suggestions of what was expected to be included in their experiences.

Issues such as nature and circumstances or context of abuse, actions taken following instances of abuse, support availability and effects related to the abuse were discussed. Probes were used when participants' responses lacked detail or clarity (de Vos *et al.* 2010: 293), as and when necessary. Probing was directed at the feelings, beliefs and experiences of the participants in order to gain understanding from their personal point of view (Groenewald 2004: 12). The probes used included statements such as: 'tell me more about that', 'tell me anything else that happened', and 'how did you feel about that?' In addition, paraphrasing was used as an interviewing technique. This involved re-stating a participant's response in a different form to confirm the meaning of a statement and to clarify unclear statements (de Vos *et al.* 2010: 289).

Notes were taken during and soon after the interview as a back-up. Through the in-depth interviews, participants provided detailed descriptions of their experiences. All participants were offered the opportunity for counselling by a psychiatric nurse at the health facility. The researcher left details of the nurse in case the participants would need it. None of the 12 participants seemed to have been affected by talking about their experiences of abuse and they did not access the counselling services during the course of the data collection period.

2.7.5 Data analysis

The information obtained in the study was systematically organized and synthesized through a process of data analysis (Polit & Beck 2006: 498). The data analysis was guided by the processes described by Collaizi (cited in Streubert Speziale & Rinaldi Carpenter 2007: 83; Holloway & Wheeler 2010: 223), and those described by Dahlberg *et al.* (2008: 234). The recorded interviews were transcribed verbatim by the researcher. The transcriptions included non-verbal information, as observed by the researcher and reported in the field notes. The transcripts were read while listening to the tapes to ensure accuracy. The transcribed data were then translated into English (See Annexure H). A peer conversant and fluent in both Chichewa and English was consulted to ensure consistency and that there would be no loss of meaning in translation.

The process of data analysis was characterised by the movement of the researcher, from the whole to the parts and from the parts to the whole, to find meaning. It was aimed at understanding each part in the context of the whole and the whole in terms of the parts. The researcher used the bridling approach, whereby one reflects upon the data with an open mind and does not make definite what is not definite. The process entails staying close to the original data in order to be as authentic as possible (Dahlberg *et al.* 2008: 236). Working with the supervisor and co-supervisor to code the transcripts assisted in ensuring credibility of the analysis process (Polit & Beck 2008: 547; Streubert Speziale & Rinaldi Carpenter 2007: 388). The following was done during the analysis process:

Description of the phenomenon from all the participants was read

Firstly, the researcher perused all the transcripts repeatedly. This gave the researcher a general impression of the content of the data. Thus, the reading and re-reading of the transcripts provided a sense of the concepts emanating from the participants' descriptions. According to Dahlberg *et al.* (2008: 238), reading and re-reading the text allows the researcher to become familiar with the data and to get a sense of the whole.

Significant statements from the transcripts were extracted

Secondly, the researcher examined each transcript line by line, sentence by sentence, and pinpointed phrases and sentences that were directly related to the phenomenon. The focus was to identify the statements that described the women's experiences. The actual words used by the participants were isolated. According to Dahlberg *et al.* (2008: 239) this is the beginning of deconstructing and organising the data into parts or smaller units, in respect of the meanings that are identified.

Contents of each significant statement were clarified to identify meanings

In this step, the researcher processed the phrases and statements obtained in step ii. The researcher identified the meanings of the phrases and statements through description of what was understood, rather than interpretation.

The identified meanings were grouped together to identify connections and relationships

This was achieved by putting together meanings that were similar or those that seemed to belong together. These are referred to as clusters of meanings (Dahlberg *et al.* 2008: 244). The clusters provide a pattern, or structure, that helps in describing the phenomenon of interest.

All the clusters of meaning were given a description, which identified all the meanings as one new whole: the essence, linking all of them together

The essence of the phenomenon and its constituents were described. Quotations from the participants were used to support the description of the constituents.

Validation of the description was done by returning to the participants for verification

The researcher went back to the participants with the exhaustive description. However, due to logistical reasons, only three of the twelve participants could be interviewed. The participants were able to say whether the exhaustive description represented their experiences. The researcher did not check the

natural attitude with the participants but rather confirmed the phenomenological attitude.

If new data were to have been uncovered during the validation, these would have been incorporated into the exhaustive description

No new data was uncovered from the three participants at that stage.

(See Annexure I for a sample of the data analysis)

2.7.6 Trustworthiness

Trustworthiness refers to the determination that study findings are accurate from the perspective of the researcher, the study participants and the readers of the report (Creswell 2009: 191). Rolf (2006: 305) states that “a study is trustworthy if the reader of the research report judges it to be so and that readers of the phenomenological study become the critical evaluators”. More important for a phenomenological study, the researcher is engaged in the analysis, as a faithful witness of the accounts in the data. The researcher is immersed in the data, while being honest and vigilant about his/her own preconceptions and beliefs. Streubert Speziale and Rinaldi Carpenter (2007: 98) report that trustworthiness of data is established when participants can recognise the findings of the study to be true. In contrast, Giorgi (2009: 311) argues that asking participants to be evaluators overlooks the issue that their description of events is from the perspective of a natural, everyday attitude, while that of the researcher is from a phenomenological perspective. These two perspectives are different and within phenomenological analysis no reality claims are made. Furthermore, Giorgi’s analysis solely relies on the researcher and that, from the stance of phenomenological reduction, no external judges are required.

In this study, the following additional criteria, as identified by Lincoln and Guba (1985: 219), were observed to ensure trustworthiness and rigour: confirmability, credibility, transferability and dependability. In addition, authenticity is discussed as a means of ensuring rigour. It should be noted that strategies used to achieve each criterion may overlap (Polit & Beck 2009: 544).

Confirmability

Confirmability relates to whether findings are representative of the participants' information (Polit & Beck 2008: 539). In this study, the researcher returned to some of the participants with a description of the analysis for verification and validation. This is referred to as 'member checking' by Creswell (2009:191). Although the description presented by the researcher is from a phenomenological attitude, participants can still recognize the description of their experience that was given from the perspective of their everyday attitude. The participants agreed that the findings were representative of their experiences. In addition, an audit trail was established so that readers of the report are able to follow all the decisions made. The audit trail was maintained through the tapes, transcripts and the data analysis procedures (Polit & Beck 2008: 544). Refer to Annexure H and I for samples of a transcripts and data analysis process, used in this study, respectively.

Credibility

Credibility, the confidence that one has in the truth of research findings, is another criterion for establishing trustworthiness (Polit & Beck 2008: 539). Credibility was established through the collection of sufficient data obtained through the in-depth interviews. In the verbal data, the researcher sought a detailed and concrete description of the experiences of the participants as a faithful presentation of what was experienced. Member checking and the use of direct quotations from participants have been used to promote credibility (Ronnevig, Vandvik & Bergborn 2009: 1678). Keeping field notes further enhanced credibility. The field notes contain the researcher's observations and summaries of the interviews (Wall *et al.* 2010: 23; Groenewald 2004: 13).

Transferability

Transferability is the degree to which the findings can be applied to other settings (Polit & Beck 2008: 539). Through a detailed and thick, description of the phenomena, consistent with data collected, readers can determine whether the findings are applicable in the settings familiar to them. Therefore, every

reader of a phenomenological study, is a critical evaluator of the researcher's intuition (Beck, 1994: 258).

Dependability

Dependability, another criterion for trustworthiness, refers to whether the data would be reproduced if a similar study was replicated (Polit & Beck 2008: 539). This was achieved by maintaining consistency throughout the research process. According to Holloway and Wheeler (2010: 298) dependable findings of a study are those that are consistent and accurate. The researcher conducted peer debriefing sessions with an objective member, regarding the data collection and analysis process, in order to maintain objectivity and consistency. Consulting with colleagues and mentors is a reflexive practice that promotes consistency (Polit & Beck 2006: 332).

Authenticity

Authenticity is achieved when strategies used are appropriate for true representation or reporting of the participants' feelings and ideas (Polit & Beck 2008: 540). According to Holloway and Wheeler (2002: 265) the study should help in understanding and improving people's situations and be fairly conducted. This study was conducted in a fair manner by following ethical guidelines and has contributed knowledge that can be used to support women living with HIV and AIDS, who experience abuse. Data audiotaping, verbatim transcription and reading transcripts while listening to the tapes are quality enhancing strategies that were used in this study to ensure authenticity (Polit & Beck 2008: 544).

In addition to the above strategies, bracketing is an essential element that should be demonstrated throughout the research process, as it impacts on the rigor and trustworthiness of the study (Hamill & Sinclair 2010: 17). In accordance, the researcher adopted openness to the process and was self-reflective to attain bracketing, by recognizing and setting aside (without abandoning) beliefs, presuppositions and biases about women, abuse and living with HIV and AIDS. Through bridling, the researcher was conscious of the potential to influence research participants, either through the questions posed

or through the data analysis and writing the exhaustive description. The consultations done with the research supervisors assisted with examining the thought processes and evolving ideas generated from the data. Table 2.2 presents a summary of the criteria and the strategies used to ensure trustworthiness in this study.

Criteria	Strategies used in the study
Confirmability	<ul style="list-style-type: none"> • Member checking - researcher returned to some of the participants to verify the findings. • Audit trail - researcher kept the tapes, transcripts and data analysis procedure used in the study. • Bracketing and bridling was utilised by the researcher.
Credibility	<ul style="list-style-type: none"> • Sufficient data was collected through in-depth interviews • Member checking was performed. • Direct quotations from participants were used. • Field notes were kept through summaries of interviews.
Transferability	<ul style="list-style-type: none"> • A Comprehensive description of the findings of the study was compiled.
Dependability	<ul style="list-style-type: none"> • Peer debriefing was conducted with an objective member. • Consistency was maintained in data collection and analysis. • The researcher consulted with mentors.
Authenticity	<ul style="list-style-type: none"> • Data was audiotaped. • Verbatim transcription was used. • Transcripts were read while listening to the tapes.

Table 2.2: Summary of criteria to establish trustworthiness

2.7.7 Ethical considerations

Ethical considerations relate to the degree to which research procedures adhere to professional, legal and social obligations, to respect the rights and values of the participants (Creswell 2009: 198). Four basic principles that should be observed in conducting research are outlined by Holloway & Wheeler (2010: 54). They are of the opinion that respect for autonomy must be upheld. Participants must be allowed free and informed choice without being coerced. The right to

self-determination allows them the liberty to refuse to participate in research without giving a reason. Non-maleficence (do no harm) and beneficence (do good) call for the weighting of benefits to the individual and society, in light of the risks that may be involved in a particular research study (Gravetter & Forzano 2009: 105). The principle of justice requires that the research procedures are fair (Burns & Grove 2009: 188; Brink 2009: 33).

The following measures were taken in this study to adhere to ethical principles and rules: Informed consent was obtained from participants' after explaining the nature and purpose of the study (See Annexure A). This ensured that they understood what the study entailed before making a decision to participate. Participation in the study was voluntary and participants were informed that they had a right to withdraw from the study at any point or refuse to respond to or elaborate on any issues raised.

Permission to conduct the study was sought from the District Health Office (See Annexure B) and the person in charge of the health facility from which study participants were recruited. Permission to record the in-depth interviews was requested from the participants. Code numbers, instead of names were used to ensure confidentiality. By not referring to the participants by name in records and reports, confidentiality was ensured (Gravetter & Forzano 2009: 113). Pertaining to anonymity, Streubert Speziale and Rinaldi Carpenter (2007: 65) note that anonymity in qualitative studies is not possible due to the close interaction that occurs between the researcher and the participants. According to Babbie (2010: 67) anonymity can be achieved if neither the researcher nor the readers of the report can identify the responses of a particular participant, while confidentiality is when the researcher can identify the participants' responses, but promises not to publicize the identity of the person. In concordance, the researcher ensured that persons other than those directly involved in the study, would not be able to link data to the sources.

The participants were informed that there would be no direct benefits for participating in the study, but that as a result of the study, the information obtained would be important and could be used to assist other women in similar situations. Indirectly, the women might have benefitted psychologically by

having an avenue to express their experiences. There was no foreseeable harm that would occur as a result of participation. However, it was anticipated that emotional distress would be experienced, as the women would have to recall painful memories of their experiences of abuse (Holloway & Freshwater 2007: 54). It was decided that in case of such distress, the interview would be stopped and resumed only if and when the participant was ready to continue. Arrangements were made to refer those willing for counselling. Privacy was maintained throughout the interview by ensuring that others did not overhear the conversation in relation to the venue where the interview was conducted. In addition, data was kept in a lockable drawer that was accessible only to the researcher. After the research is completed the data will be stored in the Department of Nursing Science at the University of Pretoria, according to the research policy of the University. Permission to conduct the study was obtained from the Research Ethics Committee of the Faculty of Health Sciences of the University of Pretoria: IRB 0000 2235 IORG0001762 and the Research and Ethics Committee of the University of Malawi:P.01/11/1028 (See Annexure A.)

2.8 SUMMARY

This chapter has given a detailed description of the theoretical and methodological assumptions guiding the study. It has discussed phenomenology both as a philosophy and a method for conducting nursing research on human experiences. A detailed section on methodology including the design, setting, population, sample, data collection and data analysis has been described. Ethical guidelines that were followed in conducting the study have been discussed. In the following chapter a detailed description of the findings of the study, from the essence of abuse experienced by WLWHA to its constituents, can be found. Quotations from participants are given to support the constituents.

CHAPTER 3

PRESENTATION OF FINDINGS FOR PHASE ONE OF THE STUDY

3.1 INTRODUCTION

This chapter presents the findings of phase 1 of the study on guidelines for the assessment of abuse of women living with HIV and AIDS. The researcher presents the results of the phenomenological analysis, as guided by Dahlberg *et al.* (2008: 241). The essence of the experiences of abuse and the constituents that support the essence are described. As indicated in the previous chapter, the data analysis was typified by a movement from the initial whole, established by reading and re-reading the transcripts, to the parts (compiled by deconstructing and synthesizing the text into meaning units) and then to a new whole (See Annexure I for an example of the data analysis). In this section, the researcher describes the new whole, which is the essence of the phenomenon of abuse and the constituents that support the essence. The findings are described without a discussion, as is typical of a descriptive phenomenological study (Dahlberg *et al.* 2008: 273). The discussion of the constituents is presented in the next chapter.

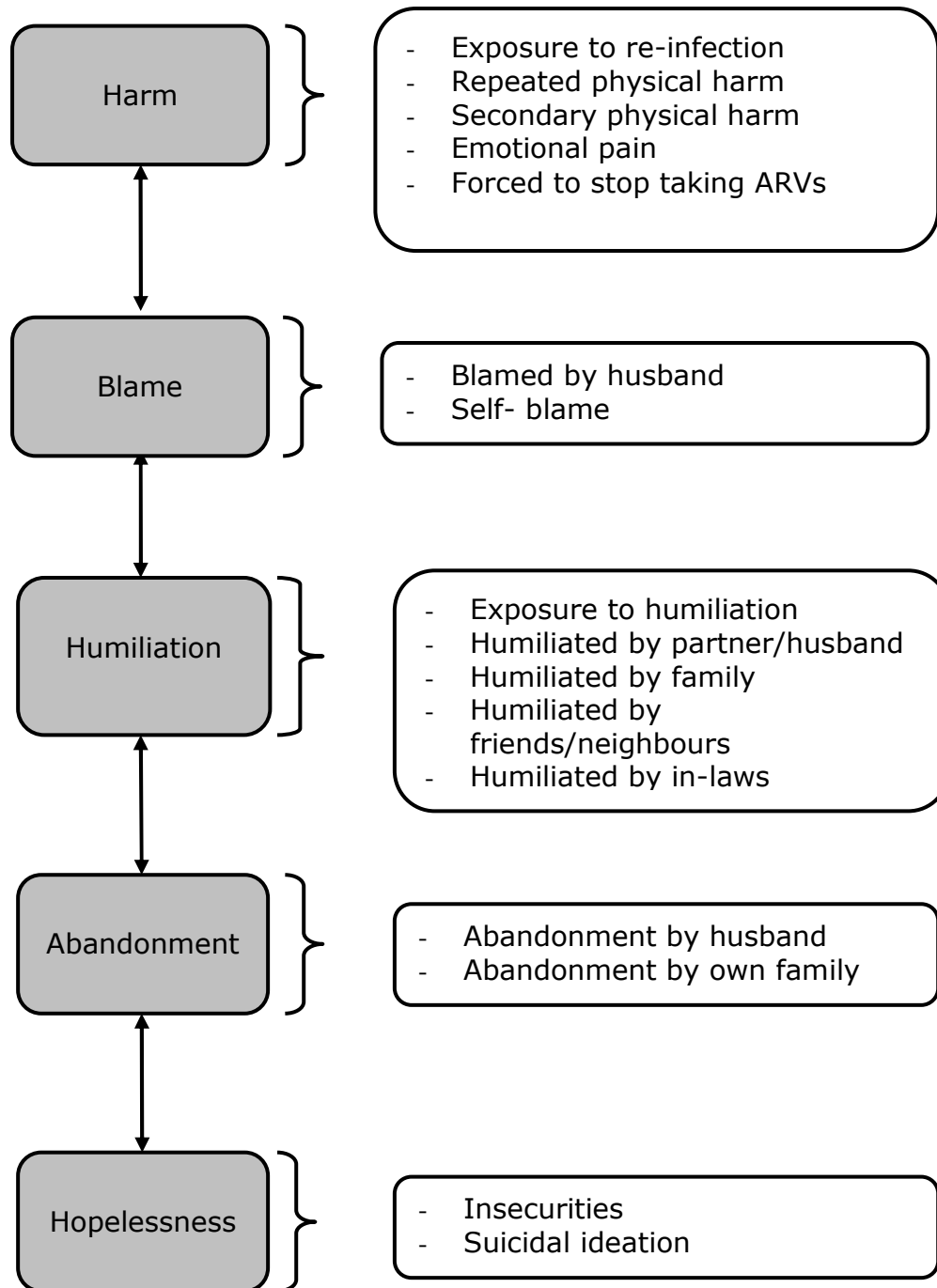
First, the essence is presented, followed by a description of the constituents. This description shows the relationship that exists between the essence and constituents (See Figure 3.1). Quotations from participants, given in italics, are used in the presentation to support the description.

3.2 DESCRIPTION OF THE ESSENCE OF THE PHENOMENON AND ITS CONSTITUENTS; THE NEW WHOLE: VIOLATING EXPERIENCES

The essence of abuse of women living with HIV and AIDS is identified as ***violating experiences***. This represents a common thread in the women's description of their experiences. The violating experiences originate from partners, family members, neighbours and friends. WLWHA expect to be treated

FIGURE 3.1

DIAGRAMMATIC PRESENTATION OF VIOLATING EXPERIENCES



case for the women in the study. They have to endure unacceptable treatment by friends, loved ones and community members. Violating experiences are degrading and disheartening. The violations are on their personhood and they feel that they have lost the inherent value of being human. Their dignity and integrity is violated by the way they are perceived, that is, as if they are less valuable compared to other people. The way they are spoken to by their family and loved ones implies that they are not respected. The way in which others in their social space react towards them indicates exclusion from friendships and supporting family relations. Their identity is tarnished and their self-worth diminished when feelings such as a loss of dignity are experienced, due to the stigma of being HIV infected. This, compounded by the violating experiences associated with abuse by family and friends, as well as community stigmatization and discrimination, is repeatedly reinforced, yielding the marginalization and disempowerment of the women and rendering them vulnerable. Their basic human rights are thus continually violated and instead of others helping them to build their sense of self-worth, they experience incidents that minimize their self-worth.

The findings from the study show that these violating experiences are evident in the interpersonal relationships that are closest to the women, such as with their spouses and family members. These interpersonal relationships are inadequate in terms of showing respect and regard for them as human beings. They feel insecure and without positive future expectations. They doubt whether they will be able to survive the infection and the violating experiences encountered because of the infection. The experiences violate self-esteem and the self-confidence needed to think about and plan for the future. Emotions such as hurt, embarrassment and no sense of belonging are common.

The violating experiences (essence) that WLWHA endure are supported by the constituents of the essence, namely: *exposure to reinfection, repeated physical harm, secondary physical harm, emotional pain, being forced to stop taking ARVs, being forced to self-blame, blamed by the husband, exposure to humiliation, humiliation by partner, humiliation by own family, humiliation by friends/neighbours, humiliation by in laws, abandonment by husband, abandonment by own family, destruction of hope of survival, being forced to*

consider suicide and being forced to feel insecure. Each of these constituents is described below. Quotations from the participants are given in italics to substantiate the constituents.

3.2.1 Exposure to reinfection

Exposure to reinfection of the WLWHA is contextually couples having unprotected sex, when the woman and the man are both HIV-positive or only the woman is HIV infected. Even when the women and the men are well informed about the importance of having safer sexual practices, to prevent secondary infection or primary infection for the non-infected partner, unprotected sex still happens. The use of male or female condoms with every sexual encounter is advocated for couples who are in sero-concordant relationships (where both partners are HIV positive), those living sero-discordantly (where only one of the partners has got the infection) and in situations when the partner's HIV status is unknown. However, the male partners are not supportive of the notion that condoms should be used at all times, which results in disagreements. As a consequence, unprotected sex becomes the acceptable practice in the relationship in order to avoid further confrontation. Even so, there is concern among the women about having unsafe sex:

"... I just observe that this is the area that he doesn't follow (protected sex). So I am a very worried person in my life because we are given instructions at the hospital but he doesn't follow them...My fears are that we are told at the hospital that we should use condoms so in our case we don't use condoms, we have plain sex."

The women are worried and afraid of the possible repercussions of having unprotected sex. Although the women are unwilling to have unprotected sex with their partners, they end up compromising (against their own beliefs about safer sex). This type of coercion could be regarded as a breach of a woman's integral right to reproductive health, safety and security. The women are aware of their rights to have sexual encounters in a manner that is safer and acceptable: *"My rights are being abused because my husband refuses to use*

condoms.” There are differences in expectation in matters of safer sex and the use of condoms between the men and the women. The women attribute this difference to men’s attitude of always wanting to do and have things the way they want it. They evidently do not want to use condoms. This kind of attitude from their partners makes them take risky actions, irrespective of the consequences of the behaviour:

“We are supposed to use condoms, but my husband is difficult. He doesn’t want to use condoms. So when I realized the truth that in the end I am going to die early, I told him that you can go ahead and marry another wife and leave me, this should not be a problem.”

Being ‘difficult’ suggests refusing to use condoms. The women are aware of the consequences of this in terms of their health. The men’s unwillingness to use condoms is viewed as being negligent or not adhering to the instructions that are given at the clinic during counselling sessions, so that the couple can safeguard each other’s wellbeing: *“I have the virus but my husband does not. At the hospital they advised us to use condoms but when I tell him he refuses.”* The women feel violated because they are forced to do what they do not want to do: have unprotected sex. They are forced to take part in unprotected sex, knowing this to be detrimental to their health and survival, but have no choice as they need their partners for financial and other support.

The need for having safer sex with partners is fortified during discussions that the women have when they get in contact with one another and also at their support group meetings. However, the problems occur when they get home. The women are not able to implement what they discussed at their sessions into practice, as their partners do not support them. The women’s attempts at negotiating condom use are in vain:

“We discuss a lot of things (at the support group) for example using condoms but when I tell him (their husbands) these things he says no he can’t use condoms...”

The reluctance to use condoms among the men could be a result of the emphasis that society places on fertility and manhood. The belief that having children is proof of one's masculinity or femininity may exert undue pressure on the men to prove their fertility through procreation. Discussions on condom use are easily rejected by the partners through asserting their power in the relationship:

"When I take condoms he uses them for three days then says no condoms, I don't have a child, I want a child."

Wanting to have children can be a strong influence, even for couples that may already have children, as it is believed in African cultures that the more children one has, the wealthier one is. Having more children may be a way of replacing those children that may have died, having been infected through vertical transmission. Although women seem to be fully aware of the negative repercussions of having unprotected sex, their individual circumstances make it difficult to take the required steps to protect themselves and their partners. They are cognizant of the impact such decisions may have on their lives: *"I know that I am putting my life in danger. It is difficult to protect one's life in such a situation, so my life is in real danger."* The women are thus subjected to the possibility of reinfection, which can further damage their immune system and accelerate deterioration in health, hence the use of the term 'danger' in reference to having unprotected sex.

Couples end up having unprotected sex, risking the acquisition of resistant strains of the virus through reinfection, or transmitting the virus to previously negative partners, in order to have children. Resistant strains of the virus are difficult to manage with the available ARVs, resulting in treatment failure, leading to deterioration in health status.

3.2.2 Repeated physical harm

Harm is a constant occurrence in the lives of the women in the study. The harm is both physical and psychological. The women are exposed to repeated insults and are beaten for various reasons: *"Then he started beating me without real*

issues." At times, it is trivial reasons that result in the beating. Issues that can easily be sorted out through discussion: *"Once in a while he beats me when we disagree and argue about issues."* The use of alcohol can also be a major precursor to the physical harm that the women endure. Men may prioritize their own pleasure over other important requirements in the home. For instance, instead of providing the family with the needed basic resources, money is spent on what would be considered non-essential, unnecessary or even luxury items such as alcohol. Unfortunately, the alcohol contributes to the men's unacceptable behaviour: *"When he has money it is used for beer. He goes to drink beer and when he comes back he beats me."*

In accordance with asserting their power and authority over women, the men do not want to be asked or to be reminded about meeting their responsibilities as providers in the home. The request to meet their responsibilities often culminates in the women being physically assaulted: *"When I raise the point that the money that you are leaving is not enough, he gets furious and shouts and closes the door and starts beating me."* Apparently the repeated assault is not unique to a particular stage of the women's lives. The women are physically harmed even when they are pregnant. Although pregnancy is supposed to be a special and highly emotional time for the women (and the men), this does not deter the men from inflicting pain and subjecting the women to actual or potential trauma, which may also affect the unborn child: *"During the pregnancy of the other children I was heavily beaten."* Violence against women seems to be so entrenched that, although laws exist against it, it is not a real deterrent to the men. Because most of the time the women never report such cases to the relevant authorities, the men get away with these actions. Women who attempt to defend themselves in reaction to having been insulted are punished by physical assault because men think they should not be challenged:

"To reach the point of beating me usually it is when he uses derogatory language concerning my mother. So when I retaliate he grabs me and beats me, only because I have retaliated. A person using derogatory language against my dead mother...! Even my father died long time ago... I get angry when he insults my dead parents whom he has never seen. So I also insult his mother as a result he ends up beating me."

Violence can affect the women's physical and psychosocial well-being, impacting negatively on their health. The women are aware of the consequences of being in a relationship characterized by abuse. They know that they are putting their lives in danger by staying in situations where there is repeated harm of any form. However, they seem to have few options available to them:

"Later the elders talked to him (husband) and I was brought back to my husband's house. I came back and settled but found that he didn't change his behaviour. He continued abusing me. Even though I am staying (it is still) a life of violence."

3.2.3 Secondary physical harm

The cumulative effects of repeated violence can result in the women experiencing secondary physical harm from the abuse that they encounter. The secondary physical harm can manifest in many forms. These manifestations are usually the aftermath of on-going stress. The human body reacts to the repeated assault that it is exposed to, in different ways. Frequent headaches, abdominal pain and other vague manifestations, are some of the symptoms that the women may present with.

Some women go to a health facility to seek care for health conditions that are a result of the constant violence in their lives. They develop psychosomatic illnesses such as ulcers. However, the origin of such symptoms is not clear enough for a relationship of cause (assault) and effect (psychosomatic illness) to be established. At times, the women sense that enduring abuse (the cause of their health problems) can have an unfavourable impact on their health, but it is during consultations when the women seek help from a health professional, that their fears concerning the likely cause of their health problems is confirmed:

"I think this (abuse) affects my health in some way when I think too much... When I got here (hospital) they found that I had ulcers so they told me that ulcers start when you think a lot."

Still, the occurrence of violence is usually shrouded in secrecy, as women do not talk about issues of abuse in their lives: *"there is no one that I have told anything (about the abuse)."* This secrecy, or silence, is one of the reasons that abuse is rarely investigated in the health facilities, where it is not a matter of routine to screen women for any history of abuse. In such cases, the women present at the health facility with signs and symptoms that are partially managed, without any link being made between the underlying cause of the illness and the cumulative effects of abuse. It is not readily recognized that the multiple episodes of violence culminate into secondary physical harm experienced by the women. The situation may exacerbate already existing conditions in the women, making them experience further diminished levels of well-being. The women are unable to cope with the stress of repeated physical and/or psychological harm that may later manifest as secondary physical harm and ill health.

3.2.4 Emotional pain

The women in the study encountered offensive and degrading experiences involving their partners, friends and families. These situations result in emotional pain for the women. They are treated unfairly and inhumanely by people who are considered to be their loved ones and the people who are close to them. The consequences of emotional pain can be devastating. The women feel betrayed on account of being treated in a way they never anticipated. The women feel hurt and let down: *"I feel pain in my heart... and I even think about getting a divorce."*

These feelings of emotional pain are an indication of immense mental suffering and anguish. The women are disappointed that they are treated in an unacceptable manner for being HIV positive, a situation that anyone could find him/herself in. All this makes them feel sad and hurt. The women's emotional pain leaves them feeling defenceless and helpless:

"It pains me a lot... It pains me because I didn't choose, it just happened to me... Nobody went to the market to choose the type of virus. This is a plague, anyone can be infected by it..."

The emotional pain may originate from what is supposed to be an ordinary conversation between women and their spouses, which turns into sessions of insult and ridicule. In the past (before knowledge of the women's positive status) such conversations did not result in unacceptable comments from the partners. The use of demeaning language towards the women when they try and discuss household issues with their spouses, causes grief and heartache. The pertinent issues raised by the women in conversations with their partners are met with unexpected hurtful responses. The women are heartbroken by such experiences:

"In the past (before the HIV-positive diagnosis) he never did what he is doing now. When you tell him there is no food for the children he shouts using derogatory language. Then I would just leave it like that."

The suppressed emotions following such encounters are very painful. The women carry around the pain and usually do not share their grief with others. There is a change of behaviour portrayed in the manner that the women are being treated, compared to the time before the HIV infection. It is painful for the women to experience this kind of behaviour, as it is new to them, an indication that their partners perceive them with a different and negative attitude. This change occurs once the woman's HIV positive status is revealed.

The women get insulted anywhere they may go and at any time, irrespective of who else may be around to hear the hurtful comments. There is no respect accorded to them as individuals, who are worthy in their own right, demonstrated by insulting remarks made: *"He is tarnishing my image"* (by making derogatory comments when other people are around). Changes in living arrangements, such as moving to a new location, do not ease the pain as the embarrassment from the partners continue to frustrate the women: *"...I have moved a lot... but everywhere I go his behaviour is the same. I find this behaviour hurtful."* All the hurtful comments, the heartache and harsh treatment become unbearable and culminate into the emotional pain.

3.2.5 Being forced to stop taking ARVs

Physical, emotional and psychological harm can be evident where the husband interferes with or denies the woman's ease of access to ARVs. The ARVs are a lifeline for the women as they depend on the drugs for survival. There are strategies that are used to deny the women access to ARVs. These are attempts by the partners to force the women to stop taking ARVs. The interference can be mechanical, by either throwing away the drugs or destroying the bottles that contain the drugs: *"sometimes he throws my drugs away."*

Tampering with accessibility to ARVs can be equated to causing harm to the women, as ARVs are supposed to be taken on a regular basis, as directed. The drug regimen is supposed to be taken consistently each day for it to be effective and to achieve the desired results of suppressing viral replication and reducing viral load. Not taking the drugs as prescribed can have severe consequences, such as the development of resistance to the drugs, so that they no longer have the expected efficacy. This can lead to complications and untimely death. Therefore, the women's health status is severely threatened if the drugs are not taken according to a set schedule. The women feel that their drugs are not safe in their own homes. As a result, they have to hide the drugs away once they receive these from the health facility, for fear that the partner would sabotage their treatment. In such situations the women have to come up with their own strategies to ensure that the ARVs are safe, by making sure that they cannot be easily found by their partners. When women have to hide the medication from their partners in their own homes, it hampers their relationship, as there is no trust, openness and transparency between the partners in the particular marriage or a steady relationship:

"When I come from the hospital and receive medicine, when I reach my home, I have to hide the bottles; otherwise he (husband) would break them."

This kind of behaviour, where there is no openness, can result in the women feeling psychologically threatened. The threat lies in that the women do not know what their partners might devise to try and stop them from taking their ARVs. As a result, there is a sense of mistrust and uncertainty that develops in

the lives of the women. They don't have any guarantee that their own attempts of trying to safeguard the drugs will be successful, because they cannot anticipate the actions of their partners. This state of affairs leaves them living in a state of anxiety all the time. Instead of providing the much needed supportive role to the women, the partners hinder adherence to treatment with ARVs.

Taking ARVs correctly and consistently, which is one of the hallmarks of effective management of HIV, is already a challenge to some of the women, as they need assistance to enable them to achieve the required adherence levels. Therefore, being forced to stop taking ARVs is of great concern to the women. It is an aspect of physical and psychological harm that they experience. It compounds the challenges that the women who are infected with HIV have to deal with in their daily lives. The women struggle to attain an acceptable level of healthy living that can be achieved through treatment with ARVs in conjunction with other accompaniments, such as good diet.

3.2.6 Being forced to self-blame

The women in the study are forced to blame themselves. They blame themselves for being HIV-positive as well as for being abused. The self-blame is a result of unfair comments that are made about the women. The women end up blaming themselves because their partners, their family and the neighbours blame them too. They internalize the blame from others and start using it against themselves. As is common with abused women, they unfairly blame themselves for causing or contributing to the unfavourable treatment that they encounter, even though they are the victims. This attitude is often due to feelings of guilt, as they hold themselves responsible for other people's actions. Eventually the women may not be able to stand up for themselves because they may feel helpless and at fault: "*I might be found to be in the wrong...*"

The women may become more vulnerable to further abuse, as they may think they deserve the treatment they receive from others. This attitude can be disempowering as the women start to feel that they are the ones who are in the wrong, generating feelings of unworthiness of other people's respect: "*What reasons will I give (for wanting to leave husband)...will I say I no longer love*

him?". The self-condemnation can become disastrous once women feel that they are incapable of loving, being loved and being accorded the dignity that they deserve, to such an extent that they accept being treated in this degrading manner.

3.2.7 Blame by the husband

The women in the study candidly disclose their HIV status to their partners. As a consequence of the disclosure, the husbands or partners blame the women for the unfortunate situation of being HIV-positive. The blame is psychologically distressing, considering that during such a traumatic time one needs comfort and reassurance. Contrary to the expectation of being supported, the women find that their partners attempt to distance themselves from the situation and state that they have nothing to do with the women being HIV-positive:

"What he said was, aah that is your problem it doesn't concern me. Maybe you got the virus from somewhere else, this should not concern me. So I just said where do you think I got the virus from?"

Along the same lines, the women are accused of infecting the men. Such allegations are made without any proof to substantiate the claims: *"I think he blamed me for being the one who infected him with the virus."* The women get the blame only because they are usually the first in the relationship to go for HIV testing. Men are reluctant to get tested even though they may be the ones engaging in risky behaviours that are responsible for the spread of the virus: *"He is always talking about me and where I got the virus from; when I tell him to go for testing he refuses."*

The women get the blame and constant reminders about how they will pass on the HIV infection to their partners. Although it is the men who are not in favour of using condoms in the relationship, they nevertheless say the women are responsible for the possibility of transmitting the virus: *"He used to say a lot of things, such as you will give me the disease."* The women are indirectly accused of being unfaithful with other men. Unfaithfulness by the women is considered to be the source of the infection. Such claims of the women's suspected infidelity

are explicitly stated: *"He said a lot of things, that I must have gotten the virus from somewhere else and brought it the home."* The blame adds to the emotional turmoil experienced by the women. They have to come to terms with their partners' accusations and they have to carry the burden alone.

3.2.8 Exposure to humiliation

The women are exposed to being humiliated by other people due to the actions of their partners and their relatives. By demonstrating acts that may have the potential to incite possible humiliation, their partners and relatives are the ones that are in the forefront leading other people to do the same. Members of the community may consider it to be acceptable to make derogatory comments, if the behaviour is initiated by those close to the women. In such a situation, other people may develop insensitivity to the feelings of the women, who are offended:

"You know these things are supposed to be confidential (HIV issues). When I come from the clinic to collect my medicine he (partner/spouse) ... takes the bottles and goes to a group of his friends and shows them, (the medication she is taking) saying; do you see this 'maize'? (Medication for HIV infection) that is what she is taking. ...So for me, I am very anxious...While chatting with his friends he takes the medicine and shows it to them."

Similar actions taken by relatives could be considered as soliciting humiliation because they can influence other people against the women. In situations where there is breach of confidentiality by family members concerning a woman's HIV positive status, it exposes the woman to potential abasement: *"They (relatives) started publicizing to others outside our household."* By disclosing the HIV status of a family member to other people, information that was supposed to be kept within the family, loss of trust by the women in the family members is brought about. Loss of trust can become a barrier to open communication within the family as the women may become reluctant to share their personal information:

"Between me and my relatives there is enmity. I felt that even if I tell them about my problems how are they going to help? Instead they would be publicizing (the condition) to other people..."

Exposure to humiliation catalysed by the women's families is affected through actions as well as through speech. It can also be explicit as well as implicit. Actions that demonstrate stigma and discrimination can result in the women feeling exposed to humiliation. Statements that are made due to misinformation and ignorance can have negative implications on the way people relate to the women: *"They say it is important (that HIV positive woman) not to share food with them (HIV-positive women)"*. These are signs of irrational fear of contagion of HIV. The impact of the actions related to the irrational fear is regrettable and degrading to the women.

3.2.9 Humiliation by partner

Apart from the exposure to humiliation from other people, there is actual humiliation experienced by the women through the actions of their partners. Such actions disregard the emotions and dignity of the women, leaving them feeling disgraced and worthless: *"While I was pregnant he started not sleeping at home. He even brings prostitutes in our house when I am there."* This kind of behaviour suggests an open challenge to the women, showing that their partners do not care about their feelings and health. The partners' actions show a lack of the love and affection that is expected from one's spouse. Such actions could imply that the women are considered to be insignificant. It is an experience which is demeaning to them.

Actions by the women, which in normal circumstances would be appreciated, are frowned upon or rejected by their partners. Because the women put effort into what they do, they end up feeling humiliated if their effort is not recognised: *"Every time I serve food for him he would break the plates, throwing away the food."* Not only does the partner refuse to eat the food but goes to the extent of throwing the food away and even breaking the plates. This reaction is indeed debasing to the women. These actions are an indication of a lack of respect for and trust of the women. Humiliation of the women targets the self-esteem and

self-worth of the person, which gets severely bruised. Continuous blame and the use of derogatory remarks against the women leave them feeling humiliated: *"He was saying I am a 'whore' and it is because of that that I got infected."* When one's own partner refers to you as a prostitute, the statement is devastating and humiliating. It implies that the woman is undignified in the eyes of the partner and the community. The lack of respect results in the men doing things that the women feel tarnishes their image:

"I am concerned about all this because... I was born here in Area (specified) and I have grown up here so because many people know me my reputation is damaged."

3.2.10 Humiliation by own family

Actual humiliation comes from the women's close relatives too, their own families. One expects to find protection and provision from the family members as they are considered to be one's immediate social support system. It is within the family that members are supposed to feel accepted for who they are, notwithstanding any negative circumstances. But in these humiliating situations their families are not a source of support but a source of ridicule:

"These are my elder sisters, they discriminate me against the others. We can't eat together, even sleeping together, we can't exchange clothes they refuse they say 'you will give us AIDS.'"

The rejection by the women's own family is evident in the actions where the family is reluctant to associate or interact with the HIV positive women, making them feel humiliated. The women's need for companionship is neglected as they are shunned from every day activities. The women feel isolated as well as excluded from others within the family:

"When I go home to my mother's place there is one person who does not see (the person is blind) when the others cook food, I eat with this person not the others. They (family members) say tell her to go we don't want her here."

It is not uncommon in the African culture for disabled persons to be discriminated against.

Allowing the HIV-positive woman to associate and eat with a disabled person, signifies that her status is considered to be undesirable and lower than theirs. They view the woman as equal to a disabled person.

3.2.11 Humiliation by friends/neighbours

Friends and neighbours also contribute to actions that are humiliating to the HIV-positive women by spreading gossip and information that can cause discomfort to the women. There are alliances that are created against the women living with HIV, to the point of discouraging others from associating with the women:

"I had an HIV test when I was expecting this child. Now it is 12 months-a year has passed. The kind of abuse (they suffer is that) people backbite and laugh at us. In the community women chat together (socialize), so some of them tell others: don't chat with so and so because she has got HIV..."

Everyday activities, such as going to the communal water point, turn into difficult tasks because the friends and neighbours find this to be an opportune time to verbally attack the women. Trips to the clinic and receiving special materials such as food parcels create a favourable environment for the humiliation to take place within the community, as the women get labelled in distasteful ways. Realising that good nutrition is essential for an HIV-positive person, some organizations provide food parcels. These may include maize flour, milk, cooking oil, and the product 'Plumpy Nut' and are given to the HIV positive women (and their children). The slander and the ridicule experienced by the women results in feelings of humiliation.

"But the problem of being ridiculed is still there. At times you can go to the water point, or sometimes when they see us going to the clinic, they make comments that are hurtful. I have heard them myself."

As a result of the behaviour of the friends and neighbours, the women feel stigmatised and discriminated against by the community: *"Then a lot of people started discriminating against me."* Since HIV has a lot of stigma attached to it, as opposed to other chronic diseases like hypertension or diabetes, the HIV-positive women experience problems when people isolate them from a group of other people and label them. For instance, in the African tradition women are expected to breastfeed their children up to the age of two years or more. However, one of the recommendations for the prevention of mother to child transmission of HIV, is for the HIV-positive woman to stop breastfeeding at six months. Thereafter, the child can be given other food but not breast milk to prevent mother to child transmission of the virus facilitated by giving breast milk as well as other food such as porridge, known as mixed feeding.

"I had another baby who is now six months. I have since stopped breastfeeding him. The problem I am experiencing is from the neighbours who say this one must have the virus..."

Visible activities that may be linked to being HIV-positive are often the cues that neighbours use to start rumours about somebody being HIV-positive. The women find that they indirectly disclose their HIV status when they stop breastfeeding their children. In addition, visits from home-based care volunteers, who are known to visit people with chronic conditions such as AIDS or cancer, can lead to speculation about a person's HIV status.

"They knew that I had HIV because this was a daughter of one of the volunteers. She (the daughter of the volunteer) was the one saying nasty things about me." There is a sense of betrayal experienced as the women witness people in whom they have put their trust and who are supposed to support them, behave in such an unacceptable manner.

3.2.12 Humiliation by in-laws

In the African setting one's in-laws are significant in a marriage. This is because to the extended family system, the in-laws can have influence over the relative's wife, which can be positive but at times also very negative. The in-laws can be

the source of infliction of humiliation. In addition to their partners, their own families, friends and neighbours, the women are humiliated by their in-laws, who demonstrate unkindness to them. In-laws can be very influential in inciting hostility towards the women: *"I am married and my in-laws discriminate me against others."*

The women's contributions at the household level are not appreciated but rejected, because of unwarranted fears and myths believed concerning HIV transmission, leading to the women feeling humiliated: *"Even now... when I cook nsima (pap) so that we can all eat together, they (in-laws) say no, you will give us the disease (AIDS)."* Being offered food is a sign of hospitality by the host. This hospitality is thus rejected. Eating together is normally cherished, as it indicates companionship and friendship. By suffering such rejection the women experience a disturbance in the normal pattern of socialization within the family and in the community.

In normal circumstances in-laws should form one's support network but, most of the time the women in the study did not experience it. Instead of being supportive, the in-laws show disinterest and neglect. The women consult their in-laws and other relatives of the husband when they encounter problems and seek assistance in resolving any marital issues amicably. However, the response is usually not satisfactory:

"I went to his aunt in Blantyre and told her, but she didn't do anything, she just said I will come to Lilongwe, I will talk to him, but up to now she has not come yet."

3.2.13 Abandonment by husband

Abandonment by husbands is threatened or actual. The initial response demonstrated upon hearing the news of the woman's positive HIV status is to leave the woman: *"His first reaction when I told him about my status was to end the marriage."* The men, who do not leave, threaten to abandon the women if they do not comply with instructions such as having a child in spite of their HIV status:

"That time I was using birth control pills, so he took my birth control pills and he was going to throw them away or I should pack up and go. So I just gave in and became pregnant, but I was telling him that we have the first child who is free from the virus but next time it may happen that the child will be infected with the virus..."

In trying to distance them from the situation, actual abandonment occurs. The man leaves the HIV-positive woman and marries another woman. The men desert the women and leave them to fend for themselves:

"When I told him that at the clinic they found that I have the virus, he didn't say anything. He just said ooh, okay. The same month he left our house and went to marry another wife in area (specified). The money that he left is the money that he had given me previously. When the money had run out, I started living a difficult life."

For many married women in Africa, the husband is the source of their livelihood and being abandoned means lacking the basic necessities of life. In the modern world, money is everything. Without money one cannot access food, soap or even shelter, when accommodation is rented. 'Living a difficult life' means the woman had to struggle to meet these basic needs.

It would seem the men prefer to live in ignorance, without knowing the women's positive HIV status. This preference is evident when they are told about the women's positive HIV status. Their reaction is to distance themselves from the issue or problem. They want to be 'physically detached' from the situation. *"What he said was, ah, that is your problem. It doesn't concern me; just pack your things and go."* This is possible when the man owns the home and he can chase the woman away. When the man is staying at the woman's home, he disappears, leaving the woman in the house: *"He (husband) is the one who packed his things because we stay at my parents."* However, the effects of such abandonment are the same, as the woman is left without the necessary support.

Pretence is also used to deal with the situation as an interim measure. The men pretend to be okay with the news of a positive HIV status, only to abandon the

woman after a while. Some of the partners are willing to go for an HIV test after the news that the wife is found positive. Nevertheless, after the test, irrespective of whether it has a negative or positive result, they still leave:

"... So after explaining everything he seemed to be touched, he didn't shout at me, he just said okay. We then went to the hospital where he was tested and was found to be positive... as of now the marriage is over... The marriage collapsed even before the child was a month old."

3.2.14 Abandonment by own family

Another painful consequence of women disclosing their HIV positive sero-status is the abandonment they experience from their own family: *"At my father's village they said they didn't want anybody with HIV. Even when I go to the village nobody shows happiness to see me."*

The family doesn't want anything to do with the HIV-positive woman. In situations of sickness, when the woman requires the support of the family, that support is not forthcoming: *"Even when I was admitted at the hospital none of my relatives came to see me."*

"But my relatives discriminate me against others. There was a time when I got sick and they abandoned me at the hospital. It was my husband who took care of me when I was discharged from the hospital."

The women interpret the abandonment as a sign of being rejected and not being cared for by their own family. The abandonment and rejection occurs across geographical boundaries. Relatives find excuses to abandon the women: *"By the grace of God I travelled to Zimbabwe in 2005 where I met my mother's relatives but they told me because they received 'lobola' (bride price) I cannot stay."* The relatives used the culturally accepted practices to effectively abandon the women. This action resulted in the woman being pushed from one place to the other, like a destitute: *"The abuse that I am facing is of having no place because my mother came from Zimbabwe..."*

Women who are abandoned by their family experience much difficulty in trying to meet the requirements for daily living. It is clear that as a consequence of being abandoned, even children may be affected by a lack of sufficient care and resources. Considering that the women's needs become even more due to their HIV status, they find it difficult to support themselves. Being abandoned becomes a major challenge. One woman who was abandoned by her family faced a real challenge because her husband, who could have supported her, had passed away. She had a child that required looking after when she was sick and she lacked the resources to support herself and her child. The participant states:

"When I got tested and the result was positive... that was in 2003, my parents abandoned me. Then my husband died and I had nobody to look after me. I lacked support for household activities. When I was sick there was nobody to help me with looking after the child... there were no relatives who visited me."

3.2.15 Destruction of hope of survival

When one is sick from a chronic condition such as AIDS, which has no cure, the tendency may be to lose hope. Yet, as a coping mechanism, one still hopes that the end is not imminent. The women in the study had the unfortunate circumstances of dealing with people who destroyed such hopes, by making statements that insinuated that the women's lives were over because of having an HIV infection.

Although the women are living with HIV, they are aware that it is not a death sentence for them. If they adhere to their treatment regimen and have a nutritious diet, HIV can be maintained and monitored like any chronic illness. However, the mean actions and unkind words of the people around the HIV-positive women cause them to feel dejected, as the people effectively destroy the women's hope of survival: *"He told me since you have the disease you are already dead."* Instead of adding to the voices of reason and instilling hope in the women to live positively with HIV, the women are constantly reminded of how they are dependent on drugs to stay alive: *"They say that we are alive because of ARVs. We are just waiting for the day to die."* Actions like these

destroy the women's hope of having any meaningful future, where plans can be made and realised: *"I can't see the future; I just live one day at a time."*

The women are forced to see themselves as doomed to death and that there is nothing they can do about it. With such remarks being made, the women may feel there is no point in making any efforts to sustain life and have any meaningful plans for the future. Thus, a feeling of hopelessness may occur because of the uninspiring comments made by those who are around them.

3.2.16 Being forced to consider suicide

Because of the suffering caused by the people they love (partners, friends and relatives), the women do not see any reason to continue living. They are forced to consider suicide as the only solution for them. It is this sense of hopelessness that drives the women to contemplate suicide as an option for ending their problems:

"What I want is to throw myself in the well, because when I tell him (husband) to go back to his home he is refusing, (when I say) go to your relatives, he doesn't leave. I have nowhere to go; I don't know if my relatives will accept me."

The desperation of the situation and the sense of having no escape from it, compounded by the thought of being abused continually, prompts suicidal ideation among the women. In these cases, this provides a comfort zone where WLWHA imagine that their suffering may be resolved. Yet the women are troubled by the fact that they are contemplating suicide. Taking one's own life may be considered to be evil or unacceptable. It goes against the beliefs of a religious or spiritual person and is believed to be an act from the devil. One woman explains her struggle:

"This is very difficult and it can make me to be tempted (to commit suicide) maybe if he continued to abuse me I would think evil (I would think) about taking poison ...that is what I thought. Now if I don't pray for a long time how can I defeat the devil? How can I be strong?"

Seemingly, relying on prayer is thought to be important in defeating the temptation of considering suicide. In contrast, it is the lack of support and insensitivity of the people surrounding the women that results in the women being forced to weigh suicide as an option to deal with their problems.

3.2.17 Being forced to feel insecure

The women feel a deep sense of insecurity due to the acts perpetrated against them. They feel incapable of making their own independent decisions: *"My wish is that we should not go back to the farm but you never know the husband's thoughts."* They feel they don't have the capacity to be self-sufficient and have to depend on the men, whatever the consequences maybe: *"I told him I was not going anywhere only if you go for the test and they find that you are fine I will leave."* The sense of insecurity is so deep that they cannot consider the possibility of an independent life: *"How can I leave?"*

The abuse leaves the women feeling financially insecure too: *"When I ask for transport money he does not give me, sometimes it is my sister who gives me the money."* Because of their economic dependence on the men, they find themselves living in even poorer economic circumstances than previously experienced when partners were more supportive:

"But since 2005 my husband has been abusive. He is a truck driver, but the way he treats me compared to the care that I and my children used to get changed."

By alluding to the husband's job as a truck driver, it is suggested that the man can ably provide for the needs of his wife and children. However, since the woman disclosed her HIV positive status, the husband's support changed drastically:

"What has changed (pause) at the house the way we eat; it is not the same (as before). He does not leave any money for me to buy food at home. My child was attending a private school now the child is in a public school; (there is) no money to buy clothes, my children are walking barefoot at school."

Because of the economic insecurity the women cannot afford basic necessities such as food: *"The man leaves us hungry without giving us help..."* They rate their living standard to be poor and backward. They are forced to depend on other people's generosity: *"My life has gone backwards. I rely on hand outs!"* There is desperation in the voices of the women as they are forced to beg in order to survive: *"I gave up and got used to that difficult life, I would go round begging."* The women are unhappy being dependent on others and do not see an end to the situation: *"I will be begging for how long?"*

3.3 SUMMARY

Findings from phase 1 of the study, which describe the experiences of abuse of WLWHA, have been presented - from the essence of the women's experiences (referred to as violating experiences) to its constituents. A detailed description of the constituents, supported by quotations from the participants, has been addressed. The constituents included: *exposure to re-infection, repeated physical harm, secondary physical harm, emotional pain, being forced to stop taking ARVs, being forced to self-blame, blame by the husband, exposure to humiliation, humiliation by partner, humiliation by own family, humiliation by friends/neighbours, humiliation by in-laws, abandonment by husband, abandonment by own family, destruction of hope of survival, being forced to consider suicide and being forced to feel insecure.*

In Chapter four, a discussion of the findings will be presented.

CHAPTER 4

DISCUSSION OF FINDINGS OF PHASE 1 OF THE STUDY FOR DEVELOPMENT OF GUIDELINES FOR ASSESSMENT

4.1 INTRODUCTION

In chapter 4, a discussion of the findings of phase 1 of the study is presented. The findings were concluded by analysing the data obtained from interviews with WLWHA on their experiences of abuse. The essence of abuse of WLWHA is identified as being violating experiences. There are seventeen constituents that illuminate the essence. They include: exposure to reinfection, repeated physical harm, secondary physical harm, emotional pain, being forced to stop taking ARVs, being forced to self-blame, blame by the husband, exposure to humiliation, humiliation by partner, humiliation by own family, humiliation by friends/neighbours, humiliation by in-laws, abandonment by husband, abandonment by own family, destruction of hope of survival, being forced to consider suicide and being forced to feel insecure (Refer to Box 4.1). These constituents relate to five concepts, namely: humiliation, hopelessness, blame, harm and abandonment as experienced by the women.

- ❖ **Humiliation:** exposure to humiliation, humiliation by partner, humiliation by own family, humiliation by friends/neighbours, humiliation by in-laws
- ❖ **Hopelessness:** destruction of hope of survival, being forced to consider suicide and being forced to feel insecure
- ❖ **Blame:** being forced to self-blame, blamed by the husband
- ❖ **Harm:** exposure to re-infection, repeated physical harm, secondary physical harm, emotional pain, being forced to stop taking ARVs
- ❖ **Abandonment:** abandonment by husband, abandonment by own family

BOX 4.1: The concepts and their constituents

The discussion provides a deeper understanding of the concepts, using relevant literature. True to the tradition of phenomenological research, the essence is not discussed with references to the literature. The discussion thereof forms the foundation for the development of guidelines regarding the assessment of abuse, as experienced by WLWHA. The guidelines were developed in phase 2 of the study and described in chapter 5.

4.2 VIOLATING EXPERIENCES: THE ESSENCE OF ABUSE EXPERIENCED BY WOMEN LIVING WITH HIV AND AIDS

Phase 1 of this study, is about the phenomenological inquiry of women's experiences of abuse. The researcher describes their experience as lived by themselves. Phenomenological research pertains to fully understanding the lived experience of people. It is the lived experience which presents the truth of the reality of an individual's life. In this study it was important to capture the women's own experiences of abuse in order to gain a comprehensive understanding. As a phenomenological researcher, upon identifying the essence, it is necessary to accurately describe the essence through language.

We access the world of knowledge from experience through consciousness. In phenomenology, the issue of essence or what makes an object that object is critical. It represents the essential properties that make the object what it is. Violating experiences as an essence (of abuse) is understood as something that is present in the consciousness of the researcher and cannot be assumed to be perceived exactly as it was experienced by the participants, who described their experiences from the perspective of a natural attitude. The phenomenological researcher adopts the phenomenological attitude. The phenomenon of the abuse of WLWHA in this study is elucidated through the women's descriptions of their experiences. The phenomenological inquiry revealed that the essence of abuse (violating experiences) originate from partners, family members, neighbours and friends of the women.

Consciousness is intentional and one can describe the nature of the intentional acts of consciousness. By assuming the phenomenological attitude, the researcher is able to describe the contents of consciousness and not the things

of the natural world. Husserl stressed that consciousness is the source of certain or reliable knowledge (West 2004: 89). Consciousness, being intentional, is focussed on something, thus, giving meaning to what exists. It is the interpretation of the undifferentiated so that it becomes differentiated and takes on meaning and existence in consciousness. Phenomenologically, the violating experiences can be viewed from the stance that people are objects in the world of others ('being for others'), where they are exposed and vulnerable.

In 'being for others' the person is in constant contact with other people (subjects) who pass judgement on the person as their object. The person, who experiences the violence and her experiencing it, is understood in terms of phenomenology as 'being with others'.

The 'others' are those who form opinions about WLWHA and might force them to be what they are not. The women, therefore, suffer shame and humiliation in 'being for others'. Being violated happens during interaction with others. It happens while 'being with others'. One cannot feel violated or ashamed without influence. Because of the relationships in 'being for others', the actions of the significant others elicit feelings of vulnerability, as the women sense that they are being unfairly judged by the others.

The violating experiences are understood to be harsh and unacceptable. The feeling of humiliation is evoked upon being perceived in such a negative manner by their loved ones. The perception of being abandoned by the others, compounds their situation of hopelessness. The realization that judgement is passed by others is distressful and causes anxiety. This feeling arises because in 'being for others', one is concerned about what other people think about oneself, to the point of being enslaved by the opinion of others. Usually people want to be viewed in a positive manner that makes them feel proud and dignified, rather than the negative, which results in suffering their 'being for others' in shame and humiliation (Cox 2009: 39). In 'being for others' one is very vulnerable. One has no protection and is exposed to the judgement of others.

The interaction between the women and the others, therefore, heightens the feelings of blame and shame. The women are conscious of themselves and

people around them in terms of what the others may think or say about them, or what they may do to them. The person is constantly confronted by the realization that they are objects in the eyes of others and they are subject to the critical evaluation of their being and behaviour. By being the “other” to other people, they are vulnerable to being belittled and humiliated by them. For the researcher, these encounters constitute the violating experiences to the WLWHA. They are subjected to becoming uncomfortably aware of themselves and the thoughts about potential or actual judgements of others upon them. These thoughts can lead to resentment and bitterness.

The researcher’s role in this study was to allow the phenomenon of abuse of WLWHA to reveal itself through the women’s descriptions, rather than to take a naive and natural attitude towards WLWHA and their experiences of abuse. In order for the phenomenon to show itself, lifeworld research demands openness from the researcher. Openness or sensitivity means seeing the world in a new way, by making oneself available to the world, to see the contents of consciousness. The researcher used sensitivity and openness with WLWHA to allow them to express themselves, concerning their experiences of abuse, so that the phenomenon of abuse could reveal itself. The open attitude involves having a discovering attitude, willingness to listen and understanding with sensitivity and respect what the women describe, to allow the phenomenon to reveal itself.

Openness promotes trust and a level of nearness that facilitates participants’ self-disclosure. This approach leads to openness to meanings and essences which allows a deeper level of understanding of the phenomenon. Identifying the phenomenon’s essence was based on the obtained data. The researcher needed to be immersed in the data and in the analytic process to ensure an accurate description. Openness during the interaction with the study participants and the data analysis process led to the identification of the essence of abuse as violating experiences.

The findings from the study show that the violating experiences are encompassed in the interpersonal relationships and are characterised by humiliation, hopelessness, blame, harm and abandonment by people close to the

women. The violating experiences may affect the women's sense of self-esteem and self-confidence in a negative way. Such violating experiences result in emotions such as embarrassment, hurt and feeling no sense of belonging. The WLWHA sense detached interpersonal encounters devoid of love, care and support. The violating experiences are characterised by feelings of unworthiness and a lack of respect and dignity. These violating experiences are directed at the core of being of the WLWHA, giving rise to a multitude of feelings and emotions, which is essentially a degradation of their existence as people.

The five concepts (humiliation, hopelessness, blame, harm and abandonment), which are encompassed in the constituents that reflect violating experiences are further discussed in order to develop a comprehensive understanding of the intersubjective and interactive encounters between the WLWHA and their partners, families, friends and neighbours, in light of the descriptions of the experiences of the women themselves. The descriptions are considered to be embodied knowledge of the women, derived from their own lifeworld of lived experiences of abuse (Carlsson *et al.* 2004: 194).

4.3 HUMILIATION

❖ **Humiliation:** exposure to humiliation, humiliation by partner, humiliation by own family, humiliation by friends/neighbours, humiliation by in-laws

WLWHA in this study experienced humiliation at the hands of the people close to them, as well as others, through the actions of the former. As a concept, humiliation has not been subjected to much rigorous and critical analysis in order to develop a clear understanding of what it is (Torres & Bergner 2010: 195). Although humiliation has a severe impact on individuals and groups, it has specifically been overlooked as far as its presentation in collective behaviour is concerned (Klein 1991: 93). Humiliation has a devastating effect on people with psychopathological consequences. Furthermore, people with psychopathological disturbances, such as depressive disorders, are at risk to be humiliated (Torres & Bergner 2010: 195).

Humiliation has been described as a major weapon that is frequently used in the oppression of women (Klein 1991: 93). Nurses should therefore not contribute to the humiliation of the women when they seek healthcare, as the latter could be humiliating in itself (Karlsson 2007: 47).

It is essential to properly describe what constitutes humiliation (Torres & Bergner 2010: 203). Goldin (2007: 13) identified two domains of humiliation. These are the 'external' and 'internal' domains. External humiliation relates to actions that can be observed, such as discrimination, disrespect and unfair treatment. Internal humiliation is a feeling that could occur when a person feels he/she is treated without respect and unfairly by others. Discrimination is the overt form of humiliation and is characterised by unequal power relations (Goldin 2007: 13).

Women in this study felt humiliated by the actions of their partners, families, in-laws, friends and neighbours, who ridiculed them for being HIV positive. This finding is similar to that of Emusu *et al.* (2009: 1368) where it was indicated that women felt humiliated by sexual violence perpetrated by their partners, with whom they were living as HIV discordant couples. The experiences of humiliation left the women feeling harassed and unable to defend themselves. Partners of the women obtained sex without consent through threats and using force. Other behaviours that spark feelings of humiliation are gossiping and spreading rumours about WLWHA. Mkandawire-Valhmu and Stevens (2010: 688) found that WLWHA were humiliated by the gossip that went around in their community about them being HIV-positive, as they were laughed at and ridiculed. In these circumstances external humiliation resulted in internal humiliation of the women.

Humiliation involves the "experience of some form of ridicule, scorn, contempt, or other degrading treatment at the hands of others" (Klein 1991: 94). It happens in interrelationships with other people. The humiliated person experiences a feeling of being discounted by others, being excluded from a group or being made to feel insignificant and to suffering disgrace. In the case of being discounted, one is powerless to do anything about it. Being excluded involves the threatening of one's personal integrity or wholeness. One feels

inferior to those who are included. Any contributions the person may make are unrecognised and not acknowledged. On the aspect of suffering disgrace, the person sustains damage to his/her sense of self and identity (Klein 1991: 94).

The person who has been humiliated experiences a form of invasion of the self where his/her personal boundaries are violated (Klein 1991: 98). The person may feel that he/she is devalued, rejected by others, ignored by the group and belittled in the eyes of others (Malterud & Hollnagel 2007: 69). Similarly, Lindner (2007: 29) defines humiliation as the 'enforced lowering of a person or a group, a process of subjugation that damages or strips away their pride, honour and dignity'. The person feels he/she is placed in a position or situation which is inferior to what they think they deserve. Humiliation is 'any sort of behaviour or condition that constitutes a sound reason for a person to sense their self-respect has been injured' (Margalit 1996: 9 cited by Lindner 2007: 29). It is behaviour in any form that makes a person feel less worthy or unworthy of respect.

All events that are perceived as excluding other people from a group is defined as meaning that the person has been rejected by the group, with the consequence of the person being humiliated (Statman 2000: 528). The experience enhances feelings of a lowered self-esteem. It can be concluded that the women in this study had these feelings of unworthiness when they experienced humiliation. The Oxford Advanced Learner's Dictionary (2010: 452) defines 'to humiliate' as: 'to make someone feel ashamed or stupid' and 'humiliation' as: 'the act of humiliating or the state of being humiliated'. The WLWHA endured humiliation from their partners, families, friends, in-laws and their neighbours.

One's personal sense of worth is greatly shaped by what other people think, what they say and the treatment that is received from them (Statman 2000: 534). A person's need to belong is essential for one's survival. As a result, being degraded, devalued or being perceived to be unworthy is threatening to people. Humiliation, shame, dignity and self-respect are concepts that are closely interrelated with one another. As such, the sense of one's value in the eyes of others is synonymous with being significant. The latter happens when people enjoy belonging to a family and believe that they are respected by the people

around them (Klein 1991: 100). There is a difference between shame and humiliation in that shame is when one feels that he/she has failed to live up to ideals of expected or suitable behaviour in one's or other people's eyes whereas humiliation is what one feels when he/she has been ridiculed or insulted (Klein 1991: 117). People believe they could deserve the shame but not the humiliation.

Distanciation is a foundation of behaviour that eventually culminates in the humiliation of others (Malterud & Hollnagel 2007: 71). Situations during which people enact distanciation result in lowered emotional involvement, as people cannot connect to others. Distanciation is considered to be degrading behaviour, practised by people who do not recognize that another person can be affected by one's performance (Malterud & Hollnagel 2007: 70). As stated earlier, humiliation is always in relation to others, which makes it interactional (Reyles 2007: 5). The consequences of humiliating experiences might differ from person to person, depending on the circumstances of the humiliation and also the person's personality. Among the many repercussions, shame and humiliation lead to a person's social isolation, as they participate less in group activities. The person experiences loneliness because of the social isolation. The isolation is an attempt to protect themselves from situations that may be perceived to be humiliating, involving the interaction with others (Reyles 2007: 5).

Humiliation threatens a person's dignity. The link between humiliation and dignity is that humiliation can be seen as a violation of one's dignity (Killmister 2009: 161; Statman 2000: 523). Hence, humiliating situations are experienced as violations of dignity where standards of public decency are not conformed to. In contrast, proponents of Kantian dignity purport that it (dignity) is inalienable and cannot be threatened and that situations that are humiliating should not result in one's dignity being stripped away (Killmister 2009: 161). Where there is humiliation and shame, humans become more aware of the importance and meaning of respect and dignity (Parse 2010: 259). This occurs for the reason that when a person is humiliated, he/she also feels disrespected, misunderstood and betrayed. Betrayal is a violation of human trust which occurs due to unexpected confidentiality breaches (Parse 2010: 259). It entails destroying a trusting relationship and the shattering of one's confidence, resulting in injury to

dignity. The women in the study felt that their dignity was threatened and their trust was destroyed due to the humiliation and betrayal by the people they loved.

Humiliation may leave one feeling helpless, confused, paralysed or filled with anger (Klein 1991: 93). As such, humiliation poisons relationships among groups and individuals. Although there are grave consequences of severe humiliation, it tends to be unrecognised and insufficiently dealt with, because humiliation is usually trivialised. While responses to humiliation may be varied, such reactions, if maladaptive, can be physically and emotionally damaging to self and others. The person may be in a state of powerlessness because of the belief that he/she has little influence or control over either causes or solutions for the problems encountered in his/her life (Teitelman *et al.* 2009: 188).

Powerlessness, hopelessness and helplessness all refer to situations where the person feels they cannot do anything about their situation. Experiences of severe humiliation might result in mental disorders, some of which are depression, suicidal states and severe states of anxiety, such as post-traumatic stress disorder (Torres & Bergner 2010: 199). These conditions are further discussed in the section entitled 'hopelessness' one of the five concepts identified from the findings of this study. Ludemir *et al.* (2008: 1016) also noted in their study on violence against women and common mental disorders that psychological violence perpetrated by intimate partners in the form of humiliation and insults was associated with mental problems. Humiliation of WLWHA may contribute to the burden of mental health conditions, including hopelessness being experienced by the women, as discussed under 4.4.

4.4 HOPELESSNESS

❖ **Hopelessness:** destruction of hope of survival, being forced to consider suicide and being forced to feel insecure

Hopelessness is one of the concepts that was identified in the analysis of the women's experiences of abuse and living with HIV and AIDS. The identification

of hopelessness is important in respect of nursing, as those affected or likely to suffer hopelessness need assistance to overcome it (Dunn 2005: 148). Hopelessness has been studied in connection with its occurrence in conditions such as depression, cancer, HIV infection and AIDS. It is the direct opposite of hope, which is considered to be a critical attribute for taking action in sustaining life. Therefore, having no hope can be detrimental to recovery from illness (Campbell 1987: 18), since hope is considered to be a coping mechanism during such trying times when the future may look bleak (Aylott 1998: 231).

Hopelessness can be presented on a continuum that includes hope, despair and hopelessness (Kylma 2005: 814). An individual may fluctuate between having feelings of hope, despair, and hopelessness and vice versa. Aylott (1998: 231) suggests that hopelessness, compared to hope, has not been fully addressed in the nursing literature. However, it has been acknowledged that people in general, or patients in particular, can be made to feel helpless and powerless, forcing them into a state of hopelessness.

Hope is having a sense of meaning and purpose in life, looking forward to the future despite the traumas and disruptive life events (Tutton, Seers & Langstaff 2009: 122). Nurses can help patients experience hope in order to avoid hopelessness, which can occur as a result of suffering from multiple sources. Hopelessness is considered worse than despair by some authors. To illustrate this difference, Kylma, Vehvilainen-Julkunen and Lahdevirta (2001: 769) suggest that a desperate person can try to do something about their problems, while a hopeless person has already given up. Hope and despair have been described in order to appreciate the experience of hopelessness, since all three are interconnected and could occur in an alternating manner in the same individual (Aylott 1998: 232). It is essential to understand the processes of hopelessness to be able to prevent some of the possibly negative effects thereof (Kylma 2005: 814).

In a concept analysis of hopelessness, aiming to clarify and understand the meaning of hopelessness, Campbell (1987: 18) reports several perspectives on the concept. Campbell found that hopelessness was predominantly believed to be a vague and diffused feeling. Nonetheless, several general meanings related

to the concept were identified. One of the meanings referred to hopelessness as feeling that 'that which is desired is not possible or it is impossible to achieve'. The other meaning relates to the existence of 'totally negative expectations' (where a person views a situation as being irremediable or incurable). It is considered to be a mechanism that protects against constant frustration (Campbell 1987: 18).

Hopelessness is defined as 'the giving up of one's hope because of a belief in a non-existent future' (Kylma *et al.* 2001: 768). It is the expectancy of negative outcomes in future events. Similarly, McClement and Chochinov (2008: 1170), focusing on a futuristic orientation, referred to hopelessness as expecting no goal attainment in an insurmountable situation. As such, it is often associated with depression and suicidal ideation. These definitions have four common elements:

- i. expectations of a negative future
- ii. a perceived loss of control concerning the future
- iii. passive acceptance of the situation and
- iv. having negative emotions

(Campbell 1987: 22).

Hopelessness is a 'sustained subjective emotional state, wherein a person sees no personal choices or alternatives to solve problems, or achieve what is desired and cannot mobilize energy to establish goals' (Carpenito 2000: 474). It is an established nursing diagnosis, also described by the North America Nursing Diagnosis Association (NANDA) as a state in which a person sees limited choices and is unable to mobilize energy (Kneisl & Trigoboff 2009: 418). These definitions suggest that a person is faced with challenges that are perceived to be impossible to overcome. On the contrary, hope believes that life can be worth living at present and in the future (Kylma *et al.* 2001: 768). Despair is seen as being linked to the experiences of hope and hopelessness.

There are many possible factors that could contribute to hopelessness. These might include how people treat one another, particularly by their significant others such as friends and family (Aylott 1998: 232). Feelings of hopelessness surface when the person encounters overwhelming experiences and feels that there is little promise held by the future (Campbell 1987: 19). Uncaring relationships such as those found among the participants in this study can contribute to the occurrence of hopelessness. As a nursing diagnosis, hopelessness has the characteristics of passivity, decreased verbal cues and verbalization and a decrease in affect (Dunn 2005: 148).

The pursuit of meaning in life can lead to a sense of emptiness or purposelessness, which in turn might give rise to despair, depression and suicidal ideation (Heisel & Flett 2004: 128). In order to curb the occurrence of hopelessness, nurses and other health professionals must be aware of the predisposing factors and the effects it could have on patients (Campbell 1987: 22). Experiences of discouragement, lack of resources, loss of trust and lack of assistance, common among the women in the study, can lead to hopelessness (Dunn 2005: 150). The women in this study were exposed to feelings of hopelessness as their partners, families, friends, neighbours and in-laws attempted to destroy their hope of survival by telling them that they had no future. They lost trust in their loved ones and lacked resources to meet the everyday basic needs because of the rejection that they experienced.

Hopelessness is categorized into three dimensions. The first is cognitive in nature and pertains to having negative expectations, especially of a dark and uncertain future. The second is affective in nature. The person has feelings and thoughts that are predominantly negative, such as lack of enthusiasm and faith. The third is the motivational aspect, characterised by negative feelings and thoughts in relation to the ability to improve or change the future. People whose lives are characterised by hopelessness do not believe that their actions can influence outcomes significantly (Kneisl & Trigoboff 2009: 418).

The women in this study experienced hopelessness on all these levels. They were made to expect negative outcomes concerning their health and lives through comments made by friends and family that their death was imminent

because they had HIV. The women believed these pronouncements and concluded that they had no future to look forward to, as there was nothing they could do to cure their condition or change their situation for the better. This finding is similar to that of Balaile *et al.* (2007: 11), where some of the women in their study reported having non-existent thoughts about the future.

Other nursing scholars have attempted to identify elements that constitute hopelessness (Gurkova, Ziakova & Cap 2011: 34). These authors suggest that hopelessness is a multidimensional and dynamic concept which has the effect of disempowering the individuals. They may perceive themselves as incapable of changing their situation. Some of the effects of hopelessness on individuals are decreased motivation, a lack of initiative, a sense of sadness and impairment in decision making.

In addition, hopelessness is a threat to 'quality and longevity of life'. Without hope, people place little value on the future, resulting in a loss of self-esteem and an increase in emotions related to the occurrence of depression (Barnett & Weston 2008: S29). Lack of hope brings about apathy and inactivity, culminating in the individual depending on others for basic needs. This dependency is a situation that further lowers the person's self-esteem. Hopelessness is one of the major characteristics of depression (Campbell 1987: 18).

Suicide, suicide attempts and suicidal ideation can be consequences of life threatening and chronic conditions (Kelly *et al.* 1998: 405). Kelly argues that although chronic illnesses such as mental disorders and HIV infection are associated with hopelessness, it is the stigma, lack of social support and isolation that can increase the likelihood of the occurrence of suicidal ideas. Experiencing abuse from family, friends or partners may compound suicidal ideation in WLWHA due to stigma, which remains a major stressor (Preeau *et al.* 2008: 920). The women in the study experienced suicidal ideation because they believed they had no solutions to their problems. Preeau *et al.* (2008: 920) reported that a long history of illness, suffering discrimination and side effects from drugs were strongly associated with occurrence of suicidal ideation in people living with HIV and AIDS (PLWHA).

Personal traits such as age less than 50 years, being of the female gender and financial insecurity also predicted the occurrence of suicidal ideation. When the interrelationships are negative, as was the case in this study, a person experiences increased feelings of loneliness (Vanderhorst & McLaren 2005: 520). Lack of social support is an important factor in the increase of psychological stressors. The women in this study had increased psychological stressors from the lack of support from family and friends, which contributed to the sense of insecurity in their lives.

Insecurity, such as financial hardship, created by experiencing abuse may result in women feeling hopeless about their individual circumstances (Barnett & Weston 2008: S29). Women in many countries feel their security is dependent on their husbands' or partners' provision thereof. Forms of security include being able to provide for the family, being well off and having a monogamous marriage. Women in this study were insecure about their relationships, their own health status and the ability to provide for themselves and their children.

4.5 BLAME

❖ **Blame:** being forced to self-blame, blame by the husband

In many contexts, having HIV is associated with promiscuity and sin. Consequently, the affected person is blamed and shamed, implying that they are perceived to have been involved in what is considered deviant and unacceptable behaviour (Nepal & Ross 2010: 25). Gender-based violence directed at WLWHA may be a part of shaming and blaming. The women are called names and they are told that they are worthless (de Sousa 2010: 246). They are also blamed for becoming burdens to their families when they become ill or incapacitated, because for many people having HIV is synonymous with suffering and death. This instils a sense of fear among those that are infected or affected by the condition (Maman *et al.* 2009: 2275). From the perspective of an oppressed group in a society dominated by males, it appears that women are blamed (de Sousa 2010: 249). The women are perceived to be sources of infection for their partners and their children. The same power dynamics that are at play based on

the broader social and cultural context, impact on the blame culture experienced in domestic violence, perpetuated by the man (who is the physically powerful member in the relationship) (Thapar-Bjorkert & Morgan 2010: 33).

When a person feels powerless they tend to develop self-blame. When the people with power, who consider themselves healthy in this case and therefore more powerful, blame them, they start to believe the 'powerful' people (Laverack 2009: 23). Thus, women are blamed and they blame themselves. They take responsibility for their victimization while men, friends, neighbours and in-laws, in the case of this study, are not held accountable for their actions (Thapar- Bjorkert & Morgan 2010: 33).

Women in this study blamed themselves and they were blamed by their significant others for being infected with HIV. Self-blame involves a feeling of being responsible for the violence or abuse happening to the self (Coffey *et al.* 1996: 451). Individuals may take the blame themselves in cases of life events that turn out to be negative. These individuals can be viewed from the two theoretical viewpoints of control and counterfactual thinking (Miller, Markman & Handley 2007: 130). The theoretical point of view of control applies when assumed that the individual may have lost control over the event which yielded a negative outcome, hence the self-blame. For example a victim may blame themselves for failing to control behaviour preceding an attack or an assault even if the behaviour may not necessarily have caused the negative outcome (Miller *et al.* 2007: 130).

In this study, the women may blame themselves for being infected with HIV and being abused. The other theoretical viewpoint of counterfactual thinking is relevant when "self-blame attributions are made that in retrospect seem to have caused the assault" (Miller *et al.* 2007: 130). These are attempts to understand how the negative experience could have been avoided. Guilt is often the emotion that follows self-blame (Parkinson & Illingworth 2009: 1589). The person may resort to 'if only' utterances, which only perpetuate and convince the person that they are indeed to blame for whatever misfortune, might have happened. As a consequence, women who blame themselves are more likely to relinquish their

attempts at control in order to guard against future failure (Miller *et al.* 2007: 130).

In the descriptions of blame, responsibility is one aspect that should be considered because these two factors (blame and responsibility) are central to the perceptions that people have in making judgements (Powell *et al.* 1998: 308). It is important to distinguish between the two in order to understand what their implications are. Blame conveys an emotional negativity. This means one is blamed for doing something bad and not something good. On the other hand, responsibility is neutral in that a person can be responsible for both good and bad.

In addition, Powell *et al.* (1998: 308) suggests that people are usually not blamed for actions of which the consequences are trivial, even if they may be responsible for that particular incident. However, when the consequences of the said actions are perceived to be dire, then blame surfaces. This is the reason why matters relating to HIV and AIDS are connected to experiences of blame. Having HIV is considered to be serious and life-threatening. Actions perceived to be intentional may be more blameworthy than those considered to be unintentional actions, thus intentionality and foreseeability are key considerations in assigning blame (Lagnado & Channon 2008: 766). Powell *et al.* (1998: 309) further suggest that 'blaming may be influenced by the observer's similarity to the victim' such that by blaming a woman for HIV infection, those doing the blaming attempt to distance themselves from the imagined character or behaviour of the blamed person.

Another aspect of blame is the 'othering' dynamic where groups of people assume that what is happening to other groups cannot apply to them (Petros *et al.* 2006: 69). In the context of HIV and AIDS, this 'othering' could present as placing blame on certain categories of people for being high risk groups for potentially being infected with HIV. This attitude has the devastating effect of preventing people from assessing themselves accurately, with regard to what their realistic chances of being infected by HIV could be. When it comes down to gender it is not surprising that the power dynamics come into play in the blame game.

Women are blamed and 'othered' because they are the weaker gender and they are predominantly dependent on their male partners for support (Petros *et al.* 2006: 69). It is believed that the disproportional occurrence of HIV and AIDS in females, compared to males adds to the 'othering', as the women may be considered dirty and immoral. It is the blame and 'othering' that lead to negative behaviours, including discrimination, tendencies towards social isolation and public shaming of women (Maman *et al.* 2009: 2274). Similarly, Miles *et al.* (2011: 493) found that discrimination of people with HIV and AIDS occurred in the form of gossiping and speculation about those infected, on issues such as how they got infected and blaming them for getting infected or endangering others with the infection.

WLWHA in this study were blamed by their partners, family and friends for being infected with HIV. They were called names suggesting that they got infected because they were prostitutes. They were blamed for the potential of infecting their partners (in the case of those who were in discordant relationships). Instead of providing support and care, (greatly needed when an individual reveals his/her HIV status), family members resorted to insults, ridicule and blame of persons living with HIV and AIDS (Dlamini *et al.* 2007: 398). The authors considered the blame as constituting an element of abuse of persons living with HIV and AIDS. Similar observations were made in another study, where women attending antenatal clinics felt that they could not predict their partners' response to their HIV-positive status, but believed that if trust was lacking in the relationship, the woman would be blamed for bringing the infection in the home and would most likely be beaten and thrown out of the house (Falnes *et al.* 2011: 12).

The feeling of blameworthiness regarding one's abuse may affect the survivor's beliefs about their self-worth. These thoughts of worthlessness may occur because the person thinks their character or behaviour is flawed (Coffey *et al.* 1996: 452). Such feelings result in high levels of psychological distress. Consequently, self-blame erodes the sense of self-worth of a victim. Lekas, Siegel and Schrimshawl (2006: 1172) reported on the internalised stigma among a group of women living with HIV. In their study, they found that the women's feelings of being stigmatised emanated from society's tendency to

blame those with the disease for being infected. It is a general stereotype that results in the assignment of blame for what is considered morally and socially unacceptable behaviours. The women are considered to have indulged in irresponsible behaviour such as promiscuity.

The continuing allocation of blame, despite the fact that HIV and AIDS can be considered chronic and relatively manageable, is a reflection of society's disapproval of those activities that are associated with the spread of HIV. The connotation of women as vectors of HIV is linked to their reproductive role, wherein they can pass the infection to a child, thereby reinforcing the opinion that women are indeed blameworthy for spreading HIV. Another group of women which is often castigated as vectors is that of prostitutes (Long 2009: 322).

The member who tests first in a relationship is usually the woman and is then blamed for bringing HIV into the family. Alleging that women are vectors of HIV infection is to be ignorant of the role of men in the equation. Women are blamed, although they might not be in control of reproductive and sexual decision making in the power hierarchy (Lekas *et al.* 2006: 1184). Blame may have adverse consequences on disclosure. Emusu *et al.* (2009: 1368) found that the question of which partner to hold responsible for bringing the infection into the relationship and blaming the woman for it, has led to the exacerbation of the occurrence of gender-based violence against women by their partners. This violence often occurs when couples counselling, (that attempts to deal effectively with the unfavourable dynamics surrounding disclosure and blame) has not been attended by a concerned couple (King *et al.* 2008: 242).

4.6 HARM

❖ **Harm:** exposure to re-infection, repeated physical harm, secondary physical harm, emotional pain, being forced to stop taking ARVs

The discourse on living positively with HIV encourages people to adopt lifestyle changes that include: having protected sex, having a healthy diet, exercising, decreasing stress levels and seeking health care services in order to enhance

immune functioning. Attempts to jeopardise such practices may constitute harm in the lives of people living with HIV and AIDS (Liamputtong, Haritavorn & Kiatying-Angsulee 2011: 448). Harm in this study of WLWHA has been viewed from a holistic perspective. It includes biological, physical and psychological effects that may result from the constituents of being exposed to re-infection, repeated physical harm, secondary harm, being forced to stop/being interrupted in taking ARVs and emotional pain. These will be discussed to emphasise how it constitutes harm to the WLWHA in the study.

The Oxford Advanced Learner's Dictionary (2010: 651) defines 'harm' as 'hurt or injury; damage done to a thing; a bad effect on something'. The synonyms of harm include the words detrimental, dangerous, unhealthy or destructive. This definition is all encompassing in addressing the bio-psychosocial aspects applicable to human beings. In this case it is applied to the WLWHA. Exposure to reinfection occurred when couples in the study engaged in unprotected sex, while repeated physical harm comprised the women's experiences of physical abuse. Secondary physical harm came about as a result of being forced to stop taking ARVs and from the emotional pain that the women suffered. Each of these aspects is further discussed below.

Exposure to reinfection is one of the challenges that women who are infected by HIV face (Matthews & Mukherjee (2009: S5). The women are concerned about reinfection between partners who are sero-concordant and about transmission of the virus to the uninfected partner in the case of sero-discordant partners or partners of unknown status. The possibility of vertical transmission to a child, should pregnancy occur, is also worrisome (Matthews & Mukherjee 2009: S5). There is a perception that the women may be infectious to their partners or their children (Long 2009: 322). The partners of the women could be seen as agents of harm when precautionary measures are not taken. Moreover, women could be unable to take responsibility for sexual safety, because of the unequal power balance between men and women, so that they are not able to dictate the conditions of sexual encounters with their partners (Long 2009: 322). Another troubling thought is the potential health deterioration that could present in the women, because of effects of further compromised immunity in cases of

reinfection or pregnancy and child birth. All these constitute unique sexual and reproductive health challenges that the women grapple with.

Mattson (2000: 335) states that unsafe sex can be potentially harmful to the individuals practising it and their loved ones. The harm could affect the people concerned personally, as stated above and social-politically, hardships to the concerned people, as they could encounter discrimination. However, Mattson notes that unsafe sex is not the problem but it is a symptom of other complex issues, such as low self-esteem and abuse on the part of the men concerned.

Women in this study reported being pressured to have unprotected sex or to have a child, in spite of the concerns they had about the negative effects of such actions. These findings are similar to those of Stevens and Galvao (2007: 1017), who reported that a sub sample of the HIV-positive women in their study reluctantly engaged in unprotected sex because their partners could not accept the use of condoms in their relationships. This situation could result in the women feeling guilty, particularly when viewed against the background of being discouraged from having unprotected sex or indeed having children, by nurses and other health care providers such as counsellors (Beyeza-Kashesya *et al.* 2009: 10).

The interest shown by WLWHA in having children is frowned upon by the community and health care workers. This poses a real challenge to the couples who wish to fulfil their desires of becoming parents, despite one or both of the partners being HIV-positive (Beyeza-Kashesya *et al.* 2009: 6). Unfortunately, in both developed and developing countries, the reproductive technologies that allow for potential harm reduction through 'artificial intrauterine insemination' or 'sperm washing insemination' and other safer methods of conception are not yet readily available nor are they economically accessible (Matthews & Mukherjee (2009: S7). This means having unprotected sex carries the risk of being potentially harmful to the unborn child, in spite of prevention of mother to child transmission programmes; as well as the infected and uninfected partner, through exposure to infection and reinfection.

The issue of super infection or co-infection with a different virus, which could occur in the course of having unprotected sex between sero-concordant partners has been well documented (Beyeza-Kashesya *et al.* 2009: 6). This information is publicised to the general population and specifically to couples living with HIV and AIDS. Other studies report lower transmission rates with the advent of highly active antiretroviral therapy (HAART). In addition, couples counselling on ovulation related sexual intercourse to facilitate conception is one of the low technology approaches (Matthews & Mukherjee (2009: 57). However, the potential for harm occurring when a partner ends up with resistant viral strains in their system is still there.

Repeated physical harm through beating, kicking or other means of hurting by using physical force can lead to injuries and pain. This may be the most obvious and immediate effect. The after-effects of repeated physical abuse of women have been well documented in the literature. For instance, Thomas *et al.* (2008: 1252) in their study on intersections of harm and health, highlight the effects of violence (particularly by intimate partners) on the health status and well-being of women. These injuries may include swelling, cuts, abrasions, bruises or fractures. The women in this study reported incidents of physical abuse, although they did not report the specific type of injuries that they suffered. These injuries, even though they may heal, can result in disabilities which can be life-changing in nature (Thomas *et al.* 2008: 1253), including chronic pain, disfigurement and impairment of mobility which can lead to reduced physical functioning.

Repeated physical harm can cause stress, affecting the mental well-being of the women. The effects include depressive symptoms and states of anxiety (WHO 2002: 102). Physical harm can also have an economic impact. It brings about reduced productivity on account of decreased performance levels and lost hours or days due to injuries. These constitute some of the secondary harm experienced by the women as indicated below.

Secondary physical harm in this study is viewed in light of the cumulative effects of the abuse endured by the women. Stress resulting from violence can adversely affect women's health, physically and mentally (Thomas *et al.* 2008:

1253). Stress directly related to the abuse may result in headaches, nausea, increased blood pressure levels and eating disorders. The authors also found that intimate partner violence can lead to the worsening of any pre-existing conditions or illnesses.

Thomas *et al.* (2008: 1253) found that the women who participated in their study linked the stress they experienced to compromised immune systems, such as lowered CD4 blood counts and an increase in the number of secondary illnesses suffered. Ultimately this leads to perceived poorer quality of life. Similarly, women in this study were able to distinguish a relationship between experiencing abuse and its effect on their health status. The WHO (2002: 102) noted that women who are abused used health services more often than their non-abused counterparts. The increased use of health services was reflected in more visits to the doctor, more hospital days, consultations with mental health specialists and more visits to the pharmacy.

Women in this study were forced to stop/interrupted in taking ARVs. Violence of any type, from abusive partners and other people, can lead to the sabotage of the victims' self-care efforts. In order for the ARVs to have beneficial results (of suppressing viral load and thereby reducing the chances of opportunistic infections), they need to be taken correctly and consistently. When ARVs are not taken according to specifications, resistant strains of the virus can occur, which become difficult to manage. Interference with self-care practices may become life-threatening (Thomas *et al.* 2008: 1253). For WLWHA this can translate into missed hospital appointments, missed drug dosages or an inability to sustain a healthy dietary intake. This can significantly increase morbidity and mortality of the women. This finding is supported by that of Liamputtong *et al.* (2011: 448), who found that women in their study had difficulties in their attempts to source nutritious food. Their living conditions impacted negatively on ARV treatment adherence and their self-care was jeopardised, leading to failure to live positively with HIV.

Emotional pain, which the women in the study expressed, may have no objective evidence for it to be verified by another person. However, the subjective evidence for the existence of emotional pain is undisputable and compelling (Biro

2010: 662). Eisenberger (2008: 189) noted that it is not coincidental that the language of pain used by those experiencing psychological or physical pain is the same (words such as I feel pain, it hurts can be used with both psychological and physical pain). Similarly, Biro (2010: 661) observed that the metaphors used by people who experienced psychological pain, were the same as those used by people in physical pain. For instance, the use of the term 'stabbing', which normally relates to the physical act of using a weapon, was also used in depicting psychological pain. There is an explanation for these similarities; because research found that there is a common neuronal pathway in the brain that is activated when both psychological and physical pain are experienced (Eisenberger & Lieberman 2004: 298).

Eisenberger (2008: 189) states that experiencing social rejection or a lack of social connection can be described as hurt feelings, using expressions such as 'broken heart, ripped apart, disintegrate or breaking apart, gaping wound, heaviness, or emptiness'. Psychological or emotional pain matters and should be taken seriously because it has adverse effects, even though there is no corresponding physical damage as evidence of injury (Biro 2010: 664).

Emotional pain is a particular type of psychological pain. The two will be used interchangeably in this discussion. Psychological pain relates to any mental mind or non-physical suffering, not limited to affecting one's emotions (Mee *et al.* 2011: 1504). The term emotional/psychological pain is used to denote pain caused by harm that threatens a person's social connections, as is the case when a person is bereaved (Bolger 1999: 344). According to Mee *et al.* (2006: 680) psychological pain is an internal response to noxious psychological stimuli; just like physical pain is a response to noxious physical stimuli. The authors identify another type of psychological pain which is a result of major psychiatric disorders such as severe depression.

In cases of pain associated with depression, sufferers have expressed the sentiment that the psychological pain was more excruciating and intense than the worst physical pain experienced, such as that of passing a kidney stone (Biro 2010: 658). The focus of this description is on the psychological pain occurring in the general population, in response to unexpected and unfavourable life

experiences, and not as a product of a major psychiatric illness. Women in this study experienced emotional pain in their daily lives originating from rejection and humiliation by people who were considered to be their loved ones or people who mattered to them.

Emotional pain can be aggravated in cases of emotional abuse where a person experiences great mental suffering, because of perceived or actual inhumane treatment. In addition, losses that a person may suffer can lead to degradation and erosion of hope. This precedes enduring and deep emotional trauma (Mkandawire-Valhmu 2010: 117). Similarly, the process of detachment from others, where part of the self is viewed as being lost, translates into emotional pain (Bolger 1999: 344). The feeling of isolation is heightened and the person questions the ability to survive without contact with significant others.

Eisenberg and Lieberman (2004: 294) refer to this feeling of aloneness as social pain. It is a distressing experience arising from the perception that there is actual or potential distance or rejection from others who are dear to you or in your social network. According to Bolger (1999: 351) "the essence of the experience of emotional pain is brokenness of the self which is felt at the affective, visceral and conceptual levels".

Emotional pain may stem from traumatic events that the WLWHA experience in relation to encounters involving abuse. The pain may occur at different times, namely the time of the event, when the person remembers the event or when talking about it or hearing others referring to the traumatic incident. Schneidman, who coined the term 'psychache' (in reference to mental pain) is cited by Orbach *et al.* (2003: 220) as stating that "mental pain is energized by frustrations related to efforts to meet essential needs such as love, control, self-image and security". These frustrations in turn initiate a set of negative emotions. Resulting from the above conceptualization, Orbach *et al.* (2003: 228) defined mental pain as "a wide range of subjective experiences characterised by awareness of negative changes in self and its functions accompanied by negative feelings". Thus, mental pain refers to the experiences of anguish and suffering (Orbach *et al.* 2003: 221).

The negative emotions initiated by frustrations related to efforts to meet essential needs, include shame, guilt, defeat, humiliation, disgrace, grief, hopelessness and rage (Orbach *et al.* 2003: 220). According to Mee *et al.* (2006: 682) psychological pain may lead to the development of depression. When experiencing excruciating life events that result in unbearable psychological pain, such as the death of a loved one, individuals are at risk of developing depression. Unbearable pain could cause the person to have suicidal ideations in an attempt to cope with the emotional pain. Such feelings of emotional pain may often be accompanied by anger or sadness at being injured or not being loved.

4.7 ABANDONMENT

❖ **Abandonment:** abandonment by husband, abandonment by own family

Abandonment or rejection, as experienced by the women in this study, is a threat to one's survival as a human being because of the importance of social ties and connectedness, essential for psychological well-being and physical health (Eisenberger & Lieberman 2004: 295). Intimate relationships act as buffers to emotional hardship and it cushions a person against many life challenges. These relationships aid coping processes that could be used to manage situations that would otherwise be difficult to deal with. This buffering effect occurs through the sharing, confiding in and support that spouses accord each other in normal circumstances (Vanderhorst & McLaren 2005: 517).

In contrast, social rejection and being ostracized is associated with negative feelings of self and diminished self-esteem (Eisenberger & Lieberman 2004: 295). Thus, distress and pain is experienced when one is excluded because the presence of others in one's circle is soothing (Eisenberger, Lieberman & 2003: 290). A person's sense of belonging is fortified by interaction with others and can be severely damaged by the human disconnectedness following abandonment (Barroso & Powell-Cope 2000: 345).

Most women who have been abandoned have been left by their partners to fend for themselves. For the women living with HIV and AIDS, abandonment may

result in the loss of reliable sources for economic support and love, earnestly needed when dealing with the physiological and psychological challenges associated with having HIV and AIDS (Carr & Gramling 2004: 38). Abandonment could result in a loss of identity for some of them. For instance, their identity as wives and the social status associated with being a wife could be compromised. This loss of identity and status may be severe when a woman is defined by being partnered or dependent on their partner (de Sousa 2010: 245). The women lose their status as wives in their community because their partners have deserted them. This loss of status equates to suffering disgrace, humiliation and shame. It becomes difficult to survive psychologically due to the loss of attachment that provides support (Adshead 2010: 207).

Consequently, the loss of one's spouse by abandonment has been associated with negative effects. The effects may include suicidal ideation, and suicide attempts, preceded by loneliness and depression (Vanderhorst & McLaren 2005: 517). Women therefore tend to mourn the loss of such relationships in addition to worrying about future losses that may occur in potential relationships because of being HIV positive and the stigma associated with it (Peterson 2010: 474).

Abandonment or rejection is a form of social exclusion. A person is made to feel that they are not welcome or that they do not belong. It is a form of harm sustained to one's social connections (Eisenberger, Lieberman & Kipling 2003: 3). Gielen *et al.* (1997: 27) found in their study that some of their respondents who were rejected or abandoned found it to be a shocking and saddening experience. This rejection and abandonment occurred after disclosing their positive HIV status to their significant others.

In another study Carr and Gramling (2004: 32) concluded that rejection was prevalent among family members, friends and co-workers of the women living with HIV and AIDS, including health workers. While these studies were conducted when ARVs were not readily available, and the threat of HIV was massively frightening, more recent studies reveal similar findings: family members react in a negative manner to disclosure of positive HIV status (Wright & Mwinituo 2010: 44). This rejection and abandonment resulted in social isolation of the women living with HIV and AIDS. In another study, women who

disclosed their positive HIV status were abandoned by their partners who were reluctant to be tested (Amuyunzu-Nyamongo *et al.* 2007: S29).

Women in this study experienced actual desertion or threats of abandonment by their partners and their families. Environments that normally should have been nurturing and loving to the women, turned out to be toxic, painful and not conducive to their state of health and well-being (Carr & Gramling 2004: 35). It is well documented that people suffering from chronic conditions such as HIV and AIDS do benefit and desire the support of their families and friends (Gielen *et al.* 1997: 23). Irrational fears of getting HIV and AIDS may result in the marginalization of those living with HIV, by outright abandonment or through subtle ways, such as avoiding any physical contact, not sharing household utensils or food or not being in close proximity to the person (Miles *et al.* 2011: 494).

Loss of social bonds that are important and feelings of social estrangement are very painful. The loss is the perception of actual or potential distance between a person and those that he/she loves or values. The distance experienced can be physical, where someone breaks the social ties and goes away, or it can be psychological, where the person demonstrates uncaring behaviours. There is evidence that rejection is associated with a negative self-esteem. The findings of this study support that of Maman *et al.* (2009: 2274) wherein participants reported that persons with HIV and AIDS were neglected and socially isolated due to fears of contracting the virus through casual contact. This irrational fear existed in spite of the widespread knowledge of accurate information on the ways in which HIV is known to be transmitted from person to person (Maman *et al.* 2009: 2278). Rejection or shunning has a negative impact on the affected person, in the form of limited social support and lack of access to necessary care for effective management of HIV and AIDS (Mill *et al.* 2010: 1474). In addition, rejection is a violation of human rights. People living with HIV and AIDS who are rejected or abandoned by their partners or family feel their dignity has been threatened and their rights violated (Kohi *et al.* 2006: 410).

Abandonment has economic implications for most women. Those women who were abandoned became poorer and had limited resources to use in their daily

life (Balaile *et al.* 2007: 15). Inadequate resources have negative repercussions. Women may not be able to meet the demands required to sustain healthy living, such as good nutrition, good living conditions and adherence to treatment with their medications (Liamputtong *et al.* 2012: 448). In a study by Dlamini *et al.* (2007: 395) it was found that being evicted from one's house due to HIV was more common among women than their male counterparts. Although disclosure is encouraged, health workers are advised to assess the individual situations of their clients because it has been associated with potential and actual risk of abandonment or rejection (Medley *et al.* 2009: 1745).

A woman who is rejected feels hurt. Her life and family dynamics are disrupted. The humiliation of being abandoned is increased by the perceived betrayal by the partner that she trusted (Stark 2007: 5). For the WLWHA, being abandoned by one's family is even more traumatic, considering the value that is placed on such relationships. The social networks established with relatives can be viewed as indestructible. In such instances the relatives effectively reject the individual through avoidance and creating social distance.

The woman will therefore have constant feelings of being abused following the rejection imposed by the relatives (Varas-Diaz, Serrano-Garcia & Toro-Alfonso 2005: 183). The situation can be worrisome, especially when the woman's livelihood is dependent on the relatives, as a potential source of support for dealing with the challenges of living with HIV and AIDS is eliminated. Abandonment, rejection or exclusion effectively results in heightened stress levels in the WLWHA (Nepal & Ross 2010: 28).

4.8 SUMMARY

In this chapter the five concepts that relate to the essence of abuse, identified from the analysis of the experiences of abuse among WLWHA have been described. The concepts include humiliation, hopelessness, blame, harm and abandonment. Experiencing the aforementioned can lead to accumulation of stress in the women. Stress is particularly detrimental for the well-being of the women. This may lead to a further compromise in immune functioning which can have negative effects on health, such as the occurrence of opportunistic

infections due to HIV and subsequent accelerated mortality among WLWHA. Following in Chapter 5 are the guidelines for assessment required to identify experiences of abuse of WLWHA. Early identification and management would contribute to better quality of life for the women.

CHAPTER 5

**PHASE TWO OF THE STUDY: DEVELOPMENT AND REFINEMENT OF
GUIDELINES FOR THE ASSESSMENT OF ABUSE OF WOMEN LIVING WITH
HIV AND AIDS**

5.1 INTRODUCTION

Phase 1 of the study focussed on describing experiences of abuse among women living with HIV and AIDS. Phase 2 of the study focuses on the development and refinement of guidelines that can be used to assess the occurrence of abuse in women living with HIV and AIDS. The draft guidelines are based on findings from the data analysis, conducted in phase 1, and an extensive review of literature. The process used to develop and refine the guidelines is described below.

5.2 DEVELOPMENT OF THE DRAFT GUIDELINES FOR ASSESSMENT OF ABUSE OF WLWHA

Guidelines are essential, as they could be used to improve health care delivery to specified populations and individuals (such as WLWHA), based on research findings. In this study the research findings of phase 1 is translated into statements (constituting the draft guidelines) with the aim to develop a final set of guidelines to bridge the gap between the findings of the research and the improvement of the nursing practice. Guidelines are systematically developed to assist providers to make informed decisions in specific circumstances in health care settings (WHO 2003: 2). The format of guidelines is chosen with its use (to improve practice) and the target audience (WLWHA) in mind (Duff 1996: 889). Guidelines constitute an aspect of knowledge and thus theory development, being rooted in research in a particular field. It is formulated in accordance with evidence provided by good research literature. The guidelines in this study are a component of knowledge development that is aimed at promoting quality of care for WLWHA who are exposed to abuse. The body of evidence on which the guidelines are based, was obtained from extensively reviewing literature related

to the five concepts (consolidated from the constituents identified during the data analysis, discussed in chapter 4).

Chinn and Kramer (2011: 2) extended knowledge development in nursing (utilizing the 'fundamental patterns of knowing' identified by Carper [1978]), by acknowledging that nursing could be more effective by encompassing the empiric, personal, ethical, aesthetic, and emancipatory patterns of knowing. Through integration of the five patterns of knowing, individuals recognise the social-political inequalities or injustices embedded in situations, to change for the better (Chinn & Kramer 2011: 64). It is for this reason that in this study, the guidelines were developed in an effort to identify the injustices and inequalities experienced by women living with HIV and AIDS (through the assessment of abuse) and contribute to nursing knowledge. Dickoff *et al.* (1968: 420) identified six aspects to take into consideration when developing a practice discipline theory. The researcher has applied this to the development of the guidelines and they include:

The goal or purpose of the activity

The purpose of developing the guidelines for assessment was to identify experiences of abuse among WLWHA. Early identification and management may contribute to better quality of life for the women.

Agency or person(s) performing the activity

In the context of this study, nurses working, in any health care setting, with women living with HIV and AIDS who experience abuse will be the agents. Other health workers who are responsible for WLWHA could also use the guidelines.

Recipients of the activity (reciency)

The recipients of the activity, or assessment using the guidelines, will be women living in Malawi, with HIV and AIDS, who experience abuse.

Framework or context

The assessment of WLWHA for abuse will take place in all health care settings where nurses interact with the women. These may include, ART clinics, support groups, antenatal and post-natal clinics.

Dynamics or energy source of the activity

The use of the guidelines for the assessment of WLWHA for abuse will be motivated by the nursing and general health care principle of providing quality and effective nursing/health care to WLWHA, who are exposed to abuse.

Procedure (guiding technique) or protocol of the activity

The assessment guidelines for WLWHA who are exposed to abuse constitute the guiding principle for the activity.

5.3 THE DRAFT GUIDELINES FOR THE ASSESSMENT OF ABUSE OF WLWHA

The issues that should be explored to identify abuse of WLWHA, in their experiences interacting with their partners, families, in-laws, friends and neighbours, were addressed in the draft guidelines. They included: humiliation, harm, hopelessness, blame and abandonment, as experienced by WLWHA.

The researcher formulated the draft guidelines for assessment based on the findings (chapter 3) and discussion of the findings (chapter 4) of phase one of the study. Initially, constituents were described, supported by direct quotations from the participants. The constituents represent the common experiences, identified during the analysis and description, regarding the abuse of women living with HIV and AIDS who participated in the study. The constituents identified from the data were consolidated into five concepts namely humiliation, hopelessness, blame, harm and abandonment. These five concepts were discussed further in chapter 4 to elucidate their manifestations and consequences. In formulating the discussion, literature relating to the concepts was extensively reviewed. The conclusions derived from the discussion were used to develop the draft guidelines for the assessment of abuse of WLWHA. It

also provided the rationale for including each of the guidelines. Thus, the findings and discussion provided a scope for the guidelines.

The process followed in the development of the guidelines is summarised as follows:

- i. Experiences of abuse among women living with HIV and AIDS were explored and described using a phenomenological study.
- ii. Findings from the data were presented so that the essence and constituents of the experiences of abuse were indicated.
- iii. An extensive review of literature was conducted to develop a more comprehensive and deeper understanding of the constituents and then discussed in chapter 4.
- iv. Draft guidelines were formulated based on the discussion presented in chapter 4, on account of the findings and the extensive review of the literature.

The guiding principles for formulating guidelines dictate that they should be credible and reliable, by meeting the criteria for high quality clinical practice (Shekelle *et al.* 1999: 596; AGREE Collaboration 2003: 4). Guidelines should be reviewed and updated regularly to ensure that new evidence and trends are incorporated. The six domains that address quality of practice guidelines include:

- i. **Scope and purpose:** the overall aim of the guideline and target population should be specified. The aim of the guidelines is to provide direction for the identification of abuse among women living with HIV and AIDS (the target population). Nurses working with WLWHA will use the guidelines.
- ii. **Stakeholder involvement:** the guideline should focus on the views of the intended users. The guidelines were based on data obtained from WLWHA. Experts in the field of gender-based violence and HIV/AIDS, all

of them nurses, contributed to the development of the guidelines through the Delphi process.

- iii. **Rigour of development:** the processes used to gather evidence for recommendations and plans for review should be specified. After collecting information from the WLWHA on their experiences of abuse, an extensive review of literature was conducted to identify the evidence supporting the guidelines. The plan for review has been included in the guidelines so that they will remain current through the incorporation of new evidence on a regular basis.
- iv. **Clarity and presentation:** The language and format used in the guidelines is simple, easy to follow and unambiguous, as prescribed by the guiding principles for formulating guidelines.
- v. **Applicability:** The guideline should be applicable to its demographic group. These guidelines are deemed to be applicable as they are based on research findings from the target population of WLWHA. However, the organizational, behaviour and cost implications of using the guidelines will be determined upon implementation.
- vi. **Editorial independence:** the researcher should not have a vested interest in the nature of the outcome of the guideline development process. Involving experts in the process strengthened the editorial independence of the developed guidelines.

The future reviewers of the guidelines should assess these aspects to determine whether it meets the quality standard. A summary of how the aforementioned domains pertain to this study is presented in table 5.1.

Domain	Description
Scope and purpose	To provide direction for the identification of abuse among WLWHA.
Stakeholder involvement	Expert nurses in the field of gender-based violence and HIV and AIDS participated in the Delphi process. Data was obtained from WLWHA.
Rigour	Data was obtained from interviews with WLWHA. Literature was extensively reviewed. Experts were used in conducting the Delphi process to refine the guidelines.
Clarity and presentation	Language used is simple and specific.
Applicability	The guidelines are based on research findings.
Editorial independence	The use of experts supported editorial independence.

Table 5.1 Domains and characteristics of guidelines for quality of practice

Source: Adapted from Shekelle *et al.* 1999: 596; AGREE Collaboration 2003: 4.

5.4 PROCESS OF REFINEMENT OF THE DRAFT GUIDELINES FOR ASSESSMENT OF ABUSE OF WLWHA

The draft guidelines for assessment were sent to an initial group of eleven experts based on the specified selection criteria. The panel of experts comprised of individuals working in the field of HIV, AIDS and gender-based violence at different levels of involvement. Of the eleven experts two responded that they could not take part in the study because of their busy schedule at the time while three gave input on the guidelines, three responded that they would give the researcher feedback. After two weeks the researcher sent reminders to the participants that did not respond and those that made a commitment to respond. One responded with input on the guidelines. The researcher sent the draft guidelines to an additional three new members who also gave their input on the initial draft. Contrary to expectations that email communication would be fast, some of the experts took long to respond so that the researcher waited for

almost two months to get all the feedback before their input could be put together for round two.

All the experts agreed that the elements of the guidelines were important. Their input was on language; others noted repetitions in some of the actions and suggested re-ordering of some of the actions. The researcher revised the areas that were perceived to be lacking clarity and sent only the revised parts of the guidelines back to the experts to be scrutinized in round two. The experts returned the guidelines and noted that they had no additional comments to make as the guidelines were acceptable. Editorial corrections were made as suggested by some of the experts. In consultation with the research supervisors, it was determined that consensus had been reached by the end of second round and that there was no need for round three. A detailed description of the Delphi method used to obtain consensus on the draft guidelines for assessment of abuse in WLWHA follows.

5.5 THE DELPHI METHOD

The Delphi method was used in this study to reach consensus on the draft guidelines for assessment of abuse of WLWHA. Originally, the Delphi technique was used as a forecasting tool for soliciting reliable information from experts in the military (Still-Gohdes & Crews 2004: 56). The Delphi method, or technique, is defined as a multistage approach using a series of data collection rounds, or stages, with each one building on the results of the previous stage (McKenna 1994: 1221). It is a way of systematically obtaining informed judgements from identified experts on a specific topic (Williams & Webb 1994: 180). In effect, the Delphi technique involves several rounds of data collection, feedback being given to the participants between rounds and allowing the participants to modify their responses in an anonymous way (Mullen 2003: 38). However, there are no techniques formally agreed upon for applying the Delphi method, yielding what are considered modified versions of the original. These versions reflect flexibility in their design, depending on the aims of each study (Keeney, Hasson & McKenna 2005: 208). The author adopted a modified version of the Delphi method for the study by presenting an already developed draft of guidelines for assessment based on the study findings and a review of literature instead of

asking the experts to come up with the areas for assessment. However, the experts were allowed to add or make changes to the draft to include areas that they considered important in the assessment of abuse in women living with HIV and AIDS.

The Delphi method is an effective and efficient way of bringing together the expertise of people that are geographically separated. It can be used to obtain judgments on issues from a panel of experts, who do not need to meet in person (Polit & Beck 2008: 327). This characteristic of 'no meeting' is cited as one of the major advantages of the Delphi method. Expert opinions can be solicited without the constraints of time and place, as is the case in face-to-face meetings (Meyrick 2003: 7). The researcher was able to utilize this method in the study to solicit the opinions of experts for refinement of the guidelines for assessment of abuse of WLWHA.

McKenna (1994: 1222) summarized the characteristics of the Delphi technique as follows:

- i. Data is obtained from a panel of experts.
- ii. There are no face-to-face meeting among the experts.
- iii. A sequence of questionnaires or interviews is used.
- iv. Consensus of opinion emerges in a systematic manner.
- v. Anonymity of responses is guaranteed.
- vi. Patterns of agreement are determined.
- vii. Two or more rounds are used, with a summary of the previous round's results communicated for evaluation by the expert panel.

5.5.1 The panel of experts

The term 'expert', as used in the Delphi process, refers to people who are well informed about a particular subject. These people could be professionally qualified specialists in their field of expertise. The authoring of books, materials and peer reviewed journal articles could be considered as having expertise in the published area of study (Baker, Lovell & Harris 2006: 62). The experts could also be ordinary people, such as patients who are familiar with the issues, depending on the topic under investigation. Thus, the characteristics that an expert should possess include being knowledgeable about the topic or having sufficient experience regarding the issue under discussion (Mullen 2003: 41).

Nursing professionals who were conversant on the issues of gender-based violence, HIV and AIDS, were consulted in this study. In doing so, the preliminary stage of refining the guidelines, before they could be adopted, was accomplished. The number of experts used in panels, employed when utilizing the Delphi method, is reported to be varied and non-prescriptive, ranging from a minimum of 4, to hundreds or even thousands of people, depending on the nature of the topic under scrutiny (Mullen 2003: 41). Typically though, panels seem to have between seven and twelve members. In this study, ten members (six from South Africa, one from Botswana and three from Malawi) constituted the panel of experts. The members from South Africa and Botswana were chosen on recommendation of the research supervisor, who was familiar with their expertise. The researcher selected the members from Malawi based on their work in the field of gender-based violence, HIV and AIDS. A detailed description of the panel members is provided under the paragraph entitled 'population and sample'.

The first step in applying the Delphi method allows for broad comments on a subject area (Efstathiou, Ameen & Coll 2008: 363). The experts are provided an opportunity to contribute information they deem important in the relevant field of study during the initial stage. Providing a list of options or suggestions of areas where consensus is sought, based on study results and an extensive review of literature, has the advantage of reducing the time period of the study (Meyrick 2003: 12). This method, of providing an initial list, as well as the

opportunity for the experts to include comments as necessary, was adopted for this study.

The subsequent round was initiated by the researcher after summarizing responses from each round. These were re-presented to the panel of experts for reconsideration in, light of the new information. Members of the panel are able to change or alter their previous position upon reviewing the input from other members (Crisp *et al.* 1997: 5). A feedback and response loop is established to manage the whole process of polling opinions together, providing controlled feedback and re-polling the issues for further evaluation by the panel of experts (Meyrick 2003: 7). The use of several rounds of this process resulted in the panel of experts providing a collective judgement on a specified topic; the process was repeated until consensus was reached (Polit & Beck 2008: 327).

5.5.2 Consensus of opinion

The issue of consensus of opinion as an outcome of conducting the Delphi technique in studies has been debated. It has been stated that consensus may not be the desired result if the goal is to specify the rationales for differing or opposing positions on a given issue (Mullen 2003: 43). Thus, whether consensus is sought, or not, may depend on the purpose and the objectives for applying the Delphi method. Where consensus is desired, however, as in the case of seeking normative views (the case in this study), the determination of what constitutes consensus may vary from study to study. Teijlingen *et al.* (2006: 249) report of studies that put their consensus cut-off points from as high as 70% to as low as 51%. Other studies considered 100% consensus as the ultimate goal to be achieved. The researcher chose 60% as the consensus cut-off point. This meant the majority of the panel were in agreement with the draft guidelines.

5.5.3 Number of rounds

The number of rounds advocated in the literature ranges from two to four, or more if consensus on the issues is not readily achieved by the panel of experts (Mullen 2003: 46). Precautions should be taken against having too many rounds.

Although having many rounds could be beneficial in some areas, it could be detrimental in others. The participants could become too fatigued to contribute efficiently. Most studies use three rounds of data collection and collation, with the number of rounds increasing as long as time allows (Teijlingen *et al.* 2006: 249). This study initially adopted the design of using three rounds of data collection to obtain consensus but after the second rounds consensus was reached.

5.5.4 Anonymity in a Delphi study

A key consideration in the Delphi process is the issue of anonymity. Information about the topic is sent to individual members of the panel in a confidential and anonymous manner (Williams & Webb 1994: 181). Anonymity is necessary because it allows members of the panel to make their contributions without being influenced by group pressure or dominant and known personalities, as may occur in a face-to-face committee meeting (Mullen 2003: 47). This anonymous process results in members 'input being assessed on merit', without the assessor being influenced by the reputation of the contributor (Meyrick 2003: 10). In the absence of hindrances that include hierarchy in a profession, members are not intimidated or inhibited in expressing their views (Williams & Webb 1994: 181).

There may be variations in the manner in which anonymity is applied in the Delphi process. Some scholars advocate that the identity of participants should not be revealed to the other members. Others prefer to keep the contributions of the experts anonymous (Mullen 2003: 46). In such a scenario a 'quasi-anonymity' is created, where the experts are known to the researcher, and to one another, but their contributions are not revealed.

A liability of the use of anonymity in the Delphi process is that members might not be committed to the process when others do not know what their contributions are (Mullen 2003: 47). In addition, they could compromise and agree with other people's opinions more readily, simply to complete the process. This would create artificial consensus because of the lack of accountability for their decision or position (McKenna 1994: 1224). It is necessary, therefore, to

consider a person's interest and commitment to a 'topic' and the process when selecting members to constitute the panel of experts (Meyrick 2003: 10).

The Delphi method was considered appropriate to apply in this study because information was solicited from experts based in countries across a wide geographical spectrum (Malawi, Botswana and South Africa). A computer based Delphi process has advantages such as time and cost effectiveness. Members need not meet face-to-face for them to make their contributions as required. The experts were requested to make judgments about a topic of common interest, namely guidelines for the assessment of abuse of WLWHA, using electronic mail. The experts who participated in the Delphi process remained anonymous to one another. The emails were sent separately to each member of the panel. This anonymity allowed for free expression of opinion (Still-Gohdes & Crews 2004: 58).

The draft guidelines for assessment were developed in light of the issues that were identified in the discussion of findings on experiences of abuse. By applying aspects of the Delphi method, the researcher presented the draft guidelines for assessment to the panel members for comment. The draft guidelines for assessment were presented to the experts as a list of statements with a request to each expert to peruse the guidelines one by one and provide an opinion or comment on its applicability or suitability for the assessment of abuse of WLWHA. The experts were also requested to reformulate the draft guidelines, should they find it necessary to do so. They were encouraged to indicate which statements were to be added or removed from the guidelines. The comments were collated for use in refining the guidelines. Two rounds were used to reach consensus on the guidelines for assessment.

5.5.5 Population and sample

The panel of experts was composed of six members from South Africa, three members from Malawi and one member from Botswana who participated in the refinement of the guidelines. The researcher contacted experts in the field of HIV, AIDS and gender-based violence recommended by the research supervisors, who could attest to their expertise. People working at clinical,

research and academic institutions were selected. A purposive sample of eleven experts, based on their work and knowledge on the subject, was compiled. The contact addresses of the experts from South Africa and Botswana were known to the research supervisor and those from Malawi were known to the researcher. The initial contact, as well as communication during the Delphi process, was conducted electronically through email. Table 5.2 provides a summary of the descriptive information about the members of the panel that were actually involved in the refinement of the guidelines for the assessment of abuse of WLWHA, listing their particular expertise.

NO	POSITION	QUALIFICATION	EXPERIENCE
1	Head of post basic nursing programme	PhD Nursing	Involved with HIV and gender issues since 1989. Founded and managed two HIV and AIDS centres. Member of several women focussed organizations. Presented research reports on gender-based violence at national and international conferences.
2	Senior lecturer	RN, PhD	Involved in home based care programming with postgraduate students and interacts with WLWHA. Lectures in community health nursing at both undergraduate and postgraduate level.
3	Senior lecturer	DCur	Teacher and midwife

4	Youth and prevention specialist	MCur, PhD scholar	<p>Works with an International organization dealing with gender-based violence partners.</p> <p>Underwent 'on the job training' in integrating gender activities.</p> <p>Supervises the implementation of gender activities.</p> <p>Participated in gender-based violence internet assessment report.</p>
5	Primary health care nurse	MCur, PhD scholar	<p>Experience in primary health care settings.</p> <p>Manages a centre for women and children's health issues.</p>
6	Senior lecturer	DCur	<p>Experience in trauma counselling and psychotherapy.</p> <p>Lectures in Mental Health and Psychiatric Nursing</p>
7	Deputy Director, HIV/AIDS/STI&TB programme manager	PhD scholar	<p>Has worked in the HIV/AIDS environment since 1992 at both regional and National level.</p>
8	Public health specialist	MPH	<p>Works in the field of promoting gender equity and minimizing gender-based violence using a tool called Africa Transformation and HIV.</p> <p>Experience working in projects managing HIV and AIDS issues at national level</p>

9	Lecturer in community health nursing and Dean of Nursing	PhD	Trainer of trainers (professional groups including health workers in gender issues. Master trainer community home based care, HIV & AIDS, Palliative Care. Lectures in community health nursing at both undergraduate and post graduate level
10	Lecturer in community health nursing	MPH	Trainer in youth behaviour change. Activist on women's sexual and reproductive health issues. Lectures in community health nursing at both undergraduate and post graduate level

Table 5.2 Descriptive information - panel of experts

5.5.6 Trustworthiness of findings

The use of a panel of experts who are knowledgeable about the topic, contributed to the trustworthiness of the Delphi process. Studies have used different consensus cut-off points, depending on the topic under scrutiny. This study adopted the 60% consensus on any given item, as it could then be assumed that more than half of the participants agreed on the issue (McKenna 1994: 1222). The use of multiple rounds also led to consensus of opinion on the development of the final guidelines for assessment (Hasson, Keeney & McKenna 2000: 1013). A total of two rounds were completed for this study. It is recommended that an audit trail, documenting all decisions during the Delphi process, is maintained. This should be kept in a journal (Skulmoski, Hartman & Krahn 2007:11). Such a journal has been kept by the researcher for review by those that would be interested in the decision trail (Refer to Annexure J).

5.5.7 Delphi round one

The researcher contacted the experts by email to invite them to participate in the refinement of the draft guidelines for the assessment of abuse of WLWHA. A description of what was expected of the experts was provided in a cover letter, containing information about the study, to allow the experts to make an informed decision on whether they were interested in participating or not (Refer to Annexure C). This process ensured informed consent. Those who were willing to participate in the Delphi process were supplied with the draft guidelines for assessment, requesting their comments on the suitability of the statements in terms of the assessment of abuse of WLWHA and any additions or changes they would deem necessary.

Keeney, Hasson and McKenna (2006: 209) state that time is a critical factor in using the Delphi technique. Adequate time should be allocated to allow for analysis and re-development for use in subsequent rounds. The experts were allowed a period of two weeks to make comments (although it took longer than two weeks). Upon receipt of the first round of responses, similarities and differences in the experts' responses to the draft guidelines were identified. All the experts agreed that the guidelines were necessary. The common observations made were on areas that lacked clarity, repetitions of content and editorial corrections. This provided input for the guidelines that were presented in the second round (Efstathiou, Ameen & Coll 2008: 363). The researcher corrected the overlaps, repetitions and the editorial errors observed by the experts.

5.5.8 Delphi round two

A revised list of guidelines for the assessment of abuse of WLWHA was formulated by the researcher for round two, guided by the responses from round 1. The researcher compiled the list of guidelines for this round, based on the observations made by the experts. The areas where there was lack of clarity were redone, repetitions were eliminated and typographical errors were corrected for evaluation in this round. Areas considered applicable and important by the experts were identified.

The experts were contacted by email once more to inform them about the second round. Again, a period of two weeks was given to allow the experts adequate time to make comments. The responses from the second round of evaluation were analysed and a summary compiled of how the experts responded to the revised guidelines. Seventy per cent of the experts said that they were satisfied with the guidelines and they had nothing more to add. A final set of guidelines was formulated and is presented in chapter 6.

5.5.9 Title and aim of the guidelines

The title of the guidelines is "Guidelines for the assessment of abuse of women living with HIV and AIDS". The name was derived from the title of the study. The guidelines are aimed at providing guidance on discerning the occurrence of abuse when assessing WLWHA. Nurses are the target users of the guidelines, while the WLWHA are the target recipients. Each guideline formulated has an accompanying rationale for being included and also the actions to be taken by the nurse. Following are the draft guidelines established to address the five areas, ascertained to pertain to the abuse of WLWHA, namely humiliation, hopelessness, blame, harm and abandonment.

5.6 THE DRAFT GUIDELINES FOR ASSESSMENT OF ABUSE OF WOMEN LIVING WITH HIV AND AIDS AND INPUT FROM THE EXPERTS

Guideline 1: Nurses are to explore the occurrence of humiliation as a form of abuse of women living with HIV and AIDS

a. Rationale

Women living with HIV and AIDS may be exposed to humiliation because of the actions of their partners, their family members, friends and neighbours. The women might isolate themselves to avoid humiliating encounters with others. If

humiliation is identified it would prevent devastating consequences in the lives of the women, including physical and psychological impacts such as mental problems (Ludemir *et al.* 2008: 1016).

Nurses could play a major role in prevention of such impacts and should make a deliberate effort to assess for humiliation, which could affect the person's ability to behave in an appropriate manner (Torres & Bergner 2010: 199). Strategies for interventions that support the women in promoting their emotional well-being should be devised.

Comments from the experts

b. Actions

When assessing WLWHA nurses should:

- | | |
|---|--|
| <ul style="list-style-type: none"> • <i>Explore any feelings expressed by the women, of being disrespected, ridiculed, or insulted by the actions of any of these persons: partners, family members or friends and neighbours.</i> | <p><i>Move the action to appear after second bullet</i></p> <p><i>Replace partners, family members or friends and neighbours with 'significant others'</i></p> |
| <ul style="list-style-type: none"> • <i>Encourage the women to express any feelings of being unfairly treated in any way as a repercussion of being HIV-positive.</i> | <p><i>Move action to appear first</i></p> |
| <ul style="list-style-type: none"> • Determine whether the women have been made to feel unrecognised, or insignificant, by the actions of others in relation to their HIV status. | |
| <ul style="list-style-type: none"> • <i>Ascertain whether the women feel they have been gossiped about, rumours have been spread about them or they have been ridiculed.</i> | <p><i>Add in their homes, communities or at work</i></p> |

- Identify whether the women feel their honour and dignity has been adversely affected or jeopardized in any way by the actions of others, on account of their HIV status.
- Establish whether the women feel ashamed or obtuse in response to the actions of others in relation to their HIV status.
- Determine if the women feel excluded, ignored or rejected in their interaction with others within their social network.
- Explore any feelings that the women have of being betrayed in their relationships with others, having caused them to become distrustful.

Guideline 2: Nurses are to identify feelings of hopelessness as a manifestation of abuse of women living with HIV and AIDS

a. Rationale

Hopelessness is recognised as being detrimental to the process of recovery from illness. It can be disempowering to individuals, as they become apathetic and inactive in dealing with their situation (Gurkova, Ziakova & Cap 2011: 34). It is necessary to identify situations or feelings that may be indicative of hopelessness in WLWHA. Early identification can facilitate instituting interventions that may promote a positive outlook on life despite the challenges

that may be encountered (Kylma 2004: 818).

By recognizing and re-evaluating the triggers for the feelings of hopelessness in their lives, the women are empowered to reflect and regain a sense of control over their life's circumstances and a movement towards hope, which is essential for having a positive outlook, is initiated (Flynn *et al.* 2000: 61).

Comments from the experts

b. Actions

In the identification of hopelessness in WLWHA nurses should:

- Inquire about the women's feelings of powerlessness in improving their situation for the better.
- Explore whether the women feel that their situation is irremediable or insurmountable and impossible to overcome.
- *Determine if the women feel they have no sense of purpose in life or that their life has no sense of meaning.*
Replace no sense of purpose with life has no sense of meaning
- Establish whether the women feel like giving up on life and giving up hope.
- *Ascertain whether they feel lonely and without social support in light of changed relationships.*
Rephrase to read 'changed relationships with significant others leave

them without family and

- Explore if they feel a diminished sense of *social support* self-esteem due to the actions of others.
- Identify any loss of motivation to deal with their situation.
- Assess any decrease in affective emotions towards themselves and other people.

Guideline 3: Nurses are to assess blame as a form of abuse of women living with HIV and AIDS

a. Rationale

Women living with HIV and AIDS might be blamed and shamed for being perceived to be sources of infection to children and their partners (Miles 2011: 493). The women's feelings of being blameworthy could affect their sense of self-worth and result in psychological distress (Lekas *et al.* 2006: 1184). Personal and interpersonal blame can lead to feelings of guilt, even though a person is not responsible or accountable for the prevailing circumstances (Parkinson & Illingworth 2009: 1610).

Blame places undue burden on the sufferer, while ignoring the complex cultural, socio-economic and political context of the underlying situation or illness. Hence, it is counterproductive to isolate for blame, one facet of the dynamic in the causation or spread of disease (Finerman & Bennet 1994: 1). Identifying the blame dynamics in a relationship could assist in offering a holistic approach of supporting women to manage disclosure in an effective manner.

Comments from the experts

b. Actions

In the assessment of WLWHA for feelings of blame nurses should:

- Explore whether the women have been called names or have been shamed in public for being HIV-positive.
- Determine whether the women have been referred to as being worthless by others because of their HIV status.
- *Ascertain if the women feel that others have considered them to be a burden for possibly having had to rely on their assistance before or in the future.* *Rephrase to read 'rely on their assistance now or in future'*
- Establish if the women have been referred to as being the sources of infection after disclosure of their HIV-positive status.
- Explore whether they feel they deserve blame and have to take responsibility for being victimized.
- Examine whether the women are being treated as different to their relatives and friends.

Guideline 4: Nurses are to focus on the occurrence of harm when assessing women living with HIV and AIDS.

a. Rationale

WLWHA might be exposed to all types of harm including physical, psychological, socio-economical and sexual, which can be detrimental to their health. Abuse of any form can disrupt the women's attempts at self-care activities, in that it could cause a failure to adopt lifestyle changes that facilitate immune functioning. The resulting stress can adversely affect the physical and mental health of the women (Thomas *et al.* 2008: 1253). Direct and indirect factors, such as being beaten and being forced to have unprotected sex respectively, that have been found to cause harm, should be explored with the women in an open and client centred manner to obtain the desired results (Mattson 2000: 333).

The issues that contribute to the harmful practices in the lives of the women should be identified and an approach adopted that can lead to the implementation of harm reduction strategies, to promote positive living (Matthews & Mukherjee 2009: S7).

Comments from the experts

b. Actions

In the assessment of factors that may contribute to harm of WLWHA nurses should:

- Explore circumstances under which the women are forced to engage in unprotected sex (predisposing them to reinfection with HIV).
- *Establish whether the women harbour any worries concerning conception and possible transmission of HIV to an unborn child.*

Add or neonate

- Determine the dangers associated with attempting to negotiate safe sex with their partners.
- *Assess any injury or pain suffered by the women as a direct or indirect consequence of their positive HIV status.* *Rephrase to read 'emotional pain'*
- *Explore any potential inhumane treatment that the women might have encountered and their feelings about it.* *Add by significant others*
- *Identify any losses that could have been suffered. Such losses may include status, income, and good health, resulting in perceived poorer quality of life.* *Add spiritual and psychological losses*
- Ascertain if feelings of being pressured or stressed by the actions of other people are experienced.
- *Determine if there is an inability to carry out self-care practices due to the interference of other people.* *Specify self-care with taking ARV medication due to lack of family support*
- Assess whether the women experience harm in relation to their basic needs of love, security and belonging not being met.

Guideline 5: Nurses are to assess the occurrence of abandonment as a manifestation of abuse of women living with HIV and AIDS

a. Rationale

Abandonment or rejection is a threat to survival. Interaction with others could be hindered by the disconnection in relationship that occurs in the case of rejection (Barroso & Powell-Cope 2000: 345). Abandonment yields loss of love, emotional and economic support (Carr & Gramling 2004: 38). It could also affect mental health. Instances of depression have been reported, following loneliness due to abandonment (Vanderhorst & Mc Laren 2005: 517).

The two types of social support are emotional and instrumental (being there to comfort and providing comfort and tangible assistance respectively). The personal attributes of people in a social support network is more important than specific persons such as partners, family and friends. However, it can be difficult to divulge personal information where there is no mutual feeling of being intimately familiar and confidentiality (Finfgeld-Connett 2005: 6). Inadequate social support could have adverse effects on WLWHA, as this is a time when they need people they would trust and rely on for emotional and material needs, required to sustain a healthy life.

Comments from the experts

b. Actions

In the assessment of WLWHA nurses should:

- Explore any feelings the women might have of being rejected by members of their social network.
- Determine whether the women experience feelings of no longer belonging to their social network.
- Identify the existence of negative feelings

about self and diminished self-esteem on account of the actions of others in their social network.

- Establish the level of deterioration in social support (so that the women have to fend for themselves) compared to previous circumstances.
 - Assess if the women have suffered a loss of identity and status, such as that of being a wife, partner or other social attachments.
 - Explore if any relationships in the women's lives have deteriorated and potential feelings of betrayal and pain with regards to this.
 - Ascertain whether the women feel that others have avoided physical or social contact with them.
 - Explore any feelings the women might have of being shunned due to their HIV status.
 - Explore issues of lacking access to necessary care that the women might experience.
 - *Determine the extent of limitations in relation to resources as a consequence of abandonment.*
- Add survival to resources to read 'survival resources'*

The researcher integrated most of comments as indicated by the panel of experts. These included removing overlaps which was noted by the majority, adding some words to improve readability of the actions and clarifying some of the actions by re writing the statements.

Table 5.3 is a summary of the sequence of all the activities conducted in the development and refinement of the guidelines for assessment of WLWHA in Malawi from the findings of in depth interviews with the women to the input obtained from the Delphi process.

1	Findings were determined from the data analysis of the interviews.
2	Literature was reviewed extensively and a discussion compiled.
3	Draft guidelines were formulated.
4	Panel of experts were selected to refine guidelines.
5	Round 1 of Delphi process was performed.
6	Guidelines were analysed and adjustments made, in line with comments.
7	Round 2 of Delphi process was performed.
8	Guidelines were analysed, adjustments made, in line with comments.
9	Final refined guidelines for assessment of abuse in of WLWHA were compiled.

Table 5.3 Summary of the sequence of activities conducted in the development and refinement of the guidelines for assessment

5.7 VALIDATION, REVIEWING AND UPDATING THE GUIDELINES FOR ASSESSMENT

In this study, the preliminary guidelines of assessment of WLWHA were developed by the researcher and then refined by involving experts in the field of HIV and AIDS. The final product was a set of guidelines for the assessment of abuse of WLWHA. However, it is recommended that the guidelines should be validated, by evaluating them with the criteria for quality clinical practice in mind, before they are disseminated and implemented. This process will ensure that the guidelines are credible, and reliable. The attributes that should be evaluated include: relevance, comprehensiveness, applicability and acceptability

using rating scales (Shekelle *et al.* 1999: 596). Guidelines should be reviewed and updated regularly to ensure that new evidence and trends are incorporated. Three to five years is considered adequate time for reviewing and updating the guidelines after being implemented in practice. It is proposed that these guidelines should be reviewed after three years.

5.8 SUMMARY

In this chapter, the researcher has described phase 2 of the study. The process of developing guidelines for the assessment of abuse of women living with HIV and AIDS was discussed. A set of five draft guidelines, with their rationale and actions, have been outlined. The Delphi process utilized to refine the draft guidelines, with the input of experts, has been presented. In chapter 6, which is the final chapter, the final guidelines, conclusions drawn from the study, the implications, limitations and recommendations are addressed.

CHAPTER 6

GUIDELINES, RECOMMENDATIONS, IMPLICATIONS, LIMITATION AND CONCLUSION

6.1 INTRODUCTION

The research on guidelines for the assessment of abuse for WLWHA was conducted in two phases and presented in five chapters. The first chapter comprised of the introduction, background information, and a reflection on the magnitude of the problem of the abuse of women. Chapter 2 presented the research paradigm and philosophy that underpinned the phenomenological approach of phase 1. In Chapter 3 the findings of phase 1 that focussed on the experiences of abuse among WLWHA were given. In Chapter 4 a discussion of the findings of phase 1 directed by an extensive literature review was presented to provide a deeper understanding of the essence of the phenomenon and its constituents. Chapter 5 and phase 2 of the study was about the development and refinement of the guidelines for assessment, based on the five concepts that were identified in Chapter 4 and the extensive review of the literature. In Chapter 6 the researcher presents the guidelines as well as the recommendations, implications and limitations of the study. The conclusions drawn from the study findings are also discussed.

6.2 SUMMARY OF THE STUDY

The objectives of the research study were firstly to explore and describe the experiences of WLWHA who were exposed to abuse (phase 1) and, secondly, to develop and refine assessment guidelines for WLWHA based on their experiences (phase 2). Data were obtained from in-depth interviews with 12 women who were living with HIV and AIDS and who had been exposed to abuse. The interviews revealed that the women's experiences were representative of the following:

- i. They encountered humiliation from their partners, their own families as well as their families-in-law, neighbours and friends.
- ii. They experienced feelings of hopelessness that were triggered by people who tried to destroy their hopes for survival.
- iii. They had thoughts of suicide and felt insecure in terms of the economic, physical and emotional aspects of their lives.
- iv. Their experiences included being blamed and also blaming themselves for being infected with HIV and suffering abuse. The partners blamed the women for infecting them with the virus.
- v. The women were also in danger of actual and potential harm of re-infection with HIV due to exposure to unprotected sex.
- vi. Physical harm was evident from being beaten while secondary harm was a result of stress suffered from the abuse. In addition, emotional pain resulted from the insults they received from others.
- vii. The effect of non-compliance to ARVs posed harm to the women in that they could develop resistance to the ARVs. This could consequently lead to deterioration in their health status which could lead to death.
- viii. Abandonment was a common occurrence among the women. The rejection was from their husbands and other family members.

The draft guidelines for the assessment of the abuse of WLWHA were developed by the researcher from the findings of phase 1 of the study and the extensive review of the literature. Thereafter, the draft guidelines were refined using the Delphi process. Eleven experts in the field of HIV, AIDS, and gender-based violence were approached to participate in the Delphi study of whom five either did not respond or declined to participate. These five were replaced and ten experts finally participated in the refinement process. Consensus among the experts with regard to the guidelines was reached after having conducted two

rounds of the Delphi process. The developed guidelines as well as the specific actions that have to be taken for its operationalization and implementation are listed next.

- i. Nurses are to explore the occurrence of humiliation as a form of abuse towards women living with HIV and AIDS.
- ii. Nurses are to identify feelings of hopelessness as a manifestation of abuse in women living with HIV and AIDS.
- iii. Nurses are to assess blame as a form of abuse towards women living with HIV and AIDS.
- iv. Nurses are to focus on the occurrence of harm when assessing women living with HIV and AIDS.
- v. Nurses are to assess the occurrence of abandonment as a manifestation of abuse in women living with HIV and AIDS.

6.3 THE GUIDELINES FOR ASSESSMENT OF ABUSE OF WOMEN LIVING WITH HIV AND AIDS IN MALAWI

PREAMBLE

Women living with HIV and AIDS encounter abuse from their partners, family and friends. Many of the women endure the abuse in silence. They do not report their experiences of abuse to nurses or other healthcare professional people for the necessary interventions to be done.

Applicable guidelines could assist nurses and other healthcare professionals to identify and address the abuse of WLWHA timeously. The guidelines developed in this study provide information on the manifestations of abuse. It was based on the experiences of WLWHA and evidence from literature and developed with consensual input by expert nurses in the field of HIV, AIDS and gender-based violence.

The researcher is a community health nurse with 24 years experience in nursing. Reading her doctoral degree, the researcher conducted a phenomenological study to explore and describe the lived experiences of WLWHA in Malawi and the

abuse they endured in order to develop guidelines for nurses to assess and take appropriate action concerning the abuse of WLWHA.

The participants narrated their experiences to the researcher during in-depth interviews guided by open-ended questions. The extensive literature review undertaken together with the findings of the study elicited in the researcher a deeper and more comprehensive understanding of the phenomenon. Having gained a better understanding and more insight into the extent of the research problem, the researcher subsequently formulated the guidelines to assess the abuse of WLWHA. Five guidelines, each with a rationale and actions to be taken by the nurse to assess whether WLWHA that were victims of abuse, were developed.

The questions contained in the guidelines need not be asked in a particular order. Nurses should keep the guidelines at hand and use it as a reference to focus on the areas that should be addressed when attending to WLWHA suspected of being exposed to abuse. Since the guidelines are inclusive of the actions nurses should take to encourage women to talk about their experiences, it is foreseen that the implementation thereof can improve the quality of care rendered to the women and promote their health and overall well-being.

Next, each of the five guidelines is discussed in depth.

Guideline 1: Nurses are to explore the occurrence of humiliation as a form of abuse of women living with HIV and AIDS

a. Rationale

Women living with HIV and AIDS might be exposed to humiliation due to the actions of their partners, their family members, friends and neighbours. The women isolate themselves in order to avoid humiliating encounters with others. If humiliation is identified, it can be addressed to prevent devastating effects in the lives of the women, including physical and psychological impacts such as mental problems (Ludemir 2008: 1016).

Nurses could play a major role in preventing of such impacts and should make a deliberate effort to assess for humiliation as it could affect the person's ability to behave in an appropriate manner (Torres & Bergner 2010: 199). Strategies for interventions that support the women in promoting their emotional well-being can then be devised.

b. Actions

When assessing women living with HIV and AIDS nurses should:

- Encourage the women to express any feelings of being unfairly treated in any way as a repercussion of being HIV-positive.
- Explore any feelings expressed by the women, of being disrespected, ridiculed or insulted by the actions their significant others.
- Determine whether the women have been made to feel unrecognised by the actions of others in relation to their HIV status.
- Ascertain whether the women feel they have been gossiped about or they have been ridiculed in their homes, communities or at work.
- Identify whether the women feel their honour and dignity has been adversely affected or jeopardized in any way by the actions of others, on account of their HIV status.
- Establish whether the women feel ashamed in response to the actions of others in relation to their HIV status.
- Determine if the women feel excluded or rejected in their interaction with others within their social network.
- Explore any feelings that the women might have of being betrayed in their relationships with others, having caused them to become distrustful.

- Explore any inhumane treatment the women might have encountered and their feelings about it.

Guideline 2: Nurses are to identify feelings of hopelessness as a manifestation of abuse of women living with HIV and AIDS

a. Rationale

Hopelessness is recognised as being detrimental to the process of recovery from illness. It can be disempowering to individuals, as they become apathetic and inactive in dealing with their situation (Gurkova, Ziakova & Cap 2011: 34). It is necessary to identify situations or feelings that may be indicative of hopelessness in women living with HIV and AIDS. Early identification can facilitate instituting interventions that may promote a positive outlook on life despite the challenges that may be encountered (Kylma 2005: 818).

By recognizing and re-evaluating the triggers for the feelings of hopelessness in their lives, the women are empowered to reflect and regain a sense of control over their life's circumstances and a movement towards hope, which is essential for having a positive outlook, is initiated (Flynn *et al.* 2000:61).

b. Actions

In the identification of hopelessness in WLWHA nurses should:

- Determine if the women feel that their lives have no sense of meaning.
- Determine the women's feelings of powerlessness in improving their situation for the better.
- Explore whether the women feel that their situation is impossible to overcome.
- Establish whether the women feel like giving up on life.
- Determine whether they feel that the changed relationships with significant others leave them without family and other social support.

- Explore if they feel a diminished sense of self-esteem due to the actions of others.
- Identify any loss of motivation to deal with their situation.
- Assess any decrease in affective emotions towards themselves and other people.

Guideline 3: Nurses are to assess blame as forms of abuse of women living with HIV and AIDS

a. Rationale

Women living with HIV and AIDS may be blamed and shamed for being perceived to be sources of infection for children and their partners (Miles 2011: 493). The women's feelings of being blameworthy by could affect their sense of self-worth and result in psychological distress (Lekas *et al.* 2006: 1184). Personal and interpersonal blame can lead to feelings of guilt, even though a person is not responsible or accountable for the prevailing circumstances (Parkinson & Illingworth 2009: 1610).

Blame places undue burden on the sufferer, while ignoring the complex cultural, socioeconomic and political context of the underlying situation or illness. Hence, it is counterproductive to isolate for blame one facet of the dynamic in the causation or spread of disease (Finerman & Bennet 1994: 1). Identifying the blame dynamics in a relationship could assist offering a holistic approach of supporting women to manage disclosure in an effective manner.

b. Actions

In the assessment of feelings of blame in women living with HIV and AIDS nurses should:

- Explore whether the women have been called names or shamed in public for being HIV-positive.

- Determine whether the women have been referred to as being worthless by others because of their HIV status.
- Ascertain if the women feel that others have considered them to be a burden for possibly having to rely on their assistance before or would have to in future.
- Establish if the women have been referred to as being the sources of infection after disclosure of their HIV-positive status.
- Explore whether the women feel they deserve blame and have to take responsibility for being victimized.
- Examine whether the women are being treated as if they no longer are similar to their relatives and friends.

Guideline 4: Nurses are to focus on the occurrence of harm when assessing women living with HIV and AIDS.

a. Rationale

Women living with HIV and AIDS may be exposed to all types of harm including physical, psychological, socio-economical and sexual, which can be detrimental to their health. Abuse of any form can disrupt the women's attempt at self-care activities, in that it could cause a failure to adopt lifestyle changes that facilitate immune functioning. The resulting stress can adversely affect the physical and mental health of the women (Thomas *et al.* 2008: 1253). Direct and indirect factors, such as being beaten and being forced to have unprotected sex respectively, that have been found to cause harm, should be explored with the women in an open and client centred manner to obtain the desired results (Mattson 2000: 333).

The issues that contribute to the harmful practices in the lives of the women can be identified and an approach adopted that can lead to the implementation of

harm reduction strategies to promote positive living (Matthew & Mukherjee 2009: S7).

b. Actions

In the assessment of factors that may contribute to harm in women living with HIV and AIDS nurses should:

- Explore circumstances under which the women are forced to engage in unprotected sex (predisposing them to reinfection with HIV).
- Establish whether the women worry about the potential transmission of HIV to an unborn child, neonate or partner.
- Assess whether the women have suffered any injury or emotional pain as a direct or indirect consequence of their positive HIV status.
- Identify any losses that have been suffered. Such losses may include status, income, good health and spirituality resulting in perceived poorer quality of life.
- Ascertain if feelings of being stressed by the actions of other people are experienced.
- Determine if there is an inability to take ARV medication due to the lack of support from family or friends.
- Assess whether the women's basic needs of love, security and belonging are not being met.

Guideline 5: Nurses are to assess the occurrence of abandonment as a manifestation of abuse of women living with HIV and AIDS

a. Rationale

Abandonment or rejection is a threat to survival. Interaction with others might be hindered by the disconnection in relationship that occurs in the case of

rejection (Barroso & Powell-Cope 200: 345). Abandonment yields loss of love, emotional and economic support (Carr & Gramling 2004: 38). It could also affect mental health. Instances of depression have been reported, following loneliness due to abandonment (Vanderhorst & Mc Laren 2005: 517).

The two types of social support are emotional and instrumental (providing comfort and tangible assistance respectively). The personal attributes of people in a social support network is more important than specific persons such partners, family and friends. However, it can be difficult to divulge personal information where there is no mutual feeling of being intimately familiar and sharing with the other person (Finfgeld-Connett 2005: 6). Inadequate social support can have adverse effects on women living with HIV and AIDS as this is a time when they need people they can trust and rely on for emotional and material needs required to sustain a healthful life.

b. Actions

In the assessment of women living with HIV and AIDS nurses should:

- Explore any feelings the women might have of being rejected by members of their social network.
- Identify the existence of negative feelings about self and diminished self-esteem because of the actions of others.
- Establish the level of deterioration in social support (so that the women have to fend for themselves) compared to previous circumstances.
- Assess if the women have suffered a loss of identity and status, such as that of being a wife, partner or other social attachments.
- Explore if any relationships in the women's lives have deteriorated and potential feelings of betrayal and pain with regards to this.
- Ascertain whether the women feel that others have avoided physical or social contact with them.

- Explore any issues of lacking access to necessary care that the women might experience.
- Determine the extent of limitations in relation to survival resources as a consequence of abandonment.

6.4 RECOMMENDATIONS

The recommendations made are based on the guidelines that have been developed. These highlight the areas that should be assessed to identify abuse of WLWHA. The guidelines should be used in practice to follow up on issues of abuse relating to WLWHA. The guidelines are not a screening tool for abuse and there is no sequence that should be followed when used in practice.

6.5 IMPLICATIONS FOR NURSING

The implications of this study for nursing in terms of practice, research and education are discussed next.

Practice

The findings of the study revealed that WLWHA experience abuse from their partners, families, friends and neighbours. Although a need exists to conduct an assessment of the abuse, the nurses do not always know how to do it and how abuse manifests itself. Nurses tend to focus on physical abuse and even then only on the physical treatment. Physical abuses are more obvious and thus more often identified than the other forms of abuse. In addition, women try to hide abuse – and often succeed in hiding it – and it thus becomes more difficult to assess. Abuse manifests in different ways; it is not limited to being cursed at, being humiliated or ignored, or being beaten. In fact, abuse can make it difficult and oftentimes impossible for the WLWHA to adhere to the prescribed treatment regimens.

This study highlighted the need for nurses to address the abuse of WLWHA in a direct manner rather than indirectly as the latter approach can create the

perception in WLWHA that nurses discriminate against them because they view them as stigmatised. The situation on the ground, however, indicates that women are not able to disclose their experiences of abuse to the health workers because of high patient loads and staff shortages. In other words, there is simply not enough available time for the nurses to spend with WLWHA to assess whether abuse is occurring or not and if it is, to render appropriate care and support. Conversely, a deliberate effort from the nurses' side to find out from these women whether they experience abuse and to what extent it happens will encourage them to confront such experiences and, together with the nurses, explore avenues to mitigate the impact of such abuse through available channels and referrals. It is only through such assessment that the women will be afforded the opportunity for quality care which will promote their efforts towards living positively with HIV and AIDS.

The use of guidelines for the assessment of abuse may facilitate the attempts to integrate care and address the fragmentation of services delivered to women living with HIV and AIDS. Furthermore, the guidelines provide an instrument for assessment which is research-based. In this way it contributes to Best Practice in assessment. In-service education or continuing professional development should be provided to health professionals addressing issues of gender-based violence and HIV in clinical settings.

Women living with HIV and AIDS should be made aware of the different manifestations of abuse so that they can seek help timeously. The guidelines to identify abuse in women living with HIV and AIDS can be used in other countries or it can be adapted for use in other countries.

Research

Follow-up research should be conducted to evaluate the guidelines for assessment to determine its applicability and suitability in practice. The process of guideline development is never complete. Once guidelines have been developed and refined it should be implemented, evaluated and adjusted continually.

Further research should be conducted to determine what the impact of using the developed guidelines is on WLWHA. The guidelines should be tested in a clinical setting so that conclusions can be drawn about its feasibility and applicability. Additional research studies is an essential component of further evaluating and confirming evidence for nursing practice by assessing the usefulness of the guidelines to enhance quality of care (Chinn & Kramer 2011: 228). The guidelines for the assessment of abuse on WLWHA could be implemented and evaluated in other settings and in other countries.

Education

Nursing education should address the intimate relationship between HIV, AIDS and abuse by focussing on more than the obvious signs of abuse. Nurse educators have up to now included general issues of gender-based violence and WLWHA in the curricula rather than the manifestations of the abuse which is critical for relevant interventions to be identified in order to address this problem. Nurses graduating from nursing colleges should be knowledgeable about the connection between HIV-positive women and abuse; the impact abuse has on women who are HIV-positive, and the consequences thereof on the health and overall well-being of WLWHA.

6.6 LIMITATIONS OF THE STUDY

Despite the insightful findings, the following limitations need to be mentioned. The findings were derived from qualitative interviews conducted with 12 women. These women's experiences may be different from WLWHA in other parts of Malawi. The participating women's descriptions were taken as a reflection of their experiences; hence the researcher took this limitation into account when the study was concluded.

The use of volunteers to participate in the study could have introduced bias in the study as volunteers tend to have characteristics that distinguish them from others. Similarly, heterogeneity of the sample might have been compromised.

6.7 CONCLUSION

The purpose of the study was to develop assessment guidelines for abuse in WLWHA based on their experiences. The study findings confirmed that WLWHA experienced abuse from their partners, their families, friends and neighbours in the form of humiliation, harm, hopelessness, blame, and abandonment. It is crucial for nurses to explore with the women such encounters as it poses a challenge for them to live positively with HIV and AIDS. Guidelines that can facilitate the assessment process have been developed and presented.

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ANNEXURE A

LETTER - APPROVAL RESEARCH ETHICS COMMITTEE

University of Pretoria
Department of Nursing Science
P.O. Box 667
Pretoria
0001

The Chairperson
College of Medicine Research and Ethics Committee
Private Bag 360
Chichiri
Blantyre 3
Malawi

Dear Sir/Madam

Re: Approval to conduct a study

I am a PhD student at University of Pretoria in South Africa. I submit this proposal for Ethical approval to conduct a study which is entitled: Guidelines for the assessment of abuse of women living with HIV and AIDS in Malawi. The aim of the study is to explore the women's experiences of abuse for purposes of developing assessment guidelines that will assist nurses to provide care and support to the women. The proposed study will be conducted at selected health facilities under Lilongwe District Health office as an entry point to identify participants for the study.

Yours faithfully

Mrs. W. Chilemba
Researcher

ANNEXURE B

**LETTER TO OBTAIN PERMISSION FROM LILONGWE DISTRICT HEALTH OFFICE
TO CONDUCT RESEARCH**

University of Pretoria
Department of Nursing Science
P.O. Box 667
Pretoria
0001

The District Health Officer
Lilongwe District Health Office
P.O Box 149
Lilongwe
Malawi

Dear Sir/Madam

Re: Permission to conduct a study

I am a PhD student at the University of Pretoria in South Africa. I request permission to conduct a study among women living with HIV and AIDS at selected health facilities that fall under the Lilongwe District Health office. The title of the study is: Guidelines for the assessment of abuse of women living with HIV and AIDS in Malawi. The aim of the study is to explore the women's experiences of abuse for purposes of developing assessment guidelines that will assist nurses to provide care and support to the women.

Yours faithfully

Mrs. W. Chilemba
Researcher

ANNEXURE C

INFORMATION LEAFLET AND INFORMED CONSENT

Guidelines for the assessment of abuse of women living with Human Immune Deficiency Virus and Acquired Immune Deficiency Syndrome in Malawi

Dear Participant

1. INTRODUCTION

This is an invitation for you to participate in a research study. This information leaflet will help you to decide if you want to participate in the study. Before you can make that decision you should fully understand what is involved. If you have any questions that this leaflet does not address, please do not hesitate to ask the researcher.

2. THE NATURE AND PURPOSE OF THE STUDY

I am conducting a research study to explore the experiences of women living with HIV and Aids who are exposed to abuse. You as a client is a very important source of information on experiences of abuse and living with HIV and AIDS.

3. EXPLANATION OF PROCEDURES TO BE FOLLOWED

Should you agree to participate in the study:

- You will be required to describe your experiences as a woman living with HIV and Aids who is exposed to abuse. The researcher will pose the question:
"Tell me about your experiences as a woman living with HIV and AIDS who has been exposed to abuse".
- The interview will be recorded with your permission.
- The duration of the interview will range between 60-90 minutes
- The conversation will take place at a venue convenient to you.

4. RISKS AND DISCOMFORTS INVOLVED

There are no risks in participating in this study. However the conversation could remind you of unpleasant memories that may be uncomfortable. You need not answer, if you do not want to. Counselling will be made available should you require it.

5. POSSIBLE BENEFITS OF THIS STUDY

There will be no direct benefit to you from participating in this study. Your participation will help in understanding experiences of women living with HIV and AIDS who are exposed to abuse. This will facilitate development of assessment guidelines that can be used to assist other women in similar situations in future.

6. WHAT ARE YOUR RIGHTS AS A PARTICIPANT

Your participation in this research is voluntary. You can refuse to participate in the study, or withdraw from it at any point without giving any reason or decline to respond to any issues raised. This will not in affect the services that you receive in any way.

7. HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria, South Africa.

8. INFORMATION AND CONTACT PERSON

The contact person for this study is Mrs Winnie Chilemba. If you have any questions please contact me - cell 07333385468;0888878014. Alternatively you can contact my supervisor- Professor Van Wyk - cell 0827761649.

9. COMPENSATION

There will be no payment for participating in the study. However a contribution towards your travel expenses will be given.

10. CONFIDENTIALITY

The interview will be done in a separate and private room. Other people will not hear the conversation that will be taking place. Your name will not be mentioned or recorded anywhere. Everything that you will tell me and all records obtained in this study will be kept private and confidential. Once I have analysed the information no one will be able to identify you. Additionally the person transcribing the interviews will sign a confidentiality clause to ensure that the information remains strictly confidential. Reports and articles in scientific journals will not include any information that may identify you or your clinic.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about the nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (information leaflet and Informed Consent regarding the study. I am aware that the results of the study, including personal details will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect any treatment/ access to services in any way.

Participant's name -----
(Please print)

Participant's signature -----Date-----

Investigator's name -----
(Please print)

Investigator's signature -----Date-----

Witness's name -----
(Please print)

Witness's signature -----Date-----

VERBAL INFORMED CONSENT

I the undersigned have read and have fully explained the participant's information leaflet which explains the nature, process, risks, discomforts and benefits of the study to the participant whom I have asked to participate in the study. The participant indicates that she understands that the results of the study, including personal details regarding the interview will be anonymously processed into research reports. The participant reports that she has had time to ask questions and has no objection to participate in the interview. She understands that there is no penalty should she wish to discontinue with the study and her withdrawal will not affect any treatment/ access to services in any way. I hereby certify that the client has agreed to participate in the study

Participant's name -----
(Please print)

Person seeking consent-----
(Please print)

Signature -----Date-----

Witness's name-----
(Please print)

Witness's signature -----Date-----

ANNEXURE D

INFORMED CONSENT FOR MEMBERS OF THE PANEL OF EXPERTS

Dear Expert

1. INTRODUCTION

This is an invitation for you to participate in a research study. This information leaflet will help you to decide if you want to participate in the study. Before you can make that decision you should fully understand what is involved. If you have any questions that this leaflet does not address, please do not hesitate to ask the researcher.

2. THE NATURE AND PURPOSE OF THE STUDY

I am developing guidelines for assessment based on findings of a study on experiences of women living with HIV and AIDS who are exposed to abuse. You as an expert are a very important source of information for refining the guidelines. It is hoped that nurses can use the guidelines in their assessment of women living with HIV and AIDS who have been exposed to abuse in order to provide relevant care and support to them. The invitation is for you to participate in a consensus building that will be conducted using Delphi technique. I have identified you as a possible participant in this exercise because of your expertise in the field of gender based violence and HIV and AIDS.

3. EXPLANATION OF PROCEDURES TO BE FOLLOWED

Should you agree to participate in the study:

- You will be required to refine the draft guidelines for assessment of abuse in woman living with HIV and AIDS.
- All the correspondence pertaining to the process will be done through email
- Experts that will participate in the study will remain anonymous to one another and your input will be regarded as confidential.
- Rounds of data collection will be used until a consensus is reached among the experts
-

4. RISKS AND DISCOMFORTS INVOLVED

There are no risks in participating in this study.

5. POSSIBLE BENEFITS OF THIS STUDY

There will be no direct benefit to you from participating in this study. Your participation will help in refining the draft guidelines for assessment of women living with HIV and AIDS who are exposed to abuse.

6. WHAT ARE YOUR RIGHTS AS A PARTICIPANT

Your participation in this research is voluntary. You can refuse to participate in the study, or withdraw from it at any point without giving any reason or decline to respond to any issues raised. This will not affect you in any way.

7. HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria, South Africa.

8. INFORMATION AND CONTACT PERSON

The contact person for this study is Mrs Winnie Chilemba. If you have any questions please contact me - cell 0734395626;0888878014. Alternatively you can contact my supervisor- Professor Van Wyk - cell 0827761649.

9. COMPENSATION

There will be no payment for participating in the study.

10. CONFIDENTIALITY

All correspondence and records obtained in this study will be kept private and confidential. Once I have analysed the information no one will be able to identify you. Additionally any person who may be involved in analysing the data will sign a confidentiality clause to ensure that the information remains strictly confidential. Reports and articles in scientific journals will not include any information that may identify you.

CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about the nature, process, risks, discomforts and benefits of the study. I have also received, read and understood the above written information (information leaflet and Informed Consent regarding the study. I am aware that the results of the study, including personal details will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect me in any way.

I the undersigned, have received, read and understood the above written information (information leaflet and Informed Consent) regarding the study. I am aware that my participation in the study will be anonymously processed. I am participating willingly. I have had time to ask questions and have no objection to participate in the study. I

understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect me in any way.

Expert's name -----
(Please print)

Person seeking consent-----
(Please print)

Signature -----Date-----

Witness's name -----
(Please print)

ANNEXURE E

INVITATION LETTER TO MEMBERS OF THE PANEL OF EXPERTS

Dear expert participant

INVITATION TO PARTICIPATE IN THE REFINEMENT OF GUIDELINES FOR THE ASSESSMENT OF ABUSE AMONG WOMEN LIVING WITH HIV AND AIDS IN LILONGWE, MALAWI

I am a PhD student in the department of Nursing Science, Faculty of Health Sciences at the University of Pretoria. I am conducting a study on Guidelines for the assessment of abuse of women living with HIV and AIDS in Malawi, under the supervision of Professor Neltjie van Wyk and Dr Leech. The purpose of the study was to describe and explore the experiences of women in Malawi in order to gain insight into living with HIV and AIDS and abuse in order to develop and refine guidelines for assessment of abuse in the women.

The objectives of the study were to:

- Explore and describe the experiences of WLWHA who are exposed to abuse.
- Develop and refine assessment guidelines for WLWHA who are exposed to abuse.

In phase 1 of the study a qualitative descriptive phenomenological approach was used to investigate the phenomenon of abuse as in the context of the experience of women living with HIV and AIDS. Data were collected using in depth interviews with the women. The findings revealed that the women face abuse from their partners, family, in laws, friends and neighbours. The abuse was expressed in the form of humiliation, hopelessness, blame, harm and abandonment.

In Phase 2 of the study the researcher developed preliminary guidelines for assessment based on the research findings from phase 1 and an extensive review of literature on the constituents and five concepts that represented the women's experiences.

You are therefore invited to participate in the refinement of the guidelines as part of the development process. There are five guidelines followed by actions that should be taken by nurses in the assessment of abuse among the women. Please read through each guideline and comment on the applicability or suitability of the guideline or make suggestions for change as necessary. This refinement process should take approximately 1 hour to complete. Space for comments is provided at the end of each actions of the guideline. You are requested to return your comments not later than (specify date).

Your comments will be highly appreciated. These comments will be collated and analysed for further refinement in round two. For any clarification that may be required, please contact me on the following:

Mrs Winnie Chilemba

E-mail: wchilemba@yahoo.com; wchilemba@gmail.com

Cell:0734395626;0888878014

ANNEXURE F

DESCRIPTIVE INFORMATION OF THE PARTICIPANTS IN THE PANEL OF EXPERTS FOR THE REFINEMENT OF THE GUIDELINES FOR THE ASSESSMENT OF ABUSE OF WOMEN LIVING WITH HIV AND AIDS

NO	POSITION	QUALIFICATION	EXPERIENCE
1	Head of post basic nursing programme	PhD Nursing	Involved with HIV and gender issues since 1989. Founded and managed two HIV and AIDS centres Member of several women focussed organizations Has presented on gender-based violence at national and international conferences
2	Senior lecturer	RN, PhD	Involved in home based care programming with postgraduate students and interacts with WLWHA. Lectures in community health nursing
3	Senior lecturer	DCur	Teacher and midwife
4	Youth and prevention specialist	MCur, PhD scholar	Works with gender-based violence implementing partners Underwent 'on the job training' in integrating gender activities Supervises partners in implementing gender activities Participated in Google gender-based violence assessment report on the internet
5	Primary health care nurse	MCur, PhD scholar	Experience in primary health care settings
6	Senior lecturer	DCur	Experience in trauma counselling and psychotherapy
7	Deputy Director, HIV/AIDS/STI&TB programme manager	PhD scholar	Has worked in the HIV/AIDS environment since 1992 at both regional and National level
8	Public health specialist	MPH	Works in the field of promoting gender equity and minimizing gender-based violence using a tool called Africa Transformation and HIV
9	Lecturer in community health nursing and Dean of Nursing	PhD	Trainer of trainers (professional groups) in gender issues, master trainer community home based care, HIV & AIDS, Palliative Care
10	Lecturer in community health nursing	MPH	Trainer in youth behaviour change and HIV, activist on women's sexual and reproductive health issues. Lectures in community health nursing

ANNEXURE G
UNSTRUCTURED INTERVIEW GUIDE

Interview Question:

Tell me about your experiences as a woman living with HIV and AIDS who has been exposed to abuse

(Probing questions, paraphrasing, clarifying will be used to explore the women's experiences based on the information they will provide during the interview)

ANNEXURE H
SAMPLE OF AN INTERVIEW TRANSCRIPT

I Tell me about your life and the abuse that you have encountered.

P There are many problems that I have encountered when we disclose our status/ get tested

I When did you get tested?

P I got tested in 2006. After I got tested I went home because I knew that to keep such news to myself would not be helpful, I needed to tell my relatives So I told my relatives that I got tested and I have been found to be HIV positive.

I Who were these relatives?

P My sisters, my brothers and members of my clan

I Did you call all of them together?

P Yes all them together. Now after I told them it happened that they started publicizing to others outside our household saying this one was found to be HIV positive, then a lot of people started discriminating me , they were telling me since you have been found to be positive there is nothing for you, you are about to die soon.

At this time I didn't really understand what they meant I am about to die so I left home and came here

I Where do you come from?

P Namitete, in Midzela village I left the village to get married, so I told my husband you should also go for testing. He went for the test and was found positive. Then we got counseling from the hospital on how we were going to live from then onwards. Since I have accepted my situation i am not able to keep it a secret. When someone is sick I want to enlighten them about their illness so that maybe they can go for testing at the hospital to know the real problem so I tell anybody and it happens that the same people probably we have argued you know women then they start ridiculing me saying isn't it that you are plump because of ARVs. I am plump from my mother's- I don't take any medicine. I told her it is true that I am taking ARVs but the way you are talking just shows your ignorance because you have not gone for testing because you never know if you got tested today you could be found with the virus yet you were ridiculing someone like me yet I am alive, I am able to advise to go to the hospital. She said I can't do that my husband is not promiscuous there is no way I can have AIDS. You are going to die. So things like those I just

accept them because i don't somebody to be sick for a long time without advising them to go for testing your blood; so if it is a woman they think once you are HIV positive and tell others they think you are going to die today or tomorrow. In 2007 I was pregnant I gave birth after following PMTCT at the hospital, the child is grown up and healthy without the HIV virus and yet I am taking medicine everyday that is what people say in the community that we are alive because of ARVs we are just waiting for the day to die so I just think that they say all this because of ignorance, they don't know about their own future at least we know about our future

I Other than telling others about your status how did your relatives behave towards you?

P Aah the only person who showed me love when I was sick was my one brother; my twin brother we were born on the same day. He is the one who loved me even more than my parents. After him it was my husband. He supported me and took care of me when I was ill, it was my husband. But my other relatives were saying if it was me that was found with the virus I could just die- I could take 'tarmec' (poison). These were my relatives telling me this so I just concluded that that if your relatives tell you this then they don't wish you well

I Do the other relatives know their status?

P Yes the other one got tested and was found negative that is why she was speaking like that. I was very sick, I was failing to even take a bath, the one who said I can take tarmec never took care of me it was my younger sister who was taking care of me giving me a bath, would cook porridge for me to eat. You know how it is done in the village, she was not using gloves when bathing me or washing my clothes. She was just doing it as for her sister. I was really worried whether I had passed the virus to her since they say if you have a cut even a small cut and you are washing such materials it is very easy to contract the virus. I told my sister to go for testing. Later she told me I went for testing with your brother in-law. I asked her how is it she said I am still okay I just said that God has favoured you. That is how we stay in the locations

I How do you feel when people say all these things?

P Eh for me I just accept whatever they say, I say okay, you are lucky because your weight is the natural weight given to you by your mother while my weight is due to ARVs. But I tell them the truth that I am HIV positive so anyone who wants to chat with me should know that she is

chatting with somebody who has the virus, if you have a problem with that, I will not force any person to chat with me. You are free. But these days many people are aware, there is no one who says nasty things, actually they tell me to encourage them so that they can also get tested because the way you look one cannot tell that you have HIV. You can live for a long time. I tell them yes. These days there are many women who come to my house to chat but I can tell that that one is discriminating me. I am able to tell if a person is discriminatory. I just accept it.

I You said you have how many children?

P I have given birth three times but two of the children died so I have one child born in 2007 the one that I followed PMTCT but the first birth was in 2003

I Tell me about what you were told about sex and how you have managed.

P We try to use condoms but my husband is difficult he does not want to so when I realized the truth that in the end I am going to die early, I told him you can go ahead and take another wife and leave me, this should not be a problem. So he said okay I will marry another wife but I will not leave you. It will be polygamy. So I agreed and he married another wife so although he abuses me in various ways I just accept it. Even if he does not come to my house to sleep I take it to be a good thing for my life so that he can sleep at the other house so that I can stay on my own. But looking at how a polygamous marriage is supposed to be like, I think I meet most of my own needs. Because I am working , although the job does not pay much to support a person's living, so in most areas I am having problems. Had it been that I was able to save and build a house at home so that when I leave I will have a place to stay, I would have said that is better but as it is he leaves everything to me saying since you are working you can provide for yourself

I When did he marry the second wife?

P He took the second wife in April last year. She now has a baby

I Did you say he also got tested?

P Yes the man got tested and he is HIV positive but he refuses to take medicine (ARVs)

I What about his immunity?

P I don't know may be it is still strong. But sometimes he gets sick suddenly yes sudden sickness to the point of being admitted at the hospital

I **Does the other woman know about his situation and about you?**

P The other wife knows. I even told her myself and asked her if she has accepted to be in such a situation. I told her I am taking medicine, she just said okay. So I don't know what her blood is like because when she was pregnant she was tested and the result was negative. When the baby was born she was tested again and she is still negative. Just today she was here at the clinic she was in our office she got tested again but is still negative

I **So are you saying you are not getting adequate support from your husband?**

P No I am not getting adequate support. My baby is HIV negative but the care she receives is poor. We can't manage to have a balanced meal, eating different things. When we eat something good it means I have some money of my own

I **What kind of work does he do?**

P He is a businessman; he sells clothes but he does not give me any money. Even when I tell him that I have no money can you give me money so that I can buy relish, he says I don't have money for relish. In such situations I sometimes take already cooked relish-beans from the hospital. I just put them in a bottle and take it home. That way we are able to eat *Nsima*.

I **What about the days when he comes to sleep at your house?**

P When he is coming to my house he brings relish. Sometimes he just leaves the relish without any tomato or cooking oil so if I don't have any money I just cook as it is just adding salt and eat. But at my friend's house he buys everything tomato, cooking oil, firewood and yet in my case I have to get firewood on credit for my fire. It means when I receive my money I have to pay these debts, after that the money is finished; soap, cooking oil everything I have to provide myself.

I **Who have you told about what is going on?**

P Our marriage counsellors are aware of everything

I **What do they say?**

P They just say time will come for you to separate in this marriage but right now just wait do not rush things; keep on observing what he is doing. They gave me the idea that if I can manage to leave him and go to a place where I wouldn't have to meet him. That is what I intent to do but because of lack of resources how can I leave, that is what I am thinking. But about the marriage I think it is better I stay out of the marriage this is because I am one of people who give advice to others here at the hospital than now that you have known your status whether you like it or not you have to use condoms so that you reduce the chance of infection from man to woman and yet I am not able t do what I tell others; my rights are being abused because my husband refuses to use condoms. So I am thinking that after my contract is finished in JUNE ON 22 June such that I will have to go and others will start the work that I do. They are going to post the vacancies on 26 May so that people can apply then they will do the interviews so that when we start may people will be in training; come 22 I will stop working if I had money I could have made plans. The money is there but it is not enough. I can start selling second hand clothes, but I really wanted to go to another place, not here so that he cannot follow me. Then I can look at a future for my child, right now, I just leave my child alone. She is 3 years old, she is young.

I Who does the child stay with?

P The child just plays around in people's homes when I knock off from work then I go round looking for my child which is not a good thing. I used to send her to school but it means paying school fees, buying a snack and a drink on my own. When I asked him for fees he would just say I don't have money. I had to make sure that every week I bought these snacks then I realized that I couldn't do it anymore, I couldn't afford; everything depended on me, the money I was receiving was so little then I decided the child would no longer go to school, so I can't tell lies, there is no proper care for my child. Many people have been telling me that I don't love my child, why do you let your child wander around carelessly. I just accepted that what you are saying is true but what else can I do. I just leave it as it is.

I If somebody was going through the same thing what would you tell them?

P If I met somebody going through similar problems I would you tell them that I have been in the same situation but what you should know is that I know that I am putting my life in danger because if a man does this and yet he got tested, he knows how he is in his body and we received counselling at the hospital but he doesn't make use of all that information; in that way it is difficult

to protect one's life because although I am taking medicine, he does not; it means when the viruses leave my body and enter his body, the viruses become resistant and when we have sex the same viruses are passed back to to me but they are now resistant. As a result I am always sick. Every week I complain about something, chest pain; I am always having prescription for these ailments and yet I am on ARVs. I can't say I have seen the benefits of ARVs because I am always sick. So if there is no cooperation in the family one can die early, usually it is the woman who is affected because our immunity is affected by child birth. So my life is in real danger. So I would tell someone that if your husband is doing what he is doing it is better you make a decision that is better for you because you should know that your life is in danger.

THANK YOU

ANNEXURE I

DATA ANALYSIS- MEANING UNITS

Participant voice	Meaning units	
<p>My fears are that we are told at the hospital that we should use condoms so in our case we don't use condoms, we have plain sex</p> <p>My rights are being abused because my husband refuses to use condoms</p> <p>We are supposed to use condoms, but my husband is difficult. He doesn't want to use condoms.</p> <p>We discuss a lot of things (at the support group)for example using condoms but when I tell him these things he says no he can't use condoms</p> <p>I have the virus but my husband does not. At the hospital they advised us to use condoms but when I tell him he refuses</p> <p>When I take condoms he uses them for three days then says no condoms, I don't have a child, I want a child I tell him if we don't use condoms we will give each other more disease, he said later on we will use condoms. Then I became pregnant</p> <p>I started living a difficult life, I started doing piece work I know that I am putting my life in danger. It is difficult to protect one's life in such a situation.</p> <p>So my life is in real danger</p>	<p>Exposure to re infection</p>	<p>harm</p>
<p>Once in a while he beats me when we disagree and argue about issues</p> <p>When he has money it is used for beer. He goes to drink beer and when he comes back he beats me</p> <p>During the pregnancy of the other children I was heavily beaten</p> <p>When I raise the point that the money that you are leaving is not enough, he gets furious and shouts and closes the door and starts beating me</p> <p>Then he started beating me without real issues.</p> <p>When I retaliate he grabs me and beats me.</p> <p>I get angry when he insults my dead parents. So I also insult his mother as a result he ends up beating me</p>	<p>Repeated physical harm</p>	<p>harm</p>

<p>These are my elder sisters, they discriminate me against others</p> <p>We can't eat together, even sleeping together, we can't exchange clothes they refuse they say you will give us AIDS</p> <p>When I go home to my mother's place there is one person who doesn't see, when the others cook food, I eat with this person not the others.</p> <p>They say tell her to go we don't want her here</p>	<p>Humiliated by own family</p>	<p>Humiliation</p>
<p>Then a lot of people started discriminating me</p> <p>The kind of abuse especially people backbite and laugh at us. Some of them tell others don't chat with so and so because she has got HIV</p> <p>The problem I am experiencing is from the neighbours who say this one must have the virus.</p> <p>But the problem of being ridiculed is still there. At times you can go to the water point, or sometimes when they see us going to the clinic, they make comments that are hurtful. I have heard them myself.</p>	<p>Humiliated by friends/neighbours</p>	<p>humiliation</p>
<p>Where I am staying although I am married my in-laws discriminate me against others</p> <p>Even now when I cook nsima so that we can all eat together, they say no, you will give us the disease</p> <p>I went to his aunt in Blantyre and told her, but she didn't do anything</p>	<p>Humiliated by in-laws</p>	<p>humiliation</p>
<p>The same month he left our house and went to marry another wife</p> <p>His first reaction when I told him about my status was to end the marriage</p> <p>He took my birth control pills and he was going to throw them away or I should pack up and go</p> <p>The same month he left our house and went to marry another wife</p> <p>What he said was, ah, that is your problem. It doesn't concern me, Just pack your things and go</p> <p>The marriage collapsed even before the child was</p>	<p>Abandonment by husband</p>	<p>abandonment</p>

<p>a month old</p> <p>He is the one who packed his things because we stay at my parents</p>		
<p>By the grace of God I travelled to Zimbabwe in 2005 where I met my mother's relatives but they told me because they received lobola I cannot stay</p> <p>The abuse that I am facing is of having no place because my mother came from Zimbabwe</p> <p>At my father's village they said they didn't want anybody with HIV. Even when I go to the village nobody shows happiness to see me</p> <p>Even when I was admitted at the hospital no one of my relatives came to see me</p>	<p>Abandonment by own family</p>	<p>abandonment</p>
<p>He told me since you have the disease you are already dead</p> <p>They say that we are alive because of ARVs. We are just waiting for the day to die</p> <p>I can't see the future, I just live one day at a time</p>	<p>Destroyed hope of survival</p>	<p>hopelessness</p>
<p>Maybe if he continued to abuse me I would think evil about taking poison that is what I thought</p> <p>What I want is to throw myself in the well</p>	<p>Forced to consider suicide</p>	<p>hopelessness</p>
<p>I might be found to be in the wrong</p>	<p>Forced to self-blame</p>	<p>blame</p>
<p>Maybe you got the virus from somewhere else</p> <p>I think he blamed me for being the one who infected him with the virus</p> <p>He is always talking about me and where I got the virus When I tell him to go for testing he refuses</p> <p>He said a lot of things, that I must have gotten the virus from somewhere else and brought it home</p> <p>He used to say a lot of things such as you will give me the disease</p> <p>He was saying I am a 'whore' and it is because of that that I got infected</p>	<p>Blamed by husband</p>	<p>blame</p>

<p>My wish is that we should not go back to the farm but you never know the husband's thoughts</p> <p>I told him I was not going anywhere only if you go for the test and they find that you are fine I will leave</p> <p>How can I leave My life has gone backwards. I rely on handouts</p> <p>It is already too late when things are bad</p> <p>He didn't consider me as a</p> <p>I gave up and got used to that difficult life I would go round begging</p> <p>I will be begging for how long?</p> <p>On other days he just leaves saying I have no money When I ask for transport money he does not give me Sometimes it is my sister who gives me the money</p> <p>The care that I and my children used to get changed, He does not leave any money for me to buy relish</p> <p>My child was attending a private school now the child is in a public school</p> <p>The man leaves us hungry without giving us help</p>	<p>Forced to feel insecure</p>	
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ANNEXURE J
AUDIT TRAIL OF THE DELPHI PROCESS

AUDIT TRAIL OF COMMENTS FROM THE PANEL OF EXPERTS DURING DELPHI PROCESS

EXPERT	COMMENT
1	Suggested: winning the woman's trust so that she can open up Add assurance of confidentiality Show clear link between powerlessness and hopelessness Specify spiritual and psychological losses; clarify meaning of interference; women were forced to have unprotected sex what about being forced to have protected sex
2	Proposes to start with building rapport with the women, add in homes, communities or at work under guideline 1, suggested to remove overlaps noted in some of the guidelines which can be grouped together Suggest changes to wording of phrases to read like questions, note that the guideline is rather long given limited time and shortage of staff in clinics
3	Suggested using the term significant others rather than specifying partner, family, neighbours and friends re ordering some of the action for logical flow; need to clarify 'worries concerning conception' clarify on suffering injury or pain whether it is physical or emotional pain; identified repetitions that need to be addressed
4	Suggested to include a preamble Comments that guidelines seems too long to be used in a clinic setting; suggested to use actual questions in the guidelines Agrees with the guidelines as being valid and relevant
5	Agrees with actions by providing additional rationales
6	Clarify link between being a burden and blame and taking responsibility in actions under guideline 1 and meaning of interference in guideline 4, noted some overlaps in actions under guideline 1 and 4
7	Identified some overlaps, agrees with the layout and contents of the guidelines as all key aspects have been addressed
8	Suggested to be careful of assessing actual experiences rather than perceived abuse
9	Identified some overlaps in the guidelines, needed action under guideline 4 on threats to negotiate safer sex to be clarified. Agrees with the parameters outlined in the guidelines. Noted that the guidelines should have included what the nurses should do to support women in such cases
10	Identified overlaps in the guidelines

ANNEXURE K

**ETHICAL APPROVAL - FACULTY OF HEALTH SCIENCES UNIVERSITY OF
PRETORIA**

THE RESEARCH ETHICS COMMITTEE, FACULTY
Health Sciences, University of Pretoria
 complies with ICH-GCP guidelines and has
 US Federal wide Assurance.



- * FWA 00002567, Approved dd 22 May 2002 and Expires 20 Oct 2016.
- * IRB 0000 2235 IORG0001762 Approved dd 13/04/2011 and Expires 13/04/2014.

Faculty of Health Sciences Research Ethics Committee
 Fakulteit Gesondheidswetenskappe Navorsingsetikerkomitee

DATE: 28/10/2011

PROTOCOL NO.	199/2010
NEW TITLE	Guidelines for the assessment of abuse in women living with HIV and AIDS in Lilongwe, Malawi.
INVESTIGATOR	Principal Investigator: Winnie Chilenga
SUBINVESTIGATOR	None
DEPARTMENT	Dept:Nursing Science, University of Pretoria Phone:0123542125 Fax:0123541490 E-Mail: wchilenga@yahoo.com Cell: 0733385468
STUDY DEGREE	PHD (Nursing Science)
SPONSOR	UNEDSA
MEETING DATE	27/10/2010 – 26/10/2011

The Protocol and Informed Consent Document were approved on 26/10/2011 by a properly constituted meeting of the Ethics Committee subject to the following conditions:

1. The approval is valid for 4 years period [till the end of December 2013] , and
2. The approval is conditional on the receipt of 6 monthly written Progress Reports, and
3. The approval is conditional on the research being conducted as stipulated by the details of the documents submitted to and approved by the Committee. In the event that a need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

Members of the Research Ethics Committee:

- | | |
|-----------------|---|
| Prof M J Bester | (Female) BSc (Chemistry and Biochemistry), BSc (Biogeochemistry), MSc (Biochemistry), PhD (Medical Biochemistry) |
| Prof R Delpont | (Female) BA + Hon., D. Criminology (Law), Honorary cum MSc., M. Sc. (Psychology), PhD (Medicine), M. Ed. Computer Aided Education |
| Prof JA Ker | MBCMB, MMedUnl, MD – Vice-Dean (ex officio) |
| Dr NK Likibi | MEd (M – Representing Ongoing Department of Health MPH) |
| Dr MP Mathebula | (Female) Deputy CPO, Steve Biko Academic Hospital, MBCMB, PDM, HM |
| Prof A Nienaber | (Female) BA(Hons)(Wilo), LLB, LL.M, LL.D (UP), PhD, Dipl.Datometrics(UNISA) – Legal advice |
| Mrs MC Nzaku | (Female) BSc(NUL), MSc(Biochem)(UCL, UK) – Community representative |
| Prof L M Ntshie | MBCMB (Natal) PCS(SA) |
| Sir S J Phatofi | (Female) B.Cur(Tot.A), B.Tax/Oncology Nursing Science) – Nursing representative |
| Dr R Reynders | MBA (Int), F.Paid (CMAA) MRCPSC (Long Con Med. Use (CMAA) |
| Dr T Rossouw | (Female) MEd (cum laude), MPhil (Applied Ethics) (cum laude), MPH (Epidemiology and Epidemiology (cum laude), D.Phil) |

ANNEXURE L

ETHICAL APPROVAL UNIVERSITY OF MALAWI



UNIVERSITY OF MALAWI

Principal
K.M Makwa, MScD PhD

Our Ref:
Your Ref.: P.01/11/028

College of Medicine
Private Bag 300
CHALHJI
Blantyre 3
Malawi
Telephone: 01 877 245
01 877 281
Fax: 01 874 700

Email: comrec@medcol.mw

1st April 2011

Mrs. W. Chienba
KCN
Pibag 1
Lilongwe

Dear Mrs. Chienba

RE: P.01/11/028 – Guidelines for the Assessment of Abuse in Women Living with HIV and AIDS in Lilongwe, Malawi.

I write to inform you that COMREC reviewed your proposal mentioned above which you resubmitted for expedited review. The following points have been dealt with:

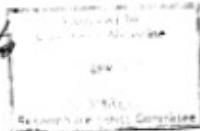
1. HIV negative group has been included to avoid being bias.
2. The issue of risk has been dealt with and been reflected in the Informed Consent

I am pleased to inform you that your protocol **was approved** after considering that you addressed all the queries raised in the initial review.

As you proceed with the implementation of your study we would like you to adhere the amended protocol ICH GCP requirements and the College of Medicine Research requirements as indicated on the attached page.

Yours Sincerely,

Prof. J.M Mhoso-Bengo
CHAIRMAN - COMREC



ANNEXURE M

LINONGWE DISTRICT HEALTH OFFICE PERMISSION TO CONDUCT STUDY

Ref. No:
Telephone No: 265 727917
Telex No: 265 727917
Teleno No:
E-Mail: lilongwedho@malawi.net



Lilongwe District Health Office
P.O. Box 1274
Lilongwe
Malawi

Please address all communications to:
The District Health Officer

28th February, 2011

Mrs W. Chlemba
Kamuzu College of Nursing
P/Bag 1
LILONGWE.

Dear Madam,

RE: PERMISSION TO CONDUCT A STUDY

With regrets we write you now this late date in response to your letter of 4th February, 2011 on the above issue. Please accept our humble apologies for a delayed response.

There is no objection for you to conduct your study at Bwaisa, Kawale, Area 18, Area 25, Lumbadzi, Mitundu, Nathenje and Kabudula. The concerned area in-charges will be communicated accordingly.

Wishing you all the best in your endeavours.

May God bless you.

Yours faithfully,


D. Kalwa
DISTRICT NURSING OFFICER