COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS

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RESEARCH OUTLINE

The research is presented in an article format including the following:

1. An overview of research and appendices
2. Five articles as follows:

	Article title	Journal submitted to
Article 1:	Stigma within the loss of an AIDS partner: A review of literature	AIDS Care
Article 2:	Coping with the stigma of the loss of an AIDS partner: A literature review	AIDS Care
Article 3:	Experiences of stigmatization of women whose partners died of AIDS	Journal of the Association of Nurses in AIDS Care
Article 4:	Coping with stigma by women whose partners died of AIDS	Journal of the Association of Nurses in AIDS Care
Article 5:	The development, implementation and evaluation of a programme for coping with stigma for women whose partners died of AIDS: A case study.	Journal of the Association of Nurses in AIDS Care

3. Conclusions, shortcomings, and recommendations for coping with stigma by women whose partners died of AIDS.

AUTHORS' CONTRIBUTION

This study has been planned and carried out by three researchers from the School of Nursing Science at the Potchefstroom Campus of the North-West University. Each researcher's contribution is listed in the table below:

Ms. M.E. Manyedi	Ph.D. student, responsible for the literature study, conducting the pilot study, implementing the research process and writing the text.
Prof. Dr. M.P. Koen Ph.D. Psychiatric Nursing Science	Promoter and critical reviewer of the study.
Prof. Dr. M. Greeff Ph.D. Psychiatric Nursing Science	Co-promoter and critical reviewer of the study.

The following statement is a declaration by the co-authors to confirm their role in the study and agree to its nature of being in the article format for submission as a thesis.

A declaration:

I hereby declare that I have approved the inclusion of all five (5) articles mentioned above in this thesis and that my role in this study complies with what is described above. I hereby give consent that these articles may be published as part of the Ph.D. thesis of

Ms Mofatiki Eva Manyedi.

_____

Prof. Dr. M.P. Koen

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Prof. Dr. M. Greeff

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ABSTRACT

The previous study on the experiences of widowhood and beliefs about the mourning process of the Batswana people found that widows were stigmatised due to cultural beliefs that made coping a difficult process for the widow. The literature revealed that widowhood following the death of a partner from AIDS is a difficult process due to HIV and AIDS being highly stigmatized. Stigma is an attribute that is deeply discrediting and devaluating to an individual social identity. It also reduces the person from her usual status to one with a tainted image due to the belief that having contracted HIV and AIDS is a choice and that an individual is responsible for her immoral behaviour. This negative attitude that amounts to prejudice contributes to the women's feelings of unworthiness. It was also found that the stigma against people living with HIV and AIDS is not only directed at them, but also to those having close relationships with them namely, their spouses, children, relatives, as well as health workers, which is known as secondary or associated stigma. The stigma was found to be attributed to discrimination based on gender, age, sexual orientation and race, hence women living with HIV and AIDS were found to be more stigmatised than men. Women whose partners died of AIDS were thus perceived by the community as having infected their partners, therefore, they were blamed, isolated and excluded from community activities. Coping with the loss of a partner was found to be a difficult process for the widow, aggravated by the death from AIDS. Some women coped by denying their late partner's status, while others kept it secret to avoid stigmatization. Some women, however, coped by challenging perpetrators of stigma about their attitude.

This study was motivated by the challenge perceived by the researcher concerning women who lost their partners to AIDS who had to be assisted with coping with stigma associated with them having had a partner who was infected and died from AIDS. The objectives of this study were to explore and describe the experiences of coping with stigma by women whose partners died of AIDS, as well as to develop, implement and evaluate a programme to assist women whose partners died of aids to cope with the stigma associated with their partner having had a relationship with an infected partner who died of AIDS. The literature was studied in order to contextualize both stigma and coping. A qualitative phenomenological design was followed in phase one of the study as well as a case study in phase two. A purposive sample was used in phase one as

well as in phase two. Data were collected by means of single open ended questions. In-depth interviews were recorded on audio tape and transcribed verbatim. Personal, observational as well as methodological field notes were written after each interview. Data analysis was conducted according to the content analysis technique of Tesch. The co-coder and the researcher analysed the data independently, after which a consensus meeting was held to finalise data. Ethical principles were applied according to Burns and Grove, as well as the Democratic Nurses Organisation of South Africa and the Department of Health. Trustworthiness of the study was ensured through the model of Lincoln and Guba. The criteria of creditability, transferability, dependability, as well as confirmability were ensured. The findings of phase one of the study as well as the literature study of stigma intervention programmes assisted in the formulation of a programme. An eight sessions programme for coping with stigma for women whose partners died of AIDS was developed, implemented and evaluated.

Phase two of the study consisted of a holistic multiple case design for presenting the developed programme. Data were collected by means of multiple sources of evidence. Data were analysed by means of a case record. Conclusions indicated that the programme for coping with stigma for women whose partners died of AIDS had a positive impact on the expansion of their coping skills.

Key Words: HIV, AIDS, coping, stigma, gender discrimination, partner.

OPSOMMING

Vorige studies oor die belewing van weduweeskap en gelowe oor die rou-proses van die Batswana het gevind dat weduwees gestigmatiseer is as gevolg van die kulturele gelowe wat die hantering daarvan 'n moeilike proses maak vir die weduwee. Die literatuur het aangetoon dat weduweeskap, as gevolg van die dood van 'n metgesel aan VIGS, 'n moeilike proses is aangesien HIV en VIGS hoogs gestigmatiseer is. Stigma is 'n hoedanigheid wat hoogs diskrediterend is en vermindering van waarde vir die individu se sosiale identiteit inhou. Dit verlaag ook die persoon se status tot een met 'n skandvlek as gevolg van die geloof dat HIV en VIGS 'n keuse is en dat die persoon daarvoor verantwoordelik is as gevolg van haar immorele gedrag. Hierdie negatiewe houding wat tot vooroordeel bydra dra ook by tot die vrou se gevoel van onwaardigheid. Daar is ook gevind dat die stigma oor HIV en VIGS nie net beperk is tot die mense wat ly aan die siekte nie maar ook gerig is op mense met naby verhoudinge met hulle naamlik, hulle huweliksmaat, kinders, familie asook gesondheidswerkers . Die stigma staan bekend as sekondêre geassosieerde stigma. Daar is ook gevind dat die stigma diskrimineer op grond van geslag, ouderdom, seksuele oriëntering en ras. Dit is gevind dat daar meer teenoor vroue gediskrimineer word as teenoor mans. Die gemeenskap het vroue wie se metgeselle dood is aan VIGS gesien as die skuldige aangesien hulle hul metgeselle geïnfekteer het. Hulle is dus geblameer, geïsoleer en uitgesluit van die gemeenskap se aktiwiteite. Hantering van die verlies van 'n eggenoot is gevind 'n moeilike proses vir die weduwee te wees wat vererger is deur die feit dat die sterfte as gevolg van VIGS is. Sommige vroue het die feit hanteer deur hulle oorlede man se status te ontken terwyl ander dit geheim gehou het om stigmatisering te voorkom. Sommige vroue het egter die probleem hanteer deur skuldiges aan die stigma uit te daag oor hulle houding.

Hierdie studie is gemotiveer deur die uitdaging ervaar deur die navorser rakende vroue wat hul metgeselle verloor het as gevolg van VIGS wie bygestaan moes word in die hantering van die stigma geassosieer met hulle verbintenis met 'n persoon wat dood is as gevolg van VIGS. Die doelstellings van die studie was om die ondervindinge van vroue wat 'n metgesel aan VIGS afgestaan het se hantering van die trauma te ondersoek en te beskryf, sowel as om 'n program te ontwikkel, te implementeer en te evalueer om vroue wie se mans aan VIGS dood is by te staan in die hantering van die trauma as gevolg van die stigma geassosieer met die afsterwe van hul mans as gevolg

van hul verbintenis met iemand wat ly aan VIGS. Die literatuur is bestudeer ten einde beide die stigma en die hantering daarvan te kontekstualiseer. 'n Kwalitatiewe fenomenologiese ontwerp is gevolg in fase een van die studie asook 'n gevallestudie in fase twee. 'n Doelgerigte voorbeeld is gebruik in beide fase een en twee. Data is versamel deur middel van enkelvoudige oop-einde vrae. In diepte onderhoude is op audio band opgeneem en verbatim getranskribeer. Persoonlike waarneminge sowel as metodologiese veldnotas is opgestel na elke onderhoud. Die data-analise is gedoen volgens die inhoudsanalise tegnieke van Tesch. Die mede-kodeerder en die navorser het die data onafhanklik geanaliseer waarna 'n konsensus vergadering gehou is om die data te finaliseer. Etiese beginsels is toegepas volgens riglyne van Burn en Grove sowel as volgens die riglyne van die Demokratiese Verpleegsters Vereniging van Suid Afrika en die Departement van Gesondheid. Die geloofwaardigheid van die studie is verseker deur die model van Lincoln en Guba. Die kriteria geloofwaardigheid, oordraagbaarheid, afhanklikheid sowel as bevestigbaarheid is verseker. Die bevindinge van die eerste fase van die studie sowel as die literatuurstudie oor stigma ingrypings programme was behulpsaam in die formulering van 'n program. 'n Agt-sessie program vir die hantering van stigma vir vroue wie se mans aan VIGS dood is, is ontwikkel, geïmplementeer en geëvalueer.

Fase twee van die studie het bestaan uit 'n holistiese meervoudige gevalle ontwerp vir die aanbieding van die ontwikkelde program. Data is versamel deur middel van veelvoudige bronne van bewyslewering. Data is geanaliseer deur middel van 'n gevallestudie. Die gevolgtrekking van die studie het aangetoon dat die program vir die hantering van stigma deur vroue wie se mans aan VIGS dood is 'n positiewe impak gehad het in die uitbouing van hulle hanteringsvaardighede.

Sleutelterme: HIV, VIGS, coping, stigma, geslagsdiskriminasie, metgesel.

OVERVIEW OF THE RESEARCH

Core terms: HIV, AIDS, coping, stigma, gender discrimination, partner

1.1 INTRODUCTION AND PROBLEM STATEMENT

The previous study conducted by the researcher as part of the Master's degree programme entitled "Experiences of widowhood and beliefs about the mourning process of the Batswana people" yielded findings that indicated that women are stigmatized, discriminated against and shunned by society due to widowhood and the mourning process (Manyedi, Koen & Greeff, 2003:78). The widows' experience of being shunned by society was found to be due to cultural beliefs that made coping with widowhood a painful and difficult process (Manyedi *et al.*, 2003:78). The statements of Bankoff (1983:836) and Parkes in Kalish (1985:207) also refer to these findings. The difficulty in coping, according to the study of Manyedi *et al.* (2003:80), is caused by the stressful life experience due to cultural beliefs of being contaminated by virtue of having lost her husband by death (Manyedi *et al.*, 2003:80; Lopata, 1988:115). The belief of being contaminated contributes to the widow's experience of isolation because of the manner in which she is treated such as her food being cooked separately as well as her eating utensils being washed and kept separate from the rest of the family's. She is also excluded from being involved in the household and community activities that she was used to carrying out before widowhood (Manyedi *et al.*, 2003:80). One of the conclusions of the aforementioned study is that the mourning process is a difficult experience to cope with for the widow, given the circumstances of being stigmatized.

The stigmatization experienced by the widows of Manyedi *et al.* (2003:78) study, can be compared to the stigmatization of HIV and AIDS. The severity of stigmatization intensifies when considering women who lost their partners due to AIDS. A known fact supported by the literature (Herek & Capitano, 1993:575; Heckman, Somlai, Peters, Walker, Otto-Salaj, Galdabini & Kelly, 1998:369; Sewpaul & Mahlalela, 1998:36; Owen, 2002:76; Nyblade, Pande, Mathur, Mac Quarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbuwambo & Bond, 2003:23; Guttman & Salmon, 2004:547), show that HIV and AIDS are highly stigmatized. Stafford and Scott (*in* Link & Phelan), (2002), Goffman (*in* Nyblade *et al.,* 2003:8), and Brown, Macintyre and Trujillo, (2003:49) describe stigma as an attribute that is deeply discrediting and devaluating

to an individual's social identity. These authors also maintain that the stigma attached to HIV and AIDS is an experience characterized by the exclusion of an individual from social responsibilities which amounts to the lowering of a person's social status, loss of respect, rejection and being suspected for having contracted the disease. Such stigma is motivated by the adverse social judgement against the person, because their sexual contact is not actually known by those stigmatizing them. It further reduces the person from the whole and the usual person, to an individual with a tainted image, thus rendering her to an experience of being an incomplete person due to the negative attributes that she is associated with (Gilmore & Sommerville in Nyblade *et al.*, 2003:8). These negative attributes are due to the perception that when someone has contracted HIV, they are responsible for their immoral behaviour, hence they are justified to suffer. Such prejudices coupled with the negative attitudes with which they are treated, may contribute to the women's feelings of unworthiness.

Researchers of HIV and AIDS also found that, in addition to the devalued status, stigmatization is not only directed at people living with this pandemic but also to those having close relationships with them, such as their spouses or sexual partners as well as other family members. Weiss and Ramakrishna (2001:17), in their paper delivered at the Stigma Conference held in 2001, with the theme: "Stigma and Global health: Developing a research agenda", concur that if someone suffers from a stigmatized disease such as HIV and AIDS, friends, loved ones, health staff as well as volunteers looking after the person become secondary targets of stigma. These people experience secondary stigma because they are considered to be close to the infected person (Weiss & Ramakrishna, 2001:17). This present research focused on women who lost their partners due to AIDS, as the closest person having had a relationship with the infected person.

Parker and Aggleton (*in* Nyblade *et al.*, 2003:8) found that the stigma is attributed to discrimination based on gender, age, sexual orientation and race to mention but a few. Yoshioka and Schustack (*in* Weiss & Ramakrishna, 2001:12) also support this view that HIV and AIDS related stigma could be attributed to the minority status or gender, because most authors do concur that women experience stigmatization more than men (Nyblade *et al.*, 2003:27; Gernholtz & Richter, 2002:99; Moutinho, 1988:23; Parker & Aggleton, 2003:13 and Serlemitsos, 2003:3). It is the gender discrimination that is believed to contribute to women being stigmatized even if their HIV and AIDS status is not known. The reason why women are marginalized and

discriminated against could be attributed to various cultural beliefs and customs within societies where they live (Sowell, Lowenstein, Moneyham, Demi & Seals, 1997:302). Hence the stigmatization of women whose partners died of AIDS because the community's perception may be that women are the ones who become infected first and are thus responsible for infecting men (Nyblade *et al.*, 2003:27). These women are, therefore, treated with suspicion of being infected therefore they are excluded from the family or community activities. Nyblade *et al.* (2003:35) discovered that the secondary stigma affecting the women whose partners died of AIDS is experienced through isolation, loss of livelihood and gossip. The people stop any interaction with the women when they realise that their partners died of AIDS.

The stigma attached to people living with HIV and AIDS affects both men and women, though the latter seem to be more stigmatized. In communities that have gender stereotypes, the problem may be so serious that women suffering from and suspected to be suffering from HIV and AIDS are sentenced to death. To cite but a few examples, in 1998 the worst scenario of gender and stigma occurred when Gugu Dlamini, a female AIDS activist was killed in Kwa-Zulu Natal Province of South Africa following her public disclosure of her HIV positive status (Brown, *et al.*, 2003:51). Stein (2000:21) discovered that a Muslim woman was sentenced to death because she disclosed her status after becoming aware that her dead husband had infected her with HIV. Owen (2002:70) confirms that in Asia such women have to cope with the additional burden of being chased away by the in-laws who also become violent against them because of their husbands having died of AIDS. This may be due to the fact that both widowhood and AIDS carry the stigma.

Coping with the loss of a partner is a difficult process in itself and when the partner dies of AIDS it makes it even more difficult. Lindemann (*in* Cleiren, 1993:14) describes coping as recovering and returning to the state that prevailed before the partner's death. According to this author, the woman whose partner has died has to emancipate herself from that relationship and readjust to the environment in order to cope. Blyth (*in* Baumann, 1998:123), mentioned feelings that the person experiences such as, sadness, loneliness, anger, guilt, frustration, anxiety, shock and helplessness. She has to cope with these feelings which she could find difficult because firstly, the stigma that she experiences may not facilitate her return to her initial state, secondly, emancipating herself from the relationship with the partner and

forming a new relationship may be a daunting task due to the aforementioned feelings.

According to Nyblade *et.al.* (2003:36), some women attempt to cope by denying their late partner's AIDS status or avoiding disclosing or talking about it if they knew about it, especially if they anticipate to be stigmatized; Alternatively, some cope by directly challenging or confronting stigmatizing attitudes, while others seek explanations apart from sexual transmission. Those explanations may be witchcraft, which is the commonest and most acceptable cause of illness. By telling others that they are bewitched, they feel relieved that they will get better care and support. Some women apparently cope by joining support groups, by volunteering to care for others or seek jobs within the circles of HIV and AIDS, while others turn to religion and prayer for comfort, solace and support (Nyblade *et al.*, 2003:36). Some women experiencing the stigma seek care and support from their families or health care providers (Nyblade *et al*, 2003:40). These health care providers are mainly nurses, because they have more contact with patients. Psychiatric nurses as professionals involved in the psychological care, especially counseling, are seen as those who could provide effective support.

Assisting these women who experience stigmatization to cope with it poses a challenge for psychiatric nurses, especially those involved with counseling people infected and affected by HIV and AIDS. The challenge facing these nurses may be concerning the strategies that will assist them to cope with their situation as discussed above. Nyblade *et al.* (2003:9) believe that this challenge is due to the fact that like community members, the health professionals, including psychiatric nurses often lack a clear understanding of HIV and AIDS. Exploring and describing these women's experience of stigma, as well as their manner of coping, provided the researcher with the information that indicated the need, approach and content for developing a programme that may assist them to cope positively with such stigma. These women need caring and compassionate psychiatric nurses, who can assist them to deal with the internal stigma manifesting with their experience of negative self concept leading to negative self identity (Fife & Wright, 2000:51). This study will benefit such women if the need for such a programme is established. The need to conduct this study is also motivated by the passion developed in the previous study with regard to the stigmatization of widows by the community, and that the researcher aspires to make a contribution to the uplifting of women in South Africa.

The literature reviewed for this study as well as the researcher's observations gave the background information that shed light on widowhood as a difficult and stressful experience for the widow. Contributing to this difficult process is the fact that widowhood itself is a stressful experience for the woman, which in this case is aggravated by HIV and AIDS. Widowhood, HIV and AIDS both have cultural beliefs attached to them. Women who have lost their partners to AIDS find themselves in a difficult situation to cope with the devaluation resulting from the loss of social status, exclusion from social activities, isolation as well as gossip about their HIV and AIDS status. The women's experience of difficulty in coping with the feelings alluded to earlier in this introduction, furnished data indicating the need for psychiatric nurses to assist them to cope with the process.

Based on the problem as explained above the following questions arise:

- What are the experiences of coping with stigma by women whose partners died of AIDS?
- How can the women whose partners died of AIDS be assisted to cope with the stigma associated with their having had a relationship with an infected person who died of AIDS?

1.2 OBJECTIVES OF RESEARCH

From the above-mentioned questions, the following are the objectives formulated for this research.

- To explore and describe the experience of coping with the stigma by women whose partners died of AIDS.
- To develop, implement, and evaluate a programme to assist women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected person who died of AIDS.

1.3 THE PARADIGMATIC PERSPECTIVE

The paradigmatic perspective of this study includes the meta-theoretical assumptions, theoretical statements and methodological statements, which are discussed in this section of the study.

1.3.1 Meta-theoretical assumptions

The meta-theoretical assumptions of this study are grounded on the researcher's own philosophy that respects the uniqueness of every person, her/his dignity, beliefs and value systems, as well as his/her culture. The meta-theoretical assumptions of this study comprise person, environment, health, illness and nursing, as described in the paragraph that follows.

1.3.1.1 Person

The researcher believes that a person is the total biological, psychological, spiritual and social being. Every person is unique in the manner that they react to stimuli within their environment, the way they think as well as their beliefs and values. Persons react to the environment based on their previous experiences. Every person is, therefore, in constant interaction with his or her environment, which may be internal or external. From previous experiences, coping strategies are developed, based on an individual's perception of the problems they encounter. Due to the life experiences that confront a person from day to day, they keep on growing, and develop better coping mechanisms for daily problems.

In this research person refers to women whose partners died of AIDS. The researcher prefers to include all potential women, whose partners died of AIDS rather than widows, to avoid discrimination because, in the African context, widows are only those who are legally married to their spouses. This research, therefore, includes those women who either cohabit with men to whom they are not married, or those who had a relationship out of wedlock. The concept women in this research is, therefore, non discriminatory.

1.3.1.2 Environment

The environment is internal as well as external and comprises all those forces that influence a person at any given time of a lifetime. The internal environment comprises all those forces that are from within namely, physical, social, spiritual and psychological, including values, beliefs as well as morals. An external environment comprises external forces namely, physical, social, psychological and spiritual. All these forces influence the person either positively or negatively. When the environmental forces are positive, an individual's reaction is positive and when

negative, the individual's reaction may also be negative, leading to ill-health. Stigma is a negative force that creates a status that may require coping strategies.

1.3.1.3 Health

Health is a state of wholeness and includes the continuum of health and illness. An individual is in a state of health when there is absence of disease and life stressors that lead to stress. Wholeness is, therefore, maintained when an individual interacts positively with his or her environment. Every individual is responsible for his or her own health. When an individual fails to maintain his or her health, he or she may seek the intervention of the health professionals.

In the context of this research, stigmatisation of women whose partners died of AIDS interferes with their health status. When these women are confronted with the stigma, the intervention of health professionals becomes necessary. Health professionals in this research are psychiatric nurses who possess specialized skills to intervene appropriately. These interventions assist the women to cope if the need exists.

1.3.1.4 Nursing

Nursing, according to the researcher's belief is a unique profession involved with caring for those who, due to ill-health, cannot take care of themselves, as well as those who due to stressful life situations, need professional guidance and advice. They are individuals who have undergone training and who are qualified as well as registered with the South African Nursing Council for the purpose of practicing this profession. Nurses in this research are psychiatric nurses who are specially trained to give such guidance and information. Nurses carry out their function by interacting with those in need of their service. Those in need of care in this research are women whose husbands died of AIDS. The psychiatric nurses' responsibility in this regard would be to facilitate the presentation of a programme designed to assist those women who require assistance to cope with the stigma associated with their having had a relationship with a partner who died of AIDS.

1.3.2 Theoretical statements

The theoretical statement for this study comprises the central theoretical argument and conceptual definitions as discussed below.

1.3.2.1 Central theoretical argument

The focus of this study is on stigmatization as a difficult process that women whose partners died of AIDS have to cope with. The widowhood status is aggravated by the presence of AIDS. Women in this context are thus faced with stigmatization of widowhood, compounded by the loss of their partners to AIDS. The stigma attached to this syndrome is associated with its incurable nature, the high death rate resulting from it, as well as the mode of transmission. The worst hit seems to be women who lost their partners to the disease and who might experience coping with this dual stigmatization as a most devastating process. There is, therefore, a need to assist them to cope with this situation. Psychiatric nurses as people trained to assist people experiencing stressful situations, could establish support systems for such people. The in-depth exploring and describing of this coping experience will lead to an understanding of the need for the development of a programme that would assist these women to cope with stigmatization of their having had a relationship with an infected person who died of AIDS.

1.3.2.2 Conceptual definitions

The following are definitions of concepts used in this study that are derived from the literature. These concepts, described in the context of this study are coping, HIV, AIDS, stigma, gender discrimination and partner.

- **Coping**

The effort made by an individual to manage situations that she appraises as potentially harmful or stressful (Lazarus & Folkman in Kleinke, 1991:3). These efforts may also be cognitive, behavioural or psychosocial strategies that an individual uses to alleviate distress (Lazarus & Folkman in Kleinke, 1991:3).

In the context of this research, coping refers to the ability of those women whose partners died of AIDS to manage the stressful situation of being stigmatized by the community. These women employ cognitive, behavioral or psychosocial strategies to deal with the stigmatizing attitudes and behaviours of those in their environment.

- **HIV**

HIV is an abbreviation for Human Immunodeficiency virus and refers to any of the viruses that cause AIDS (Branford, 1994:442).

In the context of this research HIV is referred to where women whose partners died of AIDS have undergone testing and are found to be HIV positive, thus compounding the stigma that they already experience due to their partners having died of AIDS.

- **AIDS**

AIDS is an abbreviation of acquired immune deficiency syndrome. The syndrome is caused by an HIV which is characterized by a severe loss of resistance to infection (Branford, 1994:18).

In this study women whose partners died of AIDS had to cope with the stigma associated with having had an infected partner who died of AIDS because it is a highly stigmatized disease (Nyblade *et al.*, 2001:8).

- **Stigma**

Stigma may be described as attachment of negative attributes which are discrediting and reduce an individual from his/her usual whole to one with a tainted image (Goffman in Nyblade *et al.*, 2001:8).

In this study, the stigma is a phenomenon under study where women, whose partners died of AIDS are struggling to cope with stigma.

- **Gender discrimination**

Gender is a distinction of sex based on whether one is male or female (Funk & Wagnals, 1980:266). Discrimination means acting towards someone with partiality or prejudice (Funk & Wagnalls, 1980:182). Gender discrimination thus refers to treating an individual with prejudice, based on gender.

- **Partner**

According to the Longman dictionary (1987:749), partner is either of the two people sharing an activity. Partners are people who are closely related, to an extent that they

are associated with each other. In the context of this study partner refers to a spouse or a boyfriend of a married or unmarried woman respectively, who died of AIDS.

The concept partner is preferred to spouse because both married and unmarried women are included in the study. It should, however, be borne in mind that the partners referred to in this study died of AIDS and are, therefore, discussed in their posthumus state.

1.3.3 Methodological statements

The methodological statements of this research study are grounded on the model of Botes (1995:6-22), which the researcher supports due to its perspective of the functional thought approach. The functional reasoning approach supports the premise that nursing research is practical and applicable. Research emanates from three orders that for descriptive purposes may be arranged as follows:

The first order referring to the nursing practice is from time to time confronted by problems which need solutions or improvements. These solutions are sought through research. The problem or challenge in this study is coping with stigma by women whose partners died of AIDS. Exploring the experience of coping by these women will yield the results which will assist the practice of mental health nursing.

The second order represents the methodology to be adopted. This is done in two phases: qualitative phenomenological and case study designs. From the first order information will be yielded that will lead to the development, implementation and evaluation of a programme to assist women whose partners died of AIDS to cope with the stigma.

The third order represents metatheoretical assumptions which are based on the researcher's belief of health care systems which adopt a total person approach (George 1990:267; Chinn & Kramer, 1995:181; Fitzpatrick & Whall, 1996:202; Bouwer *et al.*, 1997:23). The theoretical statement includes the central theoretical argument as well as conceptual definitions from other sources consulted for the conceptual definitions of this research namely, Kleinke (1991:3), Funk and Wagnalls (1980), Sowell *et al.* (1997:302) and Nyblade *et al.* (2001:8). Methodological statements are grounded from the model of Botes (1995:6-22).

1.4 RESEARCH METHODOLOGY

The methodology of this study follows the order discussed below, namely, the literature study to contextualise stigma and coping, the research design, the research method, as well as the ethical aspects.

1.4.1 Literature study to contextualise stigma and coping

The literature study was conducted in order to contextualize stigma and coping in the context of HIV and AIDS and is presented in two articles. Both phenomena of stigma and coping were conceptualized by critically examining and synthesizing their definitions, discussing processes as well as types, with special reference to their association with HIV and AIDS (Silverman, 2000:85).

1.4.2 Research design

A qualitative phenomenological as well as a case study research design were followed, the aim of which was to explore and describe the experience of coping with stigma by women whose partners died of AIDS (Creswell, 1998:15). In-depth interviews with participants enabled the researcher to explore and describe the phenomenon of coping with stigma. The women's experiences assisted the researcher to develop a programme to assist such women to cope effectively with the stigma associated with their having had a relationship with a partner who was infected and died of AIDS. The programme was designed from the literature study of other programmes as well as from data gathered from in-depth interviews. The programme consisting of eight sessions was implemented and evaluated in a holistic multiple case study design of four women (Creswell, 1998:63). Evidence was collected from multiple sources reflected in individual notes, transcripts, naïve sketches, as well as from field notes (Yin, 1994:78; Yin, 2003:4). The study was conducted in the five regions of the North West Province of South Africa.

1.4.3 Research method

Two phases characterized the method through which this study was conducted, namely, phase one that comprised a qualitative study that explored and described the experience of coping with stigma by women whose partners died of AIDS. Phase two comprised a holistic multiple case study for the development, implementation and

evaluation of the impact of the programme for coping with stigma by women whose partners died of AIDS.

1.4.3.1 Phase One: A qualitative study of exploring and describing experience of coping with stigma by women whose partners died of AIDS

Following is the description of the sample, data collection, data analysis, trustworthiness, as well as literature control of phase one of this research.

1.4.3.1.1 Sample

Under the sample is the description of the population, sampling and the sample size.

- **Population**

The population from which the sample was drawn consisted of women whose partners died of AIDS within a year of their loss. The first year of loss is critical in terms of the bereaved person's experience, as well as her ability to cope, because at this time the attitudes are still intensive. These attitudes are coupled with cultural beliefs, besides the partner having died of AIDS itself. The context is the five regions of the North West Province of South Africa.

- **Sampling**

A purposeful voluntary sampling technique was used (Burns & Grove, 1997:306; Streubert & Carpenter, 1999:22). Participants, in the purposeful sample were selected according to the needs of the study and they must have had the experience of the phenomenon under study (Agar, 1980:84; Hammersley & Atkinson, 1883:46 in Morse, 1991:129-132). The inclusion criteria were set out in order to ensure that participants possessed the characteristics necessary for the study (Polit & Hungler, 1995:306; Brink & Wood, 1998:319). These were as follows:

- **Selection criteria**

For the purpose of this study participants were selected according to the following criteria:

The women had to:

➢ have lost their partners due to AIDS within a year.

- be resident in any of the five regions of the North West Province of South Africa.
- be able to communicate in Setswana, Sesotho, Northern Sesotho/ Sepedi or English.
- be open and willing to share their experience in an in-depth interview.
- be willing to give consent to be recorded on an audio-tape.

1.4.3.1.2 Choice of mediators

A letter was written to the AIDS Provincial Coordinators (see Annexure A) to communicate with regional coordinators, who may in turn link with district coordinators if practicable, in order to request them to identify and refer prospective participants to the researcher. Participants had to meet the set criteria as stated in the paragraph above. Their role also included linking the researcher with prospective participants, establishing the initial rapport with them and providing their names, addresses and contact numbers. The mediators were also expected to assist the researcher to find the participants' places of residence for the sake of delivering letters requesting them to participate in the research (see Annexure B) as well as going to conduct interviews. When the mediators could not undertake this role, a breakthrough was made through a home-based care non-governmental organisation, where home-based carers identified prospective participants and accompanied the researcher to their homes in order to establish rapport. Thereafter, the researcher delivered the letters and secured appointments for interviews.

- **Sample size**

The sample size was determined by data saturation (Burns & Grove, 1997:308). Data saturation was achieved when the data became redundant and there was repetition of information from new participants (Morse in Streubert & Carpenter, 1999:22; Polit & Hungler, 1995:258). In this context, data were also regarded as saturated when confirmation by the previously collected data yielded or repeated the same information (Streubert & Carpenter, 1999:22). Data saturation was reached after thirteen in-depth interviews, but twenty were conducted to ensure richness of data.

1.4.3.1.3 Data collection

The method of data collection, writing of field notes, the physical setting, as well as the role of the researcher for this study are described as follows:

1.4.3.1.3.1 Method of data collection

The researcher requested permission to conduct research from the Directorate of Epidemiology via a letter (see Annexure C) written to the Sub-directorate of HIV and AIDS in the North-West Provincial Department of Health. Data collection was undertaken by means of a single open-ended question (Brink & Wood, 1998:322), **"Tell me how you experience coping with stigma after your partner died of AIDS"**. In-depth interviews were recorded on an audio-tape. The open ended question was first checked by experts to evaluate its applicability. The pilot study was conducted initially with one of the participants who met the inclusion criteria.

Prior to conducting interviews, the mediators arranged appointments with participants who complied with the set criteria. Interviews took place at the home of these participants to maintain and observe their privacy. This also ensured that they were free, comfortable and, therefore, able to impart the information required by the researcher (Streubert & Carpenter, 1999:23). The researcher explained to participants the expectations of the interview process to ensure that each understood before commencement. Two tape recorders were provided, of which one was electricity and the other one battery operated to have a backup system in case the power failed in the process of an interview. Interviewees were reminded about ethical considerations to be observed throughout (see ethical considerations) the research process. The interviewer/researcher employed the effective use of self as a skill to establish rapport so that she could establish a relaxed atmosphere for her interviewees to disclose information (Morse, 1989:188-189). This was also to establish trust that would reassure the participant that she was safe as she disclosed her experience (Streubert & Carpenter, 1999:24).

Participants were allowed freedom of time to respond as long as they still had information to impart. Communication techniques as described by Okun (1997:75-76) were used to facilitate the interview as follows:-

- **Minimal verbal response**

This is a verbal response by the interviewer that shows the interviewee that she is listening and interested, such as uh ..., yes ..., I see ..., ok... .

- **Paraphrasing**

The interviewer reiterates the participant's words in a different way to convey that the former understood the message.

- **Probing**

Whenever it seems that a particular statement said by the interviewee/participant still needs to be explained, the researcher asks another open-ended question in order to pursue a statement, thus allowing the participant to give more information on a particular aspect.

- **Reflecting**

The interviewer/researcher communicated implied verbal statements or observed non-verbal cues to the interviewee/participant in order to reflect her interpretation to the latter. An example would be "You seem to feel uncomfortable about saying this".

- **Clarifying**

Means that the researcher concentrates on a particular statement to seek clarity on it, such as "I don't seem to understand how often you met with him".

- **Summarising**

The researcher highlights the major affective as well as cognitive themes in a synthesized form in order to communicate to the participants what has been said during an interview. It gave both the interviewer/researcher and the interviewee/participant an opportunity to check on what had been discussed as well as their impressions about the interview.

The researcher demonstrated non-verbal communication techniques throughout the interview such as excluding any barriers between herself and the participant, maintaining an open posture, occasionally nodding, maintaining eye contact, as well as smiling occasionally to convey friendliness and that she was interested and

involved in the conversation (Okun, 1997:63). The participants were thanked at the end of the interview and the audiotape switched off.

1.4.3.1.3.2 Field notes

Field notes were written immediately after each interview (see Annexure D) to ensure that all observations were recorded whilst the researcher still remembered them clearly (Morse, 1989:116; Creswell, 1998:130). These notes were meant to record any additional information that may not have been disclosed by the participant. These included the researcher's observation as well as an account of circumstances prevailing during the interview. These notes were taken according to Schatzman and Strauss (in De Vos, 1998:285) and discussed as follows:

- **Observational notes**

Reflect an account of what happened during an interview without attempting to interpret the events. These include who, what, when, where and how of the circumstances.

- **Theoretical notes**

Theoretical notes are the researcher's self-conscious and systematic interpretation of her observations during an interview. These are described in relation to the observational notes, reflecting the meaning and conceptualising by linking the present to the previous response as done in relation to the phenomenon of stigma.

- **Methodological notes**

Create the researcher's awareness about the appropriateness of the methodology that she follows. The researcher reflects on her own process of interviewing so that it is consistent with the selected methodology (Schatzman & Strauss, in de Vos, 1998:286).

The name codes of participants, dates as well as places of interviews were recorded and arranged appropriately, in readiness for data analysis.

1.4.3.1.3.3 Physical setting

The interviews took place in the homes of participants in order to ensure privacy and comfort. Being in their homes, participants were given an opportunity to choose a

quite place with minimal distractions. Participants were requested to ensure that no disturbance occurred once the interview was in process and telephones and cell-phones were switched off. Participants were also warned that the interview could last for one to two hours. A comfortable sitting arrangement was organised and eye contact was possible. Tape recorders were checked beforehand for any defects.

1.4.3.1.3.4 The role of the researcher

Written informed consent was obtained from participants, as well as from mediators. The researcher contacted them to establish their willingness to participate in the study, as well as to give clarity of the objectives of research. After contact with potential participants was established, the researcher arranged for interviews either telephonically, by mail, or where possible by visiting personally. Appointments were confirmed in the same way at least a day before the date of the interviews. Consent forms signed by the participants were detached from the letters to serve as records of proof that the participants were willing to participate and that they did so voluntarily. A place map was obtained from the municipality in order to locate places of residence of the participants.

1.4.3.1.4 Data analysis

The interviews recorded on audio-tapes were transcribed verbatim, as well as translated from other languages into English. Data analysis was conducted according to the content analysis techniques of Tesch as discussed in Creswell (1994:15). The method included the following steps of data analysis:

- The transcripts were divided into three columns. On the left-hand side there is a column for noting concepts; the data is in the middle of the page and the right hand side is for the researcher's perceptions.
- The researcher read all the transcripts in order to get a sense of the whole idea communicated, or the themes emerging.
- The most interesting or the shortest transcript was chosen and re-read.
- Words and sentences were used as units of analysis and as such were underlined as the researcher went through the transcript again.
- The underlined spoken words and sentences were then transferred to the left column as categories. Those perceptions that struck the researcher's mind were noted in the right column.

- The categories transferred onto the right-hand side were read in order to identify the main sub-categories as well as redundant categories.
- The underlined spoken words were then transferred into a table highlighting the main categories, sub categories, as well further categories.
- These categories were finalized by revising the table as spoken words were then translated into scientific language. At this juncture the researcher had to keep in mind that further refining of that categorization could still take place.

The rest of the transcripts as well as field notes were then analysed in the same method. An experienced qualitative research specialist was requested to conduct independent co-coding. The same transcripts (see Annexure E) and field notes, as well as the work protocol were sent to the independent co-coder (Annexure F). Together with all these documents, a letter was written stating

- The objectives of the study;
- A description of the data collection method, including the single open-ended question for the participants.
- A description of the technique of data analysis.

After completion of co-coding a meeting was organised by the co-coder and the researcher. A discussion was held where both compared their analysed results in order to reach a consensus. The categories and sub-categories agreed upon were then finalized into a table that comprised the findings of the study, which then served as a basis for the discussion (De Vos, 1998:345).

1.4.3.1.5 Trustworthiness

Trustworthiness is the concept adopted by Lincoln and Guba (in Kefting, 1991:24) to explain what the quantitative researchers refer to as the validity and reliability of the study. In this study such a model suitable for qualitative research was found relevant because it ensured the rigor without compromising the relevance of this study (De Vos 1998:348). The model was integrated with Woods and Catanzano's model (1998:136). The criteria applicable to ensuring the trustworthiness of the study according to these authors are credibility, transferability, dependability and conformability.

- **Credibility**

In this study the credibility was ensured by the researcher creating enough time to get to know her participants thus establishing a trust relationship. Participants were visited at least twice before the interviews were undertaken. The researcher conducted more than one interview by going back at a later stage to verify whether the information provided by the participant was still the same. Lincoln and Guba (in Krefting, 1991:215) refer to this criterion as truth value, because women who lost their partners to AIDS are allowed to relate their lived experience of the stigma associated with their relationship with infected partners. The researcher also ensured the truth value of the study by:

- Writing field notes that were the researcher's own observations of the phenomenon of stigma. They also reflected the behaviour of these women in the context of the situation they found themselves in. These observations included the what, who, when, where and the how of the circumstances. Theoretical field notes included the researchers' inferences and associations of what she observed from setting to setting.

The researcher also guarded against some threats to validity as identified by Woods and Catanzaro (1988:137). These were observer effects, selection of participants, regression and mortality. The researcher believed that bracketing and intuiting (Burns & Grove, in De Vos, 1998:337) also ensured the truth value because the researcher put aside all that she knew about the stigma and devoted all her concentration to the experience under study in order to avoid misconstruing or misinterpreting what she heard and observed. This is where the research had to indicate in the report her engagement with the whole research situation as well as the process.

- **Transferability**

This refers to the applicability of the results to other contexts, settings or with other groups. It is also the question of whether results can be generalized to the larger populations. Krefting (in De Vos, 1998:349 argues that generalization is not applicable in qualitative research because it takes place in real or naturalistic settings, where there were few controlling variables. This criterion was, therefore, influenced by the strength of the qualitative method. The transferability of the study was not much of the researcher's responsibility but that of the individual wishing to fit the

findings in another situation or applying the method in another setting (Lincoln & Guba, in de Vos, 1998:349).

- **Dependability**

According to Lincoln and Guba (in Krefting, 1991:216), dependability refers to consistency of the data as well as to the auditability. This means that someone called to authenticate the research process should find the process acceptable. Lincoln and Guba (in Krefting, 1991:221) also advocate for replication techniques to be incorporated into qualitative research. For the sake of this study the researcher explained to participants that they were experts in the field of stigmatization because they experienced it themselves, and that they should be open in their discussion. This was an attempt to avoid a threat to consistency, as identified by Woods and Catanzaro (1988:136):

- The involvement of a co-coder also eliminated lack of consistency.
- Secondly, the study made use of the mediators, who identified potential participants for the researcher who verified if they met the set criteria.
- Participants were also required to sign the consent form to participate in the study, so that their willingness to participate was confirmed.
- To eliminate the threat of the social environment of the participants, the researcher was the only person conducting the interviews; as such the field notes indicated the discrepancies with regard to the information provided by participants.

- **Confirmability**

Lincoln and Guba (in Krefting, 1991:221) describe this as a criterion of neutrality whereby the bias of the researcher should be avoided in the procedures and the findings. In this study the researcher made available, all documents required for auditing including the raw data, field notes, as well as data analysis documents.

TABLE 1: STRATEGIES TO ENSURE TRUSTWORTHINESS

STRATEGY	CRITERIA	APPLICATION
Credibility	Prolonged field experience	Letters to request participation delivered by researcher and spending time with women whose partners died of AIDS to establish a trusting relationship. Confirmation of appointments also done personally by researcher to strengthen the relationship. Participants allowed enough time to verbalise their experiences and beliefs respectively.
	Reflexibility	Field notes were written immediately and subjected to analysis.
	Member checking	Literature control of experiences of coping with stigma was undertaken.
	Interview technique	Researcher trained on research methods and on interviewing skills. Research supervised by experts experienced in qualitative research.
Transferability	Selection of sample	The sampling method was purposive voluntary.
	Dense description	Through description of research methodology and literature control of the findings.
Dependability	Stepwise replication	Co-coder involved in independent data analysis.
	Dense description	Detailed description of methodology.
	Code-recode procedure	Data analysed twice and results compared. Consensus discussion held with co-coder.
	Peer Examination	Expert supervision provided.
Confirmability	Confirmability audit	Done by supervisors of the research.
	Reflexibility	Field notes taken and subjected to data analysis.

1.4.3.1.6 Literature control

In a qualitative study such as this, literature control done is necessary so that the findings can be discussed within the context of what is already written about stigma and coping with stigma related to HIV and AIDS (Streubert & Carpenter, 1999:61). The literature, therefore, served the purpose of validating the data, identifying that which was found in the literature but not evident in this study, or the findings that were unique to this study but not found in the literature. Data that were confirmed by literature were also indicated (Burns & Grove (2003:112 –113). Consolidation of the data was then done in order to reflect current knowledge on stigma and coping with stigma by women whose partners died of AIDS.

1.4.3.2 Phase two: Case study for the implementation and evaluation of a programme for coping with stigma by women whose partners died of AIDS

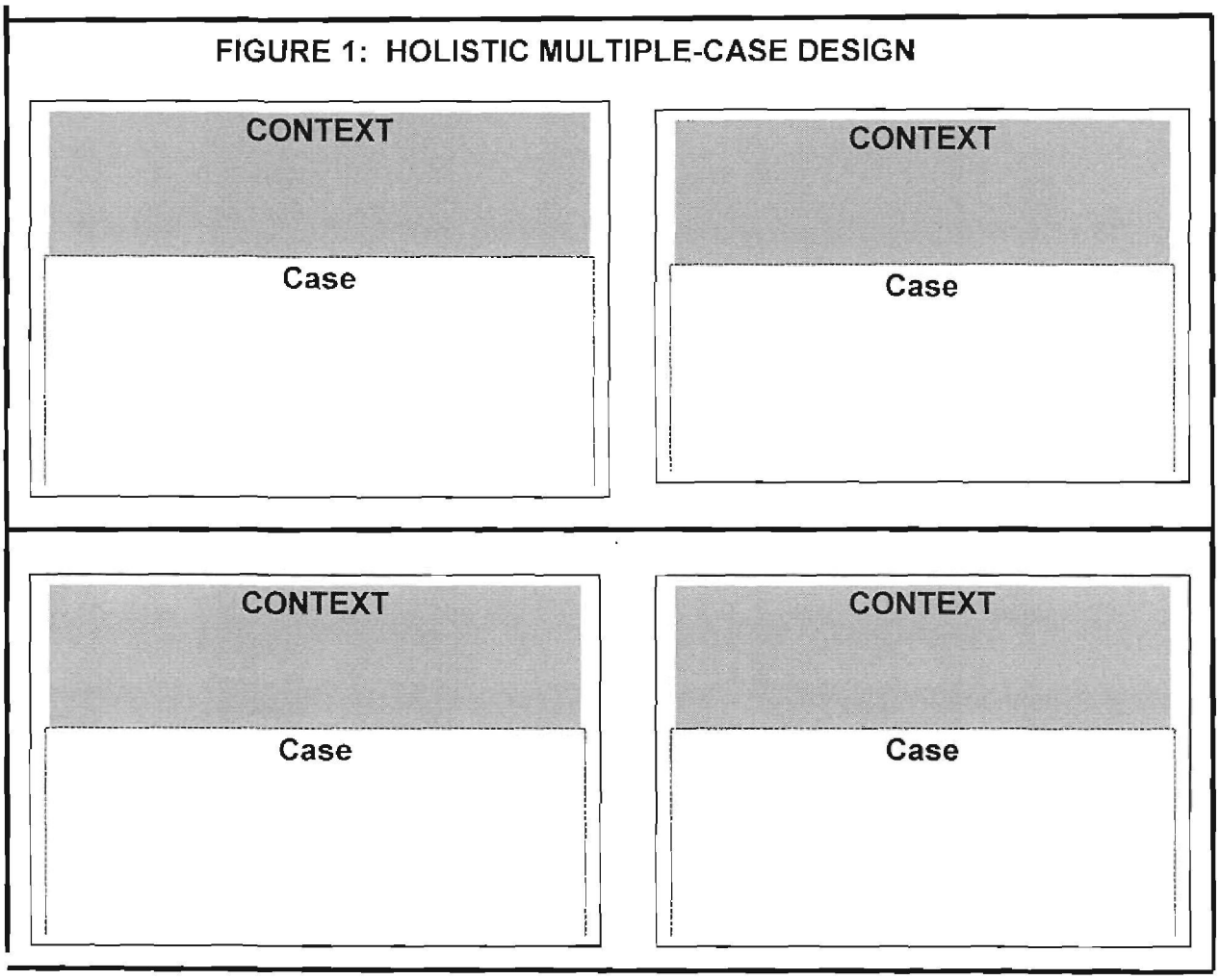
1.4.3.2.1 Literature study of existing programmes

A literature study on existing programmes for dealing with and coping with stigma was conducted in order to assist the researcher to develop a programme, as well as to compile a case record (Strydom in De Vos, 1998:182).

1.4.3.2.2 Programme development

A programme for coping with stigma by women whose partners died of AIDS was compiled from the literature study, as well as from the conceptual framework developed from the findings of phase one of this study (De Vos, 1998:110 –111). The developed programme is implemented and evaluated by applying it to selected participants as described under the case study method (Yin, 2003:40). See Figure 1.1.

FIGURE 1: HOLISTIC MULTIPLE-CASE DESIGN



Adapted from Figure 2.4 (Yin, 2003:40)

1.4.3.2.2.1 Research design

A holistic multiple case design type was chosen because the focus of this study falls within coping with stigma (Yin, 2003:39). A multiple case design is rich in this case it has its context and, therefore, represents an experiment. Yin (2003:53) recommends multiple case designs due to the advantage of their direct replication and that when conclusions coming from four cases are analysed, the benefits thereof would be much more than that of a single case (Yin, 2003:53). The fact that the context of each case differed also added to the richness of the data, hence the choice of holistic multiple case design because each case was also holistic, with its own context (Yin, 2003:40).

1.4.3.2.2.2 Research method

Attention was given to sampling, data collection and data analysis

1.4.3.2.2.3 Sampling

For the purpose of this study a purposive voluntary sampling was conducted (Babbie & Mouton 1998:166). A sample size of four women was drawn according to specific inclusion criteria that were as follows:

The women

- Have lost their partners to AIDS within a two year period
- Have been through voluntary counseling and testing and are aware that they are HIV positive
- Resided in the Mafikeng area in the Central Region of the North-West Province of South Africa
- Spoke and understood Setswana and Sesotho languages.
- Had experience of stigmatization after their partners had died of AIDS.

1.4.3.2.2.4 Data collection

1.4.3.2.2.5 Case study method

The choice of a case study method in this phase was motivated by the fact that an exploratory and descriptive method, with a real life context was found to be relevant (Yin, 2003:1; Babbie, 2004:293). A multiple, holistic case approach was followed in order to implement and evaluate the programme for assisting women whose partners died of AIDS to cope positively with the stigma associated with their having had a relationship with an HIV infected partner who died of AIDS (Creswell, 1998:63). As the programme was presented to the participants, observations were done with the aim of evaluating if there was a change with regard to coping with stigmatization (Stake in Denzin & Lincoln, 1994:238). A case study protocol was developed in order to ensure the reliability of the study as well as to guide the researcher throughout the proceedings of the study (Yin, 1994:63). This protocol considers the following aspects:

- An overview consisting of the objectives, issues, as well as aspects of stigmatization to be studied (Denzin & Lincoln, 1994:239; Yin, 1994:64).
- Field procedures to be undertaken.
- Case study question.
- A guide for the case study report.

1.4.3.2 2.6 Data collection

Data were collected as the programme was implemented to selected participants who met the selection criteria (Yin, 1994:84). Sessions were held with participants in order to implement the programme. Multiple sources of data were utilized namely, transcriptions of programme sessions, individual notes, observations, recorded field notes, as well as naïve sketches written by participants after every session (Babbie & Mouton, 2001:282). After every session the researcher collected information by interviewing those participants who could not write their own naïve sketches. Sessions lasted for a period of two hours and more. The single question, "How did you experience this session of the programme" was asked. Communication techniques such as minimal verbal response, probing, clarifying, paraphrasing, reflecting and summarizing were used as in the first phase of this study. The following skills were utilised by the researcher: observation, facilitation/teaching, listening, recording/writing skills, implementation as well as evaluation of the programme. A tape recorder was used to record information during sessions. A programme evaluation session was held almost a month after the last session.

Field notes were written immediately after an interview, reflecting all observations as well as the physical settings of the environment.

1.4.3.2.2.7 *Data analysis*

Data recorded on an audio-tape were transcribed verbatim. Naïve sketches and field notes were also subjected to data analysis. Data were analysed by including outcomes of the observations and all evidence collected (Yin, 1994:41). An open coding method was used as in phase one of this study. Themes were described in detail, with an exposition of the effects of the programme on the participants, with the researcher's interpretation and the report was compiled (Yin, 1994:73).

1.4.3.3 Ethical aspects

Ethical aspects were observed throughout this study as prescribed by the Democratic Nursing Organisation of South Africa (DENOSA) (1998:1-7), as well as according to Burns and Grove (2003:174).

- Quality of research

The researcher maintained the highest standard of research through the accredited methodologies as recommended by the promoters of this thesis, as well as the literature. All procedures were carried out with integrity as described below:

- ❖ The semi-structured open-ended interview questions were assessed by experts for validity.
- ❖ Interviews were transcribed verbatim and an independent co-coder was appointed in order to do independent co-coding of transcriptions.

- Confidentiality and Anonymity

All participants' identities were not disclosed under any circumstances and throughout the research procedures. The researcher, her promoter and co-promoter only knew names of participants. The privacy, personal worth and the dignity of the participants were maintained. The researcher made sure that there was no linking of any participant's identity or organisation with the research data (DENOSA, 1998:1-7; Burns & Grove, 2003:172).

- Consent

Permission to conduct research was obtained from the North West Provincial Department of Health, North-West University, Potchefstroom Campus Ethics Committee, as well as the Research committee of the School of Nursing Science. The AIDS co-ordinators in the Provincial Department of Health were requested to serve as mediators to link the researcher with prospective participants. The mediators provided the researcher with the names, addresses and /or telephone numbers of prospective participants. Letters to request participation and give consent were written to prospective participants to explain the research topic to them, the objectives of research, as well as the researcher's expectations of their role. They were also informed about their voluntary participation, as well as their right to withdraw at any stage of the process. They were also informed about the use of audio-tapes during interviews and the fact that confidentiality, anonymity and privacy would be maintained throughout the process.

- Benefits and risks

The researcher ensured that participants were protected from discomfort and harm by counseling or debriefing them. The researcher is an advanced psychiatric nurse,

capable of handling such a situation herself and she could have referred them for further counseling if the need arose. The researcher did, however, ensure that interviews were conducted in such a manner as to cause no or minimal discomfort. The participants were also free to discontinue their participation at any stage, had they experienced loss of interest in the process (Burns & Grove, 1998:175).

All these ethical measures, as well as the principles of human dignity (Ubuntu), were observed in order to obtain co-operation from the participants and all other parties in this study.

The presentation of this thesis followed an article approach that resulted in an overview of the research, five articles, as well as the conclusions, shortcomings and recommendations as indicated by the article layout. Appendices follow the overview of the research. The developed programme and the case record are found at the end of the thesis as appendices to the case study article. The language used in the articles is according to the guidelines for authors as required by specific journals.

SUMMARY

This overview describes the introduction, the problem statement, research objectives and the central theoretical argument. It also includes the paradigmatic perspective, research methodology and designs, which is qualitative research design in phase one and the qualitative case study design in phase two. The trustworthiness of the study as well as the ethical consideration are also discussed. This discussion concludes the overview of this thesis.

ARTICLE LAYOUT

The thesis will be presented in an article format in the following suggested sequence:

Overview of the study: The overview will include the introduction, problem statement, rationale, objectives of the study, the central theoretical argument, paradigmatic perspective as well as the research methodology.

Article 1: Stigma within AIDS loss of partner: A review of literature.

Article 2: Coping with the stigma of the loss of an AIDS partner: A literature review.

Article 3: Experiences of stigmatisation by women whose partners died of AIDS.

Article 4: Coping with stigma by women whose partners died of AIDS.

Article 5: The development, implementation and evaluation of a programme for coping with stigma for women whose partners died of AIDS: A case study.

Conclusions, shortcomings and recommendations for coping with stigma by women whose partners died of AIDS.

A programme for coping with stigma for women whose partners died of AIDS.

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APPENDIX A: LETTER TO REQUEST HIV AND AIDS COORDINATORS TO BE MEDIATORS

REQUEST FOR ASSISTANCE AS A MEDIATOR OF RESEARCH

I am a student registered for a PhD degree in psychiatric nursing at the North-West University, Potchefstroom Campus. I have to conduct research for the completion of my studies. My proposed topic is: **COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS**. The research will be conducted in five regions of the North West Province.

The objectives of the research are to:

- Explore and describe the experiences of coping with stigma by women whose partners died of AIDS.
- Develop and evaluate a programme to assist women whose partners died of AIDS to cope with stigma associated with having had a relationship with an infected partner who died of AIDS.

In order for these objectives to be achieved, the researcher will conduct in-depth interviews with women whose partners died of AIDS, who meet the set of inclusion criteria.

The criteria for inclusion are as follows:

The women must

- Be a resident of the North West Province
- Have had a relationship with an HIV and AIDS infected partner.
- Have lost their partner due to AIDS.
- Have given consent to participate and to be interviewed.
- Consent to the use of audio tapes during the interview.
- Be able to communicate in Setswana, Sesotho, Sepedi or English.

As an HIV and AIDS co-coordinator, you are requested to play the role of a mediator by linking the researcher with potential participants in your region or district. You will be expected to identify potential participants for this research and provide their names, addresses and telephone numbers to the researcher. The researcher will

then write letters to them to obtain their consent to participate in the this research. Appointments will be made with them for interviews. The in-depth interviews that will last for one to two hours per participant will be conducted at their homes, to ensure privacy and comfort. These interviews will take place from August 2005 to 2006. All the names of participants and the research proceedings will be treated confidentially and they will not appear anywhere on the tapes or research report. Participation will be voluntarily and they have the right to withdraw at any stage if they wish to do so.

Your prompt response in this regard will be appreciated so that the researcher can be able to make further arrangements.

For more information please contact the researcher at the following numbers: (018) 3892361 or email: Eva.Manyedi@nwu.ac.za.

Thanking you in anticipation.

_____
M.E. Manyedi (Researcher)

_____
Prof. Dr. M.P. Koen (Promoter)

_____
Prof. Dr. M. Greeff (Co-Promoter)

APPENDIX B: LETTER TO REQUEST PARTICIPANTS TO PARTICIPATE IN RESEARCH

REQUEST TO PARTICIPATE IN RESEARCH ENTITLED: COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS

I am a student registered for a PhD in psychiatric nursing at the North-West University, Potchestroom Campus. I'm conducting research on the above topic and will appreciate your participation as a woman whose partner died of AIDS.

The objectives of the research are to:

- Explore and describe the experiences of coping with stigma by women whose partners died of AIDS.
- Develop and evaluate a programme to assist women whose partners died of AIDS to cope with stigma associated with having had a relationship with an infected partner who died of AIDS.

Should you consent to participate in the study the benefits for you is that you will be able to talk to the researcher about your experiences as well as being exposed to the programme aimed at assisting you to cope with your experience, which is a therapeutic process.

A date and time for the interview will be arranged with you in due course. The interview will take place at your home to ensure privacy and comfort, and it will last for one to two hours. The researcher will communicate with you in Setswana, Sesotho, Sepedi or English, depending on your language of preference. An audio–tape will be used to record the interview and it will be confidential between the researcher, her promoter as well as the co-coder. The researcher may come for follow-up if more information is required, or for the sake of clarifying information. Your participation is voluntary and you have the right to discontinue at anytime when you feel like doing so. The audio tapes will be erased after data analysis. Your name is not disclosed during the research or publication of the results.

Should you experience any mental discomfort or distress as a result of your participation in this research you will be given emotional support.

You are kindly requested to complete the attached consent form to indicate that you are willing to participate in this research.

Thanking you in anticipation.

_____
M.E. Manyedi (Researcher)

_____
Prof. Dr. M.P. Koen (Promoter)

_____
Prof. Dr. M. Greeff (Co-Promoter)

CONSENT TO PARTICIPATE IN RESEARCH

RESEARCH TOPIC: COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS

The Researcher

I have discussed the objectives, benefits, risks and obligations of this research with the participant and I am satisfied that she understands all the implications thereof.

_____ _____

Researcher Date

The participant

I _____ hereby consent to participate voluntarily in the above research project. I accept that an interview will be conducted with me as personally arranged, and that an audiotape will be used to record this interview. I also accept that the researcher may conduct further interviews as may be necessary to gather more information.

_____ _____

Participant Date

APPENDIX C: LETTER TO REQUEST PERMISSION TO CONDUCT RESEARCH

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am a student registered for a PhD in psychiatric nursing at the North-West University: Potchestroom Campus. I have to conduct research for the completion of my studies. My proposed topic is: **COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS**. The research will be conducted in five regions of the North West Province.

The objectives of the research are to:

- Explore and describe the experiences of coping with stigma by women whose partners died of AIDS.
- Develop and evaluate a programme to assist women whose partners died of AIDS to cope with stigma associated with having had a relationship with an infected partner who died of AIDS.

Permission is, therefore, requested to undertake this project, as well as to allow the researcher to utilize the assistance of AIDS co-coordinators in the region and district as well as mediators. Co-coordinators will serve the purpose of linking the researcher to prospective participants of this research by providing the names, addresses as well as telephone numbers of prospective participants. Letters will be written to them in order to explain the research objectives, the procedures as well as requesting them to participate.

Should they consent to participate, in-depth interviews that will last for one to two hours per participant will be conducted at their homes, to ensure privacy and comfort. These interviews will take place from August 2005 to 2006. All the names of participants and the research proceedings will be treated confidentially and they will not appear anywhere on the tapes or research report. Participation will be voluntarily and they have the right to withdraw at any stage if they wish to do so. The benefits of participation are that they will be supported emotionally should they experience any mental discomfort from their experiences of having lost partners to AIDS.

The criteria for inclusion are as follows:

The women must

- ❖ Be residents of the North West Province.
- ❖ Have had a relationship with an HIV infected partner.
- ❖ Have lost their partner to AIDS.
- ❖ Have given consent to participate and to be interviewed.
- ❖ Consent to the use of audio tapes during the interview.
- ❖ Be able to communicate in Setswana, Sesotho, Sepedi or English.

The proposal which is in the process of being viewed by the university's ethical committee is attached.

Your prompt response in this regard will be appreciated so that the researcher can be able to make further arrangements.

For more information please contact the researcher at the following numbers: (018) 3892361, Email: Eva.Manyedi@nwu.ac.za.

Thanking you in anticipation.

_____
M.E. Manyedi (Researcher)

_____
Prof. Dr. M.P Koen (Promoter)

_____
Prof. Dr. M. Greeff (Co-Promoter)

APPENDIX D: EXAMPLE OF FIELD NOTES OF AN INTERVIEW WITH A WOMAN

Demographic notes

The interview was conducted on Saturday, 18 February 2006 at 11h30. The participant stays with her mother, three siblings (two elder sisters and one younger sister). They also have five children under 10 years in the home. She has three children (boys) and the other two belong to her sisters. She was more than willing to participate. They stay in a mud house of which two rooms serve as bedrooms, one as a kitchen and the fourth one as a dining/sitting room. She explained the unhealthy relationships at home and that she requested to be interviewed somewhere rather than at her home. She was then interviewed at the researchers' home. The environment was quiet and conducive and the interview took place in a private unused bedroom. The interview went undisturbed and lasted for one and half hours.

Descriptive notes

The participant is a twenty seven years old, well groomed lady with a fair complexion. Her facial appearance shows anger and bitterness that says "I'm ready for you to say something negative and I will retaliate". However, she gave me an accepting welcome because she was more than willing to participate in the study. She immediately started to relate her experiences to me. This was spontaneous and it was evident that she wanted someone to share her difficulties with. Her partner did not disclose his status to her until almost a week before he died in January 2006. She said that when she was told that she was positive she wanted to commit suicide until she met the support group, which she claims even now they are still a pillar of her support. She appeared ill and she was coughing throughout the interview, and had to be given a lozenge to suck so as to reduce coughing. Besides coughing, she was talking without a pause; she paused only when she noticed that I wanted to interrupt her. Her pressure of talk seemed more like ventilation of anger and bitterness.

Reflective Notes

Ms D seems a very talkative person, as she would talk until interrupted or when she realized I wanted to interrupt. I left her and gave her the liberty to talk, only coming in with a follow up focus or explorative question. She is very open about her HIV status.

She, however, expresses bitterness and anger when she expresses the way her family treats her together with her children. She talked at length about the discrimination and marginalisation that she experiences. She lost friends and family members (mother and siblings). They call her names, illtreats her as well as her children.

Ms D stated that she was not surprised that she contracted the virus because her boyfriend liked girls and was sleeping around.

Responding to how she is coping with stigma she said that she has accepted that even though she was angry with her boyfriend. The fact remains that she has the virus and she has to take care of herself. She is supported by the support group who contributed to her acceptance of the condition. She also uses religion as her coping strategy. What she emphasizes most with regard to her family's attitudes towards her is that she regards them as ignorant and insane.

Ms D stated that she is at the stage where she should get ARV's but could not get them because both her mother and her sister refused to sign for her. She seems to over-emphasise her living with HIV, and that she gets hurt when she is stigmatised and that she wishes that she could be allowed to assist other PLWA, whether at home or in hospital. Sometimes I would just listen as she rolled on and on non-stop. Even after the tape was switched off, she continued, although she was repeating what she said. She seems more concerned about her three children, who are well cared for, especially when she falls sick and cannot care for them herself.

APPENDIX E: SECTION OF A TRANSCRIPT OF AN INTERVIEW

R: I would like to thank you for allowing me to interview you. I am aware of the sensitivity of our discussion and I appreciate that you allowed me into your private territory I want to emphasise once more that your identity will remain anonymous and that you may discontinue this interview when you feel that you are unable to continue. I also request you to be free to share your experience with me.

P: OK.

R: Please tell me how you cope with the stigma after your partner died of this disease.

P: After my partner died, I had no choice but to accept his death. After his death there were rumours spreading around about me yet I learnt to accept myself and cope with the stress and everything turned alright.

R: Could you please explain to me what you mean when you say you had no choice but to accept his death?

P: Acceptance in the sense that people tend to talk about you in all kinds of manners. At the end of the day it will pass and everything will be normal because it is in the nature of people to talk.

R: I would appreciate if you say more because you also mentioned rumours. What are they saying about you?

P: What they say is "she is the one who infected her partner, she has the disease, things like that, others tend to stigmatise you and you opt to commit suicide, that is why you must be strong.

R: How do they stigmatise you?

P: I learnt about myself when I started having Std's and decided to go for testing. When the result came I tested positive. Because I had one partner that meant I contracted the disease from him.

R: Can you say more?

P: I was spiritually positive that he was the only one and no-one else was my partner but him.

R: How did you react?

P: I told no-one and continued with counseling, because they heal you emotionally until you are prepared to spill the beans to your partner. And I told him and he made no-efforts to find out about his status.

R: Then?

P: He admitted when he started developing symptoms and changing.

R: How did he change?

P: Physically, when he became sick.

R: How do you cope with the stigma and stress that people tend to cause and with what people saying?

P: Others say I was unfaithful and others say I was a whore. That is the difficult and most painful stigma for me.

R: Please tell me more about the difficulty and painfulness.

P: Painful because you know you had been faithful to your partner and then you hear such horrible things you tend to put the blame on yourself negatively.

R: What did you think that was negative about yourself?

P: I though I was not alright even if I was ...

R: Mhh!

P: Because I thought I was the one unfaithful to him yet I was not, you see we tend to blame ourselves for another one's fault.

R: How do you cope with people's attitude towards you?

P: People tend to show that they are talking about you saying you had been a whore.

R: What do you mean when saying other people lack information, what information are you talking about?

P: In the sense that an HIV positive person can't infect you with a touch, you will contract the disease when you have unprotected sex, treating wounds without wearing gloves, sharing needles, that's why I say they lack information.

R: What else do they lack besides what you have just said?

P: When they finally understand and know more about the virus everything will be okay?

R: When I look at you I see a beautiful young lady. What makes you so healthy and fit?

P: What keeps me in shape is a determination to live, accepting my status and I am boosted by ARV's and healthy food support from family and friends.

APPENDIX F: WORK PROTOCOL

WORK PROTOCOL FOR DATA ANALYSIS OF COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS

Dear Dr Mosome

I am a PhD student at the North-West University, Potchefstroom Campus, and am conducting the above-mentioned study. Thank you for your willingness to act as a co-coder. The objectives of this study are:

- To explore and describe the experience of coping with the stigma by women whose partners died of AIDS.
- To develop and evaluate a programme to assist women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected person who died of AIDS.

Your participation in this study is as follows:

There are twenty transcripts from which you are expexted to conduct co-coding. These interviews explored coping with stigma by women whose partners died of AIDS. These are to be decoded using guidelines of Tesch (*in* Creswell, 1994:153-157). The steps are as follows:

- The transcripts were divided into three columns. On the left-hand side there is a column for noting concepts; the data is in the middle of the page and the right hand side is for the researcher's perceptions.
- The researcher read all the transcripts in order to get a sense of the whole idea communicated, or the themes emerging.
- The most interesting or the shortest transcript was chosen and re-read.
- Words and sentences were used as units of analysis and as such were underlined as the researcher went through the transcript again.
- The underlined spoken words and sentences were then transferred to the left column as categories. Those perceptions that struck the researcher's mind were noted in the right column.
- The categories transferred onto the right-hand side were read in order to identify the main sub-categories as well as redundant categories.

- The underlined spoken words were then transferred into a table highlighting the main categories, sub-categories, as well further categories.
- These categories were finalized by revising the table as spoken words were then translated into scientific language. At this juncture the researcher had to keep in mind open that further refining of that categorization could still take place.

After the process of analysis and decoding, I will appreciate it if we can agree on a date on which we can meet to discuss our findings and reach consensus regarding the analysis of this data.

Your activities as a co-coder are highly appreciated and I hope that it is going to be interesting and meaningful to you as well. You are welcome to contact me should you require any clarity or further information.

Yours faithfully,

_____
M.E. Manyedi

_____
Prof. Dr. M.P. Koen

_____
Prof. Dr. M. Greeff

ARTICLE 1: STIGMA WITHIN HIV AND AIDS LOSS OF PARTNER: A REVIEW OF LITERATURE

GUIDELINES FOR JOURNAL AIDS CARE

Papers accepted become the copyright of the journal, unless otherwise specifically agreed.

All submission should be made on line at *AIDS* **Care's Manuscript Central site**. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Manuscripts should be submitted in the style of the American Psychological Association. All submissions will be sent anonymously for the observation of referees. Manuscripts can be in these formats: (i) Short reports not exceeding 1500 words; (ii) Original articles of 1,500- 3000 words. We will also consider exceptionally papers of up to 5,000 words.

Manuscripts should be double spaced, with ample margins of at least one inch. All identifying information should be removed from the manuscripts files themselves prior to submission. Proofs for checking will normally be sent to the first author named to whom any correspondence and off-prints will also be addressed. Footnotes to the text should be avoided wherever this is reasonably possible.

Papers will be considered providing that they have not previously been published or submitted simultaneously elsewhere for publication.

Di Climente, R.J., & Peterson, S. (1994). Preventing AIDS: theories and methods of behavioral intervention. New York: Plenum Press.

Philpot, C.R., Harcourt, C.L., & Edwards, J.M. (1991). A survey of female prostitutes at risk of HIV infection and other sexually transmissible diseases. *Genitourinary Medicine*, 67, 384-388.

Selwyn, P.A., & Antoniello, P. (1993). Reproductive decision-making among women with HIV infection. In M.A. Johnson & F.D. Johnstone (Eds), *HIV infection in women* (pp. 173-185). Edinburgh: Churchill Livingstone.

Title of journals should **not** be abbreviated.

Illustrations should not be inserted in the text but each provided as separate files and given figure numbers and title of paper and name. All photographs, graphs and

diagrams should be referred to as Figures and should be numbered consecutively in the text in Arabic numerals (e.g. Fig. 3). Captions for the figures should be provided and should make interpretation possible without reference to the text. Captions should include keys to symbols.

Tables should be submitted as separate files and should be given Arabic numbers (e.g. Table 3). Their approximate position in the text should be indicated. Units should appear in parentheses in the column heading but nor in the body of the table. Words or numerals should be repeated on successive lines "ditto" or 'do' should not be used.

Proofs will be sent to the author if there is sufficient time to do so. Proofs including proof of illustrations are supplied for checking and making essential corrections, not for general revision or alteration. Proofs should be corrected and returned within 3 days of receipt.

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TITLE PAGE

STIGMA WITHIN AIDS LOSS OF PARTNER: A REVIEW OF LITERATURE

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ABSTRACT

The focus of this article is on the theory of stigma within the context of women who lost their partners to AIDS. Stigma is a concept that has been attributed to diseases that were feared and that seemed strange such as leprosy, tuberculosis, mental illness and disabilities. It is said to be an attribute that is discrediting, resulting from prejudice and leads to discrimination of the stigmatized person. Its process takes the following four forms: the differentness that results in labeling; linking human differentness with negative attributes; separating "us" from "them"; as well as the dependence of stigma on power. Three types were distinguished namely, stigma directed to the stigmatized, stigma directed to self, as well as to those closely related to the stigmatized person. HIV and AIDS are stigmatized conditions where the loss of a partner necessitates coping with the stigma of having lost a partner who died of AIDS, as well as dealing with the effects of being infected with the disease themselves, if infected.

Keywords: Stigma; stigmatization;

INTRODUCTION

Stigma is a historical concept that, in health, has been attributed to diseases such as leprosy, tuberculosis, mental illness, Mental and physical disability, to mention but a few common conditions (Brown, Macintyre & Trujillo, 2006:64). The HIV and AIDS pandemic seem to be reviving this concept which became dormant owing to the massive health education campaigns that address the intensity of the stigma that was attached to the aforementioned conditions. With the ever increasing death rate of people living with HIV and AIDS (PLWA), the fear of this pandemic seems to be an arising burden, thus reviving the initial stigma. Stigmatization of PLWA seems to be brought up by the perceived mode of transmission which is predominantly sexual, the incapacitating and debilitating nature of the syndrome that creates fear in people in general, as well as the incurable nature that leads to death. All these factors have contributed to HIV and AIDS being the most stigmatized disease of this era (Nord, 1997:60; Fife & Wright, 2000:52; Herek, Capitano & Widaman, 2002:374).

HIV and AIDS stigma does not only affect the PLWA but also those closer to them including their family members, relatives, friends and care-givers. The most stigmatized family members seem to be the spouses because of their perceived sexual relationship with the affected person (O'Sullivan & Thomson, 1996:246; Nord, 1997:60). In some cultures, women who survive their partners' death are discriminated against and stigmatized (Pincus, 1974:176; Bankoff, 1983:836; Manyedi, 2003:78). The same attitudes apply to women who lost their spouses or partners to AIDS and who seem to be the most affected because they are viewed to have contributed to their status (Sowell, Lowenstein, Moneyham, Demi, Mizuno & Seals, 1997:304; Nord, 1997:60; Herek *et al.*, 2002:374). Stigmatization being a painful experience these women require support to assist them to cope with the stigma associated with having had a relationship with an infected partner who died of AIDS.

The aim of this article is to contextualize the theory of stigma on the experiences of women whose partners died of AIDS. The theory of stigma is analytically discussed, focusing on definitions, types and processes. This provides a framework for the research that will assist women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected person.

CONCEPTUALISING STIGMA

Before stigma can be conceptualized, its history is explored in order to understand its origin as well as its evolution from its origin up to the current use. The concept stigma originated from Greek, when it referred to the bodily signs that were marks exposing the unusual or the bad about the moral status of an individual. These signs were engraved into the body either by scarring or burning it so that an individual would be exposed as bad, criminal or the one to be cast off and discounted from belonging to the public (Goffman, 1963:11; Edgerton, 1967:205; Nord, 1997:22). From then, the concept evolved from being bodily signs of physical disorder until the present meaning, which is back to the original meaning of the concept, which is that of being a dreadful or disgraceful sign. Fink and Tasman (1992:18), Stengler-Wenzke, Trosbach, Dietrich and Angermeyer (2004:88), who wrote extensively on stigma of mental illness, as well as Edgerton (1967:20), a known author on mental retardation, explained that this concept originated from an ill-treatment of a person who was believed to be doing evil. This person was then burnt with a hot iron on the face, to leave a mark by which people would recognize him as an "evildoer". The mark was a brand of disgrace and shame. Nord (1997:11) also referred to this mark as that of shame and disgrace in his later writings on stigma, adding that an individual was socially discredited because of that mark. This is why even today the stigmatized person is separated from the rest, thus compounding the situation by discrediting his reputation. This is perhaps why stigmatized people tend to feel inferior. In its worst form, the stigma leads to a person being unable to come into contact with other people, or rather, if they suffer from a disease that is stigmatized, to resist disclosure as well as seeking treatment (Sewpaul & Mahlalela, 1998:39; Weiss & Ramakrishna, 2001:3; Herek, Capitano & Widaman, 2002:371; Yang, Stanton, Fang, Lin, Naar-King, 2006:717).

In summary, stigma is a concept associated with disgrace or shame (Goffman, 1963:11; Nyblade, Pande, Mathur, MacQuarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbwambo & Bond, 2003:28). This evolution indicates that the term has been associated with a bad mark or sign that people were supposed to view as disgraceful, irrespective of the fact that the sufferer might not have been responsible for that affliction (Dias, Matos & Goncalves, 2006:208). What seems to be revealed about stigma is that any condition, either physical or psychological that people cannot fully understand creates fear or uncertainty about its curability with resultant stigmatization

(Vlastof, Weiss, Ovuga, Eneanya, Nwell, Babalola, Awedoba, Theophilus, Cofie & Shetabi, 2000:1355; Yang *et al.*, 2006:718). The stigma would then be evident by the people shunning, rejecting and isolating the individual (Ware, Wyatt & Tugenberg, 2006:906). Typical examples are mental illness and mental retardation as considered by Edgerton (1967:205) to be the worst stigmatized conditions with their unpredictable and queer nature. Tuberculosis being associated with poverty, as well as leprosy with its progressive debilitating effects are also historically highly stigmatized diseases.

In this part of the article, the definitions of stigma are critically discussed, first in a broad sense, then contextualised to HIV and AIDS. The process and types of stigma are also discussed.

Defining stigma

The concept stigma is a social attribute associated with a mark of disgrace, shame and embarrassment on the side of a stigmatized person (Fick, 2005:20; Yang *et al.*, 2006:718). Goffman (1963:3) refers to it as an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one. Goffman (1963:65) goes on to explain that stigma is usually demonstrated by the people who believe that they are normal, towards those that they refer to as being abnormal. From this definition a sense that develops is that the stigma is a negative attribute held towards an individual by members of society who tend to hold a negative view of such an attribute, giving rise to a stereotype. This stereotype is based on the physical, psychological/ emotional, social or spiritual orientation that the general public has about what is regarded as normal and abnormal in a particular society (Goffman, 1963:65; Fick, 2005:20). Human beings tend to adopt certain personal attributes as normal for example with regard to our physical appearance one expects every person to have two eyes. When one sees a person with one eye one concludes that he is abnormal on the basis that one concludes that a normal person should have two eyes; As a result one stigmatises him by labeling him "one eye". One's attitude towards the person will be that of isolation, rejection and discrimination because he does not look like "us" and one fears or lacks understanding of the situation. This definition, therefore, exposes such a situation. By discriminating against the person, one is stigmatizing him, thus devaluing and discrediting his human status within the community. The definition is in itself discriminatory in its nature and it creates a social gap between the perpetrators of stigma and the

stigmatized. Goffman (1963:3) is, therefore, justified to state that stigma is associated with an attribute that is "deeply discrediting and reduces the person from a whole to a tainted, discounted one".

Weiss and Ramakrishna's (2001:5) definition, which is also social oriented, supports the above discussion as they consider stigmatization as a social process or experience characterized by exclusion, rejection, blame or devaluation. From their perspective, Weiss and Ramakrishna (2001:5) state that in stigmatizing an individual, society reduces their social value and status.

According to Nord (1997:60), the stigma is a mark of shame, disgrace and reproach. This definition is derived from the original meaning of Goffman (1963:3). The meaning exposes the concept as the signs depicting the bad character of a person being engraved into his body, either by scarring or burning in order to differentiate him from others. In the context of this study, even if these physical scars are no longer applicable, the meaning still exists. When a woman has HIV and AIDS, society scars her emotionally by labeling her with shameful, discrediting labels such as unfaithful, promiscuous, careless or irresponsible because she failed to protect herself against the virus. This could be due to the fact that women are historically and culturally stigmatized because of their gender (Gaines, 2001:117). The study conducted by Manyedi, Koen and Greeff (2003:78) revealed that in the Batswana culture the widows were stigmatized for having lost their husbands whereas widowers were not subjected to the same treatment. All these labels leave her with emotionally hurting scars, because it is stigmatizing and discrediting. This definition also casts a shadow of negativity on the victim, the stigmatized person. The shame, disgrace and reproach are unpleasant and unfavourable on the side of the stigmatized person, and favourable towards the one that stigmatizes as it empowers him/her. This is a judgemental definition.

Stafford-Clark (1986:80) definition is even more judgemental because it concludes that "stigma is a characteristic of persons that is contrary to the norm of a social unit". The question is who determines the normal or abnormal attributes in society? When one considers the illnesses for instance, some are stigmatized and others not. The answer is also based on Goffman's (1963:15) explanation that in society, one adopts some behaviours and attributes as normal, and those that negatively depart from what one considers "normal", are labeled "abnormal". This accounts for the fact that

stigma is viewed from the perspective of the stigmatisers rather than the stigmatized. Referring back to the question of illnesses, evidence could be deduced from Edgerton (1967:206) where mentally retarded patients who spent some years at an institution could not see themselves as mentally retarded. Their accounts were because the extent of stigma associated with those patients led to their complete dissociation from other mentally retarded patients (Jahoda & Markova, 2004:722; Ware *et al.*, 2006:906). This could also be supported by the fact that people suffering from stigmatized diseases hardly want to associate themselves with their counterparts with the same illness (Jahoda & Markova, 2004:722; Ware *et al.*, 2006:906). The patients in Jahoda and Markova's study (2004:723), objected to all stigmatizing attitudes and behaviours displayed by the hospital staff. Mental illness and HIV and AIDS are typical as one often hears a mentally ill patient saying, "I don't want to stay with mad people". This is evidence that even if a lack of insight could be cited, the likelihood is that the stigma plays a major role. Most definitions of stigma typically endorse the sense of it being a discreditable attribute that may be attributed to the fact that they come from those who consider themselves as normal. They, therefore, use all the terminology that portrays the stigma as a negative and non acceptable phenomenon (Miller & Kaiser, 2001:74; Jahoda & Markova, 2004:723). The situation is the same medically, socially, psychologically and spiritually because even some religious beliefs are stigmatized, the same as some cultures and languages (Goffman, 1963:14).

The writings of Goffman (1963), Edgerton (1967) and Jahoda and Markova (2004) on stigma as attached to mental illness, mental retardation, leprosy and other physical disabilities are carried further by authors who research and write about the stigma of HIV and AIDS. Herek *et al.* (2002:372) in their study conducted in the United States between 1991 and 1999 indicated that people affected by AIDS and those that are close to them, or social groups to which they belong, have been highly stigmatized worldwide. This stigma is said to have interfered with the response of society to this pandemic, especially with regard to being cared for by their families, their employment as well as their health care (Brown, Macintyre & Trujillo 2003:50; Thomas, 2006:3181; Ware *et al.*, 2006:906; Yang *et al.*, 2006:718). This stigma has also interfered with the affected persons' disclosure as well as seeking treatment. This information is complemented by the recent study conducted in five countries namely, Lesotho, Swaziland, South Africa, Malawi and Tanzania. The study has confirmed

that fear of disclosure of their status by those affected by HIV and AIDS is due to the stigma attached to this disease (Greeff, Phetlhu, Makoae, Dlamini, Holzemer, Naidoo, Kohi, Uys & Chirwa, 2007:In press). Some authors, who perhaps lack words to define this attribute, explain at length how it impacts on one's social life (Edgerton, 1967; Fife & Wright 2000:51; Sowell *et al.*, 1997; Edgerton; 1967; Walker, 1980; Weiss & Ramakrishna, 2002).

A wide range of definitions refer to the stigma of mental illness, as this is perhaps the most common area or rather, more affected by this phenomenon. Some modern definitions include "A brand, stain, blemish, defect, a scar, or mark of shame or discredit" (http://www.nostigma.samhsa.gov/topics_materials/definitions.html). When examining all these definitions, it becomes apparent that stigma is a labeling attribute, as well as a concept that is heavily laden with discrimination, as this literature states that those stigmatized are discredited, blemished, branded, isolated and devalued (Takahashi, 1997:192). These attributes are discussed within the process of stigma.

The process of stigmatization

In describing the process of stigmatization, Link and Phelan's (2002:2) approach is followed because what they refer to as components, provide guidelines of how stigma manifests itself in both the perpetrators of stigma as well as the stigmatized. However, other authors' views are also incorporated in this discussion as well as the author's own synthesis of these views.

- The first category in the process of stigmatization is the differentness that results in labeling. This view indicates that under normal circumstances there are many human differences that are considered insignificant and, therefore, ignored. It is rare for example, to find an individual stigmatized on the basis of the foot size or because of his height. However, there are those differences such as one's level of intelligence or intellectual ability, religious beliefs or sexual preferences that are considered to be significantly abnormal and hence stigmatized. This supports the argument that society tends to determine the normality and abnormality of certain attributes or which are abnormally significant or insignificant and hence, to be ignored (Link & Phelan, 2002:3). Goffman (1963:15) stated that reduction of a person from a whole to the discounted one is determined from the perspective of the perpetrators of stigma by the degree of the undesired differentness. Weiss and Ramakrishna

(2002:7) contend that stigmatization may take the form of blaming or devaluing, or the individual him/herself experiencing diminished self esteem. In considering medical conditions it can be argued that those conditions such as hypertension, melanoma and leukemia are not as seriously stigmatized as incontinence, schizophrenia, as well as HIV and AIDS, which is currently considered the worst stigmatized condition (Link & Phelan, 2002:3; Stansburg & Sierra, 2004:61; Yarhouse & Anderson, 2002:334). The degree of HIV and AIDS stigmatization led to Yarhouse and Anderson (2002:61) considering it as the "leprosy of our day".

- The second category of the stigmatizing process occurs when linking human differences with negative or undesirable attributes. It is within the societal norms when an individual who is considered different from others is associated with negative or undesirable attributes (Link & Phelan, 2002:3). This is what Goffman (1963:14) in his conceptualization of stigma described as "labeling" that links an individual with negative or undesirable characteristics that amount to a stereotype (Link & Phelan, 2002:3). These stereotypes develop into a mindset which results into the stigmatisers considering it negative. It is this negativity that develops into stigma, leading to the "us" and "them" attitude that accounts for the reason why for example, HIV and AIDS may be considered self-caused other than a head injury resulting from drunken-driving. The same as when mentally ill patients are labeled dangerous, creating a huge gap of rejection between themselves and other types of patients.

- The third category of stigmatizing occurs as a result of the human separation, that is, when we separate "us" from "them" and consider "them" as abnormal, unacceptable or deviant (Link & Phelan, (2002:4). Human beings always look at people in comparison. Those people who possess attributes that are favourable and acceptable are part of "us" and those whose attributes are considered unfavourable and unacceptable are not part of us but "them". A typical example of this explanation is that of diseases that one considers justifiable and carry sympathy such as cardiac conditions, arthritis and diabetes whereby one shows concern for such people. Those diseases that are considered unjustifiable such as sexually transmitted diseases (STD's), mental illness, tuberculosis and HIV and AIDS. One rejects those who suffer from them and hence dissociate ourselves from "them". This is the reason why one

does not only stigmatize those who suffer from those diseases but also those who are closely associated to them such as their spouses, children, family members as well as those who care for them (Fife & Wright, 2000:56; Link & Phelan, 2002:14; Yarhouse, 2003:133; Stengler-Wenzke, *et al.*, 2004:93). The "us" and "them" process could be observed in the present position in South Africa where there is an influx of black people coming from other African states. Certain attributes that are seen as different from black South Africans such as their accent, language, skin pigmentation as well as other social attributes render them to be labeled as different from "us". As a result negative social acts such as crime are linked to them, thus reducing their humanness. This behavior is tantamount to stigmatization as well as discrimination, where a stigmatized person ultimately experiences the loss of status due to being perceived as different and therefore not part of those who stigmatize. This causes concern for those who study stigma because without this categorization of people based on the perceived "negative attributes, the meaning of stigma would not be complete. It accounts for the extent to which PLHA fear disclosure s well as utilizing the resources available for them, because it could lead to their loss of status that impacts negatively on the affected individual (Parker & Aggleton, 2003:19).

The negative impact of such separation of "us" from "them" often results in "them" losing their status due to discrimination. This could be justified by the fact that whenever the concept of stigma is discussed it is often considered from the perspective of perpetrators of stigma rather than the stigmatized (Link & Phelan, 2002:4; Parker & Aggleton, 2003:19; Yarhouse & Anderson, 2002:334). It is this aspect of stigmatization that results in the stigmatized person feeling abandoned, hated, insulted as well as losing access to resources (Nyblade *et al.*, 2003:31; Stansburg & Sierra, 2004:466). Loss of status also amounts to loss of power due to the internalization of stigma.

- The last category of the stigmatizing process is the dependence of stigma on power. Link and Phelan (2002:4) maintain that power is necessary to stigmatize, therefore, the stigmatized people usually belong to the low power group of society. It would be difficult for the low power group to stigmatize the high power group. The seriousness of the loss of power is explicit in Fife and Wright (2000:56), who link the loss of power with internalized shame to

financial insecurity as well as job insecurity. This may result in a situation such as in the case of HIV and AIDS due to lack of support from family members as well as other community support systems such as the workplace and the church (Fife & Wright, 2000:56; Yarhouse & Anderson, 2002:338; Parker & Aggleton, 2003:19; Nyblade *et al.*, 2003:32).

Goffman (1963:14) in complementing the above process, categorize stigma into three aspects firstly the body abominations such as physical disabilities; secondly the blemishes of individual characters such as homosexuals, alcoholics, prisoners; as well as those that are dishonest, to mention a few. Lastly, there is stigma associated with racial discrimination, religion and ethnicity that could be transmitted through lineage. Although the above discussion casts a negative shadow of stigma, Weiss and Ramakrishna (2001) view stigma in a slightly different way though not conflicting the former views. They state that it is not all stigma types that are negative because some stigma may contribute to useful social function in that it motivates moral and ethical behavior.

From the discussion of the process of stigma it can be concluded that the concept stigma is to a greater extent a psycho-social phenomenon because its consequences affect the social as well as the psychological aspects of people's lives. The origin itself is psycho-socially based when considering that the devaluation, discrediting, discounting, disgrace and shame cast negative psycho-social effects on the stigmatized person. These effects are more understood when the types of stigma are described as follows:

The types of stigma

From Goffman's (1963) writings about stigma, various categories have been identified based on the attitudes and behaviours of both the perpetrators of stigma and the stigmatized. Nyblade *et al.* (2003:28), argue that whether the stigma is overt or covert, the experience takes three forms namely, stigmatizing and discrimination against the stigmatized (Parker & Aggleton, 2003:13), internalized stigma as experienced by the stigmatized persons, as well as the stigma and discrimination against those related to or closely associated with the stigmatized (Link & Phelan 2002:1). A detailed discussion of these types of stigma follows.

2.3.1 Stigma directed to the stigmatised

Different authors vary in terms of how they refer to types of stigma. This type of stigma ranges from stigmatizing people based on their background such as the poor, the disabled or even those suffering from specific diseases (mental illness, mental retardation, tuberculosis, HIV and AIDS, leprosy, epilepsy) to the social stigmas against criminals, prostitutes and those with same sex sexual orientation (gay and lesbians), to name but a few (Lane, 2002:215; Weiss & Ramakrishna, 2002:9; Jahoda & Markova, 2004:72; Stansburg & Sierra, 2004:460; Fick, 2005:22; Ware *et al.*, 2006:906). These attributes may be coupled with category one of Link and Phelan (2002:2), which is that of distinguishing and labeling differences and it is also referred to as the "Etic" view (Greeff *et al.,* 2007.In press). In this case, the stigmatizers who, according to Goffman (1963:15) refer to themselves as "normal", bear certain attitudes towards those they refer to as abnormal or discredited, based on their attributes referred to as abnormal, as mentioned above (Goffman, 1963:3; Walker, 1967:143; Fife & Wright, 2000:56; Link & Phelan, 2002:2 & Nyblade *et al.*, 2003:28). According to Stansburg and Sierra's (2004:460) view, the worst stigmatizing behaviour includes hatred, abandonment and insulting of the infected person by his/her family.

Goffman (1963); Edgerton (1967) and Weiss and Ramakrishna (2001) also mention the aspect of stigmatization of individuals based on their past social background or information. The research conducted by Nyblade *et al.* (2003:28), Herek *et al.* (2002:375); Link and Phelan (2003:3), Jenkins and Guanarcia (2003:413) and Thomas (2006:3181) found that most commonly, the perpetrators of stigma demonstrate differential treatment such as isolation and physical and social exclusion (Dias, Matos, & Gonzalves, 2006:212). This refers to exclusion from social gatherings, family events, and from the care and support by the family. Exclusion from public places occurs in the form of reducing interaction with the person especially in churches, shops, schools or workplaces (Fife & Wright, 2000:56; Yarhouse & Anderson, 2002:338; Parker & Aggleton, 2003:19; Nyblade *et al.,* 2003:30). Personal identity is also mentioned as one of the attributes that can expose one to discrimination. In considering that one's social background can be the basis for stigmatization, Goffman (1963:80) links this to the concept of "passing", which according to him, occurs when an individual's biography is tainted based on his/her past. The person is discredited especially by those who know his/her past without

considering the present status. Often people draw conclusions and stigmatize as though they had the whole person's background (Goffman, 1963:79). All these stigmatizing attitudes and behaviors are observable in society and on a daily basis and at times the perpetrators of stigma are hardly aware that they are committing an act of discrimination, devaluing or tainting other people. Sometimes they may not be aware that the reverse may be applicable.

Stigmatizing behaviors in this category also includes gossiping or taunting, isolation and marginalization (Nyblade *et al.*, 2003:28). These are also painful experiences on the side of the stigmatized, especially when they discover that such attitudes are displayed by their friends, colleagues, school mates, neighbors or acquaintances (Ware *et al.*, 2006:906). It is found to be strange that when one possesses a stigma attribute such as a disease, people gossip about whether he/she has it or not, whereas with diseases that do not have a stigma such as hypertension, people would openly talk about them even when they know that the individual may be suffering from it (Nyblade *et al.*, 2003:30). Stigmatizing also occurs in the form of unpleasant language used by the perpetrators of stigma such as cited by Muyinda, Seeley, Pickering, and Barton (1997:144), Miller and Kaiser (2001:74), as well as Nyblade *et al.* (2003:30), that words such as implying skeleton, walking ghost, walking corpse and close to the mortuary door are used. In addition to the above behaviours, there is also loss of identity and lack of access to resources. Sometimes when people think that the stigmatized person has no future or cannot share resources with them, they tend to treat him/her in such a manner that they would feel completely rejected or non-existent (Weiss & Ramakrishna, 2002:2; Nyblade *et al.*, 2003:31). The victim then chooses rather not to go for any counseling, treatment or any form of support due to this discrimination. All of the above is stigmatizing and discrimination against the stigmatized persons.

The stigmatizing behaviours and attitudes are described as external or enacted stigma by the Siyam'kela Research Project (2003:98), also referred to as received stigma by Greeff *et al.* (*2007, In press*). For the purpose of this research reference is made to received stigma. It is the type that refers to all types of stigmatization behaviours displayed by perpetrators of stigma towards the stigmatized, such as PLWA. These behaviours are experienced and described by those who receive the stigma because these attitudes and behaviours impact negatively on them (Ware *et al.*, 2006:906). Greeff *et al.* (*2007, In press*) categorized received stigma into nine

dimensions namely: neglecting, fear of contracting the disease, avoiding, rejecting, labeling, pestering, negating, abusing and gossiping.

Stigma directed to self

Authors vary in the manner in which they describe this type of stigma. Greeff *et al.* (2007, In press) refer to it as the "Emic" view that involves the experience of stigma by those stigmatized resulting in feelings of diminished self identity, self devaluation or inferiority (Fick, 2005:21; Nyblade *et al.*, 2003:32). It can also be linked to component four of Link and Phelan (2002:4), referring to status loss in which they argue that without this component, the term stigma holds no meaning. It involves the experience of negative attitudes by the stigmatized individuals, leading to their feelings of loss and discrimination resulting from being devalued, rejected and excluded (Link & Phelan, 2002:4). Gaines's (2001:114) view is that the manner in which the media portrays the defects, incompetence as well as the abnormalities of the stigmatized individuals, subjects them to a situation in which they cannot avoid internalizing such incapabilities themselves. This view is supported by Parker and Aggleton (2003:18) that stigmatized and discriminated against groups often accept and internalize the attitudes that they are subjected to. Goffman (1963:122) mentioned that they adopt behaviours such as avoiding friendship, maintaining a physical distance either by staying far from others or remaining indoors and avoiding door knocks and ringing telephones (Goffman, 1963:122; Sowell *et al.*, 1997:310; Stansburg & Sierra, 2004:13; Ware *et al.*, 2006:906). This behaviour, considered by Weiss and Ramakrishna (2002:3) as well as Sewpaul and Mahlalela (1998:37) as self perceived stigma, is motivated by the feelings of guilt and self depreciation which research has shown that the stigmatized people accept the guilt and shame of being labeled negatively by others. In case of diseases for example, individuals may feel guilt and blame themselves for having contracted the diseases, which is also common in HIV and AIDS, where they tend to feel inferior and insignificant, lonely, unequal with other people as well as useless (Fife & Wright, 2000:56; Link & Phelan, 2002:4; Nyblade *et al.*, 2003:32; Yang *et al.*, 2006:723). All these effects ultimately result in negative self-perception of an individual. Fife and Wright (2000:56) consider internalized stigma as constituting social rejection and financial insecurity, internalized shame and social isolation, which they refer to as "anomie".

Other aspects of this internalized stigma include despondency and loss of hope, isolation and loss of interest in life aspirations which are signs of depression (Sikkema *et al.*, 2000:617). These persons become dangerous to themselves because these feelings may often lead to either anger or aggression directed towards self or clear suicidal ideas. It is for this reason that they might need support from their loved ones, especially when such stigma is associated with an incurable or disabling disease. As mentioned earlier most stigma is directed towards people with mental illness and mental retardation. Edgerton (1967:205), in his book entitled "The Cloak of competence: stigma in the lives of the mentally retarded", described the patients' accounts of how they experienced being treated as though they were not complete human beings (Edgerton, 1976:206; Jahoda & Markova, 2004:723). Fife and Wright (2000:56) stated that internalized stigma affects the individual's self esteem, personal control as well as their body image. This is how strong internalized shame can even lead to social isolation and insecurity.

The Siyam'kela Research Project (2003:98) refers to this type as internal or felt stigma, as do Greeff *et al.* (2007, *In press*), who refer to it as internal stigma and categorize it into four dimensions. These dimensions are: Self perception, fearing disclosure, social withdrawal and self exclusion. In this research, this type is referred to as internal stigma. It consists of thoughts and behaviours that originate from the stigmatized person's own negative perceptions about him/ herself. The consequence is that it interferes with their willingness to disclose their status, or even to access resources such as voluntary counseling and testing (VCT), as well as jeopardizing their access to Anteretroviral drugs (ARV'S) (Thomas, 2006:3181; Yang *et al.*, 2001:718). In the study by Greeff *et al.* (2007, In press), the respondents from the Malawi study had a strong belief that the anxiety and worry associated with their HIV sero-positive status that they constantly experience, is a form of internally directed stigma. They also believe that these feelings are reinforced or aggravated by those who stigmatize them (Gaines, 2001:121; Melby, 2004:1). The above discussion shows that the stigma is a social phenomenon that involves holding humiliatory attitudes against people based on certain personal attributes, physical make-up or disabilities or deformities and for belonging to certain social groups such as Religious, racial or cultural. It also includes discrimination against an individual due to certain life orientations or due to suffering from certain illnesses that are perceived as

dangerous and thus evoke fear in those who stigmatize. The last category of stigma is that directed to those related to or closely associated with the stigmatized.

Stigma towards those closely related to the stigmatized

Authors of stigma refer to this type in various ways as in the former two types. Nyblade *et al.* (2003:34) refer to it as secondary stigma, meaning those related to or closely associated with the infected such as their spouses, children, family members as well as care givers which Yarhouse (2003:133) also revealed in his study. Goffman (1986) termed it "courtesy stigma", referring to the mentally ill patients' families who were stigmatized by virtue of being related to such patients. Edgerton (1967:206) gave an account of nurses who were stigmatized for working in the genito-urinary medical unit. This category has far reaching effects because it contributes to the spread of stigma, involving many people, when actually it is one person affected, and where the stigma could not even be justified, such as in case of mental illness or mental retardation (Atekyereza & Kirumira, 2004:38; Stengler-Wenzke *et al.*, 2004:90). The associated stigma according to Greeff *et al.* (2007, *In press*), refers to incidents that describe the stigma directed at those in close relationship with the HIV/AIDS affected people. Greeff *et al.* (2006, *In press*) categorize associated stigma into two dimensions: spouses, children and family members; and health workers. This research refers to this type as associated stigma.

The three types of stigma discussed above indicate that those suffering from disabilities or illnesses suffer due to the stigma they receive. Their families and health workers treating them also suffer because of this association. However, they also contribute to their own pain by stigmatizing themselves.

3. CONCLUSION

The above discussion gives a review of the literature on stigma, where HIV and AIDS is a context within which stigma is analyzed. The historical background of stigma describes it as a discrediting attribute where individuals are judged according to their differentness from others based either on the disease they suffer from, their social background, religious background or their sexual orientation. Stigma follows a certain process based on the form it takes where major themes are labeled according to differentness, negative attributes, human separation as well as power. Within the context of HIV and AIDS, stigma constitutes different behaviors and attitudes directed

towards PLWA where various authors give different descriptions that are identified into received, internal as well as associated stigma. Received stigma refers to attitudes and behaviours demonstrated by the perpetrators of stigma towards the stigmatized with its inherent dimensions leading to discrimination. Internal stigma refers to self stigmatization which causes self isolation that accounts for fear of disclosure of their status, which aggravates stigmatization that ultimately affects those closely related to the stigmatized in the form of associated stigma.

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ARTICLE 2: COPING WITH STIGMA OF THE LOSS OF AN AIDS PARTNER: A LITERATURE REVIEW

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COPING WITH STIGMA OF THE LOSS OF AN AIDS PARTNER: A LITERATURE REVIEW

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ABSTRACT

Coping has been conceptualized as efforts made by an individual to manage situations appraised to be stressful or leading to anxiety. Coping strategies identified are problem-focused or emotion-focused. Coping by focusing on emotion positive strategies seems to be recommended for meaningful coping in different circumstances. Stress is also conceptualized because coping is necessary when there is stress. Stress models identified are Selye's General Adaptation Syndrome. The stimulus-response, response based, as well as the transactional are also discussed. Some individuals seem to use defense mechanisms, which are described as psycho-analytic thought processes that protect the ego against stressful situations or anxiety. The difference is that coping strategies are developed from the cognitive behavioural tradition and are conscious, whereas defense mechanisms are designed from psycho-analytic tradition and are unconscious. Within the context of HIV and AIDS women whose partners died of AIDS experience coping as a difficult process due to the fact that widowhood and AIDS are both stigmatized, therefore, they have to be assisted to cope effectively.

Keywords: Coping; stress; defense mechanisms.

INTRODUCTION

This article focuses on a literature review of coping including its origin, types or forms as well as its process. Coping becomes necessary where there is a threat with regard to physical, psychological as well as emotional well-being. The context of coping in HIV and AIDS is highlighted as it is an integral part of this article. Stress is incorporated because it necessitates coping, therefore, stress and coping go together. Reference is also made to defense mechanisms as applicable to dealing with HIV and AIDS stigma.

CONCEPTUALIZING COPING

In discussing coping, a critical analysis of different definitions is given, followed by a brief view of stress. A description of the process of coping follows as well as defense mechanisms, as there is an argument about defense mechanisms being an integral aspect of coping. Coping is then discussed within the context of HIV and AIDS.

Coping is a concept that evolved with time as history has it that about fifty years ago the definition of the concept "cope" hardly bore the meaning related to the present one. Its meaning has been evolving from being a garment worn by priests, until currently where it has incorporated the meaning of "deal effectively or contend with"; or "manage" (Branford, 1994:200; Aldwin, 2000:71). Today coping has become a popular concept used by psychologists, nurses, social workers and others because helping professionals are frequently confronted by patients presenting with stress reactions. Patients facing stressful life situations have to be assisted by these professionals to cope with such situations. In the context of this research, coping with stigma of HIV and AIDS is the focus, therefore, the following discussion is on the conceptualization and contextualisation of coping for the purpose of better understanding of how women whose partners died of AIDS cope with the stigma.

Lazarus (1993:8) defines coping as a process that involves an individual's ongoing efforts in thought and action to manage specific demands that he/she appraises as taxing or overwhelming. It gives an idea that coping could be thinking what to do with an overwhelming situation or taking an action in attempt to resolve the stressful situation. Kleinke (1998:2) does not differ much from Lazarus as he refers to coping as associated with the efforts that one makes to manage situations one appraises as being stressful and potentially harmful. This definition is not predictive because it

does not say whether the efforts are successful or not, or whether the situation itself being appraised by the individual who is supposed to cope, is under control or not. One can view it as a suggestive process because it does not predict the outcome of coping. Other definitions, such as Parry's (1990:119) are persuasive, because they conclude that coping involves all the ways which the individual engages in order to master or to minimize the stress that result when events challenge their routine predictions about the world (Parry, 1990:119). This definition seems to be more engaging as it challenges the individual to master the ways of dealing with stress and this means that one has to engage different strategies and master the one that would make one cope successfully. This definition also highlights that once an individual experiences stress, his/her routine predictions about the world are challenged and he/she has to attempt to cope. Carr (2004:213) in his book on Positive Psychology does not necessarily provide a definition for coping but refers to coping strategies as being used to deal with situations whereby an individual perceives a discrepancy between stressful demands and available resources. This discrepancy suggests that the individual is unable to fulfill those daily demands that challenge his/her wellbeing. It is a known fact that when one's normal resources to fulfil daily demands, such as to complete a work task, to solve problems as well as to remove obstacles that prevent him/her from accomplishing his/her goals set on daily basis, coping strategies should be readily available in order to be utilized.

Aldwin (2000:71) refers to coping as an old concept that has been evolving with time. He motivates this statement by stating that in the fifties, the American dictionary referred to it as "proving oneself as a match for", whereas modern dictionaries define coping as efforts to resolve environmental pressures that could not be handled by usual means or by organized skills (Aldwin, 2000:96). This definition is by no means different from others. In most of the literature on coping, defense mechanisms feature now and then (Lazarus, 1976:85; Aldwin, 2000:96; Carr, 2004:230; Kleinke, 2004:105; Kenny, Carlson, Mc Guigan & Sheppard, 2000:94; & Parry, 1990:49).

Bailey and Clarke (1989:35) define coping as the means by which individuals attempt to control perceived demands or threat. It is further explained as the means by which an individual reduces the impact of such actual or perceived threats on him/herself irrespective of whether successful or not. This is a somewhat liberal approach because it implies that when one feels threatened by a challenging situation it is apparent that one should do something that will reduce the negative consequences of

such threat. This tells one that coping is, to a certain extent, an involuntary act, a somewhat stimulus-response reaction, the success of which is determined by the types of conscious strategies that one engages. This explanation accounts for the fact that there is positive and negative coping.

Coping with HIV and AIDS stigma, whether one is infected or affected also depend on the individual's self efficacy in dealing with the problem, hence Cassidy (1999:) viewed it as the person's cognitive and behavioural efforts to manage, minimize, master, or tolerate his/her internal and external demands. One may appreciate the broadness or openness of this definition in implying that when one faces a stressful situation, one attempts to cope in order to prevent, or minimize the impact, to master or if nothing comes our of those efforts, to tolerate the stressor. This definition supports that of Bailey and Clarke (1989:35) because attempting to cope would aim at achieving an outcome that will enable one to either reduce, master or live with the stressor. Sikkema, Kalichman, Hoffman, Koob, Kelly & Heckman (2000:622) found in their study that people with HIV and AIDS who employed active coping strategies tend to improve their quality of life that is, they may be considered as having mastered the stressor.

Coping, from the sociological perspective is support-focused. Both Myers (2000:320, and Taylor and Field (1997:182), view coping as a factor dependent upon social support systems, though the former emphasizes the social support (beloved ones) available at the time when coping is necessary. The latter, view faith and religion, as the important coping mechanisms, over and above the close people that are attached to an individual experiencing a difficult situation (Taylor & Field, 1997:182).

In the nursing context, coping refers to the process whereby the behaviour adopted by a "person facing stress" is viewed as a struggle to improve the situation, or rather, a way of getting along in the world (Wilson & Kneisl, 1996:74). Another nursing perspective complements these views by stating that coping is the process through which one manages the demands and emotions generated by the appraised stress (Boyd, 2002:930), as well as the biomedical view that considers coping behaviours as mediating the effects on blood sugar (Rice, 2000:4). The nursing literature seems to be adaptation oriented, which is somewhat related to the psychological perspective. Boyd (2002:930) ascribes to the psychologists' views that maintain that coping is the process through which the person manages the demands and emotions brought by

the stress that an individual has appraised as existing and he thus believes that positive coping leads to adaptation.

Roy (1984:59), a nurse theorist well known for her adaptation theory, contended that the output of the adaptive system is two-fold namely, adaptation and mal-adaptation. According to this theory ineffective responses or coping result in illness whereas adaptive coping leads to health. Wilson and Kneisl (1996:74) on the other hand alluded to the fact that any life threatening situation stimulates a reaction that is task orientated or defense-oriented. Defense-oriented responses usually lead to mal-adaptation which makes them undesirable. It is also stated that a person can cope at physical, social, cognitive and emotional levels (Wilson & Kneisl, 1996:74). Following is the discussion of the process of coping. Coping according to the afore-mentioned definitions appears to be a process whereby an individual appraising a stressful situation engages in some mechanisms that allow him to deal with the situation. Before the process of coping can be discussed, it is appropriate to view the concept stress.

CONCEPTUALIZING STRESS

The first definition of stress was in 1936 by Selye (1976b:64) who defined it as "the nonspecific response of the body to any demand made on it". This definition was criticized as being vague and it was reviewed as "a state manifested by a specific syndrome which consists of all the nonspecifically induced changes within a biological system". This definition does not represent the known Selye's General Adaptation Syndrome. Both definitions, however, do not indicate a situation that would evoke some voluntary response by the individual. General Adaptation Syndrome is a disruption of homeostasis through psychological stimuli (Selye, 1976b; Bailey & Clarke, 1989:4). The stimuli that may create stress may be a mental, physiological, anatomical or a physical reaction. This is an indication that stress also develops from within an individual. Bailey and Clarke (1989:4) expose three models of defining stress. First is the **stimulus-response model**, according to which stress is seen as something in the external environment which impinges on an individual. Impinging means having an effect on, which means that the said stimulus affects the person. A typical example is the extremely cold temperature which leads to changes in the body (Bailey & Clarke, 1989:4). The second model is the **response-based** definition that focuses on the physiological or psychological response to the perceived threat that

leads to stress. The third is the **transactional model** of stress which sees stress as a result of an interaction between the environment and the person perceiving or appraising the situation (Bailey & Clarke, 1989:4). Lazarus (1993:5) referred to the two types of stress that Selye describes as eustress and distress. Eustress is described as the positive type of stress and distress as the type associated with negative feelings (Lazarus, 1993:5). Eustress could, therefore, enhance the effectiveness of the immune system whereas distress could impair it.

Another definition that seems more appealing for the purpose of this article is that of Seaward (2004:5) who defines stress as inability of an individual to cope with perceived threat to his/her mental, physical, emotional and spiritual well-being that results in a physiological response. This is a comprehensive definition because it creates the awareness that there is ability and inability to "cope", therefore, stress and coping are like a disease and management. It is also comprehensive based on the fact that it makes the reader aware that any disequilibrium in the individual's mental, physical, emotional as well as spiritual well-being creates stress thus necessitating coping (Seaward, 2004:5). Coping serves as management for stress, therefore it is inevitable that one cannot discuss coping without referring to stress.

Connor-Smith, Compas, Wadsworth, Thomsen and Saltzman (2000:987) described the Confirmatory Factor Analysis, a conceptual model that includes different responses to stress by assessing voluntary coping and involuntary responses to stress. The model also considers placing stress responses according to voluntary-involuntary, engagement-disengagement and primary-secondary control. This is a broad model that shows a wide range of responses to stress as well as the relationship between stress and coping. Responses to stress also occur through either adaptation or psychological coping such as in stress management, anxiety and depression (Connor-Smith *et al.*, 2000:987). Coping also follows a structured process as discussed in the section that follows.

THE PROCESS OF COPING

When an individual faces a difficult situation such as an illness, he/she needs to learn and master new skills as well as gain information that will assist in dealing with such illness. Social supports constitute those people who will assist him/her practically, such as taking him/her to the doctor if he/she is physically ill, as well as those who will provide information on how to deal with the situation that is, professionals such as

social workers, psychologists and nurses(Taylor & Field, 1997:135). In his investigation, Burger (1992:128) concluded that those with a high desire for control engage in all efforts to collect information that will assist them to deal actively with the problem. He, therefore, concurs with those authors who maintain that problem-focused coping is desirable and, therefore, adaptive (Kleinke, 1998:5; Schonnessen & Ross, 1999:88; Parry, 1990:41; Mickelson, Lyons, Sullivan & Coyne, 2001:184; Coetzee & Spangenberg, 2003:210; Carr, 2004:217).

The process of coping according to Lazarus (1993:8) is largely influenced by how an individual appraises the event or situation that causes stress. If an individual appraises the situation as threatening or having negative effects, one is likely not to cope effectively with the stress. On the other hand, if the stressful situation is appraised as the one that an individual can have control over then he/she is likely to cope better and emerge a better or more mature person (Kleinke, 1998:21). Appraisal also influences coping with daily life because coping is not a once-in-a-while occurrence.

The daily hassles coupled with other serious problems, necessitates coping with the situation. This process consists of coping strategies that one must use which are conscious mechanisms that one must learn and put into practice while confronted with challenging situations. A challenging situation is when an individual's coping strengths or resources are being challenged (Carr, 2004:215). Most of the literature concurs that the utilization of such resources or the process may either be problem-focused or emotion-focused (Aldwin, 2000:155; Carr, 2004:216; Boyd 2002:932; Kleinke, 1998:3; Wilson & Kneisl 1996:75). Problem-focused coping involves a process whereby one actively engages in strategies aimed at solving the problem, whereas emotion-focused coping involves dealing with the emotional distress experienced due to the problem (Kleinke 1991:3; Kenny *et al.*, 2000:92; Mickelson *et al.*, 2001:184; Carr, 2000:21; Parry, 1990:46). Problem-focused is coping usually engaged if there is a positive appraisal that one can do something about the problem and emotion-focused coping usually results when an individual confronted by a problem feels challenged or lacks coping resources, and then attempts to handle the feelings caused by the problem (Kleinke, 1998:3).

Following is a discussion of coping strategies used in the process of coping.

Coping strategies

To explore the process of coping further, strategies of coping may render a more elaborate discussion. In exploring the literature on coping, Lazarus (1993:8) described coping and distinguished problem-focused and emotion-focused coping. These types are linked to functional and dysfunctional approaches. Coyne and Downey (1991:414) referred to coping in terms of approach versus avoidance. They state that the problem-focused versus the emotion-focused distinction is the most popular conceptualization of coping. These two types are, therefore, discussed in detail.

Problem-focused coping strategies

Problem-focused coping strategies are those that the individual employs with the aim of modifying the source of stress by doing something about it (Carr 2004:215; Mickelson *et al.*, 2001:184; Coetzee & Spangenberg, 2003:210). According to Kleinke (1998:3), problem-focused coping strategies can be outer-directed, being those that are oriented towards changing the situation or the behavior of others. Then there are inner-directed coping strategies that involve efforts that individuals make to alter their own attitudes and needs, thus developing new skills and responses (Kleinke, 1998:3). Problem-focused coping strategies are used for stresses in which case one can be able to modify the source of stress directly. This strategy is also referred to as task oriented, planful problem solving, confrontive or coping with the problem, because it involves active problem solving that facilitates ownership and direct dealing with the problem (Kenny *et al.*, 2000:92; Cassidy, 1999:36; Carr, 20004:217; Parry, 1990:46). Sikkema, Kalichman, Hoffman, Koob, Kelly, and Heckman (2000:622) discovered that PLWA who adopt active coping strategies improved their quality of life. However, problem-focused coping also has functional and dysfunctional strategies.

Functional strategies in this respect involve accepting the responsibility for solving the problem, gathering relevant information about the problem, as well as seeking support, advice or help. One also needs to develop realistic action plans and implement them whether alone or engaging other people. This includes focusing on the problem and ignoring competing activities, as well as being confident of one's own ability to solve a problem (Van den Bank, 2002:23; Carr, 20004:215; Van den Berg & Du Plessis, 2006:33; Hutchingson, 2006:41). Carr also maintains that in order for

one to succeed, one needs to be creative, wise and conscientious. Kenny *et al.* (2000:94) state that one needs a coping pattern that combines an easy temperament and autonomy together with willingness to seek assistance in order to succeed in coping with stress.

Dysfunctional problem-focused coping strategies are those in which an individual accepts little responsibility for solving the problem, seeks inaccurate or irrelevant information; advice and support are sought from inappropriate sources, unrealistic plans are developed, the person fails to follow-up on problem solving plans, as well as lacks confidence in problem solving ability (Carr, 2004:211). According to Carr (2004:218), problem solving skills are central to problem-focused coping strategies. Social support is also valued because people with larger social support are believed to survive many problems. Catharsis is believed to be effective based on the fact that when someone with psychological trauma is not given an opportunity to disclose and verbalize feelings, they are likely to suffer, especially those who were abused as children or victimized as adults. They, therefore, lack an opportunity to attend to their traumas and ultimately become ill. Crying is also found to be contributory to immediate relief of tension (Carr, 2004:218). Aldwin (2000:73) complements this literature in stating that coping depends on the skills that an individual brings to a particular situation or environment. This notion accounts for the fact that when people experience stress, they can either change or modify their environment. Burger (1992:128) realized that people that employ problem-focused coping strategies are those that possess a high desire for control, hence they engage in active efforts to deal with their problems. Problem-focused problem solving therefore utilizes confrontive coping, planned problem solving, seeking social support or advice to solve the problem. Emotion focused coping strategies follow next.

Emotion-focused coping strategies

Emotion-focused coping strategies refer to behavioral efforts which serve to reduce negative emotions resulting from the existence of the problem (Coetzee & Spangenberg, 2003:208). These strategies are believed to be appropriate for affective states associated with uncontrollable stresses such as in cases of bereavement. The following strategies are suitable for this type of coping: developing and maintaining meaningful support systems, catharsis, seeking meaningful spiritual support, reframing, cognitive restructuring as well as humor (Carr,

2004:217). The aim here is to redirect a stressful situation in a different way so as to cause less stress. The study conducted by Martin, Wolters, Klaas, Perez and Wood (2004:288) indicated that coping techniques frequently used by American families with HIV positive children used reframing, spiritual support and passive appraisal. This study is, therefore, supportive of the aforementioned emotion-focused coping strategies. Functional emotion-focused coping strategies include relaxation and physical exercise because they take effect by regulating the mood. There is also a range of functional strategies that do not alter the source of stress and they are support, catharsis, reframing, humor, relaxation and exercising. The belief is that they allow for the regulation of negative mood states that arise from exposure to stress (Carr, 2004:217). Their functioning is in contrast to dysfunctional emotion-focused coping strategies.

Dysfunctional emotion-focused coping strategies are amongst others, developing destructive relationships that are non-supportive, seeking spiritual support that is not meaningful, long term denial, wishful thinking, taking oneself too seriously, abusing alcohol or drugs, as well as aggression rather than engaging in physical exercise. These strategies may be amenable to short term relief, after which problems may persist. In some instances, individuals may engage in functional avoidant coping whereby an individual psychologically disengages from a stressful situation and temporarily gets involved in distracting activities. An example in this regard could in the case of an individual who, when experiencing stigma, turns off thoughts about these experiences when he/she is away from the situation. These avoidant coping strategies become dysfunctional when they are used as a long term solution to stress management (Carr, 2004:217). Mickelson *et al.* (2001:184) identified communal coping whereby the stressors are appraised as an issue affecting a group of people. It is also referred to as relationship focused coping, where individuals address their stressors within the context of relationships, therefore, it is also referred to as the social support structure.

Researchers often rely on scales that assist them to measure the individual's coping abilities. These scales give individuals the choice of responses that they usually choose when they face challenges (Kleinke, 1998:5). First, is the coping strategy indicator that consists of three indicators namely, problem solving, seeking support, and avoidance (Kleinke, 1998:5). In assessing their coping responses, individuals are usually requested to indicate what they do or how they react when faced with life

challenges. The reactions are then matched with the aforementioned indicators. The coping Inventory for Stressful Situations is also a scale that measures three of the commonly used strategies. These strategies are task coping, emotion coping as well as avoidance coping (Kleinke, 1998:6). As the terminology states, ultimately the researcher is able to categorize whether an individual uses problem-focused (task coping), emotion-focused, or the type that avoids the problem. The COPE scale (Kleinke, 1998:7) is the internationally used and commonly adopted scale that covers a wide range of responses, including the aforementioned responses. After the responses are analyzed, the researcher is able to determine the coping strategies that an individual uses when faced with life stresses. It may also assist the assessor to rate whether an individual uses problem-focused or emotion-focused strategies (Kleinke, 1998:7). Next is the discussion of the relationship between coping strategies and defense mechanisms. Both problem-focused and emotion-focused strategies have positive and negative outcomes. Problem-focused is active coping and could be preferred to emotion-focused because an individual utilizes resources within his environment to resolve the stressful situation.

Carver, Scheier and Weintraub (1989:267) attempted to explore how people cope and whether individual differences influence the individual's ways of coping. They noted that differences in coping styles are intrinsically tied to differences in personalities (Carver *et al.*, 1989:280). This implies that certain people have preferred ways of coping which may be influenced by their personalities or by other reasons. Any individual's internal environment has ego defenses that operate unconsciously to defend the fragile ego hence the following discussion of defense mechanisms.

Defense mechanisms as means of coping

Defense mechanisms are psychoanalytic thought processes that protect the ego (Seaward, 2004:78). This protection is effected by minimizing the impact of perceived threats that may lead to stress. Freud, the father of the psychoanalytic school of thought, believed that defense mechanisms are unconscious resources that are used by the ego to reduce conflict between the id and the superego, thus reducing anxiety (Gay, 1989:3). This process should always be operational, therefore, every time one anticipates a threat one engages in behaviors aimed at defending one's ego (Seaward, 2004:78), thus adapting to the situation. When adaptation is difficult, the unconscious protects the ego. This is a psychoanalytic approach of dealing with

stress (Aldwin, 2000:87). Some authors view this as maladaptive because they suppress the reality of the situation so that it is subconsciously denied (Aldwin, 2000:88; Carr, 2001). Freud's explanation of defense mechanisms is that the unconscious psychological manuevres distort or disguise unacceptable impulses and ideas, and these are kept out of consciousness (Carr 2006:231). As a result the ego suppresses them as though they never occurred, therefore, Bailey and Clarke (1989:35) refer to them as ego-defensive coping. This is protective to the individual because the problem is kept in the subconscious so that it does not surface to the conscious to be realized by an individual as this process leads to stress. This argument accounts for the protectiveness of defense mechanisms.

Aldwin (2000:87), Roy (1984:51) and Wilson and Kneisl (1996:75) on the other hand argue that an individual who is dominated by the use of defense mechanisms is referred to as maladaptive. The poor adaptation is based on the fact that these defense mechanisms distort reality. However, they are, for descriptive purposes, divided into four categories namely, protective, immature, mature and neurotic. The Freudian theory maintains that some disorders may be partly caused by inadequate use of appropriate defense mechanisms. The maladaptive use then is realized when their use renders the individual unable to judge danger or when he/she fails to realize true feelings and thoughts (Gay, 1989:3). The following are some of the common defense mechanisms as clarified and conceptualized by Kaplan and Sadock (1998:220-221).

Compensation. Taking up one behavior due to failure to accomplish another behavior for example, becoming an AIDS activist after being diagnosed HIV positive.

Denial is unconsciously avoiding the awareness of painful or unpleasant aspects of reality. An example could be an HIV positive person behaving as if it does not exist and continuing to engage in unprotected sex.

Displacement occurs when the mind redirects emotions of a "dangerous" object to a "safe" object, such a woman infected with HIV by her partner taking her anger out on innocent people.

Dissociation is separation or postponement of a feeling that would normally accompany a feeling or thought, such as failing to associate sex with HIV.

Humour tends to refocus attention towards joking in order to relieve negative tension, such as joking about HIV and AIDS.

Idealisation is presenting a painful stimulus as good thus masking the true negative feelings towards the other; an example is capitalizing on the saying that "HIV and AIDS are like any other disease" when knowing its true debilitating and incurable nature.

Projection is attributing one's own unwanted thoughts and/or emotions to others, for example blaming a partner for having infected one whereas one has been promiscuous.

Rationalization involves constructing a logical justification for a decision that was reached by different thinking. An example is "AIDS or no AIDS, everybody is going to die".

The list is long but these are those that are thought to be more applicable in the context of HIV and AIDS. The painful effects of being infected lead to the use of these unconscious mechanisms as the ego attempts to protect itself from the unbearable pain.

The difference between coping strategies and the defense mechanisms is, therefore, that coping strategies were developed from the cognitive behavioral tradition, to explain how individuals consciously deal with situations in which their external demands compromise personal strengths or resources. Defense mechanisms on the other hand, were designed from the psychoanalytic tradition to explain how unconscious processes control anxiety associated with intra-psychic factors. Most defense mechanisms, that is according to Vaillant's hierarchy from the first to the third level are maladjustive (Carr, 2004:231; Aldwin 2000:89; Lazarus 1976:72). The relationship between coping strategies and defense mechanisms is discussed further.

The object-relations theory, self psychology and interpersonal psychoanalytic traditions seem to take a different view of defenses. They view defenses as means of coping with anxiety that comes from conflicts arising when an individual wishes to express an aspect of self which is unacceptable within the circle of family, friends or the society. This individual chooses to comply with what is acceptable in a quest to gain the support of these people who are significant in his/her life. If this individual uses the primitive defense mechanism such as passive-aggression, it may help

him/her to regulate the negative emotions associated with their conflict by complying with what is expected of him/her (Carr, 2004:231; Bailey & Clarke, 1989:37; Wilson & Kneisl, 1996:76). However, the expected reaction or function may be carried out reluctantly. On the other hand, if the individual resorts to neurotic defense mechanisms he/she may handle the conflict by displacing his/her frustration to someone else (usually a defenseless person). On the positive side, he/she may use sublimation in the form of engaging in an activity that will allow him/her to release the tension physically, such as playing sport (Carr, 2004:234; Bailey & Clarke, 1989:38). This is an indication that defense mechanisms are not altogether maladaptive, but that some may be positive or adaptive.

Within the transactional approach coping is considered as a transaction between an individual and his/her environment, commonly practised within nursing. The individual's behavior will, therefore, vary according to the extent to which he/she perceives the environment to be threatening or non-threatening therefore, the reaction may sometimes be active coping or passive. Active coping may be used if the environment is perceived as life threatening, whereas if the opposite applies, an individual may decide to wait or instead of coping, alter the situation to make it more adaptable. This approach also depends on the experience one brings into the current situation, problem or the circumstances as well as his/her personality. It may, therefore, be argued that phenomenological-transactional coping is individual oriented. The approach also fits well with the nurses' approach (Bailey & Clarke, 1989:44; Coetzee & Spangenberg, 2003:206; Schonnessen, & Ross, 1999:88). It is following this approach that Bailey and Clarke's (1989:44) nursing model of coping was derived. The model classifies coping into three categories namely, direct, indirect and palliative coping. It is also consistent with the transactional approach to stress and coping.

5. CONCLUSION

Coping is a concept associated with stress whereby an individual experiencing a stressful situation has to cope in order to control the appraised demand or threat. Coping may be involuntary whereby it occurs naturally such as in psychological responses. Voluntary coping is dependent on an individual's coping strategies, the success of which is determined by their effectiveness or impact on the perceived stress models ranging from the bio-medical, sociological to adaptation. Adaptation

indicates a link between coping and stress which was identified by Selye in his description of the general adaptation syndrome (GAS). Several models of stress range from stimulus and response, response based as well as transactional models, some of which identified stress as originating from within the individual such as from physiological threats, whereas others are external environment based such as stigma. When an individual appraises stress as threatening, the anxiety levels escalate, therefore, some forms of coping becomes inevitable. The process of coping is described as either problem or emotion-focused (Lazarus, 1993:8). Both of these processes have functional and dysfunctional strategies, which are believed to be used by people experiencing the stigma of HIV and AIDS. People experiencing the stigma of HIV and AIDS are found to cope by problem-focused strategies more than they do with emotion–focused strategies. Some of them, however, cope by using defense mechanisms.

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ARTICLE 3: EXPERIENCES OF STIGMATISATION OF WOMEN WHOSE PARTNERS DIED OF AIDS

GUIDELINES FOR THE JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE

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EXPERIENCES OF STIGMATISATION OF WOMEN WHOSE PARTNERS DIED OF AIDS

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ABSTRACT

Stigma of HIV and AIDS causes concern because of the fact that it does not only affect those who are infected but also their spouses, children, close family members and those closely associated with them. Women, as the gender that is culturally dominated by men, are found to be the most affected by stigma. The focus of this study is on the experiences of women who lost their partners to AIDS and who are stigmatized due to the fact that both widowhood and AIDS carry stigma. These women were all HIV positive. A qualitative design was followed in order to explore and describe the experience of stigmatization of women whose partners died of AIDS. Findings revealed that women experience stigma that manifests in three forms namely received, internal as well as associated stigma. Received stigma was reported as experiences of gossip, rejection, avoidance, blame, abuse, neglect, fear of contagion and pestering. They also experienced internal stigma in the form of self perception, fear of disclosure, social withdrawal and self exclusion. Additional categories that could not be directly linked to stigma are experiences of deterioration in physical status leading to physical weakness, helplessness as well as preoccupation with and fear of anticipated death. Associated stigma of children and families of these women was also reported to a lesser extent. These experiences contributed to the women's loss of hope for the future. Guidelines were formulated for women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected partner who died of AIDS.

Core terms: Stigma, Stigmatization, Partner, AIDS, Widow

INTRODUCTION AND PROBLEM STATEMENT

Stigma is a concept that was first described by Goffman (1963:13) as an attribute that is deeply discrediting and devaluating to an individual's social identity. It further reduces the person from the whole and the usual person to an individual with a tainted image, thus rendering her to an experience of being an incomplete person due to the negative attributes that she is associated with (Gilmore & Sommerville in Nyblade *et al.*, 2003:8). Brown, Macintyre and Trujillo (2003:50) maintained that stigma could originate from a particular characteristic such as a physical deformity or from negative attitudes toward the behavior of a group such as homosexuals or prostitutes. The result is prejudicial thoughts, behaviors and/or actions on the side of the larger community. These thoughts, behaviors and actions are, during this era, observed with regard to the HIV and AIDS pandemic (Brown *et al.*, 2003:62). A known fact supported by the literature (Herek & Capitano, 1993:575; Heckman, Somlai, Peters, Walker, Otto-Salaj, Galdabini & Kelly, 1998:369; Sewpaul & Mahlalela, 1998:36; Owen, 2002:76 and Nyblade, Pande, Mathur, MacQuarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbuwambo and Bond, 2003:23) affirmed that HIV and AIDS is a highly stigmatized condition. The stigma of HIV and AIDS has become the cause for concern especially because it does not only affect those who are infected but also those having close relationships with them, such as their spouses or sexual partners as well as other family members. These people experience secondary stigma because they are considered to be close to the infected person (Weiss & Ramakrishna, 2001:17).

This research focuses on the woman who lost her partner to AIDS, as the closest person having had a relationship with the infected person. Women are found to be the most vulnerable to stigmatization due to the gender discrimination that still dominates our society (Nyblade *et al.*, 2003:23; Sowell, Loweinstein, Moneyham, Demi, Mizuno, & Seals, 1997:310). Stigmatization intensifies when considering women who have lost their partners to AIDS and are also HIV infected. Authors also maintain that the stigma attached to HIV and AIDS is characterized by the exclusion of an individual from social responsibilities which amounts to the lowering of a person's social status, loss of respect, rejection and being suspected for having contracted the disease. Such stigma is motivated by the adverse social judgement against the person, because these women's sexual practices and HIV status are not actually known by those stigmatizing them (Siegel & Schrimshaw, 2005:231; Thomas, 2006:3181). These negative

attributes were due to the perception that when someone has contracted HIV and AIDS they are responsible for their immoral behavior, therefore, they are justified to suffer (Thomas, 2006:3181). In this research the partners' status was known as positive. All the women were aware of their HIV positive status but some were still in denial. The prejudices coupled with the negative attitude with which women are treated may contribute to their feelings of unworthiness (Yang, Stanton, Fang, Lin, & Naar-King, 2006:722).

The literature reviewed for this study as well as the researcher's observations gave the background information that shed light on widowhood as a difficult and stressful experience for the widow (Bankoff, 1983:836; Parkes in Kalish, 1985:207; Manyedi, 2003:78). Contributing to this difficult process is the fact that widowhood itself is a stressful experience for the woman, which in this case is aggravated by HIV and AIDS. HIV and AIDS stigma affecting the infected and the affected by the disease is a major concern in many countries, especially in the Sub-Saharan Africa where the syndrome is predominant. The stigma seems to be aggravated by the fear attributed to the misconceptions regarding its mode of transmission, its debilitating nature, as well as the high rate of death (Nord, 1997:60). All these compounding factors contribute to HIV and AIDS being the most stigmatized disease. Research has also indicated that the issue of gender always features in HIV and AIDS because women are often found to be more affected by stigma when compared to their male counterparts (Fife & Wright, 2000:59; Siegel & Schrimshaw, 2003:193). This stigmatization is believed to interfere with the individual's disclosure of their sero-positive status, thus leading to the delay in seeking treatment, support by those closer to them as well as health service providers. These circumstances result in the deterioration in the women's general condition. The focus of this study is on stigmatization as a difficult process experienced by women whose partners died of AIDS. They found this process a difficult one because both widowhood and AIDS carry stigma. There was, therefore, a need to assist them to cope with the stigma associated with their having had a relationship with an infected person who died of AIDS. Psychiatric nurses as people trained to assist people experiencing stressful situations, should establish support mechanisms for such people. Exploring and describing of stigmatization experience led to the development of guidelines to assist these women to cope with stigmatization of their having had a relationship with an infected person who died of AIDS. Based on this problem statement the following research questions arise:

- What is the experience of stigmatization of women whose partners died of AIDS?

- What could be done to assist women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected person who died of AIDS?

OBJECTIVES OF RESEARCH

From the above-mentioned questions, the following objectives were formulated for this research.

- To explore and describe the experience of stigmatization of women whose partners died of AIDS.

- To develop guidelines to assist women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected person who died of AIDS.

CONCEPTUAL DEFINITIONS

The following are definitions of concepts used in this study that were derived from the literature. These concepts, described in the context of this study are stigma, stigmatization, partner, AIDS and widow. **Stigma** in this study refers to an attachment of negative attributes which are discrediting and reduce an individual from his/her usual whole to one with a tainted image (Goffman, 1963:3). Stigma could originate from a particular characteristic such as a physical deformity or from a negative attitude towards the behavior of a group of people, leading to prejudiced thoughts, behaviors and/or actions of members of the community (Brown, Macintyre & Trujillo, 2003). **Stigmatization** is a process of attaching brands of disgrace to an individual based on the perspective of the one who judges the other (South African Pocket Oxford Dictionary, 1994:953). In the context of this study, **partner** is defined according to the South African Pocket Oxford Dictionary (1994:695), which is either member of a married or unmarried couple. Partners are people who are closely related to the extent that they are associated with each other. **AIDS** is an acronym of the Acquired Immune Deficiency Syndrome. **Widow** is defined as a woman who has lost her husband by death and not married again (South African Pocket Oxford Dictionary, 1994:1115).

LITERATURE STUDY TO CONTEXTUALISE STIGMA

The literature study was conducted in order to contextualize stigma in the context of HIV and AIDS. The concept of stigma originated from Greek and referred to the bodily signs which were marks that exposed the unusual or the bad aspect about the moral status of an individual (Goffman, 1963:11). These signs were engraved on the body either by scarring or burning so that an individual would be exposed as bad, criminal or the one to be cast off and discounted from belonging to the public (Goffman, 1963:11; Edgerton, 1967:205; Nord, 1997:22). The mark or brand of disgrace and shame later became known as stigma (Nord, 1997:60). From then the concept evolved from being bodily signs of physical disorder to the current meaning, which is back to the original meaning of the concept, which is that of being a dreadful or disgraceful sign. In health, stigma has been attributed to diseases such as leprosy, tuberculosis, mental illness, as well as mental and physical disability, to mention but a few. According to Fink and Tasman (1992:18) and Stengler-Wenzke, Trosbach, Dietrich, and Mangermeyer (2004:889), this concept derived its meaning from an ill-treatment of a person believed to be an evildoer who was marked with a sign that people would recognize him/her as such, therefore stigmatized people are treated differently. This differential treatment could be attributed to prejudicial thoughts, behaviors and/or actions on the part of the perpetrators of stigma that could constitute the family, friends, co-workers, employers, health care providers and communities (Brown *et al.*, 20034:50). Weiss and Ramakrishna (2001:5) refer to it as a social process or rather, an experience characterized by exclusion, rejection, blame or devaluation.

The devaluation and stereotype was based on the fact that in society there are people who regard themselves as normal and others as abnormal, the same as some human attributes that are regarded as normal and others abnormal (Goffman 1963:65; Fick, 2005:20). Discriminating against a person who may appear different from the rest it is stigmatizing him/her, thus devaluing and discrediting his/her human status. This situation applies to physical, psychological, social as well as on spiritual aspects, because besides medical conditions, social and psychological statuses, there are religious beliefs that are stigmatizing, the same as some cultures and languages (Goffman, 1963:14; Takahashi, 1997:194). When viewing the diseases that have been stigmatized from historical times, they seem to be such that people could not understand their nature, feared them due to their strangeness, incurable nature, as well as being associated with death. Hence the stigma attached to HIV and AIDS because

it is incurable, chronic and debilitating and leads to death. However, Parker and Aggleton (2003:16) argue that the question of HIV and AIDS stigmatization has taken the form of power and discrimination. What aggravates this stigma is that people with HIV and AIDS are stigmatized together with their spouses, children, other family members as well as their health providers. Herek, Capitano and Widaman's (2002:371) research conducted in the United States of America indicated that those who are closely associated with the stigmatized persons also become stigmatized.

Stigmatization occurs in various forms that amount to three types of stigma namely, felt or perceived stigma which is associated with real or imagined fear of societal attitudes, potential discrimination arising from negative attributes or stigmatized conditions, and behaviors associated with those conditions such as promiscuity, homosexuality and drug abuse (Brown *et al.*, 2003:50). Greeff, Uys, Holzemer, Makoae, Dlamini, Kohi, Chirwa, Naidoo and Phetlhu (2006:14) refer to this type as received stigma whereas Weiss (1992) named it the "etic" or outsider's view. The second type was named by Brown *et al.* (2003:50) as the enacted stigma as distinguished from the term felt stigma, which is defined as the real experience of discrimination such as being isolated following one's disclosure of his/her HIV and AIDS status, devaluation or being considered an outcast. However, this definition differed from that of Greeff *et al.* (2006:In press), who referred to the second type as internal stigma, reflecting thoughts and behaviour that originate from within an individual's perceptions about his/her HIV status. Goffman (1963:31) gave the same type of stigma the term of "self perceived stigma", which is conceptually closely associated with "internal stigma" by Greeff *et al.* (2006:14), as well as the "insider's perspective" by Weiss *et al.* (1992). The "emic view" is the term given this type of stigma by Weiss (2003). The third type is the associated stigma, which constitutes negative behaviours and thoughts against those who are closely associated with the infected individuals (Greeff *et al.*, 2006:In press). Nyblade *et al.* (2003:28) on the other hand, argues that whether the stigma is overt or covert, the experience takes three forms namely, stigmatizing and discrimination against the stigmatized, internalized stigma as experienced by the stigmatized persons, as well as the stigma and discrimination against those related to or closely associated with the stigmatized (Link & Phelan 2002:1). These are consistent with the types identified by Greeff *et al.* (2006:In press) namely the felt, internal as well as associated stigma.

The process of stigma can be categorized into four categories namely, the differentness that leads to labeling, the stigmatizing process when linking human differentness with negative or undesirable attributes, the human separation that separates the 'us' from 'them', as well as the dependence of stigma on power (Link & Phelan, 2002:4). These differ from Goffman's (1963:14) categories that include bodily abominations, the blemishes of individual character, as well as the stigma associated with racial discrimination, religion, and ethnicity that could be transmitted through lineage.

RESEARCH METHODOLOGY

Research design

A qualitative, phenomenological research design was followed, the aim of which was to explore and describe the experience of stigmatization of women whose partners died of AIDS (Creswell, 1998:15). In-depth interviews with participants enabled the researcher to explore and describe the phenomenon of stigmatization. The women's experiences assisted the researcher to develop guidelines to assist such women to cope effectively with the stigma associated with their having had a relationship with a partner who was infected and died of AIDS.

Research Method

Sample

The population from which the sample was drawn consisted of women in the five regions of the North West Province of South Africa whose partners died of AIDS within a year of their loss.

A purposeful voluntary sampling technique was used (Burns & Grove, 1997:306; Streubert & Carpenter, 1999:22). Letters were written to the Directorate of Research in the North West Department of Health to obtain permission to conduct research. After permission was granted letters were written to the mediators who are coordinators of HIV/AIDS in the regions. The potential participants were purposively selected, due to having lost their partners to AIDS. In some instances, home-based carers provided this information and identified potential participants. The researcher then wrote letters to them, informing them about the purpose of this research, their participation as well as the inclusion criteria. The women had to have lost their partners to AIDS within a year,

be resident in any of the five regions of the North West Province of South Africa, be able to communicate in Setswana, Sesotho, Northern Sesotho/Sepedi or English, be open and willing to share their experience in an in-depth interview and be willing to give consent to be recorded on an audio-tape. The sample size was determined by data saturation (Burns & Grove, 1997:308) which was reached with the twelfth interview. The researcher conducted a further eight interviews, thus a total of twenty interviews to ensure that there was no new data elicited from interviews.

DATA COLLECTION

Letters requesting potential participants to participate in the research, with the nature of research and objectives clearly stated as follows: to explore and describe the experience of stigmatization of women whose partners died of AIDS; and to develop guidelines to assist women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected person who died of AIDS. Participants had to consent to voluntary participation as well as to recording of interviews. Data collection was undertaken by means of a single open-ended question (Brink & Wood, 1998:322-323), "**How do you experience the stigma after your partner died of AIDS"?** This question was given to experts to evaluate its applicability. The pilot study was conducted initially with one of the participants who met the inclusion criteria. The interview was tape recorded. Demographic, descriptive and reflective field notes were written immediately after each interview to ensure significant observations, as well as ensuring accurate recording (Morse, 1989:116; Creswell, 1998:130-131).

DATA ANALYSIS

The interviews recorded on audio-tapes were transcribed verbatim, as well as translated from other languages into English. Data analysis was conducted according to a content analysis technique of Tesch as discussed in Creswell (1994:15). This analysis used words and sentences as units of analysis. These words and sentences were organized into categories and sub-categories, which were refined and translated into research terminology so that they were consistent with research topic. The raw data of the same transcripts were given to the co-coder in order to do data analysis independently following the same protocol. When the co-coding was completed, a meeting was organized by the co-coder and the researcher in order to reach a consensus. A table of categories was then finalized.

TRUSTWORTHINESS

Trustworthiness is the concept adopted by Lincoln and Guba (*in* Krefting, 1991:24) to explain what the quantitative researchers refer to as the validity and reliability of the study. In this study such a model suitable for qualitative research was found relevant because it ensures the rigor without compromising the relevance of the study (De Vos, 1998:348). The model was integrated with that of Woods and Catanzano (1998:136). The criteria applicable to ensuring the trustworthiness of the study according to these authors are the credibility, transferability, dependability and confirmability. (See Table 1).

ETHICAL ASPECTS

Ethical permission was obtained from the School of Nursing Science as well as from the Faculty of Health Sciences Ethics Committees of the North-West University, Potchefstroom Campus. Permission to conduct research was also obtained from the North West Province Department of Health. A high standard of research was maintained by continued supervision by promoters, as well as by following the bibliographical style of reference of Harvard as prescribed by the North-West University's Guidelines for post-graduate studies (2005:22). DENOSA (1997) guidelines for research were also followed by not divulging the names of participants in all the research documents. Participants' rights to privacy, anonymity, confidentiality, fair treatment, as well as protection from discomfort and harm were observed throughout the study (Burns & Grove, 1997:200). Privacy was ensured by interviewing participants in their own homes and tapes were destroyed after transcribing. Anonymity and confidentiality were ensured by keeping the participants' names anonymous and confidential that is not divulging them to anybody. Fair treatment was ensured by explaining the objectives of the study, and the interview process to participants prior to obtaining their consent. They were also made aware that they could withdraw from the study at any time if they felt uncomfortable. Protection from harm and discomfort was ensured by giving the participants the freedom of not answering questions that they feel uncomfortable about. The principles of human dignity (Ubuntu) were observed in order to obtain co-operation from the participants and all other parties who were involved in this study.

DISCUSSION OF FINDINGS OF THE EXPERIENCES OF STIGMATISATION BY WOMEN WHOSE PARTNERS DIED OF AIDS

The findings of the women's experience of stigma resulted in the three major categories of the experiences of stigmatization that correspond with that of Greeff *et al.* (2006:In press) namely received, internal and associated stigma. However, in this study there were additional forms of stigma which could not be directly linked with stigma such as experiences of feelings of physical weakness and helplessness and experience of perceived deception (See Table 2 for the summary). Following is the discussion of the findings.

Experience of received stigma

Women whose partners died of AIDS expressed experiences of stigmatization in various forms, the first of which is received stigma. These were explained by women as experiences of gossip by community members, rejection by family and the community, avoidance by family and the community, blaming by family and the community, labeling by community, abuse by family and the community, neglect by family, fearing contagion by family and community and pestering by community.

Experience of gossip by community members

Experiences of gossiping confirmed what other studies found. Women whose partners died of AIDS mentioned that they realized that the community was gossiping about their situation because they often heard people telling them about the fact that they are sick despite not having disclosed their HIV status to anyone. Gossiping was also evident in that most women were accused of having infected or "killed" their late partners with HIV and AIDS, especially by their in-laws. These accusations were often without proof, therefore, the women suspected that there were rumors going around about them. Some of these rumors could be detected in the following quotes of women during interviewing.

"Where did you hang your husband's bed-linen because these people are said to be wetting themselves."
"I am no longer going to church, how can you continue going to people who gossip about you?"

Findings of gossiping supported what other authors reported that HIV and AIDS was feared and stigmatized, therefore, when someone is suspected of suffering from it there is usually gossip about the person (Nyblade *et al.*, 2003:30). Greeff *et al.* (2006:26) also found in their study that HIV/AIDS infected people expressed how families, friends, neighbours and co-workers gossip, speculate and spread rumours about their HIV/AIDS status. These rumours led to teasing, taunting, mocking and scolding by community members. The study by Petchy, Farnsworth and Williams (2000:244) reported that their participants who were attending an AIDS clinic were constantly concerned about the leakage of information about their condition. However, the experience of women being accused by their in-law's for having killed their partners is unique to this study.

Experience of rejection by family and community members

Most of the black people in South Africa especially the Batswana people of the province where this study was conducted subscribe to the culture that a married woman belongs to the husband's family after being married (Manyedi, 2003:83). However, the same study revealed that when the husband dies, the wife is usually suspected of having contributed to his death. The widows who lost their husbands to AIDS were also subjected to the same treatment of being rejected by the in-laws due to suspicions that they killed their husbands by bewitching them. This suspicion led to the women being evicted from their own homes or the in-laws' homes. This experience was described by women who participated in this study as the most painful, because they already identified with the in-laws as their immediate family. More painful still was that those women who were not married but co-habiting with their partners were denied the opportunity to pay their last respects to them, being denied the opportunity to attend their funeral. This could be realized through their expressions.

"After his death my in-laws instructed me to leave because I am the one who killed their son".

"I could not even attend his funeral because they were swearing that if they could see me there, I would follow him."

Those women staying with their own families also expressed their experience of rejection by their own families. A unique finding in this study was that of an incident where two women had to be interviewed at the researcher's home because they

expressed that their family members would not welcome their visitors because they were rejected themselves. Fife and Wright (2000:58) found what this study confirmed that women were not only rejected by their families but also by other community members. They noticed that community members had deliberately limited and reduced contact with them. The following quotes from women who were interviewed showed the rejection. This rejection was also found by Nyblade *et al.* (2003:29) in the countries where their study was conducted. However, they referred to it as differential treatment (Feitsma 2005:55).

"*My family never accepted me niks niks niks; they are the ones hurting my feelings and depressing me because they cannot accept me and they cannot support me*".

"*He found out from other members of the congregation and told me he did not want me in his church*".

Experience of avoidance by family and community

Similar to what other authors reported, women confirmed through their experiences of avoidance that people would deliberately not come into close contact with them. Behaviours such as people leaving the room when they join them, denying them participation in social activities or household chores as well as discontinuing to visit all amount to avoidance. Some such incidents were reported as follows.

"They still cannot eat with me, share the same bath and can't even speak with me".

"*I mean like it is not nice when people watch television and I come to join them they stand up one by one until I am left alone*".

The experience of avoidance confirmed what Nord (1997:61) found that some people with HIV/AIDS are shunned by their families, friends and neighbors. Nyblade *et al.* (2003:28) also discovered PLWA were socially excluded both by their families, some of who separated sleeping places immediately they learned that someone was HIV positive. The community also avoided the people when they met them at public places.

One of the ladies who looked after her aunt's house while she worked in Johannesburg, said that her aunt would not communicate nor send her any money. She only came home once a year during the festive season. She added that she had packed all the household appliances and utensils in boxes so that she may not use

them. This finding is, therefore, not unique to this study as Herek, Capitano and Widaman (2002:375) and Dias *et al.* (2006:212) found the same. They found that, like in this study, avoiding was due to misinformation about HIV and AIDS transmission.

Experience of blame by the family and community

Women interviewed for this study reported having been blamed for having infected their partners with HIV. It was observed that those who were rejected were also blamed for having contributed to the partner's death by infecting them. On the contrary, these women said that their partners were the ones who "*brought the disease in the home*", Most of them stayed home while the partner was working either at the mines or in Gauteng, coming home occasionally during holidays. The following statements were said during the interviews:

"*They say horrible things to me, that I contracted the disease purposely.*"

"*My brother said that I am going to die because I was sleeping around.*"

"Others tend to blame you and you opt to commit suicide, that is why you must be strong."

The findings regarding blaming confirmed the documentation on this subject that revealed that relatives neglected people with HIV and AIDS. Blaming was found to be due to the families and community attitudes that they brought the illness upon themselves through their immoral behaviour (Nord, 1998:60; Gaines, 2001:114; Nyblade *et al.*, 2003:30; Thomas 2006:3181; Yang *et al.*, 2006:722). In a different and unique incidence of blame one participant blamed a neighbor who was suffering from AIDS for having been promiscuous, while she was herself was blamed by her in-laws for having infected her partner.

Experience of labeling by the family and community

The community's behavior of labeling was found to be one of the common experiences that women whose partners died of AIDS experienced. It, therefore, confirmed other findings (Goffman 1963:11; Link & Phelan, 2002:3). This labeling was observed to be outstanding with the in-laws who referred to them as prostitutes and/or witches who killed their sons or brothers. Women mentioned that the most painful form of labeling

was when it was done by family members from whom the support was expected. This was evident as expressed in the following quotes:

"My brother said that I was a prostitute and I am going to die."

"Others say I was unfaithful and others say I was a whore; to me that is the difficult and most painful stigma."

Experience of abuse by family and community

Abuse of people living with or suspected to be living with HIV and AIDS was confirmed because women who participated in this study reported several incidences of verbal and physical abuse either by a family member or community members (Stansburg & Sierra, 2004:13; Yang *et al.*, 2006:722). The incidents ranged from those by family members, friends as well as by public workers such as the police officers. The following quotes by participants indicated the abuse:

"They insulted me and his sisters went out, leaving behind their mother and father, and one of his brothers said 'how do you talk to my parents, jou moeskont."

Another woman said that her brother remarked

"*You have climbed the graveyard fence and peeping into the grave.*"

Regarding physical abuse, some women mentioned incidents as follows:

"... I met these girlfriends of his and one of them poured soghum beer all over my face."

and

"*She pushed me and I fell down as I was sick and weak, I fell onto a sharp trunk of a tree.*"

Experience of neglect by family members

These women's experience of neglect was reported in the form of family members and relatives deliberately staying away from them, being denied basic needs such as food, love and sense of belonging. Most women expressed that their relatives and friends

stopped caring once they realized that their physical state was deteriorating. This attitude of neglect can be read in the following quotes:

"*My mother and my sisters would never give me food or assist me to wash or wash my children when I am sick and weak.*"

"*My aunt works in Gauteng but she would never send me anything to buy food or buy my child anything yet I am looking after her house.*"

Neglect was supported by the literature as indeed one of the behaviors displayed by those supposed to care for PLWA (Greeff *et al.*, 2006; Thomas, 2006:3181). In her study, Thomas (2006:3181) had confessions of her participants expressing how their relatives failed to care for them in their long illness, one of who stated that he was caring for his sick mother with AIDS, when he was told he was just wasting his time. This is an indication of how neglect is carried out by relatives either because they fear the disease or deliberately punish the person due to the perception that she was promiscuous. In a similar study on patients with Obsessive Compulsive Disorder, it was found that their family members neglected them because their signs seemed strange (Stengler-Wenzke *et al.*, 2004:91).

Experience of fearing contagion by the family and community

The fear of contagion is a behavior and attitude that exposed ignorance and lack of understanding of the spread of HIV by perpetrators of stigma. In Nyblade *et al.* (2003:26) it was found in one of the countries where their study was conducted that women with HIV or AIDS were no longer allowed to participate in daily household chores, particularly food preparation. Stansburg and Sierra (2004:13) also reported this. The experience included exclusion from participating in household chores such as cooking and washing of eating utensils, as well as in touching the person or her belongings. *Sowell et al.* (1997:310) also discovered that these behaviors increased as physical symptoms increased so this experience was not unique to this study. Some impressions of this behavior could be read in these statements:

"*... she thinks that as I am HIV positive when I use a utensil this AIDS ends up sticking to that utensil, because she would scour it with Handy Andy and rub it so hard that one would notice that she is washing it seriously.*"

"If I want to cook another person would volunteer to do it, yet all along they did not do it, now they can; still now I don't cook."

Experience of pestering by the community

Pestering was reported as an experience that involved repeated negative remarks made by perpetrators of stigma such that the person felt hurt and provoked. Some participants explained it as nagging where they were repeatedly asked questions that were devaluing and demeaning as stated below. Although Greeff *et al.* (2006:In press) found it as one of the dimensions, it was not found in most literature. This study supported the findings of Greeff *et al.* (2006In press). The quotes that expressed pestering were as follows:

"*What is really happening to you? No you are lying, you must be having AIDS.*"

"*Sometimes they say things that would not be said to a sound and normal person, which means they treat us like small children or people without emotions.*"

One participant summarized it as "*It is drunkards who say these things*". The woman who sounded annoyed by pestering remarked: *"Me, when they ask me are you sick I tell them 'yes I am HIV positive and I am proud."*

The second form of stigmatization experienced by these women is that of internal stigma, the discussion of which follows.

Experience of internal stigma

Internal stigmatization, according to data analysis of this study was obvious from experiences of self perception, social withdrawal, self exclusion, deterioration in physical strength, fear of disclosure as well as feelings of deception and ignorance.

Experience of self perception

This study confirmed what other authors found that PLWA experience self perception which implies negative thoughts haunting an individual about being HIV positive or having AIDS (Tirnmons & Fesko, 2004:141). Due to the fact that most of the women who participated in this study were HIV positive themselves, they expressed perceiving themselves in a negative way because of feeling uneasy about their HIV status, blaming themselves and feeling guilty, as also stated by other authors (Sowell *et al.*,

1997:310; Yarhouse & Anderson, 2002:338; Yang *et al.*, 2006:718). Women diagnosed with HIV are said to react with shock especially if they know that they were faithful to their partners (Mayers, Naples, & Nilsen, 2005:100). Even those who did not go for voluntary counseling and testing (VCT) after the diagnosing or death of their partners, found that they possessed the same feelings of viewing themselves negatively as evident in the following quotes:

"I thought I was not alright even when I knew I was."

"If I was alone I would be afraid, I would even be scared of going out, what would people think."

The study was in this respect found to be similar to the above cited studies, hence not a unique experience by these women.

Experience of fear of disclosure

Experiencing fear of disclosure was found to be similar to most studies conducted, therefore, it is not considered a unique finding (Sewpaul & Mahlalela, 1998:37; Brown *et al.*, 2003:51; Timmons & Fesko, 2004:137; Yang *et al.*, 2006:722; Ware *et al.*, 2006:907; Yarhouse & Anderson, 2002:337; Greeff, Phetlhu, Makoae, Dlamini, Holzemer, Naidoo, Kohi, Uys and Chirwa, 2007:In press). According to these authors, fear of disclosure was greatly influenced by fear of stigmatization, therefore, almost all participants in this study indicated feeling comfortable if their HIV and AIDS status was unknown, as directly quoted:

"It is hard, starting with the parents, what am I going to say?"

"I never said anything to them that I am sick; there is no one I even thought of disclosing to."

This fear of disclosure affected women in this study in the sense that they had to hide when they attended the HIV and AIDS clinic. Some attended a clinic that was far from where they stay in order not to be seen. Those who disclosed indicated that it was for the reason either of preventing gossip or for the family members to support them. However, those who hoped to prevent gossip indicated that they only aggravated the situation as those to whom they confided in continued to spread news about their status to their other friends and neighbours. The studies of Weiss and Ramakrishna

(2001:5), Brown *et al.* (2003:51) and Ware, Wyatt and Tugenberg (2006:907) stated that disclosure of being HIV positive constituted a threat to rejection, hence the fear to disclose.

Experience of social withdrawal

The findings of this study confirmed that women who participated in this study avoided any close or sexual relationships for fear of being noticed or their HIV positive status being discovered, thus resulting in rejection or discrimination. Loss of a sense of worth could also be attributed to this behaviour. The following were direct quotes that were linked to social withdrawal:

"Since he died I never thought of having a relationship; not even when they promise to use condoms."

"I am satisfied only when I am with my daughter."

The quotes were an indication that even if a greater percentage of these women mentioned having accepted their HIV status, they still did not feel comfortable in integrating into society. The behaviour was thus described as withdrawal, as also found by other authors (Nyblade *et al.*, 2003:34; Greeff *et al.*, 2007:In press).

Pre-occupation with death

Participants of this study mentioned that they were pre-occupied with thoughts of dying and that these thoughts generated fear. This was experienced as a disturbing factor because it interfered with their plans for the future as well as their positive view of life. This fear was also linked to the uncertainty about who will take care or their children after their death because most of their children were still younger than fifteen years. Their fear could also be linked to the anxiety detected in some of their statements such as:

"One must prepare oneself for the last days because you don't know where God will place you."

"... the truth is that there are times when I develop diarrhea, my problem is that at this time I develop fear then I would think that possibly my time has arrived."

This experience seems common to other studies as documented in Nyblade *et al.* (2003:34). Mayers *et al.* (2005:99), however, differed in that women in their study reported feelings of hopelessness and despondency, as well abandoning plans for the future.

Experience of self exclusion

Self exclusion was implied by women isolating themselves from attending social activities, using public facilities or services due to fear of discrimination. This becomes worse when the individual shows some signs that the community regard as obvious signs of AIDS such as loss of weight, sores, general physical wasting and weakness. The following quotes indicate such self exclusion:

"Just because I am HIV positive I just have to stay home, and just work at home."

"I no longer go to church, I read my own Bible and pray at home."

The literature confirmed regarding self exclusion as Goffman (1963:25) wrote that when stigmatized people are in a social setting, they often crouch in defense, demonstrate feelings of inferiority and avoid meeting people which is consistent with what participants reported. This view was also shared by Weiss and Ramakrishna (2001:5).

Experiences of internal stigma indicated that women had feelings of self stigmatization evidenced by their difficulty in coming into contact with other people. Stigma against those closely associated with the stigmatized is referred to as associated stigma.

Experience of associated stigma

In this study incidents of associated stigma were mentioned during interviews. This was similar to other studies such in Greeff *et al.* (2006:In press). A few incidents suggestive of associated stigma were reported by women as follows:

"My elder son was attending school but he has started refusing to attend."

"They cannot wash nappies and wash my baby when I am sick; she stays like that until I get better."

Stigmatization of the children

In the findings of this study an exceptional case reported was where the woman's children were deliberately neglected by her own mother and sisters when she felt very sick and helpless. A similar incident was reported by Thomas (2006:3183). Other incidents were those of women who were dismissed from their houses after the death of their partners and where the in-laws did not care about the welfare of the children despite being aware that the late partner was a sole breadwinner.

Experience of associated stigma by the women's family members

This study also yielded isolated incidents of associated stigma against family members of women who participated as in the case of the following quote.

"They live under shame because of me, so I told her 'mama, I am going to leave and I will seek a place to stay even if I am not working; I am not doing anything but I will get a place even if they can ask me to pay R100 I will accept it, so that I can move away from you, so that people can no longer discriminate against you because of me."

Other categories not directly linked with stigma

Experience of feelings of physical weakness and helplessness

Most of participants were sick to an extent that it was an effort to complete the interview. They were concerned about their lack of strength and the fact that their physical condition was deteriorating. This was coupled with the concern about loss of appearance and loss of body weight. They perceived these physical signs to be contributing to their being stigmatized. The following quotes confirm these concerns:

"*Yes, I had suspicions because already I was experiencing changes in my body; I was not feeling well for example I had problems with my back."*

"It was so bad my sister; my body was full of sores, I was in pain; there were cracks like this, when I was sleeping I was supposed to line the linen with something underneath, it was bleeding these lips.

These findings confirmed the literature that the physical health of HIV and AIDS people sometimes deteriorates to an extent that treatment becomes important in their lives (Timmons & Fesko, 2004:140; Thomas, 2006:3182). The latter author's patients kept

diaries in which they often mentioned having suffered from a number of physical ailments that required them to consult a doctor or even be admitted to hospital. Some of these physical ailments were those that led to their decision to go for testing. Nord (1997:60) and Mayers *et al.* (2005:104) also affirmed that the AIDS stigma is perpetuated by its progressive nature that causes severe suffering.

Experience of deception

Most literature on HIV and AIDS stated that women often complained about men being the cause of transmission of the virus because they were unfaithful in marriage or love relationships (Takahashi, 1997:196; Serlemitsos, 2003:2; Stansburg & Sierra, 2004:11; Mayers, 2005:99). Women started to realize that they were cheated on by their late partners after being diagnosed HIV positive. What aggravated these feelings was that those partners could neither disclose to them nor protect them if they found it difficult to disclose, as quoted directly from transcripts. These findings supported what was reported by Serlemitsos (2003:3):

"I heard from his sister that he had AIDS; that is when she was accusing me for having infected him."

"I suspected he was going out, but I was sick; even when I was really sick he was going out, 1999, 2000, 2001, 2002, 2003."

All participants in this study were unemployed, except three who were doing unstable piece jobs. Their partners were sole breadwinners and it was thus difficult for them to negotiate safe sex, therefore, they ended up being infected. This experience is, therefore, not unique to this study, because it was confirmed by literature that poverty continues to be a challenge for PLHA (Mayers *et al.*, 2005:105).

Having discussed the findings of the experiences of stigmatization, guidelines for women to cope with the stigma follow.

Guidelines for women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected person who died of AIDS

The following are suggested guidelines for women to cope with the stigma as discussed.

- It would be meaningful if these women were counseled in order to facilitate mechanisms that would assist them to live positively with the disease, thus being able to cope with negative remarks or behaviors aimed at stigmatizing them. The psychiatric nurses should, during pre- and post- test counseling ensure that these women understand the meaning and the implications of an HIV positive status.
- They should be taught assertive skills by simulation and role playing when they meet as support groups to assist them to react in a mature manner. Their assertive attitude could nullify any stigmatizing behaviors and would make the perpetrators of stigma feel discouraged.
- It would benefit them if counselors teach them about disclosure during counseling to enable them to make informed choices with regard to whether they need to disclose or not, how they should disclose, as well as the reasons thereof.
- It would be useful if psychiatric nurses during home visits, educate the women's families about the importance of supporting them so that they can meaningfully deal with the experiences of being stigmatized.
- It would be meaningful for psychiatric nurses to provide them with facts about HIV and AIDS so that they understand and are knowledgeable, thus dispelling some of the myths that could be contributing to internal stigmatization. Handouts could be given whenever they visit the clinics.
- It would benefit women if they were encouraged to integrate and participate in the community social activities so that the community can get used to interacting with them, and talking about HIV and AIDS frequently would free the infected from feeling guilty and blaming themselves.
- It would be an advantage for those who are spiritual to engage their pastors in order to be prayed for and to perform their spiritual rituals. Other support

systems in the church could also be used to facilitate the process of spiritual healing.

- With regard to the children, it could be advisable to be educated about HIV and AIDS so that they understand and could ask questions to clarify facts and issues around the disease. Women should discuss this with their children to empower them to respond when they are confronted with associated stigma.
- It could be meaningful to formulate a programme that will aim at assisting women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected partner who died of AIDS.

CONCLUSION

Experiences of stigmatization by women whose partners died of AIDS indicated that these women experience severe stigmatization which manifested in various forms as demonstrated by the perpetrators. The stigma was manifested as that from perpetrators, self stigmatization, associated stigma as well as other forms of experiences that were not linked to the forms of stigma identified. The women's experience of received stigma led to difficulty in accepting their status as well as making decisions to disclose their partner's cause of death, as well as their own HIV status. Their deterioration in physical condition contributed to their own internal stigma, as well as difficulty in caring for their dependent children due to loss of a breadwinner. The associated stigma against their family members made it difficult for their families to support them, therefore, they were neglected and abused by them, making it difficult for them to cope with the illness.

TABLE 1: STRATEGIES TO ENSURE TRUSTWORTHINESS

STRATEGY	CRITERIA	APPLICATION
Credibility	Prolonged field experience	Letters to request participation delivered by researcher and spending time with women whose partners died of AIDS to establish a trusting relationship. Confirmation of appointments also done personally by researcher to strengthen the relationship. Participants allowed enough time to verbalise their experiences and beliefs respectively.
	Reflexibility	Field notes were written immediately and subjected to analysis.
	Member checking	Literature control of experiences of coping with stigma was undertaken.
	Interview technique	Researcher trained in research methods and interviewing skills. Research supervised by experts experienced in qualitative research.
Transferability	Selection of sample	The sampling method was purposive voluntary.
	Dense description	Through description of research methodology and literature control of the findings.
Dependability	Stepwise replication	Co-coder involved in independent data analysis.
	Dense description	Detailed description of methodology.
	Code-recode procedure	Data analysed twice and results compared. Consensus discussion held with co-coder.
	Peer Examination	Expert supervision provided.
Confirmability	Confirmability audit	Done by supervisors of the research.
	Reflexibility	Field notes taken and subjected to data analysis.

TABLE 2: EXPERIENCES OF STIGMATIZATION BY WOMEN WHOSE PARTNERS DIED OF AIDS

COLUMN A	COLUMN B	COLUMN C	COLUMN D
EXPERIENCE OF RECEIVED STIGMA	EXPERIENCE OF INTERNAL STIGMA	EXPERIENCE OF ASSOCIATED STIGMA	OTHER CATEGORIES NOT DIRECTLY LINKED WITH STIGMA
Experience of gossip by community members	Experience of self perception	Stigmatization of children	Experience of feelings of physical weakness and helplessness
Experience of rejection by family members	Experience of fearing disclosure	Experience of associated stigma by the women's family members	Experience of deception
Experience of rejection by community members	Experience social withdrawal		
Experience of avoidance by family and community	Pre-occupation with death		
Experience of blame by family	Experience of self exclusion		
Experience of labeling by family and community	Experience of feelings of physical weakness and helplessness		
Experience of abuse by family and community	Experience of feelings of deception		
Experience of neglect by family			
Experience of fearing of contagion by family and community			
Experience of pestering by community			

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ARTICLE 4: COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS

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COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS

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ABSTRACT

Coping with widowhood within the Batswana context is a difficult process due to the cultural process that involves several practices that have to be observed. Aggravating the process is the loss of a partner to AIDS as well as their own HIV positive status of a stigmatized disease. The focus is on coping with stigma by women whose partners died of AIDS. A qualitative phenomenological design was followed in order to explore and describe coping with stigma by women whose partners died of AIDS in the North West Province. The sampling was purposive and the size was determined by data saturation. Data were collected by means of a single open-ended question. Data analysis was done by means of the technique of content analysis by Tesch. From the findings the following conclusions could be drawn: Women whose partners died of AIDS cope by focusing on the problem which includes positive and negative strategies such as undergoing voluntary counseling and testing, disclosure of their HIV status, seeking social support, adopting a healthy lifestyle, keeping their HIV status secret, expression of grief and hurt as well as threatening lawsuits against perpetrators of stigma. Regarding coping by focusing on emotions, strategies that arose from data analysis included coping by self acceptance, acceptance by family members, emotional, social and material support from families, friends, neighbors and social welfare; seeking comfort on spirituality, de-individualization of the disease, ignoring negative remarks and attitudes and forgiving, blaming their late partner or other people for their HIV status, anger directed at perpetrators of stigma, as well as coping by using defense mechanisms. Guidelines formulated as a result were aimed at assisting these women to cope effectively with the stigma associated with their having had a relationship with an infected person who died of AIDS.

Core terms: Coping, stigma, stigmatization, partner, AIDS

INTRODUCTION AND PROBLEM STATEMENT

The previous study conducted by the researcher as part of a Master's degree program: "Experiences of widowhood and beliefs about the mourning process of the Batswana people", yielded findings that indicated that women were stigmatized, discriminated against and shunned by society due to widowhood and the mourning process (Manyedi 2003:78). The widows' experience of being shunned by society was found to be due to cultural beliefs that made coping with widowhood a painful and difficult process for the widow (Bankoff, 1983:836; Parkes in Kalish, 1985:207; Manyedi, 2003:78). The stigmatization experienced by the widows in Manyedi's (2003:78) study can be compared to the stigmatization of HIV and AIDS. The severity of stigmatization intensifies when considering women, who lost their partners to AIDS. A known fact supported by the literature (Herek & Capitano, 1993:575; Heckman, Somlai, Peters, Walker, Otto-Salaj, Galdabini & Kelly, 1998:369; Sewpaul & Mahlalela, 1998:36; Owen, 2002:76, Nyblade, Pande, Mathur, Mac Quarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbuwambo, & Bond, 2003:23), shows that HIV and AIDS are highly stigmatized. This research focused on coping with stigma by a woman who lost her partner to AIDS, as the closest person who had a relationship with the infected person.

Coping according to Kleinke (1998:2), is associated with the effort that one makes to manage situations one appraises as being stressful and potentially harmful. Coping with the loss of a partner is a difficult process in itself and in the context of this study, the process is aggravated by the fact that the partner died of AIDS. Lindemann (*in* Cleiren, 1993:14) describes coping as recovering and returning to the state that prevailed before the partner's death. According to Nyblade *et al.* (2003:36), some women attempt to cope by denying their late partner's AIDS status or avoiding disclosure especially if they anticipate to be stigmatized. Alternatively, some cope by directly challenging or confronting stigmatizing attitudes or behaviors, while others seek explanations other than sexual transmission. Some women apparently cope by joining support groups, by volunteering to care for or seeking jobs within the circles of HIV and AIDS, while others turn to religion and prayer for comfort, solace and support (Nyblade *et al.*, 2003:36). Some women experiencing the stigma seek care and support from their families or health care providers (Nyblade *et al.*, 2003:40). Although the stigma against people living with

HIV and AIDS has been broadly studied, one rarely comes across stigma against women who lost their partners to AIDS, hence the researcher's interest in this study. Coping with the experience of stigmatization poses a challenge for psychiatric nurses with regard to how best these women can be assisted. Women need caring and compassionate psychiatric nurses who can assist them to deal with the internal stigma which develops due to the received stigma, leading to their experience of negative self concept as well as negative self identity (Fife & Wright, 2000:51).

From the problem discussed above, these women find themselves having to cope with, among other things, their widowhood which is a stigmatized status by itself, which is compounded by the fact that the partner died of AIDS. The stigma of HIV and AIDS as well as their own HIV status aggravate the already difficult widowhood process. The focus of this study was, therefore, on coping with stigma as a difficult process for the women whose partners died of AIDS. The stigma attached to HIV and AIDS is associated with its incurable nature, the high death rate, as well as from the uncertainty about its mode of transmission. From the problem statement as described above, the following research questions were formulated:

- How do women whose partners died of AIDS cope with the stigma associated with their having had a partner who was infected and died of AIDS?
- What can be done to assist them to cope effectively with this stigma?

OBJECTIVES OF RESEARCH

From the above-mentioned questions the following objectives were formulated for this research.

- To explore and describe how women whose partners died of AIDS cope with the stigma associated with their having had an infected partner who died of AIDS.
- To provide guidelines for women to cope with the stigma associated with their having had an infected partner who died of AIDS.

CONCEPTUAL DEFINITIONS

The following are definitions of concepts used in this study that were derived from the literature. These concepts described in the context of this study are AIDS, coping, stigma, stigmatization, and partner. **AIDS** is an abbreviation of Acquired Immune Deficiency Syndrome. **Coping** is an effort that an individual makes in order to manage situations that she appraises as potentially harmful or stressful (Lazarus & Folkman in Kleinke, 1991:3). These efforts may also be cognitive, behavioral or psychosocial strategies that an individual uses to alleviate distress. **Stigma** in this study refers to an attachment of negative attributes which are discrediting and reduces an individual from his/her usual whole to one with a tainted image (Goffman, 1963:3). **Stigmatisation** is a process of attaching brands of disgrace to an individual based on the perspective of the one who judges the other (South African Pocket Oxford Dictionary, 1994:953). In the context of this study, **partner** is defined according to the South African Pocket Oxford dictionary (1994:695) which is either member of a married or unmarried couple. Partners are people who are closely related to an extent that they are associated with each other.

LITERATURE STUDY TO CONTEXTUALIZE COPING

Aldwin (2000:71) refers to coping as an old concept that has been evolving with time. He motivates this statement by stating that in the fifties, the American dictionary referred to it as "proving oneself as a match for", whereas modern dictionaries define coping as efforts to resolve environment pressures that could not be handled by usual reflects or organized skills (Aldwin, 2000:96). This definition is by no means different from others. Coping, according to Kleinke (1998:2) is associated with the efforts that one makes to manage situations one appraises as being stressful and potentially harmful. One can view it as a suggestive process because it does not predict the outcome of coping. Other definitions such as Parry's (1990:119) are persuasive, because they conclude that coping involves all the ways which the individual engages in order to master or to minimize the stress that results when events challenge their routine predictions about the world (Parry, 1990:119). This definition seems to be more engaging as it challenges the individual to master the ways of dealing with stress. This means that one has to engage different strategies and master the one that would make one cope successfully. This definition also highlights that once an individual experiences stress, their routine

predictions about the world are challenged, therefore, they have to attempt to cope. In most of the literature on coping, defense mechanisms feature now and then because in coping they are usually used without the person being fully aware of using them (Lazarus, 1976:85; Aldwin, 2000:96; Carr, 2004:230; Kleinke, 2004:105; Kenny *et al.*, 2000:94 & Parry, 1990:49).

Coping from the sociological perspective is support-focused. Both Myers (2000:320) as well as Taylor and Field (1997:182) view coping as a factor dependent upon social support systems, though the former emphasizes the social support (beloved ones) available at the time when coping is necessary. The latter, view faith and religion as the important coping mechanisms over and above the people that are closely attached to an individual experiencing a difficult situation (Taylor & Field, 1997:137). This definition supports that of Bailey and Clarke (1989:35) because attempting to cope would aim at achieving an outcome that will enable one to either reduce, master or live with the stressor. Sikkema *et al.* (2000:622) have demonstrated in their study that people with HIV and AIDS who employed active coping strategies tend to improve their quality of life; that is, they may be considered as having mastered the stressor.

Coping with HIV and AIDS stigma, whether one is infected or affected also depends on the individual's self efficacy in dealing with the problem, therefore, Cassidy (1999:7) viewed it as the person's cognitive and behavioral efforts to manage, minimize, master or tolerate his/her internal and external demands. One may appreciate the broadness or openness of this definition in implying that when one faces a stressful situation, one attempts to cope in order to prevent or minimize the impact, to master or if nothing comes from of those efforts, to tolerate the stressor. Coping with HIV and AIDS stigma, whether one is infected or affected also depends on the individual's self efficacy in dealing with the problem, therefore, Cassidy (1999:7) viewed it as the person's cognitive and behavioral efforts to manage, minimize, master, or tolerate his/her internal and external demands.

Coping strategies can be categorized into problem-focused and emotion-focused strategies. Problem focused coping strategies are those that the individual employs with the aim of modifying the source of stress by doing something about it (Carr, 2004:215; Mickelson *et al.*, 2001:184; Coetzee & Spangenberg, 2003:210); whereas emotion-

focused coping strategies refer to cognitive problem solving and behavioral efforts which serve to reduce negative emotions resulting from the existence of the problem (Coetzee & Spangenberg, 2003:208). Both have effective strategies that are functional as well as non effective strategies that are dysfunctional.

RESEARCH METHODOLOGY

Research Design

A qualitative, phenomenological research design was followed, the aim of which was to explore and describe how women whose partners died of AIDS cope with the stigma associated with their having had an infected partner who died of AIDS (Creswell, 1998:15). In-depth interviews with participants enabled the researcher to explore and describe the phenomenon of coping. The women's experiences assisted the researcher to understand how they cope and then provided guidelines to assist such women to cope effectively with the stigma associated with their having had a partner who was infected and died of AIDS.

Research Method

The population from which the sample was drawn consisted of women in the five regions of the North West Province of South Africa whose partners died of AIDS within a year of their loss. A purposeful voluntary sampling technique was used (Burns & Grove, 1997:306; Streubert & Carpenter, 1999:22). Letters were written to the Directorate of Research in the North-West Department of Health to obtain permission to conduct the research. After permission was granted letters were written to the mediators who were coordinators of HIV and AIDS in the regions. The purpose of this research as well as their participation and inclusion criteria, were explained. The potential participants were purposively selected due to having lost their partners to AIDS. In some instances home-based care volunteers provided this information and identified potential participants. The sample size was determined by data saturation (Burns & Grove, 1997:308), which was reached with the twelfth interview. The researcher conducted a further eight interviews, thus a total of twenty interviews, to ensure that nothing new was forthcoming. Participants were selected according to the following criteria: The women must have lost their partners to AIDS within a year, be resident in any of the five regions of the North

West Province of South Africa, be able to communicate in Setswana, Sesotho, Sepedi or English, be open and willing to share their experience in an interview, as well as willing to give consent to be recorded on an audio-tape.

DATA COLLECTION

Letters requesting potential participants to participate in this study explaining the nature of research as well as stating the objectives thereof were written. Participants had to consent to voluntary participation as well as to recording of interviews. Data collection was undertaken by means of a single open-ended question (Brink & Wood, 1998:322-323), **"How do you cope with stigma after your partner died of AIDS".** This question was given to experts to evaluate its applicability. The pilot study was conducted initially with one of the participants who met the inclusion criteria. The interview was tape recorded. Demographic, descriptive, and reflective field notes were written immediately after each interview to avoid forgetting significant observations as well as to ensure accurate recording (Morse, 1989:116; Creswell, 1998:130-131).

DATA ANALYSIS

The interviews recorded on audio-tapes were transcribed verbatim as well as translated from other languages to English. Data analysis was conducted according to the content analysis technique of Tesch as discussed in Creswell (1994:15). This analysis used words and sentences as units of analysis. These words and sentences organized into categories and sub-categories were refined and translated into research terminology in order to be consistent with the research topic. The raw data of the same transcripts were given to the co-coder in order to do data analysis independently, following the same protocol. When the co-coding was completed, a meeting was organized by the co-coder and the researcher in order to reach a consensus. A table of categories was then finalized.

TRUSTWORTHINESS

Trustworthiness is the concept adopted by Lincoln and Guba (*in* Kefting, 1991:24) to explain what the quantitative researchers refer to as the validity and reliability of the study. In this study such a model suitable for qualitative research was found relevant

because it ensures the rigor without compromising the relevance of the study (De Vos 1998:348). The model was integrated with Woods and Catanzano's model (1998:136). The criteria applicable to ensuring the trustworthiness of the study according to these authors is the credibility, transferability, dependability and confirmability (See Table 1).

ETHICAL ASPECTS

Ethical permission was obtained from the School of Nursing Science as well as the Faculty of Health Sciences Ethics Committee of the North-West University, Potchefstroom Campus. Permission to conduct this research was given by the Department of Health, North West Province. A high standard of research was maintained by continued supervision by promoters, as well as by following the bibliographical style of reference of Harvard as prescribed by the North-West University's Guidelines for post-graduate studies (2005:29). DENOSA (1998) guidelines for research were also followed by not divulging the names of participants in all the research documents. Participants' rights to privacy, anonymity, confidentiality, fair treatment as well as protection from discomfort and harm were observed throughout the study (Burns & Grove, 1997:200). Privacy was ensured by interviewing participants at their own homes and tapes were destroyed after transcribing. Anonymity and confidentiality were ensured by keeping the participants' names anonymous and confidential that is, not divulging them to anybody. Fair treatment was ensured by explaining the objectives of the study and the interview process to participants prior to obtaining their consent. They were also made aware that they could withdraw from the study at any time if they felt uncomfortable. Protection from harm and discomfort was ensured by giving the participants the freedom to not answer questions that they feel uncomfortable about. The principles of human dignity (Ubuntu) were observed in order to obtain co-operation from the participants and all other parties who were involved in this study.

DISCUSSION OF FINDINGS OF HOW WOMEN COPE WITH STIGMA ASSOCIATED WITH HAVING HAD AN INFECTED PARTNER WHO DIED OF AIDS

Data analysis of this study was, for descriptive purposes, categorized into three major categories namely, coping by focusing on the problem (both positive and negative),

coping by focusing on the emotions (positive and negative), as well as coping by using defense mechanisms. However, the fact that these women experienced multiple losses such as loss of intimate relationship, loss of the family provider (breadwinner), loss of future prospects, self control and material possessions, could have traumatized them to an extent that it was difficult for them to verbalize the intensity of their pain, hence they just mentioned "I accepted" as a ready answer to the research question, despite that they would raise issues later. These findings are discussed in detail (See Table 2).

COPING BY FOCUSING ON THE PROBLEM

Women whose partners died of AIDS found coping with stigma to be a difficult process, therefore the mechanisms that they used to cope were both positive and negative. Following is a discussion on positive strategies of coping by focusing on the problem.

Positive strategies of coping by focusing on the problem

These are discussed as follows:

Undergoing voluntary counseling and testing

Women did suspect at some stage during their partner's illness that they could be infected with HIV due to the deterioration in physical health, gross loss of weight as well as their secretiveness. The secretiveness was evident in non-disclosure, refusal to be accompanied to get treatment from health centres by their partners, as well as non-compliance with treatment. Following continuous HIV and AIDS awareness talks in the media, women expressed that they opted to go for voluntary counseling and testing. About three of these women went for voluntary counseling and testing after their partners had disclosed to them. Some of them became aware after their partners' family members informed them indirectly by blaming them for having infected their sons (partners). The results led to their becoming aware of their status and thus deal with the reality of their situation. The following quotes confirm this discussion:

"The time I was told about the results I was just calm, because I am the one who wanted testing. So I did not have fear because it is our disease, and I went to test because I wanted to know my status about this disease as I heard that it is contagious.

"I learnt from myself when I started having STD's and decided to go for testing; when the results came I tested positive ...."

The above quotes indicated that these women were suspicious that their partners could have been secretive, hence they felt a need to go for testing. Typically it was found in this study that most partners kept their status secret and left it to their partners to find out through testing, which confirmed the findings of Siegel and Schrimshaw (2003:198). After realization of their HIV positive status, coping became inevitable, therefore, Ebersöhn and Eloff (2002:80) considered coping as a reaction to the question: what do I do?, in answering or reacting to this cognitive regulation, as well as her/his normative regulation. According to these eco-systemic authors an individual's cognitive appraisal gives meaning to the tension (problem) based on beliefs and values and these guide her/his decision making.

Disclosure of their HIV-status for family support

From the pre and post-test counseling that the women received some of them decided that disclosure was the most appropriate coping strategy for them. Women stated that they did it in order to get support from their family members, though a few women said they did it to prevent gossip. The following were some of the quotes that justified their reasons for disclosure:

'I tell them, even that sister told me that I must not keep it a secret; yes, I confess it to them so that when one attempts to gossip, they already hear my story."

"I did not just tell anybody, I just told my sisters whom I know that I can share my problems with."

Although disclosing their HIV positive status was difficult for the women in this study it was confirmed that most of them gained the courage and motivation to disclose once they were counseled and received more information as mentioned by Greeff, Phetlhu, Makoae, Dlamini, Holzemer, Naidoo, Kohi, Uys and Chirwa (2007:In press). This similarity also confirmed what Sowell *et al.* (1997:310) found, because a greater percentage of these women were able to ultimately disclose their HIV status to their families, relatives and friends who offered effective coping. It was also identified that

there were different reasons for disclosure or non-disclosure, the majority of whom did it in order to solicit some material as well as emotional support as it was also found by other studies (Chandra, Deepthivarma & Manjula, 2003:212; Greeff *et al.*, 2007:In press). Women in this study were able to get both emotional and material support (Sowell *et al*, 1999:310). However, there were still participants who could not disclose mainly due to stigmatization, which confirmed a similarity mentioned by these authors in their studies (Chandra *et al.*, 2003:212; Timmons & Fesko, 2004:141; Yang, Li, Stanton, Fang, Lin, & Naar-King, 2006:722).

Seeking social support

Effective coping often requires that an individual seeks assistance from others, especially if the resources to assist in coping are inadequate. The support that was sought by women in this study included joining support groups for emotional and moral support and turning to religion to seek spiritual support.

Joining support groups for emotional and moral support

This study also found that some women who participated considered joining support groups for PLWA because they identified them as resources that were readily available for support, as found by Timmons and Fesko (2004:142). According to them it is through these groups that they were able to share common problems so that they could seek solutions to the problems related to the disease, and that coping by focusing on the problem was a functional strategy that lifted their quality of life (Sewpaul & Mahlalela, 1998:37; Shernoff, 1999:82). Through these groups they were able to access some of the facilities and services available for people with PLWA. The form of support that they received from their support groups was evident in the following quotes:

"By so doing I was trying to make her aware that she can also join the support group in order to improve the quality of life."

The woman whose mother refused to sign for her issue of ARV's remarked:

"My support group will sign for me; my mother, I have taken her out of my life, I am away from her, my life is in the hands of my support group."

"I mean I am always happy when I am with them; like I am able to send them a call back if I do not have airtime."

The social support reported by these women confirmed what authors such as Howard (1996:82), Shernoff (1998:82), Feitsma, 2000:60), Kenny *et al.* (2000:94) and Coetzee and Spangenberg (2003:210) found in their studies that, people living with HIV or AIDS seek support in order to have a sense of belonging as well as sharing their feelings, experiences and how to deal with the positive sero-status.

Turning to religion to seek spiritual support

Women who were interviewed demonstrated their strong Christian faith by turning to religion when they realised that their power and strength to deal with their problems was compromised. They seemed to strengthen their relationship with God, especially because they were confronted with a life threatening situation which led to their deepened spirituality. Theron (2002:13) and Shernoff (1999:82) also discovered this to be true with people with strong Christian beliefs. Some women mentioned that they joined church organizations not only for emotional support but also for spiritual fulfillment as well as to bargain for longer life as evident in the following quotes.

"I come from the family where all of us belong to Christian organizations; when I got married my husband and I decided to join and worshipped at the LM Church; I felt at home because in my family we belong to associations and sodalities was the way of life and it brings me joy to meet with other women."

"Yes you have to pray, then God will hear you; I ask Him to increase my days of life."

These experiences are not unique to this study because other studies also found that religion has an influence on how people living with HIV amd AIDS (PLWA) cope with stigma attached to this disease (Takahashi, 1997:193; Theron, 2002:13).

Adopting a healthy lifestyle

A healthy lifestyle does in many instances offer better coping with many physical conditions (Carr, 2004:217). This study was no exception because most women who participated thought it wise to live a healthy lifestyle. Sub-categories under this category

were, complying with Anti-retroviral Therapy (ARV) treatment regimen, eating healthily in order to boost the immune system, engaging in physical exercises and practicing healthy sexual practices.

Complying with ARV treatment regimen

It has always been in the belief of the general public in South Africa, especially the Treatment Action Campaign (TAC), that the rolling out of ARV's would assist in controlling HIV and AIDS. This control would eliminate the stigma because PLWA are stigmatized due to their deteriorating health and ultimate death which is threatening to society. Those women who had already developed signs of AIDS mentioned that they thought it wise to adhere to their medical prescriptions in order to cope with the symptoms and signs that aggravated stigmatization such as sores, exhaustion, loss of weight and others. This coping strategy can be seen in the following quotes:

"They usually tell us to stick to the same time of taking treatment. My time for taking treatment is eight; so I have to eat first so I vary my food, like sometimes I eat sorghum, I eat beans; samp, mielie rice with some chicken and vegies."

"I am regular with my appointments; if anybody asks me about my problems I just say I have come for treatment, I don't have problems. I am trying to discontinue with taking alcohol, I am managing and already and I am following the instructions about my treatment."

These findings were contrary to the evidence discovered by Siegel and Schrimshaw (2005:230) that women in the highly active anti retroviral therapy (HAART) did not seem to report a significant improvement that could enable them to cope better with stigma caused by signs of the disease.

Eating healthy in order to boost the immune system

Compliance with ARV's was found not to be the only strategy for coping with stigma but women who were interviewed for this study also deemed it necessary to eat healthily as advised during counseling. The following quotes bear testimony that these women knew the importance of eating a healthy died to boost their strength:

"Even food, you must choose food. Do not eat fatty food, spicy, salty etc. You must eat vegetables, beetroots etc. They boost up you immune system."

"So I have to eat first so I vary my food; like sometimes I eat sorghum, I eat beans, samp, mielie rice with some chicken and vegies."

This experience could not be traced to the literature especially as an entity, except that Coetzee and Spangenberg (2003:210) mentioned that a problem-focused approach empowers the PLWA to consider an improved quality of life. Coping by eating a healthy diet was a unique finding to be considered as part of an approach to quality lifestyle.

Engaging in physical exercises

To increase the general health and coping with physical health, physical exercises were believed to complement healthy eating as well as the treatment. Some women were not only conscious of a healthy diet as a means of increasing their coping ability but they also mentioned that physical exercises were necessary to keep themselves fit as well as to combat stress, similar to what Kleinke (1998:54) identified as a problem-focused functional strategy. The coping strategy was expressed as follows:

"No I am fine, even exercising, when I wake up in the morning I stretch."

"So I do what I am required to do you see; and I do it with all my strength you see, I don't get tired, I exercise."

Practicing healthy sexual practices

This was found to be similar to what Siegel and Schrimshaw (2003:193) found that women who were infected by partners who concealed their status preferred to abstain as a coping measure to reduce the anger that they had against their partners. In confirming these findings, women of this study seemed to realize that re-infection constituted a threat to their health, therefore they mentioned that either practicing safe sex by using condoms or totally abstaining from sex was the best option (Weiss & Ramakrishna, 2002:8). The following quotes were what the women had to say:

"I must try hard, I have no other man straight – straight, I have no other men; if it can happen, I will use a condom."

"Things like when you get a boyfriend use condoms so that your immune system should remain effective, because your immune system is already low."

The following discussion is on ineffective strategies of coping by focusing on the problem.

Negative strategies of coping by focusing on the problem

Other coping strategies that were adopted by these women were that they kept their HIV status secret, expressed their grief and hurt as well as threatening lawsuits against perpetrators of stigma, as discussed below.

Keeping their HIV status secret

This finding is supports what was found by most authors that most people prefer to keep their HIV status confidential due to the stigma of HIV and AIDS that often interferes with disclosure and that it delays seeking treatment (Chandra *et al.*, 2003:212; Yang *et al.*, 2006:722; Greeff *et al.*, 2007, In press) as well as social support (Gaines, 2001:123). Most women preferred to keep their HIV status confidential and seemed to feel more comfortable if people did not know that their partners died of AIDS, including their own status. The following quotes revealed this experience:

"It is the pain associated with the fact that this child is saying the truth. This thing he is talking about is on me so I am afraid to tell them."

"No, the people treat me well; they never treated me anyhow because in fact no one knew what this man was suffering from."

Expression of grief and hurt

Almost ten out twenty participants of this study reported coping with stigma by ventilating their feelings mostly by crying. Crying was justified by participants as a way of dealing

with the hurt of being betrayed by someone they relied on. This was expressed in the following quotes:

"Yes, I used to feel pain, but would take it out, I used to be hurt to an extent of crying, but I told myself for how long am I going to endure it."

"I was crying, when I thought of this man, even if he could not tell me that he was sick, could he not at least use a condom? For the sake of the child, so that I could raise up the child?"

These reactions bear confirmation to what Sikkema *et al.* (2000:622) found that people experiencing stress of HIV and AIDS develop depressive symptoms, and that intense expression of feelings through crying releases stress (Wilson & Kneisl, 1996:75).

Threatening lawsuits against perpetrators of stigma

Anger was also a coping mechanism found to be used by women of this study although it could not be supported by the literature, especially threats of seeking legal measures as a means of coping with the stigma. The anger seemed to have been motivated by the gossip and labeling. This coping strategy was unique to this study. The following is what these women had to say:

"But what is there we will meet at the lawyers; yes we will go and you will talk where am I sick!."

"Yes, they will have to testify in court because they say I'm sick and I never told anyone that I am sick."

Findings that have been discussed were on coping by focusing on the problem with its various effective and ineffective mechanisms. The following is a discussion of findings with specific reference to coping by focusing on emotions.

COPING BY FOCUSING ON EMOTIONS

Coping by focusing on emotions seems to involve trying to change either what the source of stress is or how it is acknowledged (Lazarus 199:16). The way in which the women spontaneously said that they have 'accepted', aroused uncertainty with regard to

the genuineness of the statement when considering that their partners died without having disclosed their status. Another factor that created doubts about their acceptance was that some of their relatives treated them badly and that they were already diagnosed as HIV positive themselves. The following is a discussion of coping strategies that include coping by self acceptance, acceptance by family members, emotional, social and material support by families, friends, neighbors and social welfare and turning to religion to seek spiritual support.

Coping by self acceptance

The women's readily mentioning of "I have accepted" could be attributed to avoidance of talking about their painful experiences or that they have genuinely accepted their HIV and AIDS status because it did not come as a shock due to suspicions they had about their partners. This study supported the literature that found that PLHA cope better if they accept HIV as part of their lives (Howard, 1996:82; Schonnessen & Ross, 1999:88). The following quotes represent the women's voices about this issue:

"I went to the clinic and received counseling, then I was able to accept and eventually I became alright."

"I managed because I accepted. I said even if I have this disease let me accept it. This disease needs one to accept it because if you can feel too hurt, it is then that it takes an upper hand of you, so I accepted it."

Acceptance by family members

Participants reported that to be accepted by one's family was reassuring and relieved their stress and that they were freed from pain. This was expressed as follows:

"*It's because I just thought my mother would reject me; no, she accepted me and even took me to her house to nurse me.*"

"*My child has accepted me, so I no longer have problems, I am free."*

The participants' feelings of content due to being accepted by their family members was confirmation of what Brown, Macyntyre and Trujillo (2003:56) affirmed as positive coping

by PLWA, although on the contrary, Miller and Kaiser (2001:82) found that acceptance may be somewhat less adaptive for stigma than for other types of stressors because of its constant and pervasive nature. In this study the acceptance of PLWA by their families seemed to facilitate emotional, social and material support.

Emotional, social and material support by families, friends, neighbors and social welfare

All the women who participated in this study mentioned some form of support that they received from close family members, neighbors, as well as from social welfare in the form of grants. These forms of support were believed to facilitate coping in various ways as expressed in the following quotes:

"I cope with these very cents that I get from government, it is my share and my daughter's."

"My elder sister is supportive; she would come and take me to the doctor."

"When they come and find that I have not been able to cook they cook."

These forms of coping supported the findings of Martin, Wolters, Klaas, Perez, and Wood (2004:289) whose study revealed that the use of social support could assist in significant coping especially for individuals with HIV. Most women in this study also confirmed that their close families and neighbors would get concerned about whether they have food for their children so that they could assist where necessary.

Turning to religion to seek spiritual support

Women in this study who experienced stigmatization as a painful experience mentioned that they sought solace in their God by means of prayer and bargaining with Him to be healthy and to increase the days of their lives so that they could bring up their children. The following are their direct concerns:

"God is the only one who knows our days of life and who can extend."

One woman persuasively said, as though she was instructing others:

"Ask God to protect and secure you all the time; pray! That is how I manage in life."

This finding concurs with Yarhouse and Anderson (2002:339) that prayer could assist Christians with HIV or AIDS to come to terms with their relationship with God, and that such relationship may help them to resolve forgiveness issues especially that the stigma associated with HIV and AIDS may be moral-based. The women's experience of being closer to God could also facilitate their bargaining for a longer life (Yarhouse & Anderson, 2001:339).

COPING BY FOCUSING ON NEGATIVE EMOTIONS

Negative emotional coping strategies used by the women included de-individualization of the disease, ignoring negative remarks and attitudes and forgiving, blaming of their partners and other people for their HIV status and anger directed at the perpetrators of stigma, as discussed below.

De-individualisation of the disease

Women participants in this study seemed to cope by rather considering the stigma attached to HIV and AIDS as 'our problem' rather than 'my problem', hence the researcher terms it de-individualisation. This attitude could also be described as generalization of the problem, which made women feel less anxious in realizing that they are not alone in their suffering from the stigma of HIV and AIDS.

The following quotes bear evidence:

"So I did not have fear because it is our disease, and I went to test because I wanted to know ..."

"It means I'm thinking that we are of the same flock, yes we are of the same flock. So you ask yourself that am I going to be like so and so, or so and so, just like that."

These findings are similar to those by Mickelson *et al.* (2001:182) who affirmed that appraising the stress as 'ours' and dealing with it collectively does reduce its impact. Gaines (2001:121) considered stigmatized people not as de-individualising the disease as such but, that they can empathise with each other because they share the same

experiences. The women in this study did mention that they support each other in their support groups. Miller and Kaiser (2001:87) also documented that stigmatized people could probably cope through cognitive restructuring when they share the support of other stigmatized people.

Ignoring negative remarks and attitudes and forgiving

It was found to be unique that coping by ignoring public remarks was as useful, as confirmed by women whose partners died of AIDS. They expressed that it does not help to capitalize on hurting issues and that one should avoid being hurt at all times. Their ignoring and forgiveness of the perpetrators of stigma were expressed in the following manner:

"With me, even his family, I have forgiven them, my attitude towards them is positive."

"... because many things are being said so I told myself that I have to ignore, for me to be alright."

Women did not only cope by focusing on the emotions but also some used strategies that focused on negative emotions as discussed below.

Blaming of the late partner or other people for their HIV status

Women who participated in this study found themselves blaming their late partners and other people or themselves for their HIV sero-status. Much of their blaming was based on the fact that if their partners betrayed and cheated them. On the other hand, they also blamed themselves for having been ignorant and trustful even when they realized that partners were unfaithful. These are some of the examples, quoted directly from what the women said:

"... I was confused, telling him that all the time that I have been nursing you, taking you to doctors and your family accusing me for bewitching you why didn't you tell me that you had HIV and AIDS?"

"I just thought why could he not use condoms if it was hard for him to tell me?'

These findings support what other authors have found that stigmatized people tend to place their responsibility on other people, such as women blaming men for having failed to engage in safe sex. (Crocker & Major in Miller & Kaizer, 2001:82). This blaming could be attributed to the fact that the literature also refers to women being vulnerable to being infected with HIV due to their weaker economical and social position of finding it difficult to negotiate safe sex (Atekyereza & Kirumira, 2004:37). Eighteen (18) out of twenty (20) women were unemployed. Besides blaming their partners for being infected with resultant stigmatization, some women expressed anger at those who stigmatise them.

Anger directed at the perpetrators of stigma

This finding was similar to what the literature found that anger was directed at those who stigmatized women except for two out of twenty whose anger was directed at their late partners for having deceived them (Siegel & Schrimshaw, 2003:193). The following are some of the quotes that expressed anger:

"Yes it upsets me, it hurts that for how long are these people going to treat me like this."

"Sometimes I feel strong as if I can grab a person and fight, I don't know where I would get the strength from but I would feel like assaulting a person."

These findings are consistent with those of Siegel and Schrimshaw (2002:229) that interpersonal conflicts such as arguments with family members regarding HIV issues cause stress for the stigmatized women.

Some findings showed that women cope by using defense mechanisms as discussed below.

The use of defense mechanisms as means of coping with stigma

Defense mechanisms are protective mechanisms that counteract stress (Kolb, 1973:83). Participants in this study used those that were mental inhibitions such as rationalization as well as the compromise formation category such as intellectualization. Those that keep unacceptable impulses out of the consciousness such as denial and projection (Carr, 2004:2) were also used.

Coping by denial

These defense mechanisms were used by women as an indication of their painful experiences. Statements that suggested some of them were as follows:

"Even when I feel sick I don't sleep or just sit; I try to keep myself up, I refuse to be sick."

"If someone says that I am sick they will have to testify in court and show me where am I sick."

The literature on coping with stigma has identified denial as a form of escape-avoidance coping, which can prevent the PLWA to accept their status, thus gaining access to support and resources (Coetzee & Spangeberg, 2003:213). However, the same authors found that denial could make it possible for the person to make the cognitive adjustment, especially during the initial phase of shock.

Coping by projection

Projection is an inhibition defense strategy that some women used as a protective strategy to decrease the pain of stigmatization (Carr, 2004:236). The following statements confirmed that defense mechanisms are use unconsciously:

"It is drunkards who say silly things; I just ignore them."

"I heard from his sister that he was HIV positive."

Coping by rationalization

Women also used rationalization and as a way of coping because rationalization is meant to make the individual feel that her actions have been a deliberate thoughtful judgement (Carr, 2004:232), therefore, some women said that if their families accepted them, they did not care about the rest of the community. Some rationalizing statements are:

"I am HIV-positive and I am proud because I know my status."

"I no longer want any man next to me; I am only satisfied when I am with my daughter."

Coping by intellectualization

Intellectualisation was also identified in some statements such as:

"So I did not have fear because it is our disease, and I went to test because I wanted to know."

"It means I am thinking that we are of the same flock...."

These defense mechanisms are, according to Carr (2004:231), designed to protect the ego against painful experiences and ideas such as in the case of these women who are considered to have experienced multiple traumas.

GUIDELINES FOR WOMEN TO COPE EFFECTIVELY WITH STIGMA ASSOCIATED WITH THEIR HAVING HAD AN INFECTED PARTNER WHO DIED OF AIDS

The following are guidelines formulated for women to cope effectively with stigma.

- It would benefit women whose partners died of AIDS if programs are developed to facilitate Voluntary Confidential Counseling and testing (VCCT), to assist them through a process of disclosure as well as in acceptance of their status so that there is prompt seeking of treatment in order to cope, as well as preventing the debilitating effects of HIV and AIDS.

- It could be meaningful if, following their pre and post-test counseling, a follow-up is done to monitor their coping skills on subsequent visits by evaluating them so that should the need arise, help is readily available. This could increase openness that will improve coping.

- It would benefit the community to be made aware by psychiatric nurses about the need to support PLWA by accepting them and respecting their human rights such as the right to receive care and treatment, the right to belong to a family, as well as other rights that are enjoyed by all citizens, so that they can be able to cope with the disease.

- It could be meaningful for government and non-governmental organizations to support programs aimed at assisting PLWA, such as home-based care, support groups as well as other initiatives aimed at empowering these women to deal with the stigma associated with their widowhood status as well as the disease process.

- It would benefit these women if psychiatric nurses could train them by teaching assertive skills so that rather than ignoring negative remarks, they could respond in a positive and assertive manner, thus preventing aggression and negative responses.

- It could benefit women who lost their partners to AIDS if they were taught budgeting skills, so that they could use the little money that they receive from social grants effectively, in order to meet their basic needs. It could also benefit them to be advised to use NGO's that could assist them in the cultivation of vegetables so that they can produce their own, as well as accessing other support initiatives aimed at poverty relief so that the stigma could be reduced.

- It could be of their advantage if women could also be assisted to cope effectively by involving the faith-based organizations since they hold strong Christian beliefs; their ministers could be engaged to discuss with them the possibility of regular religious discussions, prayer meetings and spiritual counseling sessions, either as individuals or groups if the PLWA prefer this would strengthen their deepening spirituality, thus assisting them to cope with perceived stigmatization.

- It would benefit them if these women are educated about their treatment, emphasizing compliance and healthy lifestyle in order to enable them to cope with the disease.

- A programme for coping with stigma for women whose partners died of AIDS will be formulated in the next phase of this study.

CONCLUSIONS

In conclusion, findings on coping with stigma by women whose partners died of AIDS revealed that coping was a difficult process for these women due to their widowhood

status aggravated by the loss of a partner to AIDS, a situation which led to severe stigmatization. Their coping was also made difficult by the fact that they had lost a breadwinner, and the fact that they were infected with HIV themselves made it a complex situation. The complexity of the situation was their lack of education that led to unemployment, thus leading to a low socio-economic status, making it extremely difficult to cope with their own deterioration in physical health as well as having to care for their dependent children. Some of these women, however, coped by focusing on the problem though some of the strategies they used were effective and some ineffective. The most effective strategies that were found to have benefited these women in their coping were voluntary counseling and testing, disclosure as well as their deepening spirituality because they were perceived as having paved ways for several mechanisms that facilitated their coping such as receiving both emotional and spiritual counseling, ARV's as well as various forms of support. Although most of the strategies used to cope by focusing on the problem were effective, there were also strategies that focused on emotions that also proved to be beneficial such as their self acceptance that led to being supported by their families, resulting in positive living with the disease. These women also coped by using defense mechanisms in order to relieve the stress associated with the situation as explained above, as well as ineffective strategies both focusing on the problem as well as on the emotions, which they could be assisted to reduce through a relevant program. The development of a program that would enhance their positive coping strategies as well as facilitate the learning of new coping strategies would be meaningful to assist them to cope effectively with their having lost their partners to AIDS.

TABLE 1: STRATEGIES TO ENSURE TRUSTWORTHINESS

STRATEGY	CRITERIA	APPLICATION
Credibility	Prolonged field experience	Letters to request participation delivered by researcher and spending time with women whose partners died of AIDS to establish a trusting relationship. Confirmation of appointments also done personally by researcher to strengthen the relationship. Participants allowed enough time to verbalise their experiences and beliefs respectively.
	Reflexibility	Field notes were written immediately and subjected to analysis
	Member checking	Literature control of experiences of coping with stigma was undertaken
	Interview technique	Researcher trained in research methods and in interviewing skills. Research supervised by experts experienced in qualitative research
Transferability	Selection of sample	The sampling method was purposive voluntary.
	Dense description	Through description of research methodology and literature control of the findings.
Dependability	Stepwise replication	Co-coder involved in independent data analysis
	Dense description	Detailed description of methodology
	Code-recode procedure	Data analysed twice and results compared Consensus discussion held with co-coder.
	Peer Examination	Expert supervision provided
Confirmability	Confirmability audit	Done by supervisors of the research
	Reflexibility	Field notes taken and subjected to data analysis

TABLE 2: COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS

Coping focusing on the problem		Coping by focusing on the emotions		The use of defense mechanisms
Positive	**Negative**	**Positive**	**Negative**	
Undergoing voluntary counseling and testing - Women went for testing in order to know their status.	**Keeping their HIV status secret** - Feel comfortable when their status is not known by the community to avoid stigmatization.	**Coping by self acceptance** - Women value the importance of accepting their condition.	**De-individualisation of the disease** - Ignoring negative remarks and attitudes and forgiving.	**Coping by denial** - Women emphasize lack of obvious change in appearance. - Women emphasize that they ignore the illness by continuing with their routine.
Disclosure of their HIV status for family support - Women inform their children and family members in order to get their support. - Women disclose their sero-status to their friends and neighbours in order to prevent gossiping.	**Expression of grief and hurt** - Women expresses grief caused by death of partner	**Acceptance by family members** - Re-assured to learn that family accepts them	**Emotional, social and material support by families, friends, neighbors and social welfare** - Counselors support them - Relatives and neighbours provide material assistance - Social welfare provides grants	**Coping by projection** - Women emphasize lack of obvious change in appearance - Women emphasize that they ignore the illness by continuing with their routine.
Seeking social support **Turning to religion to seek spiritual support** **Adopting a healthy life style**	**Threatening lawsuits against perpetrators of stigma**	**Seeking comfort on spirituality**	**Blaming of the late partner or other people for their HIV status** **Anger directed at perpetrators of stigma**	**Coping by rationalization** **Coping by intellectualization**
- Complying with ARV treatment regime - Eating healthy in order to boost immune system - Engaging in physical exercise-Practising healthy sexual practice		- Women spend more time engaging in church activities - Women believe in praying as the only solution to their problems - Hold onto beliefs of God's healing powers	- Women express anger about those who stigmatize them.	

		De-individualisation of the disease - Get comfort in referring to their condition as 'ours'		
		Ignoring negative remarks and attitudes and forgiving - Women ignore all negative attitudes displayed to them. - Women forgive stigmatisers		

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ARTICLE 5: THE DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF A PROGRAM FOR COPING WITH STIGMA FOR WOMEN WHOSE PARTNERS DIED OF AIDS: A CASE STUDY

GUIDELINES FOR THE JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE

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TITLE PAGE

THE DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF A PROGRAM FOR COPING WITH STIGMA FOR WOMEN WHO'S PARTNERS DIED OF AIDS: A CASE STUDY

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ABSTRACT

The research about the experiences of stigma as well as coping with stigma by women whose partners died of AIDS showed that these women experienced severe stigmatization by their families, the community and health workers, in the form of received and internalized stigma. The severity of stigmatization made it difficult for these women to cope and they were found to be using a range of effective and non-effective coping strategies. They used mostly ineffective problem-focused strategies and very limited emotion-focused strategies, which were compounded by their low literacy level as well as their poverty status. Due to their difficulty in coping there was a need to develop a program to assist them to cope with the stigma of having lost an AIDS partner. This program was developed, implemented and evaluated by means of a holistic multiple case design with a sample of 4 women. Data was collected by means of multiple sources from transcripts of the eight sessions, naïve sketches by participants, as well as field notes from observations of individuals and of the group. Data analysis was done according to a case record. The conclusions about the impact of the program was that it had a positive impact based on the fact that these women grew from being lonely, reserved, having a negative self perception to being open about their HIV status, sharing their problems related to stigma, seeking support, being altruistic by advocating for assistance of other women in the same situation, and establishing a home-based care facility where they would assist in caring for others.

Key words: Stigma, AIDS, coping, program

INTRODUCTION AND PROBLEM STATEMENT

In 2006 it was reported that 6.5 of 46.4 million South Africans were living with HIV and AIDS (Champ, 2006:50). The escalating number of people living with HIV and AIDS coupled with a high death rate of the infected people poses a major threat in the prevention and treatment measures of this pandemic. Contributing to this threat is the degree of stigmatization and discrimination of people living with HIV and AIDS. The stigma of HIV and AIDS nullifies efforts to prevent and treat the infected or to deal confidently with the pandemic (Ogden & Nyblade, 2005:34). The difficulty in dealing with HIV and AIDS is due to the fact that the stigma makes it difficult if not impossible to go for voluntary confidential counseling and testing (VCCT), to disclose their status when already diagnosed, as well as accessing the available treatment or resources developed to assist them. The findings of experiences of stigmatization (Manyedi, Greeff & Koen, 2007a:16, unpublished article), reflected that these women experience severe stigmatization from various sources such as their families, the community as well as health workers.

In assisting people living with HIV and AIDS to deal with this pandemic, it seems that gender issues should not be overlooked because the literature has demonstrated that women are more stigmatized than men (Nyblade, Pande, Mathur, Mac Quarrie, Kidd, Banteyerga, Kidanu, Kilonzo, Mbuwambo, & Bond, 2003:23). To cite but a few examples, in 1998 the worst scenario of gender and stigma occurred when Gugu Dlamini, a female AIDS activist was killed in the Kwa-Zulu Natal Province of South Africa, following her public disclosure of her HIV positive status (Brown, Macintyre & Trujillo, 2003:51). Stein (2000:12) also reported that a Muslim woman was sentenced to death after disclosing that her late husband had infected her with HIV. In a recent case in Cape Town, South Africa, a young lady was discharged from her duties by a company after she honestly disclosed to her employer that she had tested HIV positive (ETV 19H00 Prime Time News, 29th September 2007). Women seem to be stigmatized by virtue of being considered more vulnerable than males, especially regarding HIV infection as shown by some African studies (Ogden & Nyblade, 2005:25). These authors reported that in the African countries where their study was conducted, women were often heavily stigmatized and blamed for having failed to be proper women and for bringing HIV into

the family. Another reason is said to be due to their economic subordination which makes it difficult for them to negotiate safe sex (Armstrong, 2003:24). South Africa is no exception.

The study conducted by Manyedi *et al.* (2007a:17, unpublished article) on experiences of stigmatization by women whose partners died of AIDS found that women were blamed by the community, especially their in-laws, for having killed their partners by infecting them with HIV. In cases where the family had denied their son or brother having died of AIDS, the woman was often blamed for having bewitched him (Manyedi *et al.*, 2007a:17, unpublished article). The blaming contributes to making coping with stigma a difficult experience for women due to the fact that widowhood as well as HIV and AIDS are highly stigmatized conditions (Nyblade *et al.*, 2003:23). They, therefore, have to cope with the loss of a partner on the one hand and with the fact that he died of AIDS on the other hand. In the study conducted by Manyedi, Greeff and Koen (2007b:17, unpublished article), on coping with stigma by women whose partners died of AIDS, these women were found to have used a range of effective and non-effective strategies to cope with the stigma. Some of the effective strategies that they used were those that were aimed at addressing the problem in a constructive manner such as undergoing voluntary confidential counseling and testing (VCCT) when they realized that their health was deteriorating. Also after testing HIV positive they accepted and disclosed their status to at least one or two family members in order to get their support. Some also joined support groups, turned to religion for spiritual support and resorted to a healthy lifestyle such as a healthy diet, exercises and healthy sexual practices.

Non-effective coping strategies included those that did not assist to reduce the burden such as keeping their status secret, unresolved grief, threats to sue the perpetrators of stigma, or blaming their late partners for their HIV status, to mention a few (Manyedi *et al.*, 2007b:21, unpublished article). This stigmatization which was in the form of received and internalized stigma made it difficult for them to cope. Although they had some effective coping and some ineffective coping mechanisms, their range of coping mechanisms was found to be limited to more of a problem-focused approach with little emotion-focused coping. Their limited coping strategies were also found to be

compounded by their poor literacy level as well as the general low status of rural women in South Africa (Manyedi, *et al.*, 2007b, unpublished article).

A need was then realized to develop a program for these women that would assist those that attempted to cope to strengthen their coping skills and those that could not cope at all to develop some coping skills. Other authors in their recommendations strengthened this need hence Brown *et al.* (2003:62) are of the opinion that although the problem of stigma seems to be a serious situation, something could still be done in the form of programs targeted for the stigmatized. They reviewed 22 stigma intervention studies, one of which was done in South Africa. These studies were found to have yielded unsatisfactory results regarding how the stigma was dealt with. They, therefore, recommended an approach that would include contact and information giving to people living with HIV and AIDS (Brown *et al.*, 2003:640). Ogden and Nyblade (2005:42) supported by Parker, Aggleton, Attawel, Pulerwitz and Brown (2002:15) concur with the view that programs could be the answer to reduce stigma.

The question that arose was how could women whose partners died of AIDS be assisted to cope with the stigma associated with their having had a relationship with such a person.

OBJECTIVES

From the above-mentioned question, the following objective was formulated.

To develop, implement and evaluate a program to assist women whose partners died of AIDS to cope with the stigma associated with their having had a relationship with an infected person who died of AIDS.

LITERATURE STUDY OF PROGRAMS AND INTERVENTIONS TO DEAL WITH THE STIGMA OF HIV AND AIDS

Prior to the formulation of the program various sources in the literature were consulted in order to study the types of programs that were available. The main approaches identified by Brown *et al.* (2003:53) were information/fact-based, skills acquisition, counseling, resource provision, contact with affected groups, as well as the multiple intervention programs. Information-based approaches are those that provide information to the target

group either for preventive purposes or to provide facts that may not be clear. The information referred to may be written, in the form of pamphlets, booklets, videos/ compact discs, presented factually in a class-room set up, peer education, games as well as guided group discussions (Brown *et al.*, 2003:53; Siyam'kela, 2003:3). Reddy, James and McCauley (2005:6) reported that a school-based HIV prevention program failed because of among others, inadequate preparation and lack of evaluation mechanisms that would assist to improve it. Uys (2003:10) maintained that information may be used to change attitudes, increase coping, and that if it is factual it does decrease stigma. On evaluating an information-based program that was aimed at increasing tolerance for people living with HIV and AIDS the results were mixed, implying that it could not change negative attitudes of people towards HIV and AIDS (Brown *et al.*, 2003:63; Yang, Li, Stanton, Fang, Lin, & Naar-King, 2006:23; Baker, Sartsara, Rumakom, Guest, Schenk, Pramualratana, Sujsakulwak, Panakitsuwan and Moonmeung, 2004:22). Information-based only programs may not be successful because sometimes attitudes towards the disease such as HIV and AIDS which is feared may not be easily changed by giving them appropriate information as often people are suspicious. Therefore it was found that in one of the information only studies there was some tolerance for people living with HIV and AIDS, but fears of contracting the disease by casual contact still dominated (Lane, 2002:215). Some authors refer to information only as a fact-based program, which could also include life skills teaching (Reddy, James & McCauley, 2005:1). This information based approach is used as a basis for most interventions because it has been found that in most communities, knowledge about HIV and AIDS issues is still lacking (Sowell, Lowenstein, Moneyham, Demi, Mizuno & Seals, 1997:309; Yang *et al.*, 2006:722). This knowledge could, therefore, change the people's behavior.

Skills acquisition or skills empowering programs are designed to train people living with HIV and AIDS in coping strategies, therefore most stigma intervention programs utilize the approach (Ogden & Nyblade, 2005:10). Skills acquisition is necessary in cases where people living with HIV and AIDS themselves need to be empowered to deal with stigmatization such as ignoring the perpetrators and assertiveness to confront negative attitudes and behaviors, problem solving as well as decision-making skills. Skills training is also done when a program is designed and certain people have to be empowered with

skills to administer the program to the stigmatized (Brown *et al.*, 2003:53; Uys, 2003:25). These people may be teachers, nurses, families, a management team at a workplace or any group of volunteers such as home based cares. These types of programs are useful because the number of health care workers cannot always cope with the number of people living with HIV and AIDS, requiring their services. These programs seem to overlap because there are also counseling programs (Brown *et al.*, 2003:53) that could be done through providing information in order to support either the stigmatized people or those caring for them, because they are also subjected to the same stress and stigma (Strydom & Wessels, 2006:3).

Counseling programs adopt an approach that provides information on HIV and AIDS. Time is then allowed for participants to discuss their concerns intimately after which there is provision of social support that facilitates behavior change or that motivates them to maintain positive behaviors (Brown *et al.*, 2003:53). The Horizons/Population council study conducted at ESKOM in Kwa Zulu Natal Province in South Africa found that women feared stigma more than men and, therefore recommended couple counseling in order to minimize blaming women for having not behaved well (Stewart, Pulerwitz, & Esu-Williams, 2002:4). This recommendation seems to have been based on the fact that counseling would give such women the opportunity to express their feelings whilst they receive support. Support provided to stigmatized people is not only limited to emotional but also to material support.

Material support in the form of provision of resources is another approach that was proved to be necessary, especially in impoverished communities. Coetzee and Spangenberg (2003:215) found that adequate provision of resources determines the choice of coping strategies as well as the outcome of the coping process. However, the ACORD study found that providing food rations to impoverished people living with HIV and AIDS was found to be increasing their stigmatization due to resentment from other community members (Hadjipateras, 2004:43). This led to their recommendation that stigma reduction programs should be redesigned to avoid targeting. This view shows how important it is for every researcher to be sensitive to the needs of their target group when programs are designed.

Contact sessions are those that are aimed at creating an environment where people living with HIV and AIDS could interact with other stigmatized groups (Brown *et al.*, 2003:62). This approach advocates a more personal relationship that involves people living with HIV and AIDS (PLWA) at all levels of the community (Siyam'kela, 2003:2), district and national levels (Khan & Loewenson, 2005:5). In these stigma intervention programs some authors think that it is necessary to involve people living with HIV and AIDS for their programs and policies to be successful (Busza, 1999:15). The success is due to the fact that listening to others testifying about their experiences and empathic responses that they receive from others render the situation more acceptable due to the reduction of the fear associated with the disease, all of which reduce the stigma of HIV and AIDS (Brown *et al.*, 2003:62).

A combination approach is one that combines information about stigma, coping skills acquisition or empowering, prevention, counseling as well as support (Busza, 1999:9; Parker *et al.*; 2002:14; Siyam'kela, 2003:13; Uys, 2003:28; Hadjipateras, 2004:38; Ogden & Nyblade, 2005:38). Support is also a broad concept and in the context of these programs it may refer to emotional support, spiritual support, and also material support which may require provision of resources such as medication, financial in the form of grants, food, clothes and assistance with transport. Heckman, Somlai, Peters, Walker, Otto-Salaj and Kelly (1998:372) as well as Coetzee and Spangenberg (2003:215) recommended that programs should look at whether these forms of support at disease stage do affect the coping style. They seem to have based their recommendation on the fact that black women were mostly found to be socio-economically disadvantaged as is the case with the participants of this program. Their low quality of life due to poverty is believed to be contributory to the stigma (Yang *et al.*, 2006:722).

RESEARCH DESIGN

A holistic multiple case design type 1 was chosen for this study (Yin, 2003:43). It is a rich design recommended by Yin (2003:53) due to the advantage of the direct replication of cases and that when conclusions are made they come from the analysis of more than one case, and the benefits thereof are much more than that of a single case (Yin, 2003:53). The fact that the context of each case differs also adds to the richness of the data, hence the choice of the holistic multiple case design (Yin, 2003:40) (See Figure 1).

RESEARCH METHOD

Sampling

For the purpose of this study a purposive voluntary sampling was conducted (Babie & Mouton 1998:166). A sample size of four women was drawn according to specific inclusion criteria which were as follows:

The women

- Have lost their partners to AIDS within a two year period.
- Have been through voluntary counseling and testing and were aware that they were HIV positive.
- Resided in the Mafikeng area in the Central Region of the North West Province of South Africa.
- Spoke and understood Setswana and Sesotho languages.

Participants' information

Four women who lost their partners to AIDS within a period of two years were selected from twenty women who participated in the initial study of "coping with stigma by women whose partners died of AIDS" (Manyedi *et al.*, 2007b). These women shared their experiences of stigmatization after their partners died of AIDS and would all have benefited from a program for coping with stigma. The findings thereof led to the development of this program. The women were included as participants of the implementation and evaluation of the program because they met the inclusion criteria as stated above. They were visited at their homes to inform them about the intended program as well as motivating them to participate. The aims, objectives, benefits and risks were explained to them in the language in use. On having agreed to participate, they were promised to be contacted again to inform them about the definite date, time and venue of the first meeting where they would meet their group mates to know each other and commence with the program.

Case 1

Meme*, a thirty seven (37) year old woman had three children. She was HIV positive and was tested before the death of her partner. She was doing domestic work for a local family. She was on Ante Retroviral Treatment (ART). Her common law husband died of AIDS in 2004. She was staying in a shack which she said was her original home because it was her father's, who also died shortly after the husband. She stayed with her three children, two boys and a girl, plus her late sister's son who was older than her children. She had an elder sister who was also HIV positive and stayed with them when she visited home.

Case 2

Didi*, a thirty one (31) year old widow with three children was tested HIV positive in January 2006 before the death of her partner. They were not married and she had three children, all under the age of ten. She was not employed and stayed with her children in a hired room. They lived on a government grant. She moved from her home because of the constant conflict she had with the family. She lost a brother to AIDS during the course of the program.

Case 3

Mama*, a forty four (44) year old widow was married with one daughter. She tested HIV positive in April 2006 and her husband died in June of the same year. Her daughter stayed with a relative in Barkley West where she attended school while she stayed with her brother. She was unemployed and lived on a government grant.

Case 4

Rudie*, a forty four (44) year old widow with two children, the elder of whom stayed with her parents in Vryburg and the younger one stayed with her. She tested HIV positive in 2005 and her husband died in 2005. She was not employed and stayed in a hired room with her eight year old daughter. She was unemployed and they lived on a government grant.

* Fictitious names to provide anonymity.

DATA COLLECTION

Permission to undertake this study was obtained from the directorate of epidemiology whereby a letter was written to the sub-directorate of HIV and AIDS in the Department of Health (DOH) of the North West Province. Ethical approval was obtained from the Research Committee of the School of Nursing Science, as well as from the Ethics Committee of the North-West University, Potchefstroom Campus. Participants gave permission to participate in the program as well as to the recording of sessions on audio-tape by signing consent. Prior to implementing the program the home-based care volunteers, acting as mediators, assisted the facilitator in organizing the venue. When the venue, a church hall was ready the facilitator notified participants about the date of the first meeting (session) as well as the venue. Data were collected by means of multiple sources of evidence namely, individual notes of participants drawn from tape recordings during the sessions, naïve sketches written by each participant at the end of each session as well as field notes taken by the researcher (Yin, 2003:4; Babbie & Mouton, 1998:282). The process was guided by the objectives of the sessions as laid out in the program.

PROGRAM DEVELOPMENT, IMPLEMENTATION AND EVALUATION

The program was developed from the findings of the initial study of "coping with stigma by women whose partners died of AIDS" (Manyedi *et al.*, 2007b:12, unpublished article). The findings revealed that these women experienced stigmatization because of their partners having died of AIDS. HIV and AIDS and widowhood were found to be difficult for these women to cope with, therefore they needed to be assisted to cope with this stigma associated with their having lost their partners to AIDS. The program developed for this purpose was based on the findings of as well as the literature study on programs and interventions (Manyedi *et al.*, 2007a, unpublished article; Manyedi *et al.*, 2007b:12, unpublished article). It consisted of eight sessions of interactive involvement of the facilitator and participants. The eighth and last session was held a month after the seventh session in order to evaluate the effectiveness as well as the internalization of the program content. The program was discussed with experts in the field, adjustments made and then implemented.

SESSION OUTLAY

The layout of the eight sessions of the program is as follows.

Session one: Orientation and introduction of participants

Orientation included informing the participants about the aims and objectives of the program, the layout of the program, duration of sessions, agreeing on the days and times of meetings as well as setting ground rules.

Session two: HIV and AIDS and voluntary confidential counseling and testing (VCCT) knowledge

It consisted of playing of card games on HIV and AIDS facts and knowledge, on the mode of transmission as well as the experience of VCCT which was a discussion.

Session three: Stigma, its manifestations and effects on the stigmatized persons

They watched a DVD on the discussion of stigma and its manifestations in order to relate it to their situation, did an exercise on experiencing and reacting to the effects of stigma and also an exercise on identifying support mechanisms for stigmatized individuals. The aim was to empower them so that they could fully understand stigma and stigmatization.

Session four: Creating awareness on coping

The aim of this session was to make participants understand what coping is so that they could identify their own coping styles. Participants did an exercise on identifying positive and negative coping styles, followed by a discussion to motivate the effectiveness of the styles and if not effective, how they could be improved to be effective.

Session five: Coping with internal stigma

It was designed to empower them to deal with feelings of self stigmatization. They carried out an activity on sharing of feelings and perceptions about being HIV positive themselves, followed by a discussion of these feelings and perceptions.

Session six: Dealing with disclosure

This being a difficult process the aim was to equip these women with skills used for disclosure. They discussed understanding disclosure, sharing personal views on how they personally feel about disclosure, as well as information on strategies leading to successful disclosure.

Session seven: Coping with received and associated stigma

These were types of stigma that participants identified as having affected them and they were assisted to identify strategies of coping and asking for family support. They role played incidents of stigmatization and identified strategies to cope with those behaviors and attitudes.

Session eight: Evaluation of the participants' internalization of the program

This session was conducted a month after the seventh session in order to evaluate the participants' internalization of the program, as well as the effectiveness of the past seven sessions. The benefits, shortcomings as well as future suggestions were also evaluated.

PHYSICAL SETTING

Sessions for the implementation of the program were held at the church hall which served as a venue for church meetings. It was well equipped with tables, chairs and notice boards. It was private, comfortable and quiet. All sessions proceeded without any disturbances or interruptions. The facilitator made participants aware about the importance of switching off their cell-phones to avoid disturbance and they all complied. The seating adopted for sessions was a circle for continuous maintenance of eye contact and for freedom of participation. A small bench was placed in the middle for a tape recorder, laptop computer, posters, charts and pamphlets. Ventilation was comfortable.

MULTIPLE SOURCES OF DATA

Multiple sources of data namely, transcripts, naïve sketches as well as field notes served as evidence for the case study (Yin, 2003:97). All the sessions were recorded on audiotape, transcribed and then they analyzed using the case record. Each participant

accounted for their experiences at the end of each session, by writing naïve sketches. At the end of each session, field notes of individual as well as group experiences of participants were written using observational, theoretical, as well as methodological notes (Cook & Campbell, in Babbie & Mouton, 1998:282). The observational notes reflected and accounted for what happened during sessions, without attempting to interpret the events. These included the who, what, when, where and how of the circumstances. Theoretical notes were the researcher's self-conscious and systematic interpretation of her observations during the sessions. These were described in relation to the observational notes, reflecting the meaning and conceptualizing and linking the present to the previous session respectively. Methodological notes created the researcher's awareness about the appropriateness of the methodology that was followed. The researcher reflected on her own process of facilitating sessions within the selected methodology (Schatzman & Strauss, in De Vos, 1998:286).

DATA ANALYSIS

Data obtained from transcripts, naïve sketches, as well as field notes of the individual and group experience were ordered according to the case record which is discussed in detail under findings.

FINDINGS OF THE IMPACT OF THE PROGRAMME ON WOMEN WHOSE PARTNERS DIED OF AIDS

The case record reflected a summary of the eight sessions objectives, a summary of each participant's naïve sketches for each session, followed by the researcher's observational field notes, each individual participant' as well as the group's growth during each session. The participants' naïve sketches were superficial due to their literacy level but observational field notes reflected a richer description of the experiences of the impact of the program. The discussion of the group's growth is the summary of the participants progress based on the achievement of each session's objectives as observed by the researcher and building up to the women being more able to cope with stigma. Attention is given to each session in discussing these findings.

SESSION ONE: ORIENTATION

As this was their first meeting and that they did not know each other, participants were initially not relaxed as evident in their superficial self introduction. However, some degree of relaxation was observed as the session proceeded. They were, however, keen to hear what the program was about. The purpose of the program was explained to them and they acknowledged that they needed to be assisted and empowered to cope with the effects of the disease, in particular the stigma. It was then explained that the program was going to be in eight sessions, the first of which was the one they were already attending and that each session had its own objectives. Each session was explained. At this stage they were still listening with keen interest and showing some degree of relaxation as they started to contribute. It was also explained that they needed to be committed in attending all the sessions as there would be observations and note writing to monitor their progress. The use of an audio-tape was also explained, as well as its purpose. Consent forms were signed and the dates and times for the sessions agreed upon. One could observe the relaxation as they realized that they shared the same experiences of having lost their partners to AIDS. Some degree of trust was developing and hope was expressed on their faces as they were becoming more talkative by the end of the session.

SESSION TWO: HIV, AIDS AND VOLUNTARY COUNSELLING AND TESTING KNOWLEDGE

Participants were greeted and asked how they felt. The facilitator could see from them having taken the responsibility of attending the second session that they developed more interest in the program. They were informed that the session consisted of three parts, one game and two exercises. The program started with the knowledge session which was easier for the women to manage due to the fact that it was externalized and more directed to 'other'. Objectives of the game and exercises were stated so that they could participate with objectives in their minds. The knowledge cards game was enjoyed and one could observe the developing relationship of trust and togetherness. Although some basic knowledge on facts existed, it was superficial and there were some deficits and misconceptions that had to be corrected. Among others, they did not know that drinking alcohol could contribute to being infected because when drunk, one does not have a

sense of protecting oneself. They were also impressed to learn the meaning of the commonly used acronyms like HIV, AIDS, VCCT, ARV because they said that nurses never explained them. The game brought up increased communication as it seemed to remind them about their first experiences of being diagnosed with HIV. They became more open, sharing their personal experiences of having suspected their partners of being HIV positive due to their secretiveness.

The mode of transmission was also an eye opener for them as they engaged in the discussion, arguing and confirming their facts. They could relate it to their unprotected sex. The last exercise on the experiences of VCCT triggered their emotions as they began to share how they became aware of their own HIV status and that they do not regret having been tested. What presented as a wonderful experience to the facilitator was that despite their low literacy level they could still respond appropriately to the facts on cards that were written in English. This session strengthened their relationship that resulted in more trust, evidenced by their sharing of their experience leading to being tested as HIV positive. Having learnt these facts, they gained insight into their symptoms, thus overcoming the fear associated with the misconceptions that they hear. They could then move ahead as they were empowered with knowledge.

SESSION THREE: STIGMA, ITS MANIFESTATIONS AND EFFECTS ON STIGMATIZED PERSONS

The session started on a high note as participants were looking forward to watching the DVD. When asked how they internalized the content of the previous session they all expressed how their knowledge had increased and that they started to use the right concepts confidently when they attended the clinic and to educate others. They referred to the program as "school" and to the facilitator as the "mistress" meaning lady teacher and these implied that they gained knowledge about the information that they did not have. Group cohesion was becoming evident when the Soul City DVD on stigma discussion was played, and communication amongst them increased. This was also an enriching experience because the previous session focused on stigma as a subject and how it affects the 'other'. As trust and safety developed they could move towards a more personal level and made it a 'me' experience. With more personal sharing, the level of

sharing also became deeper and it was evident that they were no longer paralyzed but in control of their feelings and could think ahead.

SESSION FOUR: CREATING AWARENESS ON COPING

By this session participants had developed trust to an extent that the two, Mama and Rudie would first meet at the latter's place and would come to the venue together. This could be that they had grown closer due to attending regularly or because of being the same age while the other two were younger. Their keen interest in the next session was also evident in their early coming, and having taken the responsibility of fetching the keys to the venue. In the introduction they expressed their enjoyment of the "school". At this stage they were free to an extent that they mentioned struggling with transport and the facilitator had to ensure that they were safe and punctual, sometimes by transporting them from their homes and back after sessions. The first activity of "becoming aware of your coping" triggered an interesting discussion as they all agreed that testing to know your status is the best thing to do and disclosure was their initial coping strategy. Having externalized the concept and then looking at their own personal way of coping also took them to an upper level of being in control of their inner self. They shared their experience of how disclosure makes coping more manageable.

They realized that they were using some effective and non-effective coping strategies. Being within a group they could learn what others were doing that could also benefit them. They, therefore, got the strength from others by expanding their personal potential of coping. They could then as a result evaluate and decide which coping strategies they would continue to use, and which were no longer useful, therefore they could be discarded from their coping menu.

SESSION FIVE: COPING WITH INTERNAL STIGMA

This session was delayed due to the missing keys to the hall. Participants had already made it their responsibility to fetch the keys from the caretaker as soon as they arrived. As a result the session was held on the corner of the verandah outside the hall due to avoiding postponement when participants were already there. However, the environment was still conducive. Meme was upset by her sister whom she informed the group that she was diagnosed HIV positive, and that she constantly accused her for not

caring and that she ill-treats Meme's children. Other members supported her by reassuring her that it could possibly be that her sister, who was admitted to hospital, had not yet accepted her status hence the bitterness. They tried on their own to reassure her, as well as to demonstrate their care and concern about such treatment.

After having looked at stigma on an external basis in session three, it was now brought closer to them on an internal basis and with the trust that developed over the past sessions, they could really take a risk to look at what was personally happening to them. Due to the strong bond that developed they could be more open about what was happening with their own self stigmatization and were supported by the group's empathic responses.

SESSION SIX: DEALING WITH DISCLOSURE

The session was one of the more intensive ones due to the fact that members had already established the degree of openness to be able to lead in discussing issues. It was noticed that although they understood that disclosure was about telling someone about one's status, their knowledge was superficial. After sharing their experiences about disclosure they were given pamphlets translated into Setswana from the Siyam'kela project (2001:160). Types and stages of disclosure were discussed in depth and at length. Participants acknowledged that they did not know that there were types and stages and that they learnt much. Their views were that when you disclose your status you do not only set yourself free but you also help those who were still hesitating to disclose. They also mentioned that you prevent men from approaching you and that you discourage rapists. It was observed that disclosure led to re-living their feelings of betrayal, therefore they developed negative attitudes towards men due to their perceived unfaithfulness. What was also impressive was that they also mentioned that when you disclose your status you also assist those who are in denial to accept their status. This was evident from their growth in their personal insight about disclosure. They realized that they were only partially disclosing which was not to their benefit. By the end of the session they verbalized that they considered increasing the number of people they will disclose to.

Didi, who had publicly disclosed her positive HIV status said that she did so due to the stress of being stigmatized by the whole family. She then decided to go public in order to seek support from outside, therefore she was at this stage, the only one who had already joined a support group. Then having looked at coping in session four, they were able to open up because they felt stronger due to a broadened capacity of coping strategies that led to deciding and making an informed decision to disclose. The decision of disclosure was also supported by gathering strength from the group member who had publicly disclosed her HIV status.

SESSION SEVEN: COPING WITH RECEIVED AND ASSOCIATED STIGMA

This session was also emotion provoking because after greeting and stating the objectives of the session they started by focusing the attention on Meme whose sister accused her of not caring and for ill treating her children. Emotions were high as she furiously expressed that she would rather take her children to a place where they would live in peace. She seemed to have been protecting her children against the associated stigma that she probably noticed. After the first exercise of sharing their experiences of received and associated stigma, Meme reflected on her experiences. She realized that she was using strategies that were not useful. By observing other members' coping skills she expanded her coping abilities. Their sharing of experiences of stigmatization reflected that once they have strengthened their own coping, evaluated it, spoken about it and observed other group members' coping and looked at internal stigma they could then make more informed choices about disclosure or non-disclosure. In identifying such behaviors they mentioned that the nurses' wearing of double masks and double gloves made them feel that they were highly infectious and because of this they felt rejected. They recommended that VCCT sites and their clinic should be rather manned by nurses and doctors living with HIV and AIDS because they would understand their situation and treat them as human beings.

In discussing how they were coping and reflecting on their strengths and capabilities after looking at how others were coping with received and associated stigma, they realized that their coping was ineffective. They then utilized new coping skills learnt from others. They also verbalized that being open to people leads to support and that the best way to treat perpetrators of stigma was to confront, ignore or avoid them. They also

realized that they were empowered with assertiveness skills such as confronting and sending the "I" messages that they had learnt during the program. Due to the freedom to express themselves that they developed in the sessions as well as the trust level that existed between them, sessions were then exceeding the set time.

The session closed on a high note after reminding them that they would break for a month during which they should practice what they had learnt and that the eighth session after a month's break would be the last one to evaluate their development in coping.

SESSION EIGHT: EVALUATION OF THE PARTICIPANTS' INTERNALIZATION OF THE PROGRAM

The session was problematic to organize despite the fact that the date was set because Mama was admitted to hospital, Didi who lost her brother earlier had also lost a cousin and Meme had to baby-sit while her employer was out of town. It took the facilitator many phone calls to organize the session. Ultimately they met after lengthy negotiations especially with Meme's employer.

Participants were an integrated group and some had been communicating on their own with one another. They knew each other's problems which meant that there was a definite trust relationship. They were also happy to meet as a group again and remarked that the "school holidays" left them feeling lonely and isolated from each other. Regarding changes effected in their lives Didi, as she always led the discussions, said that she was now stronger and able to support other people living with HIV and AIDS from the knowledge and skills that she gained from the program. Rudie also reiterated the same feelings of being stronger and brave to face the stigma and that she was going to defeat it as long as she lived. She mentioned that even the fear that she had had disappeared due to the sessions's experiences that she was exposed to, especially the support of others. Mama expressed that during her recent admission to hospital she educated some ladies with whom she was admitted in the ward and thought she motivated them through the experience she gained from the program.

The experiences gained from the sessions and their integration into their lives were evaluated. They all mentioned the development of a relationship of trust that some of them needed for support and sharing. Knowing more about HIV and AIDS dispelled their

fear, hence they could move ahead and take control. The knowledge assisted them to manage their treatment regime better as all of them were on ARV's. A further impact was that they could start sharing knowledge with others or even correcting misconceptions. They had an opportunity to look at a wider range of coping strategies and learn from one another. Looking at disclosure and hearing some of the other group members talking about positive experiences with disclosure made them realize that for their own benefit they needed to expand the circle of people to whom they disclose. Having made contact and understanding their internal stigma it became easier to deal with received stigma as well as them being stigmatized due to their partners diagnosis with AIDS.

The group experience as well as the layout of sessions had assisted them during the month break to take full control. They were no longer using defense mechanisms such as rationalization and denial. They developed stronger coping skills that facilitated them to live meaningfully with the illness to such an extent that they could more successfully manage themselves and thus cope better to assist their children and other family members. They moved from being more self centred to being more involved with others and realized that others needed education, care and support, therefore they kept contact checking on how others were doing and whether they were coping. They recommended that in the future, women who are poor should be given material and emotional support as well. They also identified pregnancy issues and that they needed to know more about HIV and AIDS in pregnancy.

The depth of their naïve sketches of session eight in comparison to the other sessions was an indication of their growth. They expressed that the program should not end. They were told that prolonging the program would not provide a solution to their coping and that they should utilize the skills and the knowledge that they gained to face coping the future, to support each other and support others who do not possess the knowledge that they have. They recommended that a home-based care program should be established for the widows, where this program could be implemented, and that the young girls needed to be taught about HIV and AIDS. In closing, they were asked to close in the manner that they would feel comfortable. Closure was done by lighting a candle as a symbol of hope. They held hands to form a chain as a symbol of

togetherness and support. They sang and Meme volunteered to pray. Those who did not have other members' contact numbers exchanged them. Members then hugged and there were fruits, drinks and cakes to enjoy.

CONCLUSIONS REGARDING THE IMPACT OF THE PROGRAM FOR COPING WITH STIGMA FOR WOMEN WHOSE PARTNERS DIED OF AIDS

The program was successful and had an impact due to the following evidence:

- The program sessions were structured and presented in such a way that it had a positive effect on the participants. Each session was intended to prepare them for the next session in such a way that the sessions followed each other in a consecutive order, with each adding more value. The orientation allowed them to get to know each other, as well as introducing the program and establishing a working relationship. The knowledge session moved to a more realistic level meaning that the participants had to face the facts of the illness. Having internalized the knowledge, they could overcome the paralysis caused by ignorance and denial due to inadequate knowledge. The knowledge empowered them to face the reality of having some of the signs or symptoms and to start taking the responsibility of seeking care and assistance. Learning about stigma manifestations and its effects allowed them to study the facts as the 'others' experience, and then moving to the effects on a more personal level. With coping developing, the session also moved from a more externalized experience to being able to look at their own coping styles. The support and trust in the group facilitated the safe environment. The success expanded by others when they disclosed facilitated a more openness towards the possibility of disclosing. Once they were more able to cope with their own problems and emotions they could extend their skills gained to support others that needed it.

- The systematic order according to which the themes of the program were structured contributed to the sustained personal growth of always starting from the external 'others' experience which is less risky, to the internal 'me' experience, which was more risky. The presence of the group provided support through the

strength and the experiences of others. The systematic structured build-up of the program allowed for growth.

- The group size and context also provided the opportunity for intimacy and to see how other participants were dealing with issues or managing their experiences in comparison with how they were personally dealing with issues. The group gave them the opportunity to discuss other possibilities of coping and using the group as a sounding board. Another strength of the program that enhanced the impact was the choice of participants. The fact that they all lost partners to AIDS meant that they could identify with each other at a similar level in terms of their widowhood status, socio-economic background, as well as their literacy level. Because of sharing the same background it was easier for them to learn from one another and adopt positive coping strategies or successes in a supportive and trusting environment.

- As the sessions progressed more trust developed and the intensity of their honest sharing of their genuine experiences increased. The intensity of their sharing exceeded the planned two hour sessions so intensive that that two hours became too short.

SHORTCOMINGS

Shortcomings regarding the development, implementation and evaluation of the program are described as follows.

- Two participants absented themselves more than once, despite the fact that they signed consent forms and committed themselves to regular attendance. This delayed the group's progress due to the postponement of sessions to allow the absent members to catch up with individual session as well as compromised the richness and sharing of experiences.

- A small group of four participants could be a disadvantage due to limiting the group strength thus depriving participants the opportunity to learn and gain from a wide variety of coping skills from others.

- The duration of two hours when considering the intensity of emotional discussions that these women had to undertake needed to be longer. Their level of understanding also differed so adequate time was needed for games and exercises in each session so that the slowest one could be accommodated.

- Posters, pamphlets and videos were mostly available in English and as a result it created a barrier to understanding for those participants who were not fluent in English.

RECOMMENDATIONS

Recommendations are made for nursing practice, nursing education as well as nursing research.

Recommendations for nursing practice

- It would be meaningful to present the program in its present layout and not just sections of it as it is structured and built up systematically to enhance the coping strategies of women whose partners died of AIDS.

- The program should be facilitated by a professional person who is experienced and effective in facilitating people who experience emotional trauma, and who are able to observe group dynamics, as well as working with people from various educational, socio-economic and religious backgrounds.

- The size of the group should be between six to eight participants in order to make provision for a broader opportunity of growth by way of sharing from a variety of coping strategies of the other members.

- It would be beneficial to participants if the duration of sessions could be increased to last about three hours in order to allow for intensive sharing of experiences leading to the development and acquiring of more effective coping skills.

- As the program progresses the facilitator should adjust the length of the session to accommodate the needs of the participants when the intensity of sharing increases and more support are needed.

- The sessions should be presented once a week to allow for the internalization of learnt coping skills in between sessions. Participants should have the opportunity to apply their new skills in reality.

Recommendations for nursing education

It would be of benefit if the program could be offered as an in-service education program for nurses who are working within the HIV and AIDS context. They should be experienced in group facilitating skills, counseling, as well as in handling group dynamics.

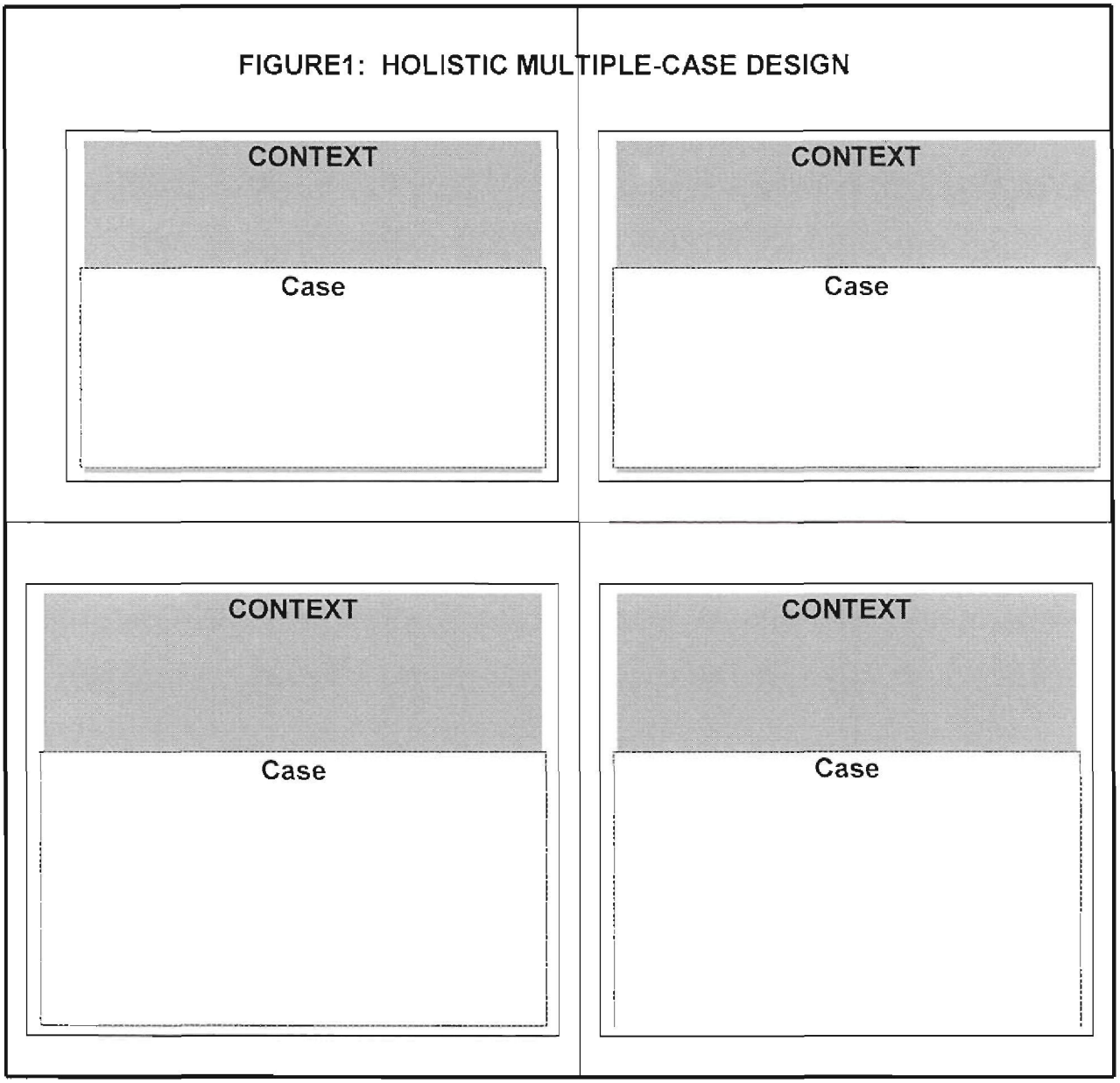
Recommendations for nursing research

Further research could be done on the long term effectiveness of the program for women whose partners died of AIDS to determine whether the effectiveness of the programme is sustainable.

SUMMARY

The development of the program and its components was meaningful in the manner in which it was structured, with the effectiveness of growth enhanced by sessions that built up to coping by the participants. The content of the program was developed to make an impact on assisting women whose partners died of AIDS to cope with stigma. The participants' widowhood status, literacy level, socio-economic background as well as their sero-positive status have contributed to the success of the program due to the homogeneity of the group that led to their cohesion, thus strengthening their coping experiences. The program would, therefore, provide a useful tool in assisting women whose partners died of AIDS to cope with the stigma associated with their having had a partner who was infected and died of AIDS.

FIGURE1: HOLISTIC MULTIPLE-CASE DESIGN



Adapted from Figure 2.4: Yin (2003:40)

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CONCLUSIONS, SHORTCOMINGS AND RECOMMENDATIONS ABOUT THE EXPERIENCE OF COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS AS WELL AS THE PROGRAMME DEVELOPMENT, IMPLEMENTATION AND EVALUATION

CONCLUSIONS, SHORTCOMINGS AND RECOMMENDATIONS ABOUT THE EXPERIENCE OF COPING WITH STIGMA BY WOMEN WHOSE PARTNERS DIED OF AIDS AS WELL AS THE PROGRAMME DEVELOPMENT, IMPLEMENTATION AND EVALUATION

Conclusions are made regarding the experiences of stigmatization, coping with stigma by women whose partners died of AIDS, as well as the development, implementation and evaluation of the programme, shortcomings, as well as recommendations for coping with stigma for women whose partners died of AIDS are discussed.

1.1 Conclusions regarding the experience of stigmatization of women whose partners died of AIDS

The experience of stigmatization of women whose partners died of AIDS reflected a four-pronged pattern consisting of stigmatization based on widowhood, HIV and AIDS, gender as well as poverty.

- Women whose partners died of AIDS experienced stigmatization based on widowhood due to the fact that within the cultural context of this study, widowhood is a stigmatized process due to cultural beliefs that they are witches responsible for having killed their partners, and that they were infested with bad luck. This belief contributed to the isolation, rejection, discrimination as well as prejudice of women by the community, such as accusing them of being responsible for the death of their partners, amounting to further stigmatization.
- Having lost their partners to AIDS which is a highly stigmatised disease predisposed these women to more stigmatisation because of stereotyping. They were blamed for being responsible for having contracted the disease. They were also blamed for having infected their partners through their promiscuity and having failed to take care of themselves. As a result women experienced severe stigmatization that was aggravated by their deterioration in physical health resulting in the community drawing conclusions that they were also infected with HIV.
- Women whose partners died of AIDS experienced gender-based stigmatization, found to be associated with both the widowhood status as well as the gender

stereotype. Both render the status of women inferior to that of men and thus attach certain attributes that undermine the status of women, resulting in stigmatization. These women's experiences were aggravated by their unique experience of being a woman, being a single woman, as well as their vulnerability in not being able to negotiate safe sex. This resulted in their having contracted HIV, thus aggravating the stigmatization by their families, the community as well as health workers.

- The study identified that the women's loss was two-fold, being the loss of a partner and companion on the one hand, as well as the loss of a breadwinner on the other hand. The women's lack of formal education as well as their unemployed status further contributed to extreme poverty that made it difficult to sustain the care of their dependent children as well as their own health, thus depending on a government social welfare grant for family support.

1.2 Conclusions regarding coping with stigma by women whose partners died of AIDS

- Women whose partners died of AIDS were found to be using some effective and some ineffective coping strategies. Their range of effective coping mechanisms was, however, limited to those that focused on the problem and giving less attention to feelings.
- The women found it difficult to cope due to stigmatization and living in poverty that further limited their range of coping strategies that were compounded by their poor literacy level as well as the low socio-economic status. Deciding to disclose their HIV status, however, contributed to their effective coping because they received family, as well as government support in the form of social welfare grants that assisted them to survive as well as augmenting their care of dependent children. Their coping was also strengthened by the support they received from support groups that they joined after disclosing their status.
- The difficulty in coping with the loss of partner to AIDS as well as their own positive HIV status resulted in their using defense mechanisms to cope with the emotional pain of having lost someone close to them as well as their perceived

deception. The use of defense mechanisms served to provide the ego strength as well as relieving the pain for these women.

- The women's range of ineffective strategies of coping that focused on the emotional level such as blaming their late partners as well as the anger towards perpetrators of stigma contributed to their delay in seeking help and support, resulting in continued denial of the illness.

1.3 Conclusions regarding the development, implementation, as well as the evaluation of the programme for coping with stigma for women whose partners died of aids

The programme was successful and had an impact due to the following evidence:

- The programme sessions were structured and presented in such a way that it had a positive effect on the participants. Each session was intended to prepare them for the next session in such a way that the sessions followed each other in a consecutive order, with each adding more value. The orientation allowed them to get to know each other, as well as introducing the programme and to establish a working relationship. The knowledge session moved to a more realistic level meaning that the participants had to face the facts of the illness. Having internalized the knowledge, they could overcome the paralysis caused by ignorance and denial due to inadequate knowledge. The knowledge empowered them to face the reality of having some of the signs or symptoms and to start taking the responsibility of seeking care and assistance. Learning about stigma manifestations and its effects allowed them to study the facts as the 'others' experience safely, and then move to the effects on a more personal level. With coping developing, the session also moved from a more externalized experience to being able to look at their own coping styles. The support and trust in the group facilitated the safe environment. The success expanded by others when they disclosed facilitated a more openness towards the possibility of disclosing. Once they were more able to cope with their own problems and emotions they could extend their skills gained to support others that needed it.
- The systematic order according to which the themes of the programme were structured contributed to the sustained personal growth of always starting from the

external 'others' experience which is less risky, to the internal 'me' experience, which was more risky. The presence of the group provided support through the strength and the experiences of others. The systematic structured build-up of the programme allowed for growth.

- The group size and context also provided the opportunity for intimacy and to see how other participants were dealing with issues or managing their experiences in comparison to how they were personally dealing with issues. The group gave them the opportunity to discuss other possibilities of coping and using the group as a sounding board. Another strength of the programme that enhanced the impact was the choice of participants. The fact that they all lost partners to AIDS meant that they could identify with each other at a similar level in terms of their widowhood status, socio-economic background as well as their literacy level. Because of sharing the same background it was easier for them to learn from one another and adopt positive coping strategies or successes in a supportive and trusting environment.
- As the sessions progressed more trust developed and the intensity of their honest sharing of their genuine experiences increased. The intensity of their sharing exceeded the planned two hour sessions so intensively that two hours became too short.

2. SHORTCOMINGS

Shortcomings regarding the development, implementation, and evaluation of the programme are described as follows.

- Two participants absented themselves more than once, despite the fact that they signed consent forms and committed themselves to regular attendance. This delayed the group's progress due to the postponement of session to allow the absent members to catch up with an individual sessions as well as compromised the richness and sharing of experiences.
- A small group of four participants could be a disadvantage due to limiting the group strength thus depriving participants the opportunity to learn and gain from a wide variety of coping skills from others.

- The duration of two hours when considering the intensity of emotional discussions that these women had to undertake, needed to be longer than it was. Their level of understanding also differed so adequate time was needed for games and exercises in each session so that the slowest one could be accommodated.
- Posters, pamphlets, and videos were mostly available in English and as a result it created a barrier in understanding for those participants who were not fluent in English.

3. RECOMMENDATIONS

Recommendations are made for nursing practice, nursing education, as well as nursing research.

3.1 Recommendations for nursing practice

- It would be meaningful to present the programme in its present layout and not just sections of it as it is structured and built up systematically to enhance the coping strategies of women whose partners died of AIDS.
- The programme should be facilitated by a professional person who is experienced and effective in facilitating people who experience emotional trauma, and who is able to observe group dynamics, as well as working with people from various educational, socio-economic and religious backgrounds.
- The size of the group should be between six to eight participants in order to make provision for a broader opportunity of growth by way of sharing in a variety of coping strategies of the other members.
- It would be beneficial to participants if the duration of sessions could be increased to last about three hours in order to allow for intensive sharing of experiences leading to the development and acquiring of more effective coping skills.
- As the programme progresses the facilitator should adjust the length of the session to accommodate the needs of the participants when the intensity of sharing increases and more support is needed.
- The sessions should be presented once a week to allow for the internalization of learnt coping skills in between sessions. Participants should have the opportunity to apply their new skills in reality.

3.2 Recommendations for nursing education

It would be of benefit if the programme could be offered as an in-service education programme for nurses who are working within the HIV and AIDS context. They should be experienced in group facilitating skills, counselling as well as in handling group dynamics.

3.3 Recommendations for nursing research

Further research could be done on the long term effectiveness of the programme for women whose partners died of AIDS to determine whether the effectiveness of the programme is sustainable.

SUMMARY

The objectives of the study were realized in that in exploring experiences of stigmatisation of women whose partners died of AIDS, it was found that women were stigmatized based on their widowhood status, having lost a partner to HIV and AIDS, gender, as well as their low socio-economic status. Coping with stigma was a difficult process for these women also based on the stigma based on the above-mentioned factors.

The development of the programme and its components was meaningful in the manner in which it was structured, with the effectiveness of growth enhanced by sessions that built up to coping by the participants. The content of the programme was developed to make an impact on assisting women whose partners died of AIDS to cope with stigma. The participants' widowhood status, literacy level, socio-economic background as well as their sero-positive status contributed to the success of the programme due to the homogeneity of the group that led to their cohesion, thus strengthening their coping experiences. The programme would, therefore, provide a useful tool in assisting women whose partners died of AIDS to cope with the stigma associated with their having had an infected partner who died of AIDS.

APPENDIX H: A PROGRAMME FOR COPING WITH STIGMA FOR WOMEN WHOSE PARTNERS DIED OF AIDS

BACKGROUND

The findings of the study conducted to explore and describe coping with stigma by women whose partners died of AIDS (Manyedi, 2006; unpublished article), revealed that these women use a wide range of strategies to cope with stigma. Some of the coping strategies showed that women adopted the problem solving approach while others used the emotions-based approach. Out of both approaches it was found that some strategies were effective and some not effective. Due to the non-effectiveness of some of the coping strategies, there was a need to develop a support programme that would assist the participants to acquire new and effective ways of coping with stigma, as well as to enhance and encourage them to use positive coping strategies that they already used during their coping process.

Goals of the programme

The goals of this programme are:

- To assist women whose partners died of AIDS to acquire skills to cope effectively with the stigma associated with their having had a relationship with an infected person who died of AIDS.
- To assist women who experience the stigma associated with having had partners who were infected and died of AIDS, to strengthen their coping strategies to be more effective.

To ensure that the programme targets the appropriate people, inclusion criteria are determined.

Inclusion criteria

Participants of this programme are included according to the following criteria. They must:

- Have lost their partners to AIDS.
- Have been through voluntary counseling and testing and are aware of their HIV status.

- Reside in the Mafikeng area in the Central region of the North West Province of South Africa.
- Speak and understand Setswana, Sesotho and Sepedi.

PREPARATION PHASE

Almost a month before commencement of the process, the facilitator, visits each potential participant. The aim of the visit is to re-establish a relationship of trust, motivate potential participants to participate in the programme. The facilitator also informs them about the purpose and goals, which are to assist them to acquire skills to cope effectively with the stigma associated with their having had partners who were infected and died of AIDS, as well as to strengthen previously used skills to be more effective. Potential participants are given time to think about it and after a few days the facilitator visits them again to further explain the need to avail themselves regularly for the duration of the programme. Each of them is also informed about the venue, the meeting time as well as the duration of sessions, which lasts for more or less two hours. The orientation and signing of consents is dealt with in the first session. All activities are conducted in their language, to facilitate their understanding and their active participation. In cases where no proper equivalent terminology is available on the spoken language, English terms that are commonly used and understood by almost every average person are used, but always ensuring that participants understand the meaning.

Setting

Meetings take place at the agreed upon venue. It has to be quiet and free of distractions, private, and conducive to interactions with comfortable chairs. There should be enough room to adjust the sitting arrangement as required. The place should also be accessible to all participants, especially if they use public transport.

SESSION OUTLAY

The programme comprises eight sessions that are conducted with a group of women who lost their partners to AIDS. Sessions are held twice a week for up to four weeks, depending on the availability of the participants. The eighth session is held about a month after the seventh, in order to allow time for the internalization of the programme,

so that it can be evaluated whether the participants experienced a change in their coping. Each session consists of the rationale for the session, objectives, the duration of the session, activities to be conducted, teaching media/aids used, specific knowledge to be covered, evaluation of the session experience, as well as follow through to the next session. Participants write naïve sketches to reflect their experiences of the session and these are attached to their notes. Naïve sketches serve the purpose of evaluating the effectiveness of each session, as well as suggesting improvement for subsequent sessions. Those who cannot write are interviewed in order to elicit their experience of the sessions.

The session outlay is as follows:

Session one: Orientation of participants

It allows for introduction of group members, orientating them, as well as dealing with contractual issues. In the orientation participants are informed again about the purpose and goals, duration of the programme, as well as what is expected of them. Contractual issues include ground rules such as regular attendance, punctuality for sessions, active and honest participation by all members, as well as commitment to all the activities and processes that will be followed in the programme. The facilitator ensures that all participants agree and do not anticipate any problems. If there are concerns regarding this contract, they are dealt with empathetically.

Session two: HIV, AIDS, voluntary conselling and testing knowledge session

The participants are given basic knowledge and facts about HIV and AIDS, as well as acronyms that are commonly used. The knowledge also includes modes of transmission of HIV as well as voluntary counseling and testing.

Session three: Stigma, its manifestations and effects on stigmatized persons

This session involves empowering participants about the stigma, its manifestations and its effects on the stigmatized person. The aim is to empower them so that they understand what it is, how it develops, how they experience it, its impact on their lives as well as how they expect to be supported and assisted.

Session four: Creating awareness on coping

It is about putting coping in perspective for participants to understand what coping is so that they identify their own coping styles as well as examining how they cope currently.

Session five: Coping with internal stigma

Participants are assisted to identify their own feelings regarding their HIV status as well as how they cope with internal stigma.

Session six: Dealing with disclosure

It is an engaging session that looks at how participants understand disclosing one's HIV status, sharing their views regarding disclosure, as well as identifying strategies that would lead to successful disclosure.

Session seven: Coping with received and associated stigma

Participants identify their experiences of received and associated stigma, strategies that they use to cope or seek support, as well as looking at other strategies that they could adopt.

Session eight: Evaluation of the participants' internalization of the programme

This session is conducted after a month of completing the programme.

PRESENTATION

Following is an outlay of the rationale, objectives, duration, activities, teaching media/aids, skills to be used, specific knowledge to be covered, and evaluation of the session experience.

SESSION ONE: ORIENTATION OF PARTICIPANTS

Rationale for the session

This initial session is necessary for the facilitator to orientate the participants about the programme and for them to know each other. The orientation clarifies how the programme will be presented so that they understand their role and that of the facilitator.

In this session, participants are also informed about the goals of the programme, how they were selected to participate, as well as the potential benefits.

Objectives of the session

At the end of the session participants should be able to:

1. Recall each other's names, their background history, as well as their places of residence.
2. Recall what they are supposed to achieve at the end of the programme.
3. Commit themselves to attend sessions regularly and punctually.
4. Sign consent forms.
5. Set and agree on the days and dates of the sessions.

Duration of the session: Two hours

Activities to be conducted: Information sharing and clarifications; signing of consent forms

Activity 1.1: Self introduction

- The facilitator greets participants, introduces herself though they should know her already.
- She acknowledges their positive response in attending the session as requested.
- She makes a short introduction that they were visited individually and motivated to attend the programme and that this is the first or initial session that they have come together. Participants are then asked to introduce themselves.
- The facilitator ensures that they have said everything that they need to know about each other. They may be asked if they are satisfied about each other's introduction.

Activity 1.2: Understanding the purpose and goals of the programme

The facilitator proceeds to inform participants that now that they know each other and they are relaxed they can now listen to the purpose and the goals so that they know what they are there for.

- They are informed that the purpose of the programme is to assist and empower them to cope effectively with the stigmatizing behaviours and attitudes that they experience as they mentioned in part one of the study.
- If they understand the purpose the facilitator proceeds to the goals and explains them as stated under goals of the programme.
- Participants are asked to seek clarity if there is anything they do not understand.
- The facilitator then explains that for the goals to be achieved they should attend regularly and contribute in the discussions, therefore they have to commit themselves.

Activity 1.3: Signing consent forms and setting dates for sessions

- Before participants can commit themselves by signing consent forms they are also informed that the programme consists of eight sessions, the first of which is the one they are attending already.
- It is explained that these sessions will involve interactive teaching, counseling and/or support, should there be a need or problems arising during interactions.
- That the facilitator will observe them throughout the sessions and write her notes after every session.
- The use of a tape recorder during sessions is also explained to them, as well as the fact that they would be required to write naïve sketches after each session.
- On agreement, consents are obtained from each participant to protect both the participants' rights as well as fulfilling the researcher's ethical conduct.
- The facilitator then takes the calendar and her diary and they agree on the days, dates, and times during which sessions will be held. Responsibilities are explained, such as sending a call back to the facilitator if they are unable to attend or if they need transport to the venue.
- They are asked if they have any issues that they would like explained and if so they are addressed. The importance of punctuality and regular attendance is emphasized. If no more issues are raised the session is summarized and closed. They are reminded about the next date and times.

Teaching media/aids used

- Flip chart and pens
- Calendar and diary
- Consent forms.

Skills to be used

- Facilitation skills in order to ensure that discussions flow and that all participate.
- Observation skills in order to observe both verbal and non-verbal cues.

Specific knowledge to be covered

The knowledge covered in this session consists of the following:

- Participants get to know each other.
- Participants are orientated about the purpose and goals of the programme.
- The programme presentation, their role and responsibilities as stated in activities above.

Evaluation of the session experience

Participants are asked how they experienced the session and they are encouraged to mention both the positive and negative aspects. They are also asked to suggest anything they wish to be included in future sessions.

Follow-through to the next session

They are given handouts on testing for HIV that are issued in different health centres, written in their language, as well general information on HIV and AIDS. They are encouraged to read them in preparation for the next session. They are asked to summarise what was covered, with the facilitator filling in their gaps. They are reminded about the date and time of the next session.

SESSION TWO: HIV, AIDS AND VOLUNTARY CONFIDENTIAL COUNSELLING AND TESTING KNOWLEDGE SESSION

Rationale for the session

It is often taken for granted that because much information about HIV and AIDS is delivered via the media, pamphlets, as well as health education at health care facilities, everybody knows all the basic facts about the epidemic. This is, however, not as it is thought because when one gets involved with people of different categories one realizes that many people are still ignorant about HIV and AIDS, while those who might have heard about it still live in denial of its existence. The other category is that of those who know bits of information and are, therefore, ill-informed. This session is an information giving session, during which participants are informed about basic facts of HIV and AIDS, as well as information on Voluntary Confidential Counseling and Testing (VCCT) and the implications thereof.

Objectives

At the end of the session, participants should be able to:

1. Recall basic knowledge and facts about HIV and AIDS, the acronyms that are commonly used when referring to HIV and AIDS, as well as their meaning.
2. Understand and be able to explain the mode of transmission of the HIV and how it cannot be transmitted.
3. Understand the process of Voluntary Confidential Counseling and Testing (VCCT) and its implications.

Duration of the session: Two hours.

Activities to be conducted: Games and exchange of information on HIV and AIDS and VCCT

The participants and the facilitator meet at the agreed upon venue and sit in a semi-circle. The facilitator greets participants and allows them to introduce themselves to each other as this is the first session. The purpose of the session is explained, as well as the duration of the session and that of subsequent sessions. This session should not

be hurried in order to allow participants enough time to know each other, trust each other, as well as emphasizing issues of confidentiality and that they will deal with sensitive issues. They agree upon ground rules as stated in the preparation phase. The facilitator explains the structure as well as the process that will be followed in the session. The following game which is designed to test their pre-knowledge is then introduced to them:

Activity 2.1: Playing game cards on HIV and AIDS knowledge

- The game consists of playing cards, each with a basic facts of HIV and AIDS. Commonly used acronyms are included.
- The facilitator instructs participants to listen to the facts that are read from the cards. Participators respond either by affirmation if they agree with the fact, or by objection if they disagree. If their response is correct the card is posted on the wall or board provided. If the response is incorrect and participants agree that they do not know the correct answer the card is put down.
- When the cards are finished then the facilitator looks at those that are not posted, and then provides the correct information. The flip chart can be used for writing new information.
- This also covers the information that may be known by participants but is found to be deficient. The information will also be given to them in a handout after the session.

Activity 2.2: Game cards on the mode of transmission of HIV

- The facilitator brings playing cards with different information about the mode of transmission of HIV, including how it cannot be transmitted.
- The facilitator gives each participant about five cards, each with a different mode in which HIV can or not be transmitted.
- On the flip chart two columns are drawn, one for how HIV can be transmitted and the other column for how it cannot be transmitted.
- Then she asks the first participant to hand over a card on how HIV can be transmitted. If the card with correct information is handed over it is pasted in the

relevant column. If it is incorrect it is pasted on the board with its face towards the board so that others may not see it.

- The game proceeds like that until all participants are out of cards.
- Then they are allowed to look at the cards pasted on the board one at a time. This time if they find that they are not sure of the information written on it they hand it over to the facilitator, until all the cards are removed from the board.
- The facilitator is then left with the cards with the information that they are unsure about. She explains the information.

Activity 2.3: Experiences of VCCT

This activity takes into cognizance the fact that participants already know their status which means they have been through testing for HIV.

- Participants are asked to share their experiences of having undergone testing for HIV.
- They are asked in particular, how they encountered the process; were they counseled prior to and after the test?
- If they were what are the advantages of counseling and how did it help them.
- The group discusses these experiences and the facilitator listens to their experiences and provides the necessary supportive counseling.
- They also discuss the advantages of having been tested, and explore the disadvantages if they had not been tested.

Teaching media/aids used

- Game cards with HIV and AIDS facts, mode of transmission and VCCT information written on them.
- Flip chart and pens.
- Pamphlets on HIV and AIDS, mode of transmission and VCCT information to hand out to participants.
- Press stick to secure the flip charts and posters.
- Posters issued by the Department of Health on the HIV and AIDS information, obtainable from health centres.

Skills to be used

- Listening skills in order to identify the message conveyed, so as to assist participants.
- Creative skills to facilitate the information in order to make sense to participants.
- Facilitation skills in order to ensure that discussions flow and that all participate.
- Observation skills in order to observe both verbal and non-verbal cues.

Specific knowledge to be covered

The knowledge in this session covers the meaning of the acronyms HIV, AIDS and VCCT, as well as basic facts about HIV and AIDS, the mode of transmission, as well as information on VCCT.

Acronyms:

- HIV: Human Immunodeficiency virus; it is a virus that depletes the human body of its immunity against diseases, therefore, the body becomes vulnerable (ACORD, 2004:5).
- AIDS: Acquired Immunodeficiency Syndrome (ACORD, 2004:5); It is a collection of symptoms that occur when the body's immune system fails. It occurs during the advanced stage of HIV infection. The person becomes sick at this stage.
- VCCT: Voluntary Confidential Counseling and Testing; A process whereby a person wishing to be tested for HIV presents herself for counseling and testing.

Basic facts and information about HIV and AIDS

- One is said to be HIV positive when one has contracted the virus and it has shown in one's blood.
- If one is HIV positive one can live for many years feeling healthy, that is, before one develops AIDS.
- The CD4 cells are essential for the immune system so HIV usually attacks and weakens and damages them. The body then fails to protect itself against many germs that cause infections.

- These germs then take advantage of the weak immune system and enter the body. One then develops opportunistic infections. This leads to a number of diseases (syndrome) called AIDS.
- After one has contracted HIV one can remain healthy for about five to ten years; this is stage 1. After some time the amount of HIV in the blood increases, meaning the increase in the viral load. As the viral load increases the CD 4 count drops (Soul City & Jacana, 2005:7).
- At this stage one can develop flu-like symptoms that come and go. You may also have painless, swollen lymph glands.
- Then one goes to a stage when one develops short periods of mild illness but one may be healthy most of the time; this is the second stage and the CD4 count may be between 350 and 500.
- Then follows the stage of severe disease when one frequently gets sick, with a CD4 count of between 200 and 350; this is the third stage.
- The fourth stage (AIDS) is when a person gets very sick, with AIDS defining illnesses such as chronic diarrhea, repeated pneumonia, TB, skin rashes or lesions, weakness and tiredness. The CD4 count drops to below 200. ARV's may relieve the person for some time (Soul City & Jacana, 2005:9).

The mode of transmission

- HIV is transmitted in three ways namely, unprotected sexual intercourse with an infected person, from an infected mother to a child during pregnancy, childbirth or breast-feeding, and from blood transfusion with infected blood.
- HIV cannot be transmitted through sharing eating utensils with an infected person, using the same chair, toilet or bath with an infected person, sharing the same bed and bed-linen with an infected person, as long as there is no sex involved, as well as through touching and kissing.

Information about VCCT

- An individual is counseled before testing, meaning that they are told about the options, that they can either be tested instantly by drawing a sample of blood by pricking the tip of a finger, squeezing blood onto the tester, and after a few

seconds the results are read. The second option is to draw blood from a blood vessel by pricking one's arm; the blood is then sent to the laboratory and one is told when to come for the results.

- Before obtaining one's blood, one is told that a positive result means that you have a Human Immunodeficiency Virus (HIV), and that a negative result means that you do not have it.
- If you are negative, you have an option to either continue abstaining from sex which means that you do not sleep with a man to avoid being infected, or you have to practice safe sex meaning that you use condoms when you have sex and that it may also be necessary to repeat your test at a later stage.
- When the test is positive one will again undergo intensive counseling to make sure that one comes to terms with the status and accepts it, and to ensure that one is supported throughout.
- The virus is transmitted in three ways namely, through sexual intercourse between a man and a woman or anal intercourse of two men; exchanging syringes when injecting drugs into the body or through a blood transfusion of infected blood, and through mother to child transmission during pregnancy, during birth or through breast-feeding.
- VCCT is important because once someone becomes aware of her status, she can be advised about a healthy lifestyle, which will ensure that their health is also monitored regularly. This advice includes precautions to prevent re-infection, as well as eating healthily in order to boost one's immune system.
- The advantages of testing are that once one knows one's status one will have a period of sadness but ultimately one will come to terms with the reality of the sickness and thus accept it; this prevents the denial and defense mechanisms used by those who find it difficult to accept the reality.
- Being HIV positive is not being sentenced to death; the reality of death is that everyone is going to die because we are not immortal, and nobody knows when; many people without HIV and AIDS have died at a young age from other causes such as motor vehicle accidents and other illnesses. HIV and AIDS can be fought, not by becoming bitter and infecting others so that they may suffer like one anticipates, but by taking extra care of oneself (Uys, 2003:10).

- Self acceptance also paves the way towards disclosure, which facilitates positive and effective coping; if one develops one's coping strategies, coping with stigmatization will become easier.

Evaluation of the session experience

- Participants are given paper sheets to write down naïve sketches of how they encountered the session and what they gained from the session.
- Those who cannot write are interviewed to allow them to state what they have learnt from the sessions.
- They are also asked to state any suggestions for the next sessions.
- The facilitator also writes field notes about the session.

Follow- through to the next session

- Participants are requested to go and think about being infected.
- How they feel about their HIV status, and how they see people living with HIV and AIDS being treated.
- They should also observe carefully how people behave towards those who are infected as well as their family members.
- They can also write down the words and gestures that people use towards them so that they present them in the next session.

This exercise will be preparing the participants for the stigma discussion in the next session. One of them is asked to summarise, after which others add what she omitted; the facilitator consolidates all inputs. They are reminded about the date of the next session and the session is closed.

SESSION THREE: STIGMA, ITS MANIFESTATIONS AND EFFECTS ON STIGMATISED PERSONS

Background

The concept "stigma" does not have a synonymous term in most of the South African black languages, therefore, it has to be explained whenever reference is made to it. It is thus not easy for an average person to understand it from the onset. This problem of

conceptualization creates difficulty in expressing feelings as well as experiences of self stigmatization by participants. This session, therefore, requires that participants should be given an opportunity to express how they understand stigma, how they experience it and what their expectations are in terms of being assisted or supported in the process.

Objectives

At the end of this session participants should be able to:

1. Explain what stigma is, how and why it develops.
2. Understand how stigma might impact on themselves.
3. Share their expectations of support and assistance.

Duration of the session: Two hours.

Activities to be carried out: Watching a DVD on the discussion of stigma and its manifestations and experiencing and reacting to the effects of stigma

The following activities are carried out in order for participants to achieve the above objectives:

Activity 3.1: Watching a DVD on the discussion of stigma and its manifestations

- The facilitator sets up the laptop computer, ready to show them a DVD on the discussion of stigma and its manifestations. The seating is in a semi-circle to facilitate a discussion.
- The facilitator greets participants and explains to them the purpose of the session. She explains that she is about to play a Soul City DVD that portrays a focus group that discusses the impact of HIV in the community.
- The discussion focuses on the stigma, how and why it develops, as well as stigmatizing views about HIV and AIDS. When they finish watching it they are asked about their own impressions as well as interpretations of the discussion.
- This is to find out whether they can identify the stigma manifestations as well as the reasons why it exists.
- Based on what they identify, each of them is asked to write on a sheet of paper what could be added to the information they have identified.

Activity 3.2: Experiencing and reacting to the effects of stigma

- Take A4 sheets of paper and cut each half.

On each piece of sheet write the following statements in English and the spoken language:

- "People with HIV and AIDS have lived their life to their satisfaction; they should not complain."
- "Why should you want sex if you are HIV positive?"
- "A woman who is living with HIV and AIDS had a reckless life."
- "That child's father died of AIDS, he should not play with our children."
- "She is so thin she should be suffering from a four lettered disease."
- "I met the lady whose husband was buried six months ago, she looks like she will follow soon."
- "Government should not bother, will it afford to take care of millions of people who are careless with their lives."
- "People with AIDS should be locked up in their rooms; why should they attend funerals."

Instructions to participants:

- These papers are folded; each participant takes one at a time, opens, reads it and tells the group how she would feel and react if that was directed at her.
- These reflections are written on the flip chart.
- Thereafter, with the facilitator guiding them they look at the reflections one by one, stating whether they are positive or not. The facilitator marks them with either "P" for positive or "N' for negative.
- Then they look at reflections that they thought were negative and discuss why they think they are negative and what could be positive.
- The facilitator replaces the negative with the positive as they proceed, until the process is completed.

Activity 3.3: Identifying support mechanisms for stigmatized individuals

Instructions

- Participants are given sheets of paper and asked to sit quietly for about five minutes.
- They think about the experiences they had in the above activity.
- They then write down how they would like to be assisted or supported in their experiences of stigma.
- Those who cannot write sit away from the others and the facilitator assists them by noting down what they suggest.
- Then the group comes together and reads out their responses one by one.
- All responses are written on the flip chart as they are read.
- They are then read again and discussed; they are asked if there are some that could be added. If not the facilitator checks the notes and states those that they did not identify, and asks them whether they could be added to the list.
- If they agree they are added.

Media/aids to be used

- Sheets of paper.
- The laptop computer and Soul City DVD that shows the discussion on the manifestations and the effects of HIV and AIDS in the community.
- Handouts with notes on types of stigma to read at home.
- Relevant charts.

Skills to be used

- Listening skills (deliberate listening) in order to elicit all significant information expressed.
- Creative skills to facilitate the discussions towards the relevant content.
- Facilitation skills to ensure that all participants get involved in a discussion.
- Observation skills to identify verbal and non-verbal cues.

Specific knowledge to be covered

Participants have to leave this session being aware of what stigma is, the types of stigma, as well as how stigma manifests itself. This information is also written in the language in use and given as a handout for them to read at home and internalise.

External stigma

It manifests in the following ways:

- Avoiding, meaning that people may be reluctant to associate with one by not wanting to use the same eating utensils or sleeping with one in the same room or bed.
- Rejecting, that is more painful when one's family members, friends or colleagues do not want one next to them.
- Blaming those infected for having been careless, immoral or promiscuous.
- Gossiping, meaning that people go about talking negatively about one being sick, and often exaggerating the illness or signs.
- Abusing PLHA physically (beating or assaulting), or verbally by using unpleasant language such as, "She's suffering from four letters" or "You are peeping into the grave".
- Neglecting, such as not caring for one when one is sick and weak (Siyam'kela, 2007:6).
- Fear of contagion, meaning that people are afraid to contract the virus from the sick person, hence they discriminate against her in several ways.
- Pestering is constantly remarking or asking one about being sick.

Internalised stigma manifests when PLHA accept the situation and stigmatise themselves and it manifests by:

- Self exclusion from services and opportunities, such as not going for treatment.
- Fearing to disclose their HIV and AIDS to those close to them because they fear rejection and discrimination.
- Social withdrawal whereby one keep away from other people or getting close to them.

- Having low self esteem or looking down upon oneself due to being infected with HIV.
- Overcompensation, meaning that PLHA believe that they have to do more in order to be accepted by others (Siyam'kela, 2007:6).
- Turning to self-abusive measures such as alcohol abuse and indiscriminate sexual activities.
- In its extreme, internalized stigma can lead to depression and suicide.

Associated stigma

It is also observed in cases where partners, children and those closely associated with PLHA are discriminated against.

- Explain that HIV and AIDS is feared by most people because it is characterized by bodily disfigurement, deterioration in health and the high rate of death. What aggravates the stigma is the signs such as gross loss of weight, diarrhea and sores especially in the mouth, making it difficult for the person to eat. The terminal phase, where in some cases a person has to wear diapers (adult disposable napkins) due to severe diarrhoea and weakness, is probably the most frightening, therefpre the stigma intensifies during this period (they probably have seen it). However, the group has to be reassured that not everybody goes through this stage because people differ in terms of their resistance to the disease, as well as their strength.
- The HIV and AIDS stigma may thus be real or perceived negative reaction to a person by people or society and it is characterized by gossiping, fear of being infected, rejected, discredited, blamed, labeled, neglected, abused pestered, negated, and differential treatment that amount to discrimination (ACORD, 2004:11; Greeff & Phetlhu, 2007:..).

The development of stigma

- This is a process which may begin with people pointing out the difference between themselves and the PLHA, and labeling it such as "she has lost weight so she must be ill".

- They move on to say that the difference is due to negative behaviour such as her illness is due to carelessness or promiscuity.
- Then they go on to separate "us" from "them" that is, we are not like that but they are like this.
- Then there may be loss of status arising from discrimination such as, "they do not deserve respect, we cannot associate with them, or we can treat them in a particular way" (Siyam'kela, 2007:7).

On this note, participants are made aware that they can be in control of what impact the stigma can have on them. They should also be reminded that women have historically, culturally and religiously always been discriminated against based on their gender or sex in the following instances:

- It is acceptable in some cultures that men with multiple sexual partners are accepted, when women are not;
- HIV and AIDS is associated with promiscuity so HIV positive women are more stigmatized than their male counterparts;
- Women with HIV and AIDS are often blamed despite that poverty leads some of them to engage in sex work to earn a living for themselves and their children.
- Then participants are made aware that if you understand HIV and AIDS and you have accepted yourself, other people's behaviour should not affect you because you shall have developed resistance against those attitudes and behaviour, and thus able to cope with them.

Evaluation of the session experience

- Participants are asked to raise questions and discuss their feelings with regard the whole session;
- They are asked to reflect in their naïve sketches, on how the experienced the discussion in this session, and to state whether they have accomplished their objectives.
- They could also be asked for suggestions in this regard. Then they should make the summary and closure.

Follow-through to the next session

- Participants are asked to go back home and to constantly think about what their purpose in life is, and whether they allow it to be influenced by other people's attitudes.
- They could also think about any difficult situations that they experienced previously as well as how they went through, dealt with or coped with it.
- This reflection will prepare them for the next session, which is coping with stigma.
- They are reminded about the date of the next session.

SESSION FOUR: CREATING AWARENESS ON COPING

The rationale of the session

It has been documented that coping with the loss of a close person to AIDS constitutes one of the difficulties that people who are HIV positive themselves face in their lives (Sikkema, Kalichman, Hoffman, Koob, Kelly, & Heckman, 2000:613). Individuals facing a difficult situation such as an illness need to learn and master new skills as well as to gain information that will assist them in dealing with such illness. It is, therefore, necessary for participants to be aware of coping so that they can be able to identify their coping skills and then learn to cope effectively with the stigma they are confronted with. Social support constitutes people in the individual's circle of contacts, who usually assist them practically, such as taking them to the doctor when they feel helpless, as well as those who will provide information on how to deal with the situation, such as professionals (Taylor & Field, 1997:135). This session, therefore, deals with information giving to participants to understand what coping is.

Objectives:

At the end of this session participants should be able to:

1. Recall the basic information on coping so that they are able to identify their own coping styles.
2. Look at their own pros and cons of their own coping styles.

Duration: Two hours.

Activities to be carried out in the session: Becoming aware of your coping

The facilitator greets the participants and she may say something to make them relax, such as asking about how they slept the previous night or how the weather is. Then she introduces the following activity that addresses both objectives:

Activity 4.1: Becoming aware of your coping

- Provide the cards with statements that represent what has been frequently mentioned by participants in phase one of the study and mark them from 1 up to 12.
- The facilitator reads them one by one.
- On the paper sheets they are given, which are also written 1 up to 12, they write 'yes' if the statement on the card represents what they do or think, and 'no' if it does not represent what they do or think.

1. If you suspect that you might be HIV infected, the best thing to do is to go for voluntary confidential counseling and testing (VCCT).
2. After learning that I am HIV positive, I told someone about it.
3. Visiting the doctor regularly and eating well are the best things to do when you are HIV positive.
4. I avoid or practice safe sex always.
5. I think the best thing is to consult traditional healers because they can heal HIV and AIDS.
6. I turn to God for spiritual healing.
7. I stopped going to church and praying because the church does not support people with HIV and AIDS.
8. After learning that I was infected by my partner I became bitter and would not communicate with him till he died and even now I have not forgiven him for that.
9. Joining a support group is important.
10. I started to talk and teach other people about HIV and AIDS.
11. I try to empower my children and save money for them so that they may survive when I am no longer there.
12. I hate everyone who stigmatizes me.

- After they have responded the facilitator reflects the responses on the flip chart that is, how many "yes" responses and how many "no" responses.
- They go through the questions with the participants. For the negative responses the facilitator asks those who responded negatively to state why it is good to react like that and how it benefits them.
- The discussion should unfold, with the facilitator checking with them whether a particular strategy is effective or non-effective. If they think it is effective or non-effective they give reasons and suggest what is effective in case of the non-effective.
- The discussion continues until they have exhausted the list. If there are additional strategies they are added and discussed as above.

Media/Aids to be used

- Sheets of paper.
- Pamphlets with illustrations that are relevant to coping with HIV are used to enhance their learning interest and understanding.
- Flip chart, pens, press stick.

Skills to be used in the session

- Teaching skills to be able to test for pre-knowledge and give new information.
- Facilitation skills to lead and guide the discussion.
- Observation skills to identify verbal and non-verbal cues.

Specific knowledge to be covered

Basic information on coping

Coping means to "deal effectively with or contend; manage" (Branford, 1994:200; Aldwin, 2000:71). Patients facing stressful life situations have to be assisted by professionals to cope with such situations. Coping, according to Kleinke (1998:2), is associated with the efforts that one makes to manage situations one appraises as being stressful and potentially harmful. There are two types of coping namely problem-focused and emotion-focused coping. Problem-focused coping strategies are those that

the individual employ with the aim of modifying the source of stress by doing something about it (Carr 2004:215; Mickelson *et al.*, 2001:184; Coetzee & Spangenberg, 2003:210). According to Kleinke (1998:3), problem focused coping strategies can be outer-directed, being those that are oriented towards changing the situation or the behaviours of others. Then there are inner-directed coping strategies that involve efforts that an individual makes to alter his /her own attitudes and needs, thus developing new skills and responses (Kleinke, 1998:3).

There are functional and non functional strategies for both types of coping. Functional strategies are those involving accepting the responsibility for solving the problem, seeking relevant information about the problem, as well as seeking support, advice or help. To succeed in coping effectively, one also needs to be creative, wise and conscientious. Some authors believe that you need a coping pattern that combines an easy temperament and autonomy, together with willingness to seek assistance in order to succeed in coping with stress (Kenny *et al.*, 2000:94). Dysfunctional problem-focused coping strategies are those in which an individual accepts little responsibility for solving the problem, seeking inaccurate or irrelevant information; advice and support are sought from inappropriate sources such as traditional healers; developing unrealistic plans motivated by perpetual denial, failure to make follow-up on problem solving plans, as well as lack of confidence in problem solving ability (Carr, 2004:211).

Emotion-focused coping strategies refer to cognitive problem solving and behavioral efforts which serve to reduce negative emotions resulting from the existence of the problem (Coetzee & Spangenberg, 2003:208). Strategies that are suitable for this type of coping are, developing and maintaining meaningful support systems, catharsis, seeking meaningful spiritual support, refraiming, cognitive restructuring and making humour out of stress (Carr, 2004:217). Functional emotion- focused coping strategies include relaxation and physical exercise because they take effect by regulating the mood. There is also a range of functional strategies that do not alter the source of stress, and they are support, catharsis, reframing and humour. Dysfunctional emotion-focused coping strategies are amongst others, developing destructive relationships that are non-supportive, seeking spiritual support that is not meaningful, long term denial, wishful thinking, abusing alcohol or drugs, as well as aggression rather than engaging in physical

exercise. These strategies give a short term relief, after which an individual has to face the reality of the problems that still exist. In some cases, individuals may engage in functional avoidant coping whereby an individual psychologically disengages from a stressful situation and temporarily get involved in distracting activities, which are not desirable.

Participants are then be engaged to seek clarity where necessary, as well as reflecting on this information in relation to what they have been doing to deal with their situation. Their inputs will be discussed.

Evaluation of the session experience

- Participants are asked to share their experience of the session.
- They are asked to write naïve sketches and those who cannot write are interviewed before the session is closed.

Follow-through to the next session

- Participants are encouraged to do self reflection on their own to evaluate whether they use realistic coping strategies that are appropriate to their situation.
- They are also requested to think about how they feel about being infected with HIV, and how they expect other people to think about them.
- They can note those for discussion in the next session, which is about coping with internal stigma. They are reminded about the next date.
- The session is summarized and closed.

SESSION FIVE: COPING WITH INTERNAL STIGMA

Rationale for the session

The stigma attached to HIV and AIDS cannot be completely eradicated due to the attitudes and the fear of the syndrome by the community, hence PLHA are also haunted by self stigmatization (ACORD, 2004:19). Coetzee and Spangenberg (2003:208) maintain that for PLHA it is crucial to ensure an optimal quality of life which is inherent in coping with one's own internal feelings and attitudes towards the disease. This session

deals with coping with internal stigma and aims at empowering participants to deal with feelings of self stigmatization.

Objectives

At the end of this session, participants should be able to:

1. Identify their perceptions of being infected with HIV.
2. Identify actions and behaviours for them to cope with internal stigmatization.

Duration of the session: Two hours

Activities to be carried out: An exercise on sharing feelings and perceptions about being HIV positive, followed by a discussion.

Activity 5.1: Sharing feelings and perceptions about being HIV positive, followed by a discussion.

The following exercise covers both objectives.

- The facilitator greets participants and asks them how they feel after the previous session. She listens and provides appropriate responses.
- The following instructions are given:
  - As they are seated the first participant tells the second one how she feels about being HIV infected.
  - The second one listens and if she thinks that she said an effective or positive response she says it loud and it is noted on the flip chart. If she thinks it is non-effective or she is not sure she whispers it into the facilitator's ear.
  - The facilitator writes it on a paper sheet.
  - When they finish the second participant does the same to the third one until they have all had an opportunity to respond.
  - The facilitator then reads aloud those that are written on a paper sheet and asks for their responses. They are all given an opportunity to answer and inappropriate answers still remain on the paper sheet. After those

strategies are exhausted they all discuss them with the facilitator explaining why the response is appropriate or non-appropriate.

- They are allowed to seek clarity where they are not sure.
- When consensus is reached, the facilitator credits positive responses against the list and finally notes the points that each has obtained. The one with the highest points gets a token.

This session should be intensive and dwell on the participants' experiences with regard to factors contributing to their self perception, self blame, withdrawal and self exclusion. It should be emphasized that these attitudes will jeopardize their chances of getting services and the support that they need. That because they need to bring up their children, they should ensure that they maintain their health in order to live longer.

Teaching media/aids to be used

- Flip chart and pens.
- Press stick, tokens in the form of key holders.
- Hand-outs of Human Rights.

Skills to be used

- Listening skills (deliberate listening) in order to elicit all significant information expressed.
- Creative skills to facilitate the discussions towards the relevant content.
- Facilitation skills to ensure that all participants get involved in a discussion.
- Observation skills to identify verbal and non-verbal cues.

Specific knowledge to be covered

Internal stigma

- Internal stigma is experienced when a person living with HIV and AIDS feels that he/she does not deserve to be treated like other people or that she/he should be discriminated against.

- It is manifested by self perception, social withdrawal, self exclusion, deterioration in physical strength, fear of disclosure as well as feelings of deception and ignorance.
- People with internal stigma often feel that they do not have rights to be treated with dignity, to access resources and services such as ARV's grants and other forms of assistance.

Strategies to cope with internal stigma

- Develop a positive attitude towards self by practicing the following strategies
    - Always tell someone about your feelings, don't keep them to yourself.
    - Practice self-talk to facilitate self acceptance.
    - Remember that you are a human being with the right to live like any other person.
    - Join the support group where you can share your experiences with others and get support.
    - Use relevant information, education and communication strategies to reach others, such as those published on posters, pamphlets and booklets.
    - Try to gain access to trained counselors or home-based carers.
    - Try to gain access to available services or resources, such as ARV's.
    - Constitutionally, every human being has rights that are supposed to be respected, so be aware of your rights. (Hand-outs on the Human Rights are given to them).
- Assistance with regard to accessing some resources that they are entitled to such as how to access government grant.
- Those who are already on Ante Retroviral Treatment (ARV's) could also be asked to share their experiences of the drugs. The importance of compliance is also mentioned, namely that compliance and a healthy lifestyle will delay the appearance of symptoms as well as prolong the lifespan.
- Participants should take precautions to prevent re-infection by means of total abstinence from sex or using condoms if one engages in sex. It should be emphasized that HIV is transmitted in three modes namely sex, blood transfusion of infected blood and mother- to- child transmission.

- It is also their responsibility once they know, to educate others, especially those that stigmatise without sufficient information.
- Eating healthily such as eating vegetables, fruit and proteins helps to build up worn out body tissue, and vitamins help for fighting diseases so you should feel healthy and restore your self esteem.
- Do regular exercise such as walking instead of using transport for short distances, and walking upstairs instead of using elevators or escalators helps to strengthen muscles and to build resistance against stress.

Evaluation of the session experience

- The session is evaluated by asking participants to reflect on their participation in the session.
- They should also reflect on newly learned strategies in an honest manner by writing naïve sketches.
- Interviews are carried out with those who cannot write.
- The session is summarized and closed provided there are no questions, which should be addressed as they are raised.

Follow-through to the next session

- Participants are requested to start effecting little changes with regard to their attitude towards themselves, such as being confident, loving and accepting themselves since they cannot change their HIV status.
- This attitude will prepare them for the next session of disclosure.
- They are reminded about the next date.

SESSION SIX: DEALING WITH DISCLOSURE

Rationale for the session

PLHA often experience difficulty in disclosing their status because of the complexity of issues surrounding disclosure such as, stigma and discrimination, prejudice and that people fear contagion (Mayers, Naples, & Nilsen, 2005:102; Greeff *et al.*, 2006, (unpublished article). The fear is associated with uncertainty with regard to what the

reaction of those that they choose to disclose to, would be. It is also influenced by their concerns with regard to the negative consequences that comprise prejudice and stigmatizing attitudes (Yang, Li, Stanton, Fang & Lin, 2006:717). PLHA, therefore, require assistance and support that will provide them with strategies to disclose their status within a conducive environment. It should be borne in mind that disclosure is a choice and that it is necessary to provide information and support and not to compel anybody to disclose their status until such time that they feel ready to do so. This session aims at equipping the participants with the necessary skills for the process of disclosure.

Objectives

At the end of the session, participants should be able to:

1. Explain how they understand disclosure.
2. Share their views on how they personally feel about disclosure.
3. Identify strategies that would lead to successful disclosure.

Duration of the session: Two hours.

Activities to be involved in this session: Discussion on understanding disclosure; sharing personal views on disclosure and information giving on strategies that would lead to successful disclosure

Activity 6.1: Understanding disclosure

The facilitator greets participants and welcomes them to the session. For a few minutes she asks them to say whether they are attempting to effect changes towards their self acceptance since the last session. After a short discussion of their reflections she proceeds with the session as follows:

- Pamphlets on "understanding disclosure" (adapted from the Siyam'kela project 2007:160) and translated into Setswana are given to participants.
- They are given fifteen minutes to read through, after which each identifies the aspect that they think represenst their views regarding disclosure, or those that they disagree with.

- They are requested to indicate on their pamphlets using a tick where they agree or a cross where they disagree with a list of those views.
- When they have completed the process they then discuss those views that need further exploration that could include the following:

Activity 6.2: Strategies that could lead to successful disclosure

- The next step becomes that of deciding whom to disclose to, as well as the reason for choosing that particular person.
- The facilitator listens to the reasons and engages all of them to contribute. Support is given where appropriate. Women are also encouraged to consider putting themselves first, that is not doing anything to satisfy other people but rather to consider their needs, unless they think that their children's needs could be compromised.
- In this session women should be referred to the first session that they should always remember that HIV and AIDS are not the only disease that are stigmatized but that there are other diseases and situations such as poverty, some ethnic groups, languages, social status, religions even the types of jobs others do.
- They should, therefore, never allow themselves to be frustrated by acts of stigma, as there is a wide range of other people stigmatised for different reasons.
- Another thing to remember is that disclosure is still controlled because they would decide whom they want to tell, who could maintain the confidentiality that there are those who prefer to go public, but that it is not compulsory.

Teaching media/aids

- Handouts on "understanding disclosure."
- Flip chart and pens.

Skills to be used

- Listening skills to elicit all significant information expressed.
- Creative skills to facilitate the discussions towards the relevant content.
- Facilitation skills to ensure that all participants get involved in a discussion.
- Observation skills to identify verbal and non-verbal cues.

Specific knowledge to be covered during the session

What is disclosure

- Disclosure means telling someone that you are infected with HIV.
- Disclosure may be full, partial, indirect, involuntary, or not to disclose at all.
- Full disclosure is when one publicly reveals her status to everybody and this is a gradual process and it may begin with family or friends, colleagues, then to the media, that is, the radio, television and to the newspapers.
- Partial disclosure is revealing your status to certain people such as your partner, family members, friends, relatives or colleagues. This is also a gradual process that involves trust because you hope that those people will keep it confidential.
- Indirect disclosure means referring to HIV and AIDS through paintings and pictures without referring to yourself. This usually occurs when one struggles to accept the status and to disclose it.
- Involuntary disclosure is when someone reveals someone's status without their knowledge or permission.
- Not revealing your status at all is referred to as non-disclosure (Siyam'kela, 2007:160).
- It should be borne in mind that it takes time to accept your status and that one's feelings change from time to time, depending on the circumstances.

Factors that influence disclosure as well as the choice for disclosure

There are reasons for any individual to want to disclose:

- Some disclose in order to get support from those close to them.
- Some disclose in order to receive government entitlements.
- Some may disclose because they are so sick that they can no longer conceal it.
- Some disclose because they need to take treatment.

- If you disclose your status, know the reasons why you want to do so.

- If you disclose to the family reassure them that you under good care and give them a chance to also accept it at their own time ans accept their responses and inform them about your future plans.
- When you disclose to children, consider their age, state of maturity and their coping ability.
- When you disclose publicly decide why you want to do it, what you would like to say, to whom you want to say it, where and when to disclose (Siyam'kela, 2007:161).

The advantages and disadvantages of disclosure

- The advantages are that you free yourself emotionally and you will access the resources such as entitlements, treatment and support from those around you.
- The disadvantages are that you may experience discrimination or stigmatization and your children may be traumatized and experience difficulty in coping.

Evaluation of the session experience

- Participants are asked to reflect on the discussions of this session and how they encountered it.
- Their responses are recorded and the session is summarized and closed, with a reminder that the next session will be the last one.
- They are given sheets of paper and pens and asked to reflect their naïve sketches of their experience of the session. Those who cannot write are interviewed individually while others are writing.

Follow-through to the next session

- Those who still find it difficult to disclose are encouraged to think about it so that they decide whether they prefer not to disclose or to make a breakthrough on a small scale, such as disclosing to a sibling, or any preferred person before the next session.
- They should be reassured that disclosure empowers them to accept their status and thus deal effectively with received stigma, which will be dealt with in the next session. The next date is agreed upon.

SESSION SEVEN: COPING WITH RECEIVED AND ASSOCIATED STIGMA

Rationale of the session

The literature on stigma reduction documented that a variety of intervention skills implemented at individual or group level could be helpful in assisting the PLHA to cope with stigma (Brown, Trujillo, & Macintyre, 2001:1; Mahendra *et al.*, 2006:7). Greeff and Phetlhu (2007) recommended that stigma interventions should be aimed at alleviating the impact of stigma on all aspects of people's lives, therefore it is necessary to teach these women skills to enable them to cope with various aspects of stigma. It is also proven by research that women living with HIV and AIDS are often more stigmatized than men for having failed in their role as proper women, and are often referred to as prostitutes (Khan & Loewenson, 2005:6; Ogden & Nyblade, 2005:25).

Objectives of the session

At the end of the session, participants should be able to:

1. Identify in the group received and associated stigma that they experienced.
2. Identify strategies for them to cope and to ask for family support.

Duration of the session: Two hours

Activities to be undertaken in the session: Exercise for sharing experiences of received and associated stigma and on identifying strategies to cope with received stigma and seeking family support

Exercise 7.1: Sharing experiences of received and associated stigma

- Participants are first greeted and asked to reflect on the previous session and perhaps share their positive experiences, especially with regard to disclosure. This would include whether they were able to expand their disclosure since the last session by telling one or more people about their HIV status. Discuss their experiences and support where necessary.
- They are then asked to role- play incidences of received stigma that they have observed or experienced.

- This is followed by a discussion to share their experiences of those incidences. Participants reflect whether they regard their reactions to have been effective or not. If not, they suggest what could have been effective and they evaluate it with the group.
- Discuss the rest of the positive responses about how participants dealt with incidents of received stigma as well as suggesting what could have been effective in cases where the group thought that responses were negative or ineffective.

Exercise 7.2: Identifying strategies to cope with received and associated stigma

- Participants are asked to reflect on their strengths, abilities, and capabilities. Based on what they have realized about themselves, they are asked to capitalize on their strengths because they will assist them to resist negative attitudes that confront them on daily basis.
- Self assertiveness is then incorporated by asking participants to do the following exercise:
  - Participants are asked to form pairs and to tell each other what they like and what they do not like about themselves. This makes them to gain more insight into themselves. Once one becomes open to self criticism, one will also learn to criticize others constructively.
  - They then tell each other what positive aspects they observed about each other since they started interacting in these sessions.
  - The next step is to tell each other what they do not like about the person. This they should do constructively without hurting each other, emphasizing on sending the 'I' messages such as, "I do not appreciate you remarking repeatedly about my loss of weight" or "I do not like people repeatedly asking me whether I am not sick, because it is my responsibility to tell them when I do not feel well".
  - Participants then come together and discuss how they experienced the exercise and how they felt when sending the 'I' messages, as well as when receiving them.
  - The facilitator then makes them aware that when people remark negatively to them, they should react by sending 'I' messages; if this is done in a non-

aggressive manner the perpetrator of stigma will realize that their remarks are not worthwhile and would refrain from doing it in future. They will in turn also feel good, telling someone what they do not like without offending them, because it promotes peace rather than bitterness.

- Participants are also invited to express different beliefs with regard to spirituality as it is known to be a diverse issue. If there are recommendations requiring the involvement of their faith leaders such as the clergy, pastors or other spiritual leaders, they could be considered. These may include to be prayed for or deliverance services or Bible studies. Participants are encouraged to do this if they believe it could help them cope better.

- They can repeat the exercise for as long as time allows, until they feel more confident to do it without feeling guilty.

Specific knowledge to be covered in this session

Experiences of received stigma

The information is reflected under different types of stigma in activity 3.3.

Associated stigma may be experienced in the following ways:

- Children of the infected person may be ill-treated. Parents of children they play with may prevent them from doing so.
- They may be told directly that their mothers are HIV infected or have AIDS.
- They may be denied access to resources such as a swimming pool, at school.
- Family members of HIV infected people may also experience incidents of discrimination negative attitudes and behaviours from other people.

Strategies for coping with received and associated stigma

- Coping strategies that are found to be effective are those that are aimed at dealing with the problem as well as the emotions namely:

- Once you are diagnosed with HIV give yourself time to resolve your guilt, bitterness and feelings of revenge and ultimately accepting your status will lead to disclosure.
- Disclosing one's HIV status so that one may continue living without hiding, feeling guilty or isolating oneself.
- Once you have disclosed your status, you will be able to get different forms of support from those close to you, as well as those that are prepared to assist people living with HIV and AIDS.
- Joining a support group will assist you to accept your status, to disclose, and get the necessary guidance, emotional and moral support from the people who understand you situation.
- If you believe in faith healing, explore it to the fullest such as consulting your priest, pastor or faith healer so that you can get the spiritual support that you need.
- If you are at a stage where you need treatment, access it, comply and seek help from your doctor or health centre whenever it is necessary and ensure that your progress is monitored.
- Practising healthy sexual practices such as abstaining or using condoms, eating a healthy diet as advised by your doctor or health practitioner, and exercising may improve your coping.
- All the above strategies will strengthen you to be in control of your life, thus eliminating your experience of received stigma or assisting you to deal effectively with received and associated stigma.

Evaluation of the session experience

- Participants conduct feedback on the session by writing naïve sketches while those who cannot write are interviewed.
- They then evaluate whether they have accomplished the objectives of the session, and if satisfied the session is closed.

Follow-through to the next session

- They are requested to go home and internalize their experiences and any changes that they manage to effect in their daily life.
- If there are difficulties that they encounter in effecting those changes, they note them so that they are discussed in the final session, which will be held after three weeks when the general evaluation of the programme will be done.
- The date of the next session is identified and agreed upon.

SESSION EIGHT: THE EVALUATION OF THE PARTICIPANTS INTERNALISATION OF THE PROGRAMME

Rationale

Every interactive programme such as this one would usually require an evaluation to see whether it was effective or not. After the participants have undergone six sessions of intensive interactive exercises and activities, it is required that they should be given an opportunity to internalize the newly acquired strategies followed by the evaluation. The purpose of this session is to evaluate whether the six sessions were effective in providing the knowledge and skills for these women to cope effectively with the stigma associated with HIV and AIDS.

Objectives

At the end of the session, participants should be able to:

1. Identify the changes that they effected in their lifestyle to reflect that they leant new strategies.
2. Give feedback in the naïve sketches regarding changes that have occurred in their lives.
3. Identify future aspects to work on.
4. Identify the positive aspects that they found in the programme.
5. Identify the shortcomings as well as recommendations for the improvement of the programme.

Duration of the session: Two hours.

Activities to be undertaken in the session: Identifying changes effected by participants, as well as those they wish to work on in the future and identifying positive aspects, shortcomings and recommendations for the programme

Exercise 8.1: Identifying changes effected by participants, as well as those they wish to work on in the future

Instructions

- Bring different pamphlets on information and issues on HIV and AIDS (written in the language they understand). Make sure they cover the content of the programme such as, basic facts and information on HIV and AIDS, VCT, stigma, coping/dealing with HIV and AIDS and/or stigma and disclosure. Ensure that they get the same pamphlets.
- Let participants individually go through the pamphlets and using a pen, make a tick (√) on the information that they have learnt a cross (×) on the information that they don't know, and an inverted u (∩) for the information they need to know in the future.
- Give them about twenty minutes to do the exercise. Meanwhile draw three columns on the flip chart to accommodate the three aspects above. Reflect them in the relevant columns on the flip chart.
- When they finish let them come together and give each a chance to read out their ticks, then the crosses, as well as the inverted u's.
- When they think they have exhausted the contents of the pamphlets, allow them to mention any additional information on the three aspects that they thought about, but did not included in the pamphlets.
- Go through the information again with them. Compare it with the feedback they gave in their naïve sketches and give them feedback of your impressions with their participation.
- The first three objectives of the session should be achieved.

Exercise 8.2: Identifying positive aspects, shortcomings and recommendations on the programme

- Again draw three columns on the flip chart and label with positive, shortcomings and recommendations.
- Allow them to say anything they want to say about the programme randomly since they started (they may not know what is positive and what is negative). As they mention things write them under appropriate columns.
- When they reach a point where they cannot say anything anymore, check whether they mentioned any recommendations and if not ask them what they think should be included in the programme.
- Let them summarise all the processes; Encourage them to continue living positively and provide follow-up opportunities such as encouraging them to continue attending their clinic, belonging to a support group and to continue with treatment.

Specific knowledge to be covered

No new knowledge to be learnt.

Evaluation of the session and closure

- Participants are asked to state what has been effective and less effective in this last session.
- The facilitator allows them to close the session the way they prefer.

CLOSURE

Closure is done in any way that members and the facilitator may find effective, such as by lighting a candle as a symbol of hope, holding hands to form a chain as a symbol of togetherness and support, singing and praying if acceptable. Contact numbers could be exchanged to facilitate communication. Members could then have some refreshments, according to organization of the facilitator.

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ANNEXURE 2: CASE RECORD OF PROGRAM IMPLEMENTATION

SESSION 2		SESSION 3	SESSION 4	SESSION 5	SESSION 6	SESSION 7	SESSION 8
HIV AND AIDS KNOWLEDGE SESSION		**THE STIGMA, ITS MANIFESTATIONS AND EFFECTS**	**CREATING AWARENESS ON COPING**	**COPING WITH INTERNAL STIGMA**	**DEALING WITH DISCLOSURE**	**COPING WITH RECEIVED ASSOCIATED STIGMA**	**EVALUATION OF THE PARTICIPANT INTERNALISA-SATION OF THE PROGRAMME**
Recall facts about HIV and AIDS, its transmission and VCT	OBJECTIVES	Identify stigma manifestations and its effects.	Realise coping and own coping strategies.	Acquire skills of coping with internal stigma.	Share views on disclosure and acquire strategies of successful disclosure.	Identify their received and associated stigma and coping.	Evaluate, identify shortcomings and recommendations.
SESSION 2		**SESSION 3**	**SESSION 4**	**SESSION 5**	**SESSION 6**	**SESSION 7**	**SESSION 8**
- Feels great and happy; - Appreciated the programme and the friendship that allowed them to discuss their difficulties and to face challenges in the community; - Thinks she knows better now, especially about alcohol. - Would like to continue with this school.	CASE 1	- Enjoyed today's session and feels as if it is one's birthday. - Feels challenged. - Realises that her "friends" here are important and that friendship is important and that they should invite others.	Today she leant many things that she did not know about. Enjoyed the session and feels she could attend the whole day. - Today it felt like a new day, almost like one's birthday. It is a challenge; - Wishes that they could love each other like sisters.	Appreciated being taught alone after she missed a session. Thanks the facilitator. She is going to fight the virus until it is completely destroyed (Strives to feel well). She will teach others that one must look after oneself and not feel inferior. What is important is that she made friends.	Learnt a lot that she did not know about. Feels she is going to defeat the virus.	Today I got support from my teacher and friends because I was upset by my sister. Feels hurt by her sister who treats her children badly. She was so hurt she wants to seek alternative accommodation so that her children should live in peace. She was thankful that she got an explanation of why her sister behaves like that.	Expressed that she appreciated the facilitator's parental role. Realised that there are people who care.
Pretended that she was illiterate in the first session but was noticed during the cards game that she could		Starting to feel free and relaxed as she realized they share concerns. Did not have much	Seems to have poor sense of worth probably because she has no support systems. Blames herself for having	She was briefed alone after she lost a session due to having gone to see the sister in	Has been observed to have rational thinking even if she looks shy and reserved.	Came being distressed because she believes that her sister ill-treats her together with	She was at work and was afraid to ask her employer to attend and the facilitator had to negotiate on her behalf. Found that she dis-

read. It could be that she lacked confidence because she first listens to what others say before she responds. Enjoyed the cards game and she did not know some of the facts about HIV and AIDS. Thinks that nurses in hospital use most English terms and seem not to care whether they understand or not. Have full understanding of VCCT.		to say about stigma and maintained. She seemed not to have known that some of her behavior could be due to the effects of stigma.	accepted her husband who was estranged.	hospital. Blames her sister for her absence because she lacks understanding. Being reminded about the importance of attending sessions regularly she continued to blame her sister.	Believes that people who do not disclose their status live with a burden.	her children. Thinks it is better to seek alternative accommodation so set her children free from the burden. Seems not to realize that could be part of the received and associated stigma because she mentioned that she is stigmatized by family members and relatives who should be her support systems.	closed to her employer (domestic worker) and that she has been accepted and receives support She always showed fear of communicating her concerns probably due to her low sense of worth. Her naïve sketch was empty but she left the facilitator with a verse which conveyed the message that she has hope that Jesus can heal her.
Feels she has learnt much that she did not know about HIV and AIDS. Will be able to help others with the information.	CASE 2	She felt that she missed the session with her group mates. Though being updated to be on the same level with others, it is not as nice as when we are together.	Learnt to forgive people who stigmatize others. She is convinced that they do not know what they are doing.	Has accepted her status and wishes that many other people could stop hiding under beds and in dark rooms. Even if people can stigmatize you it will not change how you feel about yourself.	It is important to disclose. In our village most sick people are kept under beds. We should educate them that it is better to come out.	People who stigmatize others hide their own status, they are ignorant about HIV. They need to be educated	Learnt a lot through this program. Will teach and assist others; The programme helped me to accept myself. She thought that she was rejected and only left with her children. Feels happy to realize there are people who still care. Has learnt to ignore all what people say.
She has been ignorant about how alcohol could contribute to being infected with HIV. Thinks if nurses and doctors who man their sites could teach them they would know these facts. The most talkative		Expressed that she knows the stigma because she thinks that what she experienced is the worst of it. She was mocked by her mother, siblings, and people in the village. Had to seek support from the support	She thinks that her brother who died the previous week of AIDS related causes because he refused to take her advice to go for testing. Believes her coping depends on the support she gets from her support	Took the lead in discussing her coping skills though she still sounds bitter in terms of having been blamed for infecting her late partner. Said that she relied on her support group but now realized her coping is improving since	She seems to be concerned that because she had disclosed publicly, all the others should do the same. Her public disclosure was more of pressure to receive support from others. Feels that the support of this group is	Seems to cope by realizing that she is not alone. Shared that she had to leave home because she wanted her children to be in a safe environment. Emphatic in expressing her perceptions and how she	Expressed how she improved her coping skills from being bitter to realizing that she should move forward. She now relies on prayer as she learnt from other members. Wished that the group should initiate a home-based care project where other women could be supported and

and seemingly more knowledgeable about. HIV and AIDS.		group. Had to move from her home and hired a shanty. Feels that being away from her family gave her peace of mind. Shared her experiences of stigmatization.	group. Seems to be so happy about the support that she feels she would be dead by now if it was not for the support she gets. Served as an example for others in terms of her advanced knowledge.	she started to attend these sessions Said that she coped with rejection by leaving home.	more than that of her support group.	deals with them. Her wish is to see other people accept their status so that they could team up to fight the stigma for them to cope.	assisted.
- Happy to have learnt about HIV and AIDS; Feels like her soul is set free. - Understood why they have to use condoms. - Feels that she accepted own HIV status more than before. God accepts her with her plea.	CASE 3	- Happy about the film because it shows about our life. People who abuse them with negative talks that they will infect them with HIV don't understand; they are in darkness. It is a pity because they do not know their status; they should go to test. She will sue those who talk bad about her; It is every one's disease.	Today's lesson has taught her more that she learnt previously Feels her heart is at peace and does not believe she can feel better than she feels today and, that God is the only one who can change things.	Learnt that they should be happy. It is happy we have learnt about the importance of a support group. They will assist us with emotional support. I am happy in the heart and the love of God makes me happier.	Session was helpful and I feel motivated; Was initially hurt when she was diagnosed, now she understands the process of her illness. Understands that one must not keep herself from others because she will feel lonely. Learnt that she should loose hope on her health.	This session we talked about people who treat us bad; we have to ignore them. My child is happy where she stays and attending school. She never complained about bad treatment.	Enjoyed the session pleasant experiences as it was motivating. Wishes that they assist others and progress more than they are presently. Perceived the importance of being taught about health issues. Feels she received therapy today as she was not well and had difficulty in attending today's session. At the end she felt the joy in her heart and hoped to improve. Trusts in the Saviour because He knows our lives. Asked God for more days of life for herself and the facilitator and for spiritual union.

Still demonstrated a shy attitude and still talked little Seemed to have been ignorant about many facts regarding HIV, AIDS and VCCT. She did not say it openly but one could observe from her facial expression that she did not know.		Remains soft but started to be more free and contributed more in this session. Mentioned that after disclosing to her sister, her niece burnt the clothes that she gave her, only to find out later that she is infected as well and even died last year.	Shared how confused she was when she learnt that she was HIV positive. Said she was so ignorant she did not even know what HIV was. She was also very sick but had denial because she had TB. Accepted after three months of counseling. Did not talk a lot though more free.	Always emphasizes her trust in God and prayer for coping with feelings of hopelessness and fear. Said that she did not know how to deal with her feelings of despair but now she learnt that she could talk to someone and not feel guilty.	She was now free even to start contributing before others. Believed disclosure is healing because after she disclosed to her sister she felt free. Felt more free that she could even share with others. The idea of a support group has not come to her mind, now she realized the need.	She was always commited and even started to come earlier and went to Rudie's place so that they could come together. Their relationship grew closer. Thinks that people do talk about her because she noticed some pestering but ignores it. Seems afraid of mentioning other things, but mentioned that she had no idea of associated stigma because she does not stay with her daughter.	She was not well, just discharged from hospital. Showed that she has already established a support system because she called the facilitator when she did not feel well. Because of her commitment to the session she asked the facilitator to fetch her in order to attend the session.
Thinks they should not care about discrimination talks said to them. Feels it is important for them to support each other and be hopeful; Wishes for that beautiful houses so that their children can have homes; their children should not be thrown to the street when they die.	CASE 4	Feels much better and strengthened about the motivating lesson that she has rights. Learnt that they should ignore all the labeling and negating statements because they are sick. Need to unite, build and support one another and empathise. Believes that they have to live with hope. Wishes that they could be provided with houses so that their children can have their own homes' be provided with food, education and that would be support.	Today's lesson taught me many things that I did not know. The group motivated me to take care of myself; This programme removed her from thinking negatively.	Understands that they should take care of themselves. Feels more motivated and relaxed; She will no longer think negatively and will be proud of her health.	Learnt that disclosure is helpful because one becomes more open and free inside. - Experiences less anxiety which can lead to deterioration of one's condition. Learnt that she should assist all those who still need to disclose. Disclosure shows self acceptance and enables one to face reality and the world outside.	Felt strengthened and that she has the confidence that as long as she lives she would not fear anybody. She never cares about any treatment as long as she knows that God loves her nothing can move her.	Feels empowered by the worthwhile education that she received and feels that she can educate others who are like them especially on advice of how to behave, to be brave. Feels for the young HIV positive women that they need more support so that they could take responsibility for their own lives. Motivated others that from what they learnt they should improve, gain strength and not be depressed.

Still shy and did not have knowledge of most facts.		Talked briefly and appreciated having learnt about the stigma. She was rejected by the in-laws who dismissed her after her husband died. Thinks that men are like children because they never perceive danger.	Always remarks that as long as she lives, she would not lose hope. Expressed that she did not know that she was coping when she ignored the perpetrators of stigma.	Seems more relaxed and free. Said that she would no longer be afraid after she learnt that she should be in control of her emotions. Learnt that she should accept herself as she is; maintains that it is good to live.	She said that she had disclosed to her late husband and her uncle. Does not have parents, has two sisters but has long lost contact with them, as a result she seems to lack support. She is always with her 10 yr old daughter with whom she stays. Disclosure is important for her because she thinks one becomes free; prevents men from approaching you.	Always calm, never talks much; Her comments are always the same that it is nice to live and that as long as one lives, one should remain positive.	Remains hopeful and never despairs, though she looks sick and shy about her appearance. Said that the programme provided support and she wishes it could continue. Motivated to remain positive.
They had some basic knowledge about HIV and AIDS though superficial. The information was an opportunity to clarify their uncertainties especially about the mode of infection. Strengthened relationship and meaningful trust, evidenced by their sharing of their experience. Having learnt these facts, they gained insight into their symptoms, thus overcoming the fear associated with misconceptions that are discussed in the community.	G R O U P G R O W T H	Discussion empowered them to understand the context of stigma as referring to the 'others' experiences, and then moving closer, to the more realistic 'me' experience. Having developed trust and safety, they moved from the 'other' to the 'me' experience, they got empowered to take more control.	Became aware of their ineffective coping. Participants learned about coping from the general perspective as relating to others. Acknowledged that they needed to learn more positive emotional coping; Could realize that stigmatization requires coping skills. Observed what strategies worked for others. Realized how the people's behaviors and attitudes impact on them and could take control of own coping.	Having moved from the discussion of stigma on the general perspective, and applying it to the "me" experience enabled them to realize and share their feelings about their HIV status. Trust improving to feeling more safe to share personal experiences. They could realize that they were doing something that was effective, and some strategies that were not effective. Group context assisted them to learn what others were doing that could also benefit	Having discussed coping in session four, and having opened up in session five which made them feel more stronger due to a broadened strength of coping strategies, led to deciding and making an informed decision of disclosure. The decision of disclosure was also supported by gaining strength from the group member who had publicly disclosed her HIV status.	They had established their own coping, evaluated it, spoke about it. Observed other group members' coping and applied the experience at the level of internal stigma, having considered possible disclosure or non-disclosure, were now looking at how people were reacted to them in received stigma. They then had to decide whether they were going to confirm the received stigma that they have been subjected to By then they were free to share incidents of received	The group experience as well as the layout of sessions had assisted them during the month break, to actually take full control of their own coping; They moved from rationalizing, denying and used more of positive acknowledgement of their illness. Degree of growth enabled them from being concerned about selves to expanding to being altruistic, having concern for others.

They could then move ahead as their paralysis was resolved and they were empowered with knowledge. Excited to learn new facts and knowledge. Appreciated learning acronyms and their meaning. When VCCT was discussed they believe testing is good. Starting to show congruence. With modes of transmission of HIV they knew some and did not know some. These mode were discussed as well.		Started to loosen and relax. Started to contribute meaningfully to dicussions. Some of them say church holds prayers for HIV and AIDS people forgiving heals your heart. Had not joined support group.	They were free to show stigmatization. Their diference tote program as school means that they are learning. Rudie and Martha, who stays the furthest about 10km from the venue were the first to arrive; commitment. Their commitment and willingness to attend cold be attributed to the extent to which they need assistance.	them. Showed commitment by waiting while the facilitator looked for the keys. Bond and trust growing. Degree of acceptance of their status evident. They are being discriminated against. Taught about their rights, eg to live, to treatment, to be treated by the person of their choice. Comply with their treatment regimen. All of them are on ARV's.	Already familiar to the environment, come early, dust chairs and arrange sitting. Were free to talk about disclosure and to share painful experiences. Felt free to realize that their concerns are understood. Three of them partial disclosure, one public disclosure. They were excited about the types because they did not know that there were types. They believe that disclosing is casting the burden.	and associated stigma. Participation at its highest. Focus began on one member with a personal problem. They noticed stigmatization from others. Coping strategies used are ignoring, confronting and avoiding. Made aware that their coping was superficial; that they had to deal wit h their emotions. Had to explore different coping strategies. Spirituality through prayer seem to be the preferred strategy. Joining support group also mentioned.	They learnt to be strong and brave in dealing with stigma. Share the information they were taught with others. Concern for those who were not exposed to the programme. Their fear had disappeared due to supporting each other. Were worried about HIV positive pregnant mothers and other widows. Now free to talk to anybody. Have developed into a strong support group. Learnt that taking care of themselves is part of coping. Closure meaningful; separation anxiety allayed.