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**Abstract:** The aim of this article is to explore and describe how women who lost their partners to the Acquired Immune Deficiency Syndrome (AIDS) in the North West Province, cope with the stigma of the disease. A phenomenological design was used. The sampling was purposive and the sampling size was determined by data saturation, with fifteen participants. The data was collected by means of a single open-ended phenomenological question. Data analysis was done by means of the technique of content analysis by Tesch. From the results 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, non-disclosure, expression of grief and hurt and threatening lawsuits against perpetrators of the stigma. Regarding coping by focusing on emotions, strategies that arose from data analysis included coping by self acceptance, support by the family members, the emotional, social and the material support from families, friends, neighbors and social welfare; seeking of spiritual comfort, de-individualization of the disease, ignoring negative remarks and attitudes and forgiving, blaming their late partner or other people for their HIV status, and coping by using defense mechanisms. The recommendations were made in the form of strategies to assist these women to cope effectively with the stigma. [Life Science Journal. 2011;8(S1):147-154] (21) (ISSN: 1097 – 8135). <http://www.lifesciencesite.com>.

**Key words:** Coping, stigma, stigmatization, partner, HIV/AIDS

## 1. Introduction

The focus of this article is on the strategies for coping with the stigma of Acquired Immune Deficiency Syndrome (AIDS) by women who lost their partners to the disease. These women were stigmatized as a result of having partners who died of AIDS and the discovery that they themselves were also infected with the Human Immunodeficiency Virus (HIV). At the end of 2007 it was reported that 5.7 of the 46.4 million South Africans were living with HIV and AIDS (Dube and Nkosi 2008). The stigma of HIV/AIDS seems to nullify the efforts being made to deal confidently with the pandemic, whether it is treating those infected or preventing others from being infected (Ogden and

Nyblade 2005). The difficulty of dealing with HIV/AIDS is due to the fact that the stigma itself makes is difficult, if not impossible, for sufferers to go for Voluntary Counseling and Testing (VCT), to disclose their HIV status when already diagnosed, and to access the available treatment or resources (Siyam'kela 2003). These women coped differently with the stigma, particularly because they were also HIV positive themselves.

Coping, according to Kleinke (1998), is associated with the efforts that one engages in to manage situations that one appraises as being stressful and potentially harmful. Lindemann (in Cleiren 1993)

describes coping as, recovering and returning to the state that prevailed before the stressful situation. According to Nyblade et al. (2003), some women attempt to cope with the stigma of HIV and AIDS by denying their late partners' AIDS status or, avoiding disclosure especially if they anticipate stigmatization. Alternatively, some are able to cope by directly challenging or confronting the stigmatizing attitudes or behaviors, while others seek explanations other than sexual transmission. Some women apparently, are able to 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 for comfort, solace and support (Nyblade et al. 2003).

Some women who experience the stigma seek care and support from their families or health care providers (Nyblade et al. 2003). The ability to cope with the experience of stigmatization poses a challenge for carers with regard to how best these women can be assisted. These women need caring and compassionate carers 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 and Wright 2000).

The stigma of HIV and AIDS is not decreasing and mechanisms to deal with it are required in order to assist and support those suffering from it. For this to happen, an exploration of the coping mechanisms used by women who lost their partners to AIDS, is necessary in order to inform the empowerment strategies that will assist them to cope effectively. It is for these reasons that the researcher finds this study significant, motivated by the passion to assist the widows stigmatized by the community, as well as the need to promote their mental health. The objectives are therefore, to explore and describe the experience of coping with the stigma by women whose partners died of AIDS, as well as developing mechanisms to assist these women to cope with the stigma experienced due to having lost their partners to AIDS.

The meta-theoretical assumptions of this article are grounded in the belief that every person is a totality of the biological, psychological, social as well as spiritual being. The theoretical statement of this research includes the Central Theoretical Argument as

well as the methodological statement that: Coping with widowhood status is, in itself, a difficult process due to the stress and pain of loss. In the context of this article, the difficulty is aggravated by HIV and AIDS, because both conditions carry the stigma. Women in the context of this article are faced with stigmatization of widowhood, compounded by the loss of partner to AIDS as well as their HIV positive status. The fact that these women were also HIV positive was not pre-determined but was co-incidental.

## 2. Literature Study

Coping is said to be an old concept that has evolved, according to Aldwin (2000), with time. Aldwin 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. In most of the literature on coping, it is documented that defense mechanisms feature more often because they are usually used without the person being fully aware of them (Aldwin 2000; Carr 2004; Gottlieb 1997; Kleinke 2004; Lazarus 1976; and Parry 1990).

Coping with the HIV and AIDS stigma, whether one is infected or affected, also depends on the individual's self efficacy in dealing with the problem, hence Cassidy (1999) viewed it as the person's cognitive and behavioral effort 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 out of those efforts, to tolerate the stressor. This definition supports that of Bailey and Clarke (1989) 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) confirmed in their study that people with HIV and AIDS, who utilized active coping strategies tend to improve their quality of life; that is, they may be considered as having mastered the stressor.

## 3. Research Design and methods

A qualitative, phenomenological, research design was followed with the aim of exploring and describing the experience of coping with stigma, by women who lost their partners to AIDS, and who are themselves HIV positive (Creswell 1998). In-depth

interviews with participants enabled the researcher to explore and describe the phenomenon of coping. The population from which the sample was drawn consisted of women who lost their partners to AIDS in the four regions of the North West Province of South Africa. These regions are Bojanala, Dr Ruth Mompati, Dr Kenneth Kaunda, as well as Ngaka Modiri Molema. A purposeful voluntary sampling technique was used (Burns and Grove 1997; Streubert and Carpenter 1999). The women were identified through the non-governmental organization that renders home-based care to people living with HIV and AIDS (PLHA). Home-based carers in each region obtained the consent of PLHA to connect them with the researcher. The author then visited the potential participants individually, accompanied by carers, to establish rapport as well as to inform them of her intention of conducting research. Letters to obtain their consent to participate were subsequently written and delivered personally by the researcher, thus ensuring a prolonged engagement. For the purpose of this article, 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 a semi-structured interview, be willing to give consent to be recorded on an audio-tape. The women were included on the basis of their consent to participate without considering numbers per region. A total of fifteen women were interviewed.

#### 4. Data Collection and Analysis

Data was collected by means of interviews using a single open ended in-depth question (Brink and Wood 1998), "how do you experience coping with the stigma after your partner died of AIDS?". The question was first given to experts to evaluate its applicability. The pilot study was conducted initially with one of the participants who met the inclusion criteria in order to confirm its applicability. This in-depth, single, open-ended question, was posed in order to explore the participants' experience of the stigma. The interviews were tape recorded. Field notes were written immediately after each interview to ensure that all observations were recorded whilst the researcher still remembered them clearly (Morse 1989; Creswell 1998). The interviews recorded on audio-tapes were transcribed verbatim, and translated from other languages into English. Data analysis was conducted according to the content analysis technique of Tesch as

outlined in Creswell (2003). After the co-coding was completed, a meeting was organized by the co-coder and the researcher in order to reach a consensus on the themes and categories.

#### 5. Trustworthiness

Trustworthiness was ensured using the model of Lincoln and Guba (in Krefting 1991) integrated with that of Woods and Catanzaro (1998). The criteria applicable to ensuring the trustworthiness of the study according to these authors are credibility, transferability, dependability and conformability (See table 1).

#### 6. Ethical aspects

Permission to conduct the study was obtained from the North West Provincial Department of Health as well as from the Home Based Care Organization under whose care the women were. Ethical approval was given by the North West University-Potchefstroom Campus School of Nursing as well as the Faculty of Health Sciences Ethical Committees. The participants' rights to privacy, anonymity, confidentiality, fair treatment, and protection from discomfort and harm were observed throughout the study (Burns & Grove 1997). 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.

#### 7. Results and Discussion

Data analysis on coping with the stigma by women whose partners died of AIDS showed that most of the women used the usual common coping strategies that could be classified as problem-focused and emotion-focused. These strategies were as follows: deciding on voluntary counseling and testing in order to know their HIV status, disclosure of their HIV-status for family support, joining support groups for emotional and moral support, joining church organizations to seek spiritual support, compliance with healthy lifestyle, and keeping their HIV status secret. This article revealed some unique findings that could be misunderstood as being similar to those of some of the authors referred to earlier on, whereas they are different in the manner in which they were experienced by women in this article. These are addressed in the following discussion.

## Problem-focused Coping Strategies

Coping strategies that are considered as unique include, falling back on spirituality, complying with Ante Retroviral Therapy (ART), awareness of living a healthy lifestyle, as well as disclosure versus non-disclosure of their HIV status.

### Falling back on Spirituality

One of the outstanding results in this study was that these women mentioned that after being devastated by discovering that they were HIV positive, they found effective coping to be, falling back on spirituality. This was motivated by their Christian belief that 'God is above every problem'. This they did through affiliating to church organizations both for emotional support and for spiritual fulfillment. They also mentioned that they sought solace in their God by means of prayer, and bargaining with Him to grant them health and to increase their days of life so that they could bring up their children. This is evident in the women's expressions such as, "God is the only one who knows our days of life and who can extend"; "ask God to protect and secure you all the time; pray! That is how I manage in life", and "I do ask Him to keep me until I have done my best for my children, that they become educated and achieve something you see". Yarhouse and Anderson (2002) concurred that prayer could assist Christians with HIV and AIDS to come to terms with their relationship with God. Such a relationship may help them to resolve forgiveness issues especially that the stigma associated with HIV and AIDS may be moral-based. This finding is unique because participants reported having sought solace in spirituality as their coping strategy after being devastated by the loss of their partners to AIDS, and realizing that they themselves were positive. However, they could not receive the support that they expected, but instead they were shunned and rejected by their fellow Christians. Their disappointment could be detected in their expressions such as, "I thought the church was where you would get comfort yet you don't get it at all".

"I used to sing in the church choir but my fellow members started to say funny remarks and rejected me until I stopped". These quotes indicate that even though the women resorted to falling back on spirituality for support, this was not achieved because they continued to be shunned until they quit in despair.

## Compliance with Healthy Lifestyle

Participants accepted their HIV and AIDS status and thought it wise to live a healthy lifestyle. The subcategories under this category are, complying with ART, eating a healthy diet, do physical exercises, and either abstain from sex or use condoms as it is reported by other authors (Fife and Wright 2000; Sowell et al. 1997; Weiss and Ramakrishna 2002). Participants who had already developed signs of AIDS mentioned that they thought it wise to adhere to their 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 realized in the 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 veggies" and, "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". These experiences were contrary to the evidence discovered by Siegel and Schrimshaw (2005) that women in the highly active ART did not seem to report a great sense of control or positive results. Almost all the women, over and above complying with the ART regimen, also mentioned that they adhered to a healthy diet after being advised by their counselors to do so. However, this result is also unique because although these women mentioned eating healthy as their way of coping, they did it as a response motivated by factual knowledge that they learnt during counseling. Evidence during home visits showed that due to poverty, there was actually no foodstuff and hence it was very difficult to have a healthy diet. It is documented that engaging in physical exercise could enhance coping (Carr 2004; Kleinke 1998). However, the uniqueness of this finding is that coping by doing exercises has been mentioned by these women as a known fact but, having observed their wasted state as well as their weakness due to severe weight loss one could think that they probably mentioned it to impress the researcher. Women participants mentioned either practicing safe sex by using condoms or totally abstaining from sex. As almost all of the women went through counseling, they mentioned that they were aware of re-infection hence they took precautions to prevent it as expressed in, "if I get a partner I have been warned to use a condom"; "They said that we must stay far from men or if you have one never sleep with him without a condom". Although the researcher actually observed that these women wished to take precautions, their partners did not cooperate as evident in their failure to either disclose or protect their partners. These are

problem-focused coping strategies because the women reported that they engaged in concrete measures to cope with the stigma, as opposed to the emotion-focused strategies that follow.

#### Emotion-focused functional coping

The women also mentioned that they felt emancipated from pain once they were accepted by their family members. This they 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". And, "other people think that support is only financial but that's not so, when people accept you, they support you". These feelings of the participants being happy about being accepted by their family members were believed to have contributed to positive coping by People Living with HIV or AIDS (PLHA) (Brown et al. 2003). On the contrary, Miller and Kaiser (2001), found that acceptance may be somewhat less adaptive for the stigma than for other types of stressors because of its constant and pervasive nature. This result was found to be unique because some participants were rejected by their in-laws, who became their primary family after marriage. In their culture, after marriage, the woman leaves the family to leave with the husband's family. Being rejected suddenly after the partner's death, and the fact that in-laws influenced the community and the church against them further paralyzed their coping strategies. They became severely humiliated and their ability to use their support systems became paralyzed as it was difficult even to access medical services. 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. Some of these forms of support were, for example, "the priest told me to take pride in myself and should not listen to criticism, for God has a purpose for everything in life"; "I cope with these very cents that I get from government, it is my share and my daughter's"; Another form of coping that was found was when participants considered the stigma attached to HIV and AIDS as 'our problem' rather than 'my problem' hence the researcher terms it de-individualization. Women seemed to feel less anxious in realizing that they are not the only ones suffering from and experiencing the stigma of HIV and AIDS. This experience resulted in the relief of pain associated with the HIV and AIDS stigma. The implication of

this result could be detected in the words used by these women such as, "so I did not have fear because it is our disease, and I went to test because I wanted to know ...", and "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". In the latter quotation, the participant was referring to the victims of AIDS that she saw during their final stage, in anticipation of how she is going to be like. The literature consulted does not necessarily refer to the stigmatized people de-individualizing the disease but that, they can empathize with each other because they share the same experiences (Gaines 2001). Miller and Kaiser (2001) also documented that stigmatized people, when they share the support of other stigmatized people could probably cope through cognitive restructuring. Compared with the former problem-based coping, the latter is evidence that some women coped with the stigma at the emotional level as could be detected in the manner in which they expressed themselves. However, some results showed that women coped by using defense mechanisms as in the discussion that follows.

#### Defense mechanisms as means of coping with the stigma

During data analysis the following quotes that suggest the use of defense mechanisms were detected. "I no longer want any man next to me; I am only satisfied when I am with my daughter", or "even when I feel sick I don't sleep or just sit, I try to keep myself up, I refuse to be sick" and "I am HIV-positive and I am proud because I know my status". The literature on coping with the stigma has identified denial as a form of escape-avoidance coping, which can prevent the PLHA from accepting their status and gaining access to support and resources (Coetzee and Spangenberg 2003). 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. After the analysis of the coping mechanisms used by the participants, recommendations were suggested in the last part of this article to assist them to cope effectively as some of their present coping strategies appear to be ineffective.

Table 1. Strategies to ensure trustworthiness

| Strategy        | Criteria                   | Application                                                                                                                                                                                                                                                                                                                                                  |
|-----------------|----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Credibility     | Prolonged field experience | Letters to request participation delivered by the researcher and spent time with the women to establish a trusting relationship.<br><br>Confirmation of appointments also done personally by the researcher to strengthen the relationship. The participants allowed enough time to verbalize their experiences and beliefs respectively, during interviews. |
|                 | Reflexivity                | The field notes were written immediately and subjected to analysis                                                                                                                                                                                                                                                                                           |
|                 | Member checking            | The literature control of experiences of coping with stigma was undertaken.                                                                                                                                                                                                                                                                                  |
|                 | Interview technique        | The researcher is trained on the research methods and on the interviewing skills.<br><br>Research supervised by experts who are experienced in qualitative research.                                                                                                                                                                                         |
| Transferability | Selection of sample        | The sampling method was purposive voluntary as well as judgmental.                                                                                                                                                                                                                                                                                           |
|                 | Dense description          | Through the description of the research methodology and literature control of the results.                                                                                                                                                                                                                                                                   |
| 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.<br><br>Consensus discussion held with co-coder.                                                                                                                                                                                                                                                                    |
|                 | Peer Examination           | Expert supervision provided throughout the process.<br>Ethics Committee comprises experts in the field of research                                                                                                                                                                                                                                           |
| Conformability  | Conformability audit       | Done by co-researchers who are experts in Qualitative Research.                                                                                                                                                                                                                                                                                              |
|                 | Reflexivity                | Field notes written and subjected to data analysis.                                                                                                                                                                                                                                                                                                          |

## 8. Conclusions and Recommendations

It would benefit women whose partners died of AIDS if programs are developed to facilitate Voluntary Confidential Counseling and testing (VCT), 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. Following their pre and post-test counseling, a follow-up could be 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. The community could be made

aware of the need to support PLHA 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 cope with the stigma. Government and non-governmental organizations should support programs aimed at assisting PLHA, such as home-based care, support groups and the other initiatives aimed at empowering these women to deal with the stigma associated with their widowhood status as well as the disease. It would benefit these women if they could be trained on assertive skills so that rather than ignoring all negative remarks, they would respond in a positive and assertive manner, thus preventing

aggression and negative responses. Budgeting skills are also essential so that they could effectively use the little money that they receive from social grants in order to meet their basic needs. They could also be advised to use NGO's that would 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 to their advantage if the faith-based organizations are involved since they hold strong Christian beliefs. They could benefit from prayer meetings and spiritual counseling sessions, either as individuals or as groups.

In conclusion, the results revealed that unlike what is documented in the literature, the manner of coping of these participants is different and unique. The uniqueness is that their voluntary counseling and testing is for reasons of accessing the government grant and ART due to poverty rather than just voluntary. Most of them disclosed to their close family members because they needed their emotional support as well as material support in the form of food, as most of them are not working and are dependent on their late partners. This support was needed after they were rejected by their in-laws who contributed to their paralyzed coping. Some women also mentioned that they disclosed their status with an intention of preventing gossip, but found this to be ineffective, as was their falling back on spirituality. Healthy living through eating healthy food and exercising frequently were realized as strategies that participants knew about but found difficult to comply with due to poverty. Emotion-focused functional coping revealed that the women also felt better if they considered HIV and AIDS as collective problem rather than an individual problem. Some mentioned the use of defense mechanisms as ways of coping.

Abbreviated title: Coping with HIV/AIDS Stigma by Women who lost their Partners to AIDS in the North West Province

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