

## **THE MOURNING PROCESS OF HIV-POSITIVE PREGNANT WOMEN**

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### **ABSTRACT**

The purpose of this study was to explore bereavement and grief or a sense of loss in HIV-positive women attending antenatal clinics.

An exploratory, descriptive and qualitative research design was used. Purposive sampling was applied with inclusion and exclusion criteria. The data were collected during 2004. Tesch's eight-step procedure was applied in the analysis of the data. Transcription of taped interviews was followed by reading the transcripts while comparing them with the original audio-tapes. The underlying meanings of the details were identified and described. The Kübler-Ross (1969 in Bolden, 2007) framework proved useful for contextualising the study's findings.

The findings indicated that the women experienced and expressed sadness.

All bereavement, grief, and/or a sense of loss, were painful processes experienced by pregnant women who learnt that they were HIV positive. Over and above offering the standard nursing care, midwives should implement a number of steps to support HIV-positive pregnant women and respond to their unique needs.

This study is helpful to midwives caring for HIV-positive pregnant women, who have specific needs arising from the bereavement and grief, or sense of loss, experienced on learning about their HIV-positive status.

**KEYWORDS:** antenatal care, bereavement, HIV-positive women, loss, Kübler-Ross.

## **INTRODUCTION**

Spencer (2005:230) observes that the high rate of HIV infection among pregnant women (25–35%) necessitates specialised knowledge on the part of midwives in terms of the support that they offer. HIV-positive pregnant women experience a dichotomy in that they are HIV positive, living with a chronic disease which will end in death, yet carry new life within them. Special care and support are needed to ensure a relatively healthy mother and baby. HIV-positive women also need more support and care in response to the bereavement and grief or sense of loss that they experience on learning about their HIV positive status. In this study, the experiences of HIV-positive pregnant women, in terms of bereavement and loss, and the most appropriate support on the part of midwives within this context, were explored (Edwards, 2006:680–681).

## **PROBLEM STATEMENT**

If unaware of her HIV status, a pregnant woman visiting an antenatal clinic may consent to voluntary counseling and testing (VCT). If she is diagnosed as being HIV positive, the pregnant woman requires knowledge and assistance with regard to decision-making and psycho-social support relating to HIV and pregnancy. A positive diagnosis has dire consequences, including enormous loss: loss of loved ones; individual health; future aspirations; body image as a result of HIV wasting, which is one of the characteristic symptoms of AIDS; childbearing potential; and financial resources (Minnaar & Bodkin, 2006:43). (HIV wasting can be defined as weight loss that exceeds 10% of the patient's baseline weight plus either chronic diarrhoea or fever for more than 30 days without any concurrent illness.) These negative consequences are coupled with the stigma of an HIV-positive diagnosis (Ciambrone, 2003:111; Sandelowski, Lambe & Barroso, 2004:123). Unfortunately, midwives are not always aware of needs of HIV-positive pregnant women in antenatal clinics in terms of the sense of bereavement and loss they experience. Furthermore, little is known about the specific needs of pregnant women attending antenatal clinics who have tested positive for HIV.

## **PURPOSE OF THE RESEARCH**

The purpose of the study was to explore and describe the needs arising from a sense of bereavement and loss experienced by HIV-positive women attending an antenatal clinic at a public sector tertiary academic hospital in South Africa. The following research questions guided the research:

- What are the bereavement needs of HIV-positive pregnant women?
- What are the responses of pregnant women on learning that they are HIV positive?

## LITERATURE REVIEW AND FRAMEWORK

Various studies (Anderson & Spencer, 2002:1338; Antle, Wells, Goldie, DeMatteo & King, 2001:167; Soon & Barnard, 2002:16; Walmsley, 2003:279; Yoshioka & Schustack, 2001:77) have confirmed that HIV-positive pregnant women experience suffering, fatigue, sadness, shame, blame and concern for their children. These women must deal with living and with dying; combating the disease and becoming worn out in the process. To ensure quality health care, midwives need to understand the complex experiences of these women.

### The Kübler-Ross framework

Individuals are unable to fully conceptualise their fear of loss or anticipate how deeply they may be affected by the death of another. Elisabeth Kübler-Ross (1969 in Bolden, 2007:235), in defining grief and describing the grieving process that those who have lost a loved one may experience, attempted to shed some light on grief, the grieving process, and its manifestations in individuals. Her work dealt with death and dying in general and proposed a set of stages of loss. Although she did not refer to HIV and AIDS, as the disease was unknown at the time, the researchers found in her work a valuable framework to guide the current study and to explain the mourning of HIV-positive pregnant women on learning about their own HIV-positive status during pregnancy. The Kübler-Ross framework (Kübler-Ross, 1969) as described in Telford, Kralik and Koch (2006:458) and Bolden (2007:235–237) comprises five stages, namely denial, anger, bargaining, depression and acceptance.

A brief exposition of the five stages of the Kübler-Ross framework, as applied in the context of pregnant women diagnosed with HIV, could indicate appropriate responses on the part of the midwife. Themes that emerged from this study, corresponded with the stages of death and dying as identified by Kübler-Ross, (1969) in Telford, et al(2006:458) and Bolden (2007:235–237).

In the context of the study, denial, the initial stage, is characterised by shock at learning about one's positive HIV diagnosis, and the woman is overwhelmed by the situation. Denial is a protective stage, and the midwife's role during this stage is to afford the HIV-pregnant woman the opportunity to talk about the diagnosis and to answer any questions. The second stage is anger, during which the woman perceives a threat to her personal security and experiences fear of the unknown. During this stage normal routine is disrupted, and the woman feels that she has no control over the situation. The midwife needs the ability and the skill to help the HIV-positive pregnant woman to focus and to pay special attention to her own health and that of her unborn baby. The third stage is bargaining and anticipation of loss. The pregnant woman attempts to postpone the inevitable, asking about mortality rates and life expectancy, and whether she will live

to see her baby. To answer these and other questions, the midwife needs to be equipped with the most recent information about HIV, medication, and healthy living with HIV and AIDS. Depression is the next stage; when the woman realises that the loss cannot be averted, she may descend into depression. Should a woman give up and no longer see any purpose in her life, both she and her baby are at particular risk; the midwife therefore needs psycho-social skills to help the woman focus on her health and that of her baby (Telford et al., 2006:459). The last stage is acceptance. Not all women reach this stage during their pregnancies, but the midwife should be aware of the signs of acceptance so as to be able to offer support and further encouragement (Parkes, 2002:376).

## **RESEARCH METHODOLOGY**

An exploratory, descriptive and qualitative research design was used to explore the needs of HIV-positive pregnant women attending a public antenatal clinic at a tertiary academic hospital in Gauteng. This design was exploratory in that it investigated the needs of HIV-positive pregnant women in dealing with bereavement and loss. The design was descriptive in that it provided an in-depth description of these needs, and qualitative in that it was intended to give the phenomenon of HIV in pregnancy depth, richness and complexity (Denzin & Lincoln, 2003:397; Flick, 2006:1–10).

The population included all pregnant women receiving antenatal care at a public sector tertiary academic hospital in the Gauteng Province in South Africa. During the period of the study (July 2004 to December 2005), the HIV infection rate at this hospital was 31, 31%. Interviews were conducted with six HIV-positive pregnant women during their third trimester, as by this stage of their pregnancies these women would have received HIV counselling and would have made two to three visits to the antenatal clinic.

All the participants in the study were diagnosed with HIV during their pregnancy. The participants were recruited during clinic hours. The researchers obtained permission to conduct the study from the head of the unit, the public hospital and the provincial department of health, after which the HIV-positive patients at the antenatal clinic were approached. The researchers explained the aim of the research to each prospective participant. Six patients agreed to participate and signed the consent forms. Data saturation occurred after the fifth interview, after which another interview was conducted to ensure that data saturation had indeed been reached.

Purposive sampling was the most appropriate sampling method for this study, as participants were selected on the basis of their fulfilment of the inclusion criteria, and were willing and able to examine and share their needs relating to bereavement and loss following a positive HIV diagnosis. Exclusion criteria included HIV-negative pregnant women, women unsure of their HIV status and HIV-positive pregnant women who had not received HIV counselling. The inclusion criteria were HIV-positive pregnant wom-

en attending the antenatal clinic, being aware of their HIV-positive status, receiving antenatal care at the midwifery or obstetrical unit, had received pre- and post-test HIV counselling, and had provided written consent for participation in the study (Denzin & Lincoln, 2003:101; Henning, Van Rensburg & Smit, 2004:20).

## **Trustworthiness**

Trustworthiness in respect of the interviews and data collection was enhanced by the fact that the data were collected by one person. The interview guide was reviewed after the first interview, which also served as the pre-test, and was excluded from the study. The pre-test was conducted with a participant in her third trimester who delivered her baby before the commencement of the actual data collection for the study.

Following the transcription by the researchers of the tape-recorded interviews, each participant was given the opportunity to review the transcribed interview and was asked to confirm whether this was a true reflection of what she had recounted to the researcher. Credibility was protected by the prolonged engagement of one researcher in the field, over a period of a year. Peer debriefing was done with colleagues who were not involved in the research process as such, and with whom the researcher discussed her blind spots and results. All six cases were analysed, including the negative comments, and the participants were asked to check the transcriptions after codes had been introduced. A second researcher was introduced to read the data and check the data analysis, which increased the credibility of the study.

The researcher maintained an audit trail in order to secure procedural dependability by keeping a meticulous record of the raw data in the form of field notes and audio-tapes of each interview. The method of data coding and data reduction was consistent and checked by a second person. All memorandums and notes were kept safely for future reference.

For the purpose of this study the original works of Kübler-Ross (1969) and others, namely Telford et al. (2006:458) and Bolden (2007:235–237), were consulted and adopted as a guide; the categories were constructed according to the five phases of denial, anger, bargaining, depression and acceptance (Flick, 2006:371–377).

## **Data collection**

A semi-structured, in-depth interview guide was used to collect data through interviews. The researcher explained the purpose and format of the interview to each participant, who also received an information letter and a consent form to give permission for the interview and the use of a tape-recorder. All the participants in this study received counselling both prior to and following testing for HIV and AIDS. The counsellor was a

qualified HIV and AIDS counselor and a permanent member of the staff establishment of the clinic. All participants in the study received at least two counselling sessions; some received more on the basis of their emotional state and HIV and AIDS diagnosis. The researchers asked the following questions:

- Tell me about your needs as an HIV-positive pregnant woman. Please start from the time you learned about your HIV status.
- Tell me about your specific needs in relation to loss when you learned about your HIV status.

The questions, posed to pregnant women who had recently been diagnosed with HIV, had the potential to evoke extreme emotional responses, a fact to which the researcher was sensitive. She did her best to prepare the participants for the interview by first asking questions regarding their general wellbeing and home situations, including whether they had other children at home, and only then moved on to questions regarding their HIV status and pregnancies. Some participants experienced relief at being able to speak freely about their concerns and their disease. Each interview took approximately sixty minutes, which was slightly longer than the normal clinic visit (Booth, Colomb & Williams, 2003:50).

### **Ethical Considerations**

Ethical issues were of particular importance because of the problems of confidentiality and stigma associated with HIV and AIDS (Kohi, Makoae, Holzemer, Phrtlhu, Naidoo, Dlamini & Greef, 2006:406–413). The right to privacy was ensured by the fact that one researcher conducted weekly clinical sessions at the clinic and attended to a number of patients. Therefore it was impossible to single out HIV-positive patients on the basis of their being interviewed by the researcher.

The researcher interacted with all the patients weekly at the clinic and rendered services to all the women attending the antenatal clinic. In-depth interviews were conducted in a private setting, free from interruptions. Participants were informed that they had the right not to answer any question without penalty. They were not interviewed at inconvenient times such as during their mealtimes or at night. All the participants had the right to withdraw from the study at any point without incurring any penalty (Merriam & Associates, 2002:40).

### **Data analysis**

Tesch's eight-step procedure was applied in the data analysis. The first step entailed the transcription of the taped interviews. Following transcription, the researcher read

the transcripts and compared them with the audio-taped interviews. The process of proofreading allowed the researcher to become familiar with the interviews and ‘to get a sense of the whole’. The researcher then selected the most interesting and informative interview in the sense that the participant expressed herself most movingly, saying, for instance: “I could not believe it and dying, I do not want to die” to read and to determine the underlying meaning of the detail described by the participant. Notes were made in the margins of the transcribed interview, and this process was repeated for the rest of the interviews. Furthermore, notes were made in a memorandum, setting out thoughts and ideas on the overall meaning of the interviews. A list was made of all the main topics that emerged. Similar topics were clustered (Tesch, 1990 in Creswell, 2003:191–195).

Coding was the next process in the analysis of qualitative data, and descriptive coding was used. The researcher read through the transcripts and underlined the main themes. These descriptive codes were written in each participant’s own words (Denzin & Lincoln, 2003:203). Interpretive codes were made in addition to the descriptive codes. The emerging themes in this study were linked to the Kübler-Ross’ (1969) framework of denial, anger, bargaining, depression and acceptance in order to identify patterns emerging from the data, as reflected in table 1 (Bolden, 2007:235–237).

**Table 1: Tesch’s eight steps for qualitative data analysis**

STEP	DESCRIPTION	DATA ANALYSIS
1	Get a sense of the whole.	Read all the transcriptions carefully. Write down the ideas you get from the reading of the transcripts.
2	Pick one document – the most interesting one, the shortest or the one on top of the pile.	Go through it, asking yourself “What is it about?” Write down your thoughts in the margin.
3	After completing the above step, make a list of all the topics.	Cluster similar topics together. Form these topics into columns as major topics or unique or leftover topics.
4	Go back to data with the list of topics.	Abbreviate the topics as codes and write the codes next to the appropriate segments of the text.
5	Find the most descriptive wording for the topics and turn it into categories.	Look for ways of reducing the categories by clustering together what belongs together.
6	Make a final decision on the abbreviations and categories.	Arrange the categories alphabetically.
7	Assemble the data belonging together, into groups.	Perform a preliminary analysis.
8	If needed, recode the existing data.	Recode.

## RESEARCH RESULTS

The findings indicated sadness among HIV-positive pregnant women; sadness in re-

sponse to their HIV-positive status and at the possibility of not seeing their babies grow up. Table 2 reflects five themes identified, namely, “I did not believe”, “I don’t like pity”, “I do not want to die”, “I am going to die” and “I accept this”.

**Table 2: Stages in Kübler-Ross’ framework and corresponding themes emerging from the data**

Stage in Kübler-Ross framework	Corresponding theme emerging from the study
Denial	“I did not believe”
Anger	“I do not like pity”
Bargaining	“I do not want to die”
Depression	“I am going to die”
Acceptance	“I accept this”

***“I did not believe”***

When these women were told that they were HIV positive, they reacted with shock and disbelief. This emotionally painful experience was recounted by one participant as follows: “It was hard, it was hard...” Denial was evident in response to the diagnosis as; one woman said, “It was the first time that I heard that I have HIV. I did not believe.” The denial extended to the partners of the HIV-positive pregnant women, who did not believe the diagnosis either. One participant said: “Before he was angry. He says maybe I am lying”. “He said that HIV does not affect him.”

Hence, denial emerged as a way of not thinking about the diagnosis and so erasing reality, as a possible means of helping to control the women’s emotions in response to the disease. One participant expressed herself as follows: “I must feel happy like I don’t have a problem”; another one said: “I’ll be fine...” These women also suppressed their emotions during routine antenatal visits. One participant said: “I am very scared but I am OK.” Forced happiness was evident in participants’ responses such as: “It does not mean that I do not have a future. Yes, I do have a future; yes I do trust that I have a future”. Another woman said: “I’ll be fine.” A participant commented: “I am happy now.” Another woman said very bravely: “I am very scared but I am OK.”



***"I do not like pity"***

Women in this study revealed considerable anger. This emotion is understandable when considered in light of the fact that they were experiencing the dichotomy of carrying a new life while simultaneously facing the prospect of their own death. According to the Kübler-Ross framework, anger characteristically follows denial, and the participants in the study expressed their anger by rejecting the pity expressed by others, particularly midwives. Being pitied implied that they were viewed as being different, whereas they wanted to be treated in the same way as other pregnant women. This finding is supported by Sauka and Lie (2000:737–743), and Antle et al. (2001:159–170) who refer to the need for equal treatment as the need for normalisation. One woman expressed her anger by saying: “They changed, I thought maybe because of the results. That was when they started taking care of me, because in the beginning they just left me there. I just want to be treated like I am negative; otherwise when I come here everybody will know that I am positive.” She felt that she was treated differently as a result of her HIV status and reflected as follows: “People see you and they treat you differently. But I am just like any other person. The difference between us is that I am HIV positive.” These women consequently demonstrated anger towards the caregivers, with one participant saying that: “She was pitiful towards me.” She continued, referring to the midwives: “They just see me and say, so young; she is going to die so early. “Shame.” The women demonstrated anger by rejecting pity and by criticising the midwives. Although angry, they remained submissive and subdued.

***"I do not want to die"***

Bargaining or, in the context of the study, a desperate wish not to die arises from the anticipation of loss. The women asked to live longer to see their babies, and hoped to enter into some form of agreement in order to postpone or avert the inevitable, an action described by Kübler-Ross (1969:40 in Telford et al., 2006:458; Bolden, 2007:235–237) as bargaining. The participants endeavoured to bargain by saying “I don’t want to die,” and pleading for the opportunity to make amends and thus postpone their death. In terms of the Kübler-Ross framework, bargaining is a plea for extra time; the persons promising to either change their behaviour or not asking for more should this postponement be granted (Kübler-Ross, 1969:40 in Telford et al., 2006:458; Bolden, 2007:235–237). Bargaining was revealed in the statement: “I don’t want to die, I want to see my baby first.” These women were desperate for more time on earth; one participant made the following commitment: “If I don’t die I am going to find a job, work hard. Work very hard and leave my son with something.” It is abnormal for women of childbearing age to think and to talk about death and dying.

### ***"I do not want to die"***

During the depression phase, the negative aspects and consequences of the disease dominated the thoughts of the participants. When they could no longer deny their diagnosis, they expressed their despair as follows: "There is nothing I can do". "I am HIV, I am going to die". "I said that there is nothing I can do to ease my pain that is all." Participants conveyed their despair and loss of hope and self-worth – in the words of one woman: "I used to cry out loud. He, my husband would ask me why am I crying. I hurt inside. I used to cry all the time." She went on to describe her loss of health by explaining: "I tried and tried to be a normal person. I just want to be a normal person. I am not a normal person." None of the women participating in this study mentioned suicide.

Participants described HIV and AIDS in terms of shame and fear: "I am scared because I am going to be sick," stated one participant, who qualified her statement by saying: "I am sick because I am HIV positive." Another participant reflected on her health as follows: "Now I am still OK, but I am going to be sick." Yet another woman wondered about the progression of the disease: "What will I look like? Will I just get sick and then die?" The shame relating to the loss of health following a positive diagnosis of HIV was exacerbated by the shame and fear of the loss of body image; participants felt that during the later stages of the disease they would no longer be able to conceal their illness. One woman asked: "Am I going to lose weight?" Participants saw the final outcome of a positive HIV diagnosis, apart from loss of health and body image, as death. Antle et al. (2001:161) confirm that acknowledgement that HIV/AIDS is ultimately fatal, places a heavy burden on HIV-positive pregnant women, contributing to despair.

### ***"I accept this"***

In terms of acceptance, the women did not express any hope for the right drug to cure or to alleviate the disease. The participants appeared to be ignorant about antiretroviral drugs. They expressed their personal acceptance of their illness by focusing on the kind of nutrition that could help them to sustain their health. All the participants seemed to understand the concept of caring for themselves, and articulated the fact that they had accepted their HIV-positive diagnosis, saying: "I accept this". "I have to learn to accept it"; and "It has happened and I accept this."

## **Discussion**

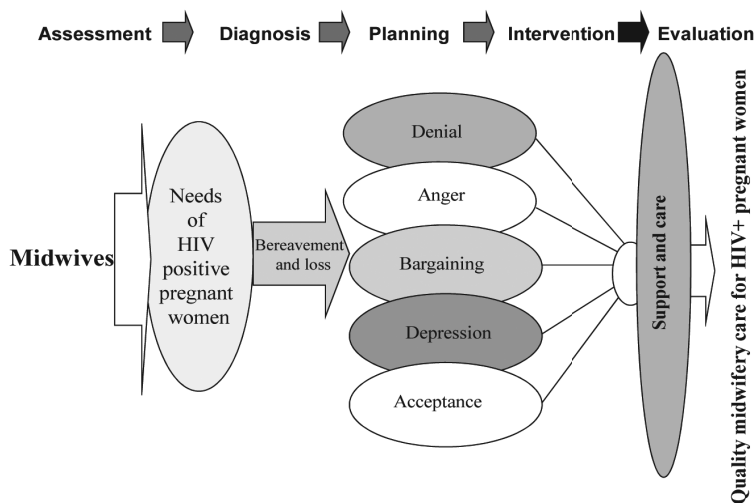
The HIV-positive pregnant participants mourned their situation of being pregnant and HIV positive. Some initially rejected the notion of the disease, but the symptoms forced them to confront reality and to think of the future and their unborn babies. The women experienced sadness because of their disease and because they might not see their children grow up. They did not disclose their status to friends and families (Kohi et al.,

2006:410–411), probably because of the stigma associated with HIV and AIDS in South Africa.

Women described their experiences of pre- and post-test HIV counselling by expressing the emotional pain evoked by the diagnosis, becoming emotional and weeping. The themes that emerged from this study on HIV- positive pregnant women, corresponded with the stages of death and dying as identified by Kübler-Ross, (1969) in Telford, et al. (2006:458) and Bolden (2007:235–237). The participants in this study all progressed through the identified stages of bereavement and loss, but not all reached the stage of acceptance.

The intervention model with regard to bereavement and loss for HIV-positive pregnant women, emerging from this study, could be used as a guideline enabling midwives to offer improved support. By following the guidelines in figure 1, midwives could assess each HIV-positive pregnant woman and respond according to her specific needs.

Participants expressed their anger by rejecting the pity of others, particularly midwives. Being pitied implied that they were different, and they asked to be treated in the same way as other pregnant women. This finding supports that of Sauka and Lie (2000:737–743), and Antle et al. (2001:159–170) who refer to the need for equal treatment as the need for normalisation – the participants wished to be like other pregnant women, focusing on preparations for the baby rather than on trying to stay alive.



**Figure 1: Midwives' interventions for HIV-positive pregnant women experiencing bereavement and grief**

## CONCLUSIONS AND RECOMMENDATIONS

The process towards acceptance of loss is a painful one for the HIV-positive pregnant woman but a caring midwife can assist her. The midwife's task is to provide support as these women progress through the stages of bereavement. Grief changes a person and affects his or her self-esteem; the person adopts new ways of coping, resulting in lifestyle changes. Midwives must allow HIV-positive pregnant women to explore their feelings about the disease, and must also provide information regarding counselling and literature on HIV and pregnancy. Midwives could emphasise the fact that these women should continue with their normal routine activities and that life will go on. Midwives must ensure that quality care is given to HIV-positive pregnant women based on understanding the significant losses these women are experiencing. For midwives to understand these women's perspectives, they must listen to what these women say.

Women grieving about their HIV-positive status need reassurance, counselling and support. Support groups are a long-term mechanism which could assist them during their journey into the unknown.

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