

EXPERIENCES OF BOTSWANA WOMEN DIAGNOSED WITH BOTH HIV/AIDS AND CERVICAL CANCER

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Submitted to the University of Cape Town

In partial fulfillment of the requirement for

MASTER OF SCIENCE IN NURSING

School of Health and Rehabilitation Sciences

Division of Nursing and Midwifery

University of Cape Town

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JUNE 2008

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ACKNOWLEDGEMENTS

I owe sincere thanks to many individuals for their support throughout the period of my studies. Without their support, this project would not have been completed.

I am so grateful for the assistance of the following:

- The women who participated in the study. Without their participation the project would not have been possible. May God almighty bless them and give them quicker recovery.
- My Supervisor, Dr Sinegugu Duma for her patience, guidance and support. I believe that without her support I would have given-up at one point. Her magnificent encouragement was very important both educationally and psychologically.
- The government of Botswana for giving me the opportunity to study. I would like to pass my sincere gratitude to all ministry of Health workers who made sure I completed my studies without any hassles by securing funds for my needs.
- I would like to thank L. Gething for spending some time going through my manuscript and assisting as needed.
- My mother, Mrs Ellen Molefe, who prayed so hard for my success. I love you so much and so grateful for your support.
- I would also like to thank all my siblings especially Tshepang Molefe for her grateful support both emotionally and financially.
- I would also like to thank my extended family and all my friends and colleagues for their support and encouragement.
- Lastly I would like to praise God for being who I am and for the strength and patience he gave me throughout the study.

ABSTRACT

The central phenomenon of interest to the researcher was the experiences of Botswana women who have been diagnosed with both HIV/AIDS and cervical cancer. The researcher wanted to know how these women and their families cope with the burden of the two 'fatal' diseases.

The purpose of the study was to explore the experiences of Botswana women who are diagnosed with both HIV/AIDS and cervical cancer. A phenomenological descriptive qualitative research design was therefore appropriate to answer the research question.

Semi-structured phenomenological interviews and field notes were used to collect data. One-to-one interviews were conducted with six women diagnosed with the two diseases. The women were selected through both convenience and purposive sampling techniques. The seven procedural steps proposed by Collaizi (1978) were then utilized to analyze the data.

The findings revealed that HIV/AIDS and cervical cancer are chronic illnesses that can instill chronic emotional pain. Reactions to diagnosis with these diseases include pain, fear or intense sadness. Coping with these conditions can be facilitated by different strategies such as acceptance, having hope, support from others and positive thinking.

The researcher used convenience sampling and the findings must therefore be applied with caution. Despite the limitations, it is recommended that health workers are well trained in dealing with issues relating to cervical cancer and HIV/AIDS in order to minimize psychological impact on the women. The findings can also be utilized to design effective community-based programmes for these women.

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CHAPTER 1

INTRODUCTION AND ORIENTATION TO THE STUDY

The central phenomenon of interest to the researcher was the experiences of Botswana women who have been diagnosed with both HIV/AIDS and cervical cancer. The researcher wanted to know how these women and their families cope with the burden of the two 'fatal' diseases. This interest was brought about by the current surge in cervical cancer cases in the country, and the relationship between the two diseases. Most women diagnosed with cervical cancer were either HIV-positive or didn't know their HIV status. Frisch, Biggar and Goedert (2000: 1507) also identified the relationship between the two diseases; in their study HIV-infected individuals had an increased risk of all types of anogenital HIV-associated cancers, especially squamous intra-epithelial lesions (SILs) of the cervix and invasive cervical cancer. Another study carried out in Lusaka, Zambia, revealed that one in five HIV-infected women screened for cervical cancer had cytological evidence of squamous cell carcinoma. One in three women in the same study had cytological evidence of high-grade SILs (Parham, Sahasrabuddhe, Mwanahamunth, Shepherd, Hicks, Stringer & Vermund, 2006: 1020).

1.1 Background and motivation for the study

According to *Terra Daily* (2006: 1), the cancer surge is overwhelming doctors in Botswana. Dr Paleske, the head of the oncology unit in Marina, the largest state-owned hospital, informed *Terra Daily* reporters (2006: 1) that outpatient visits increased from 2050 in 2002 to 5650 in 2006. Figures have more than doubled over a period of four years. Dr Paleske linked this dramatic increase with the AIDS crisis in the country, explaining that the cancer surge is caused by HIV,

which weakens the body's immune system. He reported that some of the cancers were due to HIV/AIDS while others were aggravated by the condition. Botswana National Cancer Registry (2005: 7) also reported this relationship, with cervical cancer being the most common cancer among HIV-positive women.

In New York cervical cancer was also the most common AIDS-related malignancy in women, found in 55% of women in a study there (Maiman, Fruchter, Clark, Arrastia, Matthews & Gates, 1997: 1). This led to recognition of cervical cancer as an important AIDS-defining illness in that area. In 1993 cervical cancer was also declared an AIDS-defining illness in the World Health Organization (WHO) European region because of the increase of cervical cancer cases in HIV-infected individuals (Bower, Palmier & Stebbing, 2006: 228; Maso, Serraino & Franseschi, 2001: 1196). This increase in cervical cancer cases might be due to the drop in the peak age of onset of the disease. According to Otto (2005: 248) cervical cancer occurred mainly between the ages of 35 and 50 years, but the Botswana National Cancer Registry (2004: 20) revealed that the peak age of onset is falling. It was found that 22% of the cervical cancer cases occurred before the age of 40 years, with young women of 20-24 years also being diagnosed with the disease.

The researcher had observed that diagnosis with a chronic disease can be painful and distressing. The initial diagnosis can cause a psychological crisis, with emotions ranging from anxiety, anger and fear to depression in many women. A study conducted on African American and Caucasian women also indicated several emotions after receiving a diagnosis of cancer. Most of the participants were shocked, fearful and anxious about diagnosis, surgery and treatment. Some experienced anger, but others stated that they were very calm (Lyons & Shelton, 2004: 4). Similarly, HIV/AIDS patients voice various feelings, such as feeling unloved and uncared for, inner turmoil and fear (Edwards, 2006: 683). A study conducted on HIV-positive mothers also indicated feelings of anger - to the people who had infected them, but also to themselves for allowing it to

happen. Some reported that they felt like killing themselves (Marcenko & Samost, 1999: 39).

Another study conducted on African women diagnosed with both HIV/AIDS and cervical cancer in South Africa revealed a number of emotional experiences. The women had a fear of death, did not want to face reality, and also feared leaving their children. Others got stressed and depressed since they sometimes felt isolated and not free in the midst of their communities. However, most of the women had faith in God and hoped to live long (Maboko, 2005: 38).

The WHO (2005: 37) reported that patients face many challenges after diagnosis with these diseases. The report identified challenges faced by palliative care patients as pain (64%), cough (39%), headache (38%), weakness (36%) and psychological stress (28%). Other problems were lack of food, lack of social support, irregular supply of drugs, shortage of clothing and social isolation. Problems revealed in other studies included stigma, unemployment, lack of income or financial resources to cover living and health care costs, inability to do certain household work, and family and friends' inability to adapt to the demands of the illness (Baigis-Smith & McGuire, 1995: 3; Klee, Thranow & Machin, 2000: 7).

The above issues formed the basis for this study. The challenges and needs relating to these diseases are usually addressed per disease. There is scant literature on the experiences of women with the dual diagnosis of HIV/AIDS and cervical cancer.

1.2 Magnitude of the problem

As mentioned above, the incidence of cancer is increasing rapidly. Botswana is one of the countries struggling with this overwhelming surge of cancer at a time when the government budget is over-stretched by the demands of HIV/AIDS.

This section will outline the magnitude of the two diseases and the related challenge. The magnitude will be highlighted by discussion of the two conditions separately. The issue of the dual diagnosis of cervical cancer and HIV/AIDS is still not well documented, despite growing evidence concerning the influence of HIV/AIDS and the development of certain cancers such as cancer of the cervix (Bower, Palmier & Stebbing, 2006: 228; Maso, Serraino & Franseschi, 2001: 1196; Parham *et al.*, 2006:1020; Frisch, Biggar & Goedert, 2000: 1507).

1.2.1 Cancer of the cervix

Cervical cancer is the seventh most common cancer worldwide, and the second commonest cancer among women. According to Parkin, Bray, Ferlay & Pisani (2005: 74-108) there were 493 000 new cases and 274 000 deaths in 2002, with 83% of the cases occurring in developing countries. The chance of developing the disease in those countries was 1.5% before the age of 65. Higher incidences were prominent in Sub-Saharan Africa, Melanesia, Latin America and the Caribbean, south-central Asia and south-east Asia. Mortality rates were much lower than the incidence, with mortality to incidence ratio of 55%. Survival rates varied between regions and prognosis was mostly good in low-risk areas (74.6% in the US Surveillance Epidemiology and End Results (SEER) Program and 63% in European registries). Survival rates were also fair in developing countries, where many of the cases were identified at an advanced or late stage (SEER Cancer Statistics Review, 1975-2003; Parkin, Bray, Ferlay & Pisani, 2005: 74-108; Cancer Facts and Figures, 2006: 20).

Cervical cancer remains a problem in Botswana, where the prevalence is about 31.9%. It is the most common cancer among black female patients diagnosed with cancer. As mentioned earlier, the peak age of onset of the disease has also fallen, with 22% of cervical cases occurring before the age of 40 (Botswana National Cancer Registry report, 2005: 20, 37). The number of people living with

this disease and the number of deaths seem to be growing alarmingly, just as with HIV/AIDS (UNAIDS/WHO Report on HIV/AIDS 2006: 1).

1.2.2 HIV/AIDS

HIV/AIDS is a great threat worldwide. The number of people living with AIDS and the number of deaths caused by this disease is still growing. In 2006 39.5 million people were living with HIV worldwide, an increase of 2.6 million people from 2004 (UNAIDS/WHO Report on HIV/AIDS, 2006: 1).

Sub-Saharan Africa is carrying a heavy burden from this epidemic, with two-thirds (63%) of all adults and children with HIV from this region. Thirty-two percent of all the people living with HIV globally and 34% of all deaths due to the disease in 2006 were in Southern Africa. Women were the most affected group in Sub-Saharan Africa, with a prevalence of 59% (UNAIDS/WHO Report on HIV/AIDS, 2006: 10).

Botswana is also experiencing a severe epidemic of HIV/AIDS, with an adult HIV prevalence rate of 24% (UNAIDS/WHO Report on HIV/AIDS, 2006: 10). In 2003 AIDS was the major cause of inpatient adult morbidity, with women having a higher prevalence (4135; 52.65%) than men (3719; 47.35%). Although females were most affected, inpatient mortality rates indicated a lower death rate among women (1323) than men (1365) (Botswana Health Statistics Report, 2003: 64).

1.2.3 Diagnosis with cervical cancer and HIV/AIDS

This dramatic increase in the two diseases can be a burden to the patient, family, friends and care-givers as they spend most of their time with these patients. Many HIV/AIDS patients suffer with problems similar to those of cancer patients. According to the WHO (2005: 37), these problems range from pain, dyspnoea,

wasting and confusional states to psychological distress and other devastating symptoms. The diseases are still perceived as fatal and the diagnosis is equated with death, and that causes depression and anxiety (WHO, 2005: 38; Jennings, 1997: 829; Dabash, Vajpayee, Jacob, Dzuba, Bradley & Prasad, 2005: 3). HIV/AIDS and cancer can also be distressing to the families of those affected, and profoundly impacts on both family functioning and the economic situation (WHO, 2005: 38). Diagnosis with cervical cancer seems to be more distressing than with other cancers because of its nature, beliefs around causality and the treatment modalities involved. A study on African American and Caucasians indicated that patients with cervical cancer were significantly more distressed ($x^2 = 11.58$) than patients with breast cancer (Lyons & Shelton, 2004: 4).

Life stress can negatively affect the health of the women. A study conducted on African American, Haitian, Jamaican and Bahamian women between the ages of 15 and 50 indicated increased odds of developing progressive or persistent SILs over one year. Those results indicated that life stress may constitute an independent risk factor for progression of SIL in women living with AIDS (Pereira, Anotoni, Danielson, Simon, Efantis-Potter, Carver, Duran, Ironson, Kliman & Jo O'Sullivan, 2003: 429). Stress can also trigger some psychiatric conditions. The stigma and other challenges related to these diseases can worry patients a lot, and that stress had been seen to cause depressive disorders in a study done in China. According to that study, the lifetime rate of major depression was 79% in a group of HIV-infected individuals, a difference of 75% from an HIV-negative comparison group. All the depressive episodes developed six months after receiving the results. Almost half of the depressed HIV-positive patients were also reported to have had suicidal thoughts, and one-third of that group had attempted or planned suicide at one point (Jin, Atkinson, Yu, Heaten, Shi, Marcotte, Young, Sadek, Wu & Grand, 2006: 273).

Diagnosis with these diseases does not only stress the patients, it can also stress their families or friends. A study by De Groot, Mah, Fyles, Winton, Greenwood, Depetrillos and Devins, (2005: 922) found that cervical cancer had some impacts on the women and also on their partners, with the psychosocial impact of the disease almost the same in both the partners and the affected women. Both also reported disruptions in intimacy, which was defined by spousal relationship and sex life, but women seemed to be more affected than their partners. Edwards (2006: 683) also found that diagnosis of HIV/AIDS has some serious impacts on the relationship of infected women and their partners, with relationship turbulence affecting women's adherence to highly active antiretroviral treatment (HAART) as the women felt unloved and uncared for.

Another huge problem that patients can face is stigma. A study conducted by Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo (2007: 1827) revealed that people living with HIV/AIDS in Cape Town experience a lot of discrimination and internalized AIDS stigma. One in four participants in the study reported that they had never talked to a friend about their HIV status, and one in three was not treated well by their friends and family. More than 40% of the participants had experienced discrimination due to the HIV infection, and one in five had lost their home (places to stay) or job because of their HIV status. According to Carr and Gramling (2004: 35), stigma can have a negative effect on many aspects of women's lives. They found that women spend endless hours and a lot of energy hiding their secret to avoid condemnation, rejection and pain. Some of participants even delayed seeking health care and avoided family members and friends. Participants in this study said that their greatest fear after diagnosis was not death but the negative reactions of people. Haile, Landrum, Kortaba and Trimble (2002: 79) revealed that patients can also be vulnerable to the moral evaluation of nurses working with them.

Like HIV/AIDS, cervical cancer seems to be one of the stigmatized diseases. A study conducted by Ashing-Giwa, Kagawa-Singer, Padilla, Tejero, Chhabra, Martinez and Tucker (2004: 713) revealed that the belief that cervical cancer is contagious and sexually transmitted stigmatized the condition. Some religious beliefs also increased the stigma - some women thought they had cervical cancer as a divine punishment. These beliefs delayed seeking health care and had serious negative outcomes, since the women thought that God will heal them and didn't seek medical support.

Other impacts relate to sexuality and reproductive health. A study conducted by Doyal and Anderson (2005: 2) on HIV-infected African women revealed the importance of motherhood to participants. The women said that motherhood was a source of legitimacy and identity. They said "someone who doesn't have children is less of a woman". One mentioned that she had a stillbirth after her first pregnancy and then the second one died at birth, but she was still trying to have children and was always unsuccessful. Another reported that because of her HIV-status she couldn't produce a second child and her husband left her.

Cervical cancer patients seem to be experiencing the same problems. Ashing-Giwa *et al.* (2004: 713) found that women were concerned about loss of fertility due to illness and the effects of treatment; this was felt more by women who had not yet had children, who felt their role as women had been destroyed. Like some HIV-infected individuals, some cervical cancer patients lost their husbands because they couldn't have children, and some even had to face insults from their husbands' concubines. The same study revealed that some women had no sexual desire (decreased libido) because they thought sex would hurt. Those with sexual desire had difficulty in finding partners.

These are some of the impacts of diagnosis with one of the diseases. It indicates that being diagnosed with both conditions simultaneously could be a great problem.

1.3 Problem statement

Most people view cancer as being fatal and equate it with death (Jennings, 1997: 829; Dabash *et al.*, 2005:3). Other fears stem from negative images of cancer and gynaecological care. Many people associated cancer with words like 'devour', 'eating' and 'plague' (Bingham, Bishop, Coffey, Winkler, Bradley, Dzuba & Agurto, 2003: 411). Just like cancer, diagnosis with HIV/AIDS causes psychological disturbance because of beliefs and attitudes which cause stigmatization. This stigma and fear lead to secrecy regarding HIV status, which affects a lot of women as they encounter daily challenges of the disease which force them to carefully calculate the risks associated with disclosure (Edwards, 2006: 683).

According to Botswana National Cancer Registry report (2005: 8), HIV/AIDS is assumed to be responsible for the increase in the frequency of cervical cancer in Botswana. This report also revealed that the peak age of onset of cervical cancer is falling, and that might be due to the increasing cases of HIV/AIDS. It was found that 22% of cervical cancer cases occurred before the age of 40 years. Young women aged 20-24 years were also diagnosed with cervical cancer. However, there is scant literature on the experiences of HIV-positive women who are diagnosed with cervical cancer. Some of the studies found during the literature review indicated experiences of either cervical cancer patients alone or HIV/AIDS-affected women alone. The lack of literature on dual diagnosis can make it difficult for nurses to improve the quality of care for these patients. A study of the experiences of the two conditions can highlight women's needs and therefore assist the nurses with their care.

The researcher was alarmed by the relationship between HIV/AIDS and cervical cancer and wondered how women in Botswana cope especially with consideration of the great shortage of oncology trained personnel in the country. Currently there are only two oncologists for state hospitals in the whole country and only one oncology trained nurse. The question that one might be interested

in is to know exactly how being diagnosed with the two diseases means in a country like Botswana. Being a Motswana woman, the researcher thought it will be easier to understand what it means to live with the two diseases especially considering all the cultural and spiritual believes and/or responsibilities attached to women in the country.

1.4 Purpose of the study

The purpose of this study is to explore the experiences of Botswana women diagnosed with both HIV/AIDS and cervical cancer.

1.5 Research question/problem

What are the experiences of Botswana women diagnosed and living with both HIV/AIDS and cervical cancer?

1.6 Objectives

The objectives of the study were as follows:

- To explore what it is like to be diagnosed and living with both HIV/AIDS and cervical cancer.
- To describe women's experience of living with both HIV/AIDS and cervical cancer.

1.7 Definition of terms

Cervical cancer

In cervical cancer the malignant neoplasm develops at the squamocolumnar junction, the area of the cervix where squamous cells that line the vagina and cover the outer portion of the cervix and the columnar cells that line the

endocervical canal meet. These cancer cells are new, abnormal growth of tissue which fails to fulfill its normal function, thereby forming a mass that extends beyond the boundaries of normal tissue (Otto, 2005: 4, 248).

Squamous intra-epithelial lesions (SILs)

A sexually transmitted disease which is a precursor to cervical cancer. It is the most common neoplasia of the cervix and has been associated with early age of first sexual intercourse, multiple sexual partners and infection with human papilloma virus (HPV) (Otto, 2005: 340).

HIV/AIDS

Cellular and clinical disease from initial infection and asymptomatic disease to early and late symptomatic disease (AIDS) and death, caused by human immunodeficiency virus (HIV) infection (Weller, 2005: 187).

Human Immunodeficiency virus - HIV

HIV is a lentivirus belonging to a group of viruses called retroviruses and causes HIV/AIDS (Weller, 2005: 189).

1.8 Outline of the study

Chapter 1 introduces the problem to be studied and includes the background, magnitude, context and overview of the problem. The main aim is to give a broad picture of the study and motivate for the need for the study.

Chapter 2 provides a literature review, while chapter 3 gives a full description of the methodology used, starting from the problem statement to analysis and reporting of findings. Chapter 4 gives a detailed description of the data analysis method used in the study, and Chapter 5 presents the results and findings of the study.

Chapter 6 discusses the results or findings, concludes the study, discusses its limitations and makes recommendations for further studies, and is followed by the references and annexures.

1.9 Conclusion

This chapter outlined the problem as well as the purpose and objectives of the study, and also supported the need for the study. Chapter 2 provides a cursory literature review conducted prior to the study.

University of Cape Town

CHAPTER 2

LITERATURE REVIEW

Munhall (2007: 190) states that in phenomenology the literature review is used to seek experiential descriptions of the meaning of the experience that may have been written from different perspectives. It also deepens an understanding of those perspectives. Munhall further states that although it has been suggested that this step should be delayed until interviewing participants, literature on the studied experience may be encountered when not expected. In these cases the literature should be read just like other existential material to deepen understanding and meaning.

In this study a cursory literature search was conducted prior to the study for background information and motivation of the study, and also to direct the researcher to areas that were not thought of at the beginning of the study. Review of the literature was also done after data analysis, to compare the findings with those of previous studies. Below is some of the literature that directed the researcher to certain areas.

2.1 Association of cervical cancer with HIV/AIDS

Patients affected by HIV seem to present an elevated risk of developing cancer. Meta-analysis of HPV types among women infected with HIV indicated a higher prevalence of HPV infection in HIV-positive women from Africa and South/central America (Clifford, Goncalves & Franceschi, 2006:2342), with more than one-third of all HIV-positive women with cytological abnormalities infected with HPV. According to Otto (2005: 248), history of an infection with this sexually transmitted virus increases the risk for cervical intra-epithelial neoplasia (CIN), which is a precursor to invasive cervical cancer. Other studies also revealed the

relationship between HIV/AIDS and cervical cancer, and some even stipulated that the relationship led to the declaration of cervical cancer as an AIDS-defining illness (Bower, Palmier & Stebbing, 2006: 228; Maso, Serraino & Franseschi, 2001: 1196; Parham *et al.*, 2006:1020; Frisch, Biggar & Goedert, 2000: 1507).

Although cervical cancer was declared an AIDS-defining illness in 1993, Bower, Mazhar & Stebbing (2006: 2418) argue that the available information on the relationship of the two does not provide enough evidence to make that conclusion. However, they stressed the importance of prediction of an increase in HPV-associated malignancies, including cervical cancer, among the HIV-positive population even with the use of HAART.

The relationship between prevalence of SILs and HIV status was reported by Leroy, Ladner, DeClercq, Meheus, Nyiraziraje, Karita and Dabis (1999: 105). However, they did not establish a causal relationship between HIV infection and SILs. They reported that the association was confounded by factors such as age, age at first intercourse, parity, sexually transmitted diseases and number of sexual partners. In support of this, Schuman, Ohmit, Klein, Duerr, Cu-Uvin, Jamieson, Anderson and Shah (2003: 134) propose that the likelihood of SIL regression can be associated with HIV-associated cell-mediated immunodeficiency ($CD4 \text{ count} \leq 500 \text{ cells/mm}^3$) and higher HIV loads.

Recent studies indicate that there is hope for individuals diagnosed with both HIV/AIDS and cervical cancer. A report by Biggar, Engels, Ly, Kahn, Schymura, Sackoff, Virgo and Pfeiffer (2005: 295) indicated that survival rates of persons with AIDS and those with cancer have both recently improved. Their results also revealed that the 24-month survival rate of people living with AIDS and cancer has significantly increased. These findings led to the conclusion that recent improvements in AIDS and cancer care have greatly narrowed the gap in survival between cancer patients with and without AIDS. Despite the promising survival

rate, the impact of these diseases can be traumatizing to the patients and their families.

2.2 Impact of diagnosis HIV/AIDS and cancer

The impact of terminal illnesses does not only affect the ill person but also a number of people who are related or have contact with the ill person. According to Bezuidenhout, Elago, Kalenga, Klazen, Nghipondoka and Ashton (2006: 18), diagnosis with HIV/AIDS psychologically affects children of the infected person, family members and care-givers. Emotions after diagnosis with the two diseases vary in individuals, and a study by Maboko (2005: 38) revealed emotions like shock, anger, sadness, denial and fear of death. Bezuidenhout *et al.* (2006: 19) explained that HIV-infected persons fear having to adjust to a new lifestyle.

According to Maboko (2005: 38), the impact of dual diagnosis with the two diseases can be a big blow to the women, and they usually face a difficult decision of whether to disclose their illnesses to others or not. Some of the respondents decided to disclose only about the cervical cancer and not HIV/AIDS because of fear of the discrimination and stigma that go with the disease. Failure of disclosure can lead to social isolation, which may result in emotional breakdown as feelings continue to be suppressed (Bezuidenhout *et al.*, 2006: 19).

Another impact of HIV/AIDS is the associated stigma, which affects the parental care-giving, social support and health-seeking roles of the women. Hacki, Kristin, Somlai, Anton, Kelly, Jeffrey, Kalichman and Seth (1997: 293) found that women usually use ineffective coping strategies such as denial, concealment and isolation to deal with the above effects of this disease. Their findings show that women living with HIV have special needs in the areas of social services, support systems and stressors related to their dual roles as patients and family caretakers. Women struggle to balance their own health concerns with the

demands and needs of their families. Although a lot of women in this study described positive lifestyle changes (such as getting off drugs), most attention seemed to be focused on maintaining a happy environment for the family or children despite their terminal conditions.

Like HIV/AIDS, cervical cancer does not only affect the women diagnosed with the disease. A study by De Groot *et al.* (2005: 922) found that cervical cancer has some impacts on the women and also on their partners. The study revealed that the psychosocial impact of the disease was almost the same on the partners as on the affected women. Both reported disruptions in intimacy (defined by spousal relationship and sex life), but the women seemed to be more affected than their partners. Edwards (2006: 683) also found that HIV/AIDS diagnosis had some serious impacts on the relationship of infected women and their partners, and relationship turbulence affected the women's adherence to HAART, as they felt unloved and uncared for.

There are other impacts of diagnosis with the two diseases, and violence is one of them. A study by Sowell, Seals, Moneyham, Guillory and Mizuno (1999: 611) reported violence as part of the experiences of HIV-seropositive women; 62% of the women reported some kind of verbal abuse, 14% physical abuse and 5% one incident of sexual assault. Violence included being yelled at, humiliated or made to feel worthless; physical abuse included being punched or kicked, tied up or threatened with a weapon. Sexual abuse included being forced to have sex or performing sexual acts against one's will.

2.3 Treatment for cervical cancer and HIV/AIDS

Management of HIV-positive patients with cervical cancer seems to be one of the many challenging tasks for oncologists. According to Maimam (1998: 44), the oncology team must follow the same principles in the treatment regimen as for HIV-negative individuals. Because these patients have a compromised immune

system, this report suggests extremely close monitoring to determine treatment efficacy and detect any unusual toxicities. A study conducted by Shrivastava, Engineer, Rajadhyaksha and Dinshaw (2005: 33) revealed that radiotherapy could be effective for treating invasive cervical cancer by giving palliation fraction schedules. Main problems that the study reported were gastro-intestinal (14%), skin (27%) and genito-urinary toxicity, and the increased reactions were linked to the compromised immune system of the patients. These toxicities forced the oncologists to reduce the prescribed doses of radiation, and that led to a bad outcome.

According to Abu-Rustum, Lee, Correa and Massad (2001: 89), cisplatin- based chemoradiation can also be used in the treatment of cervical cancer. However, the report indicated that compliance with this treatment is a great challenge to the oncology team. In a study conducted on indigent women they found that compliance from the patients was good, but certain haematological problems led to cancellation of the chemotherapy. The acute haematological effects were low white blood cell count and anaemia. A study conducted by Kehoe (2006: 992) found that chemoradiation seemed to be more effective. The only problem mentioned in this study was the high cost of treatment, which had a substantial effect on the well-being of the patients.

These are some of the challenges that patients undergoing cervical cancer treatment have to deal with, and it seems that the problems don't stop immediately after completing the course of treatment. According to Curtiss, Haylock and Hawkins (2006: 50) the patients continue to deal with haematological changes such as persistent anaemia and a tendency to bruise or to experience prolonged bleeding. Other problems added to these complications are premature menopause, which includes cessation of menses, hot flashes, infertility (permanent or temporary), diarrhoea and urinary incontinence. This can be a big blow to the women, since a study conducted by Doyal and Anderson (2005: 2) on HIV-infected African women showed the importance of motherhood

to participants. The women said that motherhood was a source of legitimacy and identity, and that “someone who doesn’t have children is less of a woman.” Some revealed that their husbands left them because they could not have children.

Patients also have to deal with the side-effects of anti-HIV treatment. According to Maiman (1998: 49), patients need the anti-HIV drugs for optimization of immune function and to lower the viral load, and they are now placed on newer multiple-drug regimens which are very effective. The report explained that the treatment is complex and always changing, and therefore careful attention is needed to deal with overlapping effects of these anti-HIV drugs with cervical cancer treatment.

Battaglioli-DeNero (2007: 18) reports that the adverse effects of anti-HIV drugs can lead to non-adherence to therapy, and patients need to know that these effects are temporary so that they continue with treatment. Adverse effects can include nausea, vomiting and diarrhoea with protease inhibitors, and central nervous system symptoms, dermatological conditions and lipid abnormalities with nucleoside and non-nucleoside reverse transcriptase. Several studies have also documented factors that can lead to non-adherence to antiretroviral drugs, including misplacing of medications, confusion over dosing schedules, lack of structure in daily routine, lack of understanding regarding adherence, pill burden, cost, non-disclosure of HIV status to a loved one (family or friends), and drug and alcohol abuse (Mills, Orbinski, Rachlis, Thabane, & Guyatt, 2006: 9; Battaglioli-DeNero, 2007: 18; Kalichman, Cherry & Cain, 2005: 3).

The report by Battaglioli-DeNero (2007: 19) added that some factors can be provider-related or due to over-estimation of patient adherence by nurses and physicians. Advice to health workers are that they should have good interviewing skills and avoid close-ended questions like ‘how are you doing with your treatment?’ and rather use open-ended questions like ‘what are some of the difficulties that you are having with your treatment?’ That will give the patient

room to disclose some of the things that will reveal adherence or non-adherence to therapy. In the same study it was shown that patients usually overstate their adherence because they fear criticism, don't want to disappoint the health workers or are afraid that treatment might be withheld.

Studies conducted by Kalichman, Cherry and Cain (2005: 3) and Battaglioli-DeNero (2007: 19) revealed another strategy that can deal with poor adherence, especially in persons with lower health literacy skills: a two session plus one booster session nurse-delivered counselling session. This suggestion was made looking from the point of view that nurses spend more time with patients than physicians do, thus placing them in a good position to deliver the adherence-boosting intervention.

Other factors relating to poor adherence identified by Sodergard, Hofer, Halvarsson, Sunnerburg, Tully and Lindblad (2007:113) included age, time on treatment, contact with psychiatric health care, patient-provider contacts and social support. The same report indicated the importance of readiness to start treatment over adherence. The model used indicated that readiness influences adherence; health professionals are urged to postpone treatment initiation if they underestimate the patient's ability to adhere to the treatment. The benefit of readiness is the possibility of measuring it prior to treatment initiation, thereby predicting if the patient is likely to be adherent.

The above information provided a base for some of the challenges relating to HIV/AIDS and cervical cancer, and outlined some of the interventions or models used to counteract poor adherence. Other models mentioned by Battaglioli-DeNero (2007: 20) are motivational interviewing and brief interventions. Poor adherence to drugs has led to motivations for more research on this issue, and there are other models not documented here which have been proven to work for

patients who are non-adherent and for those who are adherent, to prevent them from 'falling off the rails'.

2.4 Conclusion

The literature highlighted a relationship between HIV/AIDS and cervical cancer and some of the challenges or threat posed by diagnosis with these diseases. Despite that, there is scant literature on experiences of dual diagnosis with the two diseases. Most of the literature focuses solemnly on each condition individually. Although that information can be useful, the researcher thought it is ideal for nurses to discover what it means to live with the two conditions as the challenges posed by one of them is so traumatic. The study on experiences of African women diagnosed with the two diseases provides some of the information that we can use to help African women diagnosed with HIV/AIDS and cervical cancer but more research on such issues is important as experiences can vary depending on available resources, factors affecting health and geographical location.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter discusses the methodology used to conduct the study and the ethical considerations applied. It concludes with the limitations of the study.

The purpose of this study was to explore the experiences of Botswana women who are diagnosed with both HIV/AIDS and cervical cancer. The research question was 'What are the experiences of Botswana women diagnosed with both HIV/AIDS and cervical cancer?' A phenomenological descriptive qualitative research design was used to explore the experience of living with the two serious chronic illnesses. A descriptive qualitative design was appropriate to answer the research question.

3.2 Qualitative research design

A qualitative research design is a social inquiry which focuses on understanding how people interpret and make sense of their experiences and the world they are living in. Qualitative researchers adopt a person-centered and holistic perspective. That makes this approach an important method in nursing research. There are a number of qualitative research approaches aiming at exploring the behaviour, perspectives, feelings and experiences of people. Ethnographers focus on culture and customs, grounded theorists investigate the processes and interactions of social contexts, and phenomenologists focus on the meanings of experiences. To adopt a certain methodology the researcher has to examine the nature and type of the research question or problem, the level of skills and training he or she has and the resources available for the study (Holloway & Wheeler, 2002: 3).

The qualitative design was selected because the aim was to explore and describe human experiences of living with both HIV/AIDS and cervical cancer. The qualitative research design is a naturalistic method of enquiry emphasizing an understanding of human experience as it is lived. Qualitative researchers study participants in their own settings in order to interpret phenomena in terms of the meanings people bring to them. This includes a variety of empirical materials such as case studies, personal experience, life stories, observational and visual texts that describe routine and problematic meanings and moments in one's life (Denzin & Lincoln, 1998: 3; Polit & Beck, 2006: 16). For the current study personal experiences of women diagnosed with both HIV/AIDS and cervical cancer were explored and described according to the meaning they attached to them. Hence qualitative research design was the best methodology to use.

Qualitative research designs are reported to be an essential means to know and understand phenomena of nursing and to gain a holistic perspective. Humans need to be understood from the totality of their life pathways, and discovering the patterns and themes of nursing phenomena is a way to understand people and the ways and needs of caring life (Leininger, 1985: 23). The study of women's experiences of being diagnosed with HIV/AIDS and cervical cancer will help nurses to understand these women and their needs as the women express them.

3.2.1 Descriptive phenomenological approach

"Phenomenology is the study of the life-world, the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize or reflect on it" (Van Manen (1990: 9) cited in Munhall, 2007: 114). Phenomenologists believe that lived experiences give meaning to a person's perception of a particular phenomenon. The aim of phenomenology is to

understand lived experiences and the perceptions to which these give rise (Polit & Beck, 2006: 219). A descriptive phenomenological approach was therefore found to be appropriate for the current study because the researcher investigated the lived experiences of women diagnosed with HIV/AIDS and cervical cancer.

As a nurse, the researcher found this approach appropriate to understand the experiences of women diagnosed with both HIV/AIDS and cervical cancer. The researcher thought that use of the phenomenological approach in this study would assist nurses to respond appropriately or to undertake activities necessary to the caring relationship between nurses and women with similar ailments.

Phenomenology was reintroduced (from its origins in Aristotle's works) from the concept of 'intentionality' by philosopher and psychologist Franz Brentano (1838-1917), who was a teacher of Edmund Husserl. Husserl (1859-1938) took over from Brentano and introduced the modern philosophy of phenomenology. Phenomenological philosophy describes the development of schools with different approaches; however, the goal of each is to gain knowledge about a phenomenon (Holloway & Wheeler, 2002: 177; Munhall, 2007: 114). This study focuses on the method of the Dequesne school, guided by Husserl's ideas (the Husserlian approach).

Descriptive phenomenological studies involve four steps: bracketing, intuiting, analyzing and describing. Bracketing is the process of holding preconceived beliefs and opinions about the phenomenon being studied. Researchers do this by examining their beliefs and opinions regarding the study so that these don't influence the study. Intuiting involves remaining open to the meanings given by those who experience the phenomenon (Holloway & Wheeler, 2002: 173; Polit, Beck & Hungler, 2001: 215). Remaining open to the meanings means that the researcher has to accept and interpret the findings exactly as the participants report them, even when they are similar to or deviate from what was discovered before. The next step, analysis, helps the researcher to extract statements from

the interviews, categorize them and make sense of their meanings. This is discussed in the next chapter. The last step is where the researcher tries to understand and explain the meaning of the phenomenon as described by the participants (Polit & Beck, 2006: 220).

For the current study the Husserlian approach (descriptive) of phenomenology was chosen because the researcher wanted to understand and describe the experiences of women diagnosed with HIV/AIDS and cervical cancer without adding or subtracting anything from them.

3.2.2 Population

According to Polit and Beck (2006: 56), a population is defined as “all individuals or objects with common defining characteristics”. A reader of a research report must clearly understand the population of a study so that he or she can accurately generalize the results. In order to make sure that those findings are well generalized, the researcher must define the population by specifying the unit being sampled and the geographic location of the population (Polit, Beck & Hungler, 2001: 233; Neuman, 2004: 141). Polit and Hungler (1993: 174) also stress the importance of making a distinction between a target population and an accessible population for readers to be aware of the eligibility criteria of the study. They further explain that the eligibility criteria for inclusion in a study are the most ideal way of delimiting the population of interest. Neuman (2004: 141) defines a target population as a specific pool of cases that the researcher needs to study. An accessible population refers to all cases within the target population that are easily accessible to the researcher (Polit, Beck & Hungler, 2001: 234). In this study the *target population* was all Batswana women diagnosed with both HIV/AIDS and cervical cancer. The *accessible population* was all Batswana women diagnosed with both HIV/AIDS and cervical cancer attending the departments of oncology and gynaecology at a tertiary hospital in Botswana.

3.2.3 Sampling

Sampling is “the process of selecting a portion of the population to represent the entire population and a sample is a subset of the population” (Polit & Beck 2006: 260). Holloway (2005: 109) explains that sampling for phenomenological research does not focus on the size of sample but on the quality of the data, since the aim is not to count how many people have had a particular experience or to make quantitative comparisons between populations, the aim is to understand the phenomenon more deeply.

Because qualitative researchers are not interested in numbers but in meaning, participants are sought according to experiential fit and by looking for the qualities of a good informant. Experiential fit is where a researcher searches for participants who have either lived the experience, undergone the experience or observed an individual undergoing the experience (Munhall, 2007: 530). Munhall further states that it is important to choose participants who have a maximal level of the experience under study, and defines a good informant as an individual willing or able to give as much information as he or she can. These are the criteria most often used in qualitative sampling.

In the current study the researcher used both convenience and purposive sampling. Convenience sampling is the use of readily available participants. Purposive sampling is a judgemental sampling method in which the researcher selects informative participants or those that best represent the population under study (Polit & Beck, 2006: 262; Neuman, 2004: 140; Munhall, 2007: 230). The researcher used convenience sampling because the participants were patients staying in the interim home for radiotherapy and therefore readily accessible. The first two participants for the pilot phase were identified by nursing staff because the researcher was not familiar with the patients. The nurses in the oncology unit informed the first two participants about the study and asked them to indicate if they wanted to participate so that they could meet with the researcher. Once data collection for the main study started with preliminary analysis of data from these

two patients, the researcher identified other participants based on 'experiential fit' as part of purposive sampling. Only participants who met the inclusion and exclusion criteria were selected.

3.2.3.1 Inclusion criteria

Participants were required to meet the following inclusion criteria:

- Women diagnosed with both cervical cancer and HIV/AIDS and able to speak either Setswana or English.
- Stage of diagnosis of cervical cancer within the range of stages 0-IIIIB. Stage 0 means there is carcinoma *in situ*, no regional lymph node metastasis and no distant metastasis, while stage IIIIB is where the tumour extends to the pelvic wall and there is regional lymph node metastasis but no distant metastasis (Otto, 2001: 253).
- Women who had or did not have other chronic illnesses (e.g. high blood pressure or diabetes). An additional criterion was that the chronic medical condition should be well managed.

3.2.3.2 Exclusion criteria

Potential participants who met the following criteria were excluded from the study:

- Women at the last stage of AIDS.
- Women with cervical cancer stage IV.
- Women at the late stages of AIDS and stage IV of cancer of the cervix.
- Women with mental illnesses and those who had hearing impairments.

The researcher decided to exclude patients who met the above criteria since it could have been difficult to communicate with them due to critical conditions or communication barriers, and the researcher doesn't know any sign language.

The researcher also thought that these patients were unfit to share their experiences and that it could have caused them psychological harm.

3.2.3.3 Sample size

A sample of six participants was recruited including the two participants who were recruited for pilot purposes. This sample size of six participants is in line with the literature (Morse (1994) cited in Sandelowski 1995: 181). Sandelowski (1995:181) adds that even one case can be enough for an experience to be deemed significant for display. Holloway and Wheeler (2002: 128) state that there are no rigid rules for sample size in qualitative research, and sample size does not necessarily determine quality of the data collected. They further explain that Wolcott (1994) and Banister *et al.* (1994) claim that a large sample can weaken the trustworthiness of the study; they say that a large sample will lack depth and richness and can lead to loss of meaning of the collected data.

3.2.4 Research setting

A setting is “the physical location and conditions in which data collection takes place”. Qualitative researchers always strive to collect data in a variety of natural contexts (Polit & Beck, 2006: 213). In this study all participants were sheltered in an interim home, where they stayed to complete the radiation therapy at a local private hospital (Gaborone Private Hospital). Because of limited space the government has turned an ex-tuberculosis isolation unit into an interim home where they accommodate patients in transit from other hospitals to South Africa or to local private clinics. It accommodates cancer patients undertaking treatment at Gaborone Private Hospital and those waiting to be transferred to health facilities in South Africa for further management. A quiet room in the interim home was used; it is used as a television room and is not utilized that much during the day since most of the patients would have gone for treatment or be resting in their rooms. The set-up of the room gave the researcher and

participants enough room and a choice of seating, making the environment comfortable and relaxing, rather like sitting in a living room at home.

3.2.5 Gaining entrée

Polit and Beck (2006: 58) explain that it is essential to negotiate with the 'gatekeepers' who have the authority to permit entry. This involves negotiations with those who have the power to grant or withhold access to the setting. Researchers are advised to negotiate with those directly in charge, but also with those with the power to stop the research (Holloway & Wheeler, 2002: 40; Neuman, 2004: 273).

In the current study the researcher negotiated with the hospital superintendent and the nursing service manager. After receiving an approval letter for the study from the Ministry of Health (research department), a meeting was held with the hospital superintendent, hospital research committee and nursing service manager. A nurse was identified as a key informant (key informants are knowledgeable about a certain group and can provide a main link to participants (Polit & Beck, 2006: 274)). After gaining access to this department the researcher developed a stable, trusting relationship with the nurses there. On the first two days of the recruitment phase after gaining entrée, the researcher explained the study to all of the nurses and others working in the department, as well as her role and the importance of the study. This ensured that she was accepted by all, and assisted in the recruitment and actual data collection phase.

3.3 Pilot phase

A pilot study is “a small scale version, or trial run, done in preparation for a major study” (Polit & Beck, 2006: 506). A pilot study is used to: develop and test the adequacy of a research instrument, assess the feasibility of the study, design a protocol, assess if the protocol is realistic and workable, identify if the sampling frame and technique are effective, assess the recruitment approaches, identify problems which might occur using the suggested methods, and estimate variability in outcome to help determine sample size. Other purposes are to collect preliminary data, determine the sources needed for the study, assess suggested techniques of data analysis, develop research questions, train the researcher and, lastly, convince funding bodies that the researchers are competent and that the study is feasible and important (Teijlingen & Hundley (2001) cited in Watson, Atkinson & Rose, 2007: 619).

In the current study pilot interviews were conducted with the first two participants recruited in preparation for the main investigation. These participants shared similar characteristics with those in the main study, meeting the inclusion and exclusion criteria. The aim of the pilot study was to improve effectiveness of the researcher's data collection skills and to strengthen or modify the semi-structured interview guide. As a novice researcher, that helped me to gain some experience in interviewing and also to check that the questions were simple, answerable and clear to participants. The pilot interviews were conducted in Setswana, and based on the pilot participants' responses, no changes were made to the guide.

Data from the pilot interviews were reported in detail in addition to findings from the main study. That was important because the findings added more information to the main study. Van Teijlingen, Rennie, Hundley and Graham (2001:293) raise a concern regarding the rate at which information from pilot studies is under reported. They state that a well-designed and well-documented pilot study can inform readers about the best research process and occasionally about the likely

outcomes. They stress the importance of encouraging researchers to report their pilot studies.

3.4 Research process

The research process started with requests to conduct the study from different research bodies-University of Cape Town ethics committee, ministry of Health research unit in Botswana and Princess Marina ethics committee.

3.4.1 Sampling and recruitment

After approval from the University of Cape Town, South Africa, and the Ministry of Health (research unit), the researcher was given permission to recruit participants in the oncology and gynaecology departments by the hospital management. A letter was written to ask the nurses in these departments to assist the researcher with recruitment as needed. The recruitment period lasted for three weeks, from 24 July 2007 to 10 August 2007. In guarding confidentiality of the patients the researcher developed a trusting relationship with the nurses in the ward so that they could assist with recruitment. The first potential participants were recruited by the nurse on duty and asked to indicate if they were to participate. The first two participants were identified by this nurse, and the researcher was introduced to them. These two participants had been admitted for radiotherapy, and the researcher had the opportunity to recruit them for participation in the study. Another three participants who met the criteria were only identified by the researcher in the third week. (During the previous two weeks, only women who did not meet the criteria were in the centre.) The last participant was admitted at the end of the third week; she was identified and recruited on the second day of her admission.

Since the participants were sheltered at an interim home while awaiting radiotherapy they informed other participants about the study and that made it easier for the researcher to recruit more. The recruitment period took longer than expected. Working in the unit with an aim of finding potential participants was frustrating and exhausting as the researcher mostly worked the whole day in the unit without finding any participants. Although working in the oncology unit gave the researcher an opportunity to practice as she was still training for oncology nursing the work was more exhausting as the sole aim was to recruit participants. By the end of the third week the researcher identified the next three participants who were already at the interim home awaiting radiotherapy. The researcher noticed that the first two participants had already informed other patients about the study and that made the recruitment process easier.

After identifying each participant, the researcher explained the study in detail and the ethical considerations, obtained permission to use the recorder and outlined the benefits of participation. The researcher explained to the participants about her role as a researcher and as a postgraduate student from the University of Cape Town. The researcher wanted them to agree to participation with the knowledge that the research was done for study purposes, although there was hope that the results might be used to guide further studies on the same subject. Information sheet and consent forms (See Annexures 1 and 2) were used to explain the content of the research. Each participant was given the information sheet to go through before the next meeting, scheduled for the first interview. Arrangements for the time of the interview were made with each participant. All signed the consent forms before the interviews started.

3.4.2 Self reflection

The researcher was currently working in the oncology unit as a nurse and it was important to make sure that her role in the research was not misinterpreted by participants as that could have affected the quality of the data. She was forced to

explain time and again to participants that there was no right or wrong answer and that the important thing was to get their stories as to understand the meaning of the experiences as they experienced it, not as the researcher perceived it. There were instances whereby the participants would not want to share certain experiences with a notion that they didn't want the researcher to fail as she explained that the research was done to complete studies at the university. The researcher still explained to the participants that their experiences or stories would not affect the academic results for the researcher and that the important thing was to get their stories as real as possible.

Munhall (2007, 182) stresses the importance of the researcher as an instrument and participant in the study and how that could affect the quality of the data collected. According to her it is ideal to reflect your thoughts and why you became interested in the study as that can help the readers to understand who you are in the study, your experiential perspective and why you are engaged in the study experience.

As a professional nurse trained in psychosocial care for oncology patients, the researcher had to always remind herself that she was not in a counseling session. At one point she was forced to redirect the participants to the area of research although that was sometimes frustrating and exhausting. The researcher's area of interest had always been psychosocial oncology since she noticed patients' gratitude to counselors who always spare a minute to listen to them.

3.5 Data collection

The most common methods of data collection in qualitative research are interviewing and participant observation (Holloway, 2005: 37). The purpose of this study was to explore the experiences of women diagnosed with both

HIV/AIDS and cervical cancer. In line with this, semi-structured interviews and field notes were chosen as data collection methods because they allowed participants to describe their experiences in detail, making it easier for the researcher to understand the phenomenon under investigation.

Polit and Beck (2004: 341) explain that semi-structured interviews help to ensure that a specific set of topics are covered in the interview. A semi-structured interview is one in which topics or questions which need to be covered are listed (see Annexure 5). Researchers also use an interview guide to encourage participants to freely discuss all topics in the guide (Polit & Beck, 2006: 291).

Field notes are observations and interpretations made by the researcher in the field. They may include daily logs, but in a broad way, and are also more analytical and interpretive. They give the researcher's feelings about the research process and give interpretations to observations (Polit, Beck & Hungler, 2001: 283).

3.5.1 Phenomenological interviews

Semi-structured phenomenological interviews were used to collect data using an interview guide (Annexure 5). Probes and clarification statements were used to allow for thick description and exploration of the phenomenon (see Annexure 5). Examples of probes that were used include the questions "Please explain what you mean by that?" and "When that happened how did you feel?"

Each participant was asked whether she was still willing to participate as consented beforehand. This was when the researcher and the participant jointly signed the consent form. The request for permission to use the recorder was also repeated before the interview resumed.

3.5.2 Field notes

According to Holloway (2005: 153), field notes or observers' descriptive notes (Polit & Beck, 2006: 307) are researchers' thoughts and observations during the interview process. They are used to record information, synthesize and understand the data.

For the current study, field notes included everything not captured by the tape-recorder, e.g. aspects of the context of the study (time, place), and facial expressions and gestures of the participants observed during data collection. A description of participants and the researcher's view of what was happening in the setting were also noted down after every interview session.

The second class of field notes is reflective notes. According to Polit and Beck (2006: 307), reflective ideas that evolve during the interview and analysis of data should be documented as a continuous process. In the current study reflective notes were used to document the researcher's personal experiences, reflections and progress while in the field. All data collection methods discussed were used during the pilot phase and the main data collection phase.

3.6 Ethical considerations

The following ethical considerations were applied in the study in order to avoid harming the participants and to ensure that the study met the requirements of the Helsinki Declaration (1964).

3.6.1 Permission to conduct the study

Before commencing the study, permission was sought and granted by ethics committees at the University of Cape Town and Ministry of Health in Botswana (see Annexure 4). Permission was sought and granted from the executive officers and ethics committee of the hospital (Princess Marina Hospital) in

Botswana and the head of the oncology and gynaecology departments. A letter explaining the purpose of the study was taken to the executive officers and head of departments of the hospitals.

3.6.2 Autonomy

Respect for autonomy means that participants must make a free and informed choice to participation (Polit & Beck, 2006: 93). Informed consent is a major component in respect of autonomy. The researcher must make sure that participation is voluntary and that participants are aware of the benefits and risks of the study. Qualitative researchers view consent as an ongoing, transactional process (process consent), whereby the researcher continuously negotiates the consent, allowing the participants to play a role in the decision- making process regarding the ongoing participation (Holloway & Wheeler, 2002: 52).

In the present study:

- Written consent for participation was signed by each participant. Each received a consent form which spelled out the nature of the study, the purpose of the study, the rights to privacy and anonymity, the benefits of participation and the methods of data collection. The researcher conducted the interviews only when both researcher and participant had signed the consent form.
- An information sheet was used to explain all the details of the study a day before the interviews commenced (see Annexure 1). The information sheet was translated into a local language (Setswana) so that participants could easily understand all the details of the study. The researcher went through the information sheet with the participants and also clarified everything that was stipulated there. Participants were allowed to keep the information sheet.

- Permission to use the tape-recorder was obtained from each participant before the actual interviews (see Annexure 2).
- Participants were informed that participation was voluntary and that they could therefore withdraw at anytime without compromising the health services they were receiving at the time. They were also told the approximate duration of the interviews.

3.6.3 Confidentiality and anonymity

Anonymity occurs when no one can link the data with any participant, and means participants remain nameless (Polit & Hungler, 1993: 431). Confidentiality is a pledge made by the researcher to participants that no information will be publicly reported or made accessible to any third party who is not involved in the study. Confidentiality can protect participants from psychological harm (Holloway & Wheeler, 2002: 61; Neuman, 2004: 56). For example, if the participants decided to keep some information secret, like not disclosing the diagnosis of one of the diseases in the study (e.g. HIV/AIDS), and the researcher disclosed that information, this could cause a lot of stress to participants.

These ethical principles were maintained throughout the study in order to protect participants. Participants' names were substituted by numbers (e.g. participant 1, 2, 3, etc.) and the researcher made sure that names of the participants were not recorded on the digital voice recorder. Because some people could identify the participants from the recorded files, the researcher transferred the recorded interviews straight into computer files which could be accessed only by someone who knew the password in that user account. The researcher always used headphones to listen to the interviews in the computer. The researcher also kept the consent forms under lock and key until the research process was complete and the final write-up was submitted. Reporting of the findings was also done in such a way that no one could link information to any participant.

3.6.4 Justice

This principle includes participants' right to fair treatment and the right to privacy. The principle of justice imposes duties on the researcher to neither neglect nor discriminate against any participant. The right to fair treatment entitles the researcher to avoid any prejudicial treatment to those who withdraw from participation, and also to honour all the agreements made with the participants (Beck & Polit, 2006: 90).

In the current study of Botswana women diagnosed with both HIV/AIDS and cervical cancer, the selection of participants was based on research requirements and not on the compromised position of certain people. All agreements made with participants were honoured and everyone was treated equally. The researcher undertook agreements with the participants about many issues such as anonymity, and these agreements were strictly adhered to. The researcher respected the participants' culture or beliefs and made sure that these did not influence her treatment of participants in any way.

3.6.5 Non-maleficence

According to Miles and Huberman (1994: 289), non-maleficence means avoiding or minimizing unnecessary harm, risk or wrong. Minimizing psychological harm was done by carefully phrasing questions, and having debriefing sessions for participants to ask questions and air complaints after data collection. Arrangements were made for referrals to appropriate health or psychological services for participants who showed signs and symptoms (like depression and anxiety) necessitating referral. Being a nurse, the researcher could make an appropriate nursing diagnosis and refer accordingly.

The only potential risks identified in the study were psychological and emotional harm, and the participants were reminded about their right to share with the researcher only what they wanted to share. They were told not to feel compelled to share things that they were not comfortable in doing so.

3.6.6 Beneficence

Beneficence means maximizing good outcomes for research participants (Miles & Huberman, 1994: 289). The researcher explained that there were no direct benefits of the study, and the participants understood this before voluntarily agreeing to participate. This involved explaining how the information gathered would be used to guide further research relating to care of women with these diseases. The researcher made sure that participants understood her role as a researcher (as opposed to as a nurse) by explaining clearly the purpose of the study and its goals. They were also informed that data would be kept until the final thesis has been submitted to the university and the results indicating a pass.

3.7 Limitations of the study

Data collection took a long time, leaving a limited period for analysis and completion of the study. Some potential participants didn't meet the inclusion criteria as they were in late stages of cervical cancer and HIV/AIDS. The researcher had already anticipated this recruitment problem, since Parkin, Bray, Ferlay and Pisani (2005: 74-108) discovered that cervical cancer cases are identified at an advanced or late stage in developing countries. Arrangements were made to extend the researcher's study leave so that the data collection period could be lengthened. To make sure that the delay in recruitment did not affect the quality of the data being collected, the researcher added another week onto the period scheduled for data collection.

Another limitation of the study was exclusion of people with disabilities such as hearing impairments since the researcher was not familiar with sign language. One of the patients that could have been selected as a participant had a hearing impairment, and she was left out because of the exclusion criterion because there was no one to help with sign language. Although this didn't affect the quality of the data collected, the findings should be applied appropriately, and the researcher thinks this should be highlighted to show the importance of including people with disabilities in research studies.

3.8 Conclusion

This chapter provided a detailed description of the research methods used so that the study can be repeated by any researcher wishing to use the same methodology. The qualitative research design was useful in articulating the experiences of Batswana women diagnosed with HIV/AIDS and cervical cancer. Exploring the experiences of the women was facilitated because the design gave the women room for description of their experiences.

CHAPTER 4

DATA ANALYSIS

This chapter describes the data management strategies and data analysis methods that were used in the current study. The seven procedural steps proposed by Collaizi (1978) cited in Polit and Beck (2006: 410) and Holloway and Wheeler (2002: 181) were utilized, and the whole process will be outlined in detail. The chapter concludes with the measures taken to ensure the trustworthiness of the study.

4.1 Data management

Data management focuses on how a large amount of data is handled at different points of the research project's life. The researcher needs to know how she/he can keep track of all the data and how to permit easy and reliable use of data (Miles & Huberman, 1994: 45). Data analysis start with data management, and the steps involved are transcription, organization of data, development of category scheme, and coding of data (Polit & Beck, 2006: 399; Holloway & Wheeler, 2002: 235).

According to Halcomb and Davidson (2006: 38), verbatim transcription is a common data management strategy in nursing research and it is considered to be ideal for analysis and interpretation of verbal data. The same authors debate the necessity of transcribing all audio-recorded interview data verbatim. They argue that certain data management strategies apart from verbatim transcription must be utilized as a cost-effective, constructive and theoretically sound process. They suggested the following six-step process for data management: audio-taping of interviews and concurrent note-taking; reflective journaling immediately after interviews; listening to audiotapes and amending field notes; preliminary content analysis; secondary content analysis; and thematic review.

In the current study all interviews were transcribed verbatim by the researcher immediately after completion of each interview, and this was done to allow for detailed completion of participants' responses following the interview. The transcription process also helped the researcher to be immersed in the data and to prepare for organization of the data. The researcher decided to transcribe the data herself rather than asking for assistance as another way of guarding the confidentiality and autonomy of participants. Non-linguistic utterances like sobs and sighs, laughter and smiles were all captured as field notes and inserted in appropriate spaces in the text of the transcripts. Once all interviews were fully transcribed and printed out the researcher kept the right and left margins for comments.

The interviews were conducted in Setswana, which is a local language. The researcher transcribed all the interviews in that language in preparation for translation. All the transcripts were translated into English by the researcher, who is fluent in both languages and had an understanding of both verbal and non-verbal clues used during the interviews. A second person, a nurse by profession who comes from the same community and profession as the researcher was asked to go through both the Setswana and English transcribed interviews. There were no major changes or any disagreements regarding the transcripts.

The transcribed interview documents were saved in Microsoft Word computer files for each participant in both the hard drive and on a flash disk for back-up purposes. This ensured prevention of possible loss of data in case the computer was stolen or the main file destroyed.

There are five general principles for storage and retrieval of qualitative data as part of data management: formatting; cross-referral; indexing; abstracting; and pagination. Formatting refers to how field notes are physically laid out and structured, and cross-referral refers to a process in which information in one file shows where information for another file can be found. Indexing is another word

for coding, while abstracting refers to summarizing longer material. The last principle, 'pagination', means using numbers or letters as locators of specific material (Miles & Huberman, 1994: 45).

The above principles outline different ways of organizing data for easy retrieval. In the current study the researcher decided to use formatting. This was done by putting the transcribed interviews in computer files. The files were headed with participants' numbers (participant 1, 2, etc.) and the date of the interview for easier and flexible location of data.

4.2 Data analysis

The seven procedural steps proposed by Collaizi (1978) cited in Polit and Beck (2006: 410) and Holloway and Wheeler (2002:181), based on Husserl's philosophy, were used to guide data analysis in this study. This framework was chosen because the study was based on Husserl's concept of descriptive phenomenology. It also provided clarity in the steps of analysis. As a novice researcher, this framework was useful in explaining the interpretations of the descriptions from the participants.

Collaizi's procedural steps are as follows:

1. Reading all protocols (participants' descriptions) to acquire a feel for them.
2. Reviewing each protocol to extract significant statements; i.e. returning to each description and extracting phrases or sentences directly pertaining to the investigated phenomena.
3. Spelling out the meaning of each significant statement (i.e. formulated meanings).
4. Organizing the formulated meanings into clusters of themes:

- a) Refer these clusters back to the original protocols to validate them.
 - b) Note any discrepancies among or between the various clusters, avoiding the temptation of ignoring data or themes that do not fit.
5. Integrating the results into an exhaustive description of the investigated topic.
6. Formulating an exhaustive description of the phenomenon under study in as unequivocal a statement of identification as possible.
7. Asking participants about the findings as a final validating step.

In the current study Collaizi's procedural steps of data analysis were applied as outlined below:

4.2.1 Reading all the protocols to acquire a feel for them and extracting significant statements

The print-outs of the written interview transcripts were read and re-read to get a general sense of the overall data. The transcripts were then re-read line by line and paragraph by paragraph. That helped the researcher to understand the data further and to identify significant statements and phrases. The identified statements were marked off with different coloured pens, which facilitated the organization, identification, retrieval and analysis of meanings inherent in the data. The use of coloured pens assisted the researcher to identify 170 significant statements from the whole data set of the six participants.

4.2.2 Spelling out the meaning of each significant statement

To make sure that the significant statements were marked with the right colour, the colours were drawn on paper and the meaning of each colour given to guide the researcher for data analysis purposes. That involved going back to the text and linking the meaning with the data to identify if each statement was marked correctly. Statements which carried the same meaning were marked with same colour.

4.2.3 Organizing the formulated meanings into clusters of themes

The next step was formulation of clusters of meanings, and that was done by sorting formulated meanings into groups that represented specific themes through cutting data with the same colour and grouping them together into clusters. Each group was labelled as a theme cluster. Each theme cluster was given a main theme depending on the meaning acquired from the marked significant statements. Eight clusters were developed from the formulated meanings. The eight clusters extracted from the data were then used to describe the experiences of Botswana women diagnosed with both HIV/AIDS and cervical cancer. These eight themes were as follows:

1. Initial deep hurting pain
2. Fear for the future
3. Intimate loneliness
4. Blaming others
5. Hope in Western medicine
6. Forced acceptance
7. Support from others
8. Thankful to be alive

4.2.4 Integrating results into an exhaustive description of the investigated topic

The researcher examined the meanings of clustered themes to formulate an exhaustive description of the lived experiences of Botswana women diagnosed with HIV/AIDS and cervical cancer, and description of the meaning attached to the phenomenon. The aim of the process was to attempt to provide the results as they emerged from the data of the study.

4.2.5 Formulating an exhaustive description of the phenomenon under study in an unequivocal a statement

The researcher examined the descriptions of the meanings of the lived experiences of Botswana women diagnosed with HIV/AIDS and cervical cancer to formulate a statement describing the meaning of the phenomenon. At this stage the researcher also engaged with the research supervisor, who went through the clustered themes and supportive raw data together with the student. Once both were satisfied that the formulated themes were a reflection of the data describing the lived experiences of the Botswana women, the researcher proceeded to the next step according to Collaizi's data analysis protocol.

4.2.6 Asking participants about the findings as a final validating step

This was the last step, where the researcher went back to the participants with the results to validate whether the descriptions matched their own experiences. This was one of the steps taken to ensure trustworthiness of the study, and is known as member checking (Polit & Beck, 2006: 332).

The researcher managed to meet only three of the six participants after contacting them telephonically. This was done between 18 December 2007 and 8 January 2008. The collection of themes was presented to each participant, and the researcher translated the meaning of each theme as necessary. The participants then commented verbally on the themes, and none of the three disagreed with the findings; hence, no changes were made. The only questions that participants had were with regard to the use of the findings, and the researcher clarified that the data will be used to guide further research on the same issue, and that the manuscript will also be submitted to the University of Cape Town as a requirement for completion of studies. This last step was concluded by asking participants if they wanted any information to be excluded from the script; none indicated any information that must be excluded or changed.

4.3 Scientific rigour of the study

Trustworthiness in qualitative research is established when the findings reflect the meanings of the participants as closely as possible. The researcher must engage in activities that could assist in giving priority to the meanings of participants over his or her own interpretations for the study to be rigorous (Lincoln and Guba (1985) cited in Lietz, Langer and Furman (2006: 445). In the current study the researcher engaged in several strategies to manage the threats to trustworthiness.

4.3.1 Credibility

Credibility refers to the truthfulness of the data and the interpretations made. It emphasizes carrying out the investigation in such a way that people can easily believe the findings. The goal must be to demonstrate that the study was conducted in a manner that ensured accurate identification and description of the experiences of participants. Various techniques and activities that can be used to

make people confident with the study include thick description, prolonged engagement, external checks (peer debriefings and member checks) and triangulation. Triangulation is the use of multiple methods to collect and interpret data so as to draw conclusions about the truth of something. The four major forms of triangulation are data, investigator, theoretical and method triangulation (Miles & Huberman, 1994: 278; Holloway & Wheeler, 2002: 255; Polit & Beck, 2006: 332).

In this study the researcher described all of the procedures used in conducting the study, as detailed in Chapters 3 and 4. The research setting was explained as well as the data analysis methods used, for the reader to be able to make appropriate judgements about the degree of fit, and/or to use the same procedures in order to replicate the study under different circumstances.

The researcher kept up constant interaction with her supervisor during all levels of conducting the study, from inception of the research idea, to the proposal writing stage, through data collection and during data analysis. The research supervisor is an experienced qualitative data researcher; this was also viewed as peer debriefing, defined as the review of all the processes of the research project by a second person knowledgeable in the same field (Miles & Huberman, 1994: 278; Polit & Beck, 2006: 332).

Member checking was conducted as the final step of data analysis. This involved going back to the participants with the results to validate whether the description matched their own experiences (Polit & Beck, 2006: 332). There were no disagreements on the collection of themes.

4.3.2 Confirmability

Confirmability looks at objectivity or neutrality of the study. The goal is to assess if two or more researchers can agree on the decisions taken during the study, on the data collected and how the collected data can be interpreted. This tends to discover if there are any biases or prejudice from the researcher. General methods and procedures must be described in detail so that readers can follow the actual sequence of how data were collected, processed, condensed or transformed and displayed for conclusion (Miles & Huberman, 1994: 278; Polit & Beck, 2006: 336).

In this study confirmability was accomplished through detailed description of methods and procedures used so that the actual sequence of how the data were collected and condensed could be clear. The researcher was also aware of any possible assumptions and biases that could affect the study findings. The findings were retained and were available for reanalysis. Confirmability was also achieved by giving a detailed description of how constructs, themes and interpretations of results were achieved. A research supervisor trained in qualitative research followed the path of the researcher to see how the themes and interpretations were arrived at.

4.3.3 Transferability/external validity

Transferability looks at the extent to which the findings can be transferred or generalized to other settings or groups (Polit & Beck, 2006: 332). In this study that was accomplished by describing the characteristics of the original sample in order to allow for adequate comparisons with other samples. A detailed description of the study sample was done as well as of the setting to allow readers to apply the findings in the right situations, groups or contexts. The sample is described in detail in Chapter five, and other information regarding methodology is provided in Chapter 3 of this research report.

4.3.4 Dependability

Dependability refers to consistency and stability of data. It focuses on findings, on whether the research questions were clear, and whether the researcher's role and status were thoroughly described (Polit & Hungler, 1997: 430). According to Miles and Huberman (1994: 278), the other thing that can be done in assessing data dependability is a stepwise replication of the process of data analysis. In this study "dependability" was ensured by conducting a pilot study to determine whether the research questions and the semi-structured interview were clear. After completion of the pilot study the researcher was convinced that all the methods were fine, and then proceeded to the main study. Member checking, which involved provision of feedback to the study participants and back from the participants to the researcher regarding data, confirmed this and convinced the researcher that there was no bias on reporting of the results.

The researcher also applied all the steps in Colaizzi's method of data analysis to clarify the bases for interpretations. The researcher's role as a nurse researcher and student of the University of Cape Town was explained to the participants in order to ensure that they are aware of this and could voluntarily decide to take part in the study.

4.5 Conclusion

This chapter gave a detailed description of how data were managed, and how the themes were developed from the data from Batswana women diagnosed with HIV/AIDS and cervical cancer. This led to development of theme clusters, which will be described in detail in the next chapter.

CHAPTER 5

FINDINGS

The study was conducted with the purpose of exploring the experiences of Botswana women diagnosed with HIV/AIDS and cervical cancer. The main objectives were to explore what it is like to be diagnosed with both HIV/AIDS and cervical cancer, and to describe human experiences of living with both HIV/AIDS and cervical cancer.

This chapter discusses the findings and all the themes that were identified from the data in order to describe the experiences of six women diagnosed with HIV/AIDS and cervical cancer in Botswana and the meaning of these experiences in their lives.

5.1 Description of study participants

There were six women ($N = 6$) who participated in the study. Five of the women had been taking antiretrovirals (ARVs) for more than two years because they had been diagnosed with HIV/AIDS first and then cervical cancer later. One participant had not yet started on ARVs since she was diagnosed with cervical cancer first.

The women were aged between 32 and 55 years. Their marital status was as follows: two were married, one was divorced, and three had never been married. All participants had children; the number of children of each participant ranged between three and ten.

One participant had acquired a tertiary education certificate after matriculation, three had junior school certificates and two had primary education.

The employment status of the women revealed that none of them had a well-paying job; they were mostly supported by their children, parents or other siblings to meet their daily needs. Only two of the six participants were employed, another was self-employed and the other three were not employed. Two participants had lost their partners after a long illness, two had separated from their partners, and the remaining two stayed with their partners. Two participants reported having lost more than one child, either during birth or after delivery. The participants were from different districts within the country.

5.2 Theme clusters

The women's expressions of their experiences of being diagnosed with HIV/AIDS and cervical cancer described a range of feelings. These are described under the different themes, with supportive extracts from participants' data to show how the themes were developed. The eight main theme clusters of the women's experiences were as follows:

1. Initial deep hurting pain
2. Fear of the future
3. Intimate loneliness
4. Blaming others
5. Hope in Western medicine
6. Forced acceptance
7. Support from others
8. Grateful to be alive

5.2.1 Initial deep hurting pain

This theme was derived from the experiences of extreme or profound mental suffering that these women indicated that they had gone through. According to them, diagnosis with the two diseases was one of the most tragic things that had happened to them. One participant conveyed the depth of the pain as follows:

"[big sigh)]... It bothers me a lot. It's like I am being chopped with three axes in three different places at the same time. It's a big problem".

This clearly showed how painful it was to be suffering from the different chronic illnesses.

Another participant expressed the deep hurting pain by saying:

"I am an open person but when you are in this kind of situation you can't stop thinking about certain things. Sometimes I get so hurt that I cry, especially when I think of how my children will survive if I die ... I couldn't bear the pain seeing them crying a lot as I mentioned that their father was also sick. They kept saying, 'why our parents?'"

Diagnosis with both diseases seemed to be unbearable, compared to diagnosis with only one of them. Another participant stressed this point as follows:

"I didn't have many problems with HIV/AIDS alone. My main worry is in conjunction with cervical cancer. It stresses me a lot. They didn't want to do a hysterectomy and I ended up at my aunt's place with a lot of stress."

Another participant had this to say:

"At first I was so deeply hurt but at the end I just gave up. I also wanted to do a hysterectomy because I was suffering. Hey! I really suffered in life."

Another expressed her initial deep hurting pain as follows:

"I was so stressed at first and it was not easy, but I am better now. These things come step by step. The first experience can be so unbearable but that improves with time. These diseases can stress an individual a lot."

5.2.2 Fear of the future

This theme was identified from participants' expressions of unpleasant emotions or anxiety experienced in anticipation of what will happen in future with regard to their conditions. This included initial fear of dying and of leaving their children. One participant expressed her fear of the future as a great concern about her eldest son, who was very naughty:

"My main problem is with my firstborn child. [Quietness, crying] I am concerned that no one will take care of him if I die because he doesn't pay attention to anything that my family members say to him. I just don't know how he will survive if I don't recover. I am worried that if I die before he finishes his studies he will suffer. He doesn't have manners."

One would have thought that this woman would care less about that troublesome child, but as a mother she was even more worried about the fact that no one would like to take care of that boy in future, given his current behaviour.

One participant described her fear of the future and what might happen as follows:

"I was once scared and decided to negotiate for adoption of my children and thought of selling all my cattle. I even gave away my clothes."

Another participant's fear of the future and practical response in preparation of anticipated death was revealed by the wish to secure some money to build a home for her children:

"It was not easy at first but I am fine now. I wish to have money to start a business so that I can build a house for my children. If I die ... you can never know what this world has for you. You can never know how the people you leave behind will treat your children. It is better to leave them at your own place not at your parent's place."

For this participant fear of the future was exacerbated by the fact that one of her children was also HIV-positive:

"Sometimes I think about what will happen to my kids if I die. I am mainly concerned about the one who is taking ARVs. Who will do this tedious job that I am doing if I die. We are used to taking treatment together and have accepted that we will take it in order to raise our kids."

Another participant was not only scared for the children but was also scared that the diseases might lead to certain physical impairments. Her fear was illustrated as below:

"I am scared that they [both diseases] might kill me at night. When I have a backache like now, I just think that it might get worse leading to paralysis. I am always psychologically disturbed."

5.2.3 Intimate loneliness

Although most of the women reported receiving a lot of support from their families, they were still disturbed by the fact that they couldn't secure good intimate interpersonal relationships. Some of the women had to deal with the loss of their husbands or partners, and that made it hard for the women to cope, leading to a certain amount of grief. Some losses were due to death while others came as a result of abandonment by partners after diagnosis with the diseases. These women showed that it was not easy to secure new relationships, since it was hard to trust again or to start all over again given their conditions.

One participant described the intimate loneliness caused by her ailments as follows:

"It's like they [men] noticed that I am HIV positive. I just stay alone and lonely. Anyway I am just thankful that I am alone. [Laughing] How can I have a partner while I am sick? He will give me a lot of stress [laughing]."

Another participant expressed her intimate loneliness as below:

"I had a lot of challenges in life including pains of new diagnosis and loss of a partner who treated me badly. Although this is the case, I still need a man in my life, but not my ex-partner. My main wish now is to stay with my kids even if I don't find another partner."

For another participant, the intimate loneliness was expressed clearly as below, indicating the need for a supportive intimate interpersonal relationship:

"I do get lonely sometimes but I just accept it like that. I know that I can still have a partner although he will stress me. What's the use of dating someone who can't even take good care of me?"

5.2.4 Blaming others

This theme was developed from expressions that demonstrated how women diagnosed with HIV/AIDS and cervical cancer linked their tragedy to or blamed it on others, including their intimate partners and health service providers. Some women even blamed themselves for trusting someone who later let them down. This theme was further broken down into three sub-themes: blaming the husband or men in general; blaming herself; and blaming health service providers.

5.2.4.1 Blaming husband/ men in general

There were feelings of considerable anger elicited in cases where infidelity was known to have occurred, and some women re-experienced the feelings associated with this infidelity:

"I was not promiscuous. I think I just got infected at home. Since I met my partner I have not dated anyone else. All my children are his, even those who are late [deceased]. He is sure of that. He is the one who was dating a lot of women behind my back. He is the one who brought all this to me."

Another participant was angry and attributed her conditions to her late husband:

"My husband died in 2000. He is the one who infected me. He was diagnosed with this disease but didn't tell me. When he was about to die he told me to go to the hospital but he didn't tell me that he had the disease. Even this cancer is because of him and his diseases."

Another was forced to go for an HIV test at one stage, when the ill husband claimed that she might be the one who had infected him:

"I went to Tebelopele with him for a test. I was with him but I tested negative. He suggested that we should go for a test to identify who brought the virus. He thought I infected him, but it turned out that he was the one who was promiscuous. Later I was also found positive, so he is the one who brought me all these problems."

5.2.4.2 Blaming herself

Some of the participants blamed themselves for letting the diseases happen to them, as indicated below:

"If only I stayed and not participated in premarital sex! The church discourages that. They discourage sex before marriage. I started early and now I am paying."

Another participant blamed herself for letting herself get so sick without seeking medical advice:

"My sisters used to discuss a lot of things like HIV/AIDS, TB, etc. before I tested. I couldn't bear that and it was so painful. I always asked myself why they did that. If I could have listened to them and got the first HIV test results I wouldn't have been so sick."

5.2.4.3 Blaming health service providers

Statements used to develop this sub-theme indicated that women felt that their situations would not have been so bad if they got 'proper' and 'timely' assistance. One participant reported and blamed the unpleasant behaviour of health workers:

"I still blame health workers at the local clinic. If they could have helped me when I reported the vaginal discharge I had, maybe I would not have had cancer and AIDS. There is something that really upset me in one of the hospitals I went to. I had the heavy discharge and the doctor said the problem is brought by the fact that I didn't maintain a very good hygiene, instead of checking why. I am sure it was the beginning of cancer. If only he checked me"

Another participant had this to say:

"I went to the clinic in 1997 to do a Pap smear test and they said it was not possible to have it done on that day. If I could have done it then, maybe I wouldn't be having cervical cancer now. Perhaps they could have seen it and prevented me from having the sore in my womb that resulted in this and AIDS."

5.2.5 Hope that things will improve

Most participants indicated that they hoped that things would improve. This hope rested on medical treatment, doctors or God. They didn't only express their positive hope in terms of doctors and treatment, but also on some of the things that they had lost hope in, like traditional medicine and herbal products. For technical purposes this theme was also divided into sub-themes.

5.2.5.1 *Hope in medical treatment*

Participants who had long been on ARVs and just started on cervical cancer treatment hoped that the treatment would also prolong their lives, just as the HIV treatment did. Even those who had not started on any treatment were hopeful that the treatments for both diseases would prolong their life, and they were eager to start as soon as possible. (These were participants who were still undergoing tests like CD4 count monitoring and others to identify if they were fit to be started on treatment.)

One of the participants indicated her hope as follows:

"I have not been to any infectious disease clinic yet, at least to start ARVs. Once I start that, I hope that I will be better. "

Other participants had this to say:

"My hope increased when I started ARV treatment. Sometimes I would lose sight on the way to the clinic to take TB treatment, but I decided that I will do everything I can because I wanted treatment."

"I will just be happy if I get treatment and get healed. I just wish they [HIV and cancer treatment] can both help me. The HIV treatment has already prolonged my life and I just wish that God can help me with this one that I have just started too."

For another participant, experience with the first treatment brought a lot of hope for the later one:

"I just hope it will be cured by this radiotherapy. I was so slim before I tested and this is not my body size. So if I managed to gain a lot of weight like this, it means I will get well. This shows that cancer of the cervix is just nothing and radiotherapy will cure it."

5.2.5.2 *Hope in doctors*

Most of the participants revealed that since there was nothing they could do, they put their hope in the doctors, and were dedicated to following all of the instructions from the doctors:

"I just accepted that there is nothing I can do. I have the diseases. I just put my last hope on doctors. I know they can help me."

"God will help us and the doctors will also do their best."

One stated:

"I don't believe on what people say, but rather on what the doctor says."

Another participant expressed her hope as below:

"I prayed to God and only if I can follow the doctor's prescriptions I will be better."

5.2.5.3 *Hope or belief in God*

All participants revealed their great hope or belief in God. They repeatedly expressed how God will help them. Although they had a lot of hope in the doctors and the treatment, these women expressed how they prayed to God to strengthen the effectiveness of the treatment:

"God will always be there for me and he will heal me. I am just looking upon him for help."

For another participant the grace of God was explained in relation to past experience:

"I concluded that if I managed to live with HIV/AIDS God will help me and I will also overcome cervical cancer."

One had this to say:

"I just pray that God can help me and let me live longer to see my children grow."

5.2.5.4 Hope in traditional medicine or herbal products

The participants also expressed their loss of hope in traditional medicine and herbal products compared to modern medicine as part of their experiences. Some participants reported having used traditional medicine and/or herbal products in the early years of their diagnosis but their conditions didn't improve. The following excerpts express their loss of hope in these products:

"I want to encourage other women to visit the clinics for help, it's nothing... They should not focus on traditional medicine. It doesn't help. My father was a pastor for a Zion church and he once told me that I was given something to poison me (sejeso). He gave me some traditional medicine to take. After some time I was diagnosed with TB. Hey! I really suffered in life. My mum also gave me traditional herbs to 'steam or heat the womb' [laughing]. It didn't work and that didn't even stop the abdominal pains and the diarrhea."

"I tried some herbal Chinese products but I have now discovered that I am just wasting money."

5.2.6 Forced acceptance

In the current study this theme was developed to describe how the women tried to deal or cope with their situation of a diagnosis with both HIV/AIDS and cervical cancer in order to move on with life. The researcher used the word 'forced' to indicate how they were compelled to accept the situation that they were in, since it was beyond their control. That is why most of them said they have accepted

the situation - because they knew that without accepting it they wouldn't come to terms with their tragedy.

The following extracts show what the participants meant by accepting their situation:

"I said to myself, 'hey! What is it that can be done? I just have to accept the situation as it is'. Nothing can be done. I needed to accept the situation as it was. I just needed to admit the fact that I needed treatment for cancer, ARVs and treatment for hypertension as well."

"At the end I just gave up. I just accepted that there is nothing that I can do, I have the diseases. I have accepted the situation as it is. Listening to the news helped me to accept the fact that it's a disease like any other disease. Nowadays I am not even ashamed of taking the pills anywhere."

"I had given up in life because I didn't know my main ailment. It was difficult at first but at the end I forced myself and just said, God I have accepted, there is nothing I can do."

Another participant said:

"It was not easy at first but I am fine now. I wish to have money to start a business so that I can build a house for my children. If I die ... you can never know what this world has for you ..."

5.2.7 Support from others

This theme was developed from the different kinds of support, assistance or encouragement that the participants received from others, including financial, emotional and even physical support. The support that these women got helped them to cope with the challenges of the diseases, and for some it even facilitated acceptance of their situation.

The following extract indicates support that was received from children:

"I don't have any problems now and my children always remind me to take the pills."

This extract illustrates support received from a mother and other family members:

"My mother took care of me when I was very ill. So I knew the importance of letting her know about my illnesses so that she could take care of herself as a care-giver. My sisters also gave me a lot of support. They made sure that I got the right food and that I don't overwork my body at any time. They tried all their best to show me that I am still their sister and that they love me. They take care of me and my children since I am not working. I am their burden together with my children."

Some of the participants mentioned the support that they got from other women with the same conditions:

"When other women who had long started treatment shared their experiences with us I had hope that I will get better."

"I am positive because I saw a lot of women with the same conditions at the hospital. They looked healthy and beautiful. They told us that they have finished their treatment. They gave me a lot of hope. They really helped and sharing their experiences with us was so interesting."

Another participant mentioned the kind of support that she got from health workers:

"Sometimes I go to the clinic to discuss my problems with counsellors especially if I can't cope."

5.2.8 Grateful to be alive

Although most of the participants were so worried about their conditions, some expressed gratitude for things such as being given treatment and other positives things which brought a smile to their faces:

"I am just thankful that we are able to get treatment for both diseases. I have long started ARVs and now I have been sent here for cervical cancer treatment."

Another expressed her relief by mentioning how things changed after disclosing about her conditions to her children:

"My first child was not performing well at school but after that she started to study hard and she is now better. Even at home they are always trying their best to behave well. For that I am grateful. Perhaps they realized that if I die, they will be nothing."

Although diagnosis with the two illnesses was traumatic, one participant expressed her happiness at being alive in order to see her children grow:

"It is so painful but we told ourselves that we will take this treatment in order to raise our children. I am happy that I am always there to assist them as necessary."

Another expressed her gratitude at being alive as follows:

"I know this won't last forever. I am just happy that I am alive. If it was not due to my illness my family will have fallen apart. God has his ways of amending things and I still have hope that everything will be fine soon."

5.3 Serendipitous discoveries

Other things which were not within the scope of the study were serendipitously discovered from the data. On consultation with the research supervisor, the researcher realized that such data are also important and must be included in this research report in order to guide further research.

5.3.1 Connection between the two diseases

This serendipitous data included revelations of how the participants viewed the connection between or relationship of the two diseases. Some participants expressed the connection of the two diseases as an intertwined single condition. Others clearly related to the two conditions as two separate diseases which did not have an influence on one another.

Of those who saw a connection or relationship between the two conditions, one indicated the association by relating the death of her children to cervical cancer:

"When the doctor told me that I had cervical cancer, I thought that all my babies were conceived with the presence of cervical cancer and that affected them. That is why they all died with the diagnosis of HIV. It is clear that both conditions killed my babies and are going to kill me sooner or later."

Another participant expressed it as follows:

"I just told all of them so that they can be aware of my condition of the AIDS in the cervix. In that way when AIDS kills me everybody will think it is cancer - and yes, it will be it too."

For others there was no association between the two conditions and they always addressed them as two different diseases which did not influence each other:

"It was not easy too when I was told that I had cervical cancer. I got better after intense counselling from the clinic. I noticed that it is just like any other

condition. I concluded that if I managed to live with HIV/AIDS God will help me and I will also overcome cervical cancer."

5.3.2 Role of the media in screening

Another serendipitous discovery in the study of women diagnosed with both HIV/AIDS and cervical cancer was the importance ascribed to the media in teaching women about the importance of screening for cervical cancer and HIV:

"I knew of cervical cancer and the Pap Smear test before. I learnt about it from the radio but I didn't have an idea of how somebody can get it. Because of that little information I decided to test and the results came positive."

For another participant a research study unexpectedly helped her to discover that she had cervical cancer:

"When I went for a check up in order to start ARV treatment I met one lady who was doing research. She asked if there was anything bothering me and I told her about my abnormal vaginal discharge that didn't respond to treatment. She advised me to do a Pap smear and that's when she gave me a specimen form to take to the nurses for the test."

5.4 Summary of the findings

The experiences (and meaning of these) of Batswana women diagnosed with HIV/AIDS and cervical cancer were discovered and described. They included deep hurting pain, fear of the future, intimate loneliness, and blaming others. The data also revealed that women reacted differently from each other once diagnosed with both of these diseases. This often led to different ways of coping, which included placing hope in medical treatment, forceful acceptance of the situation, receiving and appreciating support from others, as well as being grateful for being alive.

The influence of the media and research on the women's health was serendipitously found to be very important in assisting women in going for screening for both cervical cancer and HIV. This screening should be encouraged at all levels.

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CHAPTER 6

DISCUSSION, RECOMMENDATIONS AND CONCLUSION

This phenomenological study aimed to explore and describes the experience of being diagnosed with HIV/AIDS and cervical cancer, and the human experience of living with the two diseases. The findings demonstrate that being diagnosed with these two chronic illnesses is an extremely painful experience that can instill fear for the future and lead to intimate loneliness. Other experiences associated with being diagnosed with these two illnesses included blaming others, placing hope in medical treatment, forceful acceptance of the situation, receiving and appreciating support from others and being grateful for being alive.

This chapter discusses the findings of the study in relation to pertinent literature as well as conclusions and recommendations for researchers and health workers. It concludes with the limitations of the study.

6.1 Discussion

6.1.1 Impact of diagnoses

The first three themes that emerged most strongly when discussing the experience of living with the two illnesses - deep hurting pain, intimate loneliness and blaming others - indicated some of the impacts of the illnesses. Consistent with the findings of the current study, Maboko and Mavundla (2006: 27) revealed that the experience of being diagnosed with HIV/AIDS and cervical cancer can have a number of impacts on the women. Considerable attention has also been given to the impact of either HIV or cervical cancer alone in a number of studies (Ahlstrom, 2007: 81; Pelcastre-Villafuerte, Tirado-Gomez, Mohar-Betancourt &

Lopez-Cervantes 2007: 3; De Groot *et al.*, 2005: 922; Ashing-Giwa *et al.*, 2004: 3; Lyons & Shelton, 2004: 13).

6.1.1.1 Deep hurting pain

The findings revealed that participants experienced extreme emotional pain following the diagnosis with the two illnesses. For some participants the deep hurting pain was experienced as a continuous process, while for others it was experienced as intermittent pain triggered by certain factors at different times. These findings are similar to those in the study by Ahlstrom (2007: 81), who reported that diagnosis with a chronic illness can lead to chronic sorrow of a substantial degree. In that study 53% of the participants were found to fulfill four of the six criteria of chronic sorrow, these six criteria being loss experience (ongoing or single event), pervasive sadness or grief, permanent sadness or grief, periodic sadness or grief, potentially progressive sadness or grief, and periods triggered by occurrence of events. The findings from the current study fulfilled three of the criteria, namely an experience of loss, periodic sadness, and periods triggered by certain events.

The deep emotional pain was also shown by the report of the First Nations of the Quebec and Labrador Health and Social Services Commission (2004: 43). In this report HIV/AIDS was identified as one of the chronic diseases which can lead to an extreme experience of deep emotional pain. The same report explained that emotional pain comes from the intense spiritual or psychological suffering, and can lead to physical symptoms and difficulty in coping. Just like HIV/AIDS, some studies also reveal great psychological disturbance after diagnosis with cervical cancer (Ashing-Giwa *et al.*, 2004: 3; Lyons & Shelton, 2004: 13). The latter studies reveal that women diagnosed with cervical cancer had negative psychological reactions such as shock, depression and anxiety.

6.1.1.2 Fear of the future

This theme expressed the anxiety experienced by the women in anticipation of what will happen in future with regard to their conditions. Several studies indicate that fear and other negative psychosocial reactions are common reactions after diagnosis with a chronic illness (Pelcastre-Villafuerte, Tirado-Gomez, Mohar-Betancourt & Lopez-Cervantes, 2007: 3; Ashing-Giwa *et al.*, 2004: 3). Lyons and Shelton (2004: 13) also discovered that fear was one of the emotional reactions related to cervical cancer diagnosis and treatment.

Likewise, Maboko and Mavundla (2006: 27) discovered that fear is a common issue for patients diagnosed with HIV/AIDS and cervical cancer in South Africa. In this study the findings revealed that this was brought on by several thoughts - fear of death, fear of leaving their children alone, fear of alienation and fear of the unknown. These women couldn't face the reality of death, and it was difficult for them to accept the perceived actual ending of their lives. They were also worried about what would happen with regard to treatment. Fear of leaving their children alone was one of their main concerns - the women thought of what would happen to their children once they had died. These findings are similar to those of the current study among Botswana women diagnosed with HIV/AIDS and cervical cancer.

Since fear overwhelmed their thoughts, most of the women in the current study decided to plan ahead in case the unwelcome threat became reality. Some of the participants decided to give away their children for adoption and give away all their clothes and cattle, while others aimed to secure some money to build houses for their children. Marcenko and Samost (1999: 40) conducted a study and reported similar findings, with HIV-positive mothers reporting to have made formal plans for their children in preparation of an unwelcome death, including making a will and finding a deposit to buy a house so as to not leave the children homeless.

Maboko and Mavundla's study (2006: 27) also reported fear of the unknown related to thoughts of what will happen concerning HIV treatment. Contrary to their study findings, the current study revealed that fear of the unknown was related to thoughts about complications of the two illnesses. For example, one of the participants was worried that the diseases might lead to other complications such as paralysis.

6.1.1.3 *Intimate loneliness*

Results from the current study revealed that participants were disturbed by the fact that they couldn't secure good intimate interpersonal relationships. Some had lost their husbands or partners to HIV/AIDS, while for others the loss was a result of abandonment by partners after diagnosis with HIV/AIDS or both illnesses. These women showed that it was not easy to secure new relationships since it was hard to trust again or start all over again. Maboko and Mavundla (2006: 28) discovered that being diagnosed with HIV/AIDS and cervical cancer usually poses a threat to the relationships of the patients. The women may feel lonely and isolated, or feel that they are no longer accepted in certain prior relationships, either with their families or their partners.

A study by Ahlstrom (2007: 79) also concurred with the results of the present study that diagnosis with these diseases may lead to intimate loneliness due to abandonment by partners. Ahlstrom revealed that divorce was viewed as a traumatic event - even in cases where the divorce happened before diagnosis with a chronic illness. Participants in the same study attributed divorce to diagnosis with their chronic illnesses. In their study on women diagnosed with cervical cancer, Ashing-Giwa *et al.* (2004: 3) also showed that those women who still had sexual desires did not find it easy to secure relationships. The same study revealed that those women who had had hysterectomies were perceived to be lacking sexual desire, leading to abandonment by partners. One of the

participants in the study reported that her husband left her for another woman, and expressed the pain and loneliness by stating that it had been a nightmare since she had to deal with the pain of abandonment due to the disease and also with trauma caused by the ex-husband's new woman, who called to insult her about her condition.

Most of the participants indicated considerable fear of dating again after losing their partners, although they were lonely. The same thing was discovered in the study conducted by Ashing-Giwa *et al.* (2004: 9), where single women found it difficult to date after diagnosis while married women started having relational difficulties.

A study conducted by De Groot *et al.* (2005: 922) found that cervical cancer alone can also have some impact on the women concerned and also on their partners. Both the women and their partners reported disruptions in intimacy (defined by spousal relationship and sex life), but women seemed to be more affected than their partners. Edwards (2006: 683) also found that HIV/AIDS diagnosis has some serious impacts on the relationship of infected women and their partners; this relationship turbulence was reported to affect the women's adherence to HAART because they felt unloved and uncared for.

6.1.1.4 Blaming others

Women in the current study linked or blamed their tragedy to others including their intimate partners. This is similar to the findings of a study conducted in England which reported that a positive test for cervical cancer can lead to guilt and blame for the cause of the HPV infection (McCaffery, Waller, Nazroo & Wardle, 2006: 171). Women were reported to have continued to search for an understanding of who caused the infection, and tended to blame their partners. Most of the women in the current study believed that they were infected at home

since some knew that their partners were promiscuous and therefore suspected that they had brought the illnesses to them.

Contrary to the finding of McCaffery, Waller, Nazroo and Wardle (2006: 171) that women in their study felt guilty that they got the infection due to carelessness, none of the participants in the current study felt that they were infected due to their own promiscuity. Most women in the current study blamed themselves for trusting someone else who destroyed their lives.

The findings also revealed concern among participants with regard to health care services. A considerable amount of blame was placed on health service providers, since the women believed that if they could have been assisted well in advance, they wouldn't have got HIV/AIDS and cervical cancer. This is contrary to the findings of Karasz, McKee and Roybal (2003: 199), which reported dissatisfaction with care without blaming health service providers.

6.1.2 Dealing with experiences of diagnosis with HIV/AIDS and cervical cancer

Coping with a chronic illness can be very difficult. In their experiences of being diagnosed with HIV/AIDS and cervical cancer, Batswana women coped in different ways. The experience seemed to have closed doors in certain areas of the women's lives, but opened doors to other areas. Important coping strategies identified were placing hope in treatment or God, acceptance, support and thankfulness for being alive.

6.1.2.1 Hope

The findings of the current study indicated the need to place hope in something in order to move on with life. The National Institutes of Health (1996: 7) states that hope is another way of coping with chronic illness, quoting one participant's words on hope as follows: "I think we have to have a belief in something. It's like a cushion to fall back on. You must have hope or I don't think you can survive. People have to find out what they believe in to have hope."

The current study also revealed the importance of hope in coping with diagnosis of HIV/AIDS and cervical cancer. Participants revealed their hope in doctors, treatment and God. Almost all of the participants in the study expressed their hope in God as one way of coping with the diseases. Very similar findings emerged in a number of studies on HIV-positive individuals and women diagnosed with cervical cancer or having abnormal cervical cytology from countries with Christianity as a religion. Most of the individuals in these studies used a deep and abiding faith in God to cope (Feitsma, Koën, Pienaar & Minnite, 2007: 61; Lyons & Shelton, 2004: 13; Maboko & Mavundla, 2006: 28; Marcenko & Samost, 1999: 40; Doyal & Anderson, 2004: 1734).

Participants in the current study believed that God will strengthen them and help so that the doctors and treatment will enable them to survive longer. The hope placed in treatment and doctors is in line with findings in the study by Ashing-Giwa *et al.* (2004:9) and a report by the National Institutes of Health (1996: 7).

6.1.2.2 Acceptance

Participants in the study also expressed the need to accept a certain situation in order to move on as another way of dealing with the pain of diagnosis with HIV/AIDS and cervical cancer. This concurs with the findings from the study by Maboko and Mavundla (2006: 26) of African women diagnosed with HIV/AIDS

and cervical cancer. A similar finding of acceptance was also discovered by Duma (2006: 170) in her study of the theory of women's journey of recovery from sexual assault. This was reported as "pragmatic acceptance", where women needed to accept their traumatic situation for pragmatic purposes in order to move on to the next phase in their journey of recovery. Acceptance is a coping strategy that has been discussed in several studies of chronic illnesses (Feitsma, Koen, Pienaar & Minnite, 2007: 58; Lyons & Shelton, 2004: 13; National Institutes of Health, 1996: 3).

6.1.2.3 Support

Another coping strategy discovered in the current study is support from family, women with the same conditions, and health workers. Almost all participants in the study said they had been assisted either by their families or health service providers. According to the report by the National Institutes of Health (1996: 4), co-operation with the health care team can help to find answers to certain problems, and can keep a person going. The same report discusses the importance of deepening personal relationships, especially with children and other family members. Those people closer to an ill person are reported to be an anchor and a source of strength. This is also in line with the findings of a study conducted by Lyons and Shelton (2004: 17).

As mentioned earlier, the findings from this study of Batswana women diagnosed with cervical cancer and HIV/AIDS indicated that support from others who are experiencing the same problem can also be helpful. Support groups and informal networks are therefore recommended (National Institutes of Health, 1996: 5). According to Marcenko and Samost (1999: 40), the amount of support that is available can facilitate better coping in women diagnosed with a chronic illness like HIV/AIDS. This study discovered that those HIV-positive mothers who had

been receiving considerable support from friends, family and more formal support groups were coping well in comparison to those who received less support.

6.1.2.4 *Being grateful for being alive*

The current study revealed that although diagnosis with these illnesses was a painful experience, some participants expressed gratitude for being alive. They identified some of the things that brought a smile to their faces once diagnosed with these diseases, and used them to facilitate coping. Some women expressed their gratitude for being given the chance of survival by being given treatment. One of the participants described how disclosure of her conditions changed the behaviour of her children. According to Marcenko and Samost (1999: 40), positive thinking and maintaining a positive outlook are essential to good health. In their study thinking about negative things impacted negatively on the health of HIV-positive mothers.

The National Institutes of Health (1996: 4) indicated that coping with a chronic illness involves releasing control over certain aspects of life. Although most people usually feel angry after diagnosis, it is possible to find ways to have control again. The same report also added that positive thinking can help people to gain control of their life again.

6.2 *Other important issues*

The current study also included revelations of how the participants viewed the connection or relationship of HIV/AIDS and cervical cancer. Some participants expressed the connection of these two diseases as an intertwined single condition. Others related to the two conditions as two separate diseases which did not influence one another. Maboko and Mavundla (2006: 26) discovered that African women diagnosed with HIV/AIDS and cervical cancer experienced the

two as similar diseases. The same study explained that the women viewed the two diseases as a similar condition because a few of them had prior knowledge of HIV/AIDS, and when told that they had cervical cancer they assumed that the two conditions were similar.

Something that was serendipitously discovered was the importance of the media in teaching about health conditions and the importance of research in facilitating early diagnosis of diseases that can be screened for.

6.3 Limitations of the study

Although this study provides a rich description of the experiences of Batswana women diagnosed with HIV/AIDS and cervical cancer, there are some limitations that should be noted. Since the researcher used convenience sampling, the findings must be applied with caution since they might not represent all Batswana women diagnosed with HIV/AIDS and cervical cancer. The researcher explained the methodology used in this study in detail so that the findings can be applied appropriately.

6.4 Recommendations for the study

Information from the study revealed the great need to tackle women issues in Africa and therefore the following is recommended:

6.4.1 Recommendations for future research

The findings from the current study highlight the need for more research on the experiences of women diagnosed with HIV/AIDS and cervical cancer in Africa. To improve the quality of life of these women there is a need for better documentation on living conditions, and in-depth descriptions of culturally appropriate interventions on issues relating to diagnosis and men should be

included in those studies. Documentation or studies on perception and/or knowledge of men regarding conditions like cervical cancer is essential.

6.4.2 Recommendations for health workers

Despite the limitation of the study, health workers must be aware of the deep emotional pain and other reactions that go hand in hand with diagnosis of these two conditions, and make sure that the women are receiving the necessary services. It is therefore recommended that investment should be considered to train health workers within a professional ethos of respect and dignity taking into account people's different needs at different stages in their lives. Incorporating the findings into the curriculum and in-service education addressing issues on HIV/AIDS and cancer is essential. Nurses caring for these patients can use the results to assess and manage their patients in a comprehensive and multidisciplinary manner. Health workers also have a responsibility to ensure that information is communicated to women in way that ensure that they understand the facts while limiting the anxiety and sense of stigma around infection.

The findings should be taken into consideration when designing or planning the content of health programs aiming to modify society behaviour towards HIV/AIDS and cancer. More educational programs regarding reproductive issues should be planned to target the whole society especially men as that is essential to overcome some beliefs and challenges negatively affecting the women's health. Lastly programs should be improved to cater for HIV affected individuals. Although HIV affected women can use common health services, because of stigma, social vulnerability and illness needs their issues or problems should be addressed in ways that are supportive and enabling.

6.5 Conclusion

HIV/AIDS and cervical cancer are chronic illnesses that can instill chronic emotional pain, just as with other chronic illnesses. Reactions to diagnosis with these diseases include pain, fear or intense sadness. The emotional pain comes from intense spiritual or psychological suffering, and can lead to physical symptoms and difficulty in coping. Coping with these conditions can be facilitated by different strategies such as acceptance, having hope, support from others and positive thinking. Support can come from children, family members, informal or formal groups and health service providers.

The study attained its purpose of exploring women's experiences of being diagnosed with both HIV/AIDS and cervical cancer. That was achieved by conducting one on one interviews with women diagnosed with both illnesses. The findings will be shared with health officials in Botswana to guide further research on issues concerning women with the same problems.

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University of Cape Town

Annexure 1: Research Information Sheet (English)

RESEARCH TITLE: Lived experiences of women diagnosed with both HIV/AIDS and cervical cancer.

RESEARCHER : Tshireletso Molefe

Dear Madam

I am a nurse conducting a study as a requirement for my masters through the University of Cape Town. I would like to invite you to take part in this study which aims at describing and understanding human experience of living with both HIV/AIDS and cervical cancer. This study has been approved by the University of Cape Town Research Ethics committee (REC REF 181/2007) and the Botswana ministry of Health Research Ethics Committee (REF No: PPME-13/18 PS Vol. I (62)).

Benefits:

The information gathered will assist nurses and other health professionals to understand challenges of women diagnosed with both HIV/AIDS and cervical cancer and their needs.

Time:

I will need approximately one hour of your time to conduct the interview and about 5 minutes for you to complete a short biographical questionnaire.

Costs:

There will be no costs involved in your participation of the study.

Ethical considerations in the study:

Your participation in the study is completely voluntary. If at any time during the study you wish to withdraw I would like to assure you that your withdrawal will not

be judged negatively or bring any form of compromise to your treatment or to that of your family members. After the beginning of the interview you can refuse to answer any specific questions or terminate the interview at any point and that will also not have any effect on services that you or your family receives from health providers. Please ask questions if further information is needed and note that this is an opportunity for you to ask questions regarding your medical condition.

I will be audio taping the interviews and then transcribe them to paper. All the information gathered will be handled with care and kept confidential by all means. Participants' names will not be recorded on the study records and computer files, rather they will be substituted with identification numbers. No identifying information will be entered in the computer. Computer files will be restricted by use of a password. Identifying information will be destroyed as soon as data analysis is completed. If during the course of the interview you decide that something should not be included in the study findings, please feel free to indicate that.

If you are willing to take part in this study please indicates so and I will contact you for arrangement of the setting, signing of the consent form and the date of the interview. The consent form is a form that indicates that the aims and nature of this study have been explained to you.

Thank you

Tshireletso Molefe (Miss)

E-mail: tmolfidos@yahoo.com

Cell: 073 462 5170/ (267) 72637321

Annexure 1: Research Information Sheet (Setswana)

SETLHOGO SA TLHOTLHOMISO: Go tshela ka mogare wa HIV/AIDS le kankere ya Popelo: Potsolotso ya bo mme kwa Gaborone le Francistown .

MOTLHOTLHOMISI : Tshireletso Molefe

Mme

Ke go laletsa go tsenya letsogo mo ditlhotlhomisong tse di ka nthusang go itse botlhoki le dikgwetlho tsa go tshela ka mogare wa HIV/AIDS le kankere ya popelo. Ke bereka ke le mooki mme jaanong ke na le kgatlhego ya go itse ka botshelo jwa bomme ba ba tshelang le malwetsi a. Se se nkgwetlhile go dira ditlhotlhomiso mabapi le se. Ke dira se e le bontlha bongwe jwa go fetsa dithuto tsame tse dikgolwane tsa booki (MSc Nursing) ke lebagane thata le bolwetsi jwa kankere (Oncology speciality). Ke letleletswe go dira se ke ba komiti ya sekole kwa Cape Town (REC REF: 181/2007) le ba lephata la botsogo mono Botswana (Ref No: PPME-13/18 PS Vol. I (62)).

DINTLHA TSA BOTLHOKWA

Nako ya puisanyo mo tlhotlhomisong

Go tsenya letsogo mo ditlhotlhomisong tse go tla go tlhoka go tsenelela puisanyo e e ka se feteng metsotso e e masome a marataro (Oura). Mo godimo ga moo ke tla tlhoka metsotso e ka nna metlhano go tsaya diaterese tsa gago.

Tse di tlokegang kana tiriso ya madi

Ga o na go lopiwa kana go latlhegelwa ke madi ka gope mabapi le puisanyo.

Melawana ya ditlhotlhomiso tsa botsogo

Go tsenelela puisanyo go ka kgonagala ka boithopo jwa gago. Se se raya gore ga o patelediwe go tsenelela puisanyo e, gape o na le kgolesego ya go fetogela maikutlo a gago nako nngwe le nngwe. Fa o sa tlhole o na le kgatlhego o

rotloediwa go tlhalosa seo. Go dira jalo ga go kake ga ama ka gope meamuso e wena le ba lelwapa la gago le e bonang mo go ba botsogo. Fa re sena go simolola puisanyo e, o na le tshwanelo ya go gana go araba dipotso tse di sa go itumediseng. O ka botsa dipotso fa go na le sengwe se o batlang tlhaloso ya sone fa re tsweletse le puisanyo ya rona. E ke tshono ya go bua ka dilo dingwe tse di ka tswang di go tshwentse kana o tlhoka go di sedimosetswa ka malwetsi a.

Ke tla bo ke dirisa sekapa mantswa (tape recorder) gore se tle se nthuse go gakologelwa tse re di buileng mo puisanyong ya rona. Ke go solofetsa gore sengwe le sengwe se re tla se buang e tla nna kgang yame le wena. Se se raya gore batho ga ba na go itse fa ele wena o buileng mafoko a a kwadilweng. Maina a botlhe ba ba tsenelelang puisanyo ga a na go kwalwa gope, go tsenngwa mo sekapa mantsweng kana mo sebala makgolong. Boemong jwa maina ke tla dirisiwa dinomoro go nthusa fa ke setse ke goboka dintlha tsa puisanyo ya rona. Ga gona sepe se se tla tsenngwang mo sebala makgolong kana mo mokwalong se se tla lemotshang babadi kana ope fela gore ke mang yo a neng a bua eng. Fa ke santse ke dira tshoboko ya dipuisanyo ga gona yo o tla nnang le bokgoni jwa go bula difaele tsame mo sebala makgolong. Seo se tla kgonagadiwa ka go dirisa dinomoro tsa sephiri go tsena mo difaeleng tseo.

Dilo tse di ka fang batho lesedi la gore ke mang yo o buileng eng di a go nyelediwa fela ka bofebo morago ga tshoboko ya dipuisanyo tsa rona. Fa ele gore morago ga puisanyo o na le dilo dingwe tse o sa batleng dika tsenngwa mo mokwalong ntswa go se ope yo o tla lemogang fa di builwe ke wena, nna le kgololesego ya go ntemotsha seo.

Fa o na le keletso ya go tsenelela dipuisanyo tse, ke kopa o nkitsise gore re dumalane ka nako le lefelo la puisanyo. Ka nako eo re tla bua gape ka pampitshana e o tshwantseng go e tlatsa e e supang fa o dumela go tsenelela puisanyo e, mme e bile o tlhaloseditswe ka botlalo ka ditlhotlhomiso tse.

Go tsehya letsogo ga gago mo ditlhotlhomisong tse go ka go sologela molemo
thata mme e bile go ka thusa bomme bale bantsi mo isagong.

Ke a leboga.

Tshireletso Molefe (Mme)

E-mail: tmolfidos@yahoo.com

Cell: +2773 462 5170/ +267 72637321

Tel: +267 591 6344

University of Cape Town

Annexure 2: Research Consent Form (English)

RESEARCH TITLE: Lived experiences of women diagnosed with both
HIV/AIDS and cervical cancer.

RESEARCHER : Tshireletso Molefe

I..... (NAME), have understood what the study is all about. The researcher explained in detail about the project and all the ethical issues applied. I agree strongly to take part in the study and allow the use of a tape recorder. I have not been forced to take part in the study and this means that I volunteered willingly. I also understand that after the interview begins I can refuse to answer any specific questions or terminate the interview at any point and that will not have any effect on services that I or my family receives from health providers.

The study will be beneficial in the sense that information gathered will be used to improve participants' care and that of other women with the same medical problems. The other benefit is that participants will have the opportunity to share their concerns and ask questions. The researcher acknowledges that sharing information regarding the two diseases can disturb emotionally and she is committed to assist by making referrals to appropriate health, social or psychological services.

The interview will be conducted at a place convenient to each participant and this means that it can either be at home or in a quiet room in the hospital especially for those who have not disclosed their status.

DATE..... RESPONDENT'S SIGNATURE.....

DATE..... RESEARCHER'S SIGNATURE.....

Tshireletso Molefe (Researcher)

Cell: (00267) 72637321

Supervisor: Dr SineguguDuma

email: sduma@uctgsh1.uct.ac.za

Annexure 2: Research Consent Form (Setswana)

SETLHOGO SA TLHOTLHOMISO: Go tshela ka mogare wa HIV/AIDS

kankere ya popelo kwa Botswana: Potsolotso ya bo mme kwa Gaborone le Francistown .

MOTLHOTLHOMISI

: Tshireletso Molefe

Nna _____ (leina), ke tlhalogantse se ditlhotlhomiso di buang ka sone. Motlhotlhomisi o ntlhaloseditse ka botlalo mabapi le ditlhotlhomiso tse. Ke dumela go tsenya letsogo le gore motlhotlhomisi a dirise sekapa mantswe (tape recorder). Ga ke a patelediwa go tsenelela puisanyo e. Se se raya gore ke ithaopile ka go rata game. Ke itse gore fa re setse re simolotse dipuisanyo tsa rona nka kgona go gana go araba dipotso dingwe kana nka fetogela ditshwetso tsame tsa go tsenelela puisanyo. Seo ga se kake sa ama ka gope meamuso e nna le ba lelwapa lame re e bonang mo go ba botsogo.

Ditlhotlhomiso tse di botlhokwa ka di ka thusa go eketsa kitso ka malwetsi. Kitso eo eka gwetlha ditlhotlhomiso tse di tseneletseng tse di ka thusang bo mme ba seemo se setshwanang le se mo isagong. Go tsenelela go ka thusa gape go bona sebaka sa go bua ka dilo dingwe tse di go tshwentseng le go sedimosetswa ka dingwe tse o sa di tlhaloganyeng ka malwetsi a. Motlhotlhomisi o dumela thata fa go bua ka malwetsi a go se motlhofo mme e bile go ka tshwenya thata mo maikutlong. Ka jalo o ikemiseditse go thusa botlhe ba ba tsenyang letsogo ka go ba fetisetsa kwa ba ka bonang thuso e e tlhokegang teng. Seo se tla dirwa go lebilwe botlhoki ka bongwe ka bongwe. Fa o na le keletso ya go botsa sengwe kana o batla thuso nngwe o ka ikgolanya gape le ba lepatha la ditlhotlhomiso (Health Research Unit) mo nomorong kana mogaleng (Tel: 391 4467).

Ke tla bo ke dirisa sekapa mantswa (tape recorder) gore se tle se nthuse go gakologelwa tse re di buileng mo puisanyong ya rona. Ke go solofetsa gore sengwe le sengwe se re tla se buang e tla nna kgang yame le wena. Se se raya gore batho ga ba na go itse fa ele wena o buileng mafoko a a kwadilweng. Maina a botlhe ba ba tsenelelang puisanyo ga a na go kwalwa gope, go tsenngwa mo sekapa mantsweng kana mo sebala makgolong. Boemong jwa maina ke tla dirisiwa dinomoro go nthusa fa ke setse ke goboka dintlha tsa puisanyo ya rona. Ga gona sepe se se tla tsenngwang mo sebala makgolong kana mo mokwalong se se tla lemotshang babadi kana ope fela gore ke mang yo a neng a bua eng. Fa ke santse ke dira tshoboko ya dipuisanyo ga gona yo o tla nnang le bokgoni jwa go bula difaele tsame mo sebala makgolong. Seo se tla kgonagadiwa ka go dirisa dinomoro tsa sephiri go tsena mo difaeleng tseo.

Dilo tse di ka fang batho lesedi la gore ke mang yo o buileng eng di a go nyelediwa fela ka bofebo morago ga tshoboko ya dipuisanyo tsa rona. Fa ele gore morago ga puisanyo o na le dilo dingwe tse o sa batleng dika tsenngwa mo mokwalong ntswa go se ope yo o tla lemogang fa di builwe ke wena, nna le kgololesego ya go ntemotsha seo.

Fa o na le keletso ya go tsenelela dipuisanyo tse, ke kopa o nkitsise gore re dumalane ka nako le lefelo la puisanyo. Ka nako eo re tla bua gape ka pampitshana e o tshwantseng go e tlatsa e e supang fa o dumela go tsenelela puisanyo e, mme e bile o tlhaloseditswe ka botlalo ka ditlhotlhomiso tse.

Puisanyo e tla tshwarelwa mo lefelong le le siametseng yo o dumetseng go tsenelela puisanyo. Se se raya gore e ka nna ya nna kwa lwapeng kana mo phaposeng e e didimetseng mo sepateleng.

Letsatsi _____ Mme : _____

Letsatsi _____ Motlhotlhomisi: _____

Princess Marina Hospital
P.O. Box 258
Gaborone Botswana



Tel: 3621400
Fax: 3973776
Email: ygureja@gov.bw (chairman)
chakawa@hotmail.com (secretary)

PMH INSTITUTIONAL RESEARCH AND ETHICS REVIEW BOARD

Our Ref: PMH2/11B/07-011

Date: 24/07/2007

The Principal Investigator
Ms Tshireletso Molefe
Assistant Nursing Officer/MSc Nursing (Oncology) Student
P. O Box 106, Manyana

Dear Madam,

Re: Lived Experiences of Women Diagnosed with Both HIV/AIDS and Cervical Cancer

I am pleased to communicate the PMH IRB's conditional approval following an expedited review of the study protocol submitted.

The approval is effective from the date of this letter provided you comply with the list of conditions given below.

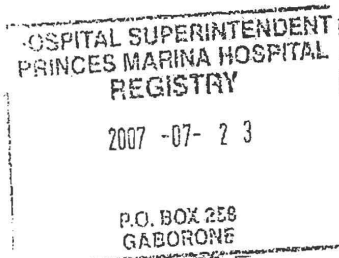
Committee expects you to: –

1. Resubmit for re-approval of the protocol if there are expected or unexpected changes at any time of the study.
2. Submit a copy of the report at the completion of the study for our records.
3. Seek permission from hospital management prior to commencement of the study.

On behalf of the Committee, I wish you success in this important endeavour.

Yours truly,

24/07/07
Chakawa Nthomiwa (Secretary)
Administration Block – 3rd floor
(o) 3621479/3621735/3621728



Please give assistance as required
Thank you

TELEPHONE: 3632000
FAX: 3914467
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD



MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE
BOTSWANA

REPUBLIC OF BOTSWANA

REFERENCE No: PPME-13/18 PS Vol I (62)

June 26, 2007

Ms Tshireletso Molefe
Box 106
Manyana

Permit : LIVED EXPERIENCES OF WOMEN DIAGNOSED WITH BOTH HIV/AIDS AND CERVICAL CANCER

your application for a research permit for the above stated research protocol refers. We note that you have satisfactorily revised the protocol as per our suggestions.

Permission is therefore granted to conduct the above mentioned study. This approval is valid for a period of 1 year effective June 26, 2007.

This permit does not however give you authority to collect data from the selected facilities without prior approval from the management of the facilities. Furthermore, consent should be obtained from all participants.

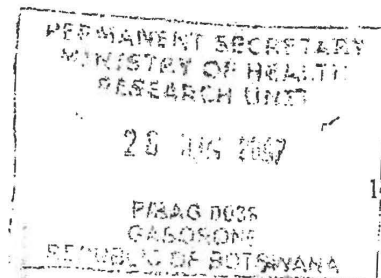
The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal will need to be resubmitted to the Health Research Unit in the Ministry of Health.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research Unit, Ministry of Health within 3 months of completion of the study.

Approval is for academic fulfilment only

Thank you.

S. El-Harabi
For/Permanent Secretary Ministry of Health





UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: lanices@uct.ac.za

30 May 2007

REC REF: 181/2007

Ms T Molefe
Nursing & Midwifery
Health & Rehabilitation Sciences

Dear Ms. Molefe

PROJECT TITLE: EXPERIENCES OF BOTSWANA WOMEN DIAGNOSED WITH BOTH HIV/AIDS AND CERVICAL CANCER

Thank you for submitting your study to the Research Ethics Committee for review.

DATE OF MEETING: 25 MAY 2007

DECISION: It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Methodologically, we recommend that the researcher considers using a snowball method of recruitment or asks nursing colleagues to distribute brochures about the study so participants can decide whether to take part whilst maintaining their confidentiality.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC, REF in all your correspondence.

Yours sincerely

A/PROF. M. BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

lanices

Annexure 5: Interview guide (English)

1. How did you find out that you were HIV positive and have cervical cancer?
2. How did it make you feel to know that you are HIV positive and have cervical cancer at the same time?
3. Probing questions regarding fears, hopes and any other relevant things based on what the participant says in regard to the two questions above.

Annexure 5: Interview guide (Setswana)

1. O itsile jang gore o na le mogare wa HIV gape o na le kankere ya popelo mme?
2. O ile wa ikutlwa jang fa o lemoga fa o na le mogare wa HIV gape o na le kankere ya popelo ka nako ele nngwefela?
3. Dipotso tse di tla latelang e tla nna tse di tla gwetlhang mme go tswela ka puisanyo. Dipotso tsa teng di tla itebaganya le dipoifo, tsholofelo, dikgwetlho le dilo tse dingwe tse di tlhokafalang go lebilwe se mme a tla se buang mabapi le dipotso tse difa godimo.