

CHAPTER 1

Orientation to the study

1.1 INTRODUCTION

This study aims to explore and describe the experiences of African women with both HIV/AIDS and cervical cancer in a public hospital. The diagnosis of a chronic disease may be a painful and distressing experience for women. The pain that they go through may be a dominant physical and psychological issue in their lives. The diagnosis of both HIV/AIDS and cervical cancer may also affect members of the family as well as colleagues at work. These people are with the diagnosed person on a daily basis. The experiences of a chronic disease may go beyond the patient and affect the health care professionals as well, as they are the ones involved in the management of the patient on a day-to-day basis. The findings of the study may help public health officials and other health care professionals in the management of these women.

1.2 BACKGROUND TO AND MOTIVATION FOR THE STUDY

This study focuses on the experiences of African women diagnosed with both HIV/AIDS and cervical cancer. The malignancies of some women with gynaecologic cancers are related to HIV/AIDS, and cancer of the cervix appears to be more aggressive in HIV-positive women than in those whose malignancies are not related to an HIV-positive status (Rubin & Williams 2001:204). In the United States of America (USA) the Center for Disease Control (CDC) has accepted cancer of the cervix in the presence of HIV infection as an AIDS-defining illness and may be the most common AIDS-related malignancy in women

(Maiman, Fruchter, Clark, Arrastia, Matthews & Gates 1997:76; Rubin & Williams 2001:203).

A higher incidence of invasive cervical cancer has been observed in HIV-positive women compared to HIV-negative women (The needs of HIV-infected women: gender news 1997:30). Cervical cancer occurs mainly between 40 and 60 years of age, but there is evidence that the peak age of onset is falling, possibly due to changes in social habits (The South African National Cancer Registry 1996:29). According to the South African National Cancer Registry (1996:29), the most common causes of cervical cancer are first intercourse at an early age and the number of sexual partners. Furthermore, there was a high mortality rate among Black adults, followed by Whites, Coloureds and Asians, thereby dispelling the myth that cancer is a disease of older people. The South African National Cancer Registry (1996:29) found that in 1990-1991, one quarter of all cancers occurred before the age of 50.

Young women aged about 21 years are now diagnosed with cervical cancer and also suffering from HIV/AIDS. Cervical carcinoma is now the most common initial AIDS-defining illness in many women receiving radiation therapy at the Hillbrow/Johannesburg Oncology Department. Some of the women are diagnosed with HIV/AIDS before the diagnosis of cervical cancer. Others are found to be HIV-positive during screening for cervical cancer (Maiman et al 1997:77; The needs of HIV-infected women: gender news 1997:31).

The psychological effects associated with HIV testing and cancer diagnosis vary considerably. African women suffer psychologically even before they undergo an HIV/AIDS test or cervical screening. Screening for a pre-cancerous condition may be distressing for women. According to Davey, Austoker and Jansen (1998:264), the impact of anxiety may be harmful to women, they may also be reluctant to follow up the results, go for treatment and return for regular cervical screening. With regard to human papilloma virus (HPV), Butcher (2001:1044-1047) found that women often experience negative emotions such as

anger, fear and panic about the possibility of testing positive to HPV. Testing positive to a virus that causes cervical cancer may be a painful experience for women. Butcher (2001:1045) adds further that this may result in serious psychological problems for affected women. Therefore a woman with a diagnosis of both cervical cancer and HIV/AIDS may go through many painful experiences, which need to be investigated. It is therefore necessary to determine the experiences that women go through after a diagnosis of HIV/AIDS and cervical cancer.

These two diagnoses affect African women physically, emotionally, sexually, psychologically and socially (Butcher 2001:1044). There can be fear of discrimination and negative societal reaction against people with HIV/AIDS (Sherr, Hankins & Bennett 1996:47). In south India, for example, Chandra, Deepthivarma and Manjula (2003:212) found that women feel that their diagnosis may lead others to label them or attribute their sickness to a bad character. This diagnosis in African women may not be just a physical matter because diseases that arise from sexual activity are a source of stigma (Sherr et al 1996:47). These diseases are considered fatal and spreading, so disbelief is a common reaction to the diagnosis.

Apart from the emotions experienced by people with a terminal illness, strategies for coping with the illness range from initial denial to ultimate acceptance (Bury, Morrison & McLachlan 1992:128-129). By denying the disease, people with a terminal illness like cancer, are allowing time to pass for their panic to subside. Bury et al (1992:129) state that for many, denial is a familiar coping mechanism. Many have no experience of working through difficult and painful feelings and so the process of denial may continue for some time.

The diagnosis of terminal illnesses like cervical cancer and HIV/AIDS is a life-changing experience, and shatter any dreams that women may have of starting a family or new relationships in the future (Bury et al 1992:126). After living a healthy life, it may be

frightening to come face to face with mortality, especially for a woman who has both a positive HIV antibody result and cancer of the cervix (Bury et al 1992:128). The fear of HIV/AIDS and cancer may be paralysing because people associate these diseases with death.

Gore-Felton, Vosvick, Bendel, Koopman, Das, Israelski, Herrera, Litzenberg and Spiegel (2003:539) examined the prevalence of sexually transmitted diseases (STDs) as well as the relationships between STDs and the coping strategies used to deal with the stress of living with HIV/AIDS, in a sample of 179 men and women. Of the sample, 61% were diagnosed with AIDS and 39% reported with STD post-HIV diagnosis (Gore-Felton et al 2003:539). Gore-Felton et al (2003:540) found that individuals who put others at risk used fewer active behavioural coping strategies and more alcohol-drug coping mechanisms. The study focused mainly on men or gays and lesbians. The study did not demonstrate the experiences or the coping mechanisms of women with HIV/AIDS.

According to Jenkins and Guarnaccia (2003:409), coping processes are better understood by looking at how people cope with certain types of stressors rather than treating coping as a stable personality trait. Their findings show cancer-specific denial to be effective for women coping with mastectomies, whereas generalized denial did reduce distress. Some patients need to be supported emotionally by family and friends. Jenkins and Guarnaccia (2003:409-410) found further that "anticipating and receiving HIV-positive results is often the most significant HIV-related stressor". For people suffering from HIV/AIDS, disease-related stressors may not include only fatality, specific symptoms, treatments, side effects, and other physical features, but also secondary social concerns, such as lifestyle stigma, impoverishment and relational implications of getting and passing on the infection (Jenkins & Guarnaccia 2003:410).

Pakenham and Rinaldis (2002:203-219) developed the HIV/AIDS stress scale to measure HIV/AIDS-related stress and coping strategies. A total of 132 homosexual/bisexual men with HIV/AIDS were interviewed, and completed the HIV/AIDS stress scale and measures of coping strategies, appraisal, social support and adjustment (that is, depression, social adjustment, number of HIV symptoms, and subjective health status). Pakenham and Rinaldis (2002:203) are of the view that due to these stressors HIV homosexual men have elevated levels of psychological morbidity compared to sero-negative comparison groups. Furthermore, it is very important that psychological factors resulting in variations in adjustment to HIV/AIDS including physical health be identified. Pakenham and Rinaldis (2002:205) maintain that many HIV/AIDS-specific stressors affect people infected with HIV, in particular homosexual men. These may include social isolation, multiple bereavements, stigma, and rejection related to being HIV-positive and sexuality.

Chandra et al (2003:207) examined aspects of self-disclosure of sero-positive status among 68 patients (35 men and 33 women) infected with HIV in south India. Data was collected through in-depth interviews to assess ways in which HIV-related disclosure took place and factors that influenced disclosure. Chandra et al (2003:207) found that people who are aware of their HIV status are frequently faced with the difficult decision of whether or not to disclose their sero-status to others. "The way each person experiences and copes with the illness is reflected in this choice" (Chandra et al 2003:207).

The above issues therefore form the basis for this study on the experience of African women diagnosed with HIV/AIDS and cervical cancer. According to O'Sullivan and Thompson (1996:166), research on gay and lesbians is not uncommon in the medical and scientific fields. Women's experiences of the diagnosis of HIV/AIDS and cancer may be different from that of men and/or gays and lesbians. Women's bodies are different to men's, with a different reproductive system, hormonal differences, and body weight to fat ratio (O'Sullivan & Thompson 1996:166). Women's experiences of a terminal illness may differ

from men's. Little is known about the experiences of women diagnosed with HIV/AIDS and cervical cancer. This highlights the psychosocial aspects of patients living with cancer.

1.3 STATEMENT OF THE PROBLEM

Assessing research in HIV/AIDS and cancer, and the invisibility of women, O'Sullivan and Thompson (1996:166-167) state that most studies on the experiences or disclosure, consequences and treatment of HIV/AIDS have been conducted on men (or gay men). Shisana and Zungu-Dirwayi (2003:21) point out that in the 1980s not much was known about HIV/AIDS. It was defined as a disease of men who had sex with men and consequently stigmatized. South Africa shared the belief that the disease was exclusive to homosexuals. According to Sherr et al (1996:29), most of the literature on the experiences of HIV/AIDS is based on studies of gay men. Little research has compared the experiences of three subgroups, namely women, gay/bisexual men and heterosexual men, with regard to the chronic illnesses of HIV/AIDS and cancer in their lives. This may include the experiences of men diagnosed with Kaposi's sarcoma, which is related to HIV/AIDS. They may differ in various specific aspects that affect HIV/AIDS or cancer concerns and coping, such as ethnicity, risk factors, family support and obligations, social isolation, educational level, income, access to health care and involvement with the community (Jenkins & Guarnaccia 2003:411).

No research has been done on the experiences of women diagnosed with both HIV/AIDS and cancer. Due to this lack, it is not clear to medical practitioners what they should be looking for in order to ensure earlier recognition of HIV/AIDS-related illnesses, such as cervical cancer in women (O'Sullivan & Thompson 1996:171). O'Sullivan and Thompson (1996:167) point out that most of the existing studies on women have been concerned with the transmission of HIV/AIDS and the effects of the disease on newborn babies. The Department of Health (2002:6) and Williams, Gouws, Colvin, Sitas, Ramjee and Karim

(2002:305) conducted studies on the prevalence of HIV/AIDS among pregnant women. O'Sullivan and Thompson (1996:167) examined the role of women as mothers-to-be in order to find out the consequences for children of having an HIV-positive mother.

Not only homosexuals feel the impact of HIV/AIDS on their lives, but women as well. Women also experience the impact of cervical cancer on their lives. O'Sullivan and Thompson (1996:171) maintain that women remain "statistically insignificant" and are always discounted, for example, "the epidemiology of HIV is interpreted through the number of people with a diagnosis of AIDS". Therefore, the Government and the Department of Health base planning and budgeting for services and support on this type of information. Sherr et al (1996:29) state that all women, irrespective of whether they are pregnant or not, suffer psychological complications from HIV/AIDS and cancer, and very few studies have examined these systematically. They found that even though there may be little reason to believe that women's emotional reactions differ, their manifestations, triggers and coping strategies may not be the same. This problem led the researcher to undertake this study.

1.4 RESEARCH QUESTION

In the light of the foregoing, this study aims to answer the following question:

How do African women experience the diagnosis of both HIV/AIDS and cervical cancer?

1.5 PURPOSE OF THE STUDY

The purpose of this study is to

- explore and describe African women's experience of both the diagnoses of HIV/AIDS and cervical cancer

- develop guidelines for the support of African women suffering from both HIV/AIDS and cervical cancer.

The exploration of African women's experience of the diagnosis of both HIV/AIDS and cervical cancer will lead to the development of support guidelines for public health officials.

1.6 PARADIGMATIC PERSPECTIVE

In this study the researcher entered the field without any preset theoretical framework of reference by utilizing bracketing and intuiting. Streubert Speziale & Carpenter (2003:22) define bracketing as "the cognitive process of putting aside one's own beliefs, not making judgements about what one has observed or heard, and remaining open to data as they are revealed". In addition, the researcher has to explicate own thoughts, feelings, and perceptions about the experiences of these women. The researcher did not read any literature on this topic, and didn't know anything about the experience of women diagnosed with an illness like HIV/AIDS and cervical cancer.

Johnson (2003:148) is of the view that the process of communication affects the relationship between the healthcare professional (sender) and the patient (receiver). In addition, the ability to communicate effectively may deepen the relationship between the healthcare professional and the woman diagnosed with both HIV/AIDS and cervical cancer. Johnson (2003:148) maintains that many problems experienced in relationships are a result of failure to communicate effectively. This study indicated the importance of communicating effectively with these women in order to explore and describe their experiences, and find constructive ways of dealing with these experiences.

1.7 DEFINITION OF TERMS

For the purposes of this study, the following terms are used as defined below.

- **Acquired immune-deficiency syndrome (AIDS)**

According to Weller and Wells (2001:13), "AIDS is the extreme end of the spectrum of disease caused by human immuno-deficiency virus (HIV) infection, and impairs the body's cellular immune system".

- **African woman**

In this study, "African women" refers to Black women.

- **Cancer**

Weller and Wells (2001:69) define cancer as a general term to describe a malignant growth. It is a disease of the body's cells. This means that cells might grow in an uncontrolled and abnormal way.

- **Cervical cancer**

According to Butcher (2001:1044), cervical cancer is cancer affecting the cervix (mouth of the womb). Cervical cancer is the second most common female cancer in the world.

- **Cervical screening**

Butcher (2001:1044) describes cervical screening as the detection of any abnormal cell division in the cervix with a Pap smear (a quick and painless test). Cervical screening is

one of the best preventive approaches in the world for detecting and diagnosing cervical cancer.

- **Disease**

Gilbert, Selikov and Walker (1996:7-8) define a disease "as a physical concept linked mainly to the body and an "objective" condition in which the internal functioning of the body is impaired" (e.g. by a virus).

- **Experience**

By "experience" we mean the perceptions of the world, these might include objects, other people, visual images, colour, movement, sounds, behaviour, interactions, that is, the totality of what is perceived (Chinn & Kramer 2004:61). This study explores and describes the lived experiences of African women diagnosed with both HIV/AIDS and cervical cancer.

- **Human immuno-deficiency virus (HIV)**

HIV is the virus that causes AIDS.

- **Human papilloma virus (HPV)**

According to Butcher (2001:1044), "HPV is the main precursor to cervical cancer and is a sexually transmitted".

- **Illness**

Gilbert et al (1996:7-8) define an illness “as a psychological concept linked to the individual that can mean an experience of the disease, and a “subjective” phenomenon in which a person can perceive herself as not feeling well”.

1.8 RESEARCH DESIGN

A qualitative research approach that is explorative, descriptive and contextual was used for this study. Qualitative research enables researchers to study human action from the perspective of the participants themselves (insiders’ perspective), as opposed to quantitative research, which studies human behaviour (Babbie & Mouton 2001:53, 270).

1.9 RESEARCH METHODOLOGY

1.9.1 Population and sampling

A non-probability sampling was used because is suitable for pilot, exploratory or in-depth qualitative studies (Polit & Hungler 1999:284). In this study, purposive sampling was used. In a qualitative study, a smaller number of participants are selected in comparison to a quantitative study in which researchers select many subjects representative of a larger population (Babbie & Mouton 2001:175; Burns & Grove 1999:356). The main aim of the study was to include as much information as possible or to acquire an in-depth understanding of the experiences of African women diagnosed with both HIV/AIDS and cervical cancer (Lincoln & Guba 1985:201).

1.9.2 Data collection

In-depth semi-structured phenomenological interviews were used for data collection. The researcher selected this method for data gathering to make sure that the research topic (African women’s experience of both HIV/AIDS and cervical cancer) is adequately covered

with the research participants (Polit & Hungler, 1999:332). In-depth semi-structured interviews allowed the respondents to express their experiences of HIV/AIDS and cervical cancer and help the researcher to gain insight into their lived experiences of the two diseases (Burns & Grove 1999:359). Furthermore, interviewing enabled researchers to explore other aspects that may emerge during the course of the interview (De Vos 1998:300). The researcher also made use of field notes and tape-recording to refer to later during data analysis (De Vos 1998:285).

1.9.3 Data analysis

Data analysis in qualitative research starts during interviewing and not after all the data has been collected (De Vos 1998:334; Polit & Hungler 1999:573). The data analysis and interpretation assisted the researcher to formulate guidelines for the support of women diagnosed with both HIV/AIDS and cervical cancer. Tesch's method of descriptive analysis was used during data analysis (De Vos 1998:343-344).

1.10 OUTLINE OF THE STUDY

Chapter 1 introduces the problem to be studied and motivation for the study.

Chapter 2 describes the research design and methodology and measures for ensuring trustworthiness.

Chapter 3 deals with the literature review and the findings.

Chapter 4 discusses guidelines for the support of African women diagnosed with both HIV/AIDS and cervical cancer.

Chapter 5 concludes the study, discusses its limitations and makes recommendations for further study.

1.11 CONCLUSION

This chapter outlined the problem, the purpose and objectives of the study, as well as the research design. Chapter 2 discusses the research methodology of the study.