

CHAPTER 4

Guidelines for the support of women diagnosed with both HIV/AIDS and cervical cancer

4.1 INTRODUCTION

Chapter 3 discussed the research findings with reference to the literature review. This chapter describes the guidelines developed in the light of the findings for the support of women diagnosed with both HIV/AIDS and cervical cancer in radiation oncology departments in public hospitals and the community. The guidelines are described in three broad phases, namely

- Management of symptom experience.
- Improvement and maintenance of communication channels between women and health care providers.
- Improvement of support mechanisms for women living with HIV/AIDS and cervical cancer.

4.2 GUIDELINES FOR THE SUPPORT OF WOMEN DIAGNOSED WITH HIV/AIDS AND CERVICAL CANCER IN THE RADIATION ONCOLOGY DEPARTMENT IN A PUBLIC HOSPITAL AND IN THE COMMUNITY

The researcher developed these guidelines from the research findings as well as the literature review. They guide the support and management of women diagnosed with HIV/AIDS and cervical cancer.

4.2.1 Phase 1: Management of symptom experience

Hudson et al (2003:484) define "symptoms within the University of California, San Francisco, model of symptom management as subjective experiences that reflect changes in an individual's bio-psychosocial function, sensation or cognition". Furthermore, this model acknowledges the relationship between signs and symptoms, noting that they bring problems to the attention of the patient or the healthcare professional.

4.2.1.1 Symptom experience

This study found per vaginal bleeding, pain and headaches to be the most frequent reported symptom experiences. For intervention purposes, guidelines should be developed to inform women who are diagnosed with HIV/AIDS and cervical cancer how to manage these symptoms.

4.2.1.1.1 Per vaginal bleeding

The findings from this study suggest that women living with HIV/AIDS may be at high risk of developing cervical cancer. Some of the respondents were bleeding a lot. If diagnosed with HIV/AIDS and there is irregular or per vaginal bleeding, it is important for the patient to

- Explain this experience to the doctor, either a general practitioner or an oncologist (specialist).
- Communication with the doctor is important so that they may be tested for cervical cancer (Rubin & Williams 2001:464).

Assessments

- Physical examination. The importance of physical examination of these women may reveal an ulcerated lesion in the cervix (Rubin & Williams 2001:464). In addition, this may be done if women complain of abnormal vaginal bleeding, including post-coital bleeding, irregular menses or postmenopausal bleeding.
- Cervical screening. A Pap smear may be done to detect and diagnose cancer of the cervix.
- A full blood count may reveal anaemia due to bleeding and raised white cell-count where there is chronic infection. This is important if the patient is to receive chemotherapy as part of the treatment.
- If abnormal bleeding continues, the doctor may consider admitting the patient to the ward and transfuse the patient.

Management

- If cervical cancer is detected and diagnosed, the patient must be referred for radiation therapy treatment. If cervical cancer is detected at an early stage, the patient may be given radical treatment. Communication of the doctor and patient is very important. The patient needs to understand what is palliative or radical radiation therapy. Furthermore, they must know what is radiation therapy.

4.2.1.1.2 *Pain*

The respondents also experienced pain.

- When managing women who are experiencing pain, healthcare providers should understand that the pain is unbearable, women may spend sleepless night due to

pain, women experience pain all the time and the study found that pain became the focus of the respondents' lives.

Pervan et al (1995:591) state that assessing pain is not an easy task because of the subjectivity of the pain experience, but it is very important to assess pain in order to attempt effective control. Furthermore, it is very important for healthcare professionals to determine the nature of pain, its patterns, factors that affect its manifestation, the effect it has on sleep patterns, what precipitates it and what relieves it.

- ***Healthcare professionals should empathise with these women when they describe how they experience pain.***

Healthcare providers should learn to understand that to the patient, pain means whatever they say it does (Pervan et al 1995:594).

- Communication between the healthcare professionals and these women need to be effective, and it is important that the healthcare professionals understand them. The healthcare professionals must assess these patients properly to find-out what makes them weak, not to eat and loose appetite.

Healthcare professionals should learn to put themselves in the patients' place. This will make patients feel accepted.

- ***Pain control***

Healthcare professionals must:

- Make an accurate assessment of the cause of pain whether is due to the radiation treatment or HIV/AIDS and cervical cancer.
- Have empathy and understanding.
- Explain and plan clearly for action to women diagnosed with both HIV/AIDS and cervical cancer in a language they will understand.
- The doctor to prescribe pain killers or morphine depending on the nature of the pain.

4.2.2 Phase 2: Improvement and maintenance of communication channels between patients and healthcare professionals

4.2.2.1 Patient-healthcare professional relationship

The study found that the respondents lacked knowledge of the diagnosis of cervical cancer and HIV/AIDS and how they can be treated. Marelich and Murphy (2003:478) stress that health care professionals, that is, doctors, nurses and radiation therapists, must understand that if questioned or challenged, patients may only be striving for a better understanding of their diagnoses (illnesses).

- If experiencing any physical symptoms, consult the doctor or the health care professionals at the clinic or the hospital.
- Encourage women to open up, and describe their experiences to the doctor or healthcare professional. This will promote a free flow of communication between the two.
- Encourage women to ask questions about the diagnoses of HIV/AIDS and cervical cancer, as well as the treatment. This will help them to have a proper understanding of what is going to happen to them.

4.2.2.2 *Healthcare professional-patient relationship*

Marellich and Murphy (2003:478) maintain that healthcare professionals should help these women, and develop affable relationships by opening communication channels. In addition, they must be available at all times to ensure the woman's well being.

- Explain the diagnosis of HIV/AIDS and cervical cancer to women, and that the patient should receive counselling about the two illnesses. These women need support and to be encouraged at all times.
- Women must be told about HIV/AIDS and its management. It is important that women have the necessary information about HIV/AIDS and are open about their diagnosis. This may reduce the risk of transmission of the disease.
- Women must be told about cervical cancer and its management. It is important that they understand what cervical cancer is as this will help them to allay any fears they may have about the treatment.
- Healthcare professionals should encourage these women to communicate their fears about the treatment so that they can be given appropriate treatment or medication.
- Explain about the side effects of the treatment. The side effects include tiredness, weight loss and sterility. Women must be made aware of the side effects through counselling and education (Pervan et al 1995:487).

4.2.3 Phase 3: Improvement of support mechanisms for women living with HIV/AIDS and cervical cancer

The role of healthcare providers, that is, therapeutic radiographers, oncology nurses, and doctors constitutes a unique and complex relationship with cancer patients (Johnson 1999:17). Developing a relationship with women diagnosed with HIV/AIDS and cervical cancer is important. This can be achieved by:

- Understanding their experiences regarding the two diagnoses in their lives.
- Understanding their experiences as they undergo radiation therapy treatment.
- Enhancing awareness as healthcare providers of the treatment as experienced by these women.

4.2.3.1 Importance of support mechanisms

The nature of support they received in their families, friends, and other women during their time of radiation therapy was an important element of the women's experience. This study found that they cannot endure the experience of living with HIV/AIDS and cervical cancer without such support mechanisms. This can be implemented in the following manner:

- ***Development of support mechanisms during radiation therapy treatment***

The sense of having the same experience seems to bond women with HIV/AIDS and cervical cancer receiving radiation therapy. The study found that they always shared the experience of the disease among themselves in the waiting room while waiting for treatment. The women supported one another (patient-to-patient communication) and also when they saw other patients' condition improving they became hopeful.

Development of support mechanisms in the radiation therapy department and in the hospital will:

- Serve as a source of clinical reassurance. Johnson (1999:22) states that patients diagnosed with chronic illnesses quickly become "lay experts".
- Help women with similar experiences to develop skills in managing and recognizing symptoms.

- Assist these women to participate in the “clinical system”, and their relationship with healthcare professionals changes (Johnson 1999:22).
- Help other women with similar experience (HIV/AIDS and cervical cancer) to allay their fears regarding radiation therapy.

The lived experiences of women diagnosed with both HIV/AIDS and cervical cancer can have important implications for radiation therapy radiographers who play a key role in delivering cancer treatment and supporting these patients.

- ***Development of post-radiation therapy treatment support mechanisms***

Post-radiation therapy support mechanisms can be developed and implemented in the community and in public hospitals. For some of the women in the study, completion of treatment may mean returning to living a normal life. Women diagnosed with both HIV/AIDS and cervical cancer can play a major role in educating the community about these diseases. Some women talked of the possibility of using their experiences to help others faced with the same illnesses. They can help to

- Educate and support women in the community with the same experiences.
- Educate young people about HIV/AIDS and cervical cancer.
- Educate other women about cervical cancer.
- Educate women about radiation therapy treatment.

Some of the women were faced with uncertainty in their lives. Johnson (1999:23) states that some patients feel insecure and uncertain at the end of active treatment because they see it as a relaxing of the clinical surveillance of their disease. They may worry that non-attendance at the hospital on a regular basis may allow their disease to progress unnoticed.

Understanding the lived experience of people living with HIV/AIDS is very important for the planning and implementation of appropriate health and social care (Anderson & Doyal 2004:95). Furthermore, HIV services are rated very highly by most women. These services may include:

Healthcare support services

- Women diagnosed with HIV/AIDS and cervical cancer may regard healthcare support services as a safe environment.
- The importance of continuity of care for these women must be emphasized.
- Support networks in the hospital or community may be a source of information and support.
- Support networks are important to ensure the confidentiality of women with these diagnoses.

Social support

In Hong Kong, Lau, Tsui, Li, Chung, Chan and Molassiotis (2003:704) found that patients living with HIV/AIDS receive less social support. In addition, they have no one to share their interests with or even ask for small favours. Family members (patient-to-family communication) should be involved in the care of women diagnosed with HIV/AIDS and cervical cancer. It is important that when they disclose their diagnosis, they are not discriminated against. Family members must be aware of the needs of these women:

- Women diagnosed with HIV/AIDS and cervical cancer must be supported.
- They need to be appreciated.
- They must be encouraged to live positively.
- They must be comforted.

- They need friends to be close to.
- They need a family member to turn to in times of trouble.

Spiritual support

The study found that women diagnosed with both HIV/AIDS and cervical cancer feel a need for spiritual support. The respondents expressed their hope in God. This may involve including the chaplain in the care of women diagnosed with HIV/AIDS and cervical cancer. The role of the chaplain in the public hospital and community may involve:

Offering hope

Circumstances like the diagnosis of HIV/AIDS and cervical cancer in their lives can break a woman's spirit (Pervan et al 1995:354). This is important because:

- They believe that God will give them strength to live with HIV/AIDS and cervical cancer.
- They are ready for anything.
- Believe that God is with them all the time.

Emotional support

Women diagnosed with HIV/AIDS and cervical cancer face a crisis in their own lives (Pervan et al 1995:353). In addition, this may consist of certain behaviour and feelings, such as crying, attempted suicide and feeling inferior. The feelings may include guilt, worthlessness, fear, horror, despair, anger or sadness (Pervan et al 1995:353).

In this study, some of the respondents cried before the interview, were fearful, angry, depressed and sad. They need to be supported emotionally so that that they may be able to cope with HIV/AIDS and cervical cancer in their own lives. Chaplains and the community should and can play a major role in supporting these women.

Counselling these women may play a major role. Their families or support groups can help these women to adjust emotionally, and empower them to cope with these two diagnoses.

4.3 CONCLUSION

This chapter described guidelines for the management of women diagnosed with HIV/AIDS and cervical cancer in public hospitals and the community. The importance of communication between healthcare providers and women suffering from these two diagnoses was emphasised.

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