

## **CHAPTER 1**

### **OVERVIEW FOR THE STUDY**

#### **1.1 INTRODUCTION**

This chapter provides an overview of the study and summarises the background and research methods.

#### **1.2 BACKGROUND OF THE STUDY**

“Cervical cancer can have devastating effects with a very high human, social and economic cost affecting women in their prime.” Dr.Rengaswamy Sankaranarayanan (International Agency for Research on Cancer and World Health Organization, 2013).

Cervical cancer is a health problem of the developing world, as approximately 84% of all women diagnosed with cervical cancer live in developing regions (International Agency for Research on Cancer and World Health Organization, 2014). Literature focuses primarily on the prevention and treatment of cervical cancer and qualitative work investigating the experiences of women living with cervical cancer is scarce. In addition, no study investigating how women living in Africa experience brachytherapy could be found. This study fills this knowledge gap by reflecting on these experiences.

Cancer continues to be a significant public health problem throughout the world. According to the latest Globocan statistics (International Agency for Research on Cancer and World Health Organization, 2014), cervical cancer is the fourth most common cancer in women worldwide. In developing countries, approximately 493 000 women are newly diagnosed with cervical cancer each year and approximately 274 000 will die from this disease despite the fact that cervical cancer is highly preventable through cytological screening programmes which facilitate the detection and treatment of precancerous lesions (Ashford & Collymore, 2005; Snyman, 2013b). Additionally, late presentation and lack of treatment facilities also contribute to the high death rate (Moodley, 2009). In South Africa, the exact number of women diagnosed with cervical cancer is not clear due to the pathological based cancer registry not being maintained (Denny, 2010).

Infection with Human Papilloma Virus (HPV), a common virus, which is transmitted by close contact, including penetrative and non-penetrative sexual contact is responsible for 99% of cervical cancers. The persistence of the virus may cause precancerous and, later, cancerous changes by interfering with normal control of cell growth (World Health Organization, 2006).

The pre-invasive and early stage of cervical cancer usually remains asymptomatic until the disease is locally advanced (World Health Organization, 2006). Advanced disease presents with common symptoms such as abnormal vaginal bleeding which could be post coital, inter-menstrual or post-menopausal, or an increased duration and amount of menstrual flow or watery serosanguineous vaginal discharge. According to the World Health Organization (2006) the late symptoms may include dysuria, urinary retention and haematuria as well as symptoms such as rectal bleeding, bowel obstruction and constipation which suggest tumour invasion of the bladder or the rectum, whilst oedema of the lower extremities may be the result of lymphatic obstruction.

According to the World Health Organization (2006), treatment for the individual patient is formulated once a histological diagnosis of cervical cancer is established. The International Atomic Energy Agency (IAEA) (2012) directs the treatment of cervical cancer in resource limited centres and states that the treatment of cervical cancer is guided by the age and the general health of the patient, as well as the extent of the presence of any complicating abnormalities. The International Atomic Energy Agency guidelines stipulate brachytherapy is mandatory for the curative treatment of all invasive cervical cancers. To achieve a maximum cure rate, brachytherapy is usually combined with external beam radiotherapy.

### **1.3 RESEARCH PROBLEM AND QUESTION**

Brachytherapy is an intrusive procedure and involves placing uterine applicators in the vaginal fornices under conscious sedation. The rate used determines the time the patient will be kept in isolation, as well as the total dose to be used and the number of sessions the patient will have (International Atomic Energy Agency, 2012). It is not known how South African women undergoing brachytherapy experience this procedure as no literature investigating this issue could be found. The research question for the study is therefore: *What are the lived experiences of women diagnosed with cervical cancer treated with brachytherapy at an academic hospital in Gauteng?*

#### **1.4 PURPOSE OF THE STUDY**

The purpose of the study is to gain an understanding of the lived experiences of women treated for cervical cancer at an academic hospital in Gauteng receiving brachytherapy.

#### **1.5 THEORETICAL FOUNDATION OF THE STUDY**

The study is underpinned by the Roy Adaptation Model (RAM). This model, developed by Callista Roy, provides a useful framework for nursing care for persons both in health and illness as according to the model, health and illness are inescapable dimensions of a person's life. The person, viewed as a bio-psycho-social being is in constant interaction with a changing world and uses intrinsic and learnt biological, psychological and social mechanisms to cope with the changing world (Current Nursing, 2012). This model was applicable to the study as the researcher believes cancer changes the lives of people suffering from this disease, necessitating adaptation to their altered unique wholeness.

#### **1.6 RESEARCH METHODS**

The setting for this study was the Radiation Oncology Department at an academic hospital in Gauteng. A qualitative approach and descriptive phenomenology design was selected for the study. The study population comprised all patients undergoing brachytherapy for cervical cancer at the academic hospital. Purposive sampling, a sampling method to consciously select specific people, selected the sample of 16 women who were 18 years and older, diagnosed with cervical cancer, receiving brachytherapy and able to speak Basic English. The sample size was determined by data saturation, which means no new information was obtained (Polit & Beck, 2012).

Unstructured, individual interviews were conducted to gather the data as it allowed the researcher to investigate the experiences of the participants without utilising any prior information, experience or opinions regarding the phenomenon under study (Polit & Beck, 2012). General information (Appendix A) was obtained before the interviews. One opening question was asked: *Please tell me what it is like for you to get brachytherapy?* The technique of probing was employed during the interview process. Probing is a process of eliciting more detailed information from participants in an interview than was volunteered in the first reply (Polit & Beck, 2012). This strategy is used to obtain the maximum amount of data, to verify what was heard and what was meant by participants. Care was taken by being sensitive and not forcing participants to answer questions they preferred not to. The issue of bracketing was also

employed in this study by holding in abeyance any preconceived beliefs or opinions about the phenomena under study, although the researcher was conversant with the phenomena which otherwise could have been taken for granted (De Vos et al., 2012; Polit & Beck, 2012).

The interviews were recorded by audio tape and field notes were also made during and immediately after the interviews. Field notes are a written account of the things the researcher hears, sees experiences and thinks about in the course of interviewing (De Vos et al., 2012). The interviews were conducted in a quiet and private room at the Radiation Oncology Department.

Data gathering and analyses were done concurrently. Polit and Beck (2012) describe data analysis as the systematic organisation and synthesis of research data. The interviews were transcribed verbatim and the transcripts double checked for accuracy. The data were analysed according to the steps as described by Giorgi. Trustworthiness was established according to the strategies promoted by Lincoln and Guba, as explained by Shenton (2004).

## **1.7 OPERATIONAL DEFINITIONS**

Definitions for the purpose of this study are as follows:

Advanced cervical cancer: According to the International Atomic Energy Agency (2012), advanced cervical cancer refers to Stage IB2 and IIA2  $\geq$  4cm; IIB; IIIA; IIIB and IVA cancers. For the purpose of this study however, advanced cervical cancer will refer to Stage IIB, IIIA, IIIB and IVA cancers, as these patients are not candidates for surgery but would be treated with radiotherapy with or without concomitant chemotherapy.

Curative treatment: Curative treatment for patients with advanced cervical cancer (Stages IIB to IVA) consists of external beam radiation, which is the standard treatment, plus brachytherapy with or without concomitant chemotherapy. Cisplatin, administered on a weekly basis is currently the drug of choice (International Atomic Energy Agency, 2012).

Lived experience: According to Polit and Beck (2012), lived experience is defined as the meaning given to a particular phenomenon as perceived by each person.

## **1.8 CHAPTERS OF THE STUDY**

The study is divided into the following chapters:

Chapter 1: Overview of the research study

Chapter 2: Literature review

Chapter 3: Research design and research method

Chapter 4: Results of the study

Chapter 5: Justification, recommendations, limitations and reflection

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

In Chapter 1, an orientation for the study was provided. Chapter 2 focuses on the review of the literature in terms of the theoretical foundation of the study and cervical cancer as a public health problem.

#### **2.2 THE THEORETICAL FOUNDATION OF THE STUDY**

As mentioned in Chapter 1, the theoretical foundation underpinning this study is the Roy Adaptation Model (RAM). This model was developed in 1964 by Sister Callista Roy, of Saint Joseph of Carondelet, in response to a challenge by her professor, Dorothy E. Johnson, with emphasis on the person's ability to adapt to the environmental stimuli to achieve survival, growth, development and mastery. The model has been reconceptualised for use in the twenty-first century and continues to be refined. The model has gone through dynamic processes over the years and has been implemented in numerous hospitals and other healthcare settings. The model has since been applied to diverse populations, adaptive needs and developmental stages (Fawcett, 2005; Phillips, 2010).

The model, as illustrated in Figure 2.1, rests on five concepts: adaptation which is the goal of nursing, the person who is an adaptive system, the environment providing stimuli, health which is the outcome of adaptation and nursing which promotes adaptation and health (Current Nursing, 2012; Roy & Andrews, 1999).

##### **Adaptation**

Adaptation is a process by which individuals as well as groups of people integrate with the environment and is achieved by means of conscious awareness, self-reflection and the choices made. Adaptation is effective when an individual is able to respond positively to a changing environment without any adverse effect on their normal life. The choices made by individuals and groups of people and how they integrate with the environment are achieved by means of conscious awareness and self-reflection.



Figure 2.1. Roy Adaptation Model

Source: Emporia State University Kansas.

#### The person

The person is a bio-psycho-social being who is in constant interaction with a changing world in which health and illness are inevitable dimensions. To respond positively to the changing world, the person uses both inherent and learnt biological, psychological and social mechanisms to adapt to the changes. The person does not only include individuals but also groups such as families, communities and even society, which can function as a unit for certain purposes (Current Nursing, 2012; Roy & Andrews, 1999).

#### The environment

The environment is made up of both internal and external influences which can either threaten or promote the person's unique wholeness. In addition, there is a positive correlation between the person and the environment, which either affects the person's ability to adapt, or fail to do so. (Current Nursing, 2012; Roy & Andrews, 1999).

## Health

According to Roy (Current Nursing, 2012; Roy & Andrews, 1999), a person's life consists of inevitable dimensions including health and illness. Health is the state of being free from illness or injury. Health is also considered to be a reflection of how successful an individual has been in adapting to the environment and the person's ability to meet the goals of survival, growth, reproduction and mastery.

## Nursing

Nursing involves the manipulation of stimuli such as contributing to health, quality of life and dying with dignity, as well as the assessment of the factors which influence adaptive abilities and the interactions with the environment. The goal of nursing is to promote clients adaptive responses in relation to the adaptive modes, the adaptation level and the various stimuli (Current Nursing, 2012; Roy & Andrews, 1999).

This theory therefore fitted well with the current study as it intended to investigate the lived experiences of women undergoing brachytherapy for cervical cancer and how that affected both the internal and external environment of these patients.

## **2.3 CERVICAL CANCER AS PUBLIC HEALTH PROBLEM**

### **2.3.1 Epidemiology of cervical cancer**

Cervical cancer continues to be a significant public health problem throughout the world. According to the latest Globocan statistics (International Agency for Research on Cancer and World Health Organization, 2014), cervical cancer is the fourth most common cancer in women and seventh overall, with an estimated 528,000 women newly diagnosed each year. Cervical cancer is also the fourth most common cause of cancer deaths, as 266 000 women worldwide die from this disease each year. The largest majority (approximately 85%) of women diagnosed

with cervical cancer live in the less developed regions of the world, where this disease accounts for almost 12% of all female cancers. High risk regions include Eastern Africa (42.7% of the global cervical cancer burden), Melanesia (33.3%), Southern (31.5%) and Middle Africa (30.6%). Rates are lowest in Australia/New Zealand (5.5%) and Western Asia (4.4%). Cervical cancer remains the most common cancer in women in Eastern and Middle Africa.

According to the International Agency for Research on Cancer and World Health Organization (2014), the incidence of cervical cancer in sub-Saharan Africa is 34.8 per 100 000 women and out of this, 22.5 per 100 000 die from the disease. In South Africa, cervical cancer is the second most common cancer in women and the most common amongst black South African women, however the exact number of women diagnosed is unclear due to the pathological based cancer registry not being maintained (Denny, 2010) and possible underreporting (Albrecht, 2006). According to the South Africa National Cancer Registry published by the National Health Laboratory (2007), the histological diagnosis of cervical cancer in women is 1 in 41 South African women and it is estimated that the disease kills approximately 8 women in the country every day with the World Health Organization projecting this will increase to 12 deaths per day by 2050 (Snyman, 2013a).

### **2.3.2 Cervical cancer as preventable disease**

The basic underlying cause of cervical cancer is persistent infection with oncogenic types of HPV. Most cervical cancers (approximately 70%) are caused by HPV types 16 and 18 (World Health Organization, 2006), whilst other oncogenic types being 31, 33, 45 and 58 are found less common and also have different prevalence in different geographical areas (Smith et al., 2007). The persistent of HPV progressing to cervical cancer is not very clear but it is believed the following contribute to its occurrence:

- HPV-related co-factors including viral type and viral load and simultaneous infection with several oncogenic types.
- Host-related co-factors including immune status. For instance, people with immunodeficiency (such as that caused by HIV infection) have more persistent HPV

infections and a more rapid progression to pre-cancer and cancer. Parity also plays a role as the risk of cervical cancer increases with higher parity.

- Exogenous co-factors including tobacco smoking, co infection with HIV or other sexually transmitted agents such as herpes simplex virus 2 (HSV-2), Chlamydia trachomatis and Neisseria gonorrhoea and long-term (>5 years) use of oral contraceptives (Itano & Taoka, 2005; World Health Organization, 2006).

Cervical cancer develops slowly and it takes 10 to 20 years for mild dysplasia to develop into invasive cancer resulting in cervical cancer being a relatively easy disease to prevent. Cervical cancer is the result of persistent infection with certain high-risk types of HPV 16 and 18, which have been identified as being responsible for the vast majority of cervical cancers in Africa (World Health Organization, 2006).

Cervical cancer can be prevented by primary or secondary means. Primary prevention refers to efforts to prevent a disease from ever occurring by means of increasing public knowledge and the ability of individuals to make healthy lifestyle choices and vaccination. For cervical cancer, health education would include encouraging women not to smoke or to stop smoking, postponing sexual activity to older age, using barrier methods during sexual intercourse to prevent spread of human papillomavirus and other sexually transmitted diseases as well as effectively managing these diseases (Snyman, 2013b). According to Snyman (2013b), two vaccines have been developed in the quest for the primary prevention of cervical cancer, which is a major achievement in the protection of girls between the ages of 9 and 12 years against developing cervical cancer in later life. In addition, vaccination is less complicated than implementing a secondary cervical cancer screening programme and can serve as a platform for educating the rest of the adult population.

Secondary prevention is screening of target groups and is aimed at detecting and treating women having early signs of cervical cancer. According to the Alliance for Cervical Cancer Prevention and World Health Organization (2004), cervical screening tests include visual inspection with acetic acid (VIA), cytology (Pap smear) and tests to detect the Human papillomavirus (HPV). The Pap smear has been used for secondary prevention for the past five decades in countries where formal population-based screening has been implemented and has resulted in a remarkable reduction in the prevalence of the disease.

In South Africa, the National Department of Health (2000) has instituted a screening policy but this has yet to be formally implemented countrywide. The current policy offers women who are asymptomatic and 30 years of age or older three smears at ten-yearly intervals. In addition, women screened for the first time at age 55 or older will have only one smear if the first smear is normal. Unfortunately the screening takes place on an opportunistic basis and is estimated to be as low as 13% (Moodley, 2009; Snyman, 2013a). According to Moodley (2009), there is an issue with women refusing to avail themselves for screening despite being close to a health care facility. According Snyman (2013b), many women in South Africa have a low literacy level and little knowledge about cervical cancer and the test used to screen for it. This situation is aggravated by inadequate communication of information about abnormal test results and the timing of follow-up screening tests which are necessary for the proper functioning of a formal population-based screening programme.

### **2.3.3 Clinical manifestation of cervical cancer**

According to the World Health Organization (2006), pre-invasive and early stage cervical cancer usually remains asymptomatic. Symptoms start occurring when the disease is locally advanced. The most common early symptoms are:

- Abnormal vaginal bleeding, such as post-coital bleeding, post-menopausal or inter-menstrual bleeding and spotting between periods, or an increase in the duration and amount of menstruation,
- An unusual watery serosanguineous vaginal discharge which may contain some blood and may occur between menstruations, or after menopause,
- Dyspareunia.

The late symptoms may include:

- Urinary frequency and urgency,

- Backache,
- Lower abdominal pain.

The very late symptoms include:

- Severe backache,
- Weight loss,
- Bowel obstruction and constipation which suggests tumour invasion of the rectum while decreased urine output suggests obstruction of the ureters,
- Oedema of the lower extremities may be the result of lymphatic obstruction,
- Breathlessness due to anaemia, or rarely, lung metastases or pleural effusion.

#### **2.3.4 Diagnosis and staging of cervical cancer**

The strategies adopted in the proper management of cervical cancer depend on a histological examination of tissue biopsy taken from the lesion and the understanding of the extent of the stage of the disease, providing a definitive diagnosis of cervical cancer.

Various investigations are essential to stage cervical cancer. According to the World Health Organization (2006), a speculum, vaginal and rectal examination, intravenous pyelogram (IVP) or abdominal ultrasound are mandatory, whilst a cystoscopy, proctoscopy, cone biopsy, endocervical curettage or smear, chest X-ray and skeletal X-ray or bone scan if the patient experiences bone pain are supplementary. Optional investigations to inform additional treatment include blood test for HIV and syphilis, full blood count, computerised tomography (CT) scan of abdomen and pelvis and magnetic resonance imaging (MRI) of pelvis.

According to the International Federation of Gynaecology and Obstetrics (World Health Organization, 2006; International Atomic Energy Agency, 2012), the recommended staging of cervical cancer is based on the tumour size, the extent of the disease and metastasis to distant organs such as the extrapelvic lymph nodes, kidneys, bones, lungs, liver and brain. The extent of cervical cancer is assessed clinically by means of history taking and physical examination to include a careful pelvic examination, supplemented by a limited number of relatively unsophisticated investigations such as speculum vaginal and rectal examinations, which are only feasible in many low resource settings. Table 2.1 provides an investigation into the staging and treatment for cervical cancer according to FIGO.

Table 2.1: FIGO staging of cervical cancer

| Stage | Description                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | Five year survival with optimal treatment |
|-------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------|
| 0     | Carcinoma in situ, cervical intraepithelial neoplasia Grade III. This is not considered invasive cancer, since the lesion has not gone beyond the basement membrane.                                                                                                                                                                                                                                                                                                                                                          |                                           |
| I     | <p>Carcinoma confined to the cervix. Extension to the uterus is disregarded.</p> <ul style="list-style-type: none"> <li>• IA: Micro-invasive carcinoma strictly confined to the cervix. Can only be diagnosed by microscopy; it is not clinically visible.</li> <li>• IA1: Stromal invasion no greater than 3.0 mm but in depth and not more than 7.0 mm in horizontal spread.</li> <li>• IA2: Stromal invasion of more than 3.0 mm but not more than 5.0 mm in depth and with horizontal spread of 7.0 mm or less</li> </ul> | <p>98%</p> <p>95%</p>                     |

|     |                                                                                                                                                                                                                                                                                                                                                                                                    |                          |
|-----|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| II  | <p>Carcinoma confined to the cervix. Extension to the uterus is disregarded.</p> <ul style="list-style-type: none"> <li>IIA: Spread beyond the cervix, including upper two-thirds of the vagina, but not to tissue around the uterus (parametria)</li> <li>IIB: Spread beyond the cervix, with parametrial invasion, but not as far as the pelvic wall or the lower third of the vagina</li> </ul> | <p>75%</p> <p>65%</p>    |
| III | <p>Tumour extends to pelvic wall or involves lower third of the vagina, or causes hydronephrosis or non-functioning kidney.</p> <ul style="list-style-type: none"> <li>IIIA: Invasion of the lower third of the vagina, with no extension to the pelvic wall.</li> <li>IIIB: Extension to the pelvic wall, or hydronephrosis or non-functioning kidney.</li> </ul>                                 | <p>30%</p> <p>30%</p>    |
| IV  | <p>Tumour has spread</p> <ul style="list-style-type: none"> <li>IVA: Spread to involve the mucosa of the bladder or rectum.</li> <li>IVB: Spread to distant organs, such as extrapelvic lymph nodes, kidneys, bones, lungs, liver and brain.</li> </ul>                                                                                                                                            | <p>10%</p> <p>&lt;5%</p> |

Source: World Health Organization (2006)

## 2.4 TREATMENT OF CERVICAL CANCER

The International Atomic Energy Agency (2012) guides the treatment of cervical cancer in resource restricted settings and states the treatment of each woman should be carefully tailored to ensure the best possible outcome for her. However, the overall patient assessment, patient co-morbidities, social and educational factors and availability of quality treatment modalities such as surgery, radiotherapy and chemotherapy plays a vital role in the selection of the treatment.

The International Atomic Energy Agency (2012) divides the treatment of cervical cancer into two categories: curative and palliative. Women with Stage IVB cancer should receive palliative care,

which could include palliative radiotherapy to palliative specific symptoms, as cure is no longer possible. Women with early stage cervical cancer who are medically fit for surgery should have surgery, either a cone biopsy or hysterectomy according to the stage of disease, with or without radiotherapy, whilst patients unfit for surgery should receive radiotherapy. Patients with advanced cervical cancer (Stages IIB to IVA) are treated with external beam radiation and brachytherapy with or without concurrent chemotherapy. The effect of concurrent chemotherapy is however limited as it increases the five year survival rate with 6%. The total treatment, including the external beam radiation and brachytherapy should be completed in eight weeks and any delays or interruptions in treatment should be avoided. In addition, the overall treatment time should be as short as possible and there should be no interruption between the external beam and brachytherapy components of the treatment.

Radiotherapy over the pelvic area is strongly associated with certain chronic side effects which can have a negative influence on the quality of life of the women. These side-effects include vaginal dryness, chronic enteritis chronic cystitis, chronic proctitis, infertility, sexual dysfunction and pelvic fibrosis (Itano & Taoka, 2005; World Health Organization, 2006).

#### **2.4.1 External beam radiation**

External beam radiation is considered to be the standard treatment for late cervical cancer. External beam radiation, also referred to as teletherapy, refers to the delivery system for local treatment of cancer with the radiation machine, such as the cobalt 60 or the linear accelerator, generating ionising radiation by accelerating electrons along a tube. Individual patients undergo a thorough sophisticated treatment planning which determines the amount of radiation to be delivered thus minimising its effects to normal organs and tissues. The patient is then positioned on the treatment couch with the radiation beam directed at the tumour site. The required total dose of radiation is given once daily for five days per week until the overall total dose is reached (Itano & Taoka, 2005; Newton et al., 2009).

#### **2.4.2 Brachytherapy**

According to Newton et al. (2009), brachytherapy refers to a radioactive material placed into the tumour, or near the tumour site, which may be temporary or permanent. The placement of the source can either be intracavity, intraluminal or interstitial. Brachytherapy can be used alone or as adjuvant treatment in combination with external beam therapy to increase the total dose to a

specific target depending on the tumour volume, tumour extensions and risk of lymph node involvement.

There are different radiation dose rates by which intracavity brachytherapy is administered: low dose rate (LDR), pulsed dose rate (PDR), medium dose rate (MDR) or high dose rate (HDR).

The total dose to be used and the number of sessions the patients will have depend on the rate used as well as the time the patient is kept in isolation. The low dose rate (LDR) and the high dose rate (HDR) are the most commonly available brachytherapy devices used today with similar effectiveness, but are different in terms of time spent at the hospital and the number of insertions (International Atomic Energy Agency, 2012; World Health Organization, 2006).

Brachytherapy is mandatory for the curative treatment of all patients with invasive cervical cancer and is an intrusive procedure which involves placing uterine applicators containing a radiation source into the vaginal fornices and tissues surrounding the cervix under conscious sedation. The radiation source is directed to the cancer on the cervix, uterus and upper vagina and tissues surrounding the cervix taking care not to expose the bladder and the rectum.

Brachytherapy can be delivered in various ways, either as a single fraction of treatment for three to four days after completing external beam radiation therapy, or concurrent with the external beam radiation usually once weekly for four weeks (World Health Organization, 2006).

### **2.4.3 Chemotherapy**

Chemotherapy is a systemic treatment used to prevent cancer cells from multiplying, invading or metastasizing as cancer primarily spread by direct extension and through the lymph nodes or bloodstream. The goals of chemotherapy are aimed at cure, control and palliation. However, the achievement of these goals also depends on factors such as the stage of the disease at diagnosis, performance status of the patient and other socioeconomic influences (Newton et al., 2009). According to Newton et al. (2009), chemotherapy may be given as adjuvant, neoadjuvant, chemopreventive and myeloablative treatment. Unfortunately chemotherapy leads to common complications which include anorexia, mucositis, nausea and vomiting, electrolyte imbalance, fatigue and alopecia which can affect the quality of life of patients (Itano & Taoka, 2005).

## **2.5 SUMMARY**

In Chapter 2, the theoretical foundation for the study and cervical cancer as a serious health problem were described. In Chapter 3, the research methods will be discussed.

## **CHAPTER 3**

### **RESEARCH DESIGN AND METHODS**

#### **3.1 INTRODUCTION**

The focus of this chapter is to describe the research design and methods used in the study as well as the measures taken to ensure the trustworthiness of the findings. The ethical principles will also be described.

#### **3.2 RESEARCH METHODS**

##### **3.2.1 Research design**

According to Burns and Grove (2011), the research design of a study serves as the blueprint and exerts control over factors which could interfere with the validity of the study. A qualitative design and descriptive phenomenological approach (Begley, 2008) was selected for the study. Qualitative research is subjective and is used to describe and give meaning to life experiences. Qualitative research involves the investigation of phenomena, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using flexible research designs involving unstructured or semi-structured interviews and observation. Data analysis analyses words rather than numbers. A qualitative design was chosen as it allowed the researcher to gain insight into the phenomenon, brachytherapy, in its entirety rather than focusing on a specific concept (Polit & Beck, 2012).

The aim of phenomenological research is to understand the careful description of human behaviour from the perspective in which it takes place. Through in-depth conversations, researchers strive to gain entrance into the informants' world and have full access to their experiences as human behaviour cannot be separated from the context in which it is lived (Polit & Beck, 2012).

Descriptive phenomenology was first developed by Husserl, whose philosophy emphasised descriptions of human experience (Polit & Beck, 2012). According to Polit and Beck (2012), the descriptive phenomenologist insists on the careful description of ordinary conscious experiences of "things" as people experience them. These "things" include hearing, seeing, believing, feeling remembering deciding, evaluating and acting. The phenomenologist believes

lived experiences give meaning to each person's perception of a particular phenomenon. Using a descriptive phenomenological approach was appropriate for this study as the researcher wished to describe how women experience the brachytherapy they undergo for cervical cancer and what they understand of the procedure.

According to Lopez and Willis (2004), Husserlian phenomenology requires bracketing. Bracketing is a process in which the researcher holds in abeyance preconceived beliefs and opinions about the phenomenon under study. Bracketing is an interactive process which involves preparing, evaluating and providing systematic ongoing feedback about the effectiveness of the bracketing which can never be achieved totally. However, the researcher should strive to bracket out the world and any presumptions in an effort to confront the data in pure form noting interests which might be taken for granted, identify any feelings which may indicate lack of neutrality or being biased. Burns and Grove (2011) added that bracketing is the means by which the researcher denies herself or himself of any knowledge of the experience being studied.

The researcher used the guidelines of Ahern (1999) to bracket. As guided by these strategies, the researcher used reflexivity to put aside personal feelings and preconceptions about the experience of receiving brachytherapy. Specifically she clarified her personal value systems, acknowledged areas in which she could be subjective and became aware of feelings which might indicate a lack of neutrality. The researcher discussed the research process with her supervisor to prevent blocks during the research process.

### **3.3 STUDY SETTING**

The academic hospital selected for the study is in the Gauteng Province of South Africa, the smallest of the nine provinces comprising only 15% of the country's total 1 220 813 square kilometres. However, Gauteng hosts the largest population, consisting of 12.2 million people with 263 000 made up of cosmopolitan nationals (South Africa Population Census, 2011).

The hospital where the study was conducted is a specialist academic hospital with 1088 beds and more than 4000 professional and support staff members. The hospital offers specialist inpatient and outpatient services and serves as referral hospital for a number of regional hospitals. As this hospital is part of the public health care system, health care services are offered free of cost. Patients from all over South Africa and other African countries are treated at

this hospital, which also serves as a training institution for the University of the Witwatersrand (Wikipedia, 2014). The Department of Radiation Oncology, one of the specialised departments, was established in 2005, but the delivery of both external beam radiation and brachytherapy became fully operational in 2006. The department has five clinics serving patients with different types of cancer including head and neck, gastrointestinal and skin, breast and gynaecological cancers. According to the department's database, 3 699 patients with different cancers visited the clinics during the year 2011, of which one third of the patients suffered from gynaecological cancer and between 662 and 721 had cervical cancer.

Most patients referred to the department are treated on an outpatient basis; those who are too ill to come to the hospital on a daily basis are admitted to the ward. In addition, patients who live far from the hospital and are not able to afford transport costs to and from their homes are temporarily lodged at interim homes run by non-governmental organisations for a token fee for the maintenance of these facilities to allow their daily needs being catered for.

### **3.4 POPULATION AND SAMPLING**

According to Burns and Grove (2011), the population, also referred to as the target population, is the entire group of individuals or elements who meets the inclusion criteria of a study. The target population for the study comprised all patients undergoing brachytherapy for cervical cancer at the specific academic hospital in Gauteng. Purposive sampling was used to select the sample involving women 18 years and older, receiving brachytherapy for cervical cancer and able to speak Basic English. Purposive sampling is the conscious selection of specific information rich participants and particularly suitable for phenomenological work (McCance & Mcilfattrick, 2008). Women who received at least one brachytherapy treatment were considered to be information rich and were consciously selected for the study. Women who were waiting for treatment of chemo radiation as well as those waiting to be reviewed were also recruited for the study. The sample totalled 16 women and was determined by data saturation, which means no new information was obtained (Polit & Beck, 2012).

### **3.5 DATA GATHERING**

Twenty four unstructured individual interviews (Burns & Grove, 2011) were conducted after gathering general information (Addendum A) from the 16 participants. Unstructured interviews are interviews conducted without the researcher utilising any prior information, experience or opinions in a particular area. Unstructured interviews are used to determine individuals'

perception, opinions, facts and forecasts and their reactions to initial findings and potential solutions. This interview technique was applicable to the study because it is discursive and allowed the researcher and participant to explore a specific phenomenon. Unstructured interviews also help in understanding the experience of and the meaning participants make of their experience (Polit & Beck, 2012). One question was asked: *Please tell me what it is like for you to get brachytherapy?* The researcher used probes and prompting questions (Polit & Beck, 2012) to encourage participants to expand on their experiences. The question was pre-tested using the first interview thus allowing the researcher to gather data prior to the actual study to identify problems and the time required for each interview. (Burns & Grove, 2011; Polit & Beck, 2012). No problems were experienced during the pre-test as the participant was able to understand and answer the question posed to her. The data gathered by means of the pre-test was included in the study. The data were gathered during June and July 2014.

The interviews were recorded by audiotape and field notes, the major sources of data in a qualitative study, were made during and immediately after the interviews. The audio-recorded interviews were transcribed verbatim and the field notes, which are non-linguistic utterances such as a nod, smile and sigh (De Vos et al., 2012) which could not be recorded with the audiotape, were added to the transcriptions.

The planning for data gathering was as follows:

- Permission to conduct the study was obtained from the Human Ethics Committee of the University of the Witwatersrand and hospital management. In addition, the Head of the Department of Radiation Oncology and the Nursing Unit Manager supported the study.
- The researcher practiced as a registered nurse in the Department of Radiation Oncology and was familiar with the surroundings and known to the participants. The researcher purposively selected and recruited eligible women who were waiting for treatment to participate in the study. The study was explained to the selected women and upon accepting the invitation to participate, an information document (Addendum B) was given to them whereafter written informed consent was obtained (Addendum C). Participants signed a separate consent form for the audio-taping of the interview (Addendum D).
- The interviews were conducted during June and July, 2014 in a quiet and private room

with only the researcher and participant present. Sufficient time was devoted to every participant to allow for field notes to be written (De Vos et al., 2012). The first interview with each participant lasted approximately an hour and the follow up interviews, on average, 30 minutes.

- The researcher introduced herself to the participant and asked them to introduce themselves in return. The researcher reiterated participant's rights to withdraw from the study and how anonymity would be maintained.
- An arrangement was made with a registered oncology nurse, experienced in counselling patients with cervical cancer, to counsel those who became emotional. The researcher planned to re-schedule the interview whenever the need arose; no referral was required.

### **3.6 DATA ANALYSIS**

According to Polit and Beck (2012), data analysis is a process used to organise, provide structure and elicit meaning from data, as well as the process of bringing order, structure and meaning to the collected data. In addition, qualitative analysis attempts to capture the richness of themes emerging from participant's talks (De Vos et al., 2012). Giorgi's data analysis method (Polit & Beck, 2012) was used to analyse the data. The steps in the data analyses process were as follows:

Step 1: The transcribed interviews were read and re-read to get a sense of the whole experience. The idea was to obtain a description and not to explain or construct.

Step 2: The whole description was broken into several parts to determine the meaning of the experiences. The parts relevant to the phenomenon being studied were identified. This process of delineating parts is referred to as meaning units which express participants' own meaning of the experience.

Step 3: The meaning units identified by the researcher were transformed. The researcher looked for perceptions and emotions which were expressed by the participant's description in order to come up with findings. At this point the psychological intentions contained in the meaning of the description were developed.

Step 4: The psychological intentions were summarised according to the meanings in order to express the lived experiences of the participants.

### **3.7 TRUSTWORTHINESS**

Trustworthiness is defined as believing in something which is completely reliable.

Trustworthiness encompasses credibility, transferability, dependability and confirmability (Polit & Beck, 2012). Lincoln and Guba's guidelines, as explained by Shenton (2004), were used to enhance the trustworthiness of the study.

#### **3.7.1 Credibility**

Credibility involves two aspects: first, conducting the study in a way that enhances the believability of the findings and second, taking steps to demonstrate credibility in a research report (Polit & Beck, 2012). The following measures were applied to the study to enhance the credibility:

- Adoption of a well-established research method: The researcher selected a well-known research method.
- Early familiarisation with the participating organisation: The researcher had familiarised herself with the culture of the Department of Radiation Oncology, as she practiced as a registered nurse in the department prior to the gathering of the data.
- Peer scrutiny of the research project: The research proposal was evaluated by members of the Department of Nursing Education and the Postgraduate Committee of the School of Therapeutic Sciences.
- Frequent debriefing sessions: The researcher and supervisor held frequent debriefing sessions during all phases of the study.
- The authority of the researcher: This was established as the researcher had practiced in an oncology care setting for eight years prior to the study.

- Member checks: The researcher verified the accuracy of the data on the spot by rephrasing the question and summarising the interview at the end.
- Tactics to enhance the honesty of the participants: Participation was voluntary and participants were given the opportunity to refuse participation. This allowed only those who were willing to participate and offer information freely and honestly to take part in the study.
- Iterative questioning: Probes were used during the interviews to illicit a detailed description. Questions were rephrased to ensure that what was recorded was exactly what the participants said.

### **3.7.2 Transferability**

Transferability refers to the extent to which findings of descriptive data are applicable to another context. The researcher must demonstrate that the results of the work at hand can be applied to other situations and a wider population (Shenton, 2004). The following measures were applied to the study to enhance the transferability:

- Sampling: All patients undergoing brachytherapy for cervical cancer at the specific academic hospital in Gauteng where eligible and a purposive sampling method was employed.
- Saturation of data: Data were gathered until saturated.
- Dense description: In this chapter of the study, thorough descriptions of the context, participants, methodology, analysis and interpretation were given.

### **3.7.3 Dependability**

Dependability refers to the stability (reliability) of data over time (Polit & Beck, 2012; Shenton, 2004). The researcher gave a detailed account of the phenomenon so that replication of the work in the same context using the same methods and same participants will result in similar conclusions being obtained. Dependability was enhanced by the following measures:

- The research design and its implementation: In-depth voice recorded interviews were transcribed. Participants were given pseudonyms and the analysis was done according to these pseudonyms.
- The operational detail of data gathering: Interviews were transcribed before allocation of themes.
- Reflective appraisal of the project: Provision of a dense description of the research methodology and research process in this chapter.

### **3.7.4 Confirmability**

This criterion is concerned with establishing that the work's findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher. In other words, data is not invented by the researcher. Confirmability allows any observer to trace the course of the research step-by-step via the decisions made and procedures described thus avoiding the emergence of partiality about the accuracy, relevance or meaning of the data (Polit & Beck, 2012: 585; Shenton, 2004). Confirmability was enhanced by:

- Confirmability audit: The findings of the research are based on data gathered from the audiotape recorder interviews and not based on the researcher's opinions; nor do the findings reflect the biases, motivations, or perspectives of the researcher.
- Reflective commentary: The researcher rephrased questions by means of probing to ensure transcription of data expressed the lived experience of participants

## **3.8 ETHICAL CONSIDERATIONS**

In accordance with the Belmont report (Polit& Beck 2012), ethical conduct in nursing research is intended to safeguard the integrity of participants and the research process. The following measures were applied to ensure the study was conducted in an ethical manner:

- Permission to conduct the research: The research proposal was presented and assessed by the peer review process of the Department of Nursing Education to ascertain its

feasibility. The research proposal was refined and submitted to the Postgraduate Committee of the School of Therapeutic Sciences for further assessment and approval, whereafter it was submitted to the Human Research Ethics Committee. Ethical clearance was obtained (**Clearance certificate number: M140462**)(Addendum E). Permission to conduct the study was obtained from the Gauteng Department of Health and the Chief Executive Officer of the hospital and approval obtained. In addition, the Head of the Department of Radiation Oncology and the Nursing Unit Manager supported the study.

- Informed consent: An information document was first given to the participants (Addendum B) and then informed consent, in writing, was obtained (Addendum C) for both participation and audiotaping (Addendum D). Interviews were conducted in a quiet and private place at the department with only the researcher and participant present. The participants were allowed to withdraw from the study at any time.
- Anonymity of participants: Anonymity simply means protecting confidentiality and this occurs when there is no direct link between the data and the participants (Polit & Beck, 2012: 162). This was ensured by not using the participants' actual names during the gathering of the data.
- Confidentiality: Confidentiality is the promise of not divulging the information obtained but only using it for the intended purpose (Polit & Beck, 2012: 162). The following measures were adopted to enhance confidentiality:
  - Pseudonyms were used instead of actual names.
  - The transcribed interviews were transferred to a flash drive and deleted from the researcher's computer.
  - All data sheets and flash drives were sealed in an envelope and placed in a safe in the Department of Nursing and will be destroyed three years after publishing the report.

- The transcribed data were saved with a password known only to the researcher and supervisor.

### **3.9 SUMMARY**

In Chapter 3, the research methods were described in detail. Methods used to ensure trustworthiness and ethical considerations of the study were explained. The results of this study will be presented in Chapter 4.

## **CHAPTER 4**

### **FINDINGS AND DISCUSSION**

#### **4.1 INTRODUCTION**

In Chapter 3, the research design and methods were provided. In this chapter the demographic information of the participants will be presented followed by a short history of each participant and the major themes that emerged from the data. The findings will also be discussed.

#### **4.2 THE PARTICIPANTS**

Sixteen women participated in the study. The average age of the participants was 42 years and ranged from 30 to 59 years. The majority of the participants were single parents between the ages 40 and 49 years, had more than two children, lived in urban communities and had never had Pap smear screening. The participants came from seven different cultural groups and the group with the highest representation was Zulu (5 of 16). The demographic information of the participants is presented in Table 4.1.

**Table 4.1 Demographic information of the participants**

| <b>Characteristics</b>           | <b>n</b> |
|----------------------------------|----------|
| <b>Age group</b>                 |          |
| 30-39                            | 5        |
| 40-49                            | 9        |
| 50-59                            | 2        |
| <b>Marital status</b>            |          |
| Single                           | 9        |
| Married                          | 3        |
| Divorce                          | 1        |
| Widow                            | 3        |
| <b>Residing place</b>            |          |
| Urban                            | 15       |
| Rural                            | 1        |
| <b>Number of children</b>        |          |
| Two children                     | 5        |
| More than two children           | 11       |
| <b>Culture group</b>             |          |
| Zulu                             | 5        |
| Coloured                         | 4        |
| Sotho                            | 1        |
| Xhosa                            | 3        |
| Pedi                             | 1        |
| Tsonga                           | 1        |
| Afrikaans                        | 1        |
| <b>Cervical cancer screening</b> |          |
| Yes                              | 4        |
| No                               | 12       |

#### 4.2.1 History of the participants

A brief history of each participant is provided. The names used are not the real names but pseudonyms.

- *Nancy*. Nancy was a 43 year old Tsonga, a single mother who lived in a two bedroom apartment with her three children and had never had a Pap smear. She initially noticed a creamy vaginal discharge but did not bother to seek a solution until she suddenly realised that this discharge had become offensive. She then decided to go to the hospital to obtain health care.
- *Ivy*. Ivy was a 32 year old Zulu woman, a single mother of two, living in a bachelor's apartment and unemployed. She confirmed she never had a Pap smear despite being informed of this procedure by a friend. She started experiencing spotting, vaginal bleeding and lower abdominal pain but ascribed it to the contraceptive injection she had started having. After a period of two months, she decided to go to the hospital and was subsequently diagnosed with cervical cancer.
- *Linda*. Linda was an Afrikaans speaking woman. She was a 45 year old divorcee with five children, who were living with her in a three bedroom house. She had an abnormal yellowish vagina discharge with heavy bleeding for more than three months before deciding to go to the hospital. She was diagnosed with cervical cancer following a series of investigations. According to her she had never had a Pap smear done.
- *Lois*. Lois was a 56 year old post-menopausal Zulu woman who was "happily married." She had four children and lived with her husband and one child, as the older children had left home. She had had one normal Pap smear but the second one was abnormal. Her husband encouraged her to seek health care leading to her diagnosis of cervical cancer.
- *Peggy*. Peggy was a 34 year old Pedi woman, a single mother of two and lived with her children in her mother's house. She had a bloody, offensive vaginal discharge and lower abdominal pain. She also experienced dyspareunia, which she discussed with a friend who advised her to seek health care. She confirmed she had never had a Pap smear done.

- *Debbie*. Debbie was a 40 year old Xhosa speaking woman and a single mother of three children. She noticed an offensive vaginal discharge associated with post-coital bleeding. She also experienced severe abdominal pain which forced her to seek health care. She was later diagnosed with cervical cancer after a series of investigations were conducted. She had never had Pap smear.
- *Irene*. Irene was a 47 year old Sotho woman, married with two children. After having had a normal Pap smear she felt there was no need for a second test. She developed an abnormal vaginal bleeding resulting in her constantly having to wear a sanitary towel even when she was not menstruating. This became too much of a bother so she decided to seek health care and was later diagnosed with cervical cancer.
- *Pious*. Pious was a coloured women married with two children. She was 46 years old and had never had a Pap smear. She normally menstruated for three days but this increased to five days, which alarmed her as she was expecting a decrease in the number of days as she was of the opinion she was approaching menopause. She had a Pap smear done and was shocked with the diagnosis of cervical cancer.
- *Claudia*. Claudia was a 38 year old Zulu speaking widow, living in a two bedroom house with her three children. She experienced an offensive bloody vaginal discharge but did not pay attention to it. The lower abdominal pain she developed forced her to seek health care. She had never had a Pap smear done.
- *Sandra*. Sandra was a 54 year old post-menopausal Zulu widow with two adult daughters. She lived alone as both her children were married and living with their husbands. She experienced post-menopausal bleeding four years after her last menstruation. The unexpected bleeding irritated her so much that she told a friend who advised her to seek health care. Sandra had one normal Pap smear before her diagnosis.
- *Monique*. Monique was a 39 year old coloured single parent with three children who all lived together in a two bedroom house. She started experiencing lower back and abdominal pain and yellowish vaginal discharge which she described as foul smelling

and irritating. She had never had a Pap smear. She went to the hospital where she was diagnosed with cervical cancer.

- *Rachel*. Rachel was a 40 year old Zulu speaking widow with three children living in a two bedroom house. She had had Pap smear done, the results of which were positive and was referred to the hospital, but she never went to consult and forgot about the Pap smear. She developed a bloody, offensive vaginal discharge which reminded her of the Pap smear results and was a great concern to her. She showed the results of her Pap smear to a friend who is a health worker and subsequently encouraged her to immediately seek health care. She blamed herself for her diagnosis because she said if she had gone to the hospital when she was referred, she might not have had this cancer.
- *Imelda*. Imelda was a 43 year old coloured single mother of four. She lived with three of her children as the elder one lived elsewhere with her partner. She had never had a Pap smear done. She started bleeding vaginally and this was accompanied with blood clots and lower abdominal pain. She self-medicated for a period of four weeks and when all proved futile, she finally went to the hospital where she was told she has cervical cancer.
- *Jocelyn*. Jocelyn was a 36 year old coloured single mother of four. She was unemployed and lived with her children. She lamented about not immediately seeking health care when she began experiencing severe abdominal pain and a creamy vaginal discharge. She confessed that although the discharge was severe she was not worried until the discharge became very offensive and confided in her friend who motivated her to go to the hospital. According to her she wept bitterly when she was diagnosed of cervical cancer.
- *Kiki*. Kiki was a 40 year old Zulu speaking woman, a single parent with three children living in her mother's house because she was unemployed. She never had a Pap smear done. She experienced a severe creamy vaginal discharge which resolved spontaneously without any medication. She later noticed spotting in between menstruation and experienced severe abdominal pain. She sought health care once she started bleeding vaginally.

- *Lily*. Lily was a 42 year old Zulu speaking woman who had four children. She was a single mother and had never had Pap smear done. She experienced lower abdominal pain and a bloody vagina discharge coupled with heavy menstruation for about three months before seeking health care. She went to the hospital where she was told she had cervical cancer which was of great concern to her.

#### 4.3 THEMES ARISING FROM THE DATA

Two themes arose from the data: the treatment experience and experiencing emotional distress.

##### **Theme 1: “*Your womb is being ripped out.*” The treatment experience**

The participants agreed that brachytherapy was a negative experience. Participants’ described it in terms of “don’t like it”, “terrible”, “horrible”, “bad” and the “worst experience ever.” Pain was major issue and some were overwhelmed by the “hell” they experienced during the procedure, especially when the applicators were inserted. Some even preferred to die than to undergo another treatment, whilst others were of the opinion that the procedure was quite bearable.

Rachel explained: “...*the insertion is the worst and very painful...*”

Nancy added:

*“When applying their thing, it’s like somebody who is cutting your nails...each treatment through the vagina feels like it’s been through a meat grinder”.*

Lois said:

*“...they were shoving stuff in your vagina...painful, painful stuff... I’d rather die of cervical cancer than going through the procedure...like something cutting through the soft skin in your vagina...a sharp knife...”*

Linda added:

*“It’s hard...it was painful...like they are putting something in your womb”*

For Peggy, the procedure was not as painful as described by some of the other participants.

She said: “...*painful...not too much, for the first time it was painful but the second and third time it was not painful...*”

Irene agreed: *“...they put something through my womb...yea, it was a little bit sore...”*

Participants reacted differently when they experienced severe pain; some called out whilst others wept or kept quiet. Lilly explained: *“...ah! I screamed, I screamed, I could not take the pain...for me it was like I could rip the thing out...it was so horrible...”*

Emelda said: *“...I really screamed...I couldn't hold the screaming...I even cried because the whole procedure was so painful...”*

Kiki explained: *“...I was feeling sore, it was very sore...it was very, very sore but I didn't cry...I can't scream because it's my culture...”*

Some participants found the removal of the applicators also painful. Lois explained: *“...pain...worse when they are taking it out...just when you think it is over, they tell you it's over, and they are still going to take out and the pain gets just even worse...”*

Linda agreed and said: *“...they come and take it out, it is painful...whenever they take it out it is painful...”*

Many participants compared the pain with childbirth, a process they preferred to brachytherapy. Some were of the opinion that childbirth only lasts for one day compared to the various brachytherapy treatments scheduled for them. Lois said: *“...you feel the pain worse, worse, worse than child birth...in short I'd rather have 20 more kids than have one brachytherapy.”*

Sandra said:

*“...it's painful...even having a baby is much better really because... these things, they are metals...that they put it in you...”*

Imelda added:

*“...you see I feel like I was in labour but not that yah, it was very bad, even the labour pains are much better because they will pass but this pain was worse hmm even labour pains are painful but normal...”*

Kiki responded:

*"...actually when the baby comes out is better than brachytherapy, when the baby come you finished, you can't hear the pain but that one..."*

The participants agreed the pain they experienced during the treatment was caused by the fact that the analgesia they received prior to the brachytherapy did not work well and was not "strong" enough. Imelda said: *"...the injection and the tablet were not strong enough to hold the pain that I was feeling with that instrument yea!"*

Rachel described her pain experience: *"The injection that they give us for pain...I don't know but I cannot see that it really works... it doesn't really help..."*

Jocelyn said:

*"...they told me that this tablet and this injection will keep you not feeling the pain but it didn't work that way... I felt exactly everything like you tying a knot inside of me... it was so very sore"*

Claudia concluded:

*"Eish! I feel so very painful because that pill and injection didn't drug me..."*

Some participants were of the opinion that if they could be put asleep during the procedure they would not feel the pain. Ivy said: *"... I was given injection it made me weak but it didn't work...I didn't fall asleep I was awake all the time when they were working on me... I was feeling every minute in which they are working... if they can give me a stronger injection for me to sleep and not to feel the pain..."*

Participants did not only experience pain during the treatment but also complained about unrelieved pain lasting for hours and even days after the procedure. Kiki said: *"... when you sit down, when you walk its sore after that yoh! ... for me, it take me three days for the sore even to go ..."*

Peggy added: *"... the vagina is still hot, yes still hot and painful ... two days, three days then afterwards you get normal again."*

Participants experienced dysuria after the procedure. Most described their urine as “hot.” Imelda described her experience as follows: *“...the whole day and the following day...I feel the pain when am urinating...I feel like I can hold the urine because when it comes it’s hot and still burning...I have to force myself and pee and that was very painful when you go to the toilet...”*

Debbie said:

*“...eish even... if I pee is like I pour spirit(s) on the wound... I feel like screaming or jump but I couldn’t do that and if you are in the toilet alone you can make some noise...burning urine, burning...you know”*

Lily responded:

*“After that I went home, when I went to toilet to urinate, it was burning...it was severely, severely painful, I was like crying...yoo! It was painful...and the urine is trickling hot”*

Monique said:

*“...yoo! It’s too painful when you go to the toilet if you finish doing the brachytherapy for the first time when you go to the toilet it’s too painful...like the hot water, you see the fire when you burn...I was screaming and crying”.*

Brachytherapy was a negative experience, characterised by pain which was so severe for some that they could not help but cry out. Participants compared brachytherapy to childbirth – a process they preferred as the agony was less. The analgesia they received prior to the procedure, did not prevent them from experiencing pain. It was primarily the insertion of the applicators into the uterus that was responsible for the severe pain but some also experienced the removal of the applicators painful. The brachytherapy resulted in dysuria which was experienced as having a hot vagina and urine and added to the participants suffering.

## **Theme 2. Experiencing emotional distress: “I was scared and shocked”**

Participants experienced emotional distress before, during and after having brachytherapy. They feared the procedure even before having it and the rest of the treatment after having had the first. Linda said: *“...I was scaring before I go...”*

Imelda added: *“... I think the whole day...”*

Debbie concluded: *"...I couldn't sleep ...I'm thinking of the agony I'm gonna go through"*.

For Claudia, she was terrified during the procedure. She said: *"... it makes me scare...to see the doctors get something inside of you...this doctors is going to kill me or... you know...I can't explain"*.

Participants feared the next treatment. Peggy said: *"... I was scared and shocked...you keep thinking...like every time when I manage to go to HDR, I am never happy"*

Lois responded:

*"...even for your next appointment you remember precisely ...like I am right now, so scared I have been since yesterday...I keep thinking... I can do nothing but thinking..."*

The "opening" and "hanging" of their legs demeaned participants and added to the emotional distress they experienced. Imelda explained: *"...they put my legs up...hmm, it was a shame for me to hang my legs and opening for somebody else's like I was exposing myself..."*

Jocelyn said:

*"...look, my legs were tied up, am on my back yea...humiliating... the less I talk about it the better because if I talk about it, it hurts me because it brings back..."*

Kiki added:

*"They make me to open my legs...it was not comfortable but...I opened it because I want my life..."*

Debbie explained:

*"...you open your legs wide...the way you lie down...they see through you ...you don't feel good...my daughter is nineteen now, if I can just ask her to expose herself to me I don't think she can feel comfortable..."*

Not having the same doctor and having nurses and other observers present added to the humiliation participants experienced. Imelda said: *"I was surrounded by other nurses and doctor... yah there was four of them and a doctor and they were all standing next to me and*

*watching hmm...yah I felt like everybody watching me and... I felt helpless because I didn't know what to do..."*

Lily added:

*"...they taking your legs apart... like fastening your legs and everybody can see you know, all my genital parts is like open... yea, it was... humiliating for my legs to be set apart like this...I felt embarrassing because... everything is like wide open"*

Rachel said:

*"...every time it's somebody else, maybe still be a woman you know, you feel that shyness err... always other faces of the students coming in and out so for me it's a bit of humiliating...I ...I think it's more humiliating for the patient as you might think like I think...that also makes it bad for us because emotionally you know you are so worried and you are so depressed..."*

Most participants did not feel prepared for the treatment and that nothing was explained to them during the procedure. In addition, some were of the opinion that the health care professionals did not display a caring attitude towards them; a situation that added to their suffering. Pious said: *"...at least somebody talk for (to) the doctor for am here at the hospital because am sick you know, yea...he is not (to) treat me like the dog or like...I don't feel ok .... because eish...the doctor is being serious, rush you know...and not smiling...I want the doctor to treat me like ...yea like human..."*

Lois said:

*"...nobody tells you what's happening... no communications with patients, I suppose may be we might be too illiterate..."*

Imelda added:

*"...doctor must try to...explain to you and tell you this side you are going to do this and this...I was expecting them to tell me what they are going to do to me this side...I felt so sad, so bad even if someone told me before what is going to happen there, maybe I will have prepared myself..."*

Rachel concluded:

*"...I am not certain that they know exactly what they are putting these ladies through... nobody, none of the medical staff ever said listen, this is what we gonna do err nobody, up until now...at least there should be more education and then we will be emotionally, psychologically, everything, we will be more prepared for what is coming...I wasn't prepared completely of what gonna happened because I find that they do not tell us exactly how the procedure is, what they gonna do you know..."*

Despite the fact that some participants were not prepared for the procedure, others found the health care professionals supportive and caring. Monique described her experience: *"...I find the doctor and introduce herself...I felt comfortable...they say you must relax you will be ok"*

Sandra said:

*"...the nurses they make you comfortable, relax...they help you to go and lie down in the bed...they were friendly, loving, helping even the doctors everybody..."*

Religion also served as a source of comfort and hope and they trusted in God to heal them and help them get through the procedure. Lily explained: *"...trust in God, He is the only person that will walk with you that long route and at the end of the tunnel there is the light and are healed..."*

Irene added:

*"I keep on praying...after that I experienced that there is a change in my body..."*

Jocelyn said:

*"...oh God...I went through it and then it was finished and I said thank you God that it was finished..."*

Rachel said:

*"...hope and pray in faith because...I am eating faith and it was alright, so yah I know its only faith that gets us through this"*

Nancy said:

*"So many things were going through my mind so I was just praying that I will be well"*

Brachytherapy was a humiliating experience - a procedure some participants did not feel prepared for. In addition, participants feared the first treatment and even the follow up treatment. They found it hard to be in the lithotomy position and the mere fact they had to open their legs was experienced as demeaning. Not having the same doctor inserting the applicators and observers present added to their emotional distress. Having faith in God assisted them to tolerate the procedure and provided hope to be cured and healed whilst caring staff promoted comfort.

#### **4.5 DISCUSSION**

Receiving brachytherapy was not easy. As evident by expressions such as *“terrible, bad, worst ever”*, brachytherapy was a negative experience. Participants felt unprepared for the procedure due to unmet informational needs and some experienced the health professionals as rude and uncaring. In addition, having more than the essential staff present when they were at their most vulnerable, with their legs *“wide open”* for staff to *“see through you”*, added to their emotional distress. Velji and Fitch (2001), in a study reporting the experiences of Canadian women who received brachytherapy, found the information that women received prior to the treatment and the care they received from nurses during the procedure shaped their experience positively or negatively. In addition, Brandt (1991) found a significant relationship between the fear and anxiety women experience before brachytherapy and unmet information needs. Considering these factors it is not surprising that women in the current study feared brachytherapy and considered it to be a negative experience. However, to conclude that the negative experiences of participants in the current study were caused by their unmet information needs and the lack of care they expected would be over simplifying a complex issue. The nature of the procedure expressed as *“shoving stuff in your vagina”* played a major role in how participants experienced brachytherapy. This finding is in contrast with the findings of Velji and Fitch (2001), who found that the treatment modality itself did not play an important role in how women experienced brachytherapy.

The participants experienced both physical and emotional pain. As evident by *“I was scaring before I go”*, participants feared the procedure before they had been treated and even the follow up treatments expressed as *“so scared I have been since yesterday”*. Andersen et al. (1984), in a study exploring survivorship issues in women diagnosed with gynaecological cancer, found that levels of anxiety and distress in women remained high before, during and after brachytherapy. Kwekkeboom et al. (2009) found that pre-treatment distress is significantly

higher than the distress women experience before the second brachytherapy. It is not clear whether the distress level of women in the current study decreased after the first treatment as distress levels were not measured. However, distress after the first treatment was still a reality for some of the women in the current study.

The severe pain participants experienced was described as *“something cutting through the soft skin in your vagina”* and *“the pain that you feel is like it’s all over you... like a sharp knife in your heart”* added to their suffering. As evident from *“I screamed, I could not take the pain”* the pain was so severe that some participants could not help but cry out. According to Arnold et al. (2007) and Chapman (2012), pain is a common symptom amongst persons receiving any form of cancer treatment and is a reality for about 50 to 53% of patients at all disease stages and about 62 to 88% of patients with advanced disease. Nail (1993), in a study exploring how women diagnosed with gynaecological cancer cope with intra-cavity brachytherapy, found most women experience varying degrees of pain during the procedure. Kwekkeboom et al. (2009) found that the majority of women in their study experienced mild to moderate pain during the brachytherapy procedure, whilst Rollison and Strang (1995) found more than half (13 of 20) of the patients in their study experienced moderate to severe pain during these procedures. Although the current study did not assess the levels of pain it provides evidence of the experience of severe pain during brachytherapy procedures. In addition, as evident by *“they told me that this tablet and this injection will keep you not feeling the pain but it didn’t work that way”* and *“I was given injection it made me weak but it didn’t work”* the conscious sedation participants received did not prevent them from experiencing pain. According to Gordon et al., 2005 and Puntillo et al., 2002, unlike other forms of cancer pain, procedural pain can be anticipated and prevented.

As described by *“...I couldn’t sleep...I’m thinking of the agony I’m gonna go through and “I think the whole day”* women experienced high levels of anxiety. Warnock (2004), in a study investigating experiences of gynaecological cancer patients treated with brachytherapy, found a relationship between pain and anxiety and difficulty coping during the procedure. It was not clear whether the pain was raised by the anxiety or the anxiety which resulted in pain.

As evident by *“...my legs were tied up, am on my back yea...humiliating... the less I talk about it the better because if I talk about it, it hurts me...”* and *“they make me to open my legs”* having to lie in the lithotomy position was experienced as humiliating and caused emotional pain.

Literature describing how women experience lying in this position seems unavailable and therefore it is not possible to support or contradict the participants' experience. In addition, the women preferred childbirth, which is described by Simkin (1996) to be the ultimate painful, emotional distressing, vulnerable and exhausting event in a women's life, to having to undergo brachytherapy supporting the statements of Velji and Fitch (2001) and Kwekkeboom et al. (2009) that intracavity brachytherapy is a very unpleasant and uncomfortable procedure.

Participants' belief in God brought comfort and hope, as supported by *"I hope and pray in faith, it's only faith that gets us through this"* and *"He is the only person that will walk you that long route and are healed."* Participants trusted God to provide them with strength to tolerate the treatment and heal them. According to Wachholtz and Pearce (2007), people rely on their religious faith in order to cope with any kind of life challenges. Furthermore, spirituality and religion have the ability to reduce stress whilst prayer has the ability to distract from pain. It was positive to find that nurses and doctors supported participants. As illustrated by *"they make you comfortable, relax...they help you to go and lie down in the bed...they were friendly, loving, helping, even the doctors, everybody"* some participants experienced the staff as caring and comforting. Attree (2001) found that patients considered good quality care as patient-focused, individualised care based on their needs, provided in a humane manner by means of a caring relationship. As illustrated in the current study, being with the participants was also experienced as good care. Providing good quality of care gives patients the feeling of being the focus and being genuinely cared for which enables the development of trust and confidence – something needed when being treated with brachytherapy.

When applying the Roy Adaptation Model of Nursing (Roy 1970) to the findings, it is evident that cervical cancer changed the health status thus their bio-psycho-social being. In addition to having to adapt to a having cancer, the participants had to adapt to a threatening environment consisting of painful, humiliating treatment and uncaring staff which influenced their unique wholeness. Nursing restored their dignity by providing loving care and support.

#### **4.6 SUMMARY**

This chapter presented and discussed the findings of the study. In Chapter 5 the study will be justified and concluded. The limitations and the researcher's reflection will also be presented.

## **CHAPTER 5**

### **JUSTIFICATION, LIMITATIONS, RECOMMENDATIONS AND REFLECTION**

#### **5.1 INTRODUCTION**

The focus of this chapter is to justify the study in terms of the research purpose and appraisal of the limitations of the study. Finally, recommendations as well as the final conclusion of the study are presented.

#### **5.2 JUSTIFICATION**

The purpose of the study was to describe the lived experiences of cervical cancer patients undergoing brachytherapy in an academic hospital in Gauteng. In Chapter 3, the research design and methods were described in detail, whilst Chapter 4 presented the findings and discussed using Giorgi's analysis approach. The lived experience of women undergoing brachytherapy in an academic hospital was identified and the characteristics of the experiences presented. It can therefore be stated that this study is justified in that the purpose has been achieved.

#### **5.3 LIMITATIONS**

Only women treated at the one academic hospital were included therefore the findings cannot be generalised to women receiving brachytherapy in other private and public hospitals. Women had to be able to speak and understand basic English to be included in the study, therefore the findings cannot be generalised to women who can only speak an indigenous language. In addition, participants did not represent all the cultural groups in South Africa, therefore the findings might not be applicable to women of other cultural groups. The researcher did not take the number of brachytherapy session the participants had into consideration which could have influenced the findings as the longer the brachytherapy sessions, the deeper the experiences would be.

This was a qualitative study and no such study reflects the only true meaning as there could be more than one interpretation of the narratives. Lastly, literature investigating experiences of brachytherapy focuses primarily on women who received low dose rate treatment, complicating comparisons. However, the author believes the themes which emerged from the data were

authentic and could be applicable to other women receiving brachytherapy as there are overlapping issues which might apply to all these women.

#### **5.4 RECOMMENDATIONS**

The findings of the study provide several answers regarding the lived experiences of women undergoing brachytherapy and also uncovered various areas for further research.

- Nurses should assess the information needs of women scheduled for brachytherapy and ensure these needs are met to reduce the anxiety the women experience.
- Nurses should assess the pain of patients undergoing brachytherapy. This assessment could also be done as a research project to have scientific evidence of the pain levels of women during the various phases of the treatment.
- Nurses should advocate for the revision of the conscious sedation protocol in an attempt to prevent the pain women experience during the procedure. The outcomes of the pain assessment recommended in the previous bullet can serve as motivation for such revision.
- Nursing education regarding cancer care should also be geared towards pain preventions and its effective management and could be included in the syllabus of oncology nurses.
- A multi professional approach could be of great benefit if in-service workshops for nurses and patients on what to expect whilst receiving brachytherapy treatment is organised regularly.
- Lastly the use of complementary therapies in conjunction with pain-relieving medicines could be explored.

#### **5.5 RESEARCHER'S REFLECTION ON HER EXPERIENCE**

Reflections are part of every human endeavour and are a process whereby human beings examine their personal thoughts and actions. The researcher would like to use this opportunity to share her experiences with the reader.

Although the researcher was familiar with brachytherapy as a very unpleasant and uncomfortable procedure associated with pain, she was not aware of the level of pain women experienced. The researcher felt deeply sad to hear that women feel so humiliated and traumatised when they had to open their legs and when their legs were hung. She was sad that the woman had to endure the eyes of observers, which are unfortunately a reality in an academic hospital. Listening to the agony and suffering participants shared and becoming aware of how participants endured the procedure were very moving, but also a wake-up call to be grateful for her own good health.

The researcher established a trusting relationship with all 16 participants who felt comfortable sharing their experiences with her. In addition, about 10 participants kept in contact with her and called from time to time to clarify issues with regard to their follow-up, medication and other social related issues such as one asking to be informed about any job vacancy.

## **5.6 CONCLUSION**

The study demonstrated that being treated with brachytherapy was a negative experience for the participants. They feared the procedure, before receiving the first one and even after having had one and felt unprepared due to unmet informational needs and some experienced the staff as uncaring. In addition, having more than the essential staff members present when they were at their most vulnerable – lying on their backs with their legs wide open was a humiliating experience. The pain participants experienced was so severe some could not help but cry out as the conscious sedation they received did not prevent them from experiencing pain. The dysuria they experienced after the treatment added to their suffering. However their belief in God comforted them and gave them hope to be healed and cured, whilst caring staff comforted and supported them.

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**DATA COLLECTION SHEET FOR GENERAL INFORMATION**

- 1. Age-**
- 2. Marital Status-**
  - a. Single ☐
  - b. Married ☐
  - c. Divorce ☐
  - d. Widow ☐
- 3. Cultural group-**
- 4. Where live –**
  - a. rural
  - b. urban
- 5. How many children do you have**
  - a. None
  - b. 1
  - c. 2
  - d. More than 2
- 6. Have had any cervical cancer screening**
  - a. Yes
  - b. No

## ADDENDUM B

### INFORMATION DOCUMENT

#### **Study title: WOMEN'S LIVED EXPERIENCES OF BRACHYTHERAPY FOR CERVICAL CANCER**

Good day Madam,

My name is Alberta Delali Dzaka. I am currently registered as a student in the Department of Nursing Education at the University of the Witwatersrand and would like to conduct a study entitled **“Women’s lived experiences of brachytherapy for cervical cancer”**.

I would like to invite you to consider participating in this research study where I would use the words that people tell me. If you should you agree to take part in the study, I will interview you for about an hour. I will ask you to tell me about your experiences during the brachytherapy treatment. With your permission I will make a tape recording of our discussion. You will however have to give me permission to do this by signing the consent form. Only a few women (about 20) will take part in the study and the interviews will take place in the Radiation Oncology Department in a quiet and private place.

There are no direct benefits to you as the participant. However, the findings will assist nurses to identify and manage patient problems based on their needs. Should you decide not to participate in the study, you will not lose any benefit to which you are entitled. Even if you decide to take part in the study, you may at any time during and immediately after the interview say if you do not want to take part in the study any more, and you will still not lose any benefits to which you are entitled. However, once the interview has been typed, I will not be able to identify your interview any more as all names will be removed. This means you would not be able to withdraw from the study any more. Also, please note that you will not receive any money or goods should you choose to take part in the study.

I will keep information confidential. Personal information may be made known if the law says so, research records may be inspected to look at the quality and the Research Ethics Committee can inspect how I analyzed what you told me. After analyzing the information, all data sheets and flash disk will be sealed in an envelope and placed in a safe in the Department of Nursing Education for a period of three years after the report has been published where after it will be destroyed. When I write a report on what all the women told me, you might identify your words. People who will read the report would however not know that this is what you said. If you have any question, or further information about the study, do not hesitate to contact me, my cell phone number is 0837499270. Should you have any question about your rights as a study participant, or questions concerns about any aspect of this study, please call the Ethics Department of the University of the Witwatersrand on +27 11 717 1234 or my Head of Department, Prof J E Maree at 011 488 4272.

Thank you for your consideration.

.....

Alberta Delali Dzaka.

## ADDENDUM C

### CONSENT FORM

I have been given the information sheet on the research Title: **“Women lived experiences of brachytherapy for cervical cancer”**. I have read and understood the information sheet. If I agree to participate in the study, I will be interviewed for approximately one (1) hour about my experiences during the cervical cancer treatment and the disease.

I understand that it is up to me whether or not to participate in the interview and that there will be no penalty or loss of benefits am entitled if I decide not to participate. I also understand that I may discontinue participation at any time the interview has been typed without any penalty or loss of benefits to which am otherwise entitled.

I understand that the researcher involved in this study will make every effort to ensure confidentiality and my name will not be used in the study reports. No identifying information will be included when the interview is transcribed. I have been given the contact details that I may call if I have any questions or concerns about the research.

This study has been explained to me. I have read and understand this consent form, I agree voluntarily to participate in the interview for this study.

.....  
Signature of participant

.....  
Date

.....  
Witness

.....  
Date

ADDENDUM D

CONSENT FOR AUDIO-TAPING OF THE INTERVIEW

I, .....have consented to be a participant in the study being conducted by Miss Alberta Delali Dzaka. I have been given the information document on the research Title: **“Women’s lived experiences of brachytherapy for cervical cancer”**. I have read and understood the information document.

I have been asked to give my consent to the interview being audio-taped to aid accurate collection and analysis of information. I also understand that I can decide whether or not the interview should be recorded and that there will be no penalty or loss of benefits am entitled if I decide not to allow the interview to be recorded.

I give my consent for the interview being audio-taped ☐

I do not consent to the interview being audio-taped ☐

.....  
Signature of participant

.....  
Date

.....  
Witness

.....  
Date

## **ADDENDUM E**

### **ETHICAL CLEARANCE**