WOMEN'S EXPERIENCES OF LONG-TERM EFFECTS OF CERVICAL CANCER AND ITS TREATMENT

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DECLARATION

I, Sophai Namukonda Ntinga declare that this research is my own work. It is being submitted for the degree of Master of Science (Nursing) in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree in any other University.

Signature: SNamukonda .....

Sophai Namukonda Ntinga

17TH ..... day of MAY 2014

Protocol Number **M130344**

DEDICATION

Thank you God, you have done it again. Indeed I can do All things through Christ who strengthens me.

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ABSTRACT

Cervical cancer has a major impact on women's lives especially in developing countries where it is the leading cause of death due to late presentation. Cervical cancer usually remains asymptomatic in the pre invasive and early stages until the disease is locally advanced. The treatment for cervical cancer is guided by the age and general health of the patient as well as the extent of the cancer and presence or nature of any complicating abnormalities. Radiotherapy is the major treatment modality for cervical cancer and approximately 60% of patients with cervical cancer receive radiotherapy at some point during the treatment of the disease. Cervical cancer and its treatment can result in physical, psychological and sex-related effects.

Research problem, question and purpose: Little is known concerning cervical cancer treatment related effects South African women experience 12 months after completing treatment as no literature exploring this subject could be found. The research question is therefore: What long term effects do women treated for cervical cancer at an academic hospital in Johannesburg experience 12 months after completion of treatment? The purpose of the study is to explore the effects women experience after 12 months of treatment for cervical cancer with radiotherapy.

Design: A qualitative method and descriptive phenomenological design was used for this study. The setting was the Department of Radiation Oncology at an academic hospital in Johannesburg. The population comprised all women diagnosed with cervical cancer who completed radiotherapy treatment 12 months prior the study. Purposive sampling was used and the sample totalled 16 (n=16). Data were collected using open-ended, unstructured interviews.

Findings: The responses elicited from the interviews, women experience problems related to Physical, Social-economic. Psycho-spiritual and sexual problems of being treated for cervical cancer.

Conclusion: Women experience physical problems which has an impact on their social-economical, psycho-spiritual and sexual lives as a result of long-term effects of cervical cancer and its treatment

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CHAPTER 1

OVERVIEW FOR THE STUDY

1.1 INTRODUCTION

This chapter presents an overview of the study and includes the background to the study, the problem statement, the purpose, the significance and relevant definitions. An overview of the research method is also provided, as well as a description of the measures to ensure trustworthiness and ethical considerations.

1.2 BACKGROUND OF THE STUDY

Cancer is a global public health problem, the second most common cause of death in the developed world and one of the three leading causes of death in the adult population in developing countries. Cancer is responsible for 12.6% of all deaths, which is more than the combination of deaths caused by HIV and AIDS, malaria and tuberculosis (World Health Organization and International Union against Cancer, 2005).

Cervical cancer, after breast cancer, is the second most common cancer in women globally (World Health Organization, 2010) and approximately 500 000 women are newly diagnosed annually. More than 85% newly diagnosed women live in developing countries where cervical cancer accounts for 13% of all female cancers (Ferlay et al., 2010). In Africa, with a population of 267.9 million women aged 15 years and above, it is estimated that 78 897 women are diagnosed with cervical cancer annually and 61 671 (78%) will die from the disease (Ashford & Collymore, 2005) as women present with advanced disease (Denny, 2010).The exact number of South African women diagnosed with cervical cancer is not clear due to the pathological based cancer registry not being maintained (Denny, 2010) and underreporting (Albrecht, 2006). However, the 2005 Cancer

Registry (National Health Laboratory Service, 2012) indicates that cervical cancer was responsible for 17.76% of all female cancers reported during that year.

Treatment for cervical cancer varies according to the stage of the disease and includes cryotherapy for preinvasive disease, surgery for early stages and radiotherapy with or without chemotherapy for invasive disease (Itano & Taoka, 2005). Radiotherapy causes both acute and late effects. Acute effects are those experienced during and immediately after radiotherapy, whilst late effects can develop months to years after treatment (Faithful, 2006). Physical effects resulting from radiotherapy include diarrhoea, constipation, lymphedema, menopausal symptoms, poor body image, sexual and or vaginal disfunctioning, dyspareunia (Park, Bae & Nam, 2007) and chronic fatigue (Vistad, Fossa, Kristensen & Dahl, 2007). These physical effects have an impact on the emotional, psychosocial and sexual life (Saewong & Choobum, 2005; Korfage et al., 2009), thus affecting the performance of housework, paid employment and social activity, which could be attributed mainly to physical problems women experience (Vistad et al., 2006).

1.3 PROBLEM STATEMENT AND RESEARCH QUESTION

Literature is a guide to what the long-term effects of radiotherapy for cervical cancer are. However, it is not known how women experience these effects as no literature describing this issue could be found. The research question for the study is therefore: How do women diagnosed with cervical cancer and treated with radiotherapy at an academic hospital in Johannesburg, experience the long-term effects of the disease and treatment?

1.4 PURPOSE OF THE STUDY

The purpose of the study was to explore how women diagnosed with cervical cancer and treated with radiotherapy at an academic hospital in Johannesburg, experience the long-term effects of the disease and treatment.

1.5 SIGNIFICANCE OF THE STUDY

This study was conducted to investigate which of the known late effects of the treatment of cervical cancer are problematic to women and how they experience them. Knowledge of these experiences will enable nurses to reflect on the supportive care provided to these patients and determine whether the identified problems are managed and how to improve the management thereof. This will also help assess and manage these problems adequately and measures can be put in place where possible before, during and after treatment to prevent some of the problems that will be identified.

1.6 OPERATIONAL DEFINITIONS

Cervical cancer

Cancer that affects the uterine cervix; the uterine cervix is the neck of the uterus in women (Brooker, 2006).

Late effects

For the purpose of this study, late effects refer to the cancer and treatment related complications that women experience 12 months after completing radiotherapy.

Radiotherapy

Radiotherapy refers to the use of ionizing radiation in the treatment of patients with benign and malignant diseases (Otto, 2007).

1.7 RESEARCH METHODS

A qualitative method (Begley, 2008) and descriptive phenomenological design (McCance & Mcilfatric, 2008) was used for this study. The setting was the Department of Radiation Oncology at an academic hospital in Johannesburg. The population comprised all women diagnosed with cervical cancer who completed radiotherapy treatment 12 months prior the study. Purposive sampling (McCance & Mcilfatric, 2008) was used in order to obtain greater richness of data for the study. All women recruited for the study were willing to participate and the sample totalled 16 (n=16). Data were collected using in-depth interviews. An interview guide (Appendix D) directed the collection of general information whereafter one question was posed to participants. Probes were used to increase detailed explorations (Appendix D). The interview guide was pre-tested using the first participant. The data were analysed using the Colaizzi method as described by Polit and Beck (2012). The use of Lincoln and Guba's framework (Guba & Lincoln, 1995 in Polit & Beck, 2012) was to enhance the trustworthiness of the findings. The ethical guidelines outlined in the Belmont Report (Polit & Beck, 2012) applied to the study.

1.8 OUTLINE OF THE STUDY

This study will be presented as follows:

Chapter 1: Overview of the study

Chapter 2: Literature review

Chapter 3: Research methods

Chapter 4: Findings and discussion

Chapter 4: Limitations, recommendations and conclusion

1.9 SUMMARY

This chapter introduced the reader to the study. The problem statement, research question and the purpose have been stated. In addition, an overview of the research methods including the plan of research action has been provided.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In the previous chapter, an overview of the study was provided. This chapter provides a literature review in order to enhance the reader's understanding of cervical cancer and its treatment.

2.2 INCIDENCE OF CERVICAL CANCER

According to the World Health Organization (2010), cervical cancer is the second most common cancer in women globally. More than 85% of the global burden occurs in developing countries, where it accounts for 13% of all female cancers (Ferlay, Shin & Bray et al., 2010). There are approximately 500 000 women newly diagnosed with cervical cancer annually worldwide, resulting in a 50% mortality largely due to late presentation and lack of treatment facilities (Moodley, 2009). According to Ashford and Collymore (2005), cervical cancer has a major impact on women's lives especially in developing countries where it is the leading cause of death in women. In developing countries, approximately 493,000 women are newly diagnosed each year and approximately 274,000 die from this disease mainly because screening programmes are not well established.

Over 80% of women newly diagnosed with cervical cancer live in developing countries and most of them are diagnosed when the disease is advanced (World Health Organisation (WHO), 2006). In Africa, with the population of 267.9 million women aged 15 years and above, it is estimated that 78 897 women are diagnosed with cervical cancer annually whilst 61 671 (78%) will die from the disease (Ashford & Collymore, 2005). Cervical cancer is not only a common cancer amongst poor women, but cure rates are low because they present with advanced disease (Denny, 2010).The exact number of South African women diagnosed with cervical cancer is not clear due to the

pathological based cancer registry not being maintained (Denny, 2010) and underreporting (Albrecht, 2006). However, the 2005 Cancer Registry (National Health Laboratory Service, 2012) indicates cervical cancer was responsible for 17.76% of all cancers occurring in women reported during that year.

2.3 RISK FACTORS

According to the WHO (2006), the primary underlying cause of cervical cancer is infection with human papillomavirus (HPV), a very common virus transmitted sexually. Even though HPV is the most important risk factor, epidemiologic studies have identified several other factors, a finding that helps explain why HPV infections resolve spontaneously in some women and progress to invasive cancer in others (Varricchio, 2004). There are more than 40 mucosal HPV types, which can infect the lower genital tract in human beings and approximately 15 of these types are associated with carcinogenesis. HPV 16 and 18 are the two high-risk viruses responsible for approximately 70% of all cervical cancers worldwide and also responsible for the vast majority of cervical cancers in Africa, as well as South Africa (Snyman, 2013).

Various co-factors have been identified which, according to the World Health Organization (2006) are:

- low immune status and HIV infection therefore increases the risk;
- high parity;
- tobacco smoking;
- co-infection with HIV or other sexually transmitted agents such as Herpes Simplex Virus 2, Chlamydia trachomatis and Neisseria gonorrhoea;
- long-term, more than 5 years, use of oral contraceptives;
- vitamin deficiencies.

2.4 PREVENTION OF CERVICAL CANCER

Cervical cancer has a natural history and it usually takes 10 to 20 years for precursor lesions caused by HPV to develop into invasive disease (WHO, 2006). Cervical cancer is preceded by a preinvasive condition known as intraepithelial lesion or cervical intraepithelial neoplasia (Varricchio, 2004). Cellular changes taking place range from premalignant changes that is; mild to moderate to severe cervical intraepithelial neoplasia (CIN), to carcinoma in situ (CIS), to invasive disease (Itano & Taoka, 2005). Carcinoma in situ and pre-invasive forms are curable; at the onset of the disease, cellular growth is slow but once it is invasive, it grows rapidly. Therefore, the prolonged natural history of the disease makes it ideal for screening interventions (Varricchio, 2004). This also means that most cervical cancers can be prevented by early detection and treatment of precancerous lesions (WHO, 2006).

2.4.1 Primary Prevention

Primary prevention of cervical cancer refers to the prevention of HPV infection and co-factors known to increase the risk of cervical cancer (WHO, 2006) or at least preventing persistent infection of the cervix with HPV (Denny, 2010) and include:

- education and awareness on the need to reduce high risk sexual behaviours, abstinence, having one faithful sexual partner and the use of condoms;
- the development and introduction of effective and affordable HPV vaccines;
- efforts to discourage tobacco use.

2.4.2 Secondary Prevention

Secondary prevention of cervical cancer relies on the detection of cervical cancer precursors and the removal of the transformation by either excision or ablation (Denny, 2010). This is achieved through screening which aims at detecting precancerous changes, which if not treated may lead to cancer. Early detection according to the WHO, (2006) includes:

- organised screening programmes, targeting the appropriate age groups and with effective links between all levels of care;
- education for healthcare providers and women in the target group on benefits of screening, age at which cervical cancer most commonly occurs and also signs and symptoms;
- follow-up of patients who are positive on screening, to ensure a diagnosis is made and the disease is appropriately managed;
- treatment of precancer, using relatively simple procedures to prevent the development of cancer.

2.4.3 Screening tests currently available.

According to the WHO (2006), cervical cancer screening tests available include:

- Cytology-based: Conventional (Pap smear) and liquid based, this requires highly trained personnel, well equipped laboratories, transport of specimens and an effective system for collecting information and following up patients.

- Visual inspection with acetic acid (VIA) or Lugol's iodine (VILI), has shown promise in controlled research settings but not widely implemented. Promising alternatives to cytology where resources are limited. Results are available immediately eliminating the need for multiple visits in most cases and reducing loss to follow-up.

- HPV-DNA Tests are also commercially available but the disadvantages include the need for sophisticated laboratory facilities and high cost

2.4.4 Prevention of cervical cancer in South Africa

The most powerful tool to date for prevention of cervical cancer has been the implementation of national, organised mass cytology-base screening programmes, because where this has been successful, the incidence of cervical cancer has been reduced dramatically. In 2000, South Africa

implemented a cervical cancer screening policy expecting to reduce the cumulative incidence of cervical cancer by approximately two-thirds (Denny, 2010). The national policy supports primary and secondary prevention and targets women 30 years and older. Women, no younger than 30 years, are offered three (3) free smears with a 10 years interval in between each smear. Those screened for first time at the age of 55 or more will have only one smear if first smear is normal. Women with low-grade squamous intraepithelial lesions require re-screening in 12 months' time, whilst those with high-grade lesions should be referred for colposcopy.

However, there has been a low screening uptake in South Africa despite the national screening policy, as the policy has not been formally implemented countrywide. It is estimated that screening coverage is mainly done on an opportunistic basis, with the uptake as low as 13% (Snyman, 2013).

2.5 SIGNS AND SYMPTOMS OF CERVICAL CANCER

Cervical cancer usually remains asymptomatic in the preinvasive and early stages until the disease is locally advanced (WHO, 2006; Otto, 2007). The early signs of disease include a thin, watery discharge that usually is blood tinged, but as it progresses, the patient has frequent episodes of bleeding (Varricchio, 2004). The episodes of bleeding include abnormal vaginal bleeding which could be postcoital, intermenstrual or post-menopausal or an increase in length and amount of menstrual flow and a watery serosanguineous vaginal discharge. Late symptoms may include dysuria, urinary retention, haematuria and hydronephrosis and also bowel symptoms such as rectal bleeding, bowel obstruction and constipation, which suggest tumour invasion of the bladder or the rectum. Edema to the lower extremities maybe as a result of lymphatic obstruction, pelvic or sciatic pain suggests nerve involvement (Otto, 2007).

2.6 DIAGNOSIS OF CERVICAL CANCER

2.6.1 Diagnosis and Management of Precancerous Lesions

Further investigations are needed with a positive or abnormal screening test, in order to make a definitive diagnosis and the standard method for diagnosis of cervical precancerous lesions is histopathological examination of tissue obtained through biopsy guided by colposcopy. Precancerous lesions are treated by means of cryotherapy and loop electrosurgical excision procedure (LEEP); cold knife conisation is appropriate when the eligibility criteria for cryotherapy and LEEP are not met, but hysterectomy should not be used to treat precancer unless there are other compelling reasons to remove the uterus (WHO, 2006).

2.6.2 Diagnosis of Cervical Cancer

Cervical biopsy, when abnormalities are identified, confirms the diagnosis of cancer (Itano & Taoka, 2005). For invasive cervical cancer, speculum, vaginal and rectal examination, intravenous pyelogram (IVP) and abdominal ultrasound serves as the main guide for staging, but cystoscopy, proctoscopy, chest x-ray, skeletal x-ray or bone scan, abdominal or pelvic computed tomographic (CT) scan, magnetic resonance imaging (MRI), or positron emission tomography (PET) scanning can also be done to evaluate extent of the local lesion, metastasis to regional lymph nodes and distant metastasis (Itano & Taoka, 2005; WHO, 2006). All these investigations are to determine the stage and the treatment to be employed (Itano & Taoka, 2005). Laboratory studies, usually done include complete blood count to look for evidence of anemia and chemistry studies to evaluate renal and liver function (Moore-Higgs, 2007) and blood for HIV and syphilis, may inform additional treatment (WHO, 2006).

2.7 HISTOLOGIC TYPES

According to Itano and Taoka (2005), there are two main histologic types of cervical cancer, namely squamous carcinoma and adenocarcinoma. Squamous carcinoma is the most common and occurs in 85% to 90% of women. According to Moore-Higgs (2007), approximately 7% to 10% of cervical cancers are classified as adenocarcinoma, which occurs in younger women and carries a poorer prognosis, has bulky endocervical tumours, which are aggressive in nature and is less responsive to treatment.

2.8 STAGING

Staging is according to the International Federation of Gynecology and Obstetrics (FIGO) and takes into account the clinical extent of disease, which includes the cervical biopsy findings, the class of cytologic interpretation and histologic grade (Varricchio, 2004). The stage ranges from Stage 0 to stage IVB, as presented in Table 2.1.

Table 2.1. FIGO Staging of Cervical Cancer

Stage	**Description**
0	Carcinoma in situ
I	Cancer has invaded the cervix but has not spread anywhere else Stage 1AI: Invasion is less than 3mm deep and less than 7mm wide Stage 1A2: Invasion is between 3mm and 5mm deep and less than 7 mm wide
1B1	The cancer is no larger than 4cm
1B2	The cancer is larger than 4cm
II	Cancer has spread beyond the cervix, but it is still within the pelvic area

IIA	Cancer has spread beyond the cervix to the upper part (but not lower third) of the vagina
IIB	Cancer has spread to the parametrial tissue next to the cervix
III	Cancer has spread to the lower part of the vagina or pelvic wall. The cancer may be blocking the ureters
IIIA	Cancer has spread to the lower third of the vagina but not pelvic wall
IIIB	Cancer extends to the pelvic wall and/or blocks urine flow to the bladder
IV	Cancer has spread to nearby organs or other parts of the body
IVA	Cancer has spread to the bladder or rectum
IVB	Cancer has spread to distant organs beyond the pelvic area

(Varricchio, 2004)

2.9 TREATMENT FOR CERVICAL CANCER

The choice of treatment is determined by the FIGO stage of disease (Varricchio, 2004). Primary treatment may be surgery or radiotherapy, or occasionally a combination of both; chemotherapy may be given concurrently with radiotherapy but is not a primary treatment (WHO, 2006).

2.9.1 Treatment for Early Cervical Cancer

The International Atomic Energy Agency's (IAEA, 2010) guidelines for treatment of early stage cervical cancer are as follows:

- Stage IA1: Total abdominal hysterectomy with or without salpingo-oophrecteomy; if there are contraindications to surgery, the patient can be treated with intracavitary brachytherapy alone.

- Stage IA2: Radical trachelectomy and pelvic lymph node dissection (PLND) or modified radical hysterectomy and PLND with or without tailored adjuvant radiotherapy, if surgery is contraindicated, brachytherapy alone or in combination with external beam radiotherapy (EBRT).

- Stage IB1-IIA1: If surgery, then modified radical hysterectomy and PLND with or without tailored adjuvant radiotherapy or definitive radiotherapy; if the patient is not fit for surgery, then definitive radiotherapy.

2.9.2 Treatment for Advanced Stage Cervical Cancer

Mainstay treatments for advanced stages are:

- Stage IB2-IIA2: Modified radical hysterectomy in selected patients with postoperative radiotherapy, or radio-chemotherapy, based on histopathological features.

- Stage IIB-IVA: These patients are not candidates for surgery and standard treatment is EBRT plus brachytherapy with or without concomitant chemotherapy.

- Stage IVB: Radiotherapy with or without chemotherapy if microscopic para-aortic lymph node involvement, unless medical contraindications are present or if distant metastasis cure is not possible; treatment is palliative and radiotherapy may be useful in the palliation of specific symptoms.

The indication from above is that approximately 60% of patients with cervical cancer receive radiotherapy at some point during the treatment of the disease (Newton, Hickey & Marrs, 2009). Chemotherapy is not a primary therapy, but may be given concurrently with surgery or radiation to

treat bulky tumors (WHO, 2006). Ozsaran et al. (2003) also supports concurrent chemoradiation for locally advanced cervical cancer as treatment of choice in suitable patients providing high response rates with acceptable toxicity.

2.9.3 Radiotherapy

The goal of radiotherapy is to destroy or inactivate cancer cells, but normal cells are also affected and local tissue change caused by ionizing radiation can have systemic effects with alterations occurring in various physiological processes. The radiation effects on mammalian tissue should be viewed as a succession of processes extending from microseconds to months and years after exposure to ionizing radiation (Moore-Higgs, 2007). Side effects are a result of radiation on normal tissues and can cause acute side effects that occur during , weeks or months after radiotherapy, whilst late effects occur months to years after radiotherapy and are permanent (Itano & Taoka, 2005).

Acute effects of radiotherapy may be skin reactions ranging or progressing from mild hyperpigmentation, dry or even moist desquamation, acute cystitis which could result into dysuria where patients report increased frequency, urgency, hesitancy and increased nocturia, diarrhoea, vaginal mucositis where patients report symptoms of discomfort and dyspareunia, fatigue and bone marrow suppression (Moore-Higgs, 2007).

Late effects of radiotherapy include proctitis which might lead to development of ulcers, strictures and rectal bleeding, haemorrhagic cystitis, early menopause, chronic lymphedema of lower extremities, fistulae may form between the bladder and vagina, vagina and rectum, bowel and vagina or bowel and bladder and also vagina stenosis which might cause sexuality problems (Moore-Higgs, 2007).

Burns et al. (2007) revealed a range of bladder problems after radiotherapy including urinary frequency and incontinence, which was a severe problem, but found even persistent mild symptoms had an impact on daily lives of women treated for cervical cancer, including sexuality. There was a link between cancer treatment and sexuality largely due to the physical problems and psychological difficulties in maintaining an effective sexual relationship. This is in line with a study conducted by Bloom, Petersen and Kang (2007) who reported micturitic problems as well as hot flashes and vaginal dryness. In this study, depressive symptoms, anger and confusion revealed a significant association between high levels of social support and less cancer specific distress. Furthermore, Bloom et al. (2007) seem to support the earlier findings of Juraskova et al. (2002) where common physical changes were reduced libido, shortened vagina and decreased lubrication implying high levels of sexual dysfunction. Vistad et al. (2011) also found that chronic pain was significantly more prevalent in women treated for cervical cancer than in women generally.

2.10 SUMMARY

This chapter provided the reader with literature related to the disease, incidence, risk factors, prevention, diagnosis, treatment and acute and late effects of radiotherapy. The following chapter presents the research methods.

CHAPTER 3

RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

This chapter describes the research methods used in this study including the research design, the study setting, sample criteria, the sampling process, data collection and analyses procedures, the ethical principles underpinning the study and the measures applied to enhance the trustworthiness of the findings.

3.2 RESEARCH DESIGN

A qualitative research method and descriptive phenomenological design based on the tradition of Husserl (McCance & Mcilfatric, 2008) was used to explore the research problem. According to Burns and Grove (2007), qualitative research is a systemic, subjective methodological approach used to describe life experiences and give them meaning. Miller, (2010) also states that qualitative research refers to a method of inquiry in which the researcher, acting as data collection instrument, seeks to answer questions about how or why a particular phenomenon occurs.

Descriptive phenomenological research insists on careful description of ordinary conscious experience of everyday life (Polit & Beck, 2012). Lopez and Willis (2004), describe Husserl's philosophy to be experiences as perceived by human consciousness, which has value and should be an object of scientific study. Husserl believes subjective information is important to scientists seeking to understand human motivation, because human actions are influenced by what people perceive to be real and human beings generally go about the business of daily life without critical reflection on their experiences. Therefore, the study uses this scientific approach to bring out the essential components of the lived experiences of long-term effects in women who have received

radiotherapy for cervical cancer. This is the essence, referring to the most essential meaning for a particular context that forms the consciousness and perception (McCance & Mcilfatric, 2008).

3.3 RESEARCH METHODS

According to Polit and Beck (2012), research methods are techniques researchers use to structure a study and to gather and analyse information relevant to the research question. These research methods, discussed below, include the study setting, target population, sample and sampling method, data collection procedures and strategies for analysing the data.

3.3.1 Study Setting

The conducting of the study was at an academic hospital, in Gauteng Province, with 1088 beds serving patients from across the province and neighbouring provinces. The hospital offers specialist inpatient and outpatient services, serves as a referral hospital for a number of hospitals in its referral chain and holds professional and support staff of more than 4000 people.

The hospital has various specialised departments. Cancer patients have access to surgery, chemotherapy and radiotherapy as major treatment modalities for management of cancer. The radiation oncology department delivers radiation treatment through teletherapy (EBRT) and brachytherapy, which is high dose rate (HDR), on an outpatient basis. Patients receiving radiotherapy are reviewed every week and those for follow-ups are seen on a specific day of the week. Women who have been treated for cervical cancer are also scheduled for follow up on a specific day each week (Johannesburg Hospital, 2013). Approximately 360 women treated with radiotherapy for cervical cancer are reviewed every month.

3.3.2 Population and sampling

The population, also referred to as the target population, is the entire set of individuals who meet the sampling criteria (Burns & Grove, 2007). The population for the study comprised all women 12 months after completion of radiotherapy for cervical cancer. Purposive sampling was used to select participants who were 18 years and older, able to speak and understand basic English, diagnosed with cervical cancer and had completed radiotherapy 12 months prior to the gathering of the data. Purposive sampling is a judgemental or selective sampling method where certain participants are consciously selected for inclusion in a study (Burns and Grove, 2007). According to McCance and Mcilfatric (2008), purposive sampling is particularly suited for phenomenological studies as this sampling method allows the selection of participants with rich information from which the researcher can learn much in terms the of events, incidences and experiences of central importance for the study. Sixteen (n=16) women were recruited for the study and all were willing to participate.

3.3.3 Data Collection

Data were collected using open-ended, unstructured interviews. Unstructured interviews are interviews in which the researcher asks respondents questions without having a predetermined plan regarding the content or flow of information to be gathered (Polit & Beck, 2012). The researcher used the interview guide (Appendix D) which had only one open ended opening question and three probes. To maintain the focus of the study, all the participants were asked the same opening question: "*Please tell me about the problems you are experiencing now, since you got the treatment for cervical cancer".*

To ensure clear understanding of the question a pre-test was done using the first participant. A pre-test is a trial run to determine, as far as is possible, whether the instrument is clearly worded and

free from major bias and whether it solicits the type of information envisioned (Polit & Hungler, 1997). Since the question was well understood by the first participant it was not necessary to change it and the data were included as part of the study.

After the initial question, each participant was expected to proceed with the expression of the problems she is experiencing. This was followed by probes such as "tell me more about" to elicit detailed exploration. According to Polit and Hungler (1997), probes are prompting questions that encourage the respondents to elaborate on the topic.

Interviewing techniques commonly used were paraphrasing so as to enhance meaning, clarification for unclear statements and minimal verbal or nonverbal responses, summaries to confirm if researcher understood the participant clearly and occasional nodding "mmm, yeah, Ok, alright," which encouraged the participants to talk freely and tell stories in their own words as they convey concern and interest (Polit & Beck, 2012).

At the end of each interview, the researcher thanked the participants for being part of the study and asked for permission for a follow-up interview, should more information be required and to verify the findings.

The researcher used bracketing throughout the study so as not to influence findings in anyway. Polit and Beck (2012) defines bracketing as the process of identifying and holding in abeyance, preconceived beliefs and opinions about the phenomenon under study. According to Lopez and Willis (2004), an essential component of Husserlian phenomenology is the belief that the researcher shed all personal knowledge to enable her to grasp the essential lived experiences of those being studied. The guidelines of Ahern (1999) were used to bracket and the researcher reflected on anything she would take for granted whilst conducting the research, the power

hierarchy and potential role conflict. The researcher also clarified her personal value systems, acknowledged any subjectivity she might have had and attempted to recognise feelings that could indicate lack of neutrality.

All interviews were audiotaped for verbatim transcription. Audiotapes contain more than words, they contain feeling emphasis and nonverbal communication, which are as important to communication as words (Burns & Grove, 2007). To enrich audiotaped interviews, field notes were written during and immediately after the interviews and inserted and validated at relevant points during transcription. Field notes represent the participant observer's efforts to record information and synthesise and understand the data (Polit & Beck, 2012). Each interview lasted approximately 60 minutes, followed up by shorter interviews of approximately 20 to 30 minutes, when the researcher needed additional information and clarify issues.

Data analysis commenced immediately after the first interview and continued with on-going data collection. Sixteen participants were interviewed in order to obtain greater richness of data for the study.

Planning for the data collection was as follows:

- Permission to conduct the study was obtained from the Post Graduate Committee of the University of the Witwatersrand (Appendix F), Human Ethics Committee, (Appendix G) and the CEO of the hospital (Appendix E). The head of the Department of Radiation Oncology and the Unit manager also supported the study.

- The researcher had been practicing, as a registered nurse, in the radiation oncology department prior to collection of data and was familiar with the setting. The researcher

purposively selected participants to be included in the study. Once the participant was identified, the researcher personally approached and invited her to participate after explaining the study (Appendix A), informed consent (Appendix B) for inclusion in the study was obtained and permission for voice recording was sought, if they agreed consent for recording (Appendix C) was obtained.

- The interviews were conducted in a private room and the seating was arranged in such a manner that it allowed the participant and the researcher to communicate freely.

- The in depth interview process started in an informal and friendly manner. According to Polit and Beck (2012), interviewers must prepare respondents for the interview by putting them at ease as part of this process involves sharing pertinent information about the study. The introductory phase involved explaining to the participants the purpose of the study, their expected role, the amount of time needed to complete the interview and the use of the voice recorder. The first few minutes also helped both parties to settle in (Polit & Beck, 2012).

- At the beginning of the interview, the participants were informed of the measures that would be taken to protect anonymity and confidentiality. Demographic data were collected before the interview.

3.4.4 Data Analysis

Data analysis is the systemic organisation and synthesis of research data (Polit & Beck, 2012). Data collection and analysis occurred concurrently as interviews were transcribed verbatim immediately after the interview. The Colaizzi method (Polit & Beck, 2012) was used to analyse the

data. The Colaizzi seven-step procedure for analysis is, according McCance and Mcilfatrick (2008), an appropriate data analysis framework for Husserlian phenomenological research.

The steps of the data analyses process (Polit & Beck, 2012) were applied as follows:

Step 1: Read all protocols to acquire a feel for them.

- All the transcribed interviews were read and reread until the researcher had a full understanding of the content.

Step 2: Review each protocol and extract significant statements.

- After the researcher had a full understanding of the content and she highlighted significant statements in each transcribed interview using different colours; statements with similar problems experienced had one colour, continuing with different colours of highlighters for different problems experienced.

Step 3: Spell out the meaning of each significant statement.

- At this stage, the researcher looked for the meaning of each colour code of the significant statements highlighted as in step 2.

Step 4: Organise the formulated meanings into clusters of themes.

- At this point, the researcher had four broad themes identified: physical problems, socio-economic issues, psycho-spiritual issues and sexuality. Each major theme had subcategories, which were clusters of similar problems experienced. There was also a fifth broad theme with a few problems experienced which did not fit into the four major themes

identified but were considered important to the study, therefore, it was called health system setbacks.

Step 5: Integrate results into an exhaustive description of the phenomenon under study.

- After identification of the major themes, the researcher gave a detailed description of how the women, living with cervical cancer, experienced the effects of radiotherapy 12 months after completion of the treatment.

Step 6: Formulate an exhaustive description of the phenomenon under study in a statement of identification as unequivocal as possible.

- While describing the late effects women experienced 12 months from completion of radiotherapy treatment in relation to the identified themes, the researcher was able to add some narrative statements, which give identification, from participants having experienced the phenomenon under study

Step 7: Ask participants about the findings thus far as a final validating step.

- The findings were presented to the participants and the researcher confirmed it to be a true reflection of their experiences relating to themes that had emerged from the transcribed interviews, which is also the phenomenon under study. The researcher informed the participants telephonically and was able to do so, as she had gotten permission at the end of the interviews to contact them if there was need for more information and to validate the findings.

3.4 MEASURES TO ENHANCE TRUSTWORTHINESS

According to Polit and Beck (2012), trustworthiness answers the question on how one can trust that the researcher has offered an accurate and insightful representation of the phenomenon investigated. Rolfe (2004) however, is of the opinion that a study is trustworthy only if the reader of the research report judges it so. Lincoln and Guba's framework, as explained by Shenton (2004), was applied in the current study to ensure the findings are a true reflection of the women's experience.

3.4.1 Credibility

Credibility refers to the confidence in the truth of the data and interpretations of them (Polit & Beck, 2012). The following measures applied, according to Shenton (2004), were to enhance the credibility of the findings

- Early familiarity with culture of the participating organisation: Before data collection commenced, the researcher was already placed at the site of data collection.

- Measures taken to ensure honesty in the informants: Participants were given the opportunity and informed they were free to refuse to participate in the study so that only those genuinely willing participated and offered data freely with honesty.

- Iterative questioning: The researcher used probes during the interviews to elicit detailed data and rephrasing questions to return to matters previously raised by participants to ensure what was recorded was exactly what the participants said.

- Member checks: Checks relating to the accuracy of the data took place on the spot by paraphrasing the questions and the researcher would give a summary at the end of the

interview to check if she had recorded according to what was being said by the participants. The researcher also audio recorded the interviews and when transcribing both verbal and non-verbal expressions were transcribed. At the end of data analysis, verification of the emerged themes was done where participants confirmed the emerged themes were a true reflection of the data collected during the interviews.

3.4.2 Dependability

Dependability refers to the stability, that is, reliability of data over time and conditions (Polit & Beck 2012) and according to Shenton (2004):

- The research design and implementation has to be explained in detail. A detailed explanation of the research design and implementation has been given and this allows for dependable results and the study to be repeated.

3.4.3 Transferability

Transferability refers to the extent to which findings can be transferred to or have applicability in other settings (Polit & Beck, 2012). Shenton's explanation (2004) was employed as:

- Sufficient description of the context, the number of participants, data collection methods employed and limitations has been provided

- to allow extent of transferability of the results and comparisons can be done.

3.4.4 Confirmability

Confirmability is concerned with establishing that data represents information participants provided, findings reflect the participants voice and not that of the inquirer/researcher (Polit & Beck, 2012).

- An in-depth methodological description of the study has been given and Shenton (2004) is of the view that this allows for scrutiny of the research results.

3.5 ETHICAL CONSIDERATIONS

The ethical guidelines from the Belmont Report (Polit & Beck, 2012) were applied in the study. The Belmont Report describes three broad principles on which to base standards of conducting research in an ethical manner: beneficence (minimise harm and maximise benefits), respect for human dignity (right to self-determination and full disclosure) and justice (right to fair treatment and privacy).

To ensure the above principles were adhered to, the following were applied:

- The proposal of the study was presented to the Department of Nursing Education and the University Post Graduate Committee for peer review and permission to commence the study was granted.

- The proposal was presented to the Human Ethics Committee of the University of the Witwatersrand and ethical clearance was granted.

- Permission to conduct the study was obtained from the Chief Executive Officer of the hospital (appendix E). The head of the department and the unit manager of the Oncology Unit also supported the study.

- An information leaflet was first given to the participants (Appendix A), whereafter informed consent was obtained (Appendix B) from those willing to participate in the study and consent to audio tape the interviews (Appendix C) was also obtained. Interviews were conducted in a private room.

- Human dignity was respected, including the right to self-determination, as participants were made aware of their right to withdraw freely from the study if they so wished, with no effect on their care. Confidentiality measures were adhered to, by not divulging the information obtained and using it only for the intended purpose.

- After the transcription, the interviews were transferred to a CD and deleted from the computer. All data sheets and the CD were sealed in an envelope and placed in a safe in the Department of Nursing Education, to be kept for a period of three years after the report has been published whereafter it will be destroyed.

3.6 SUMMARY

In this chapter, the research design and method of the study were described in detail. Measures to enhance trustworthiness as well as ethical considerations were discussed.

CHAPTER 4

FINDINGS AND DISCUSSION

4.1 INTRODUCTION

In the previous chapter, the research design and method were provided. This chapter presents the findings and discusses the major themes that arose with regard to the views and opinions of the participants about women's experiences of long-term effects of cervical cancer and its treatment. To begin with, the biographic information of the participants has been presented, followed by the discussion of the findings, a brief conclusion of the findings and a summary.

4.2 PARTICIPANTS

The average age of the participants was 44 years and ranged from 27 to 59 years. Most were single and lived in urban communities. Nearly one third of the participants did not have a personal monthly income, whilst the rest had a monthly income ranging from R870 to R6650. The participants were diagnosed with cervical cancer ranging from stage IB to stage IV and all had received external beam radiation, either alone or in combination with brachytherapy and chemotherapy. A detailed description of the demographic data of participants is presented in Table 4.1.

Table 4.1 Demographic information of the participants (n=16)

Characteristic	**n**
Age group	
20-29	1
30-39	3
40-49	7
50-59	5
Marital status	

Single	8
Married	5
Widowed	3
Residing place	
Urban	12
Rural	4
Monthly personal income	
No income	5
R1 to R2000	7
R2001 to R4000	3
R4001 to R6000	0
R6001 to R8000	1
Stage of disease	
IB to II	4
IIA to III	9
IIIA to IV	3
Treatment	
External beam radiation only	1
External beam radiation and brachytherapy	11
External beam radiation, brachytherapy and chemotherapy	3
Surgery, external beam radiation and brachytherapy	1

To introduce the participants to the reader, a succinct history of each participant is provided in Table 4.2

Pseudonym	**Age**	**Marital status**	**Personal Monthly income(R)**	**Place of residence**	**Stage of disease**	**Treatment received**
Mary	30	Single	Nil	Urban	IIB	External beam radiation and brachytherapy
Rose	46	Married	1000	Urban	IIB	External beam radiation and brachytherapy
Mwaba	59	Single	Nil	Urban	IB	External beam radiation and brachytherapy
Jane	35	Single	870	Urban	IIB	External beam radiation, chemotherapy and brachytherapy
Eunice	43	Single	Nil	Rural	IV	External beam radiation and

						brachytherapy
Annie	54	Single	6650	Urban	IB	Surgery, external beam radiation and brachytherapy
Hildah	54	Widow	1100	Urban	IB	External beam radiation and brachytherapy
Suzie	37	Widow	3500	Urban	IIA	External beam radiation and brachytherapy
Maggie	41	Single	1500	Rural	IIIB	External beam radiation and brachytherapy
Karen	41	Married	4000	Urban	IIB	External beam radiation and brachytherapy
Maureen	40	Married	Nil	Urban	IIB	External beam radiation, chemotherapy and brachytherapy
Diana	44	Married	Nil	Rural	IIIB	External beam radiation and brachytherapy
Nana	47	Widow	1200	Urban	IIIB	External beam radiation and brachytherapy
Ezra	50	Married	3500	Urban	IIB	External beam radiation and brachytherapy
Carol	27	Married	1000	Urban	IIB	External beam radiation and brachytherapy
Fenny	57	Single	1200	Rural	IIB	External beam radiation and brachytherapy

Five themes arouse from the data:

- Physical consequences;
- Socioeconomic problems;
- Sexual problems;
- Spiritual issues;

- Health system challenges.

4.3 THEMES ARISING FROM THE DATA

4.3.1. Theme 1: Physical consequences

Participants experienced various physical problems related to the treatment they received namely chronic fatigue, bowel, bladder, vaginal and hormonal problems, pain and insomnia.

Chronic fatigue was a major problem for most and participants described their fatigue as "getting tired," "dizziness" and "weakness." The chronic fatigue women experienced had a negative influence on their daily lives as it limited their normal activities of daily living such as cleaning their homes and preparing meals. Mary described her experience:

> *"During the day am alone at times and I have to cook and fix things I feel dizzy, during the day yes, the heart pumps very fast as if something wrong is going to happen like, cleaning, cooking, fetching water, I feel something bad, I cannot go out of the house."*

Hildah said:

> *"…am just tired sometimes, I just make food, clean the dishes and then am tired and just lie on the bed, generally sometimes I woke up in the morning when I go to preschool to take my granddaughter, when I come back I feel tired you know, just make some tea and some breakfast when I finish I lie in bed."*

Most participants experienced chronic pain described as general body pain, pain in the abdomen, back and joints. The chronic pain some experienced added to their suffering as it influenced the activities of daily living negatively. Jane explained how her pain experience influences her life:

"I feel pain [pointing at the lower back and abdomen]……always there……especially at the back, I take pain killers and go to sleep but when I woke up the pain is there, last night the pain got worse…I can stand for only two hours but not three hours then the pain is worse…"

Hilda said:

"…just that pain which comes and goes, comes and goes…..you know this back pain when it comes, I feel like screaming, I feel like, am just thinking, oh my God, why, why this pain come now, I must do this and this and this, but I can't because of the pain,…sometimes I drink water, it helps sometimes…"

Some participants developed lymphedema in their legs, which they experienced as painful and added to their suffering. Fenny explained:

"…….you feel it every month and am changing in my legs, look at me [showing her legs], you see, look at my legs, you see it pains every day…I can't walk."

The location of the pain determined whether participants had the confidence to report it. Women who experienced back and abdominal pain reported their pain during follow-up consultations, but those who experienced shoulder pain were reluctant to mention it as the medical personnel would tell them it was not directly related to their cancer and therefore their pain was not managed. Ezra explained:

"…it's just pain here, and when I come to tell the doctors I have pain here and here [pointing arms and joints] the doctors said no, am working here for the cancer not for the pain here and here, I also have got the problem but I can't tell them…"

Participants also experienced vaginal problems and reported suffering from pain, vaginal stenosis, dryness, itchiness, rash and discomfort, vaginal bleeding and discharge. Fenny who experienced vaginal pain and dryness described her experience as follows:

> *"…I was feeling pain in my vagina, aaaaa sometimes my vaginal became too dry, and that vaginal cream it helps a lot, we must have it a lot because from that you feel hot you know, you can feel it deep in your vagina…..you feel something and you feel fresh."*

Annie described her vaginal bleeding and Maureen her slight vaginal bleeding and stenosis as follows:

> *"….I was bleeding through the vagina, but it's not too much, you see when you go to the toilet then you see blood" (Annie).*

> *"…. The vaginal is small that's the main one, that one……bleeding small not serious" (Maureen).*

In addition to the problems already described, women also experienced bowel and bladder problems. Bowel problems consisted of diarrhoea, constipation and proctitis, whilst bladder problems consisted of dysuria, urgency and urinary incontinence. Some participants also had vesico-vaginal, even recto-vaginal, fistulae.

Diana explained how her recto-vaginal fistula influenced her life:

> *"After a year, eeee I found out that the poo (stool) comes out through the vagina…it wasn't painful but disgusting, cause you can't just walk freely because anytime it comes out a lot so that poo I had to go for this colostomy…then after that I was okey but now I have got*

problem of urine….it's like I can't hold urine… I have to go to the toilet now…that's my problem…"

Carol described her experience as follows:

"…bleeding sometimes it's heavy, it's thick, sometimes it's not coming through the womb the cervix, it's coming where I get urine… it's painful….blood comes through the urine, so it's blood then urine sometimes the blood block the urine to come out."

A couple of participants experienced hormonal problems like hot flashes and early menopause. Rose explained how her body changed after treatment:

"……eeeee but my body was changing, eeee I didn't have eeee menstruation was stopping, the other thing eeee, I think I had, two years after that eeee something like am not the same…"

Maureen experienced hot flushes and said:

"I don't have many problems…..eeeee hot flushes…..it's just sometimes you feel like you don't have feelings anymore but not always……yeeee hot flushes heeee…when you put makeup, when you go out you feel like you are sweating, like you never put makeup, that's how it's affecting me."

Participants experienced insomnia as a result of pain and unknown causes. Maggie said:

"Am not sleeping well, because am in pain…"

Maureen did not know why she was experiencing insomnia:

"Am sleeping but since I had treatment I woke up maybe at 2 am in the morning until 4 o' clock in the morning…..I don't know, I don't know, everyday."

4.3.2 Theme 2: Socioeconomic consequences

The physical problems participants experienced influenced women's lives negatively and resulted in financial hardship, social problems and body image changes. Most of the women experienced financial difficulties, being unable to work because of the chronic fatigue. Those who were able to work could not do hard physical work or lift heavy things, or could not work every day thereby reducing their monthly income.

Maggie said:

"I feel weak, I feel my heart, when I clean my house, eish it's too much, ….I am not working right now so life is tough, my children are suffering from January till now, they go to school no transport, food they are suffering, my husband the money it's not enough…to buy groceries, food and everything, it's not enough."

Suzie who had to provide not only for her own children but also for her mother and sisters explained:

" …because maybe if am working, that's why I feel tired, am working what I want to work, I just work because I have to pay rent, buying is a problem to me, my husband does not work so am alone. I am working five days my boss said you must work four days to support my kids, my mother and sisters."

Rose explained how she had to decrease her working hours:

"...it's affecting my work because that time, I left the work and then asked them to give me, maybe twice a week, so they gave me twice and sometimes three times a week…I cannot work every day because am getting the pain in the hand...even the money cannot get so much…pay according to work."

Jane said:

"…….everywhere gets swollen like something was beating me, I can't even able to work and that's the problem……I have to work for my children… I want to work for my children but I can't, it's difficult [sobbing]…"

Some women experienced anxiety worrying something "wrong" would happen, the changing attitudes of their husbands, sleeplessness, their children suffering, pain and stress. In addition, the fact that some participants were solely responsible for their children added to their suffering. Maggie explained her experience:

"Heish it's too much….my husband nay, he is not feeling alright with me, he has changed, complaining everything that I feel alright, I do not feel alright, he is saying am sick."

Carol said:

"….so you have to take care of yourself, your children, you buy everything for them, school fees, clothes to put on, everything, so that's why am very worried…"

The women also found it challenging to return to the hospital for follow-up visits, as they did not have money for transport. Fenny described her experience:

"…they said I must come back for the blood but I didn't have money to come you know if you are not working…"

Some participants were abandoned by their partners because of the disease and therefore lost the financial support provided by them, leaving them to care for themselves and their children. Fenny explained:

"When your husband want to have sex, the bleeding is coming out, it draws my husband away from me, it draws my husband away till today…..we are the women…to look after the children while these men are going away leave us with these children…"

Some women experienced anxiety worrying something "wrong" would happen, the changing attitudes of their husbands, sleeplessness, their children suffering, pain and stress. In addition, the fact that some participants were solely responsible for their children added to their suffering. Maggie explained her experience:

"Heish it's too much….my husband nay, he is not feeling alright with me, he has changed, complaining everything that I feel alright, I do not feel alright, he is saying am sick."

Carol said:

"….so you have to take care of yourself, your children, you buy everything for them, school fees, clothes to put on, everything, so that's why am very worried…"

Some women experienced body image changes, which were expressed as the "body not the same" and "no feelings like a woman." Not having pubic hair was also a problem for some of the participants, which robbed them of being women and turned them into babies. Diana said:

"And as you see the hair is not there as a woman, just the hair is not there after radiation, like a baby."

Being incontinent was another problem women faced, as it changed their way of dressing and reduced their freedom and influenced their social lives, as they always had to check that they had not soiled themselves. Diana and Nana said:

"I am worried….. I can't be free all the time, I have to check all the time maybe it's wet on the trousers or on your skirt….now is my main worry…" (Diana)

".....you see now I have to cover with a blanket here [pointing at the small blanket she has wrapped around her hips] and you see I wear two skirts….it's a problem for people not to see and then you can't go to people's houses, he is going to say that what's wrong now… you are worried what if I wet the bed, it's very bad to the people, even at home you must go fast because it will come out and then what if you are in somebody's house, it's a big problem." (Nana)

Participants were fully aware of the necessity to prevent vaginal stenosis by dilating their vaginas daily. However, their socio-economic status did not always award them the opportunity to perform this procedure as some shared one-roomed dwellings. The facilities provided at work were also not conducive for vaginal dilations due to having access only to communal toilets and showers and the only free time was the hour lunch time. Karen said:

"The problem is that sometimes I do not have privacy, because you have to be at work and my child is old now, so I do not have privacy…when they are at school am at work, at work

time is only at break, but what can I use the toilet…there is only one toilet we share. Lunchtime… I've got only one hour…"

Support from family members had a positive influence on the lives of some of the participants and helped to cope. The support mainly came from parents, children, spouses and other family members. The support was in terms of finance, performing household chores and encouragement. Mary explained:

"I get a lot of support with my parents…"

Rose added:

".....I like it because my family from that time…they support me too much, my children and husband support me …even the food my daughter, she would say mummy I buy you fruits, I buy you and you must eat, they support me too much and my son, they support me they even buy for me the tablets for appetite, I can't feel like am so lonely and then sometimes, I thought that I had no cancer before hahahaha…"

4.3.3 Theme 3: Sexual problems

The physical consequences of the disease and treatment had a negative influence on the sexual relationships of participants. Some experienced that their spouses were unable to cope with their altered sexuality caused by their vaginal changes. Some of the women experienced their husbands complaining that their vaginas were short, dry and tight, they did not want to have sex because the participants were tired, had waited long before resuming sexual intercourse and thought sex was painful for women. Rose explained:

"Usually my husband eeee, because I was, my vagina was changing, my vagina was becoming short and so they gave me the KY jelly to be used… it was hard because my husband was complaining that my vagina is not the same like he knows, it was hard, it was paining when we meet. He said to me I must go back to the doctor to tell that there was a problem."

Maggie described her experience:

"Heish it's too much, my husband nay, he is not feeling alright with me, he has changed…he is saying am sick…it's not okey, he doesn't want to have sex because I feel tired, he just complains."

Karen added:

"Yea eish this thing is affecting my life, the vagina sometimes my boyfriend came, if you want to make sometimes my vagina is tight, tight, tight, tight, he is complaining, he is complaining, its worrying me a lot, he has to push and push and push…"

Some participant expressed how they engaged in sexual intercourse merely to satisfy their spouse, without them or their spouses enjoying this intimacy. Maureen said:

"He is not having sex because he thinks it's painful…..I think he doesn't enjoy sex anymore because I can see eeee hahahaha I can see, I can see that aaaaa not like before anymore…..I can see it because we don't sex like before, he takes long, I can see it he is just doing to satisfy me, I was worried but am fine, I understand what he is going through."

Diana explained:

" The feeling to have sex like a woman is not there, but I can't tell him that, I can't tell him that, sometimes maybe let's say when he feels like, if he wants to, it's better if I feel that time, but if he wants me in that moment even if I don't feel like…..If you are a woman, you have to sleep with your husband anytime that he wants, but he touches and there is nothing… it can be so bad….yea if he wants something he wants now you must give him what he wants, if not it might be a problem" (Diana).

Some participants experienced a loss of desire for sex, as they no longer had "feelings like a women". Carol described her experience:

"I don't want sex anymore, am not feeling like to have sex, my feelings it's not there, just because am feeling that am sick I do not want my husband anymore…..also my husband takes long or even if I had some feeling that I want sex but my husband I think he is also have problems about sexuality, it takes long to meet me to have sex so that's why sometimes I lose appetite and that's why am feeling pain inside when I have sex, even if I tell him, he said that he is not feeling to have sex……so even if I have feelings where can I get a man to have sex with, I just sleep and have dreams and forget about that."

4.3.4 Theme 4: Spiritual issues

Spiritual issues also resulted from the physical problems the participants experienced. Most participants blamed themselves for their life situation, for not having enough money to buy food and visit loved ones and seeing children fighting. They also experienced cancer as a neglected disease and were afraid of death. "Why me?" was a question they asked God very often. Hildah said:

"….just like that, last year my sister passed away, then last year again my granddaughter passed away yoooo, it's just like that and am asking why why…"

Ezra said:

"Sometimes eeeee my children they spoke, am bad, am bad, am bad…..my children they fight….I don't know, I don't know, this is affecting me too much, too much, too much…"

Fenny experienced cancer to be a neglected disease with those suffering from AIDS getting preference. She said:

"…now people are crazy with AIDS, all the money about HIV/AIDS they are running round for people with HIV/AIDS, what about us?... what about cancer?"

Carol's experience of the consequences of her disease and treatment created anxiety about dying and the care of her children. She said:

"Aaaaa because am not feeling well in the body, the urine is not coming to the way, the blood is coming to the other side why? And am thinking about my children they are still young, no one who can look after them since I have no mother, no father, am the only one to look after them, if am dying no one can take care of my children so am very very worried about my life…"

Most participants experienced prayer and faith in God as a source of hope and strength. They believed that with God everything would be "alright". A belief in God as all knowing also helped them to have courage and confidence as Annie, Maureen and Carol explained:

"I believe in God, to move on yes……but if the doctor says do this, you must do it,….but I told God, if you believe in God, nothing can happen to you, and if you have got cancer, it's not the end of the world, your time will come when everybody is going to die….you see when you look at me who can tell I have got cancer, nobody, nobody, but am telling you since 2006" (Annie).

"Just the prayer hehehehe, I just feel good you know, hmmmm, you just say dear God help the doctors to see if there is something wrong from there you take it from there" (Maureen).

"Only to go to church to pray, yes to invite God in my life to help me, to save me to all these situations, I believe in God, yea to give me hope and power to come to the doctors if the doctor say that your problem is this and that then I go to God to tell God, to tell God that I have got this and that, the only way to survive it's you most to give me strength, to give me power to overcome this situation, you are the only one who can save me, who can heal me" (Carol).

4.3.5 Theme 5: Health system challenges

The health care system added to participants' suffering. Participants were of the opinion that they received no assistance with health problems at primary health clinics, for as soon as their status as a cancer patient was known, they were referred to the hospital where they were treated. Conversely, they were of the opinion that the medical practitioners at the cancer clinics only focus on cancer and do not take notice of other health problems, leaving them without the health care they needed. In addition, having to travel to hospitals for treatment posed the challenge of distance and cost. Fenny described her experience:

"... the chemo, the radiation helps a lot but we need as cancer patients we need to have a little clinic, a special doctor near to our clinics so that if we are sick, they can help us…I start at 4 o'clock to here, I didn't have money and am sick, when we go to the clinic they said we are not treating cancer here, you see, will you please go to…."

Ezra said:

"….doctors said no, am working here for cancer not for pain here and here…..I also have got the problem but I can't tell them…"

Participants also experienced an information deficit and felt they received inadequate information and health education about cancer, cancer treatment, the side effects of treatment and the importance of follow-up consultations. Hildah expressed her experience as follows:

"Ahhhh I don't know, heee why we must keep here, why we must come to check every month, every year, every month, every year, check the doctor check" (Hildah)

Diana said:

"You know what, the people say that there are medicines that you must take like the mixtures, the herbal mixtures, and the many other things that you can take so I wanted to ask, how possible to use these things"

Carol concluded:

"Aaaaa I can ask that this cancer as you are studying you know much than me you know better than me, I didn't know anything…"

4.4 DISCUSSION

The study provided evidence that women treated with radiotherapy for cervical cancer experience various late effects due to the treatment and the disease. These experiences result in various physical problems, which have a negative influence on their social, economic and sexual lives.

Chronic fatigue expressed as “weakness” and “getting tired” was a major problem for these women and is nothing new, as this is a well-known phenomenon in patients treated for cancer. Maree, Mosalo & Wright (2008), in a South African study exploring the most common symptoms in patients suffering from advanced cancer, found a high prevalence of fatigue and Vistad et al. (2007), in a study conducted in Norway, found chronic fatigue a problem for cervical cancer survivors. Suffering from chronic fatigue had a negative influence on women’s lives – domestic chores were burdensome and they were unable to work to earn an income, a situation adding to their burden, as they were concerned about how they would take care of their families. The health care system also added to their financial suffering by not providing primary health care services at their local clinics, but referred them back to the hospital, a costly exercise for women already struggling to attend scheduled follow-up visits due to the lack of transport money. It is known that cervical cancer is a disease of poor and disempowered women (Denny, Quinn & Sankaranarayanan, 2006) with the public health care system failing women in terms of early diagnosis (Van Schalkwyk, Maree & Wright, 2008; Maree, Langley & Nqubezelo, 2014), but evidence could be found in support of the finding of the health care system’s failure to provide primary health care services to patients with cancer. This is disturbing as it adds to the burden of cancer patients.

It was interesting to find that pain, especially back pain, remained a problem and whether this is disease and treatment related is unclear. Andreyev (2007) found nearly one third of all patients

would experience some degree of abdominal or rectal pain after pelvic radiotherapy and that the nature of the pain experienced was such that it influenced daily living; a finding supported by the current study.

Bowel and bladder effects related to cervical cancer and its treatment were a great challenge to the women and added to their suffering. Burns et al. (2007), in a study focusing on assessing the impact of late treatment effects in cervical cancer conducted in the UK, revealed a range of bladder problems after radiotherapy to the pelvis, including urinary frequency and incontinence. The bowel problems support the findings of Abayomi, Kirwan and Hackett (2005), who found most women described how bowel problems often re-appeared after the period of recovery; diarrhoea could either be continuous or alternate with periods of constipation.

Experiencing bladder and bowel symptoms not only changed the way women dressed, as evidenced by "you see I wear two skirts," but also influenced their social lives expressed as "it's you can't go to people's houses." Burns et al. (2007) found even persistent mild bladder symptoms had an influence on the daily lives of women treated for cervical cancer. Lukazc et al. (2012), in a study investigating how accidental bowel leakage influences the quality of life of women living in the US, support the findings of the current study by describing how the changes in participation in social activities led to feelings of frustration and influenced the emotional health of the participants in their study. When exploring how women living in the community manage their fecal incontinence, Peden-McAlpine, Bliss and Hill (2008), found they had to consider the distance from home before accepting invitations to participate in social activities. The anxiety about the risk of accidents in public places brought a sense of discomfort of being in a public place and limited women's ability to engage in productive work outside the home. Hagglund and Ahlstrom (2007), in a Swedish study focusing on the meaning of women's experience of living with long-term

urinary incontinence, found some women had to plan their working days with reference to access to a toilet.

The study provided evidence that the women experienced various vaginal problems which had an influence on their sexual lives. Lack of privacy expressed as "I do not have privacy" prevented some from dilating their vaginas, adding to sexual dysfunction caused by the shortening and dryness of their vaginas. Vistad et al. (2006), in a study conducted in Norway, also reported vaginal dryness, whilst Saewong and Choobun (2005) explain that radiotherapy directly affects vascular and genital elasticity tissue resulting in shortening and narrowing of the vagina causing patients to experience dyspareunia or difficulty in penetration.

Women in the current study also experienced dyspareunia described as "it was paining when we meet" and difficulty in penetration described as "he has to push and push and push…" The sexual dysfunction caused worry amongst the women, "it's worrying me a lot," leading to sex being done only to satisfy or please the spouse and a loss of sexual desire. Burns et.al (2007) support these findings, as the participants in their study also experienced anxiety about sexual activity and lacked interest in sex which had an adverse influence on intimate partner relationships. Mercadante et al. (2010) are however of the opinion that sexual dysfunction is often both physical and psychological. It is therefore quite possible that the spouses, who complained how the vagina was short, dry or tight, took a long time to resume sex thinking it was painful for the women, which could have added to the women's sexual dysfunction.

As supported by "…am not feeling well in the body…very, very worried about my life…" spiritual problems were mainly due to physical, social and economic problems the women were experiencing. Women were anxious because their husbands complained they were sick and were worried due to the financial difficulties they were experiencing and being unable to adequately take

care of their families especially children, eventually they were unable to sleep, blamed themselves and viewed cancer as a painful disease. It is therefore quite reasonable to say some of the women experienced spiritual distress.

According to the North American Nursing Diagnosis Association (2001), spiritual distress is defined as "the disruption in the life principle that pervades a person's entire being and that integrates and transcends one's biological and psychosocial nature." Villagomeza (2005), in a study on spiritual distress in adult cancer patients, described spirituality in relation to connectedness, faith and religious belief system, value system, sense of meaning and purpose in everyday life and amidst suffering, sense of self-transcendence, sense of inner peace and harmony amidst chaos of life and sense of inner strength and energy which is integrative and unifying beyond the physical realm. During spiritual distress, the patient loses hope, questions his or her belief system, or feels separated from his or her personal source of comfort and strength (Villagomeza, 2005). In the current study, the majority of the women explained how belief in God, through prayer and going to church, was a source of strength and hope to help them cope and they had confidence in God as all knowing and that everything would be fine.

As supported by "I didn't know anything," the study has provided evidence of a lack of reinforcement of information and education on cancer, its treatment, side effects of treatment and the importance of follow-ups. Burns et.al (2007) support this finding and revealed that the women in their UK study also felt there was inadequate provision of information about treatment effects. This is contrary to the WHO's (2006) recommendations on the management of patients with invasive cancer, which stipulates these patients have to be made aware they will need long-term follow-up, have contact with the cancer unit where they received treatment and need information about late complications after radiotherapy.

It was positive to find that a good support system played a huge role in women's lives, as those supported by their families and relatives were able to cope and move on with life despite the physical or social problems being experienced; "they support me too much…" and "I thought that I had no cancer before…" serves as evidence. Bloom et.al (2007), in a study conducted in Europe focusing on multi-dimensional quality of life amongst long-term adult cancer survivors, showed that depressive symptoms, anger and confusion revealed a significant association between high levels of social support and less cancer specific distress. Maree et al. (2013), in South African study, found women whose life partners were caring and supportive, seemed to be in a better position to receive support after diagnosis and during treatment than those who lived with uncaring and unsupportive partners. The women in the current study who experienced support are indeed the lucky ones.

4.5 SUMMARY

The chapter provided for the discussion in detail, showing the problems women experience as physical problems, social-economic issues, pyscho-spiritual issues, sexual issues and healthy system challenges.

In Chapter 5, the study will be justified, recommendations for future research will be made and the limitations of the study will be discussed.

CHAPTER 5

JUSTIFICATION, LIMITATIONS AND RECOMMENDATIONS

5.1 Introduction

In the previous chapter, the findings of the enquiry were presented and discussed in detail. This chapter provides justification of the study, limitations to the study and recommendations. The focus of this study was to justify the study in terms of the research purpose. The focus is further to evaluate the study in terms of positive contribution to the body of scientific knowledge and to discuss the limitations of the study. Finally, further research to be conducted will be presented as well as the conclusion of the study.

5.2 Justification of the study

The study will be justified in terms of purpose of the study, which was to explore how women diagnosed with cervical cancer and treated with radiotherapy at an academic hospital in Johannesburg experience the long term effects of the disease and treatment.

In Chapter 3, the research method and design was described in detail and in Chapter 4, the findings were described and discussed. The problems women experience, have been discussed in terms of physical problems, social-economic issues, psycho-spiritual issues, sexual issues and healthy system challenges. It can therefore be stated that this study is justified in that the purpose has been achieved.

5.3 Limitations of the study

- Only women treated at the one academic hospital were included in the study and the participants were homogenous in that only one racial group participated, therefore the findings cannot be generalised to other racial groups.

- Only women who could speak and understand basic English were included in the study, therefore the findings cannot be generalised to other women who can only speak an indigenous language.

- Findings cannot be generalised to women who had treatment for cervical cancer longer than 12 months as only women who had completed treatment 12 months prior to the study were included in the study.

- 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.

5.4 Recommendations

This study provides several answers regarding long term problems women experience after radiotherapy for cervical cancer. It is recommended that nurse researchers and nurse clinicians in collaboration with the multi-professional team and cervical cancer survivors develop and test interventions to address the late side-effects of cervical cancer to improve the disease and treatment related outcomes of these women.

Further studies can be done to investigate experiences of cervical cancer and its treatment in women longer than 12 months after treatment, the current study can also be used as point of departure to develop a questionnaire and follow up with a quantitative study in order to include more respondents.

For clinical practice it could be recommended that patient education skills of nurses working with these patients be scaled up. Doctors and nurses could be made aware of patients' needs regarding pain management and other mentioned challenges, thus patients should be treated holistically.

5.5 Conclusion

This study has provided evidence that women experience various physical problems due to the long term effects of cervical cancer and its treatment. These physical problems have an influence on their social, economic, psychological and sexual lives. The women are affected financially as they are unable to work or do hard jobs as they tire easily and eventually are unable to take care of their families. Women are also affected negatively socially, as they do not freely move in public and even fear to visit their loved ones as its embarrassing when they have soiled themselves. Physical problems also influence their sexual lives, as they experience discomfort when having sex with their spouses leading to fear of having sex, loss of sexual desire and changes to their body image. However, good support from families and having a belief in God as all knowing is a source of strength, which influences these women positively.

REFERENCES

Abayomi, J., Kirwan, J. & Hackett, A. (2009). The prevalence of chronic radiation enteritis following radiotherapy for cervical or endometrial cancer and its impact on quality of life. *European Journal of Oncology Nursing*, 13:262-267.

Ahern, K.J. (1999). Ten Tips for Reflective Bracketing. *Qualitative Health Research*, 9: 401-411.

Albrecht, C. (2006). Overview of the South Africa cancer research environment as a basis for discussions concerning the activation of CARISA (*Cancer Research Initiative of South Africa).* Cape Town.

Andreyev, J. (2007). Gastrointestinal symptoms after pelvic radiotherapy: a new understanding to improve management of symptomatic patients. *Lancet Oncol*, 8:1007-17

Ashford, L. & Collymore, Y. (2005). *Preventing Cervical Cancer Worldwide: Population Reference Bureau*, online <http//www.prb.org/pdf05/prevent cervical cancer-brief_eng.pdf> [accessed 17/05/2012].

Begley, C. (2008). Approaches to research. In: Watson, R., Mckenna, H., Cowman, S. & Keady, J. (Eds), *Nursing Research: Designs and Methods* (pp. 13-21). Edinburgh: Churchill Livingstone.

Bloom, J.R., Petersen, D.M & Kang, S.H. (2007). Multi-dimensional quality of life among long-term adult cancer survivors. *Psycho-Oncology*, 16:691-706.

Brooker, C. (2006). *Churchill Livingstone's Dictionary of Nursing*. Philadelphia: Elsevier.

Burns, N. & Grove, S. (2007). *Understanding Nursing Research*. St. Louis: Elsevier.

Burns, M., Costello, J., Ryan-woolley, B. & Davidson, S. (2007). Assessing the impact of late treatment effects in cervical cancer: An exploratory study of women's sexuality. *European Journal of Cancer Care*, 16: 364-372.

Denny, L. (2003). Cervical cancer: the South African Perspective. *International Journal of Gynecology and Obstetrics,* 95:5211-5214.

Denny, L. (2010). Cervical Cancer in South Africa: An over-view of current status and prevention strategies. *CME,* 28(2): 70-73.

Denny, L., Quinn, M. & Sankaranarayanan, R. (2006). Chapter 8: Screening for cervical cancer in developing countries Vaccine, 24(S3): S3/71-S73/77.

Department of Health, (2000). *National Guideline for Cervical Cancer Screening Programme*. Government printers, Pretoria, SouthAfrica.

Faithful, S. (2006). Radiotherapy. In: Kearny, N. & Richardson, A. *Nursing patients with cancer*. P 265-282. China: Elsevier.

Ferlay, J., Shin, H.R., Bray, F., Forman, D., Mathers, C. & Parkin, D.M. (2010). Estimates of Worldwide Burden of Cancer. *International Journal of Cancer,* 127(12): 2893-2917.

Haas, M.L., Hogle, W.P., Moore-Higgs, G.J. & Gosselin-Acomb, T.K. (2007). *Radiotherapy: A Guide to Patient Care*. St Louis: Elsevier.

Hägglund, D. & Ahlström, G. (2007). The meaning of women's experience of living with long-term urinary incontinence is powerlessness. *Journal of Clinical Nursing,* 16:1946-1954.

http://www.Johannesburghospital.org.za

Itano, J.K & Taoka, K.N.(2004). *Core Curriculum for Oncology Nursing*. 4th Edition. Elsevier.

Juraskova, I., Butow, P., Robertson, R., Sharpe, l., Mcleod, C. & Hacker, N. (2003). Post-treatment sexual adjustment following cervical & endometrial cancer: A qualitative insight. *Psycho-Oncology*, 12: 267-279.

Kim, S.H., Kang, S., Kim, Y.M., Kim, B.G. & Seong, S.J. (2010). Prevalence and Predictors of Anxiety and Depression among Cervical Cancer Survivors in Korea. *Int J Gynecol Cancer*, 20(6):1017-24; 9.

Korfage, I.J., Essink, M.L., Mols, F., Vande-Poll, F.L. et al. (2009). Health-related quality of life in cervical cancer Survivors: a population-based survey. *Int J Radiat Oncol Biol phys*, 73(5):1501-9.

Langhorne, M.E., Fulton, J.S & Otto, S. (2007). *Oncology Nursing*. 5th Edition. Elsevier.

Lopez, K.A & Willis, D.G (2004). *Qualitative Health Research.* Descriptive versus Interpretative phenomenology: Their contributions to nursing knowledge. *Qual Health Res*, 14:726.

Lukacz, E.S., Brown, H.W., Wexner, S.D.,Segall, M.M. & Brezoczky, K.L. (2012). Quality of life impact in women with accidental bowel leakage. *Int J Clin Pract*, 66(11):1109-1116.

Maree, J. E., Mosalo, A. & Wright, S.C.D. (2013). 'It depends on how the relationship was before you became ill': Black South African women's experience of life support through the trajectory of cervical cancer. *European Journal of cancer care*. Doi: 10.1111/ecc.12051

Maree, J.E., Langley, G. & Nqubezelo, L. (2014). “Not a nice experience, not at all”: Underprivileged women’s experiences of being confronted with cervical cancer. *Palliative and Supportive care.* Doi: 10.1017/S1478951513001247.

McCance, T. & Mcifatrick, S. (2008). Phenomenology. In: Watson, R., Mckenna, H., Cowman, S. & Keady, J. (Eds), *Nursing Research: Designs and Methods* (pp. 243-250). Edinburgh: Churchill Livingstone, UK.

Mercadante, S., Vitrano, V. & Catania, V. (2010). Sexual issues in early and late stage cancer: a review. *Support Care Cancer*; 18(6): 659-665.

Miller, W.R. (2010). *Qualitative Research findings as Evidence:* Utility in Nursing Practice. *Clin Nurse Spec*, 24(4):191-193.

Moodley, M. (2009). Cervical Cancer in South Africa: The Challenges. *SA Journal of Gynaecological Oncology,* 1 (1): 11-13.

National Health Laboratory Service, (2012). “*Cancer Statistics*” http://www.nioh.ac.za/?page=cancer_statistics&id=163.

Newton, S., Hickey, M. & Marrs, J. (2009). *Mosby Oncology Nursing Advisor: A Comprehensive Guide to clinical practice*. St. Louis: Elsevier.

Nolan, M. (2008). Qualitative Data Analysis: Achieving Order out of Chaos. In: Watson, R., Mckenna, H., Cowman, S. & Keady, J. *Nursing Research: Designs and Methods*. (P 341-352.) Edinburgh: Churchill Livingstone, UK.

Nursing Diagnoses: Definitions and classification. (2001-2002). Philadelphia: North American Nursing Diagnosis Association 2001.

Ozsaran, Z. Yalman, D., Yurut,V., Aras, A., Ozsaran, A., Hanhan, M. & Haydaroqlu, A. (2003). Radiochemotherapy for patients with locally advanced cervical cancer: early results. *Eur J Gynaecol oncol*, 24(2):191-4

Park, S.Y., Bae, D.S., Nam, J.H., Park, C.T., et al. (2007). Quality of life and sexual problems in disease-free survivors of cervical cancer, compared with general population. *American Cancer Society*, 110 (12): 2716-25.

Penden-McAlpine, C., Bliss, D. & Hill, J. (2008). The experience of community-living women managing fecal incontinence. *West J Nur Res*, 30(7): 817-835.

Polit, D.F. & Beck, C.T. (2012). Nursing research, *Generating and Assessing Evidence for Nursing Practice*. London: Lippincott, Williams & Wilkins.

Polit, D.F. & Hungler, B. (1999). *Essentials of Nursing Research, Methods, Appraisal and Utilization.* 4th Edition, Lippincott, Philadelphia.

Population Reference Bureau & Alliance for cervical cancer screening. (2004). *Preventing cervical cancer worldwide*; Population Reference Bureau, Washington, USA.

Saewong, S. & Choobum, T. (2005). Effects of Radiotherapy on Sexual activity in women with Cervical Cancer. *J Med Asso*, 88 (2): S11-S15.

Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, 22:63-75.

Snyman, L.C. (2013). Prevention of cervical cancer-how long before we get it right. *S Afr J OG*, 19(1):2-3.

Van Schalkwyk, S.L., Maree, J.E. & Wright, S.C. (2008). Cervical cancer: the route from signs and symptoms to treatment in South Africa. *Reproductive Health Matters*, 16:9-17

Varricchio, C.G. (2004). *A Cancer Source Book for Nurses*. Eighth Edition. Jones and Bartlett, London.

Villagomeza, L.R. (2005). Spiritual distress in adult cancer patients. Toward conceptual clarity. *Holistic Nurs Pract*; 19(6) 285-294.

Vistad, I., Fossa, S.D., Kristensen, G.B. & Dahl, A.A. (2007). Chronic Fatigue and its correlates in long-term survivors of Cervical Cancer treated radiotherapy. *International Journal of Obstetrics and Gynaecology*, 114(9): 1150-8.

Vistad, I., Cvancarova, M., Kristensen, G.B & Fossa, S.D. (2011). A study of chronic pain after radiotherapy in Survivors of locally advanced cervical cancer. *J Cancer Surviv*, 5(2): 208-16.

Vistad, I., Fossa, S.D. Kristensen, G.B & Dahl, A.A. (2007). Chronic fatigue and its correlates in long-term survivors of cervical cancer treated with radiotherapy. *BJOG*, 114(9): 1150-8.

World Health Organisation, (2006). *Comprehensive Cancer Care. A guide to essential practice*. Geneva, Switzerland.

World Health Organisation and International Union against Cancer, (2005). *Global action against cancer*. WHO and IUAC. Switzerland.

Zeznock, D.E., Gilje, F.L. & Bradway, C. (2009). Living with urinary incontinence: Experiences of women from 'The last Frontier'. *Urologic Nursing*; 29(3): 157-163, 185.

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APPENDIX A

INFORMATION DOCUMENT

Study title: WOMEN'S EXPERIENCES OF LONG-TERM EFFECTS OF CERVICAL CANCER AND ITS TREATMENT

Good day Madam

My name is Sophai Ntinga and I am currently registered as a student at the University of the Witwatersrand in the Department of Nursing Education. I would like to conduct research on the long-term effects of cancer of the mouth of the womb, also known as cervical cancer and its treatment, to learn what women experience. Research is the process to learn the answer to a question. If we can answer this question, it will help nurses to care for patients in a better way. I am approaching you to help us find out what women experience, as you had treatment with the machine (radiotherapy) for this illness (cancer of the mouth of the womb). This is not part of the routine care but will help us answer the above question.

I would like to invite you to consider participating in this research study. For this study, I will use the words that people tell me and should you agree to take part in the study, I will interview you for about an hour. I will ask you about your experience since the completion of your radiotherapy treatment. With your permission and signing of a consent form, I will make a tape recording of our discussion. Only a few women (about 16) will take part in the study and the interviews will take place in the Radiation Oncology Department in a quiet and private room.

You might become emotional during the interview, as you will be relating your experiences now that you have completed your treatment. Should you become emotional and not wish to continue. I

will stop and reschedule the interview. With your permission, I will ask Sr Lucy Nqubezelo who works in the clinic to counsel you, her contact number is 011-488 2047.

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. You can decide whether you would like to take part in the study or not, you will not lose any benefits to which you are entitled. If you decide to take part in the study, but decide to withdraw at any time during or immediately after the interview, you may do so without loss of any benefits to which you are entitled. However, once our interview has been typed, I will not be able to identify your interview as all names are removed, which means you will be unable to withdraw from the study. 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 requests, research records may be inspected to view the quality and the Research Ethics Committee can inspect how I analysed what you told me. On completion of information analysis, all data sheets and the 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 publication of the report, where after it will be destroyed. When I write the report on what all the women told me, you might recognise your words, however people who will read the report will not be able to identify them.

If you need further information about the study, please contact me, via my phone number, 0732358835.

If you would like more information about the ethical permission of the study, or would like to report or complain about how the study was done, please contact Prof Peter Cleaton-Jones, on 011 717 2301 during office hours or by e-mail at Peter.Cleaton-Jones@wits.ac.za.

Thank you for taking the time to read this information sheet.

Yours sincerely,

Sophai Ntinga

APPENDIX B

CONSENT FORM

I have been given the information sheet on the Research Title: "***Women's experiences of long-term effects of cervical cancer and its treatment***". I have read and understood the information sheet. If I agree to participate in the study, I will be interviewed for approximately 45 minutes to one hour about my experience since the completion of cervical cancer treatment and the disease.

I understand it is up to me whether or not to participate in the interview and that there will be no penalty or loss of benefits to which Iam entitled if I decide not to participate. I also understand that I may discontinue participation at any time until 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)

…… (Signature of researcher) …….. (Date)

APPENDIX C

CONSENT FORM FOR RECORDING INTERVIEW

I have been given the information document on the Research Title: "***Women's experience of long-term effects of cervical cancer and its treatment***". I have read and understood the information document.

I understand that I can decide if the interview should be recorded and there will be no penalty or loss of benefits to which I am entitled if I decide against the recording. I also understand that I may discontinue participation at any time without any penalty or loss of benefits of which am otherwise entitled.

I understand that information from the recording will be transcribed and transcripts will be given a code and my name will not be mentioned. I understand that I can ask the person interviewing me to stop recording, and to stop the interview altogether, at any time.

I consent voluntarily for the researcher to record the interview.

…… (Signature of participant) …….. (Date)

…… (Signature of researcher) …….. (Date)

APPENDIX D

INTERVIEW GUIDE

1. **Age-**

2. **Cultural group-**

3. **Where living**

Urban		Rural		Other	

4. **Marital status**

Married		Single		Widow		Divorced		Other	

5. **Living arrangement**

With Husband		With Partner		With adult children		With young children		Other	

6. **Personal monthly income**

7. **How many people depend on this income?**

8. **Do you take care of anybody?** **If yes, who?**

9. Stage of the disease -

10. Treatment

External beam radiation		Brachytherapy		Chemotherapy		Other	

Interview questions

Opening question: Please tell me what problems caused by the treatment you received for the cancer, are you experiencing at this stage?

- Physical problems
- Psychosocial
- Other

APPENDIX E

University of the Witwatersrand

Faculty of Health Sciences

Department of Nursing Education

7 York Road

Parktown 2193

The Chief Executive Officer, the Nursing Manager and the Unit Manager

Charlotte Maxeke Johannesburg Academic Hospital

Parktown 2193

Johannesburg

Dear Sir/Madam,

RE: PERMISSION TO CONDUCT RESEARCH AT THE ONCOLOGY DEPARTMENT

My name is Sophai Ntinga, a student at the University of the Witwatersrand, Johannesburg, currently registered for Master of Science in Nursing Oncology in the Department of Nursing Education. I am hereby asking for permission to undertake a research study at the Johannesburg Academic Hospital. I am investigating, "Women's experiences of long-term effects of cervical cancer and its treatment".

The purpose of this study is to explore critically the experiences of women who have been treated with radiotherapy for cervical cancer after 12 months of treatment. This study will contribute to the provision of holistic care to the women in the follow up period post treatment for the cancer of the cervix.

Participation to this study is voluntary and confidential. The participants' name will not appear anywhere and only code numbers will be used. The interviews will be conducted in a quiet and private room for approximately one hour. The information will be used for the intended purpose only. The participants are free to withdraw from the study at any time if they so wish without any negative consequence to their care. An informed written consent will be obtained from all patients to be included in the study. Patient signing of the consent will indicate acceptance to participate in the study. A tape recorder will be used during data collection and permission will be sought. Participants will be free to reject the audio-tape if they so wish. I hope to conduct this study in the Oncology department where women come for their follow-up care after radiotherapy treatment.

The name of the participating Hospital and patients involved will not be divulged in the research report. Ethical clearance has been sought from the Human Research Ethics Committee of the University of the Witwatersrand. Please find the attached copy of my research proposal.

Thanking you in anticipation for allowing me to conduct the study. Your permission is valuable and highly appreciated.

Yours faithfully

Sophai Ntinga (MSc Nursing Student)

Date……..

APPENDIX F

ETHICAL CLEARANCE CERTIFICATE

R14/49 Sophai Namukonda Ntinga

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130344

NAME: (Principal Investigator) Sophai Namukonda Ntinga

DEPARTMENT: Department of Nursing Education
Charlotte Maxeke Johannesburg Acedemic Hospital

PROJECT TITLE: Women's Experiences of Long Term Effects of Cervical Cancer and its Treatment

DATE CONSIDERED: 05/04/2013

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Prof Lize Maree

APPROVED BY:
Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 08/05/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature

Date 10/05/2013

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX G

PERMISSION TO CONDUCT RESEARCH

GAUTENG PROVINCE

HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. L. Mngomezulu
(011): 488-3793
(011) 488-3753
24th May 2013

Ms. Sophai Ntinga
MSc Nursing Student
University of the Witwatersrand

Dear Ms. Ntinga

RE: "Womens experiences of long term effects of cervical cancer and its treatment"

Permission is granted for you to conduct the above research as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Approved / not approved

Bogoshi

Ms. G. Bogoshi
Chief Executive Officer
27/5/2013