BRACHYTHERAPY FOR CERVICAL CANCER: GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT

by

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DECLARATION

I, **Deirdré Long**, do hereby declare that the work submitted here is the result of my own independent investigation. I further declare that this work is submitted for the first time at this university/faculty towards a Philosophiae Doctor degree in Oncotherapy. This thesis has not previously been submitted by me to any other university/faculty as part of any qualification.

_____ _____

Ms D. Long **Date**

I hereby cede copyright of this thesis in favour of the University of the Free State.

_____ _____

Ms D. Long **Date**

DEDICATION

I would like to dedicate the thesis to my husband:

MICHAEL

His mouth is most sweet,

yea, he is altogether lovely.

This is my beloved, and this is

my friend.

Solomon's Song 5:16

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ABBREVIATIONS / ACRONYMS / SYMBOLS

AAPM	**American Association of Physicists in Medicine**
ABS	**American Brachytherapy Society**
ACCP	**Alliance for Cervical Cancer Prevention**
ACMP	**American College of Medical Physicists**
ACR	**American College of Radiology**
ACRO	**American College of Radiation Oncology**
APA	**American Psychological Association**
BCCEWG	**Brachytherapy Cervical Cancer Expert Working Group**
CD	**Compact Disc**
CD-ROM	**Compact Disc-Read Only Memory**
CEO	**Chief Executive Officer**
cf	**check reference**
CMC	**Computer Mediated Communication**
CT	**Computed Tomography**
CTV	**Clinical Tumour Volume**
CUT	**Central University of Technology**
DIRAC	**Directory of Radiotherapy Centres**
EBRT	**External Beam Radiotherapy**
e.g.	**for example**
E-mail	**Electronic mail**
et al.	***et alii* (and others)**
etc.	**etcetera**
FIGO	**International Federation of Gynaecologists and Obstetricians**
GB	**Gigabyte**
GEC-	**Groupe Européen Curiethérapie-**
ESTRO	**European Society for Radiotherapy and Oncology**
GLOBOCAN	**Global Burden of Cancer**
GTV	**Gross Tumour Volume**
GYN	**Gynaecological**
HIV	**Human Immunodeficiency Virus**
HPV	**Human Papillomavirus**

IAEA	**International Atomic Energy Agency**
ICO	**Institut Català d´ Oncologia**
ICRU	**International Commission on Radiation Units and Measurements**
IOM	**Institute of Medicine**
IPFCC	**Institute for Patient- and Family-Centered Care**
MCG	**Medical College of Georgia**
MEDLINE	**Medical Literature Analysis and Retrieval System Online**
MRI	**Magnetic Resonance Imaging**
NHS	**National Health System**
NRC	**National Research Corporation**
NRF	**National Research Foundation**
Ovid	**Objective view and interaction design**
PC	**Personal Computer**
PubMed	**Public/Publisher MEDLINE**
3D	**Three Dimensional**
TRIP	**Turning Research Into Practice**
UFS	**University of the Free State**
UK	**United Kingdom**
USA	**United States of America**
viz	**namely**
WHO	**World Health Organization**
&	**and**
%	**Percentage**
Gy	**Gray**

DEFINITIONS

BRACHYTHERAPY The first form of conformal radiotherapy that involves treatment with radioactive sources (usually sealed) within or very close to the target (Stewart, Halloway & Devlin 2013).

CERVICAL CANCER Cancer or tumour of the neck (cervix) of the uterus (Viswanathan 2013).

FOCUS GROUP Focus groups are group interviews (De Vos, Strydom, Fouché & Delport 2011). They consist of small groups of people who are brought together by the researcher to explore attitudes, perceptions, feelings and ideas about a specific topic (Denscombe 2007).

GUIDELINES A document that includes a set of statements that suggest or recommend specific professional behaviour, endeavour, or conduct for specific group of professionals (APA 2002).

HIGH DOSE RATE Implant procedures may be classified in terms of source loading technology (preload, manually afterload or remotely afterload) and the dose rate used (low, medium or high). High dose rate: over 12 Gy per hour (ICRU 38 1985).

INTRACAVITARY The positioning of applicators (bearing the radioactive sources) into a body cavity in close proximity to the tumour (Williamson, Allen Li & Brenner 2013)

PATIENT-CENTRED CARE	An innovative approach to planning, delivery and evaluation of health care that is grounded in mutual partnerships among health care providers, patients and families (IPFCC 2012).

CONCEPT CLARIFICATION

ACADEMIC PATIENT

The term "academic patient" refers to a governmental or state patient. The research site, the Department of Oncology, Universitas Annex is an academic hospital that forms part of the Universitas Academic Complex.

PATIENT MANAGEMENT

Numerous proposed definitions of patient-centred care encompass similar core concepts, but there are no globally accepted definitions (ACSQHC 2012). The Institute for Patient- and Family-Centred Care defines patient-centred care as an innovative approach to planning, delivery and evaluation of health care that is grounded in mutual partnerships among health care providers, patients and families (IPFCC 2013).

This study used a patient-centred care approach to establish guidelines to facilitate quality patient management in a multidisciplinary environment. The guidelines address the non-technical aspects of patient management. For the purpose of this study, the term "patient management" was associated with the patient-centred care for cervical cancer patients receiving high dose rate-intracavitary brachytherapy.

SUMMARY

Key terms: Brachytherapy, high dose rate, cervical cancer, guidelines, patient-centred care, multidisciplinary team, qualitative, phenomenology, quality patient management.

This study was undertaken to establish guidelines to facilitate quality patient management for cervical cancer patients, receiving high dose rate-intracavitary brachytherapy, in a multidisciplinary environment. An extensive literature search found that guidance to service providers and members of multidisciplinary teams (radiation oncologists, radiation therapists and oncology nurses) is limited to the organisational and technical aspects of high dose rate-intracavitary brachytherapy treatment delivery. The aim was thus to formulate patient-centred guidelines that could be used as a tool to guide members of multidisciplinary teams in providing quality patient management to this group of women in governmental and private brachytherapy units in South Africa.

A prospective, qualitative study with a phenomenological approach was chosen as the framework for the study. The study was approved by the management of the hospital and the department and by the Ethics Committee of the Faculty of Health Sciences, University of the Free State. All participants gave written informed consent before participation. The study objectives were approached in five stages.

In stage one the study utilised semi-structured, one-to-one interviews in English, Afrikaans or Sesotho in order to gain a detailed picture of a participant's experience and perceptions of patient management while undergoing brachytherapy. In order to include the opinions of women across the age spectrum into the study, the researcher purposively recruited participants from each of the following three age groups: 30-45 years; 46-60 years and 61years and older. Each age group included at least one private and one local oncology patient. Hospitalised patients were also included in the study sample. The sample size for this study was determined by saturation of the data. Saturation was reached having interviewed twenty-eight participants.

Interviews were conducted by a multilingual female social worker. An open-ended interview schedule in English, Afrikaans and Sesotho were designed by the researcher and provided the interviewer with a set of predetermined questions that guided the interviewing process. The participants had to respond to open-ended questions (with probes) at the department of Oncology, Universitas Annex, Bloemfontein after their third brachytherapy treatment. The order of questions in the interview schedule simulated the path of events that each participant had gone through at the department (from the new patient clinic up until brachytherapy treatment delivery). Interviews were audio recorded and transcribed before qualitative analysis by the researcher.

Understanding and acknowledging the patient's unmet needs were fundamental to the development of the proposed guidelines. The analysis identified shared and unique experiences amongst the 28 interviewed participants. Four themes with sub-themes were identified from the data: (1) informational needs, (2) patient disposition towards treatment, (3) psychological experience and (4) physical experience.

In stage two the scope of the proposed guidelines was formulated by (1) the integration of the patient experience of stage one, together with (2) a literature search and (3) the knowledge and experience of the researcher. The proposed guidelines addressed logistical matters of the practice setting and the collective and exclusive roles and responsibilities of members of the multidisciplinary team at the new patient clinic and the brachytherapy unit of the department. The proposed guidelines were aligned with the flow of patient management in the Department of Oncology.

In stage three of the research study the proposed guidelines were reviewed by members of the multidisciplinary team of the Department of Oncology who regularly interact with this group of patients. Twenty members of the multidisciplinary team working at the brachytherapy unit of the Department of Oncology, Bloemfontein, with at least a year's experience of service delivery at the brachytherapy unit, were purposively selected to participate in the focus group interviews. Focus groups usually include six to ten participants and therefore the twenty selected participants were divided into two focus groups. Each focus group was compiled in such a way that the members were comparable regarding professional category and years of experience. Medical physicists

were excluded as they are not directly involved with the management or care of patients at this unit.

The two focus group interviews took place on the same day. The setting was familiar and in close vicinity for the participants. The focus group interviews were conducted in English so as to accommodate all participants. The duties of the group facilitator were performed by the study promoter, while the duties of assistant facilitator during the focus group interviews were performed by the study co-promoter.

The topic guide for the focus group interviews was the list of proposed guidelines. The focus group interviews were guided by the interview schedule, during which general and specific, open-ended questions were asked. After discussions by the focus group, each section was summarised in agreement with the focus group by the assistant facilitator. An opportunity was provided for the focus group members to add additional information to the proposed guidelines.

The proposed guidelines proved to be clear and concise and structured and formulated in an explanatory and understandable manner that is easy to apply by all disciplines working at the new patient clinic and the brachytherapy unit. In total, six additional guidelines were proposed, twelve guidelines were amended and four guidelines were omitted. The words “shared responsibilities” were changed to collective responsibilities and the roles and responsibilities of members of the multidisciplinary team were allocated to a specific member/s.

In stage four of the research study the amended guidelines were reviewed by heads or designated representatives of governmental and private brachytherapy units in South Africa. This stage was undertaken to gather their opinions and views on the applicability and feasibility of the guidelines. Electronic mail interviews in English were conducted with seven heads or designated representatives. The layout and formulation of the guidelines were accepted by all the participants as it was found to be well compartmentalised with well-defined mandates. In addition the guidelines would be practical to implement at brachytherapy units as the layout and formulation of the guidelines are logical, clear and concise. Seventeen additional guidelines were proposed, two guidelines were amended and one guideline was omitted. The feedback

assisted the researcher in further refining the proposed guidelines, before the final presentation in stage five of the research.

The final guidelines presented in stage five of this research study provide a framework that clearly defines the collective and exclusive roles and responsibilities of members of multidisciplinary teams for implementation at the new patient clinic and brachytherapy unit, respectively. In addition, the guidelines address the practice setting of brachytherapy units, ensuring a secure environment for the patient. Although individual unit activities may differ and resource constraints may prevent the full implementation of the guidelines, these guidelines could be implemented with some refining and focussing on what is already in practice.

The researcher therefore conclude that the study aim and objectives have been achieved and that the guidelines will make a significant difference to the patient's experience of patient management at brachytherapy units in the country.

OPSOMMING

Sleutelterme: Bragiterapie, hoë dosis tempo, servikale kanker, riglyne, pasiënt-gesentreerde sorg, multidissiplinêre span, kwalitatief, fenomenologie, kwaliteit pasiëntbestuur.

Hierdie studie is onderneem om riglyne vir gehalte pasiëntbestuur te fasiliteer vir pasiënte met servikale kanker wat hoë dosis tempo-intrakavitêre bragiterapie ontvang in ’n multidissiplinêre omgewing. ’n Omvattende literatuursoektog het bevind dat leiding vir diensverskaffers en lede van multidissiplinêre spanne (bestralingsonkoloë, bestralingsterapeute en onkologieverpleegkundiges) beperk is tot die organisatoriese en tegniese aspekte van die lewering van hoë dosis tempo-intrakavitêre bragiterapie behandeling. Die doelwit was gevolglik om pasiënt-gesentreerde riglyne te formuleer wat gebruik kan word as ’n hulpmiddel om lede van multidissiplinêre spanne te lei in die verskaffing van gehalte pasiëntbestuur van hierdie groep vroue in staats- en privaat bragiterapie-eenhede in Suid-Afrika.

’n Prospektiewe, kwalitatiewe studie met ’n fenomenologiese benadering is gebruik as die studie-raamwerk. Die studie is goedgekeur deur die bestuur van die hospitaal en die departement, en die etiekkomitee van die Fakulteit Gesondheidswetenskappe, Universiteit van die Vrystaat. Alle deelnemers het geskrewe ingeligte toestemming gegee voor deelname. Die doelwitte van die studie is in vyf fases benader.

In fase een van die studie is semi-gestruktureerde, individuele onderhoude in Engels, Afrikaans en Sesotho gebruik om ’n omvattende beeld van ’n deelnemer se ervaring en persepsies van pasiëntbestuur tydens bragiterapie behandeling te verkry. Om die opinies van vroue oor die breë spektrum van ouderdomsgroepe te verkry, het die navorser pasiënte doelgerig as deelnemers geselekteer uit elk van die volgende drie ouderdomsgroepe: 30-45 jaar; 46-60 jaar en 61 jaar en ouer. Elke ouderdomsgroep het ten minste een privaat en een plaaslike onkologie pasiënt ingesluit. Gehospitaliseerde pasiënte is ook in die studie steekproef ingesluit. Die grootte van die studie steekproef is bepaal deur datasaturasie. Saturasie is bereik nadat onderhoude met agt-en-twinitg deelnemers gevoer is.

Die onderhoudvoerder was ’n veeltalige vroulike maatskaplike werker. Die ope-vrae vraelys in Engels, Afrikaans en Sesotho is deur die navorser saamgestel en die voorafbepaalde vrae is deur die onderhoudvoerder gebruik tydens die onderhoude. Oop-vrae (met ondersoekende vrae) is aan die deelnemers by die Departement Onkologie, Universitas Annex, Bloemfontein, gevra na hul derde bragiterapie behandeling. Die volgorde van die vrae was so saamgestel dat dit die pasiënt se bestuur in die afdeling simuleer (nuwe pasiëntkliniek tot bragiterapie behandeling). Onderhoude is op band opgeneem en getranskribeer voor kwaliatiewe ontleding deur die navorser.

Begrip en erkenning van die pasiënt se onvervulde behoeftes was die grondslag vir die ontwikkeling van die voorgestelde riglyne. Gemeenskaplike en unieke ervaringe van die 28 deelnemers is tydens analisering van die data geïdentifiseer. Vier temas met onderafdelings is geïdentifiseer: (1) ’n behoefte aan inligting, (2) die pasiënt se houding teenoor die behandeling, (3) sielkundige ervaring- en (4) fisiese ervaringe.

In fase twee is die omvang van die voorgestelde riglyne geformuleer deur (1) die integrasie van die pasiënt ervaring van fase een, gekombineer met (2) ’n literatuursoektog en (3) die kennis en ervaring van die navorser. Die voorgestelde riglyne spreek logistieke aangeleenthede van die praktykomgewing en die kollektiewe en eksklusiewe rolle en verantwoordelikhede van lede van die multidissiplinêre span by die nuwe pasiëntkliniek en die bragiterapie-eenheid van die departement aan. Die voorgestelde riglyne is met die vloei van die pasiëntbestuur in die Departement Onkologie belyn.

In fase drie van die navorsingstudie is die voorgestelde riglyne geëvalueer deur lede van die multidissiplinêre span van die Departement Onkologie wat op ’n gereelde basis interaksie het met hierdie groep pasiënte. Twintig lede van die multidissiplinêre span wat werksaam is by die bragiterapie-eenheid van die Departement Onkologie, Bloemfontein, met ten minste ’n jaar se ervaring van dienslewering by die bragiterapie-eenheid is doelgerig geselekteer om aan die fokusgroeponderhoude deel te neem. Fokusgroepe bestaan gewoonlik uit ses tot tien deelnemers en daarom is die twintig geselekteerde deelnemers verdeel in twee fokusgroepe. Elke fokusgroep is saamgestel sodat die groepe vergelykbaar was ten opsigte van professionele kategorie en jare

ervaring. Mediese fisici is uitgesluit aangesien hulle nie direk betrokke is by die bestuur of sorg van pasiënte by hierdie eenheid nie.

Die twee fokusgroeponderhoude het op dieselfde dag plaasgevind. Die omgewing was bekend en maklik bereikbaar vir die deelnemers. Die fokusgroeponderhoude het plaasgevind in Engels om alle deelnemers te akkommodeer. Die studie-promoter het die funksies van ŉ groepfasiliteerder verrig, terwyl die mede-promoter opgetree het as assistant-fasiliteerder tydens die fokusgroeponderhoude.

Die besprekingsgids vir die fokusgroeponderhoude was die lys voorgestelde riglyne. Die fokusgroeponderhoude is gelei deur die ondershoudskedule waartydens algemene en spesifieke, oop-vrae gevra is. Die besprekings wat gevolg het na elke afdeling tydens elke fokusgroep, is deur die assistent-fasiliteerder opgesom met instemming van die fokusgroepe. ŉ Geleentheid is aan die fokusgroep-deelnemers gegee om bykomende inligting tot die voorgestelde riglyne by te voeg.

Die voorgestelde riglyne is aanvaar as duidelik, bondig en gestruktureer en geformuleer op ŉ beskrywende en verstaanbare wyse sodat dit maklik toegepas kan word deur al die dissiplines werksaam by die nuwe pasiëntkliniek en die bragiterapie-eenheid. ŉ Totaal van ses addisionele riglyne is voorgestel, twaalf riglyne is gewysig en vier riglyne is uitgelaat. Die woorde "gedeelde verantwoordelikhede" is verander na kollektiewe verantwoordelikhede en die rolle en verantwoordelikhede van die multidissiplinêre span is aan ŉ spesifieke lid of lede toegewys.

In fase vier van die navorsingstudie is die gewysigde riglyne geëvalueer deur hoofde of aangewese verteenwoordigers van staats- en privaat bragiterapie-eenhede in Suid-Afrika. Die fase is onderneem om hul menings oor die toepaslikheid en uitvoerbaarheid van die riglyne te verkry. Elektroniese pos onderhoude is in Engels met sewe hoofde of aangewese verteenwoordigers gehou. Die uitleg en formaat van die riglyne is deur al die deelnemers goedgekeur, aangesien bevind is dat dit goed gegroepeer was met goed gedefinieerde mandate. Verder is die riglyne gesien as prakties uitvoerbaar deur bragiterapie-eenhede, omdat die uitleg en formaat logies, duidelik en bondig is. Sewentien addisionele riglyne is voorgestel, twee riglyne is gewysig en een riglyn is

uitgelaat. Die terugvoer het die navorser gehelp om die voorgestelde riglyne verder te verfyn voordat dit finaal in fase vyf van die navorsing aangebied word.

Die finale riglyne soos aangebied in fase vyf van hierdie navorsingstudie bied ’n raamwerk wat duidelik die kollektiewe en eksklusiewe rolle en verantwoordelikhede van lede van multidissiplinêre spanne definieer vir implementering by onderskeidelik die nuwe pasiëntkliniek en bragiterapie-eenheid. Verder spreek die riglyne die praktykomgewing van bragiterapie-eenhede aan om sodoende ’n veilige omgewing vir die pasiënt te verseker. Alhoewel individuele eenhede se aktiwiteite mag wissel en beperkings op hulpbronne die volledige implementering van die riglyne mag verhoed, kan die riglyne met verdere verfyning en deur te fokus op dit wat reeds in die praktyk plaasvind, geïmplementeer word.

Die navorser kom dus tot die gevolgtrekking dat die doelwitte van die studie bereik is en dat die riglyne ’n betekenisvolle verskil sal maak wat betref die pasiënt se ervaring van pasiëntbestuur by bragiterapie-eenhede in die land.

CHAPTER 1

GENERAL PERSPECTIVES AND ORIENTATION

There is no one type of patient and no single way of treating everyone. Moreover, every patient has a different view on the quality of his meal or her environment. But there is a way to be sure each patient gets care needed in a nurturing environment - by providing care that consciously adopts the patient's perspective (Gerteis, Edgman-Levitan, Daley & Delbanco 1993:5)

1.1 INTRODUCTION

Globally, cervical cancer is the fourth commonest cancer in women with 86% of cases occurring in developing countries, representing 13% of female cancers (GLOBOCAN 2012). These countries make up roughly 85% of the world's population, but possess only one-third of the world's radiation equipment (DIRAC 2013). Fisher, Hansen, Mundt and Daugherty (2013:8) stated the following: *"…it is not an exaggeration to say that cancer represents an imminent crisis for developing countries".* These authors reported that cervical cancer is one of the most common cancers in developing countries and one that requires brachytherapy in order to achieve the highest control rates.

The American Brachytherapy Society (ABS) recommends that brachytherapy be included as a component of the definitive radiation therapy for cervical cancer, based on the Patterns of Care studies (Nag, Erickson, Thomadsen, Orton, Demanes & Petereit 2000). The Patterns of Care studies have demonstrated that recurrences and complications are decreased when brachytherapy is used in addition to external beam radiotherapy. There are many sets of guidelines to assist institutions to develop or optimise brachytherapy facilities regarding treatment regimes, techniques, dose specification and treatment planning methods (Nag, Dobelbower, Glasgow, Gustafson, Syed, Thomadsen & Williamson 2003). However, previous research into women's experiences of brachytherapy treatment has been limited (Warnock 2005; Kwekkeboom, Dendaas, Straub & Bradley 2009). Although previous studies

have investigated the lived experience of patients with gynaecological cancer (Chan, Molassiotis, Yam, Chan & Lam 2001; Molassiotis, Chan, Yam & Chan 2002), patients in these studies received a combination of cancer treatments and their specific experience of undergoing internal radiation treatment remains relatively unexplored. This view has been supported in the work of So and Chui (2007) and the authors suggested that more information concerning patients' experiences could help healthcare workers to gain a deeper understanding of the process and thereby provide better care for this particular group of women.

In 2001, the US Institute of Medicine (IOM) *Crossing the Quality Chasm: A New Health System for the 21st Century* defined quality care as safe, effective, patient centred, timely, efficient and equitable (IOM 2001). Charmel and Frampton (2008) stated that this report reinforces patient-centred care not only as a way of creating a more appealing patient experience, but also as a fundamental practice for providing high quality care in the United States. The report defined patient-centred care as "*care that is respectful of and responsive to the individual patient preferences, needs and values, ensuring that patient's values guide all clinical decisions*" (IOM 2001:3).

If health care is to become truly responsive to the needs and desires of the patient, then it will be necessary to refine the skills and capacity of health professionals (ACSQHC 2012). Quality patient-centred care can thus be enhanced in health care systems by providing health care workers with practice guidelines that are statements suggesting or recommending specific professional behaviour, endeavour or conduct (APA 2002). Understanding the gynaecologic cancer experience and the extent to which needs are being met by the existing services is a first step toward planning and improving the care women receive (Walton, Reeve, Brown & Farquha 2010). Booth, Beaver, Kitchener, O'Neill and Farrell (2005) reported that the management of patients with gynaecological cancers is an important facet of the current thrust to improve cancer care**.**

This research study therefore aimed to identify the needs of the patient and to address these needs by formulating guidelines to assist radiation oncologists/registrars, radiation therapists and oncology nurses in providing quality patient management for cervical cancer patients receiving high dose rate-intracavitary brachytherapy. For the purpose of this study, the term '*patient management*' will be associated with the patient-centred care for cervical cancer

patients receiving high dose rate-intracavitary brachytherapy. Hereafter reference will be made in the thesis to the Department of Oncology, Universitas Annex, Bloemfontein, as the Department of Oncology.

This chapter provides a broad overview of cervical cancer in Africa, specifically brachytherapy as treatment modality as well as related guidelines. It reviews patient experience with regards to brachytherapy and describes the concepts and evidence regarding quality patient-centred care. In addition, the researcher describes the framework of the study which includes the setting, research questions, purpose and study objectives, methodological approach, motivation and significance of the research. The chapter concludes with ethical considerations, the personal view of the researcher and a conclusion.

1.2 INCIDENCE OF CERVICAL CANCER ON THE AFRICAN CONTINENT

The Global Burden of Cancer (GLOBOCAN) estimated that worldwide, annually 528 000 women are newly diagnosed with cervical cancer and that 266 000 women die from the disease (GLOBOCAN 2012). Almost nine out of ten (87%) cervical cancer deaths occur in the less developed regions. In Africa, with a population of 267.9 million women aged 15 years and older at risk of developing cervical cancer, approximately 80 000 women are diagnosed with cervical cancer per year, with just over 60 000 women dying from this disease annually. Cervical cancer is the most common cancer in women in sub-Saharan Africa, accounting for 22.2% of all cancers in women as well as being the most common cause of cancer death among women (Anorlu 2008). Simonds (2009) also reported that cervical cancer is one of the most prevalent causes of oncological mortality and morbidity in sub-Saharan Africa. High-risk regions, with estimated age-standardised rates of over 30 per 100 000, include Eastern Africa (42.7), Southern (31.5) and Middle Africa (30.6) (GLOBOCAN 2012). The most recent age-standardised incidence rates of cervical cancer in countries of Southern Africa indicated that Swaziland (50 per 100 000), Lesotho (35 per 100 000) and South Africa (26.6 per 100 000) are the top three high-risk countries, while Namibia (15.8 per 100 000) had the lowest incidence rate (WHO/ICO 2010). Furthermore, because accurate incidence data is not available in most poorly-resourced countries, under-reporting is high (ACCP 2004).

A lack of effective screening programs aimed at detecting and treating precancerous conditions is a key reason for the much increased cervical cancer incidence in developing countries (Sherris, Herdman & Elias 2001). Denny (2011) reported that the huge difference in cervical cancer incidence in developing versus developed regions is a reflection of the absence of national cervical cancer screening programmes in most developing countries. The reality is that many women will miss the opportunity for preventative measures due to poor health services and socio-economic factors (Simonds 2009). Cervical cancer thus presents in women in the locally advanced stages of the disease where surgery is no longer an option for treatment. The management of cervical cancer continues to be a major challenge in many developing countries, especially in sub-Saharan Africa, due to the lack of surgical facilities, skilled providers and radiotherapy services (Anorlu 2008).

In South Africa, with a population of 52 982 000 (Statistics South Africa 2013), the estimated number of new cases of cervical cancer in 2008 was 5 743 and the projected number of new cases for 2025 will be 7 329 (WHO/ICO 2010). The incidence of cervical cancer in South Africa compared to Southern Africa and the World is shown in Table 1.1.

Table 1.1 Incidence of cervical cancer in South Africa, Southern Africa and the world

Incidence rate per 100 000 women per year	**South Africa**	**Southern Africa**	**World**
Crude incidence rate	22.8	22.5	15.8
Age-standardised incidence rate	26.6	26.8	15.3
Cumulative risk (%). Ages 0-74 years	2.9	2.9	1.6

(Adapted from WHO/ICO 2010)

In 2012, the mid-year population estimates of the Free State Province, South Africa, were 2 753 200 (Statistics South Africa 2013). In addition, in 2007 the Universitas Academic Complex was responsible for a population of 5 404 052 from surrounding provinces and 1 845 243 from Lesotho (Universitas Academic Hospital 2007). The total potential catchment population serviced by the tertiary health sector in the Free State in 2007 was approximately 10 million. The Department of Oncology, which is part of the Universitas Academic Hospital Complex of the Free State, registered 17 141 patients from 2008 to 2013 of which 2 705 patients were gynaecological patients (Figure 1.1). (Department of Oncology 2014).

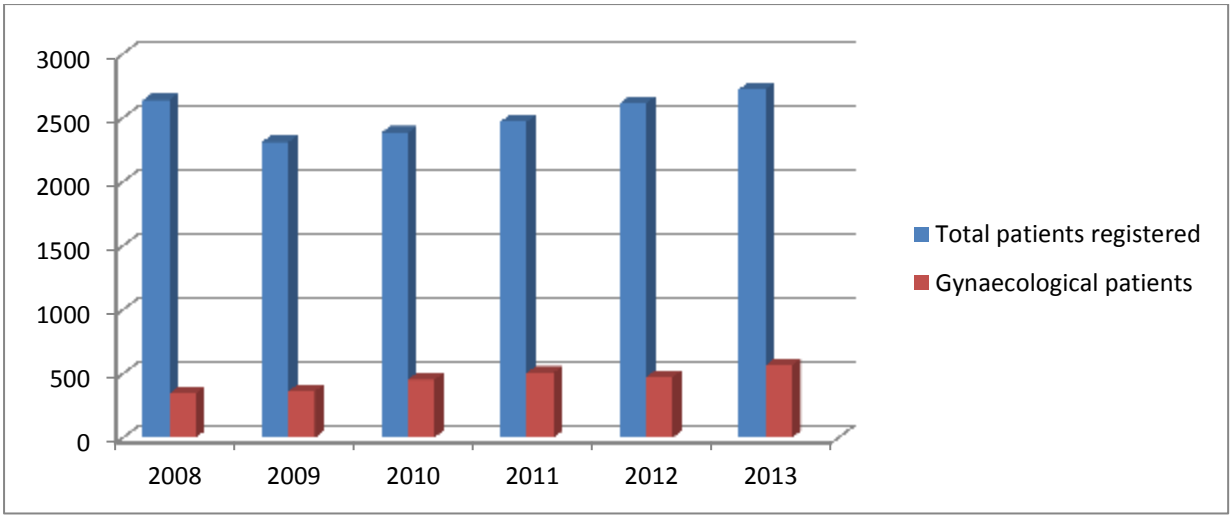

Figure 1.1 Patients registered versus gynaecological patients treated at the Department of Oncology (Department of Oncology 2014)

Cervical cancer is the most prevalent gynaecological cancer in the Department of Oncology (Table 1.2) and standard therapies in the treatment of locally advanced cancer of the cervix include radiotherapy, surgery and platinum-based chemotherapy.

Table 1.2 Gynaecological cancers treated at the Department of Oncology (Department of Oncology 2014)

Diagnosis	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**
Cervical cancer	315	303	353	422	388	480
Endometrial cancer	12	22	53	33	38	41
Ovarian cancer	7	27	28	22	22	14
Uterus cancer	3	2	2	3	2	2
Vaginal cancer	1	2	6	5	2	4
Cancer of the vulva	6	7	10	22	23	24
TOTAL	**344**	**363**	**452**	**507**	**474**	**565**

1.3 BRACHYTHERAPY

The authors of *"Principles and Practice of Radiation Oncology"* stated that the aim of radiotherapy is to deliver a precisely measured dose of radiation to a defined tumour volume with as little damage as possible to surrounding healthy tissue, resulting in eradication of the tumour, a high quality of life and prolongation of survival at a competitive cost (Halperin, Wazer & Perez 2013). According to Patel, Rai, Mallick and Sharma (2005) the curative potential of radiotherapy in the management of cervical cancer is enhanced by the use of high dose rate brachytherapy.

Simonds (2009) stated in his article on radiotherapy for cervical cancer in sub-Saharan Africa that treatment with brachytherapy is an essential part of therapy and the lack of access to this treatment in many developing countries undoubtedly contributes to poorer outcomes with radiotherapy. The frequency with which high dose rate brachytherapy is utilised depends on the incidence of a particular cancer in that country and whether the site can be effectively treated by high dose rate brachytherapy. Consequently, the cervix is the most common site treated by high dose rate brachytherapy in developing countries (Nag, Dally, De la Torre, Tatsuzaki, Kizilbash & Kurusun 2002).

1.3.1 Brachytherapy as treatment modality

The term brachytherapy is derived from *"brachio*", the Greek word meaning *"short*". Brachytherapy was the first form of conformal radiotherapy that involves treatment with radioactive sources (usually sealed) within or very close to the target tissue and allowing high cancer to normal tissue dose ratios (Stewart, Halloway & Devlin 2013). It is an invasive procedure and consists of positioning applicators (bearing the radioactive sources) into a body cavity in close proximity to the target (Williamson, Allen Li & Brenner 2013). All intracavitary implants are temporary implants that are left inside the patient for a specified time to deliver the prescribed dose. In addition, implant procedures may be classified in terms of source loading technology (preload, manually afterload or remotely afterload) and the dose rate used (low, medium or high).

Three categories of brachytherapy were defined in Report 38 of the International Commission on Radiation Units and Measurements (ICRU) viz: (a) Low dose rate: a range of 0.4 to 2 Gy

per hour; (b) Medium dose rate: a range of 2 to 12 Gy per hour and (c) High dose rate: over 12 Gy per hour (ICRU 38 1985). Williamson *et al*. (2013) reported that high dose rate brachytherapy uses dose rates in excess of 0.2 Gy/minute (12Gy/hour). Williamson *et al*. (2013) stated that modern high dose rate remote after loaders deliver instantaneous dose rates as high as 0.12 Gy/second (430Gy/hour) at a distance of 1 cm, resulting in treatment times of a few minutes.

Since Margaret Cleaves first performed intracavitary brachytherapy for cervical cancer in 1903, the radiotherapy of cervical cancer has traditionally been based on low dose rate-intracavitary brachytherapy (Ferrigno, Nishimoto, Dos Santos Novaes, Pellizon, Maia, Fogarolli & Salvajoli 2005). High dose rate brachytherapy was developed to overcome some potential disadvantages of low dose rate brachytherapy, especially in the treatment of cervical cancer. It allows for shorter treatment times, resulting in reduced hospitalisation costs owing to outpatient therapy, a reduced risk of applicator movement during treatment and a larger throughput of patients in a busy department (Nag *et al*. 2000). Thomadsen and Das (2013) confirmed that outpatient treatments are advantageous over inpatient treatments characteristic of low dose rate brachytherapy with regards to patient comfort, patient health and economics.

1.3.2 Clinical suitability for brachytherapy

Cancers with clinically and radiologically well-defined margins and a low risk of regional and metastatic spread are the most suitable for brachytherapy as a single treatment modality. However, brachytherapy is becoming increasingly important when integrated with external beam radiotherapy (EBRT) to give a highly localised boost (Stewart *et al.* 2013). EBRT is thus used to sterilise a larger area of possible microscopic or nodal spread with high dose rate-intracavitary brachytherapy used for areas of gross macroscopic or microscopic residual disease.

Treatment for cervical cancer varies according to the stage of the disease, location of the tumour and patients' general health and age (ACS 2012). Patients with locally advanced cervical cancer (stages IB2 to IVA) require treatment with EBRT with concurrent chemotherapy as a radiation sensitizer followed by high dose rate-intracavitary brachytherapy (Viswanathan & Erickson 2010). The clinical effectiveness of brachytherapy has been established in randomised clinical trials (NICE 2006). Evidence confirms that brachytherapy

as used for dose escalation after EBRT for cervical cancer significantly improves survival (Viswanathan 2013). This finding is consistent with the statement made by Lanciano, Won, Coia and Hanks (1991) that high dose rate-intracavitary brachytherapy is an essential component of the radical treatment of cervical cancer and that its omission has long been shown to result in poorer survival. Therefore, high dose rate-intracavitary brachytherapy is a standard part of the treatment of locally advanced cervical cancer after EBRT; brachytherapy alone may be used as primary treatment for selected cases with early stage (stages IA to IB) cervical cancer. The treatment is repeated several times, once weekly, on an outpatient basis.

1.3.3 The availability of radiotherapy services in Africa

Africa consists of 52 countries with an estimated population of over a billion people, but is the least developed region with respect to radiotherapy services (Barton, Frommer & Shafiq 2006). In addition, many barriers prevent access to radiotherapy services as safe and efficient use of radiotherapy requires trained oncologists, physicists, radiation therapists and nurses. Services can be provided only in metropolitan cities and many patients will need assistance for travel and accommodation during treatment. Thus, the availability of radiation services in South Africa may still be very limited for large numbers of cervical cancer patients, where caseloads may exceed 600 cases a year in some of the centres (Simonds 2009). Adequate access to radiotherapy is a crucial component of modern multidisciplinary cancer care (Barton *et al*. 2006).

Abdel-Wahab, Bourque, Pynda, Izewska, Van der Merwe, Zubizaretta and Rosenblatt (2013) conducted a survey on radiation oncology departments in Africa through the Directory of Radiotherapy Centres (DIRAC) and this information was supplemented by that available from International Atomic Energy Agency (IAEA) Regional African and Interregional project reports for 2010. Of the 52 African countries included, only 23 are known to have EBRT. These facilities are concentrated in the southern and northern states of the continent. Abdel-Wahab *et al.* (2013) reported that about 18% of centres are equipped with three to four EBRT machines. Some advanced centres in Egypt and South Africa are equipped with five or more radiotherapy machines. These centres constitute, however, only about 2% of the radiotherapy centres in Africa.

Brachytherapy resources (high dose rate or low dose rate) were only available in 20 of the 52 African countries. Of the 99 brachytherapy services in the entire continent, the countries with the greatest numbers were South Africa (21), Morocco (15), Algeria (15), Egypt (nine), Tunisia (eight) and Nigeria (seven) (Abdel-Wahab *et al*. 2013:). The radiation therapy resources in Africa are demonstrated in Table 1.3.

Table 1.3 Radiotherapy resources in African countries

Countries with major resources	**Linacs 2010**	**External Beam Radiotherapy 2010**	**Low dose rate**	**High dose rate**	**Brachytherapy**
South Africa	78	86	0	11	11
Egypt	54	76	1	6	7
Morocco	23	27	2	8	10
Algeria	11	20	13	1	14
Tunisia	6	16	4	1	5
Nigeria	5	9	3	2	5
Libya	1	5	2	1	3
Sudan	2	6	1	1	2

(Adapted from Abdel-Wahab, Rosenblatt, Van der Merwe, Pynda, Izewska and Meghzifene 2011)

1.4. GUIDELINES FOR BRACHYTHERAPY

Guidelines refer to statements that suggest or recommend specific professional behaviour, endeavour or conduct for health care workers (APA 2002). They are intended to facilitate the continued systematic development of the profession and to help assure a high level of professional practice. The World Health Organization (WHO) declared that their guidelines generally meet a global need, have a public health perspective and do not duplicate existing resources (WHO 2012). Guidelines for health services resulting from valid and appropriate outcome studies have the potential to promote consistency and quality of care (Perez, Halperin & Lievens 2013). The values of practice guidelines in medicine include minimizing inappropriate practice variations, providing reference points for education/practice, improving patient care and outcomes, providing criteria for self-evaluation, setting indicators for external quality review, assisting with service coverage and reimbursement and decreasing overall cost of medical care (Perez *et al*. 2013).

The ABS recently published consensus guidelines for locally advanced carcinoma of the cervix (Viswanathan & Thomadsen 2012). Viswanathan and Thomadsen (2012) reported that the ABS endorses the use of brachytherapy as an integral component of the definitive treatment of locally advanced cervical cancer. In this article the ABS recommendation of the year 2000 were revised by members of the ABS with expertise in gynaecologic brachytherapy. The updated recommendations covered aspects of pre-treatment evaluation and treatment, as well as dosimetric issues for locally advanced cervical cancer. The new 2012 recommendations also address image-guided treatment planning and delivery and recommended reporting parameters for quality assurance. Specific commercial equipment, instruments and materials are described for necessary procedures. Practitioners and cooperative groups are encouraged by the ABS to use these recommendations to formulate treatment and dose-reporting policies (Viswanathan & Thomadsen 2012).

Other than the abovementioned ABS guidelines, there are sets of published guidelines available to assist institutions to develop or optimise brachytherapy facilities. These include:

- In 1995 the American Association of Physicists in Medicine (AAPM) published a number of Task Group reports primarily with respect to technical, quality assurance and other brachytherapy physics issues (Nath, Anderson, Luxton, Weaver, Williamson & Meigooni 1995).
- In 2000 the ABS published recommendations for high dose rate brachytherapy for carcinoma of the cervix (Nag *et al.* 2000). This report presented guidelines for using high dose rate brachytherapy in the management of patients with cervical cancer, taking into consideration the availability of resources in most institutions.
- In 2002 the Advisory Group of the International Atomic Energy Agency (IAEA) published recommendations for implementation of high dose rate ^{192}Ir brachytherapy in developing countries (Nag *et al*. 2002). Nag *et al.* (2002) stated that the decision to select high dose rate in preference to alternate methods of brachytherapy is influenced by the ability of the machine to treat a wide variety of clinical sites. The authors concluded that in departments with personnel and budgetary resources to support this equipment appropriately, economic advantage becomes evident only if large numbers of patients are treated.
- In 2003 the ABS, The American College of Medical Physics (ACMP) and The American College of Radiation Oncology (ACRO) proposed standards for clinical

brachytherapy whereby practitioners are encouraged to use the standards to design and implement consistent and efficacious brachytherapy programs (Nag *et al*. 2003).

- In 2005 the Gynaecological (GYN) GEC-ESTRO working group published recommendations on concepts and terms in three dimensional (3D) image based 3D treatment planning in cervix cancer brachytherapy with emphasis on Magnetic Resonance Imaging (MRI) assessment of Gross Tumour Volume (GTV) and Clinical Tumour Volume (CTV) (Haie-Meder, Pötter, Van Limbergen, Briot, De Brabandere, Dimopoulos, Dumas, Hellebust, Kirisits, Lang, Muschitz, Nevinson, Nulens, Petrow & Wachter-Gerstner 2005).
- In 2006 recommendations were proposed by the gynaecological (GYN) GEC/ESTRO working group on concepts, terms and 3D image-based, treatment planning in cervical cancer (Potter, Haie-Meder, Van Limbergen, Barillot, De Brabandere, Dimopoulos, Dumas, Erickson, Lang, Nulens, Petrow, Rownd & Kirisits 2006).
- The 2010 report published by the Brachytherapy Cervical Cancer Expert Working Group (BCCEWG) aimed to provide advice to facilitate high-quality delivery of brachytherapy for cervical cancer services in the province, Ontario, Canada (Morton, Walker-Dilks, Baldassarre, D`Souza, Falkson, Batchelar, Gutierrez & Bak 2010). These recommendations address the characteristics of the practice setting, including facilities, equipment, delivery suite, imaging technologies, treatment planning and dosimetry; the practice team, including team members, roles, training, team caseload and qualifications; and the quality assurance aspect, including documentation, audit, safety and quality control.

The above-mentioned clearly indicates that available guidelines for service providers and members of multidisciplinary teams (radiation oncologists, medical physicists, radiation therapists and oncology nurses) are limited to the organisational and technical aspects of high dose rate-intracavitary brachytherapy treatment delivery. Donabedian (1988) stated that the goodness of technical care is proportional to its expected ability to achieve those improvements in health status that the current science and technology of health care have made possible. It is apparent that currently, there is little evidence available to suggest that guidelines are available to advise members of multidisciplinary teams to provide quality patient management for patients with locally advanced cancer receiving high dose rate-intracavitary brachytherapy. It is thus the researcher's concern that 3D, image-guided treatment planning and delivery might have compromised the quality of patient management

delivered to this group of patients. The patient experience of high dose rate-intracavitary brachytherapy needs to be explored and addressed by the use of unambiguous documentation fully describing the duties of each team member to ensure patient satisfaction has been achieved.

1.5 PATIENT EXPERIENCE

Patient experience is recognised as one of the central elements of healthcare quality in the National Health System (NHS) in England along with safety and effectiveness (Sizmur & Redding 2009). This has triggered strong interest in understanding the best ways in which to measure patient experience among NHS trusts and their managers, clinicians and staff. In England, the Department of Health has launched a programme of national surveys in which every NHS Trust is required to survey their patients once a year. In Switzerland the National Coordination and Information Office for Quality Improvement has recommended Picker survey instruments to investigate patient experiences of health care administered in 300 hospitals on an annual basis (Jenkinson, Coulter & Bruster 2002).

1.5.1 Patient experience related to low dose rate brachytherapy

Early studies done by Andersen, Karlsson and Tewfik (1984), Nail (1993) and Rollison and Strang (1995), used instruments such as Likert-like scales and self-report inventories to establish the incidence and degree of concern women experience in relation to selected measures. Although recent studies done by Chan *et al*. (2001); Molassiotis *et al.* (2002); Sekse, Raheim, Blaka and Gjengedal (2012) and Wainer, Willis, Dwyer, King and Qwada (2012) have investigated the lived or treatment experience of patients with gynaecological cancers, they did not aim to capture patients' descriptions of, or their feelings concerning brachytherapy treatment. This perspective was central to a study conducted by Velji and Fitch (2001). The purpose of their study was to explore and document the lived experience of inpatients receiving low dose rate brachytherapy for gynaecologic cancer. Velji and Fitch (2001) concluded that when dealing with brachytherapy treatment, women are concerned with the context in which the treatment is provided and the care that is associated with the treatment.

Warnock (2005) explored the experiences of patients before, during and after low dose rate brachytherapy. Nursing staff assessed patients' pain during their hospitalisation for low dose rate brachytherapy treatment. Coping strategies, post-treatment concerns and the characteristics of patient information were identified. Warnock (2005) concluded that research into this aspect of radiotherapy is needed to build a greater understanding of women's experiences of treatment.

So and Chui (2007) explored the experiences of women undergoing low dose rate brachytherapy treatment by conducting unstructured, telephone interviews with eight patients. The most distressing aspects of undergoing internal radiation reported by the patients were the experience of isolation and various physical and psychological symptoms. Back pain was the most consistent and intense symptom experienced. The psychological distress experienced by the participants of the study was related to the presence of the radioactive substance inside the body. Patients felt anxious, because of the potential pain that would result if they moved and feelings of fear, worry and anxiety were compounded by the fact that they were on their own in the room. This caused these women to feel more vulnerable, isolated and helpless. Specific provisions in the physical environment, psychological support provided by healthcare professionals, family and fellow patients and a positive attitude helped them to cope. The findings highlighted the importance of adequate preparation of patients, carers and friends before the procedure. The finding is consistent with those of Kamer, Ozsaran, Celik, Bildik, Yalman, Bolukbasi and Haydaroglu (2007) that, having evaluated the anxiety levels of women undergoing intracavitary brachytherapy, concluded that women needed to be given detailed information before brachytherapy application, to reduce anxiety.

1.5.2 Patient experience related to high dose rate brachytherapy

Although the use of high dose rate brachytherapy has increased and replaced low dose rate brachytherapy in many practices over the past 20 years (Viswanathan, Creutzberg, Craighead, McCormack, Toita, Narayan, Reed, Long, Kim, Marth, Lindegaard, Cerrotta, Small & Trimble 2012), most of the published studies to date explored only the inpatient patient experience of low dose rate brachytherapy. All high dose rate-intracavitary brachytherapy treatments are administered on an outpatient basis and therefore outpatient treatments present many advantages (cf. 1.3.1) over the inpatient treatments characteristic of low dose rate

brachytherapy (Thomadsen & Das 2013). In one of the few studies published on the patient experience of receiving high dose rate-intracavitary brachytherapy, Kwekkeboom *et al*. (2009) investigated the patterns of pain and distress during high dose rate brachytherapy for cervical cancer patients. This study explored women's experiences of pain and distress over a series of five high dose rate brachytherapy procedures and found that for most patients, high dose rate brachytherapy delivered with conscious sedation was well tolerated with only mild pain and distress. However, a small number of patients experienced more significant symptoms and required additional medical and psychosocial support.

The abovementioned studies on patient experience of both low dose rate and high dose rate brachytherapy were all conducted in northern hemisphere, developed countries such as Canada, the United Kingdom (UK), Turkey, China and the United States of America (USA). Patient experience of high dose rate-intracavitary brachytherapy treatment and care in women in the third world and especially in South Africa has yet to be explored. Reflecting on the notions of all the above mentioned authors, it is clear that research regarding patient experience of high dose rate brachytherapy for locally advanced cervical cancer is limited. The purpose of the current study was therefore to explore the patient experience of South African women receiving high dose rate-intracavitary brachytherapy and to integrate their unmet needs and suggestions in developing guidelines to facilitate quality patient management in a multidisciplinary environment on the African continent.

1.6 QUALITY OF CARE

In order to define "*quality*", it is necessary to consider whether one assesses only the performance of practitioners or also the contributions of patients and of the health care system (Donabedian 1988). Detailed information concerning the causal linkages between the structural attributes of the settings in which care occurs, the processes of care and the outcome of care are needed to be taken into account. Donabedian (1988) stated that the science and art of health care, as they apply to both technical care and the management of the interpersonal process are at the heart of the metaphorical family of concentric circles depicted in Figure 1.2.

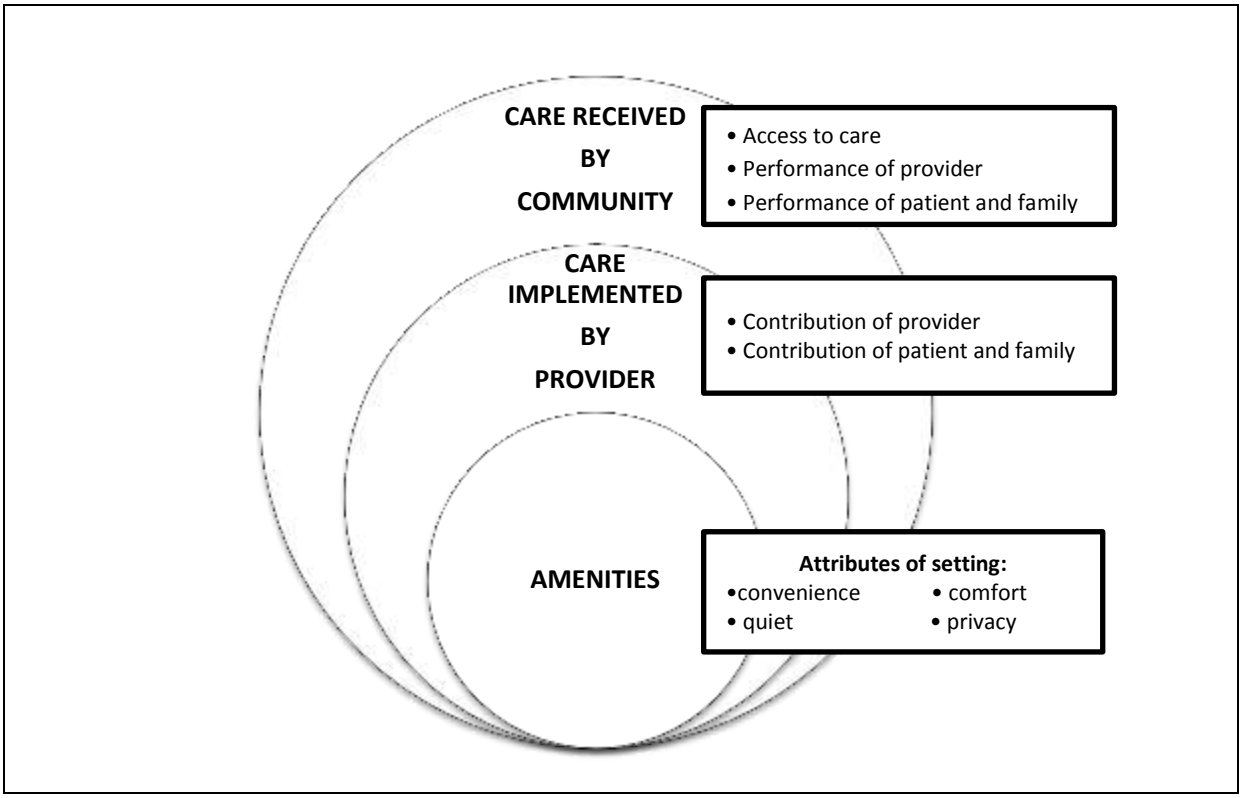

Figure 1.2 Levels at which quality of care can be assessed (Adapted from Donabedian 1988)

The inner circle presents the amenities of care, these being the desirable attributes of the settings within which care is provided. It can include aspects such as convenience, comfort, quiet and privacy deemed necessary for the patient. In private practice, it is the responsibility of the practitioner to provide these. In institutional practice, the responsibility devolves to the owners such as governments (Donabedian 1988). The next circle, moving away from the centre, includes assessments of quality of contributions to care made by the patients themselves as well as members of their families. Donabedian (1988) stated that although his concern was primarily with the performance of the service providers, it is now shared by provider and consumer. The management of the interpersonal process by the practitioner influences the implementation of care by and for the patient. Lastly, the outer circle is representative of the care received by the community as a whole, whereby the social distribution of levels of quality in the community needs to be judged. This depends on who has greater or lesser access to care and who, after gaining access, receives greater or lesser qualities of care (Donabedian 1988).

In health care, continuous quality improvement is most effective when used as an integral part of a scientific approach to improving clinical practice (Perez *et al*. 2013). A potential strength is the ability to motivate good performers to excel and to place emphasis on generating new methods for achieving improvement. It is suggested that limitations of this model are a too-narrow focus on administrative (as opposed to clinical) aspects of care and a lack of attention to problems of overuse or underuse. Perez *et al*. (2013) stated that several major strategies have been advocated to move the health care delivery system toward improving quality. However, the challenges are (a) to always provide effective care to those who could benefit from it, (b) to always refrain from providing inappropriate services and (c) to eliminate all preventable complications.

1.6.1 Patient-centred care

Over the past two decades, patient-centred care has become internationally recognised as a dimension of the broader concept of high-quality health care (ACSQHC 2012). In 2000, a five-day seminar was held in Salzburg, Austria, where 64 people from 29 countries examined what health care could become in a utopian land called "*People Power".* They envisaged informed and shared decision making, mutual commitments to quality and health outcomes and patient partnership in governance (Delbanco, Berwick, Boufford, Edgman-Levitan, Ollenschlager & Plamping 2001). The phrase *"nothing about me without me"* was their guiding principle; this phrase has since been popularised by authors and regulators and is considered synonymous with efforts to advance a vision for patient-centred care (Davis, Schoenbaum & Audet 2005).

Numerous proposed definitions of patient-centred care encompass similar core concepts, but there is no globally accepted definition (ACSQHC 2012). Patient-centred care is:

> "*an innovative approach to planning, delivery and evaluation of health care that is grounded in mutual partnerships among health care providers, patients and families. Patient-centred care applies to patients of all ages and it may be practiced in any health care setting*" (IPFCC 2013:9).

WHO uses the term '*responsiveness*' in preference to patient-centred care. Responsiveness describes how a healthcare system meets people's expectations regarding respect for people

and their wishes, communication between health workers and patients and waiting times (WHO 2000). WHO stated that recognising responsiveness as an intrinsic goal of health systems reinforces the fact that health systems are there to serve people.

1.6.2 Eight dimensions of patient-centred care

Modern concepts of patient-centred care are based on research conducted in 1993 by the Picker Institute in conjunction with the Harvard School of Medicine (ACSQHC 2012). The Eight Dimensions of Patient-Centred Care was developed based on research by the Picker Institute and Harvard Medical School. The research involved thousands of interviews and the experiences of caregivers and patients (NRC Picker 2012). The eight dimensions of patient-centred care were originally documented in the book, *Through the Patient's Eyes: Understanding and Promoting Patient-Centred Care* (Gerteis *et al*. 1993). The dimensions are:

- Respect for the patients' preferences and values
- Emotional support
- Physical support
- Information, communication and education
- Continuity and transition
- Coordination of care
- Involvement of family and friends
- Access to care

This framework clearly defined the patient's perspective for the first time and served as the foundation for the National Research Corporation (NRC) Picker surveys measuring patient experience of health care (NRC Picker 2012).

1.6.3 Benefits of patient-centred care

Research done by Charmel and Frampton (2008); Jha, Orav, Zheng and Epstein (2008); Meterko, Wright, Lin, Lowy and Cleary (2010) and Stone (2007) have shown that there are many benefits to patient-centred care, broadly categorised as care experience, clinical and operational benefits. Studies show that when healthcare administrators, providers, patients

and families work in partnership, the quality and safety of health care rise, costs decrease and provider and patient satisfaction increase (ACSQHC 2012).

Stone (2007) examined the data of inpatient units at two similar hospitals in the USA over five years. One hospital introduced an extensive program of patient-centred practices and the other continued their usual practices. Stone (2007) found that the patient-centred inpatient unit consistently demonstrated a shorter average length of stay, a statistically significantly lower cost per case, a shift in emphasis from the use of higher cost staff to lower cost staff and higher than average overall patient satisfaction scores. This finding is consistent with other benefits associated with patient-centred care that include decreased mortality (Meterko *et al*. 2010); decreased emergency department return visits, fewer medication errors, lower infection rates (AHRQ 2013); higher functional status (Flach, McCoy, Vaughn, Ward, Bootsmiller & Doebbeling 2004); improved clinical care (Jha *et al*. 2008) and improved liability claims experience (Charmel & Frampton 2008). Increasing patient satisfaction through patient-centred approaches also increases employee satisfaction and this, in turn, improves employee retention rates and the ability to continue practicing patient-centred care (Charmel & Frampton 2008).

The Institute for Patient- and Family-Centered Care stated that patient-centred care has become the business model for the Medical College of Georgia (MCG) Health System in Augusta, Georgia, because it positively affects each of the MCG's business metrics (finances, quality, safety, satisfaction and market share) (IPFCC 2013). Three years of accumulating quality improvement data by the Institute for Patient- and Family-Centered Care, showed that patient satisfaction increased from the 10^{th} to 95^{th} percentile and the volume of discharges increased by 15.5%. The length of stay in neurosurgery decreased by 50%, medical errors decreased by 62%, staff vacancy rates decreased from 7.5% to 0% and that the perception of the unit by doctors and staff underwent a positive change. Such findings led Charmel and Frampton (2008) to conclude that patient-centred care is not merely philosophical, it is sound business practice.

1.6.4 The Batho Pele principles

On October 1, 1997, The Batho Pele ("*Putting People First*") principles were introduced in South Africa by the Mandela Administration which required that eight service delivery

principles be implemented by governmental institutions (South African Government Information 2007). These eight Batho Pele principles were developed to serve as acceptable policy and legislative framework regarding service delivery in the public service (Figure 1.3).

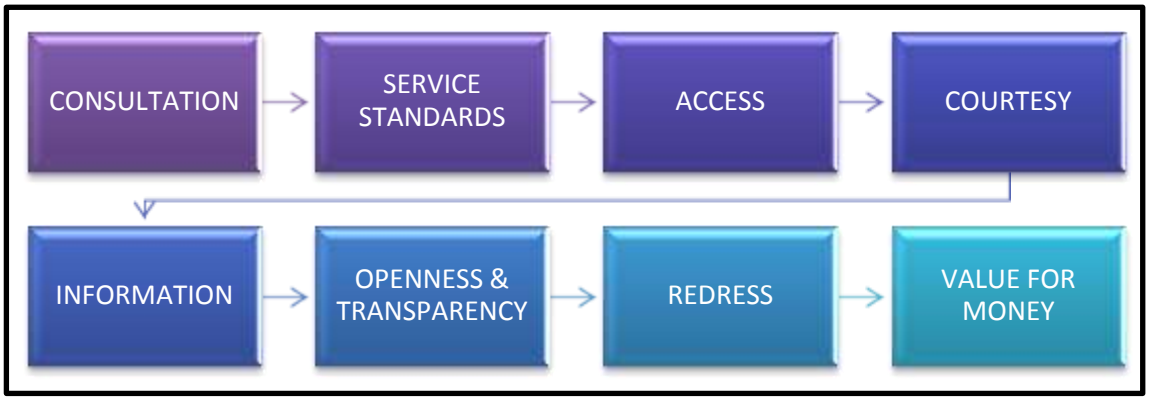

Figure 1.3 The eight Batho Pele principles (South African Government Information 2007)

These principles are a South African initiative which aims to enhance the quality and accessibility of government services for patients by improving efficiency and accountability to recipients of public goods and services (South African Government Information 2007). The following is an overview of what governmental patients should expect from the South African service provider (South African Government Information 2007):

Consultation*:* Patients should be consulted about the level and quality of the public services they will receive and whenever possible, should be given a choice about the services that are offered.

Service standards: Patients should be told what level and quality of public services they will receive so that they are aware of what to expect.

Access: All citizens should have equal access to the services to which they are entitled.

Courtesy: Patients should be treated with courtesy and consideration.

Information: Patients should be given full, accurate information about the public services they are entitled to receive.

Openness and Transparency: Patients should be told how national and provincial departments are run, how much they cost and who is in charge.

Redress: If the promised standard of service is not delivered, patients should be offered an apology, a full explanation and a speedy and effective remedy. When complaints are made, a sympathetic, positive response should be received.
Value for money: Public services should be provided economically and efficiently in order to give the best possible value for money.

This framework clearly defines the patient's perspective of quality and accessibility of government services for patients. These principles are aligned with the following Constitutional ideals (South African Government Information 2007):

- Promoting and maintaining high standards of professional ethics
- Providing service impartially, fairly, equitably and without bias
- Utilising resources efficiently and effectively
- Responding to people's needs; the citizens are encouraged to participate in policy-making
- Rendering an accountable, transparent and development-oriented public administration

In order to provide patients diagnosed with locally advanced cervical cancer, receiving high dose rate-intracavitary brachytherapy, with quality patient management it was thus necessary for the researcher to explore the patient's perspective of services delivered and to compile guidelines with a patient-centred care approach. These guidelines could provide a framework to facilitate quality patient management in a multidisciplinary environment. Clinical practice guidelines are widely used as effective tools for improving the management of patients with cancer (Fevers, Burgers, Haugh, Brouwers, Browman, Cluzeau & Philip 2005). The authors reported that clinical practice guidelines are important tools for encouraging a comprehensive approach to cancer care and contribute to bridging the gap between research results and clinical practice to improve the management of patients with cancer.

1.7 SETTING

The Department of Oncology, provides oncology services to a large geographical area including the Free State, Northern Cape and Lesotho. Women from the surrounding areas have to leave their families, jobs and homes in order to receive radiotherapy treatment for cervical cancer which is administered over a six week period. Patients diagnosed with locally advanced cervical cancer, International Federation of Gynaecologists and Obstetricians

(FIGO) stages (IB2-IVA) are treated with a combination of EBRT with concurrent chemotherapy and high dose rate-intracavitary brachytherapy. The standard prescribed radiotherapy treatment protocol of the department consists of 25-28 daily fractions of EBRT and five high dose rate brachytherapy treatments that are administered once weekly. Concurrent chemotherapy is administered as a radiation sensitizer, once weekly, not given on the day of a patient receiving high dose rate brachytherapy.

The brachytherapy unit in the department is currently the only facility in the Free State to administer this specialised treatment for women diagnosed with locally advanced cervical cancer. This service is being utilised to treat patients referred from four private oncology practices, three locally and one situated in Kimberley. The department, in association with the Cancer Association of South Africa (CANSA), initiated a free and low cost accommodation and transport option for patients at two halfway houses, Katleho and Olea, respectively. These halfway houses are situated within a five to eight kilometre radius of the department and patients are transported daily to the radiation department for their radiotherapy.

The management of governmental and private patients, receiving high dose rate-intracavitary brachytherapy, in the department is depicted in Figure1.4 that shows the sequence of events.

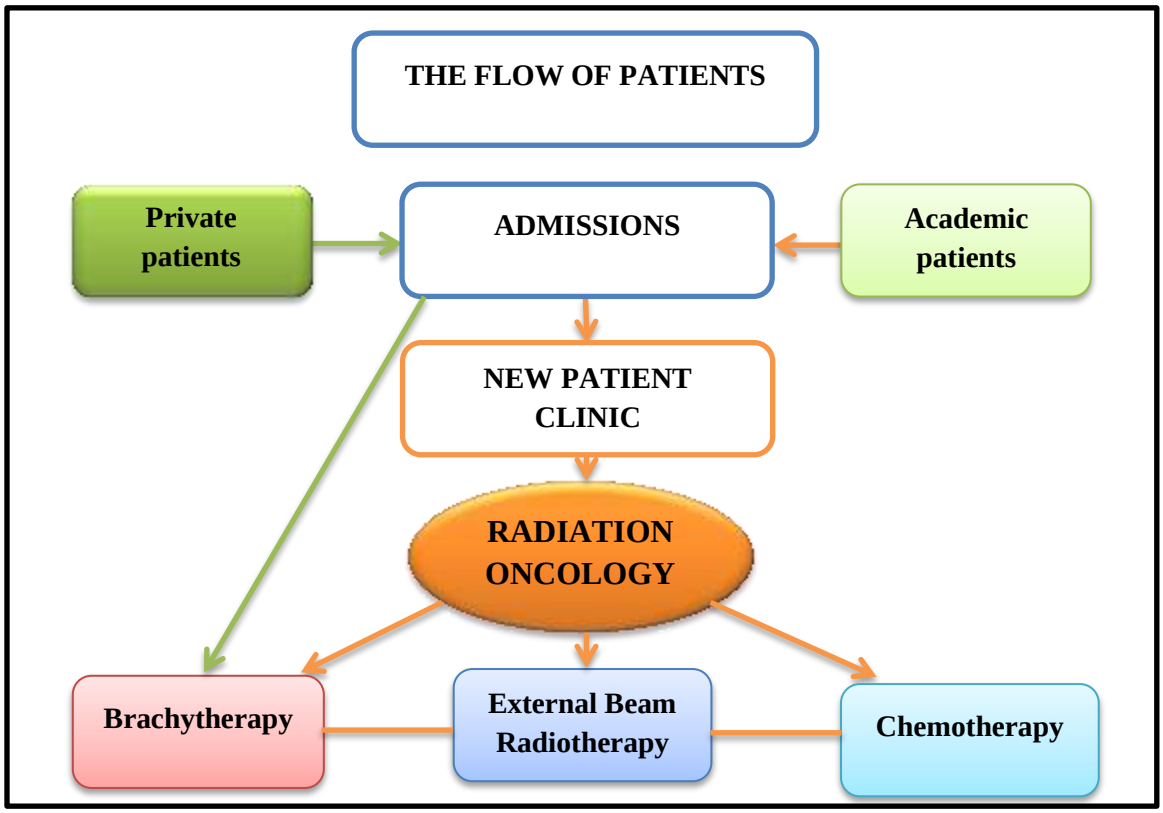

Figure 1.4: The flow of patients at the Department of Oncology: Sequence of events

The advent of high dose rate-intracavitary brachytherapy in the department, which has the advantages of individualised dosimetry, outpatient treatment and elimination of radiation exposure of medical personnel, introduced a convenient treatment option for cervical cancer patients, permitting treatment of 25-30 patients weekly. The number of patients treated per annum from 2008 to 2013 is depicted in Figure 1.5 (Department of Oncology 2014).

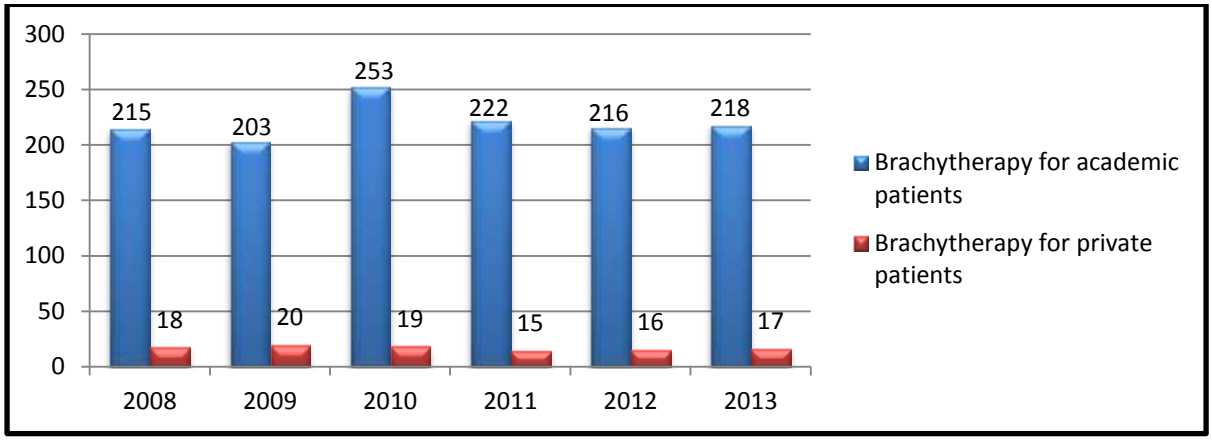

Figure 1.5 Brachytherapy for cervical cancer patients at the Department of Oncology (Department of Oncology 2014)

The delivery of cervical brachytherapy in the department requires the collaboration of a multidisciplinary team that includes a radiation oncologist, radiation oncology registrar, medical physicist, radiation therapist and an oncology nurse. The recognition that no one skill can be completely isolated or is absolute when dealing with people in a clinical context is thus important and a fluency in both technical and relational (i.e. interpersonal skills, communication) skills must be embedded into the delivery of brachytherapy for cervical cancer patients (Morton *et al*. 2010). Morton *et al.* (2010) provided organisational and technical advice to facilitate quality care and the following roles and responsibilities were allocated to members of the multidisciplinary team that are also relevant to the Department of Oncology:

The radiation oncologist is responsible for the overall medical care of the patient and for the choice and placement of after loading applicators, target volume and normal tissue identification and treatment prescription. The radiation oncologist must review and approve the prescription and the treatment plan, attend the treatment and remove the applicators. Some of these duties may be delegated to appropriate staff, under supervision.

The medical physicist is responsible for the overall quality assurance of the treatment, which includes commissioning of the treatment unit and applicators and reviewing the quality assurance programme. The physicist is responsible for the treatment planning and delivery and may also fulfil the role of the dosimetrist.

The radiation therapist operates the brachytherapy treatment unit, acquires the images, sets up the patient, programs the unit, treats the patient, checks for source retraction, completes the documentation and secures the unit. The radiation therapist assists the radiation oncologist in the choice of the applicator, patient set-up and applicator insertion and removal.

The oncology nurse starts intravenous lines, assists in the sedation of the patient, administers medication, monitors the patient during the procedure, delivers immediate post-treatment care to the patient and carries out any other delegated medical act as the local situation requires.

However, it needs to be mentioned that although the medical physicists plays a major role in the treatment planning and delivery of the patient, they were excluded from the current study as they are not directly involved with the management or care of patients in the Department of Oncology.

1.8 RESEARCH QUESTIONS

The research was guided by the following question:

What are the needs and expectations of women diagnosed with cervical cancer, while receiving high dose rate-intracavitary brachytherapy treatment at the Department of Oncology, Bloemfontein?

The following subsidiary questions flow from this:

- How do these patients conceptualize brachytherapy treatment?
- Is patient satisfaction achieved during treatment delivery?
- Is there a way of ensuring that the needs and expectations of the patients are adequately managed by members of a multidisciplinary team?

Given the particular specific needs of cervical cancer patients receiving high dose rate-intracavitary brachytherapy in a multidisciplinary environment, it is important that patients themselves indicate the issues they consider to be of particular importance to them. Therefore, to formulate guidelines designed to improve patient management, with a focus on patient-centred care by members of a multidisciplinary team, patient assessment of the importance of specific aspects of their management while undergoing brachytherapy treatment was required. Feedback from the patients themselves therefore allowed the *participants' points of view* to be heard, with their own words constituting the data. The outcome of the patient interviews in the study was then integrated in the formulation process of the guidelines.

1.9 PURPOSE AND OBJECTIVES OF THE STUDY

The purpose of this study was to establish guidelines to facilitate quality patient management for cervical cancer patients, receiving high dose rate-intracavitary brachytherapy, in a multidisciplinary environment. The aim was therefore to formulate *patient-centred* guidelines that could be used as a tool to assist or guide members of multidisciplinary teams in providing quality patient management to this group of women in governmental and private brachytherapy units in South Africa.

To achieve the purpose of the study, the following objectives were pursued:

Stage one: ***Patient interviews***

To explore the patient experience, while undergoing high dose rate-intracavitary brachytherapy. This was done by conducting in-depth, individual semi-structured interviews with purposively selected participants.

Stage two: ***Formulation of the proposed guidelines***

To formulate guidelines for quality patient management by conducting an extensive literature search for related guidelines, incorporating the findings of stage one and the knowledge and experience of the researcher.

Stage three: ***Focus group interviews***

To review and refine the proposed guidelines by means of focus group interviews conducted with members of the multidisciplinary team at the Department of Oncology, Bloemfontein.

Stage four: ***National review***

To review the proposed guidelines by heads or designated representatives of governmental and private sector brachytherapy units in South Africa and to incorporate their advice into revisions of the original draft of these guidelines.

Stage five: ***Presentation of the final guidelines***

To present the final guidelines for quality patient management in a multidisciplinary environment.

1.10 METHODOLOGICAL APPROACH

Qualitative research explores complex phenomena encountered by clinicians, health care providers, policy makers and consumers in health (Tong, Sainsbury & Craig 2007). These authors stated that qualitative studies use non-quantitative methods to contribute new knowledge and to provide new perspectives in health care. Phenomenology, as well as basic qualitative research designs was chosen for the conduct of the current study.

1.10.1 Research design

1.10.1.1 *Qualitative research*

Qualitative approaches have been influential in establishing and recognising the importance of both external and internal aspects of human behaviour. While quantitative methodology has only addressed external behaviour, qualitative methodology has understood the value of social and mental processes operating within the context of an encounter or activity (Weingand 1993). Moreover, the strength of qualitative research is that it allows the participants' points of view to be heard, with their own words constituting the data (Clark 1998). For the research questions to be adequately answered, a qualitative approach was thus required. Qualitative data takes the form of words (spoken or written) and visual images

(observed or creatively produced) and are associated primarily with strategies of research such as ethnography, phenomenology and grounded theory.

Despite the polarisation over the relative legitimacy and value of quantitative and qualitative methods and data, Maxwell (2010) has supported the inclusion of numerical data in qualitative research practices and reports. Maxwell (2010:476) stated the following: "*I agree that there are legitimate and valuable uses of numbers even in purely qualitative research and I don't see the distinction between numerical and verbal data as a useful way of distinguishing between qualitative and quantitative research"*. Maxwell (2010) emphasized one specific distinction between qualitative and quantitative approaches that he deems important. This is the distinction between thinking of the world in terms of variables and correlations and in terms of events and processes. Although the formulation of the guidelines of the current study was not based on patient numbers, patient numbers and quotes were provided when necessary to support statements made during the focus group interviews of the study.

1.10.1.2 *Phenomenology*

Creswell (2007) regards a phenomenological study as a study that describes the meaning of the lived experiences of a phenomenon. Phenomenology originated from the work of Alfred Schutz who aimed to explain how the life world of subjects is developed and experienced by them (Schutz 1967). Life world refers to a person's conscious experience of everyday life and social action.

The social world is complex and rarely straightforward. A phenomenological approach allows the researcher to deal with this complexity. It calls for the researcher to delve into phenomena in depth and to provide descriptions that are detailed enough to reflect the complexity of the social world in special localities such as hospitals (Denscombe 2007). At the root of phenomenology is the intent to understand the phenomenon under study in the participants' own terms and therefore to provide a description of human experience as it is experienced by the participants (Bentz & Shapiro 1998) allowing the essence to emerge (Cameron, Schaffer & Hyeoun 2001). Leedy and Ormrod (2005) proclaim that the final result of a phenomenology study is a study that attempts to understand people's perceptions, perspectives and understanding of a particular situation.

Although many versions of phenomenology exist, it is most often grouped into two main types (Denscombe 2007). One version derives from the European tradition which is more applicable to the discipline of philosophy and the other, the "*new phenomenology*", has a North American origin (Crotty 1996). The present study will follow the North American version of phenomenology which emanates from the "*social phenomenology*" of Alfred Schutz. The North American version is more commonly linked to the disciplines of sociology, psychology, education, business studies and health studies. The defining characteristic of the North American approach lies in its concern with the ways people interpret social phenomena (Schutz 1967). Although phenomenology lacks scientific rigour, it will not be a disadvantage to this study, because this study will follow a descriptive approach (De Vos, Strydom, Fouché & Delport 2011).

Phenomenology is concerned, first and foremost with human experience and deals with the ways people interpret events and literally make sense of their personal experiences. Phenomenology is suited to small-scale research and data collection generally relies on in-depth, tape-recorded interviews which are in line with the methodology of this study (Denscombe 2007).

1.10.2 Research methods

The process whereby qualitative research is designed follows a cyclic path in order to allow for critical reflection on one stage before proceeding to the next. It is therefore the suitable research method to understand and to address the characteristics necessary for optimizing patient care in a multidisciplinary, health care environment.

Identifying and refining the research topic of the current study required qualitative methods for information collection. It comprised of semi-structured interviews, a literature search, focus group interviews and electronic mail (e-mail) interviews. The tools used to collect data included interview schedules, transcriptions and audio recording.

1.10.2.1 *Semi-structured interviews*

In qualitative health research, in-depth interviews are often used to study the experiences and meanings of disease and to explore personal and sensitive themes (Tong *et al.* 2007). The

interviews can also help to identify potentially modifiable factors for improving health care. In the current study, in-depth semi-structured interviews were conducted to explore the experiences of participants and the meanings they attribute to them. The participants were encouraged to expand on their psychological and physical experiences by asking them open-ended questions during one-to-one interviews. The interviews were audio recorded, transcribed and where necessary translated into English. Detailed descriptions of the sampling methods, interviews, data collection, data analysis, findings and discussion are provided in Chapter 2, Patient experience and perspectives.

1.10.2.2 *Literature search*

A comprehensive literature search on published guidelines, advising members of multidisciplinary teams to facilitate quality patient management for cervical cancer patients receiving high dose rate-intracavitary brachytherapy, was performed. A full description of the literature search will follow in Chapter 3, Formulation of the proposed guidelines.

1.10.2.3 *Focus group interviews*

Focus group interviews are semi-structured discussions with groups of four to twelve people that aim to explore a specific set of issues (Tong *et al*. 2007). Morgan (1997) described focus group interviews as a research technique that collects data through group interaction on a topic determined by the researcher. The emphasis is on insights, attitudes, responses and opinions of the participants (Burns & Grove 2001). A detailed description of the focus group interviews is provided in Chapter 4, Multidisciplinary staff perspectives.

1.10.2.4 *Electronic mail interviews*

New information and communication technologies have more recently opened up new opportunities for qualitative researchers (De Vos *et al*. 2011). All kinds of computer mediated communication tools such as e-mail and chat boxes have been developed (FQS 2006). Meho (2006) predicted that the use of e-mail to collect qualitative data will certainly expand as Internet access and use become more prevalent. Benefits associated with the use of e-mail interviewing in qualitative research stipulated by De Vos *et al.* (2011) will be expanded on in Chapter 5, National Perspectives and Formulation of Final Guidelines.

1.11 MOTIVATION AND SIGNIFICANCE OF THE STUDY

In a department where the majority of women are diagnosed with locally advanced cervical cancer, the implementation of the ^{192}Ir Nucletron Microselectron© high dose rate brachytherapy treatment system in April 1994 introduced a convenient treatment option for these women. Long (2007) conducted a retrospective study on the dose effectiveness and incidence of late rectal complications of high dose rate brachytherapy in the radical treatment of cervical cancer. The aim of the research was to determine whether the fractionation schedule delivered biologically effective doses that lead to local tumour control without severe late rectal complications over a five year period. Published results of the study confirmed that the fractionation schedule had delivered acceptable pelvic control rates and low incidence of late radiation complications (Long, Friedrich-Nel, Goedhals & Joubert 2011).

However, despite the positive clinical outcome of the research, associated with the technological advances that took place in the department, the patient experience of receiving high dose rate brachytherapy in the department has yet to be explored. A literature search has indicated that few studies have been published on (a) the patient experience of receiving high dose rate-intracavitary brachytherapy as treatment modality and (b) a lack of recommendations or guidelines for use by members of multidisciplinary teams in providing quality patient management for this group of women.

The researcher was therefore motivated to explore the patient experience in the Department of Oncology, thereby expressing an interest in understanding the "*lived experience*" from the patient's point of view. Exploring and understanding the cancer experience and the extent to which needs are being met by the existing services would therefore aid the researcher to address the patient's needs by formulating proposed guidelines. Proposed guidelines, with a patient-centred care approach, could be used to guide or assist service providers and members of multidisciplinary teams to facilitate quality patient management in their departments or units. Thereby, setting a framework that would improve patient management and promote consistency and quality of care for this group of women.

1.12 ETHICAL CONSIDERATIONS

1.12.1 Approval

The proposal for this study was submitted to and approved by the Ethics Committee of the Faculty of Health Sciences, University of the Free State (UFS) (Appendix 1). The allocated Ethics Committee number (ECUFS 97/2012) was used on documents pertaining to the study. Permission to conduct the study was obtained from the Head of the Department of Oncology, Universitas Annex, Bloemfontein and the Chief Executive Officer (CEO) and Head of Clinical Services, Universitas Academic Hospital, Bloemfontein (Appendices 2 and 3, respectively).

1.12.2 Informed consent

The researcher was personally involved in the recruitment of all the participants (patients, focus group members and heads or designated representatives) of the research study. The potential participants of stages one, three and four of the study were invited to participate both orally and in writing. They were informed of the purpose of the study and that participation was voluntary and that they could withdraw from the study at any time without explanation. The participants gave written consent before participation commenced and permission for conversations to be audio-recorded in stage one and three was obtained. By signing the consent document, all the participants of the study thereby gave the researcher the right to present and publish the results of the study at congresses and in relevant medical journals, respectively. The invitation, background and consent letters used in the study are attached as appendices and will be referred to in the relevant chapter.

1.12.3 Confidentiality

The interview schedules, audio tapes and transcribed data were coded alphanumerically, thereby ensuring confidentiality during the analysis and reporting of the findings. No names or personal information were made known and no respondent's name appeared on any document. Except for the e-mail interview schedules, all interview schedules and transcribed data were returned in sealed envelopes to prevent any accidental viewing by other parties. Only the researcher and the study promoters had access to the data. The data will be kept in a

secure, fire-and waterproof container for fifteen years in the archives of the Department of Oncology, Universitas Annex, Bloemfontein, Free State.

1.13 PERSONAL VIEW OF THE RESEARCHER

> *Every researcher has a relation to the topic: some are more distanced and some are closer* (Aigen 2012:5).

Twenty-one years of service delivery in the Department of Oncology, as radiation therapist, has exposed me to different treatment regimens for different types of cancers. However, it was with cervical cancer patients that I identified myself the most and this motivated me to conduct research on both the clinical and social outcomes of them receiving the invasive procedure of high dose rate-intracavitary brachytherapy. I am of the opinion that although the Department of Oncology offers patients 3D image guided treatment planning and delivery, there is a concern that technological advances might have compromised the quality of patient management delivered to this group of women. Assuming something without concrete evidence is poor practice and I therefore made it my intention to firstly explore the patient experience of receiving the invasive procedure of high dose rate-intracavitary brachytherapy in our department. Secondly, I wanted to see whether our service delivery has rendered patient satisfaction and thirdly to address their unmet needs by compiling guidelines. The guidelines will provide a framework whereby members of our multidisciplinary team could facilitate quality patient management at the unit. It is also my concern that while Velji and Fitch. (2001) were the first to capture patients' descriptions of the brachytherapy experience, limited research findings have been published on this topic during the past thirteen years.

A phenomenological approach to the study enabled me to understand the brachytherapy experience through the *patient's eyes.* It also allowed me to obtain multiple viewpoints from local and national members of multidisciplinary teams regarding the proposed guidelines. In order to cover a range of perspectives, I needed to be inclusive and expansive when selecting participants for stage one of the research study. Understanding and acknowledging their unmet needs reinforce the importance of providing a framework, in the form of guidelines. The guidelines can be used to assist radiation oncologists/registrars, radiation therapists and oncology nurses in facilitating quality patient management in a multidisciplinary environment. By listening to the patient's audio-recordings and simultaneously reading the

transcripts, I could for the first time "*really*"understand their fears and concerns as portrayed in their voices. However, it was necessary for me to maintain an objective approach to their responses in order to develop guidelines that are patient-centred, but also realistic, practical and sustainable for implementation.

The end goal for me was thus to formulate guidelines that have a patient-centred care approach that are feasible and applicable for implementation by our department in Bloemfontein, as well as governmental and private brachytherapy units in South-Africa. The guidelines were developed for use in a third world country, but might also be applicable globally in first world countries.

1.14 ARRANGEMENT OF THE THESIS

The research findings and the final outcome are arranged as follows:

Chapter 1: ***General perspectives and orientation***. In this chapter the background to the study is presented with literature incorporated into the contents of this chapter. The research questions, purpose and objectives are stated. The research design and the methodological approach are discussed, providing the reader with an overview of the contents of this study. The chapter includes the motivation and significance of the study, ethical considerations and concludes with the personal view of the researcher.

Chapter 2: ***Patient experience and perspectives.*** This chapter explores the patient experience of receiving high dose rate brachytherapy in the department. It includes a detailed discussion of the methodology, presents the findings of the patient interviews, followed by a discussion, limitations and conclusion.

Chapter 3: ***Formulation of the proposed guidelines.*** This chapter deals with the development of the proposed guidelines for use by members of a multidisciplinary team to facilitate quality patient management. It discusses in detail the formulation process of the proposed guidelines, after which the draft guidelines are presented. The chapter concludes with a discussion, limitations and conclusion.

Chapter 4: ***Multidisciplinary staff perspectives*****.** This chapter concentrates on the multiple viewpoints obtained during the focus group interviews. It provides a detailed description of the methodology, findings of the two focus group interviews and presents the amended guidelines, followed by a discussion, limitations and conclusion.

Chapter 5: ***National perspectives and formulation of final guidelines.*** This chapter reports on the opinions and views obtained from heads or designated representatives of governmental and private brachytherapy units in South Africa, concerning the proposed guidelines. It focuses on the methodology, findings of the e-mail interviews and presents the final guidelines, followed by a discussion, limitations and conclusion.

Chapter 6: ***Researcher perspectives and reflection.*** This chapter provides an overview of the study and presents the researcher's reflection on the outcome of the research study. It includes the significance and limitations, followed by recommendations and concluding remarks.

1.15 CONCLUSION

Chapter 1 provided the reader with some insight into the incidence of cervical cancer on the African continent, thereby emphasizing the importance of brachytherapy as an integral component of the definitive treatment for women diagnosed with locally advanced cervical cancer. A comprehensive review of topic related literature has indicated that research on the patient experience of receiving high dose rate brachytherapy is limited and that brachytherapy related guidelines to facilitate quality patient management is currently lacking. The chapter included a detailed description of what quality care entails and reviewed international concepts and evidence regarding patient-centred care.

This chapter also provided the reader with a detailed description of the research setting, addressed the research questions, purpose and study objectives. It also demonstrated the appropriateness of phenomenology as study design as it would enable the researcher to capture the experiences, views and opinions of the participants by utilising qualitative research methods. The motivation and significance of the research study was presented, consideration was given to ethical aspects and the chapter concluded with the personal view of the researcher and arrangement of the chapters.

In the next chapter, Chapter 2, Patient Experience and Perspectives, the methods used to explore the patient experience, thereby identifying their needs and expectations of management will be reported and discussed.

CHAPTER 2

PATIENT EXPERIENCE AND PERSPECTIVES

2.1 INTRODUCTION

The American Brachytherapy Society endorses the use of brachytherapy as an integral component of the definitive treatment for locally advanced cervical cancer (Viswanathan & Thomadsen 2012). However, the invasive procedure of high dose rate-intracavitary brachytherapy presents patients with a wide range of physical and psychological challenges (Warnock 2005). Research into women's experiences of this treatment has been limited, especially on the African continent. Jenkinson *et al*. (2002) confirmed that there is increasing interest in eliciting feedback from patients to highlight aspects of care that need improvement and to monitor performance and quality of care. Understanding the cervical cancer experience and the extent to which needs are being met by the existing services is a first step toward planning and improving the care women receive (Walton *et al*. 2010).

This chapter explores the experiences of women with cervical cancer who received high dose rate-intracavitary brachytherapy. It provides a detailed description of the methodology including the study sample, interviewer details, research tools, pilot study, data collection and analysis. The findings of this chapter will be reported according to the identified themes and sub-themes whereafter the findings will be discussed and limitations will be pointed out. The chapter concludes with closing remarks.

2.2 METHODOLOGY

Interviewing is the predominant mode of data or information collection in qualitative research (De Vos *et al.* 2011). The interview is a social relationship designed to exchange information between the participant and the researcher. Seidman (1998:1) stated the following: "*one interviews because one is interested in other people's stories…stories are a way of knowing*." Both parties, the researcher and the participant, are thus necessarily and unavoidably active and involved in meaning-making work (Holstein & Gubrium 1995). Sewell (2001:1) defined

qualitative interviews as "*attempts to understand the world from the participant's point of view, to unfold the meaning of people's experiences and to uncover their lived world prior to scientific explanations*".

2.2.1 Study design

A prospective, qualitative study with a phenomenological approach was chosen as the framework for the study. At the root of phenomenology is the intent to understand the phenomenon under study in the participants' own terms and therefore to provide a description of human experience as it is experienced by the subjects (Bentz & Shapiro 1998) allowing the essence to emerge (Cameron *et al*. 2001). The aim is, as far as possible, to highlight essential meanings of the phenomena in the life world (Dahlberg, Dahlberg & Nystrom 2008; Giorgi 1997; Van Manen 1990).

2.2.2 Target population and sampling

Qualitative research tends to adopt an approach to sampling which is based on sequential discovery of instances to be studied and which emphasizes the inclusion of special instances more than is generally the case with quantitative research (Denscombe 2007). Therefore, non-probability, purposive sampling as supported by Patton (2002) was utilized to identify and recruit eligible patients for the study. The researcher was personally involved in the identification and recruitment of the patients at the brachytherapy unit. Inclusion criteria included women diagnosed with International Federation of Gynaecologists and Obstetricians (FIGO) stages I-III cervical cancer, undergoing high dose rate brachytherapy treatment at the Department of Oncology, Bloemfontein, who agreed to participate in the study. The inclusion and exclusion criteria for these participants are shown in Table 2.1.

Table 2.1 Inclusion and exclusion criteria of cervical cancer patients undergoing high dose rate brachytherapy treatment

Inclusion criteria:
1. Patients treated for cervical cancer, FIGO stages I-III, at the Department of Oncology, Universitas Annex, Bloemfontein, Free State.
2. Private and academic patients.
3. Patients who receive a combination of radiotherapy and chemotherapy.
4. Patients who have received a third high dose rate brachytherapy treatment.
5. Patients who receive EBRT and high dose rate brachytherapy over a six week period.
6. Patients with the ability to understand spoken and written English/Afrikaans or Sesotho.
7. Patients who have read the information letter on the study and signed the informed consent document.
Exclusion criteria:
1. Patients who had a hysterectomy before radiotherapy.
2. Patients who are part of other trials who receive treatment other than the standard treatment protocol.

Patton (2002) stated that there are no rules for sample size in qualitative inquiry. Sample size depends on what we want to know, the purpose of the inquiry, what is at stake, what will be useful, what will have credibility, and what can be done with the available time and resources. Denscombe (2007) suggested that the sample needs to be of an adequate size and that samples should not involve fewer than thirty participants.

In order to include the opinions of women across the age spectrum into the study, the researcher purposively recruited participants from each of the following three age groups: 30-45 years; 46-60 years and 61years and older. Sample size for this study was determined by saturation of the data. Saturation of information is the point in the study where researchers begin to hear the same information repeatedly being reported and they no longer learn anything new (Monette, Sullivan & De Jongh 2005). Saturation was reached having interviewed twenty-eight participants.

Each age group included at least one private and one local oncology patient. Hospitalised patients were also included in the study sample. Demographic and medical details (age, staging of cancer, race/ethnicity, home language, language interviewed, private/academic status, residence during treatment, educational level and employment status) were collected

from the patients' medical records and patients themselves in order to describe participants' characteristics. For the purpose of this stage of the study, the term '*academic*' will be used as classification for the governmental patients.

The researcher recruited cervical cancer patients undergoing high dose rate brachytherapy by utilising the weekly brachytherapy treatment schedule. Only patients who had already received their third high dose rate brachytherapy treatment were selected for the one-to-one interviews. The researcher handed out information letters in English, Afrikaans and Sesotho to the potential participants two days prior to the intended interviews (Appendices 4 to 6), explaining to them the purpose of the study and addressed any questions, if necessary. All the participants were informed that the one-to-one interviews would be audio recorded. They were reassured that the recordings would be used for research purposes only. Letters of informed consent in English, Afrikaans and Sesotho were signed to ensure compliance with the Ethics Committee of the Faculty of Health Sciences (UFS), Bloemfontein (Appendices 7, 8 and 9, respectively). Arrangements were made to conduct the interviews in a locale at the brachytherapy unit at a date and time convenient to the patients, interviewer and the researcher.

2.2.3 Interviewer

As the quality of the interviews depended to a large extent on the experience of the interviewer, the criteria in Table 2.2 were used to select an appropriate interviewer for the study.

Table 2.2 Criteria for interviewer

1. Female interviewer.
2. Patient management experience.
3. Not affiliated to the brachytherapy unit.
4. Resident in Bloemfontein.
5. Fluent in English, Afrikaans and Sesotho.

The researcher was personally involved with the selection of an appropriate interviewer for the study and was responsible for coordination of the interviews. It was essential to the study that the interviewer was not affiliated to the brachytherapy unit of the department, so as to

maintain a non-biased approach. On acceptance to participate in the study, a contract was signed by the interviewer and the researcher, with a third party as witness. Payment for the interviewer's service rendered was included in the budget of the study.

The interviews were conducted by a female multilingual social worker. Although the interviewer was inexperienced regarding research and conducting research interviews, her eleven years of experience as a social worker and her fluency in Sesotho, Afrikaans and English confirmed her eligibility as an interviewer. The researcher conducted an interview with the selected interviewer whereby the interviewer was briefed on the purpose and intended outcome of the interviews. The interviewer was given copies of the interview schedule in Sesotho, Afrikaans and English so as to familiarise herself with the questions. The majority of the patients treated at this facility are fluent in at least one of these languages. The interviewer did not wear a uniform during the interviews, thus emphasizing the fact that she was not part of the multidisciplinary team working at the brachytherapy unit.

2.2.4 Research tools

2.2.4.1 *Interview schedule*

An open-ended questionnaire in English, Afrikaans and Sesotho was designed by the researcher as an interview schedule as an appropriate instrument to engage the participant and to designate the narrative terrain (Appendices 10, 11 and 12, respectively). The advantage of open-ended questions was that the information gathered by way of the responses was more likely to reflect the full richness and complexity of the views held by the respondent (Denscombe 2007). The interview schedule provided the interviewer with a set of predetermined questions that guided the interviewing process. Probes were used to address issues that did not come from asking the open-ended questions. The order of questions of the interview schedule simulated the path of events that each participant had gone through at the department (from the new patient clinic up until treatment delivery). This was done to capture the patients' experiences in similar order. The following aspects were addressed by the interview schedule: treatment related information given and understood, participants' perceptions, expectations and impressions, waiting room, treatment room and recovery room experiences and suggestions for improvements.

2.2.4.2 *Audio recording*

All twenty-eight interviews were audio recorded. Due to the fact that the audio recordings were a once-off recording with the participants, the researcher ensured that the equipment was fully functional before each interview. A 4GB Sony Stereo recorder with high sensitivity microphones, an expandable memory card and with a built-in memory recording time was used to capture the interviews. The researcher initiated each interview by recording the date and the patient's radiotherapy number after which the researcher left the room, leaving the interviewer alone to conduct the interview with the participant. The equipment used supplied adequate sound, had a reliable power source plus back-up in case of emergency and had sufficient memory to cover the planned duration of the interview without the need to reload the recorder (Denscombe 2007). Each audio recorded interview was down loaded onto a personal computer (PC) and copied onto a compact disc (CD) and memory stick as backup. One master copy was placed in a secure place for safekeeping. Audio recordings offer a permanent record and one that is fairly complete in terms of the speech that occurs (Denscombe 2007). The verbatim data was transcribed and where necessary translated into English by staff of the Unit of Language Facilitation, an accredited facility of the University of the Free State.

2.2.5 Data collection

The interviews of the twenty-eight participants were carried out between July and November 2012. This study utilised semi-structured, one-to-one interviews in order to gain a detailed picture of a participant's experience and perceptions of patient management while undergoing brachytherapy. Open-ended questions were asked of the participants and they were encouraged to describe their feelings, concerns, reactions and reflections in relation to their experiences. The semi-structured, one-to-one interview allowed for flexibility in following up particular interesting avenues that emerged during the interview and the interview schedule was therefore used to guide the interview. The interviews were conducted in the participant's language of preference (English, Afrikaans or Sesotho) and were audio recorded.

The interviews were conducted during the week preceding the patient's fourth brachytherapy treatment. The reason why the interviews were not conducted after the fifth treatment

delivery is because patients have been away from their homes for a long time and would be in a hurry to return home. The researcher is of the opinion that after having received three brachytherapy treatments, the patients would have gained sufficient experience of patient management in the department to relate to the interviewer.

The researcher performed the duties of an assistant facilitator, which included operating the audio recorder and handling of the logistics. The date, time and locale for the interviews were arranged so as to not inconvenience the participant and were therefore scheduled on days when the patient had to come to the hospital for their external beam radiotherapy treatment. The six private participants of the study were interviewed on the morning prior to their fourth brachytherapy treatment, before they were sedated. The chosen locale was conducive to private conversation and situated at the brachytherapy treatment unit. The audio recorded interviews lasted between 16 and 40 minutes each with a mean of 27.1 minutes.

2.2.6 Pilot study

The interview schedule was proof read by the study promoters and translated into Afrikaans and Sesotho before commencement of the pilot study. It was pilot tested in all three languages and these participants were included in the final sample of the study. One participant from each language group (English, Afrikaans and Sesotho) was chosen to participate in the pilot study which added to the linguistic validation of the interview schedule. The pilot study ruled out the presence of items which were ambiguous and/or unclear, thus ensuring that the design and instructions of the questionnaire were understandable. In order to trace the participants and to maintain confidentiality, each interview schedule and audio recording was coded according to the participant's radiotherapy number (RT number). The pilot study enabled the researcher to familiarise herself with some of the practical aspects of the interviews (e.g. scheduling of interviews, interviewing time, audio recording etc.). One question was deleted from the interview schedule as it was deemed irrelevant to the study. The word "*inside radiation*" instead of *"internal radiation"* was used to refer to brachytherapy treatment as it was more commonly known amongst the participants. Although minor modifications were made to the interview schedule with a view to quality interviewing during the main investigation, the information collected in the pilot study was useful as the alterations to the interview schedule did not change the tool sufficiently to warrant deletion of information.

2.2.7 Data analysis and presentation

This study utilised a phenomenological method of analysis derived from Giorgi (1985). Giorgi's method of analysis aims to uncover the meaning of a phenomenon as experienced by a human through the identification of essential themes. The transcribed and translated data were analysed manually by the researcher by applying the following steps:

- The transcripts were read and reread in order to familiarise the researcher with the text.
- Since phenomenology is interested in meanings, the researcher read through the text once more with the specific aim to identify meaning units from the participants' descriptions of their experiences which were grouped according to the headings addressed by the interview schedule. Eleven of the twenty-eight transcribed interviews were purposively selected by the study promoters to check for variation in interpretation, thus ensuring the credibility and dependability between the data and the findings made by the researcher. These selected transcribed interviews were representative of women of all the age groups, languages, private or academic classification, residence during treatment and education levels. The suggestion was made to the researcher to maintain an objective approach and to provide an interpretation of the findings that was patient-centred.
- In order to counteract for non-verbal reactions not being documented was to simultaneously listen to the audio recordings while reading the transcripts and noting where participants' tone of voice emphasized certain important issues or topics discussed.
- The meaning units were transformed into conceptual language and those with shared characteristics were grouped together to build categories. All transformed meaning units were synthesised into a general description of the phenomenon to capture the essence of participants' lived experiences, while undergoing high dose rate brachytherapy.
- Categories of experiences were summarised into related statements and theme titles allocated. Sub-themes covering different aspects within each theme were identified.

Alphanumeric coding was used to describe the profile of each participant when direct quotes were used. English translations of the Afrikaans quotations were included in parenthesis

immediately following each quote, while the Sesotho remarks were only given in English. Words which were added to the quotes that were not included in the original translation were written in square brackets. It was further indicated in the findings whether the suggestions made by the participants were prompted or not.

2.2.8 Rigour

Letts, Wilkins, Law, Stewart, Bosch and Westmorland (2007) stated that the overarching concept when considering rigour in qualitative research is "*trustworthiness".* Trustworthiness can be defined as the extent to which the findings are an authentic reflection of the personal or lived experiences of the phenomenon under investigation (Curtin & Fossey 2007). The issues of rigour were dealt with using Lincoln and Guba's (1985) criteria which include credibility, transferability, dependability and conformability. Guba proposed these four criteria that he believes should be considered by qualitative researchers in pursuit of a trustworthy study (Shenton 2004).

2.2.8.1 *Credibility*

Credibility which is related to the "*true"* picture of the phenomenon (DuFon 2002) was achieved in stage one of the current study. Participants were encouraged to be frank at the outset of the interviews and informed that there were no right answers to the questions that were asked and that they could withdraw from the study at any point. The interview schedule was proof read by the study promoters and pilot-tested in order to increase the credibility of the research tool. The open-ended interview schedule included probes that elicited detailed data and iterative questioning. The audio recordings of the interviews also lent themselves to being checked by other researchers or promoters which contributed to the validity.

Frequent debriefing sessions or meetings between the researcher and promoters were held to provide a sound platform for the researcher to test her developing ideas and interpretations. Eleven of the twenty-eight transcribed interviews were purposively selected by the study promoters and checked for variation in interpretation, thus ensuring the credibility and dependability between the data and the findings made by the researcher. Findings of the study were evaluated by the researcher through reflective commentary. The background, qualifications and aggregate experience of the researcher added to the credibility of the study.

According to Patton (2002), the credibility of the researcher is especially important in qualitative research as it is the person who is the major instrument of data collection and analysis. The thick description of the phenomenon under scrutiny and literature reviews of women's experiences of brachytherapy treatment (cf. 1.5) added to the credibility of the study.

2.2.8.2 *Transferability*

Transferability is related to whether the findings can be transferred to other situations (DuFon 2002). Transferability of this stage of the current study was ensured by a detailed description of the study sample of twenty-eight women of different cultural and socio-economic backgrounds and the description of their experiences ensured transferability.

2.2.8.3 *Dependability*

Dependability relates to the consistency between the data and the findings. Lincoln and Guba (1985) stressed the close ties between credibility and dependability, arguing that, in practice, a demonstration of the former goes some distance in ensuring the latter. The methodology of data collection, analysis and interpretation was described in detail and peer reviewed by the study promoters.

2.2.8.4 *Conformability*

Conformability is the qualitative investigator's comparable concern to objectivity (Shenton 2004) which involves the strategies used to limit bias in the research (Letts *et al*. 2007), specifically the neutrality of the data and not that of the researcher (Patton 2002). Conformability was enhanced through the researcher being reflective and having the ideas and interpretation of the data peer reviewed or scrutinized by the study promoters. The researcher was not present during the patient interviews as to ensure a non-biased approach.

2.3 FINDINGS

2.3.1 Participant profile

Alphanumeric coding (e.g. P1: 47, Aca, Ses, Ses, Kat, Pri) was used to refer to the profile of each participant when direct quotes were used (Table 2.3).

Table 2.3 Patient interviews: Alphanumeric coding of participant characteristics

Age	30-73	
Classification	Academic	Aca
	Private	Pr
Home and interview languages	Sesotho	Ses
	Afrikaans	Afr
	English	Eng
Residence during treatment	Katleho	Kat
	Olea	Ol
	Ward	Wrd
	Local	Loc
Educational level	No formal education	No
	Primary	Pri
	Secondary	Sec
	Tertiary	Ter

Twenty-eight participants, aged between 30 and 73 years, who had been diagnosed with cervical cancer (Stages IB-IIIB$_2$) and had completed three high dose rate brachytherapy treatments, were included in the study (Table 2.4). Ten of the participants were in the age group 30-45 years, twelve of the participants were in the age group 46-60 and six of the participants represented the age group 61 years and older. The sample size consisted of eighteen black, six white and four coloured participants of whom eighteen were from the Free State, nine from the Northern Cape and one from Gauteng. Seventeen of the twenty-eight participants' home language was Sesotho and the remaining eleven participants' home language was Afrikaans. Six of the participants whose home language was Sesotho, preferred to conduct their interviews in English and one Sesotho speaking participant preferred to speak in Afrikaans during the interviewing process. All of the eleven Afrikaans speaking participants chose to conduct their interviews in Afrikaans.

Twenty-two of the twenty-eight participants of this study were classified as academic participants and six of the participants were private patients. Nine of the fifteen participants who stayed at the halfway house Katleho came from other Free State towns, while six of the participants had residence in the Northern Cape. One of the two ward participants of the study came from Bloemfontein, while the other one came from the Northern Cape. Six of the participants stayed at the halfway house Olea during their treatment. One of them came from Gauteng, three participants had residence in other Free State towns and two participants came from the Northern Cape. Five participants of the study were local and had residence in Bloemfontein.

The educational level of the twenty-eight participants was as follows: Two of the participants had no formal education; ten had received primary schooling; eleven participants completed secondary schooling and five participants finished their tertiary education.

Table 2.4 Patient interviews: Participant profile

Participant number and Alphanumeric coding	Race	Age	Classified As Private/ Academic	Home Language	Language interviewed	Residence during treatment	Educational level	Employment status
P1 P1: 47,Aca,Ses,Ses,Kat,Prim	Black	47	Academic	Sesotho	Sesotho	Halfway house: Katleho	Primary	Unemployed
P2 P2: 73,Aca,Ses,Ses, Kat,Prim	Black	73	Academic	Sesotho	Sesotho	Halfway house: Katleho	Primary	Unemployed
P3 P3: 40,Aca,Afr,Afr,Kat,Sec	Black	40	Academic	Afrikaans	Afrikaans	Halfway house: Katleho	Secondary	Unemployed
P4 P4: 40,Aca,Afr,Afr,Ol,Sec	White	40	Academic	Afrikaans	Afrikaans	Halfway house: Olea	Secondary	Unemployed
P5 P5: 33,Aca,Ses,Ses,Wrd,Sec	Black	33	Academic	Sesotho	Sesotho	Ward patient	Secondary	Unemployed
P6 P6: 55,Aca,Ses,Eng,Kat,Sec	Black	55	Academic	Sesotho	English	Halfway house: Katleho	Secondary	Unemployed
P7 P7: 68,Aca,Ses,Ses,Kat,No	Black	68	Academic	Sesotho	Sesotho	Halfway house: Katleho	No formal	Unemployed
P8 P8: 55,Aca,Ses,Eng,Kat,Sec	Black	55	Academic	Sesotho	English	Halfway house: Katleho	Secondary	Unemployed
P9 P9: 50,Aca,Ses,Ses,Kat,Sec	Black	50	Academic	Sesotho	Sesotho	Halfway house: Katleho	Secondary	Unemployed
P10 P10: 57,Aca,Afr,Afr,Kat,Prim	Coloured	57	Academic	Afrikaans	Afrikaans	Halfway house: Katleho	Primary	Unemployed
P11 P11: 55,Aca,Ses,Afr,Kat,Prim	Black	55	Academic	Sesotho	Afrikaans	Halfway house: Katleho	Primary	Unemployed
P12 P12: 50,Aca,Afr,Afr,Kat,Prim	Coloured	50	Academic	Afrikaans	Afrikaans	Halfway house: Katleho	Primary	Unemployed
P13 P13: 64,Aca,Afr,Afr,Ol,Sec	White	64	Academic	Afrikaans	Afrikaans	Halfway house: Olea	Secondary	Unemployed
P14 P14: 41,Aca,Afr,Afr,Loc,No	White	41	Academic	Afrikaans	Afrikaans	Local patient: Bloemfontein	No formal	Employed

Table 2.4 Patient interviews: Participant profile (continued)

Participant number and Alphanumeric coding	Race	Age	Classified As Private/ Academic	Home Language	Language interviewed	Residence during treatment	Educational level	Employment status
P15 P15: 61,Aca:,:Ses,Kat,Sec	Black	61	Academic	Sesotho	Sesotho	Halfway house: Katleho	Secondary	Unemployed
P16 P16: 69,Pr,Afr,Afr,Loc,Ter	White	69	Private	Afrikaans	Afrikaans	Local patient: Bloemfontein	Tertiary	Unemployed
P17 P17: 30,Aca,Ses,Eng,Kat,Sec	Black	30	Academic	Sesotho	English	Halfway house: Katleho	Secondary	Unemployed
P18 P18: 41,Aca,Afr,Afr,Kat,Prim	Coloured	41	Academic	Afrikaans	Afrikaans	Halfway house: Katleho	Primary	Unemployed
P19 P19: 56,Aca,Ses,Ses,Kat,Prim	Black	56	Academic	Sesotho	Sesotho	Halfway house: Katleho	Primary	Unemployed
P20 P20: 51,Aca,Ses,Ses,Kat,Prim	Black	51	Academic	Sesotho	Sesotho	Halfway house: Katleho	Primary	Employed
P21 P21: 38,Pr,Ses,Eng,Ol,Ter	Black	38	Private	Sesotho	English	Halfway house: Olea	Tertiary	Employed
P22 P22: 35,Aca,Afr,Afr,Wrd,Sec	Coloured	35	Academic	Afrikaans	Afrikaans	Ward patient	Secondary	Unemployed
P23 P23: 55,Pr,Ses,Ses,Ol,Prim	Black	55	Private	Sesotho	Sesotho	Halfway house: Olea	Primary	Unemployed
P24 P24: 36,Pr,Ses,Eng,Ol,Sec	Black	36	Private	Sesotho	English	Halfway house: Olea	Secondary	Employed
P25 P25: 37,Aca,Afr:,Afr,:Ol,Ter	White	37	Academic	Afrikaans	Afrikaans	Halfway house: Olea	Tertiary	Unemployed
P26 P26: 48,Pr,Ses,Eng,Loc,Ter	Black	48	Private	Sesotho	English	Local patient: Bloemfontein	Tertiary	Employed
P27 P27: 55,Pr,Afr,Afr,Loc,Ter	White	55	Private	Afrikaans	Afrikaans	Local patient: Bloemfontein	Tertiary	Employed
P28 P28: 61,Aca,Ses,Ses,Loc,Prim	Black	61	Academic	Sesotho	Sesotho	Local patient: Bloemfontein	Primary	Unemployed

****Abbreviations used for alphanumeric coding:*** *Participant number:* ***P1****; Age:* ***47****; Classification: Private* ***(Pr)*** *Academic (****Aca);*** *Home and interviewed languages: Sesotho-****Ses****, Afrikaans-****Afr,*** *English-****Eng****; Residence during treatment: Katleho-****Kat****, Olea-****Ol,*** *Ward-****Wrd,*** *and or Local-****Loc****; Educational level: None-****No,*** *Primary-****Prim****, Secondary-****Sec,*** *Tertiary-****Ter****.*

2.3.2 Participant experience

The analysis identified shared and unique experiences amongst the twenty-eight interviewed participants. Four themes with sub-themes were identified from the data (Figure 2.1): (1) informational needs, (2) patient disposition towards treatment, (3) psychological experience and (4) physical experience. Each sub-theme includes the related findings, suggestions made by the participants to improve patient management and a summary.

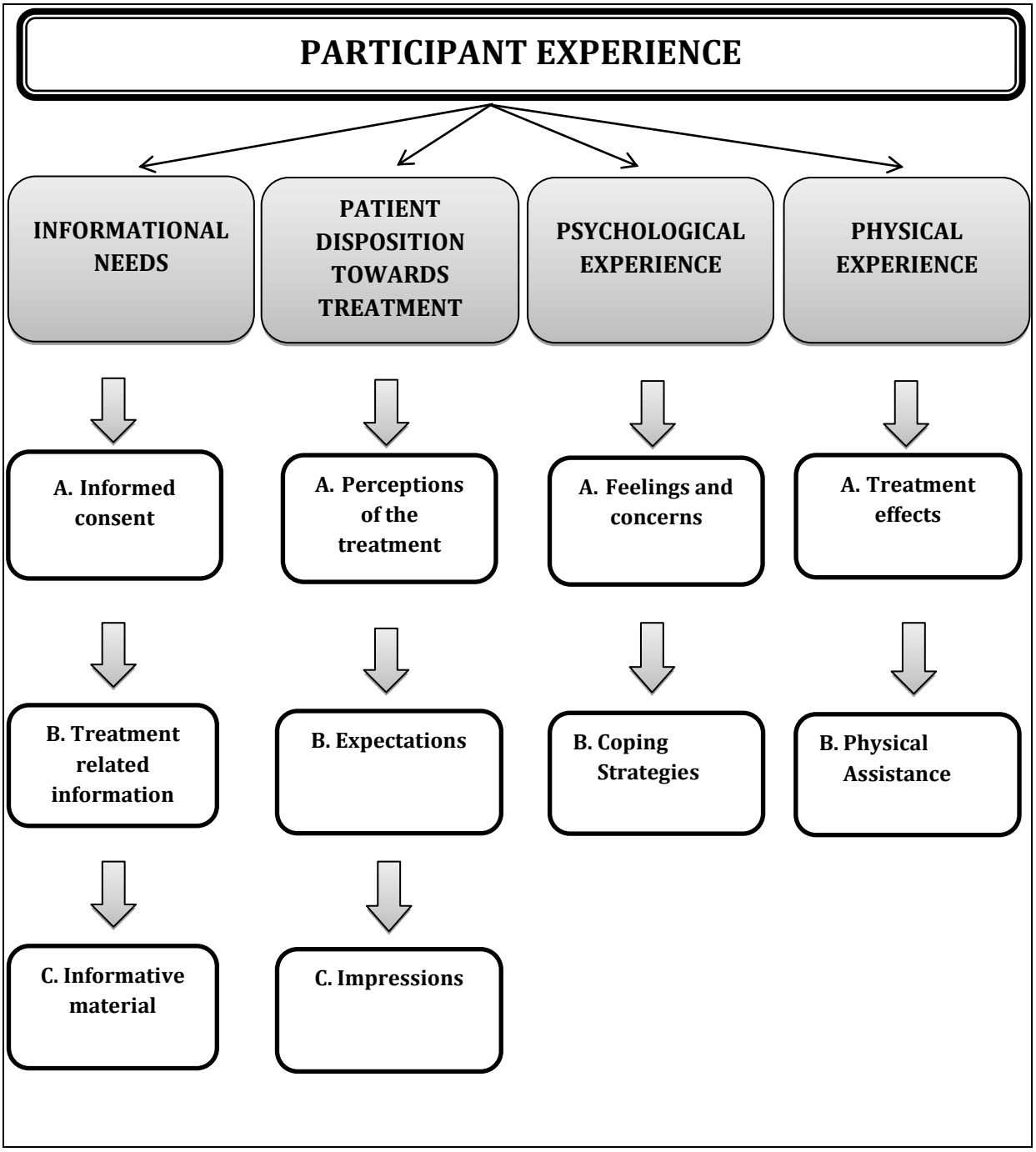

Figure 2.1 Identified themes and sub-themes of participant experience

2.3.2.1 *Informational needs*

A. <u>Informed consent</u>

A.1 Findings

A.1.1 Language of communication

The interviewed participants were asked to state in which language they were informed of their forthcoming brachytherapy treatment at the new patient clinic and were prompted whether they understood the language in which they were addressed.

The majority of the participants were Sesotho speaking of whom only a few reported being addressed in their home language. Those who were addressed in Sesotho reported that they understood very well what was explained to them and one participant who received an explanation of the inside radiation from a black female doctor had the following to say:

> *Yes, I did understand very well what was said* (P2: 73, Aca, Ses, Ses, Kat, Prim)

The following comment was made by a Sesotho speaking participant who received an explanation of the treatment procedure by the attending nurse in her home language:

> *But there was a nurse here and she would explain to us everything in Sesotho* (P9: 50, Aca, Ses, Ses, Kat, Sec)

This participant was pleased that she had received more information on the treatment procedure in her home language. Most of the Sesotho speaking participants however received an explanation of the treatment procedure in English and understood what was explained to them. The following comments were made by two participants:

> *They explained everything to me on what is going to happen. The whole procedure* (P24: 36, Pr, Ses, Eng, Ol, Sec)

> *But he explained me with English. But I do understand* (P21: 38, Pr, Ses, Eng. Ol, Ter)

Few Sesotho speaking participants who were addressed in English did not fully comprehend what was explained to them. A private, Sesotho speaking participant who received an explanation on the procedure from the attending nurse in English, made the following comment:

> *I was only able to understand few parts to tell the honest truth* (P23: 55, Pr, Ses, Ses, Ol, Prim)

A few of the Sesotho speaking participants were addressed in Afrikaans. The findings show that these participants did not understand fully what was explained to them:

> *I could not understand as they were speaking in Afrikaans* (P9: 50, Aca, Ses, Ses, Kat, Sec)

> *They spoke in their own language, but I can understand Afrikaans a bit, but I do get lost here and there; She explained the whole process to me. I asked if they were going to perform an operation on me or not?* I *did not really understand anything about this treatment… I was clueless.* (P20: 51, Aca, Ses, Ses, Kat, Prim)

> *There are some parts I missed, because I could only get it here and there* (P28: 61, Aca, Ses, Ses, Loc, Prim)

One Sesotho speaking participant, who received an explanation of the brachytherapy treatment in Afrikaans and English, had the following to say:

> *…but I told them I would like to get the explanation in Setswane or Sesotho as well, because there other girls there who were training from the army and one of them came and explained everything to me* (P19: 56, Aca, Ses, Ses, Kat, Prim)

The Afrikaans speaking participants received explanations of the treatment in their home language. All of them understood what was explained to them as indicated by the following remarks:

> *…hy't my rerig goed ingelig. Ek moet sê…hulle het nie informasie teruggehou nie* (…he informed me very well. I must say…they did not withhold any information) (P25: 37, Aca, Afr, Afr, Ol, Ter)

> *Ja nee, ek het hulle goed verstaan* (Yes, I understood them very well) (P4: 40, Aca, Afr, Afr, Ol, Sec)

A.1.2 Opportunity for questions

Most of the participants reported that they were given an opportunity to ask questions by the informing doctor, before signing consent. One participant reported the following:

> *I asked about the inside radiation: Hey doctor, how is it going to make?* (P8: 52, Aca, Ses, Eng, Kat, Sec)

However, some of the participants said that they had no questions, because they felt they were adequately informed, while a few participants felt that they would ask questions at a later stage. One patient said she felt there was not time to ask and made the following comment:

> *There's some lot of things that I want to know* (P21: 38, Pr, Ses, Eng, Ol, Ter)

One elderly patient said the following:

> *...jy weet 'n mens is dom. Jy's bang. Jy weet nie watse vrae om te vra nie* (…you know a person feels stupid. You're scared. You don't know which questions to ask) (P13: 64, Aca, Afr, Afr, Ol, Sec)

One of the participants who were not given an opportunity to ask questions said that it did not worry her too much, because she understood some of the things that were explained to her. A ward patient said she would have liked to ask the doctor the following:

> *I would ask about sex* and *will I still be able to give birth though?* (P5: 33, Aca, Ses, Ses, Wrd, Loc, Sec)

Another participant made the following statement:

> *I did not get a chance to ask all those questions* (P20: 51, Aca, Ses, Ses, Kat, Prim)

She wanted to know whether she would be well after the treatment and if she needed to come back or not. When prompted how she felt when she was not given an opportunity to ask questions, another participant said she felt bad, but thought that she would wait and see for herself. She did not verbalise her questions, because she thought it would be too presumptuous to ask and she was scared of wasting the doctor's time. She made the following statement:

> *Ek het maar net geluister en gedink ek kyk maar net hoe gaan dit* (I only listened and thought I will see how it goes) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

A.1.3 Reasons for signing consent

One participant said she gave consent for the inside radiation, because she felt the treatment would be more effective for her type of cancer and that it was advantageous to give the doctor (personnel) permission to proceed with the treatment. Some participants gave consent for the brachytherapy treatment, because they were told that surgery was not an option and the inside radiation was part of the advised treatment. The following statement was made:

> *…en dis noodsaaklik. Dus, jy moet dit maar net doen. Jy't nie rerig 'n keuse, dink ek nie* (…and it's necessary. Thus, you just have to do it. You haven't really got a choice, I don't think) (P25: 37, Aca, Afr, Afr, Ol, Ter)

A forty-one year old participant said she gave consent, because she had small children and wanted to get healthy for their sake. One participant said that she gave consent, because they

had told her that the treatment would not be so bad and that she should sign. She said the following:

> *Nou ja, toe teken ek, want niemand het vir my beduie…* (In any case, I signed, because no-one showed me…) (P13: 64, Aca, Afr, Afr, Ol, Sec)

Most of the participants said that they had come to the hospital for help, because they had been bleeding for a long time. They all wanted to get better and be healed or cured from their illness which motivated them to sign the consent letter. These are some of their comments:

> *I came here to get well*; *So I agreed and said they can go on as I was very ill and I could take it no longer[!]* (P2: 73, Aca, Ses, Ses, Kat, Prim)

> *I will agree to anything that they will do as long as I get all the help I need* and *I put my faith into it, after the way everything was explained to me and that I will be well* (P7: 68, Aca, Ses, Ses, Kat, No)

> *I agreed to have this radiation treatment, because I was desperate to receive help* (P19: 56, Aca, Ses, Ses, Kat, Prim)

A.2 Patient suggestions

• Provide easily understood information in the patient's home language.

> *Toe sê ek nee, probeer dit huislik praat net in simple Afrikaans, dat ek kan verstaan* (I said no, rather speak in simple Afrikaans which I can understand) (P10: 57, Aca, Afr, Afr, Kat, Prim)

> *It would have been nice if I got an explanation in Sesotho* (P23: 55, Pr, Ses, Ses, Ol, Prim)

• Provide patients with information about sexual intercourse and the possibilities of subsequent childbearing.

• Provide patients an opportunity to ask questions.

• Obtain consent from patients before allowing medical students into the treatment room (Prompted).

> *Maar ek dink hulle moet mens net vroegtydig sê. Dan sal mens sommer wegbly, maar ek jok. Nee, ek dink hulle moet net oppas vir dit…* (But I think they should inform a person beforehand. Then one would stay away, but I lie. No, I think they must be careful of that…) (P16: 69, Pr, Afr, Afr, Loc, Ter)

A.3 Summary

Participants who were informed about their forthcoming brachytherapy treatment in their home languages reported that they understood what was explained to them. Although the majority of the participants were Sesotho speaking, only a few were addressed in their home language. Sesotho speaking participants who were addressed in English had a better understanding of what brachytherapy entails than those who were informed in Afrikaans. The participants indicated that they would prefer to be informed in their home language.

Most of the participants were granted an opportunity to ask treatment related questions before signing consent. Some participants did not want to ask questions, as they felt they were either adequately informed, they could ask questions at a later stage, they felt presumptuous and/or inadequate to ask questions or did not want to waste the doctor's time. The few participants who were not given an opportunity to ask questions wanted more information regarding the following: sexual intercourse, child bearing, brachytherapy treatment, success or outcome of the treatment and follow-up dates. All participants reported that they gave consent for the brachytherapy treatment, because they "were ill", "needed help" and "were desperate to be cured" and "to get well".

B. <u>Treatment related information</u>

B.1 Findings

Participants were questioned during the interviews on treatment related information conveyed to them at the new patient clinic. The following themes emerged: (1) treatment methods; (2) side-effects; (3) sexual intercourse; (4) pre-treatment preparation; (5) scheduled appointments; (6) explanation of the treatment procedure; (7) waiting period; (8) follow-up appointments; (9) opportunity for questions and (10) signing consent.

B.1.1 Treatment methods

Participants reported that they had received information regarding other possible treatment modalities, from the informing doctor. They were informed why surgery was not an option and that radio-chemotherapy would be the best treatment method. A participant was told that after the "machine", she needed to go for the inside radiation and had the following thought:

I thought that because this cancer it's inside, it should be cured from the inside (P6: 55, Aca, Ses, Eng, Kat, Sec)

A thirty year old participant said that they had discussed the option of surgery with her, but because she had no children and was newlywed, radiation would be the best option, because the cancer had spread.

B.1.2 Side-effects

Less than half of the participants reported that they were informed about possible side-effects they might experience, while undergoing brachytherapy treatment. Expected side-effects such as infection, nausea, diarrhoea, burning of urine, pain, swelling and shrinkage of the cervix were mentioned to some participants. One of the participants said that on the first day, the doctor explained everything fully to her and she was informed about the complications she could expect after the treatment e.g. constipation, bleeding and how to manage these side-effects. She also received much information from patients who had already received inside radiation.

The following remarks were made by participants who said that they were not really informed of the side-effects of the inside radiation:

> *…ek het nou nie eintlik regtig 'n "clue" daarvan nie* (…I do not actually have a clue about it) (P12: 59, Aca:Afr, Afr, Kat, Prim)

When prompted if she understood what was meant by the side-effects of the treatment, the participant made the following comment:

> *They never told me. They only said to me that when they are done with me, I will experience pains, but I should not take anything for them. I will be fine* (P19: 56, Aca, Ses, Ses, Kat, Prim)

A private participant said that no-one said anything about the side-effects to her, but she could remember that at the private hospital they explained to them that they would not be able to eat things like meat and that she would have to abstain from oily foods. She made the following statement:

> *I was not aware that it has the same after-effects as the one we were doing at [private hospital]* (P23: 55, Pr, Ses, Ses, Ol, Prim)

B.1.3 Sexual intercourse

Most participants reported that they were not informed about sexual intercourse, while undergoing brachytherapy treatment. One participant said she overheard the nurse explaining to a new patient about sex and made the following comment:

> *…hy't nie rerig direk met my gepraat nie* (…he didn't really speak directly to me) (P22: 35, Aca, Afr, Afr,Wrd, Sec)

She overheard that she should engage in sex with her husband, as this would ensure that the vagina would stay open. Another participant said that she intended to ask the doctor about it as she was a married woman. A forty-eight year old participant said that they did not say anything; because she had informed them that she did not have a partner and that she was a single parent. She made the following comment:

> *But, so they didn't go deeper with it* (P26: 48, Pr, Ses, Eng, Loc, Ter)

There were three elderly participants (61, 64 and 69 years old) who said that they were not informed about sex and one of them said that they did not inform her as they thought she was too old and she was a widow. When it was suggested that they only talked about sex with young people who was sexually active, the participant replied with the following:

> *So you can understand that I am not that person anymore* (P28: 61, Aca, Ses, Ses, Loc, Prim)

B.1.4 Pre-treatment preparation

Most of the participants indicated that they were not given any instructions to follow on the evening prior to and on the morning of their first brachytherapy treatment. One of the participants said that they did not tell her how she had to prepare for her brachytherapy treatment. She was only told that she needed to go to the "slaughterhouse" on the following day. A private participant said that the nursing staff did not say anything to her at the private hospital and that she was only given a letter informing her of the date on which she needed to be at the governmental hospital for her brachytherapy treatment. The following prompted remarks were made by some of them:

> *They never told me* (P15: 61, Aca, Ses, Ses, Kat, Sec)

> *Nee, hulle het niks gesê nie. Ek het gewonder of moet ek of nie. Maar ek het 'n stukkie toast geëet en tee gedrink* (No, they did not say anything. I was wondering, should I or not. But I ate a piece of toast and drank tee) (P16: 69, Pr, Afr, Afr, Loc, Ter)

But this one, even if you eat, it does not matter (P19: 56, Aca, Ses, Ses, Kat, Pr)

Only one of the participants who received pre-treatment instructions knew she had to abstain from food from ten o' clock the previous night and not to have anything to drink or eat on the morning of her brachytherapy treatment. Not one of the participants was given a laxative on the day prior to their treatment. One of the participants said they were not to wash with soap water and to avoid eating breakfast and when prompted if she knew the reason why she had to abstain from food, she said she did not really know why, but thought that it would make it easier to radiate her. Another participant said that she was just told to go to the unit and to make sure that her stomach was clean so that the treatment would not fail. She understood that if her rectum was full, the machine would not work. When prompted whether she knew if she could eat anything prior to her treatment, she had the following to say:

I can eat. Maybe porridge? But just a little. Not too much (P6: 55, Aca, Ses, Eng, Kat, Sec)

A participant said that she was told to wash herself with salt water and she understood that she could eat food on the night before the treatment, but not the following morning as her stomach needed to be empty. When prompted whether she knew if she could eat food prior to her treatment, she had the following to say:

I must not eat in the morning (P8: 52, Aca, Ses, Eng, Kat, Sec)

The participant said that she was told by the doctor that she may not eat anything on the day of the inside radiation. She said that she might have a cup of coffee or tea to drink. When prompted if she knew why she had to abstain from food, she said that she did not really knew why, but suspected that it was for the same reason that a person had to abstain from food before going for an operation.

There were a few participants who were not informed of the day on which they were to receive their inside radiation and could therefore not follow the pre-treatment instructions. One of them said that she was told on her arrival at reception that she needed to prepare for her inside radiation. The private participant said that she was not informed of the pre-treatment preparation and went for a normal radiation at a private hospital. She made the following statement:

So I was sitting there and the nurse came and told me I was supposed to be at internal radiation. Then I just came here [Governmental hospital] (P24: 36, Pr, Ses, Eng, Ol, Sec)

An academic participant said she did not really receive any information on what she had to do prior to the treatment. She was at the accelerator when she was informed to go for the inside radiation. She made the following comment:

Toe't ek nie eers geweet dit is my dag van binne bestraling nie (I did not even know that it was my day for inside radiation) (P25: 37, Aca, Afr, Afr, Ol, Ter)

When prompted how it made her feel that she was not informed of the pre-treatment preparation or of the date of her treatment delivery, she said she felt traumatised, because she did not have an opportunity to prepare herself mentally for it. However, she mentioned that she could have asked someone, but that they as patients could not expect that, amongst the hundreds of patients, the personnel would get the information through to all the patients.

B.1.5 Scheduled appointments

Some participants said that they were not informed on the specific date that they were going to receive their brachytherapy treatment. One participant said she arrived at reception only to be told that she had to go for the inside radiation. She said that she was not aware that there was a list at the halfway-house Katleho where she could go and check whether she was scheduled for her treatment on the following day. She felt that she could have prepared herself mentally for the treatment day and could have dealt with her fears and worries beforehand if she was given a date for the brachytherapy treatment. When prompted how she could have prepared herself better for her first treatment, the patient had the following to say:

If I had been told of the first day, I think I would have been able to prepare myself mentally and dealt with all the fears and the worries beforehand (P1: 47, Aca, Ses, Ses, Kat, Prim)

Another participant said that she was only told the morning of the procedure that she would be going for inside radiation and made the following remarks:

They said to me in the morning, please note that you will be moving to the other side; They did not make time to explain to me and say please know that you will be going for the treatment tomorrow morning (P7: 68, Aca, Ses, Ses, Kat, No)

When prompted how it made her feel, she had the following to say:

> *Because I did not really understand the whole procedures, I thought to myself that maybe that is how they work and I will have to abide* (P7: 68, Aca, Ses, Ses, Kat, No)

The ward participant said she was under the impression that she was being fetched by the porters for her outside radiation, but was pushed to the brachytherapy unit. The patient did not talk to anyone about her worries and fears. She sat there waiting for someone to come and inform her about the treatment procedure and made the following comment:

> *Maar nie een het gekom nie (*But no-one came) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

When prompted concerning her worries, she said that she was wondering what they were going to do to her, because it was her first time and she did not know what to expect. Another participant said that she felt traumatised by not being informed on which day she was scheduled to go for her brachytherapy treatment

B.1.6 Explanation of the treatment procedure

The majority of the participants reported that they received an explanation of the procedure on their arrival at the brachytherapy unit. The attending nurse at the unit was mostly responsible for informing the participants of the treatment procedure, only a few were informed by a physician. A participant said that although she felt really scared on arrival at the unit, the way that she was approached by the nurse made her feel very good and she felt comforted. On the patient's arrival at the unit, the nurse gave her an explanation of what she could expect from the treatment. The following remarks were made by some participants:

> *There was a nurse who explained everything to me on my first day here. Even though I was still a bit scared, but there after I felt better* (P1: 47, Aca, Ses, Ses, Kat, Prim)

> *They did much better than what the friend of mine said; So by the time when I went in, I was prepared, because I knew what was going to take happen* (P15: 61, Aca, Ses, Ses, Kat, Sec)

> *…they make sure that you understand very well so that you do not become scared and want to run away* (P15: 61, Aca, Ses, Ses, Kat, Sec)

An uninformed participant said that no-one had told her about the procedure for the treatment and when she had asked a fellow patient what the inside radiation was about she was told that

"irons were going to be placed inside her womb". When prompted how she felt about the people who did not explain things to her, she said the following:

> *…ek vat hulle nie sleg nie. Want ek weet nie, mag hulle my sê of mag hulle my nie sê nie. Dit is die ding* (…I have no bad feelings towards them, because I don't know whether they may tell me or not. That's the thing) (P11: 55, Aca, Ses, Afr, Kat, Prim)

A participant said that they came to the unit, but no-one discussed the treatment with them. One of the patients had asked her to explain the procedure to her and she said the following:

> *Toe sê ek vir haar, jy weet, ek weet nie wat is binne bestraling nie, want niemand het met ons dit bespreek nie. Ons het hiernatoe gekom, ons het uitgetrek en ons het gewag* (I then said to her, you know, I don't know what is inside radiation, because no-one discussed it with us. We came here, got undressed and then we waited) (P13: 64, Aca, Afr, Afr, Ol, Sec)

A ward participant said that when she arrived at the unit, she was not given any instructions or told what to do and what not. She said that not one of the nurses spoke to her about the inside radiation. She had the following to say:

> *Hulle het net vir my gevat daai eerste dag en ingestoot* (They just took me on that first day and pushed me in) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

However, when she arrived for her second inside radiation, she overheard the treatment procedure being explained to a new patient by the attending nurse and asked the nurse what she needed to know.

> *…ek het self gevra* (…I asked) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

When prompted how it made her feel not receiving any information orally (or by a booklet), she said she felt bad for herself and for those who cannot read. There was however, one participant who preferred not to be informed about the brachytherapy treatment and made the following comment:

> *…in fact, I asked them not to tell me anything. I will have to see for myself. Don`t explain anything, because I was afraid, to be honest* (P6: 55, Aca, Ses, Eng, Kat, Sec)

She indicated that she might have run away if she knew what was going to happen to her.

B.1.7 Waiting period

Some of the participants of the study said that they were informed on how long they needed to wait before going for their treatment. However, one of the participants said that although she was told how long she had to wait, it felt too long. Only one participant was given a specific time as shown by the following:

> *Yes, sister told me an hour and forty minutes* (P17: 30, Aca, Ses, Eng, Kat, Sec)

Another participant said that all the patients were informed that the doctor would arrive at nine o'clock. When prompted if it was acceptable for her to wait, she said that it was and that it was no problem. The following remarks were made by some of the participants when asked if someone explained to them how long they had to wait:

> *They did, but we did not wait that long though* (P19: 56, Aca, Ses, Ses, Kat, Prim)

> *The sister just tells me I must come here and then I'm going to wait. They say: Mother you are going to wait some couple of minutes. When you hear the bell rings, you must know somebody's finished there inside. Now it is you who's going to come* (P8: 52, Aca, Ses, Eng, Kat, Sec)

When the participant was prompted how she felt about being informed on how long she needed to wait, she said the following:

> *Hey, it was nice for me* (P8: 52, Aca, Ses, Eng, Kat, Sec)

One participant said that she was told by the nurse that the doctor would come at ten o'clock, but the doctor only came later, because he was still busy at the clinic. When prompted whether having to wait for the doctor was acceptable to her, she made the following comment:

> *Ja, hy was aanvaarbaar…want ek is nou klaar gesê hoe laat die dokter kom* (Yes, it was acceptable, because I was already told how late the doctor would come) (P11: 55, Aca, Ses, Afr, Kat, Prim)

A private participant said that she was told that if she was there at half past seven to eight, she would not wait too long. On her arrival, they phoned the doctor informing him that she had arrived. She made the following comment:

> *Really, I don't wait* (P26: 48, Pr, Ses, Eng, Loc, Ter)

Words such as a "few minutes", "couple of minutes" and "a little while", were used to inform the participants on how long they had to wait before going for their treatment. One participant who were not informed by the personnel on how long she had to wait before treatment delivery had the following to say:

> *I did not know if it was going to be 5 minutes or 10 minutes. I just did not know* (P7: 68, Aca, Ses, Ses, Kat, No)

When prompted how it made her feel, the participant had the following to say:

> *Not good. But what can I do, sometimes we don't know who to ask* (P7: 68, Aca, Ses, Ses, Kat, No)

She said that if she was given a time, she would have arrived at the appropriate time, without having to sit for a longer period than necessary. One participant said that she sat for a while, maybe half an hour, depending on which patient gets called in first. They were told to switch their phones off, had no watch and could therefore not tell the exact time she waited. When prompted whether she thought that the waiting time was too long or acceptable, she made the following comment:

> *...partykeer voel dit vir my dis te lank, jy wag te lank* (…it sometimes felt too long for me, you wait too long) (P18: 41, Aca, Afr, Afr, Kat, Prim)

A ward participant said that she was brought to the waiting room and instructed to lie on the bed in the waiting room. When asked if there was a bed in the waiting room, she said that there was a small bed inside the waiting room and was told to lie on it. The patient said that after a long time, she was told to get off the bed, onto a chair and was given syrup to drink. She made the following comment:

> *En na 'n lang ruk, toe word ek weer gesê, nee jy moet afklim…* (And after a long time, I was told again, now you must get off the bed…) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

When prompted how it made her feel, not knowing how long she had to wait before going for her treatment, she said it worked on her nerves, because she did not know what to expect and was wondering how the apparatus would work. She had the following thought:

> *Sal jy lewendig uitkom?* (Will you come out alive?) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

The following remark was made by a participant from the private hospital:

Here we did not have a clue how long were going to wait... (P23: 55, Pr, Ses, Ses, Ol, Prim)

B.1.8 Follow-up appointments

Some participants reported that they were informed about their next follow-up appointment. One of them said that she was told to go for her follow-up appointment at a governmental hospital close to her home and said the following:

I'll have to go back for the check-ups (P6: 55, Aca, Ses, Eng, Kat, Sec)

Most of the participants stated that they were not informed about the follow-up appointment and some said that they were probably going to receive a follow-up date on the day they finished their treatment as indicated by the following:

Maybe on the final day before they discharge me, that is when they might say something (P5: 33, Aca, Ses, Ses, Wrd, Loc, Sec)

B.2 Patient suggestions

• Appoint a person to inform all the new patients on the treatment procedure, preferably in their home language. (Prompted)

...daar is mos nou iemand voltyds. So elke tyd as daar nuwe mense kom, daar moet iemand voltyds altyd vir hulle sê: ...Jy is by die binne bestraling. Dit werk so en met hulle gesels oor dit. Sodat mense kan gewoond raak. Sodat jy weet as jy na dié plek toe gaan, moet jy weet wat word spesifiek verwag (…there is now someone full-time. So every time new patients arrive, there should be someone full-time, talking to them and say: You are at the inside radiation. It works like this and talk to them about it so that they can get used to it. Then you will know that when you go to this place, you must know exactly what to expect) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

…vernaam vir die Swartes. Jy weet, Hulle kan nie alles verstaan nie (…especially for the Black people. You know, they don't understand everything) (P13: 64, Aca, Afr, Afr, Ol, Sec)

• Information sessions prior to treatment.

So, voordat jy hom by die binne bestraling kry, moet jy eers vir hom miskien 'n dag of twee vat en sê: Môre is jou dag. Maar môre sal dit, dit gebeur en dit gebeur (So, before you get the patient for the inside radiation, you must take a day or two and say the following: Tomorrow is your day. Tomorrow, this, this and that will happen to you) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

…kan help as hulle 'n inligtingsessie gee wat om te verwag en hoekom doen hulle dit en wat is die gevolge… (…could help if they give an information session on what to expect and why they do it and what are the consequences…) (P25: 37, Aca, Afr, Afr, Ol, Ter)

• Address the following issues during information sessions: (Prompted)

› What patients can expect from the treatment?
› What will be done to them? and
› Will brachytherapy be a painful procedure or not?

• Schedule treatment times for private patients not too early (07:30) due to the heavy traffic flow early in the mornings. They would prefer not to be rushed and would like to be given some time to relax before going into the treatment room.

• Inform patients how long they need to wait before treatment delivery.

• Inform patients on how long the treatment would last. (Prompted)

• Inform patients that a scan procedure will be performed before commencing with the brachytherapy treatment.

…as hulle dit net vir die pasiënt ook kan sê. Ons gaan jou elke keer eers deursit en dan die bestraling doen. Dan weet mens wat om te verwag (…if they can tell this to the patient. Everytime we are first going to put you through and then give the radiation. Then one knows what to expect) (P16: 69, Pr, Afr, Afr, Loc, Ter)

• Give patients a second explanation of the treatment procedure inside the treatment room.

B.3 Summary

The majority of participants reported that they did not receive any information regarding the possible side-effects of the brachytherapy treatment. Information concerning the pre-treatment preparation was the poorest addressed and some participants, including private participants reported that they were not informed regarding the precise date their brachytherapy treatment was scheduled for. These participants could therefore not follow the pre-treatment regimen which plays an important role during treatment delivery and outcome. According to the majority of the participants the issue of sexual intercourse was not discussed with them, especially with those who were older and/or had no partners.

C. Informative material

C.1 Findings

All the participants were prompted if they would prefer to be given a booklet or pamphlet on brachytherapy and its possible side-effects. The majority of the participants indicated that they would want such a booklet or pamphlet and these were some of their responses:

> *Ja, ek dink dit sal baie, dat baie mense daar lees en sien…Sal iets goeds wees* (Yes, I think lots of people will read it and see…It will be good) (P12: 50, Aca, Afr, Afr, Kat, Prim)

> *Ja, as ek net gesien het wat sou gebeur het, dan was ek miskien nie so bang nie, want ek was vreeslik gespanne* (Yes, if only I could see what would happen. I would have not been so scared, because I was very tense) (P13: 64, Aca, Afr, Afr, Ol, Sec)

One participant made the following comment:

> *Maar hier het ek nie 'n pamflet gekry nie. So ek het nie geweet wat om te verwag nie*" (But I did not get a pamphlet here and so I did not know what to expect) (P13: 64, Aca, Afr, Afr, Ol, Sec)

When a private participant was prompted whether she was given any reading material, concerning the brachytherapy treatment, she said that at the private hospital they only gave them blue books to read about radiotherapy. She reported that the information was written in English and made the following comment:

> *No, they are not helping at all, because they are written in English and I can't even read them. I speak Sesotho[!]* (P23: 55, Pr, Ses, Ses, Ol, Prim)

When prompted how it made her feel when she was not given anything to read to increase her knowledge on the brachytherapy treatment, she said the following:

> *It is a tough case to deal with, but what can I say?* (P23: 55, Pr, Ses, Ses, Ol, Prim)

Some of the participants said that the procedure was well explained to them and did not see the need for a booklet or pamphlet. The following comment was made by one of the participants when prompted whether she would have liked to be given a pamphlet prior to treatment delivery that would help her to understand the procedure better:

Nie rerig nie, want hulle verduidelik so mooi, ek bedoel die mense hierso, die staf hier is fantasties! Hulle verduidelik jou presies wat gaan gebeur (Not really, because they explain so nicely, I mean the people here, the staff, are fantastic! They explain to you exactly what is going to happen) (P4: 40, Aca, Afr, Afr, Ol, Sec)

When a participant was prompted how she felt by not getting an opportunity to read more about the treatment, she had the following to say:

You know, since I was afraid, I felt it much better not to know anything. Just to meet it face to face; Really, I didn't want to even read anything about it; I think I would have been more afraid, understanding (P6: 55, Aca, Ses, Eng, Kat, Sec)

C.2 Patient suggestions

• Provide patients with pamphlets or booklets on the disease and brachytherapy treatment procedure and possible side-effects.

If you could just give us those pamphlets or the books so we can read and learn more and understand this radiation treatment (P5: 33, Aca, Ses, Ses, Wrd, Loc, Sec)

• Provide patients with informative material that is printed in their home language e.g. Sesotho, Afrikaans and English. (Prompted)

• Provide patients with information during information sessions.

It's simple when they talk to me; They talk to me really clearly (P26: 4, Pr, Ses, Eng, Loc, Ter)

C.3 Summary

Most of the participants expressed their need to be given disease specific and treatment related informative material to read prior to their brachytherapy treatment. However, a few of the participants said that they preferred to be given only a verbal explanation of their forthcoming treatment.

2.3.2.2 *Patient disposition towards treatment*

A. <u>Perceptions of the treatment</u>

A.1 Findings

The term "brachytherapy treatment" for cervical cancer was not commonly understood amongst the participants of the study and they all, except for one, referred to it as "the inside

radiation" and in Afrikaans as "die binne-bestraling". Some thought that it was a type of operation to the womb, while others presumed that the cancer or infection was going to be "burnt from the inside". Only one patient referred to it as "brachytherapy treatment". One of the private patients who had access to the internet, made the following comment:

> *Ek het nie eens geweet mens noem dit Brachytherapy nie* (I did not even know it is called Brachytherapy) (P16: 69, Pr, Afr, Afr, Loc, Ter)

Participants' perceptions of what brachytherapy treatment entailed differed. Some of the participants used words such as "heat" and/or "burn" to describe how the infection or cancer inside their wombs would be treated. One patient understood the following:

> *They are going to produce heat that will burn or heat the infection inside your womb* (P1: 47, Aca, Ses, Ses, Kat, Prim)

A few participants said that the inside radiation was a more effective or intensive treatment as it radiates directly onto the tumour and the following statement was made by one of them:

> *Volgens hulle moet binne ook bestraal en dit gaan my van binnekant af gesond maak* (According to them it is necessary to radiate inside also and it will cure me from the inside) (P18: 41, Aca, Afr, Afr, Kat, Prim)

The inside radiation was seen by few of the participants as a treatment to the womb that would ensure that the cancer would not spread. Some participants were under the impression that they were going to receive a type of operation to the womb and the following comments were made:

> *I thought that when you get here, they begin operating you while you are still conscious…* (P9: 50, Aca, Ses, Ses, Kat, Sec)

> *I thought they were going to remove the womb and burn me* (P17: 30, Aca, Ses, Eng, Kat, Sec)

> *They told me that they were going to perform an operation on me using machines…* (P28: 61, Aca, Ses, Ses, Loc, Prim)

All the participants indicated that they knew that a machine was going to be inserted into them in order to administer the inside radiation, but had different descriptions of the machine. Some perceived the apparatus to be small, long and thin, while others thought it would be something big and the following comments were made:

…dis seker die groot iets wat hulle indruk, ek weet nie en dan plug hulle hom in…en dan sit hulle die elektrisiteit aan (…it's probably something big they push in, I don't know and then they plug it in…and switch the electricity on) (P13: 64, Aca, Afr, Afr, Ol, Sec)

I was expecting that maybe they are going to hang my feet there above and put something which is [very] big inside (P26: 48, Pr, Ses, Eng, Loc, Ter)

More than half of the participants perceived the brachytherapy treatment as a series of five treatments, however some of them thought it would be a once-off treatment. The following statements were made:

I never thought I have to go many times (P6: 55, Aca, Ses, Eng, Kat, Sec)

You know, because the doctor didn't explain me anything about the treatment, it's everlasting or once-off. So really, I don't know (P21: 38, Pr, Ses, Eng, Ol, Ter)

A.2 Summary

The term "*brachytherapy*" for cervical cancer was not commonly understood amongst the participants of the study and they all referred to it as "the inside radiation". All the participants indicated that they knew that a machine was going to be inserted into them in order to administer the inside radiation, but had different perceptions of how the apparatus would look.

B. Expectations

B.1 Findings

Some of the participants said that the treatment was explained to them and it was exactly what they expected it would be like and made the following comments:

So, by the time when I went in, I was prepared, because I knew what was going to happen (P15: 61, Aca, Ses, Ses, Kat, Sec)

It was exactly the way the doctor explained me (P21: 38, Pr, Ses, Eng, Ol, Ter)

The majority of the participants however indicated that the treatment was not what they expected it to be. The following remarks were made:

I think it was not as complicated as I had thought it would be (P1: 47, Aca, Ses, Ses, Kat, Prim)

Things that I was thinking, it's not like that (P21: 38, Pr, Ses, Eng, Ol, Ter)

Ek het gedink dit gaan meer erger wees as wat dit was. Ek het gedink, joh, ek gaan nie kan loop nie, maar dit was nie so nie (I thought it was going to be worse than what it was. I had thought that I would not be able to walk, but it was not like that) (P4: 40, Aca, Afr, Afr, Ol, Sec)

Maar ek het mos ge-verwag, dinges, dat ek moet ge-operasie word…ek wil hom uit…laat hy uitgegaan het, klaar,ja (But I thought that I had to receive an operation;…I want it out…out of me, finish, yes) (P11: 55, Aca, Ses, Afr, Kat, Prim)

A few of the participants indicated that reference was made to the brachytherapy unit as the *"slaughterhouse".* One participant said that she felt traumatised by the word "slaughterhouse" being used and prevented her sleeping prior to the treatment. She made the following comment:

Hy was nie soos ek dit verwag het nie, want ek het gedink 'n mens word gesny…jy gaan slagpale toe (It was not what I expected it to be, because I thought a person gets cut…you go to the slaughterhouse) (P12: 50, Aca, Afr, Afr, Kat, Prim)

Another participant said that it was not what she expected, because she was expecting to feel a big thing being inserted into her that would cause her pain and made the following statement:

But no, it's not like that; But really, it was just a small thing (P26: 48, Pr, Ses, Eng, Loc, Ter)

A few of the participants said that the treatment was not what fellow patients had told them it would be like and made the following comments:

I think, because when we get here we are very scared, because people say a lot of thing, but I realised that we get nervous over nothing really; No, it did not go the same way…after what most people told us we were very scared and thought about every bad thing under the sun we could think of, but when we got here, there it was totally the opposite of it (P28: 61, Aca, Ses, Ses, Loc, Prim)

…*maar dit was nie so gewees soos toe ons pasiënte gepraat het onder mekaar nie* (…but it wasn't how we as patients had spoken amongst each other) (P12: 50, Aca, Afr, Afr, Kat, Prim)

Even that machine was not as bad as people made it out to be. You don't feel the heat as people had said we would (P2: 73, Aca, Ses, Ses, Kat, Prim)

Most of the participants felt that the procedure was not bad, because they did not experience much pain due to the sedation given to them. The following remarks were made:

> *I was in there. I didn't remember anything*; *I slept. I didn't even know what was happening to me* (P6: 55, Aca, Ses, Eng, Kat, Sec)

> *Yes, they do a very nice job. You do not get to see a thing and you wake-up in the next room, get dressed and then you leave* (P28: 61, Aca, Ses, Ses, Loc, Prim)

B.2 Summary

The majority of the participants indicated that the actual treatment itself was not what they expected it to be, due to preconceived ideas. Most participants perceived the treatment to be one or more of the following: (1) complex and painful procedure; (2) a procedure during which a "big thing" would be inserted into their cervices; (3) a type of an operation after which they may not be able to ambulate and; (4) a procedure where they would "feel heat" during treatment delivery. A few participants said they felt traumatised by people referring to the brachytherapy unit as a *"slaughterhouse".* Some participants said they expected the worst as they listened to accounts related by fellow patients. Participants concluded that the treatment was totally the opposite from what was expected and that it was not as bad an experience as initially thought.

C. <u>Impressions</u>

C.1 Findings

C.1.1 The personnel and service delivery

All the participants reported that they were very impressed with the manner in which they were welcomed at the unit and with the tidy and clean appearance of the unit. Most of the participants said they received a warm welcoming on arrival at the unit. They met people with friendly faces, full of life and energy, who spoke to them friendly and who responded to their questions. The following comments were made:

> *They were very, very friendly. Seriously, I thought they were very friendly for me* (P8: 52, Aca, Ses, Eng, Kat, Sec)

> …*Daai mense is sommer sharp [!]* (Those people are sharp!) (P11: 55, Aca, Ses, Afr, Kat, Prim)

> *Everyone here was so kind and nice towards me, they treated me well*; *They are a nice bunch of people, always smiling and laughing and that's what really made me feel at home* (P15: 61, Aca, Ses, Ses, Kat, Sec)

Jy voel, in jou hart voel jy, jy is spesiaal (You feel, in your heart, you feel, you are special) (P16: 69, Pr, Afr, Afr, Loc, Ter)

…die eintlike ding wat my ook baie goed laat voel is net die vriendelikheid van mense (…the main thing that makes me feel very good, is just the friendliness of people) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

A few of the participants reported that although they experienced severe pain during the treatment, the friendly and helpful personnel made them persevere. One participant said that even though she might not yet be healed, the manner in which the personnel smiled at her every day, made her feel very good. She recalled a woman in the treatment room, rubbing her hand and said there was always a hug or something given to her.

Most of the participants said that they did not mind being treated by either male or female doctors. These were some of their remarks:

I do not have a problem with it. I do not mind really. As long I get necessary help (P1: 47, Aca, Ses, Ses, Kat, Prim)

They think of you as a patient (P6: 55, Aca, Ses, Eng, Kat, Sec)

My health comes first my dear and in life we have to accept such things sometimes (P23: 55, Pr, Ses, Ses, Ol, Prim)
…I only care about is my body and I want to get well (P28: 61, Aca, Ses, Ses, Loc, Prim)

Some participants were adamant about being treated by female doctors only and a few of them said that they resigned themselves to being treated by male doctors as they felt they had no choice. The following remark was made by an elderly participant:

Ag, jy weet, ons hou nie daarvan nie, maar ons moet dit maar aanvaar. Ek meen, hulle is dokters (You know, we do not like it, but we have to accept it. I mean they are doctors) (P13: 64, Aca, Afr, Afr, Ol, Sec)

She did not like being treated by male doctors, because she was old and felt shy. One participant said that she was really very lucky to be treated by the same female doctor and made the following comment:

…dit is nice want dan, jy bou soort van 'n verhouding. So jy ken die dokter en jy's gemaklik met die dokter (…it is nice, because you built a relationship. You know the doctor and you feel comfortable with the doctor) (P25: 37, Aca, Afr, Afr, Ol, Ter)

You know I prefer it if it is a female doctor, because a female doctor understands all the female parts (P9: 50, Aca, Ses, Ses, Kat, Sec)

So, toe dink ek, ai, soms tyd like ons nou nie mansmense nie (So, I was thinking, oh, certain times, we don't like men) (P12: 50, Aca, Afr, Afr, Kat, Prim)

A few participants said that they preferred being treated by male doctors and one of them made the following comment:

Eintlik, ek wil nou nie ons vrouens slegmaak nie, maar die manne werk baie netjies, baie versigtig (Actually, I don't want to bad mouth the women, but the men work very neatly and very carefully) (P18: 41, Aca, Afr, Afr, Kat, Prim)

C.1.2 The hospital surroundings and environment

Almost all participants said that they did not know where to report for their brachytherapy treatment, but were directed or taken to the brachytherapy unit by personnel. The only participant who knew where the unit was situated, had previously been admitted to a ward at the oncology department. One of the participants said that a nurse was kind enough to show them around, because they were unfamiliar with the hospital. A private patient said she did not know where to go, because she was only familiar with the surroundings at the private hospital as she had been there for almost six weeks. She made the following comment:

…Even to get to this room again…if it had not been for her, I would have been lost (P23: 55, Pr, Ses, Ses, Ol, Prim)

A participant said that people at the clinic showed them where to go and were directed by a white lady, at the reception, where to go for her treatment. When prompted if she was left alone, wandering around the hospital, the patient made the following statement:

Everyone you meet here at this place, offers to help the minute when they see you (P28: 61, Aca, Ses, Ses, Loc, Prim)

One participant made the following remark when prompted how it made her feel to have known where to go:

…dit was goed gewees om nie te sukkel nie, want reeds mos nou bang (It was good not to struggle, as I was already scared) (P4: 40, Aca, Afr, Afr, Ol, Sec)

A participant from a private hospital said that she arrived early and found the unit deserted. She was informed that she needed to open a file at Admissions. This experience made her feel tense, because she came for her treatment, but was sent back and forth.

A participant from a private hospital said that she was very impressed with the department and made the following comment:

> *Ek kon nie glo dat die Onkologie afdeling van 'n staatshospitaal so mooi is nie* (I could not believe that the Oncology department of a governmental hospital could be so beautiful) (P27: 55, Pr, Afr, Afr, Loc, Ter)

Although the participant felt that the unit appeared too clinical, she commented that the personnel appeared pretty in their uniforms, looked well groomed and were friendly. Some of the participants mentioned how they appreciated the heaters in the waiting room during the cold winter months. The following remarks were made:

> *They even had heaters switched on for us* (P9: 50, Aca, Ses, Ses, Kat, Sec)

> *Kyk ons is gewoonlik maar vroeg hier, want ons kom mos nou saam met die Olea bussie…en hulle sit vir jou in die ander kamertjie waar dit lekker warm is…* (Look, we usually arrive here early, because we come with the Olea bus…they put you in a small room that is nice and warm) (P4: 40, Aca, Afr, Afr, Ol, Sec)

One participant said that she was satisfied with a place that was clean, where she could sit and read a book and where the personnel were friendly. Some of the participants were also impressed by the appearance of the treatment room and felt that it was nice and clean. Most of the participants felt that the patient care was good and the following comment was made by one of them:

> *…die plek is aangenaam.Hy is mooi skoon. Hulle se mense is vriendelik* (…the place is pleasant. It is nice and clean. The people are friendly) (P11: 55, Aca, Ses, Afr, Kat, Prim)

C.2 *Patient suggestions*

• Introduce patients to the personnel working at the brachytherapy unit.

• Give patients a choice of being treated by a female oncologist/registrar.

> *…as hulle dalk kan kyk dat net vrouens dalk die binne-bestraling kan doen* (…if they can see to it that only female doctors perform the inside radiation) (P4: 40, Aca, Afr, Afr, Ol, Sec)

• Provide patients beforehand with directions where to report for their first brachytherapy treatment.

> *Miskien kan hulle dit 'n bietjie verbeter en die pasiënt inlig vir as jy die eerste keer kom* (Maybe they can improve it a little bit and inform the patient, concerning coming for the first time) (P16: 69, Pr, Afr, Afr, Loc, Ter)

Moet jy nou daar wees of hierso? (Must you be there or here?) (P16: 69, Pr, Afr, Afr, Loc, Ter)

• Show patients the brachytherapy treatment room prior to treatment.

• Upgrade the waiting room by supplying the following:

› Television (Prompted)

Maybe there could be a television in there where you can look at something, but not thinking about this radiation; *So it's better to get something to take your mind off from it* (P6: 55, Aca, Ses, Eng, Kat, Sec)

› Books with information on the treatment to keep them busy if they were alone

Soms is jou nou alleen daar en nou sit jy nou met daai vrees (Sometimes you are alone in there and then you sit there with that fear) (P12: 50, Aca, Afr, Afr, Kat, Prim)

› Magazines and a radio

…as daar miskien tydskrifte is of daar miskien net 'n radio kan wees (…if there could be some magazines or maybe a radio) (P14: 41, Aca, Afr, Afr, Loc, No)

› Flowers

One participant suggested some flowers. She said that because it was a governmental hospital, she could not expect fancy couches.

• Upgrade the recovery room by supplying the following:

› Drinking water facilities

Weet jy ek sal sê dit sal nogal 'n goeie ding wees as hulle dalk net vir mens soos water of iets net neersit in die recovery room. As jy wakker word, dat jy net so bietjie water kan drink (You know, I would say that it would be a good thing if they could put some water in the recovery room. That when you wake up, you could drink some water) (P4: 40, Aca, Afr, Afr, Ol, Sec)

› Refreshments

So maybe after we received treatment, they can give something to eat or to drink (P21: 38, Pr, Ses, Eng, Ol, Ter)

• Ensure that patients are in a safe and secure environment by ensuring only one entrance to the recovery room.

…I was afraid of this door, because we come with this, this one here; And you are alone and there's no security…Come here and just stole your things (P26: 48, Pr, Ses, En, Loc, Ter)

The following comments were made by some of the participants on service delivery at the unit, having completed three brachytherapy treatments:

I was treated very well and the service was good (P28: 61, Aca, Ses, Ses, Loc, Prim)

…when it was my turn and I got inside, I realised that the nurses in there can really take care and make us able to relax (P1: 47, Aca, Ses, Ses, Kat, Prim)

I think they are doing a great job (P1: 47, Aca, Ses, Ses, Kat, Prim)

They must just keep it up! (P17: 30, Aca, Ses, Eng, Kat, Sec)

Hulle doen 'n goeie werk. Almal. Die dokters, die nurses, die radiografiste, die receptionist, die skoonmakers (They all are doing good job. Everyone. The doctors, the nurses, the radiographers, the receptionist, the cleaners) (P25: 37, Aca, Afr, Afr, Ol, Ter)

C.3 Summary

All participants were touched with the friendliness with which they were welcomed at the unit and words such as kind, helpful and friendly were often used by them. The clean and tidy appearance of the unit did not go unnoticed by the participants. Some of the participants reported that they appreciated the heaters that were provided to make the ambient temperature of the waiting room warmer during the winter months. Although a few participants preferred to be treated solely by female doctors, most of the participants were satisfied being treated by either a male or female doctor. One participant stated that she preferred being treated by the same doctor, because throughout her brachytherapy sessions they got to know each other and she felt comfortable in her presence. All the participants spoke highly of the service delivery at the unit and words such as "keep it up", "great job" and "the service was good" were used by them.

2.3.2.3 *Psychological experience*

A. Feelings and concerns

A.1 Findings

All participants described feelings of fear regarding their forthcoming treatment. The majority of the participants used words such as "very scared", "frightened", "fearful", "very nervous", and "worried", "tense" and "terrified" to describe how they felt. The following were their concerns and insight into this phenomenon was provided by their comments.

A.1.1 Fear of the unknown

> *That I was coming to do this treatment and I did not know what was going to happen* (P7: 68, Aca, Ses, Ses, Kat, No)

> *How is it going to happen? What will happen and all that?* (P6: 55, Aca, Ses, Eng, Kat, Sec)

A.1.2 Fear of receiving a sedative

> *I became even more nervous when they told me that I was going to be sedated as well* (P23: 55, Pr, Ses, Ses, Ol, Prim)

> *…gaan ek reg wakker word? Hoe gaan ek voel van die sedasie?* (…am I going to wake-up properly? How will I feel after the sedation?) (P25: 37, Aca, Afr, Afr, Ol, Ter)

> *So I was scared that maybe I'm going not to be wake up* (P26: 48, Pr, Ses, Eng, Loc, Ter)

A.1.3 Fear of experiencing pain

> *Is it painful?* (P21: 38, Pr, Ses, Eng, Ol, Ter)

> *So I was worried I'm going to get hurt* (P24: 36, Pr, Ses, Eng, Ol, Sec)

A.1.4 Fear of getting burnt

> *…want jy worry, hoe brand ek nou? Hoe gaan ek lyk nou as ek gebrand word?* (…because one worries: how will I get burnt? How will I look, after getting burnt?) (P11: 55, Aca, Ses, Afr, Kat, Prim)

> *They say; you are going to burn. You are going to burn. So I was so worried* .(P8: 52, Aca, Ses, Eng, Kat, Sec)

A.1.5 Worried about the outcome of the treatment

A lot went through my mind, that maybe I might not live after that. I might not live. I might not even get well (P1: 47, Aca, Ses, Ses, Kat, Prim)

Am I going to be cured? (P21: 38, Pr, Ses, Eng, Ol, Ter)

That blood; I will have a lot of pain after that; *I will get sick* (P17: 30, Aca, Ses, Eng, Kat, Sec)

A.1.6 Scared of the treatment, due to untrue stories told by people and fellow patients

…they don't talk true (P8: 52, Aca, Ses, *Eng, Kat, Sec*)

And those who have been here already exaggerate about things and they make them to be very worse … We come here already nervous (P28: 61, Aca, Ses, Ses, Loc, Prim)

It's not alright to give people a bad report and scare them like that, because now you then become so uncomfortable and nervous talking to them (P1: 47, Aca, Ses, Ses, Kat, Prim)

A.1.7 Scared of the treatment machine

…they said to us that people died from this machine and that some of them were distorted in shape (P2: 73, Aca, Ses, Ses, Kat, Sec)

Jo! I was very, very frightened. Really (P26: 48, Pr, Ses, Eng, Loc, Ter)

A.1.8 The "slaughterhouse"

Ons het gevra en hulle het gese slagpale, toe daai vrees was daar gewees…" (We asked and they said "slaughterhouse". Then we felt fearful…) (P12: 50, Aca, Afr, Afr, Kat, Prim)

…Slaughterhouse, that's what freaks people out about this place… (P28: 61, Aca, Ses, Ses, Loc, Prim)

However, one participant said that she could not speak to anyone about her fears and concerns, because the nurses were very busy at the brachytherapy unit and made the following comment:

…there was no-one to talk to, because the nurses were very busy; Oh, they were very busy (P21: 38, Pr, Ses, Eng, Ol, Ter)

A concern that was raised by two participants, prior to their first treatment, was that they might not be able to wake up the following morning and feared that the instruments which

were placed inside of them might not work and the machine might stop working. One of them also stated that she was concerned that the treatment might fail and she might have to come again, if she ate too much.

A.2 Patient suggestions

• Utilise the time spent in the waiting room to prepare the patients psychologically for their forthcoming treatment.

> *I think if they would encourage us and speak to us, try to make us feel calm and relaxed, because you know people are different. Some became more nervous than others* (P19: 56, Ses, Ses, Kat, Prim)

> *Because you guys are experts around here, you can use this time to talk to us and encourage us to make us feel less stressed and teach us as well when we are home how to conduct ourselves…* (P28: 61, Aca, Ses, Ses, Loc, Prim)

• Special attention needs to be given to elderly patients - to reassure and calm them by fully explaining.

A.3 Summary

Shared and unique psychological experiences were identified. The majority of the participants used words such as "very scared", "frightened", "fearful", "very nervous", "worried", "tense" and "terrified" to describe how they felt. Almost half of the participants were scared of the brachytherapy treatment machine itself, because of being related to scary or untrue stories told by people and fellow patients and by reference being made to the brachytherapy treatment unit as the "slaughterhouse". Even though most of the participants received a subsequent, detailed explanation of the forthcoming treatment from the attending nurse, almost half of them still expressed feelings of fear, anxiety and stress.

B. <u>Coping strategies</u>

B.1 Findings

Some of the participants felt at liberty to speak to someone about their fears and concerns. Participants spoke to family, friends, fellow patients and personnel at the brachytherapy unit about their forthcoming treatment. Many participants however said that they preferred not to speak to someone about their fears and concerns and said it was "their secret" and kept their feelings to themselves. One of them said that she had no-one to talk to and kept this thing a

secret, because she was too ashamed to talk to anyone about it and that those who wanted to know about it could come to the hospital and see for themselves. When prompted why she wanted to keep it to herself, she made the following comment:

> …it was my business and mine alone (P19: 56, Aca, Ses, Ses, Kat, Prim)

A minority of participants preferred not to speak to anyone, because they felt they were adequately informed. The coping strategies described by the participants could be grouped into the following categories:

B.1.1 Encouragement from personnel

> *The sister. That was the only one that I tell: Sister, I'm very, very much afraid of this* (P6: 55, Aca, Ses, Eng, Kat, Sec)

> *…they make sure that you understand very well so that you do not become scared and want to run away* (P15: 61, Aca, Ses:Ses, Kat, Sec)

B.1.2 Support from roommates or fellow patients

> *She explained a lot of things to me"*; "*…she did me a great help and I am glad I met her "and "…she really motivated me and made me to be strong* (P23: 55, Pr, Ses, Ses, Ol, Prim)

> *…we would sit down and talk about it together. So when we went in we knew what to expect…* (P20: 5, Aca, Ses, Ses, Kat, Prim)

> *Yes we do meet with others and talk about things*; *We talk and when one of us is not feeling well, we come and encourage one another* (P28: 61, Aca, Ses, Ses, Loc, Prim)

B.1.3 Support from family

> *Ek het baie met my pa en ma gepraat. Baie ondersteun. Ek het baie gehuil en dan sê my pa, dit sal regkom. So ons moet net hoop en bid en dit sal als regkom* (I spoke a lot to my dad and mom. Lots of support. I cried a lot and then my dad said that it will get better. So, we must just hope and pray and all will end well) (P14: 41, Aca, Afr, Afr, Loc, No)

B.1.4 First-hand experience

> *I am going to Bloemfontein and I will see for myself what happens when I get there, If I die, it will be my time to die* (P2: 73, Aca, Ses, Ses, Kat, Prim)

…you know when people explain things to you, but sometimes you want to see for yourself (P15: 61, Aca, Ses, Ses, Kat, Sec)

…ek dink dit is maar net 'n kwessie van wag en kyk wat gebeur (…I think it's a matter of wait and see what will happen) (P25: 37, Aca, Afr, Afr, Ol, Ter)

One participant said that going for the inside radiation was the same as going to initiation school and made the following comment:

…you have to go through it to know about it; Just like when a woman goes into labour, she does not go around telling people the ins and outs that happen in there (P19: 56, Aca, Ses, Ses, Kat, Prim)

B 1.5 Positive attitude

A private participant said that she sat contemplating about her cancer and that it felt unreal to her. It was something she had to deal with, mentally, on a day to day basis. This patient said she thought it important to have a positive attitude during the treatment period and expressed the following thoughts while waiting:

…jy gaan hier deurkom, jy gaan anderkant uitkom en dit gaan suksesvol wees (…you will get through it, you will overcome and it will be successful) (P27: 55, Pr, Afr, Afr, Loc, Ter)

If you want to get well, you make peace with things (P28: 61, Aca, Ses, Ses, Loc, Prim)

B.1.6 Religion

One participant said that she was not scared at all, because she had faith in God and knew that she was going to get well. A few participants reported that they spent their time in the waiting room by praying or reading the Bible on their cellular phones.

B.2 Patient suggestions

- Prevent patients from being scared and stressed by informing them that they will be given a sedative before treatment delivery that will help them not to experience pain during treatment delivery. (Prompted)

If I knew it is not painful, I don't have to be scared and stress unnecessary (P21: 38, Pr, Ses, Eng, Ol, Ter)

B.3 Summary

Although many of the participants preferred not to speak to someone about their fears and concerns, they all related to some or other coping strategy. Six coping strategies were

identified: (1) encouragement from personnel, (2) support from roommates or fellow patients, (3) support from family, (4) first-hand experience, (5) positive attitude and (6) religion. Encouraging words from personnel were appreciated and helped some participants to relax before treatment delivery. Most of the participants found comfort in speaking to fellow patients and roommates about their forthcoming treatment, while others indicated that they would rather see for themselves. A few participants relied on their faith to see them through.

2.3.2.4 *Physical experience*

A. <u>Treatment effects</u>

A.1 Findings

A.1.1 During treatment delivery

Most of the participants complained that the treatment was not pleasant when they experienced pain during treatment delivery. One participant had the following to say after having received her first inside radiation:

> *Ek weet net ek het vir hulle geskree: Julle skroei my van binne [!] Want dit was erg* (I only know that I screamed at them: You are burning me on the inside [!] It was terrible) (P13: 64, Aca, Afr, Afr, Ol, Sec)

She said that after the first inside radiation she felt that she could not continue with the treatment, because it was so painful. However, the second treatment was better as she did not experience any pain, because she had asked her doctor to increase her sedation medication. Some of the participants however related that they were conscious during their second and third treatment deliveries and experienced severe pain. One participant said that she had woken up during the treatment delivery and that it was not nice at all. She said that she was lying there with "pain below" and wished and prayed that it must end quickly. Another participant said that she did not sleep during the second and third inside radiation treatments and could feel how the applicators were placed in and removed out of her womb. The following comments were made by two of these participants:

> *Personally, I wish it was not there* (P24: 36, Pr, Ses, Eng, Ol, Sec)

> …*daai narkose, hy maak my niks* (…that anastetic, it did nothing to me) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

One participant said that she did not experience pain during her first treatment delivery, but with the second one, she felt like screaming, because of the pain. She complained that she never slept during treatment delivery and made the following statement:

> *I felt it when they were putting their stuff inside me*; …*I never experienced that much pain;* Because *I was awake, I could see and feel everything that they were doing and I could even feel the pain* (P1: 47, Aca, Ses, Ses, Kat, Prim)

Another participant said that her first experience of the inside radiation was not a bad one due to the fact that she felt nothing after receiving the sedative and could not remember anything. It made her sleep during the treatment delivery and she only gained consciousness after it was completed. She experienced no pain afterwards. She made the following comment:

> *…my eerste ervaring was goed* (…my first experience was good) (P4: 40, Aca, Afr, Afr, Ol, Sec)

However, this was not the case for her second and third treatment deliveries. She woke up during treatment delivery with the applicators inside her and said that it was not a pleasant experience as she experienced pain.

Although the treatment delivery was painful to some participants, they endured it for the following reasons:

> *Al is dit pynlik, maar op die einde van die dag survive ek darem* (Even if it's painful, but at the end of the day, I survived) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

> *But, it's there to help us* (P24: 36, Pr, Ses, Eng, Ol, Sec)

A.1.2 Post treatment delivery

Most of the participants reported that they experienced dizziness after their brachytherapy treatment. The following side-effects of the sedation medication were reported: "Sleepy", "drugged", "tired", "weak", "nausea", "confused" and some participants said that they experienced pain after their treatment delivery. All the participants were prompted whether they felt hungry or thirsty after waking up in the recovery room. Some indicated that they were thirsty and one participant made the following comment:

> *Ek was, jy's baie dors. Jy's baie dors as jy daarvan af kom. Gewoonlik drink ons maar sommer klaar hier, daar by die kraan.* (I was, you are very thirsty. You are very thirsty when you come from there. We usually drink there, from the tap) (P18: 41, Aca, Afr, Afr, Kat, Prim)

Some participants said that they were very hungry and made the following statements:

...jy is baie honger, want jy't mos nie die oggend geëet nie. So jy is honger (…you are very hungry, because you did not eat anything in the morning. So therefore, you are hungry) (P4: 40, Aca, Afr, Afr, Ol, Sec)

Jy voel regtigwaar honger, want kyk jy eet mos nou ook nie. En jy eet ook nie eintlik goed, want jy's nou so op jou "nerves"...van daai slagpale... (You really are hungry, because you haven't been eating. And you don't eat well, because you are nervous…of the "slaughterhouse"…) (P12: 50, Aca, Afr, Afr, Kat, Prim)

Only a few participants reported that they were both hungry and thirsty, while some of the participants said that they did not require any refreshments.

A.2 Patient suggestions

• Administer adequate sedation medication to prevent them regaining consciousness.

• Administer a bigger dose of sedative for better pain control. (Prompted)

• Find a way of making the treatment less painful. (Prompted)

Hulle moet 'n manier kry om dit minder pynvol te maak (They must find a way to make it less painful) (P1: 47, Aca, Ses, Ses, Kat, Prim)

Die pynbeheer is nie vir my baie goed nie "(The management of pain is not very good for me) (P25: 37, Aca, Afr, Afr, Ol, Ter)

• Complete the treatment, before patients experience pain. (Prompted)

They should, so that at least by the time when you begin experience pains, they already done with you (P1: 47, Aca, Ses, Ses, Kat, Prim)

The abovementioned participant made the following remark:

…this happened on the second day; they took their time before they put in their instruments in me and started working; ...I had already so much pain; I realised the first time they put them in very quickly, but now they were very slow and they did struggle (P1: 47, Aca, Ses, Ses, Kat, Prim)

• Only wake up in the recovery room.

...as jy in die recovery room kom, eers wakker word (…if a person can only wake-up in the recovery room) (P4: 40, Aca, Afr, Afr, Ol, Sec)

A.3 Summary

The main symptom reported by the participants during treatment delivery was pain. The level of pain reported by them varied from mild to severe across the series of procedures. Some of the participants recalled pain from previous procedures, despite the use of sedation. A few of the participants indicated that they had asked the attending doctor to increase the sedation medication before treatment delivery. The most emotionally uncomfortable aspect was their concern that they might regain consciousness during treatment delivery.

B. <u>Physical assistance</u>

B.1 Findings

B.1.1 Assistance in the recovery room

Some participants said that there was someone in the recovery room to attend to them on awakening. One participant said that she felt that it was good that there was someone to see to it that she did not fall from the bed, to help her off the bed to escort her to the bathroom, because she felt dizzy. The following remarks were made by academic and private participants:

> *I felt that I was well taken care of and they were very attentive towards me* (P1: 47, Aca, Ses, Ses, Kat, Prim)

> *They would come in here, walk up and down, check up on us and go back again. But they would not take that long* (P19: 56, Aca, Ses, Ses, Kat, Prim)

> *Hulle is baie, baie behulpsaam* (They are very, very helpful) (P16: 69, Pr, Afr, Loc, Ter) *Yes, they are always there watching over us* (P23: 55, Pr, Ses, Ses, Ol, Prim)

However, half of the participants remarked that there was no-one attending to them when they woke up in the recovery room. The following comment was made by a participant:

> *When I woke up, there was no-one in here, but I managed to get up all by myself* (P20: 51, Aca, Ses, Ses, Kat, Prim)

This group of participants said that they woke up, got dressed and left the recovery room without anyone seeing to their well-being. One participant made the following remark when she wanted to leave the room:

Whether it was out of that door or out of this door, I don't know. I was still a little bit dizzy (P6: 55, Aca, Ses, Eng, Kat, Sec)

When an elderly participant was prompted how she felt about no-one attending to her, she said the following:

Not good at all, because at the time when I tried to get up, I fell. (P7: 68, Aca, Ses, Ses, Kat, No)

She said that she struggled, because she was alone and could not get back onto the bed again. The participant decided then to get dressed and left the recovery room, because she needed to catch the bus back to Katleho.

When a private participant was asked if there was someone around when she woke up in the recovery room, she made the following statement:

It's my problem that I saw that the staff is shortage now here, because when they put you here, ne, they go outside, You are alone; There's no one who's accompanying you this side (P26: 48, Pr, Ses, Eng, Loc, Ter)

She said that she was left alone and there was no bell to ring if she needed some assistance/help. She even told the nurse the following:

I'm waiting for you to tell me whether I can go (P26: 48, Pr, Ses, Eng, Loc, Ter)

The participant received the following response from a staff member:

…but when you think that you are not feeling ok, don't be afraid coming back and report us that you are not feeling ok (P26: 48, Pr, Ses, Eng, Loc, Ter)

A ward participant said that she never woke-up in the recovery room, only in the ward and made the following comment:

There had never been a time I find myself waking up in here (P5: 33, Aca, Ses, Ses, Wrd, Loc, Sec)

A few participants reported that they had seen some patients leaving the recovery room with drips still attached to their arms. One of them made the following comment:

So, toe sê ek, kyk, somtyds maak 'n mens 'n fout (So then I said, look, sometimes one can make a mistake) (P12: 50, Aca, Afr, Afr, Kat, Prim)

B.1.2 Assistance to mode of transport

A few participants indicated that they did not need any assistance to their mode of transport or to the ward. Some of the interviewed participants said that no-one escorted them to their mode of transport, while a few participants said that they made arrangements with fellow patients/roommates to accompany them to their transport. The following remarks were made by them:

> *Maybe, if I didn't make that arrangement, the sister would have helped me* (P6: 55, Aca, Ses, Eng, Kat, Sec)

> *Ons kyk maar vir mekaar uit* (We are looking out for one another) (P25: 37, Aca, Afr, Afr, Ol, Ter)

All of the local, private participants were accompanied by family members, while those who stayed at Olea where escorted to the transport area by roommates/fellow patients.

B.2 Patient suggestions

• Have personnel present to assist the patients in the recovery room on their arrival from the treatment room.

> *They should have people in here to assist patients when they come back from the radiation room to help us to get dressed if they see that the patient is till drowsy…* (P20: 51, Aca, Ses, Ses, Kat, Prim)

> *Ek dink dis nodig lat daar iemand is wat kyk na ons wat hier klaar met die binne bestraling is* (I think it's necessary that there is someone, looking after us when we are finished with the inside radiation) (P18: 41, Aca, Afr, Afr, Kat, Prim)

> *Please, when we come in here, you should always keep an eye on us to see how everyone is doing and make sure that we are all right…* (P23: 55, Pr, Ses, Ses, Ol, Prim)

• Have personnel present to prevent patient accidents.

> *daar moet hulle altyd iemand hou daar of iemand laat kyk sodra jy uitkom. Want as jy wakker skrik…jy's deurmekaar. Jy weet nie waar jy is nie. Dan spring jy op en toe't ek nou die dag geval* (they must always have someone there, because when you wake up…you are confused. You don't know where you are. You jump up and I fell the other day) (P12: 50, Aca, Afr, Afr, Kat, Prim)

> *… when you are alone, you can fall sometimes* (P8: 52, Aca, Ses, Eng, Kat, Sec)

> *Eendag toe sit ons in die wagkamer…. toe sien ek lat 'n pasiënt op die vloer val van bedwelmgeit. Toe roep ek die suster…* (One day, we sat in the waiting room. I then saw a patient falling to the floor from being drugged. I then called the sister…) (P18: 41, Aca, Afr, Afr, Kat, Prim)

• Have someone present to remove the drips from patients' arms.

…wat 'n probleem is, na die binne bestraling was daar twee mense wat die drippetjies wat hulle vir ons gee hier, dan vergeet hulle om daai drippetjie uit te haal en die mense het gegaan met hulle (..it is a problem, after the inside radiation there were two people with drips which they give here to us, then they forget to remove those drips and the people left with it) (P12: 50, Aca, Afr, Afr, Kat, Prim)

Daar moet iemand wees. Dis mos baie kere wat daar, een pasiënt was twee keer al 'n ding oorgekom het met die drip, al uit gegaan het. Wat hulle nie afgehaal het nie (There must be someone. It was many times that, it happened twice to one patient that left with a drip, that they did not remove it) (P18: 41, Aca, Afr, Afr, Kat, Prim)

• Have enough personnel working at the unit, especially inside the recovery room.

It's my problem that I saw that the staff is shortage now here, because when they put you here, ne, they go outside, You are alone; There's no one who's accompanying you this side (P26: 48, Pr, Ses, Eng, Loc, Ter)

• Assistance to mode of transport.

…they should assist us to walk if we want to walk somewhere else and if we need to catch transport they should help us to get there as well (P20: 51, Aca, Ses, Ses, Kat, Prim)

*Daar moet iemand wees wat vir jou wag en vir jou neem tot by die vervoer (*There should be someone waiting for you, taking you to the transport) (P18: 41, Aca, Afr, Afr, Kat, Prim)

• See to the patients' well-being before letting them go.

Dat hulle iemand vir jou kan, ja, laat sit n bietjie en kyk dat jy reg is en dan kyk of jy kan tot daar loop of iemand vra om vir jou te help tot daarso (They must give you someone, yes, to let you sit and see that you are fine to walk or ask someone to help you there) (P12: 50, Aca, Afr, Afr, Kat, Prim)

• Someone to take the patients with a wheelchair to the transport area or the ward.

There should be somebody here to take you in a wheelchair to where you need to be…to catch your transport (P7: 68, Aca, Ses, Ses, Kat, No)

• Provide a bell to ring in a case of emergency.

They are not around and there is not a bell. Something you can be able to ring them that side to say: Please help[!] (P26: 48, Pr, Ses, Eng, Loc, Ter)

B.3 Summary

Half of the participants said that they were left unattended inside the recovery room and a few adverse incidents were reported by some of them. A participant said that there was no bell to ring for assistance and she did not feel safe being left alone in the recovery room. Although the majority of participants experienced dizziness as a side-effect of receiving the sedation, only a few were escorted to their mode of transport. Some participants said that they made arrangements with fellow patients to accompany them to their transport.

2.3.2.5 *Participants' final remarks*

The following were the comments made by participants on their physical well-being, having completed three brachytherapy treatments:

> *The pains I had before I came here are gone. Even the bleeding has stopped and I can see that I am going to receive my healing* (P5: 33, Aca, Ses, Ses, Wrd, Loc, Sec)

> *I feel much better. And I feel stronger than the first time when I come here. I was very sick, but after the inside radiation, Joe, I can even run.* (P8: 52, Aca, Ses, Eng, Kat, Sec)

> *I came here looking for help and that is what I got*; *I was really happy with this treatment. I put my faith into it after the way everything was explained to me and that I will be well*; *…And well, guess what? I am fine now* (P7: 68, Aca, Ses, Ses, Kat, No)

2.4 DISCUSSION

The findings revealed participants' shared and unique experiences of receiving high dose rate-intracavitary brachytherapy. A phenomenological approach was useful in providing a description of human experience as it is experienced by the subjects (Bentz & Shapiro 1998) allowing the essence to emerge (Cameron *et al*. 2001). Their experiences were described within the following four overarching and inter-related themes: informational needs, patient disposition towards treatment, psychological and physical experiences.

Patients of different ethnic groups all indicated that they preferred to be informed of their forthcoming treatment in an understandable language. Although the majority of participants of the current study were Sesotho speaking, only a few were informed of their brachytherapy treatment in their home language. Communicating disease and brachytherapy treatment

related information in a language other than their home language has proven to be an unmet need for most of the Sesotho speaking participants. Participants' feelings of fear and anxiety were reduced when they were informed of their subsequent treatment in their home language. This is consistent with the findings reported by Kamer *et al.* (2007) who stated that patients need to be given detailed information before the brachytherapy application to reduce anxiety.

Access to information concerning the disease, its treatment and its consequences for patients with gynaecological cancer is clearly important (Stead, Brown, Fallowfield & Selby 2003). More than half of the participants of the current study reported that treatment related information was not or inadequately discussed with them. Treatment related information such as the possible side-effects, sexual intercourse, pre-treatment preparation, scheduled appointments and follow-up appointments were poorly addressed. The term "*side-effects*" was not understood or was misunderstood by some participants. In a study conducted by Kavanagh and Broom (1997) women also reported that they did not understand specific meanings of technical terms. However, the abovementioned findings could be due to the language barrier or be the outflow of receiving too much or little information on the day of signing consent for the brachytherapy. The importance of sharing appropriate information cannot be overstated, since too much or too little, or even inaccurate information may generate negative energy which induces unwanted vigilance and paranoia, making patients sensitive to even the slightest effects of their disease or treatment (Mayer, Terrin, Kreps, Menon, McCance, Parsons & Mooney 2007). A Bloemfontein study conducted by Masalla, Friedrich-Nel and de Waal (2009), has found that when patients, diagnosed with different types of cancers, were asked if they received pre-treatment counselling before commencement of treatment, 27% responded that they never received any information, 40% said they received limited information, while the remaining 33% said that they were thoroughly informed. Counselling of patients should therefore not be a process that is limited to the acquisition of informed consent from patients, but rather a continuous process of communication and counselling that seeks to address patient fears and anxieties and to maintain a positive attitude towards treatment (Masalla *et al*. 2009).

Although the majority of the participants in the current study were given an opportunity to ask questions before signing consent, some felt inadequate or presumptuous to voice their questions. Some participants reported that they did not want to waste the radiation oncologist's time and would ask treatment related questions at a later stage or would "*see for*

themselves". The few participants who were not given an opportunity to ask questions said they wanted information on the following: sexual intercourse, child bearing, brachytherapy treatment, outcome of the treatment and when they needed to come back for check-ups. Kavanagh and Broom (1997) recommend that practitioners should spend time informing patients and answering their questions. The staff could explain the meaning of medical terms, details of the procedure, treatment options and the after effects women might experience as well as encouraging questions to explore other issues the women thought important.

The majority of participants of the current study indicated that although they were not given any informative material prior to their brachytherapy treatment, they would have liked to be given cancer-specific material such as pamphlets or booklets. Some participants were misinformed by fellow patients' untrue stories. Providing patients with informative material, information sessions and a video presentation prior to treatment delivery in their home language, could reduce anxiety and be used as a coping strategy. Warnock (2005) reported that all the interviewed patients volunteered that being shown the treatment room had played a positive role in preparing them for brachytherapy. Stewart, Wong, Cheung, Dancey, Meana, Cameron, McAndrews, Bunston, Murphy and Rosen (2000) stated that although most women preferred to receive information from their physician or health care providers, they also wanted to receive information (in decreasing order) from cancer-specific printed material such as pamphlets and brochures, general print books, broadcast media, videotapes, telephone information lines, audiotapes, internet and CD-ROMs. Second to information from health care providers (chiefly physicians), women still preferred conventional printed materials as key information sources.

The term "*brachytherapy*" for cervical cancer was not commonly understood amongst the participants, irrespective of their educational level, and they all referred to it as "*the inside radiation*". Participants perceived the treatment to be one or more of the following: (1) complex and painful procedure; (2) a procedure during which a "big thing" would be inserted into their cervices; (3) a type of an operation after which they may not be able to ambulate and; (4) a procedure where they would "feel heat" during treatment delivery, However, after the initial treatment, participants concluded that the treatment was totally the opposite from what was expected and that it was not as bad an experience as initially thought.

No patient was looking forward to their forthcoming treatment. Findings of the current study showed that almost all of the participants expressed negative feelings about their upcoming treatment. Participants used words such as "very scared", "frightened", "fearful", "very nervous", "worried", "tense" and "terrified" to describe how they felt. The data suggest three possible explanations for this. Firstly, fear of the unknown and of the outcome of the treatment. Secondly, participants' concerns were related to those aspects of treatment perceived as unpleasant, such as experiencing pain, side-effects of the sedation and equipment and of treatment failure. Thirdly, some participants said that they were frightened by the scary, untrue stories related by fellow patients. Some people referred to the brachytherapy unit as a place where patients are "burnt on the inside". Positive outcomes, such as reduction in anxiety have been identified in patients who had been provided with concrete, objective information concerning the procedural and sensory aspects of treatment prior to, and during, a course of external beam radiotherapy (Johnson 1997; Poroch 1995).

A range of coping strategies were identified by the participants of this study and were grouped into the following six categories: encouragement from personnel (especially the attending nurse), support from roommates or fellow patients; support from family, first-hand experiences, positive attitude and religion. A few of the participants reported that although they experienced severe pain during treatment delivery, it was the friendly and helpful personnel that enabled them to persevere. Flanagen and Holmes (2000) suggested that social support is not a simple coping strategy, but is something that has to be worked at, or managed, by patients if benefits are to be gained. Chan *et al.* (2001) identified the importance of support from healthcare professionals, family and friends. The authors So and Chui (2007) also reported fellow patients receiving the same treatment to be a valuable support as they could understand their sufferings better and were able to serve as a comrade in the battle against cancer. Several studies indicated that "being positive" is an effective coping strategy for relieving symptoms of distress (Ekfors & Petersson 2004; Kuo & Ma 2002).

The symptoms reported by the participants were similar to those reported by Kwekkeboom *et al.* (2009); Rollison and Strang (1995) and Warnock (2005). Current findings have indicated that patients' experience of pain varied between mild to severe across the series of procedures. However, the main concern was gaining consciousness during treatment delivery and thus having to experience pain. Dissatisfaction of the management of pain was reported by most participants of the current study and needs to be addressed as the negative

connotations could prevent these participants from completing their prescribed treatment protocol. Kwekkeboom *et al*. (2009) stated that a subset of woman reported having recalled pain from previous procedures, despite the use of conscious sedation medications.

Half of the participants indicated that they were left unattended inside the recovery room and a few adverse incidents were reported by them. Examples of adverse incidents: (1) a patient fell off her bed in the recovery room; (2) a few patients left the recovery room with drips still attached and (3) some patients left the recovery room, feeling dizzy and asked fellow patients to escort them to their mode of transport. This focused the attention to the importance of the organisation of care and having an integrated support service strategy that extends beyond the acute phase and is flexible enough to meet the different types of needs that will arise post-treatment (Walton *et al*. 2010).

Providing patients with sufficient and understandable information emerged as a key issue that needs to be addressed. The general underlying principle is that the communication of the radiation oncologists/registrars at the new patient clinic should be sincere and focused on the patient, taking into account cultural and language barriers and individualize to the type of treatment offered (ACR 2012). Providing understandable information to Sesotho speaking patients in a department where the majority of members of the multidisciplinary team are only fluent in English and Afrikaans, set challenges to health professionals in communicating disease and treatment related information to patients. Current resources in the department do not allow for beneficial interventions such as a medical trained interpreter, psychologist and sufficient nursing personnel to assist and observe patients post-brachytherapy in the recovery room.

Patient-centred care has become internationally recognised as a dimension of the broader concept of high quality care (ACSQHC 2012). WHO (2000) stated that recognising responsiveness (patient-centred care) as an intrinsic goal of health systems reinforces the fact that health systems are there to serve people. The eight dimensions of patient-centred care of the NRC Picker Institute (NRC Picker 2012) and the eight Batho Pele principles of the South African Government (South African Government Information 2007) are both frameworks that define the patient's perspective of service delivery and aims to enhance the quality of services rendered to the patient. The findings of this stage of the study have demonstrated that five of the eight dimensions of patient-centred care of the NRC Picker Institute (cf. 1.6.2)

were addressed. Respect for the patients' preferences and values, the involvement of family and friends and access to care were aspects that were not reported by the patients as it was not relevant to the study. The identified themes and sub-themes (cf. 2.3.2) of the patient interviews of the current study are aligned with five of the eight Batho Pele principles (cf. 1.6.4). The principles on access to care, openness and transparency and value for money were not defined by the patient's perspective of management in the department.

2.5 LIMITATIONS

The key limitations of this stage of the study were as follows:

The limitation of using only audio recording to capture data is that it only captures speech and misses non-verbal communication. However, this is a qualitative research study with the focus on patients describing their experiences and therefore audio recording would provide sufficient data. The intrusiveness of video recording (Haidet, Tate, Divirgillo-Thomas, Kolanowski & Fapp 2009) deterred the researcher from applying it.

The researcher did not attend the interviews as an observer during which non-verbal communication could have been documented.

Although the room at the brachytherapy unit that was used to conduct the interviews was conducive to private conversation; the "DO NOT ENTER" sign on the door was ignored and interrupted the audio recorded interviews of two participants.

The interviews were conducted at the brachytherapy unit, encouraging participants to consider only the brachytherapy part of their radio-chemotherapy treatment. However, a few participants gave answers that were related to their external beam radiotherapy treatment and chemotherapy.

Some of the participants misunderstood some of the questions that were asked during their interviews and therefore some of their responses could not be included in the results of this study.

The study focused on the experiences of women, while receiving high dose rate-intracavitary brachytherapy and therefore long term issues such as late radiation complications were not considered.

2.6 CONCLUSION

This stage has demonstrated that participants who participated in the study are faced with the same psychological and physical challenges than their counterparts of first world countries. Providing patients with sufficient and understandable information could lessen feelings of fear and anxiety towards treatment delivery.

There is however the possibility that some of the 28 participants' reported experiences and perceptions of their treatment may not be an objective reality of events. However, their voiced experiences cannot be ignored and will thus be of inestimable value together with findings in the literature and the aggregate experience of the researcher in formulating guidelines to facilitate quality patient management for this group of women. The study identified women's unmet needs that provide a focus for improvement in patient management. Future research into women's experience of receiving high dose rate-intracavitary brachytherapy in third world countries is encouraged.

In the next chapter, Chapter 3, Formulation of the Proposed Guidelines, the findings of stage one will be integrated into the guideline formulation process that comprises of a literature search and the experience of the researcher.

CHAPTER 3

FORMULATION OF THE PROPOSED GUIDELINES

3.1 INTRODUCTION

The patient experience and perspectives that were voiced during stage one of the research study, highlighted the need for a patient-centred, comprehensive and integrated approach to supportive cancer care (Walton *et al.* 2010). Steps or action need to be taken to ensure that quality patient management is being delivered by members of the multidisciplinary team in the Department of Oncology. Booth *et al.* (2005) stated that the management of patients with gynaecological cancers is an important facet of the current thrust to improve cancer care. The authors suggested that once women are in the health care system much more needs to be done by key personnel to help patients deal with their physical and psychological needs. Clinical practice guidelines could be used to promote effective and efficient health care (Fevers *et al.* 2005).

Practice guidelines are intended to improve outcomes for service users, improve service users'experiences of receiving care and to reduce any unintended harm that may be a consequence of an intervention (Gould 2010). Bastian (1996) was one of the first to attract attention to patients' participation in guideline development. This finding is confirmed by The Australian National Guidelines' development program that stipulates that the development process of guidelines must incorporate the perspectives and expertise of consumers (NHMRC 1995).

This chapter aims to formulate guidelines that consciously embrace the *patients' perspective* of their management. It provides background information on the development and implementation of guidelines, a detailed description of the methodology employed, presentation of the proposed guidelines, followed by a discussion, limitations and a conclusion.

3.2 GUIDELINE DEVELOPMENT AND IMPLEMENTATION

Guidelines refer to statements that suggest or recommend specific professional behaviour, endeavour or conduct for health care workers (APA 2002). They are intended to facilitate the continued systematic development of the profession and to help assure a high level of professional practice. Kirk and Reid (2002) defined guidelines as assessment or intervention protocols developed by panels of experts (usually interpreted as practitioners and academics, but increasingly including service users and carers). Guidelines are intended to reduce variability in services, increase the reliability of practice behaviours and thereby increase the confidence of service users in the effectiveness of services rendered (Rosen & Proctor 2003). The formulation of practice guidelines is a relatively recent development in the social world, because of their antecedents in evidence-based medicine (Gould 2010). Gould (2010) stated that methods for producing guidelines have been dominated by quantitative approaches to systemic reviewing with relative little attention given to the integration of qualitative forms of knowledge, such as the voice of service users.

The UK Royal College of General Practitioners published its first clinical guidelines for good practice in 1986. In the USA the practice guideline movement is even more prominent; in 1997 the American Medical Association listed 2 200 practice guidelines (Fletcher & Fletcher 1998). Guideline development experts have often turned to consider consumers mainly because patient pressure is believed to be effective in changing professional behaviour (Bastian 1996). The primary intention of integrating qualitative research in practice guideline development is that qualitative data, particularly that which captures the experiences of those receiving an intervention, contextualises and assists interpretation of findings from evidence derived from research (Arai, Popay, Robers & Roen 2004; Thomas, Harden, Oakley, Oliver, Sutcliffe, Rees, Brunton & Kavanagh 2004).

Literature on characteristics of effective guidelines is limited (Burgers, Grol, Zaat, Spies, Van der Bij & Mokkink 2003; Fevers *et al*. 2005). Burgers *et al*. (2003) identified characteristics of effective guidelines using a large sample of concrete recommendations with contrasting compliance rates. In order to guarantee adherence to guidelines, Burgers *et al.* (2003) suggested that the applicability of recommendations is at least as relevant as their support with evidence. Important barriers to the application of recommendations are concerned with the need for new skills and the complexity of the recommendations and that pilot testing of

the guideline amongst target users may provide additional information on barriers to implemenation.

Grol, Dalhuijsen, Thomas, In't Veld, Rutten and Mokkink (1998) suggested that controversial recommendations, vague and non-specific recommendations, and recommendations that demanded an alteration in existing routines and habits, were less likely to be followed. Grilli and Lomas (1994) confirmed that complexity and triability of recommendations could partly predict the level of compliance with a guideline. However, when the recommendations are easy to follow and compatible with norms and values, the application of the recommendations will be facilitated (Booth *et al*. 2005). Further research in this area is necessary to ensure that guidelines are developed in a way that is optimally effective in improving patient care (Baker 2001).

3.3 METHODOLOGY

Bastian (1996) proclaimed that methods for seeking consumers' views fall within three main categories of activity: representatives' involvement in group decision making, consultation and the use of research literature describing people's experiences. In combination, these three strategies can enable consumer views to be considered better, allowing consumers to play a key role in shaping health care services.

The methods of guideline development should ensure that managing patients according to the guidelines will achieve the desired outcomes (Shekelle, Woolf, Eccles & Grimshaw 1999). The WHO (2012) advised guideline developers to plan and define the scope of a guideline. This means to consider why the guideline is necessary. Is the guideline intended to respond to poor practice or try to change clinical practice or health policy? This should be the focus of most guidelines and it is what differentiates guidelines from textbooks or reference works.

3.3.1 Practical planning

Having explored the patient experience of receiving high dose rate-intracavitary brachytherapy in stage one of the research study, the need for formulation of practice guidelines in this setting was confirmed. Explicit and detailed information about the objectives and context of the guideline development, including the methods used and the

people and organizations involved in the development process are very important elements to include (Fevers *et al.* 2005). The WHO (2012) provided practical aspects that need to be considered when planning and formulation of the guidelines. It is necessary to consider the research or guideline objectives, target audience, timelines, funding, existing guidance and resources, evidence base, guideline development group, type of publication and translations involved (WHO 2012). The practical planning of the formulated guidelines in the current study is shown below.

Setting objectives. The proposed guidelines of the current study were formulated to facilitate quality patient management for patients with locally advanced cervical cancer, receiving high dose rate-intracavitary brachytherapy treatment and to ensure that quality patient management is being delivered by members of multidisciplinary teams of brachytherapy units.

Target audience. The guidelines were formulated to be utilised by radiation oncologists/radiation oncology registrars, radiation therapists and oncology nurses that are affiliated to brachytherapy units.

Timeline. It took the researcher 24 months to complete this research study to formulate the guidelines for implementation.

Funding. Sufficient funding was made available for the researcher to pay for the transcribing and where necessary, translation of audio recorded interviews, editing and printing of documents.

Existing guidance and resources. A literature search has confirmed that there are currently no guidelines with a patient-centred care approach to facilitate quality patient management in a multidisciplinary environment for cervical cancer patients receiving high dose rate-intracavitary brachytherapy.

Evidence base. Published research on the patient experience of receiving high dose rate-intracavitary brachytherapy is limited and restricted to the lived experiences of women of first world countries. The findings of stage one of this prospective research study was used to formulate the proposed guidelines.

Persons involved. The researcher, supervised by two study promoters, was responsible for the formulation of the guidelines. In addition, the guidelines were reviewed and refined by members of the multidisciplinary team (stage three) and by national heads or designated representatives of brachytherapy units (stage four).

Type of publication. Electronic versions will be most useful for the guideline users, accompanied by short paper publications, wall charts and pamphlets

Translations. In a country where eleven official languages are spoken, the researcher would suggest that the guidelines be published in English as most health professionals should be fluent in this language. The WHO (2012) suggested that once having established a credible reason to formulate guidelines, the next step is scoping of the guideline.

3.3.2 Scoping the guideline

The WHO (2012) defined scoping the guideline as the process of defining what the guideline will include and not include. Scoping is considered one of the most difficult, but vitally important aspects of guideline development. WHO made the following statement:

"*If you get the scope right, the guideline should be manageable"* (WHO 2012:10)

The scoping procedure of the current study was guided by *The WHO Handbook for Guideline Development* (WHO 2012) to formulate the proposed guidelines. The scoping procedure suggested by this organization included the following: (1) list the priority topics, (2) search the literature, (3) draft potential recommendations, (4) sharpen the focus, (5) formulate questions, (6) review and (7) reconsider. It needs to be emphasized that the guideline formulation process of the current study is an adaptation to that proposed by WHO (2012).

3.3.3 Guideline formulation process

The guideline formulation process of stage two comprised of (1) the integration of the patient experiences of stage one, together with (2) a literature review on guidelines for patient management for cervical cancer patients receiving high dose rate-intracavitary brachytherapy

and (3) the knowledge and experience of the researcher with regard to service delivery at the brachytherapy unit. The guideline formulation process is depicted in Figure 3.1.

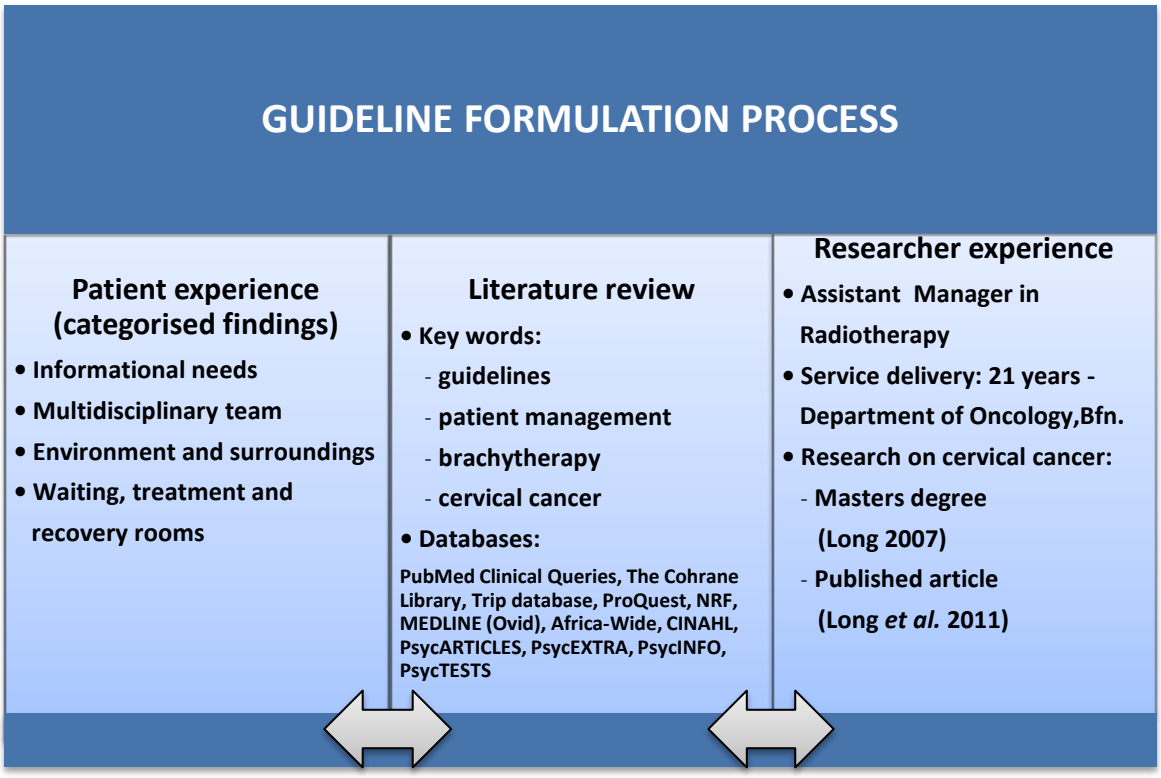

Figure 3.1 Guideline formulation process

3.3.3.1 *Patient experience*

Findings of the patient experience of stage one of the research study (cf. 2.3.2) were categorised according to the following: (1) informational needs, (2) the multidisciplinary team, (3) the environment and surroundings and (4) waiting, treatment and recovery rooms (Appendix 13). All the related suggestions made by the participants of stage one of the research were listed according to the above-mentioned themes.

3.3.3.2 *Literature search*

Identifying and assessing existing guideline documents covering the same issue are best done by performing a literature search. The purpose of a literature review is to collect all available evidence and assess its potential applicability to the clinical question under consideration (Shekelle *et al.* 1999). Booth (2011) advised that it is helpful to identify key items of qualitative research, as well as other examples of research, to inform the background and conception of the review.

The aim of the literature search in the current study was to systematically identify and synthesize relevant evidence from the literature in order to answer the following key question:

Are there currently, published guidelines on the management of patients receiving high dose rate-intracavitary brachytherapy, based on the patient experience?

The researcher performed a comprehensive search for published guidelines on patient management for cervical cancer patients receiving high dose rate-intracavitary brachytherapy by utilising the following databases: MEDLINE with full text (Ovid), ProQuest; NRF; PubMed Clinical Queries; TRIP database; The Cochrane Library, Africa-Wide, CINAHL with full text, PsycARTICLES, PsycEXTRA, PsycINFO and PsycTESTS. The electronic databases were searched by using the following key words: "qualitative", "guidelines", "quality patient management", "cervical cancer", "high dose rate brachytherapy", "patient experience". Published guidelines on high dose rate-intracavitary brachytherapy focus on the technical and organisational aspects of treatment delivery and neglect to explore the patient experience of treatment delivery.

Since Velji and Fitch (2001) first captured patients' descriptions of the low dose rate brachytherapy experience, limited research has been published on this topic during the past thirteen years. Published research on the patient experience of receiving brachytherapy is mostly centred on the inpatient experience of patients receiving low dose rate brachytherapy (Christman, Oakley & Cronin 2001; So & Chui 2007; Warnock 2005). The study conducted by Kwekkeboom *et al.* (2009) explored women's experiences of pain and distress over a series of five high dose rate cervical brachytherapy procedures. In the abovementioned study the experiences reported were those of women from first world countries, which might differ significantly from the experiences by South African women.

Other than the ABS guidelines, there are sets of published guidelines available to assist institutions to develop or optimise brachytherapy facilities (cf. 1.4). A literature search done by Morton *et al.* (2010) based on international consensus and expert opinion identified twenty guidance documents regarding the organisational and technical requirements for the delivery of high dose rate brachytherapy. These documents were required to comment on at least one of the following: 1) practice setting; 2) practice team; and 3) quality assurance. Even though

the recommendations addressed the practice setting and the duties of the practice team in brachytherapy units, it did not incorporate the "*patient's perspective"* of treatment delivery.

The researcher therefore concluded that there are currently no published guidelines that have adopted and integrated the "*patient's perspective"* of receiving high dose rate-intracavitary brachytherapy into the guideline development process. Therefore, by combining the categorised findings of stage one of the research study and the researcher's experience of service delivery at the brachytherapy unit, the proposed guidelines were formulated to facilitate quality patient management in a multidisciplinary environment. By doing so, the researcher will make a significant contribution to address the existing gap.

3.3.3.3 *Researcher experience*

The advent of high dose rate brachytherapy in the Department of Oncology in 1994 introduced not only a convenient treatment option for patients with cervical cancer, but also provided the researcher with a wide range of research possibilities. Since the implementation of the high dose rate brachytherapy treatment system, the researcher was motivated to conduct research studies on the following: (1) utilising brachytherapy as treatment modality for malignant melanoma of the skull; (2) an analysis of dose effectiveness and incidence of late rectal complications of high dose rate brachytherapy in the radical treatment of cervical cancer (Long 2007; Long *et al*. 2011) and (3) the current study, entitled: Brachytherapy for cervical cancer: guidelines to facilitate quality patient management in a multidisciplinary environment. Knowledge has been acquired and experience gained over the twenty-one years of the researcher's service delivery in the department.

Exploring and understanding the cancer experience and the extent to which needs are being met by the existing services aided the researcher to address the patient's needs by formulating the proposed guidelines. Formulating the proposed guidelines with a *patient-centred care approach* presented the researcher with challenges, because methods for producing guidelines have been dominated by quantitative approaches to systematic reviewing with little attention given to the integration of qualitative forms of knowledge (Gould 2010). The researcher referred to the WHO Handbook for Guideline Development (WHO 2012) for assistance in the formulation process of the guidelines.

Being part of the multidisciplinary team at the brachytherapy unit has taught the researcher the importance of communication skills amongst team members, the importance of collaborative relationships with patients and team members and the importance of every member fulfilling his or her duties before, during and after treatment delivery. A multidisciplinary approach to inform the patient concerning her brachytherapy treatment constitutes good clinical practice, ensuring a smooth treatment transition for the patient.

3.3.4 Rigour

Trustworthiness of this stage of the research study was established by considering the four criteria proposed by Lincoln and Guba (1985) which include credibility, transferability, dependability and conformability.

Credibility was achieved by the integration of the patient experience, a literature search and the researcher's experience of service delivery at the brachytherapy unit. Transferability was ensured by the detailed description of the guideline formulation process, preceded by the practical planning of the proposed guidelines and a detailed layout of the roles and responsibilities of each member of the multidisciplinary team. Dependability was achieved by the sound guideline formulation process that was used to develop the proposed guidelines. The proposed guidelines were peer reviewed by the study promoters to ensure that the findings were successfully integrated into the formulation of the proposed guidelines. Conformability of the proposed guidelines was assured as the proposed guidelines have a patient-centred care approach.

3.4 PROPOSED GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MUTLIDISCIPLINARY ENVIRONMENT

Brachytherapy is an interdisciplinary procedure and the aim of the proposed guidelines is to provide team members with guidance to facilitate quality patient management as an essential component of patient satisfaction with services rendered. The researcher therefore aimed to formulate guidelines that would address the practice setting and the shared and exclusive roles and responsibilities of members of the multidisciplinary team working at the new patient clinic and/or the brachytherapy unit. The proposed guidelines were numbered

alphanumerically to aid the discussion and review processes of the final guideline formulation.

GUIDELINES

Section A: Requirements in the practice setting

1. An environment that is clean, tidy and patient friendly by incorporating the following in the waiting room: television, books with information on the treatment, newspapers, magazines, radio and flowers.
2. A bed in a separate room, in close proximity to the waiting room, where ward or ill patients could await their treatment under supervision.
3. Patients are in a safe and secure environment by ensuring only one entrance to the recovery room.
4. Sufficient personnel to attend to patients in the recovery room, preventing adverse incidents from occurring.
5. A bell to ring in case of an emergency in the recovery room.
6. Water drink facilities for the patients in the recovery room.
7. Refreshments for the patients before they depart from the unit.
8. Wheelchairs for patients who are too weak to walk to their mode of transport.

Section B: Shared roles and responsibilities

<u>Information</u>

1. All members of the team are responsible for the accuracy of the information and for making certain that the information is understood by the patient.
2. Inform the patient about her disease and forthcoming treatment in her home language.
3. Inform the patient of the availability of the services of an interpreter.
4. When an interpreter is used, documentation should be placed in the patient's medical file, indicating the name and qualification of the person who acted as an interpreter.
5. Explain the nature of the proposed treatment by making reference to brachytherapy as the inside radiation.

6. Avoid inappropriate terminology such as “burn”, “heat” and “slaughterhouse”.
7. Avoid using technical terms such as “side-effects”.
8. Allocate a member of the multidisciplinary team to inform the new patient of her forthcoming brachytherapy treatment, preferably a day or two prior to the scheduled treatment.
9. Make use of information sessions, informative material such as booklets or pamphlets, or digital video display, to inform patients of what brachytherapy entails.
10. Informative material and a digital video display should be available in at least Afrikaans, English and Sesotho.
11. Discourage the patient from gaining treatment related information from fellow patients.
12. Questions should be directed to members of the unit.
13. Ensure that the informed consent letter of the patient has been signed before her first treatment delivery.
14. Obtain consent from the patient before allowing medical or nursing students into the treatment room.
15. Inform the patient on a weekly basis of the timing of her next brachytherapy treatment.
16. Explain to the patient how the brachytherapy procedure will be incorporated into her six week treatment schedule.
17. Inform the patient that she will receive information regarding her follow-up appointments at completion of her radiotherapy treatment schedule.

Directions

18. Allocate a person to provide the new patient, who is unfamiliar with the hospital surroundings, with directions on where to register and to report for their first brachytherapy treatment.
19. Show the new patient the location of the unit and introduce her to the personnel.

Pre-treatment preparation

20. Provide the patient with detailed instructions regarding her pre-treatment preparations on the evening and morning prior to receiving the brachytherapy.

Treatment procedure

21. Provide the patient with an estimated waiting time.
22. Provide the patient with an estimated treatment time.
23. Provide the patient with an explanation if treatment has been delayed.
24. Inform the patient in the recovery room of the outcome of the treatment and if necessary, provide her with a rescheduled date in case of treatment cancellation.
25. Allocate a person to escort patients to their mode of transport or back to the ward.

Section C: Exclusive roles and responsibilities

C.1 New patient clinic

Radiation oncologist/radiation oncology registrar

Informed consent

1. Informed consent for the brachytherapy procedure must be obtained by or under supervision of a licenced physician qualified to perform and familiar to the procedure.
2. Informed consent must be obtained and documented prior to the initiation of brachytherapy where conscious sedation will be administered.
3. A physician who is not fluent in the language of the patient should use the services of an interpreter who is fluent in the language the patient can understand and that of the physician.
4. Provide the patient with an opportunity to ask treatment related questions before signing the consent form. Encourage them not to be ashamed or to feel inadequate to ask questions.
5. Have consent forms available in alternative languages such as Sesotho, English and Afrikaans.

Specifications for informed consent

During the process of obtaining informed consent, the physician should inform the patient of the following:

Treatment procedure

6. Ensure that the patient understands that brachytherapy is not an operation to the uterus, but radiation to the inside of the cervix.
7. Explain to the patient that she will receive conscious sedation to prevent discomfort and pain during treatment delivery. She will wake up in the recovery room after which she will be able to go home.

Treatment effects

8. Provide the patient with understandable information on the possible side-effects of the treatment.
9. Discuss the aspect of sexual intercourse and childbearing with all the patients, irrespective of their age or marital status.

C.2 Brachytherapy unit

Radiation therapist

1. Explain to the patient briefly the radiotherapy procedure that will take place and that the brachytherapy treatment delivery will be preceded by a CT scan procedure.
2. Show the new patient the inside of the treatment room and the treatment unit.
3. Inform the patient that during treatment delivery, she can communicate to personnel outside the treatment room via an intercom system and a video camera will provide visual communication with her.
4. Inform the patient that there are safety mechanisms in place if machine breakage occurs and that the applicators can be removed, if necessary.

Oncology nurse

1. Show the new patient the location of the dressing, waiting and recovery rooms.
2. Utilise the time spent in the waiting room to prepare the new patient emotionally for the treatment. Listen to her fears and concerns, especially the elderly.
3. Provide the new patient with a detailed explanation of their role during the treatment procedure.

4. Have nursing personnel present to assist the patient in the recovery room on her arrival from the treatment room.
5. Ensure that the ward patient has fully recovered, before sending her back to the ward.
6. See to the well-being of each patient before she leaves the unit.

Radiation oncologist/radiation oncology registrar

1. The attending radiation oncologist or radiation oncology registrar should introduce him/herself to the patient.
2. Provide the patient with an explanation of the procedure he/she will be performing.
3. Provide the patient with the choice of being treated by a female or male radiation oncologist or radiation oncology registrar.
4. Ensure that each patient is treated weekly by the same radiation oncologist or radiation oncology registrar.
5. Keep the patient sedated until her treatment is completed and the applicators have been removed
6. Documentation should be made of the sedation requirements during the procedure for future reference in following treatments.
7. Individualise the sedation dosage.

3.5 DISCUSSION

The Department of Oncology utilises treatment schedules or protocols for the treatment planning and delivery of high dose rate-intracavitary brachytherapy for patients diagnosed with locally advanced cervical cancer. However, these schedules do not address patient management at the brachytherapy unit. The proposed guidelines were formulated to be used as a tool by members of the multidisciplinary team of the department in providing quality patient management for this group of patients. The proposed guidelines were allocated to members of the multidisciplinary team according to their duties at the new patient clinic and the brachytherapy unit, respectively. Although the medical physicists are part of the multidisciplinary team and perform the duties of dosimetrists and are responsible for the treatment planning and delivery at the unit, they were excluded from this study as they are not directly involved with patient management.

Findings of stage one of the research have indicated that patients' informational needs were not adequately met. Therefore, the researcher included section B (shared roles and responsibilities), in the proposed guidelines ensuring that all members of the multidisciplinary team provide the patient with sufficient and understandable information before, during and after their treatment delivery. In section C.1 (exclusive roles and responsibilities of the radiation oncologist/registrar at the new patient clinic) the researcher focused on the exclusive roles and responsibilities of the radiation oncologist/registrar working at the new patient clinic. Patients are faced with psychological challenges such as fear of the unknown. The proposed guidelines in this section focus on informed consent and stipulate the importance of communicating disease and treatment related issues to the patient thereby reducing the patients' feelings of fear and anxiety towards the brachytherapy treatment.

Brachytherapy is an invasive procedure and it is thus necessary that every member of the multidisciplinary team working at the unit is fully aware of their responsibilities to ensure a smooth transition for the patient. Therefore, the researcher formulated guidelines for section C.2 (exclusive roles and responsibilities at the brachytherapy unit) that address the individual roles and responsibilities of the radiation oncologist/radiation oncology registrar, the radiation therapist and the oncology nurse. However, these roles described are not mutually exclusive, but depending on case load and facility preferences, may be performed by different team members..

3.6 LIMITATIONS

Literature on integrating qualitative evidence in practice guideline development is limited, because methods for producing guidelines have been dominated by quantitative approaches (Gould 2012).

3.7 CONCLUSION

The proposed guidelines were formulated to assist or guide members of the multidisciplinary team of the Department of Oncology in providing quality patient management for cervical cancer patients receiving high dose rate-intracavitary brachytherapy. The layout of the proposed guidelines aligned itself with the flow of events or activities in the department to

ensure ease of implementation. The proposed guidelines clearly define the collective and exclusive roles and responsibilities of members of the multidisciplinary team for implementation at the new patient clinic and brachytherapy unit, respectively. In addition, the guidelines address the practice setting of brachytherapy units, ensuring a safe and secure environment for the patient.

In order to guarantee adherence to the proposed guidelines, it is thus necessary that the proposed guidelines be reviewed by members of the multidisciplinary team of the department. Conducting focus group interviews with the abovementioned members of the department will determine whether implementation of the proposed guidelines is feasible and applicable.

In the next chapter, Chapter 4, Multidisciplinary Staff Perspectives, the scope of the guidelines will be reviewed and refined by two focus groups. The methodology and the findings of the focus group interviews will be reported and the amended guidelines will be presented.

CHAPTER 4

MULTIDISCIPLINARY STAFF PERSPECTIVES

4.1 INTRODUCTION

Guidelines are developed to close the gap between research and practice (Burgers *et al*. 2003). The proposed guidelines formulated in stage two of the current research study need to be reviewed by professionals in the department who regularly interact with brachytherapy patients. Booth *et al*. (2005) encourage pilot testing of the guidelines amongst target users. This is supported by Shekelle *et al.* (1999) that stated that the group assembled to translate the evidence into practice should be multidisciplinary. It is therefore an important part of the research to obtain the opinions and views of members of the multidisciplinary team of the Department of Oncology regarding the proposed guidelines.

This chapter provides a detailed description of the methodology used to gather feedback on the proposed guidelines from members of the multidisciplinary team. The findings of the focus group interviews are reported, the amended guidelines will be presented, discussed, followed by limitations and the conclusion.

4.2 METHODOLOGY

Focus group interviews are a means of better understanding how people feel or think about an issue, product or service (De Vos *et al*. 2011) and stimulate spontaneous exchanges of ideas, thoughts and attitudes in the security of being in a crowd (Krueger & Casey 2000). In contrast to the phenomenological lived experience approach of stage one of the current study, the focus group interviews as a method of data collection is more directed at and designed to explore the views and opinions (De Vos *et al*. 2011) of members of the multidisciplinary team in the department. The purpose of the focus group interviews was to gain multiple viewpoints from members of the multidisciplinary team in the Department of Oncology and to promote self-disclosure among participants on the proposed guidelines.

4.2.1 Focus group interviews

This section describes the recruitment protocol of the participants and the number and size of the focus groups.

4.2.1.1 *Selection and recruitment of focus group members*

Almost every aspect of a focus group interview depends on who the participants are. The right group composition will generate free-flowing discussions that contain useful data (De Vos *et al*. 2011). Members of a focus group should feel comfortable with each other, so that every member will participate in the discussion and it is therefore recommended that members for the focus group should be selected with care and caution (Rabiee 2004). Like most qualitative methods, focus groups rely on purposive sampling (De Vos *et al*. 2011). Therefore, the twenty-two members of the multidisciplinary team working at the brachytherapy unit of the Department of Oncology, Bloemfontein, with at least a year's experience of service delivery at the brachytherapy unit were selected to participate in the focus group interviews. Medical physicists were excluded as they are not directly involved with the management or care of patients at this unit.

The researcher personally recruited the focus group members. Two weeks prior to the focus group interviews, the researcher contacted the potential participants and invited them to participate. Invitation letters in English or Afrikaans were handed out (Appendices 14 and 15, respectively).

4.2.1.2 *Preparation for focus group interviews*

Members who agreed to participate in the focus group interviews were provided with a consent document in English or Afrikaans (Appendices 16 and 17, respectively). Personal and demographic details gathered were used to describe the group members. One week prior to the focus group interviews, the researcher provided each member who had signed the consent document with a sealed envelope, containing background information in English and Afrikaans (Appendices 18 and 19, respectively) and a copy of the proposed guidelines for review (Appendix 20). This gave the participants eloquent time to study the proposed guidelines before the focus group interviews. However, the participants were requested to

refrain from discussing the proposed guidelines with the researcher or any other member of the multidisciplinary team prior to the focus group interviews. The participants were informed about their time commitment as Rabiee (2004) deemed it as ethical and good practice. The researcher made follow-up phone calls to every participant, one day prior to the interviews, reminding them of the time and date of the scheduled focus group interviews.

4.2.1.3 *Number and size of the focus groups*

The potential participants were purposively divided into two focus groups by the study promoters as to accommodate all members of the multidisciplinary team working at the brachytherapy unit of the department. The two groups were compiled in such a way that they were comparable regarding professional category and years of experience. Coulter, Adams and Shekelle (1995) made the statement that individuals' biases may be better balanced in multidisciplinary groups and such a balance may produce more valid guidelines. Denscombe (2007) reported that it is generally recommended that a focus group should consist of between six and nine people. This allows for a fair range of opinions and experiences to be voiced by the participants. Too few members limit adequate discussion and too many members make effective functioning of the group difficult. Rabiee (2004) also reported that the number generally suggested as being manageable is between six and ten participants; large enough to gain a variety of perspectives and small enough not to become disorderly or fragmented.

4.2.2 Facilitation team

The facilitation team consisted of a group facilitator and two assistant facilitators, each with certain tasks to perform.

4.2.2.1 *Group facilitator*

The group facilitator is also known as a moderator. The group facilitator should have the necessary ability to guide the group process, be comfortable and familiar with the group process and have previous experience in working groups (Freitas, Oliveira, Jenkins & Popjoy 1998). De Vos *et al*. (2011) suggested that the group facilitator should guide the interview, while the group discusses the topics that the facilitator raises. The role of the facilitator is

both to ensure that the group functions effectively and that it achieves its aims. The process is best moderated by someone familiar with the management of the clinical condition and scientific literature, but who is not an advocate. He or she stimulates discussion and allows the group to identify where true agreement exists, but does not inject his or her own opinion in the process. This requires someone with both clinical skills and group process skills (Shekelle *et al*. 1999).

The duties of the group facilitator were performed by one of the study promoters. The group facilitator is an academic staff member of the Department of Clinical Sciences, Central University of Technology (CUT). As guided by the literature (Nyamathi & Shuler 1990), the group facilitator encouraged the expression of different opinions, helped group members to be more specific in their responses, directed discussions and probed participants without biasing responses.

4.2.2.2 *Assistant facilitators*

An assistant may assist the facilitator in handling distractions and also act as a backup to the recorded communication (Nyamathi & Shuler 1990). The assistant could be referred to as a recorder, observer, analyst and even consultant (Morgan & Krueger 1998). Rabiee (2004) recommended that one should have a note keeper present to observe non-verbal interactions, indicate the impact of the group dynamics, to document exchanges of views in order to supplement the oral text enabling a fuller analysis of the data.

The duties of an assistant facilitator during the focus group interviews were performed by one of the study promoters. The assistant facilitator is an academic staff member of the UFS. The assistant facilitator was responsible for making field notes on verbal and non-verbal aspects of the participants' reactions during the focus group interviews, summarising the responses at the end of each section discussed and supplying the participants with patient quotes and percentages of the patients' responses when requested.

The researcher was not present during the focus group interviews, so as to maintain a non-biased approach. This was deemed necessary, because the participants were all work colleagues of the researcher and the researcher's presence would have had the potential to impact on the participants' responses. The researcher performed the following duties of an

assistant facilitator: preparing the seminar room for interviewing by placing the chairs around the oval table, setting up the recording equipment, welcoming of participants, providing participants with logistical aspects of the interviewing process, eliminating disturbance and having refreshments available.

4.2.3. Research tools

The opinions of the participants concerning the proposed guidelines were collected by using an interview schedule, audio recordings and field notes.

4.2.3.1 *Interview schedule*

The group facilitator made use of an interview schedule (Appendix 21), to elicit the focus group's responses and opinions by facilitating conversational dialogue concerning the proposed guidelines. The schedule was designed by the researcher to assist the facilitator and assistant facilitator during the focus group interviews to facilitate the discussion, encourage participation and allow for a flow of the discussion. The topic guide for the focus group session was the list of proposed guidelines. The interview schedule provided the facilitator with a set of predetermined questions that guided the interviewing process. The interview schedule contained general and specific, open ended questions to gather feedback from the participants on the proposed guidelines.

The assistant facilitator was provided with two interview schedules. The first interview schedule was similar to that used by the group facilitator, but made provision for non-verbal behaviours to be noted onto the interview schedule (Appendix 22). The second interview schedule was used as a back-up tool and contained patient numbers and quotes that could be referred to when deemed necessary to support statements made during the focus group interviews (Appendix 23).

4.2.3.2 *Audio recording*

The two focus group interviews were audio recorded. Due to the fact that the audio recordings were a once-off recording with the participants, the researcher ensured that the equipment was fully functioning before each interview. In focus groups, recording equipment

is essential (De Vos *et al*. 2011). De Vos *et al*. (2011) suggested that it is useful to have two recorders running simultaneously in case of mechanical or electricity failure. The researcher made use of two stereo recorders with high sensitivity microphones, expandable memory cards and built-in memory to capture the interviews.

4.2.3.3 *Field notes*

The study promoter who performed the duties of an assistant facilitator during the focus group interviews made detailed field notes during each interview. The field notes included summaries of each section discussed, non-verbal behaviours of the participants and highlighted amendments made to specific guidelines discussed. Notes were also taken by the group facilitator and were discussed by the facilitation team after the focus group interviews. Field and Morse (1995) described field notes as a written account of what are heard, seen and experienced by the assistant facilitator during the course of collecting or reflecting on the data obtained during the focus group interviews.

4.2.4 Course of the focus group interviews

The two focus group interviews took place on 22 September 2013 and were both conducted in seminar room 2 of the department at 12:00 and 13:30, respectively. The setting was familiar and in close vicinity for all the participants. Participants were seated around an oval table to encourage conversation. Before commencement of each focus group interview the researcher welcomed the participants, introduced the facilitation team and presented the participants with logistical aspects of the interviewing process. As guided by the literature (Krueger & Casey 2000; Monette *et al.* 2005), the focus group members were encouraged to share their points of view, experiences, wishes and concerns regarding the proposed guidelines, without feeling intimidated by colleagues.

The focus group interviews were conducted in English so as to accommodate all participants. However, it was made clear by the researcher that participants were welcome to express themselves in Afrikaans to ensure clarity and that these comments would be translated into English by the group facilitator. Members of the focus groups were reminded that the interviews were being recorded for reference and transcription purposes. The focus group interviews were guided by the interview schedule, during which general and specific

questions were asked. Feedback on the layout and formulation of the proposed guidelines was gathered, whereafter questions were directed to each focus group, concerning each individual section of the proposed guidelines. After discussion by the group, each section was summarised in agreement with the focus groups by the assistant facilitator. An opportunity was provided for the focus group members to add additional information to the proposed guidelines after which they were thanked for their participation. All documents handed to the participants a week prior to the focus group interviews were retrieved at the end of each focus group interview.

4.2.5 Data analysis and presentation

The aim of analysis is to look for trends and patterns that reappear within a single focus group or among various focus groups. Barbour and Kitzinger (1999) mentioned that analysis would involve, at the very least, drawing together and comparing discussions of similar themes and examining how these relate to the variation between individuals and between groups. De Vos *et al.* (2011) stated that the basis for analysis is transcripts, tapes, notes and memory. The process of data analysis began during the data collection process, by skilfully facilitating the discussion and generating rich data from the audio recorded focus group interviews, complementing them with observational notes (Rabiee 2004). The transcripts, audio recordings and field notes of the current study were analysed manually by the researcher by applying the following steps:

- The audio recorded interviews were down loaded onto a PC and copied onto a CD and memory stick as backup. One master copy was placed in a secure place for safekeeping. The verbatim data was transcribed by staff of the Unit of Language Facilitation of the UFS.
- The researcher listened to the recordings, while comparing the content with the transcripts of the two focus group interviews. The transcripts were read in their entirety several times to familiarise the researcher with the content of the text.
- The field notes were incorporated.
- Amendments and added guidelines were highlighted in blue and the guidelines that were omitted were shown in red for easy identification.
- The raw data were grouped according to the following main themes:

  A. The Practice setting

B. Collective roles and responsibilities
C. Exclusive roles and responsibilities
C.1 New patient clinic
C.2 Brachytherapy unit

- Sub-themes were grouped accordingly.

The findings are presented as follows:

- Findings of the two focus group interviews were reported according to the layout of the interview schedule.
- If one participant's response led to group agreement, it was reported as a group's response and was thus not reported individually.
- Additional/amended or omitted guidelines were reported.

4.2.6 Rigour

The trustworthiness of this stage of the study was dealt with by using Lincoln and Guba's (1985) criteria (cf. 2.2.8) that entails credibility, transferability, dependability and conformability. The current study followed a clear procedure of data analysis which increased the rigour of the study. The trustworthiness of the focus group interviews was assured by a detailed debriefing session between the researcher and the promoters immediately following the focus group interviews.

Credibility of the focus group interviews was achieved as the focus group members were encouraged to interact with each other as their constructive feedback would be used to refine the proposed guidelines. Participants were informed that there were no right or wrong answers, only different points of view and opinions and that they could withdraw from the study at any point. The interview schedule was proof read by the study promoters. The open-ended interview schedule included probes that elicited detailed data and iterative questioning. The audio recordings of the interviews also lent themselves to being checked by other researchers or promoters which contributed to the validity. The researcher's familiarity with the brachytherapy environment, qualifications and 21 years of service delivery and patient management at the unit, added to the credibility of the study. According to Patton (2002), the credibility of the researcher is especially important in qualitative research as it is the person who is the major instrument of data collection and analysis.

The transferability of the focus group interviews was achieved by the multiple viewpoints obtained during the audio recorded interviews of members of the multidisciplinary team (head of the department, radiation oncologists, radiation oncology registrars, radiation therapists and oncology nurses).

In order to minimise the potential bias introduced in analysing and interpreting focus group data, Krueger and Casey (2000) pointed out that analysis should be systematic, sequential, verifiable and continuous. Dependability of the two focus group interviews was thus ensured by the consistent method used during both interview procedures. The same setting, facilitator, assistant facilitator and interview schedule were used for both focus group interviews which took place on the same day and with half an hour between each session. Following this path provides a trail of evidence, as well as increasing the extent of dependability, consistency and conformability of the data (Lincoln & Guba 1989).

Conformability was achieved by peer debriefing sessions following the interviews and by the researcher not being present during the focus group interviews. Recommendations based solely on clinical judgement and experience are likely to be more susceptible to bias and self-interest (Shekelle *et al*. 1999). Therefore, individuals' biases were better balanced in multidisciplinary groups and such balance may produce more valid guidelines.

4.3 FINDINGS

4.3.1 Participant profile

Twenty of the twenty-two potential participants who were invited to take part in the two focus group interviews consented to participation. The two participants who declined the invitation had personal commitments to attend. Each focus group consisted of ten participants. Occupation, race, gender and years of experience at the unit of each participant were used to describe their profile. Their years of experience were calculated from the date of their employment in the department up until the date of the focus group interviews, 20th September 2013. The socio-demographic details of the two focus groups are shown in Tables 4.1 and 4.2, respectively.

Table 4.1 Focus Group 1: Socio-demographic details of participants

Occupation	Race	Gender	Years of experience at the unit
Radiation oncologist	White	Female	18 years and 9 months
Radiation oncologist	White	Male	11 years and 3 months
Radiation oncologist	Black	Female	4 years and 11 months
Radiation oncologist	White	Male	7 years and 9 months
Radiation oncology registrar	White	Female	2 years and 11 months
Radiation oncology registrar	White	Male	2 years and 6 months
Radiation oncology registrar	White	Female	1 year and 9 months
Radiation therapist	White	Female	18 years and 9 months
Radiation therapist	White	Female	10 years and 3 months
Oncology nurse	Black	Female	9 years and 4 months

Table 4.2 Focus Group 2: Socio-demographic details of participants

Occupation	Race	Gender	Years of experience at the unit
Radiation oncologist	White	Female	18 years and 9 months
Radiation oncologist	Indian	Female	7 years and 2 months
Radiation oncologist	White	Female	5 years and 4 months
Radiation oncology registrar	White	Male	4 years and 9 months
Radiation oncology registrar	Asian	Female	2 years and 1 month
Radiation oncology registrar	White	Male	1 year and 1 month
Radiation therapist	White	Female	18 years and 9 months
Radiation therapist	White	Female	18 years and 9 months
Radiation therapist	White	Male	3 years and 9 months
Oncology nurse	White	Female	3 years and 2 months

4.3.2 The focus group interviews

The duration of the focus group interviews was 70 and 85 minutes respectively. Participation varied amongst the two focus group interviews. The members of the one focus group responded more enthusiastically in comparison to that of the other focus group where response was less spontaneous. Feedback from one focus group was more academically inclined. Participants of the other focus group had a more personal approach where statements were more defensive. Most of the participants seemed to be unfamiliar with the interviewing process and appeared to be hesitant at first. However, once the interviewing process progressed, the participants started to engage spontaneously and provided constructive feedback on the proposed guidelines.

4.3.3 Participant feedback

In this section, the findings of the focus group interviews regarding the layout and overall opinion on the proposed guidelines are reported initially. Thereafter the findings on each of the sections (A-C) are provided according to the following four separate sections:

1. Feedback on each guideline.
2. Availability of resources.
3. Additional/amended or omitted guidelines.
4. Summary.

4.3.3.1 *Layout and formulation of the proposed guidelines*

Focus group 1: The focus group reported that the layout of the proposed guidelines was acceptable, made sense and was structured and formulated in an explanatory and understandable manner.

Focus group 2: The focus group reported that the layout of the proposed guidelines was clear, concise and understandable. All the participants agreed with the formulation of the proposed guidelines.

4.3.3.2 *Overall opinion of the proposed guidelines*

Focus group 1: The focus group reported that the proposed guidelines would achieve the researcher' aim which was to provide quality patient management for cervical cancer patients undergoing brachytherapy. However, there were a few aspects that the group indicated would not be feasible to implement. The group agreed that the proposed guidelines would be largely applicable for use by members of the department.

Focus group 2: This focus group agreed that the proposed guidelines would largely be applicable for use by members of the multidisciplinary team as it was to a large extent practice in the department and requires implementation for accreditation purposes. The focus group concluded that there were indeed some aspects of the guidelines that could be implemented to improve patient management in the department.

4.3.3.3 *Section A: Requirements in the practice setting*

A.1 Feedback

Guideline A.1
An environment that is clean, tidy and patient friendly by incorporating the following in the waiting room: television, books with information on the treatment, newspapers, magazines, radio and flowers.

Focus group 1: The focus group reported that items such as a television, radio and flowers in the waiting room are luxuries and incorporation would depend on the resources available. The group indicated that items such as flowers, a radio and a television should rather be included as examples and not as requirements for the practice setting.

Focus group 2: The focus group stated that the guideline should not specify items such as flowers, radio and a television. The group reported that due to cultural differences a radio and television in the waiting area would not be feasible and would add to the noise level in the hospital. The group therefore suggested that items such as a television and a radio should be excluded from the guideline. The group made the statement that due to limited resources, the

request for flowers should also be excluded from the guideline. However, the group agreed that supplying the patients with magazines and informative material would be in order.

Guideline A.2
A bed in a separate room, in close proximity to the waiting room, where ward or ill patients could await their treatment under supervision.

Focus group 1: The guideline was accepted without amendment.

Focus group 2: The focus group reported that it is not practical to have a bed in a separate room due to the layout of the unit, but made the suggestion that ward or ill patients could be observed in the recovery room. It was suggested by the group that partitioning could be used to provide patients with more privacy.

Guideline A.3
Patients are in a safe and secure environment by ensuring only one entrance to the recovery room.

The guideline was accepted without amendment by both focus groups.

Guideline A.4
Sufficient personnel to attend to patients in the recovery room, preventing adverse incidents from occurring.

Focus group 1: The focus group acknowledged that there are times that patients are without assistance in the recovery room as the department has only one professional nurse working at the unit. The group suggested that it would be feasible to allocate a student nurse to attend to the patients in the recovery room.

Focus group 2: The focus group agreed that although one professional nurse could not sufficiently attend to the needs of all the patients, the resources and logistical aspects in the department did not allow for allocating extra nursing staff in the recovery room. The group

suggested that this guideline should also state that patients should be monitored post-brachytherapy.

Guideline A.5
A bell to ring in case of an emergency in the recovery room.

Focus group 1: The focus group acknowledged that an emergency can occur in the recovery room and that the department should consider providing patients with a bell to ring in case of an emergency. The group agreed that the installation of a bell for use in emergencies in the recovery room would be feasible.

Focus group 2: The focus group acknowledged that there is currently no bell in the recovery room for patients to ring for assistance. The group suggested acquiring a manual bell for patients to ring in case of an emergency.

Guideline A.6
Water drink facilities for the patients in the recovery room.

Focus group 1: The guideline was accepted without amendment.

Focus group 2: The focus group mentioned that the unit has a water drink facility outside the recovery room.

Guideline A.7
Refreshments for the patients before they depart from the unit.

Focus group 1: The focus group stated that although it would be the ideal to provide meals and snacks for everybody, available resources did not allow for this provision. The group mentioned that the department supplies meals for some patients and that this guideline should be excluded.

Focus group 2: The focus group stated that it would be the ideal to provide every patient with a meal, but the department has limited resources. The group agreed that it would not be

practical to implement this guideline, because sedated patients should abstain from refreshments after treatment delivery. It was stated by the group that this guideline should be omitted.

Guideline A.8
Wheelchairs for patients who are too weak to walk to their mode of transport.

The guideline was accepted without amendment by both focus groups.

A.2 Availability of resources

Focus group 1: It was commented by the focus group that it would be ideal to provide patients with meals and/or snacks. However, the department would not be able to fund this luxury. The installation of a bell for use in emergencies in the recovery room would be feasible to implement.

Focus group2: The focus group agreed that although one professional nurse could not sufficiently attend to the needs of the patients, the resources and logistical aspects in the department did not allow for allocating extra nursing staff in the recovery room. It was mentioned that it would take a lot of effort to get the funds to provide patients with the ideal requirements.

A.3 Additional/amended or omitted guidelines

- Additional guideline: Provide the patient with privacy in the recovery room by making use of partitioning.
- Amended guideline: Patients should be monitored post-brachytherapy. (Guideline A.4)
- Omitted guideline: Refreshments for the patients before they depart from the unit. (Guideline A.7)

A.4 Summary

Focus group 1: The focus group reported that they agreed with the guidelines set out in this section. However, the group indicated that although some of the requirements in the practice setting would be the ideal to implement, realistically, it would be difficult to implement due to financial restraints. The group agreed that the proposed guidelines on requirements in the practice setting would differ from unit to unit and that each unit (private or governmental) should attempt to make the environment as pleasant and as comfortable as possible for the patients. Guidelines A.1, A.4, A.5 and A.7 of section A were specifically discussed in more detail by this focus group.

Focus group 2: The focus group reported that they agreed with the guidelines set out in this section. However, the group indicated that some of the requirements in the practice setting were merely suggestions made by the patients to make them feel more comfortable, but not necessarily practical to implement. The group felt that the patients do not always realize the seriousness and the clinical importance of having a quiet and controlled environment. The group however acknowledged that the environment in their unit may be inadequate and could be addressed by the proposed guidelines. Guidelines A.1, A.2, A.4, A.5 and A.7 of section A were specifically discussed by this focus group.

4.3.3.4 *Section B: Shared roles and responsibilities*

B.1 Feedback

Guideline B.1
All members of the team are responsible for the accuracy of the information and for making certain that the information is understood by the patient.

Focus group 1: The focus group reported that the radiation oncologist/ radiation oncology registrar, the radiation therapist and the oncology nurse should all explain their roles in the process of treatment delivery to the patient. The focus group allocated this shared responsibility to all members of the multidisciplinary team as each member is responsible to inform the patient of his or her role during treatment delivery.

Focus group 2: The focus group reported that all the role players are responsible to provide the patient with the necessary information. However, the group stated that each of the role players have a different way of explaining brachytherapy and thus could be confusing to the patient. It was mentioned that patients are not a uniform group and do not all relate in the same way to information and the suggestion was made that certain key words should be used by all members.

Guideline B.2
Inform the patient about her disease and forthcoming treatment in her home language.

Focus group 1: The focus group reported that it is not always possible to address the patient in her home language as some of the patients come from areas such as Ethiopia and the Transkei. The group reported that it is a problem if the patients do not understand English, because the department does not have medically trained interpreters readily available. However, it was stated by the group that the radiation oncologists/registrars should try as far as possible to address the patient in her home language. The focus group allocated this responsibility to the radiation oncologist/ radiation oncology registrar and the interpreter at the new patient clinic.

Focus group 2: The guideline was accepted without amendment.

Guideline B.3
Inform the patient of the availability of the services of an interpreter.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to be performed by the radiation oncologist.

Focus group 2: The guideline was accepted without amendment.

Guideline B.4
When an interpreter is used, documentation should be placed in the patient's medical file, indicating the name and qualification of the person who acted as an interpreter.

***Focus group 1*:** The focus group reported that due to financial constraints the department enlists the use of cleaners or nurses to act as interpreters. The group stated that this guideline should be amended as it is not practical and it would be degrading for the person who acted as an interpreter to provide his or her qualification. The group agreed that the person who is used as an interpreter should at least sign his or her name in the patient's file. The focus group allocated this responsibility to the radiation oncologist/radiation oncology registrar and the interpreter.

Focus group 2: The guideline was accepted without amendment.

Guideline B.5
Explain the nature of the proposed treatment by making reference to brachytherapy as the inside radiation.

Focus group 1: The focus group reported that the term "*inside radiation*" was used amongst the patients and the group indicated that they were not comfortable using this term to explain the nature of the treatment. The group indicated that patients might perceive brachytherapy as a treatment in which they might have to swallow something. It was suggested by the group that the radiation oncologist/registrar should use a diagram or a cartoon to explain brachytherapy to the patients. The focus group allocated this responsibility to the radiation oncologist/radiation oncology registrar.

Focus group 2: The guideline was accepted without amendment.

Guideline B.6
Avoid inappropriate terminology such as "burn", "heat" and "slaughterhouse".

***Focus group 1*:** The focus group reported that the guideline should be omitted as the words heat, burnt and slaughterhouse were offensive. It was stated by the group that these words are not to be used by any professional in describing brachytherapy to the patients and could be linked to the patients' perceptions of the treatment.

Focus group 2: The focus group reported that this guideline is a reflection of words used by the patients to explain their perceptions of brachytherapy treatment. It was stated by the group that these terms were *"picked up"* by the patients and suggested that this guideline should be omitted.

Guideline B.7

Avoid using technical terms such as "side-effects".

Focus group 1: The focus group reported that the term "*side-effects*" is a standard term and should be used. It was stated by the group that the radiation oncologists/registrars should provide the patient with examples of side-effects before the patient signs the informed consent form. However, the group indicated that there is sometimes a language barrier and cleaners are not trained interpreters. The focus group decided that this guideline should be omitted.

Focus group 2: The focus group reported that the term "*side-effects*" should not be avoided. It was stated by the group that it is a technical term and that there is no alternative term to use. It was mentioned by the group that when the term "*side-effects"* is used, the oncologist provides the patient with examples of possible side-effects. They also said that it should be omitted.

Guideline B.8

Allocate a member of the multidisciplinary team to inform the new patient of her forthcoming brachytherapy treatment, preferably a day or two prior to the scheduled treatment.

Focus group 1: The guideline was accepted without amendment. The focus group allocated the responsibility to the radiation therapist.

Focus group 2: The guideline was accepted without amendment.

Guideline B.9

Make use of information sessions, informative material such as booklets or pamphlets, or digital video display, to inform patients of what brachytherapy entails.

Focus group 1: The focus group acknowledged that the department does not provide patients with a booklet or a pamphlet on brachytherapy treatment and that this needs to be addressed. The group had mixed feelings on using digital video display to inform patients on brachytherapy. The group reported that a cartoon and not real life pictures could be useful in assisting them to explain the treatment procedure to the patient. Showing the patient real life pictures could also be too descriptive and unnerving and the group suggested that they should rather explain verbally, taking into account the patient's cognitive abilities. The focus group allocated this responsibility to the radiation therapist.

Focus group 2: The focus group agreed with the guideline, but was unsure if they wanted to include a "*digital video display"* in the guideline. The group indicated that it could be useful when designed in a manner that is not too graphical for the patient. A suggestion was made by the group that the video display could be a two minute display of informing the patient of the procedure, without the visuals. However, the group had the concern that a digital video display would not help the situation, only makes matters worse and that the procedure is explained well enough orally to the patient at present.

Guideline B.10 Informative material and a digital video display should be available in at least Afrikaans, English and Sesotho.

Focus group 1: The guideline was accepted without amendment.

Focus group 2: The focus group observed that the informative material written in Afrikaans and English is acceptable, but that Sesotho is not a language spoken in other provinces.

Guideline B.11 Discourage the patient from gaining treatment related information from fellow patients**.**

Focus group 1: The focus group suggested changing the wording of this guideline to the following: "Encourage the patient to ask treatment related questions from personnel at the unit when remarks made by fellow patients are confusing or contradicting." The focus group allocated this responsibility to all the members of the multidisciplinary team.

Focus group 2: The focus group mentioned that patients do tend to talk to one another at the halfway house, Katleho, and in so doing frighten each other. It was suggested that members of the multidisciplinary team should encourage the patients not to listen to fellow patients, but to direct treatment related questions to personnel at the unit.

Guideline B.12
Questions should be directed to members of the unit.

The guideline was accepted without amendment by both focus groups.

Guideline B.13
Ensure that the informed consent letter of the patient has been signed before her first treatment delivery.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the radiation oncologist/radiation oncology registrar.

Focus group 2: The guideline was accepted without amendment.

Guideline B.14
Obtain consent from the patient before allowing medical or nursing students into the treatment room.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the radiation oncologist/radiation oncology registrar.

Focus group 2: The focus group mentioned that medical or nursing students should be present to observe the procedures as the hospital is an academic institution. It was stated by the group that students are in the process of being educated and should be present when informed consent is taken.

Guideline B.15
Inform the patient on a weekly basis of the timing of her next brachytherapy treatment.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the radiation therapist working at the accelerator.

Focus group 2: The guideline was accepted without amendment.

Guideline B.16

Explain to the patient how the brachytherapy procedure will be incorporated into her six week treatment schedule.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the radiation oncologist/radiation oncology registrar and the radiation therapist.

Focus group 2: The guideline was accepted without amendment.

Guideline B.17

Inform the patient that she will receive information regarding her follow-up appointments at completion of her radiotherapy treatment schedule.

Focus group1: The guideline was accepted without amendment. The focus group allocated this responsibility to the radiation oncologist/radiation oncology registrar and the radiation therapist.

Focus group 2: The guideline was accepted without amendment.

Guideline B.18

Allocate a person to provide the new patient, who is unfamiliar with the hospital surroundings, with directions on where to register and to report for their first brachytherapy treatment.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the clerical staff of the department.

Focus group 2: The guideline was accepted without amendment.

Guideline B.19

Show the new patient the location of the unit and introduce her to the personnel.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the nurse working at the clinic and the clerical staff of the radiation department.

Focus group 2: The guideline was accepted without amendment.

Guideline B.20

Provide the patient with detailed instructions regarding her pre-treatment preparations on the evening and morning prior to receiving the brachytherapy.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the oncology nurse.

Focus group 2: The focus group reported that the responsibility to inform the patient of her pre-treatment preparation should be allocated to the radiation therapist working at the accelerator and not the brachytherapy unit.

Guideline B.21

Provide the patient with an estimated waiting time.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the radiation therapist and the oncology nurse.

Focus group 2: The guideline was accepted without amendment.

Guideline B.22

Provide the patient with an estimated treatment time.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the radiation therapist and the oncology nurse.

Focus group 2: The guideline was accepted without amendment.

Guideline B.23

Provide the patient with an explanation if treatment has been delayed.

Focus group 1: The guideline was accepted without amendment. The focus group allocated this responsibility to the radiation therapist and the oncology nurse.

Focus group 2: The guideline was accepted without amendment.

Guideline B.24

Inform the patient in the recovery room of the outcome of the treatment and if necessary, provide her with a rescheduled date in case of treatment cancellation.

Focus group 1: The focus group reported that the radiation therapists at the accelerator and not the brachytherapy unit should inform the patients of the outcome of the treatment as it would be senseless to inform a sedated patient on the outcome of her treatment. The group made the suggestion to remove the words "*in the recovery room*" from the guideline. The focus group allocated this responsibility to the radiation therapist working at the accelerator.

Focus group 2: The guideline was accepted without amendment.

Guideline B.25

Allocate a person to escort patients to their mode of transport or back to the ward.

The guideline was accepted without amendment by both focus groups.

B.2 Availability of resources

Focus group 1: The focus group reported that the ideal would be to have a medically trained interpreter, but due to financial restraints it would not be possible to train or employ a medically trained interpreter. The group indicated that providing patients with pamphlets or booklets would be feasible and could be done by the department.

Focus group 2: The focus group stated that resources of the department did indeed allow for the implementation of some of the guidelines. Many, in their opinion, were already in practice.

B.3 Additional/amended or omitted guidelines

- Amended guideline: When an interpreter is used, documentation should be placed in the patient's medical file, indicating the name of the person who acted as an interpreter. (Guideline B.4)
- Amended guideline: Encourage the patient to direct treatment related questions to members of the unit when remarks made by fellow patients are confusing or contradicting. (Guideline B.11)
- Omitted guideline: Avoid inappropriate terminology such as "burn", "heat" and "slaughterhouse". (Guideline B.6)
- Omitted guideline: Avoid using technical terms such as "side-effects". (Guideline B.7)

B.4 Summary

Focus group 1: The focus group indicated that although they agreed with most of the proposed guidelines in this section, the group wanted to clarify certain aspects. Guidelines B.1, B.2, B.4, B.5, B.6, B.7, B.9, B.11 and B.24 of section B were discussed in more detail by this focus group. The group indicated that the heading of section B should be rephrased to "*collective responsibilities"* and the group allocated the guidelines to a specific member/s of the multidisciplinary team.

Focus group 2: The focus group agreed with a few of the guidelines in this section. Guidelines B.1, B.6, B.7, B.9, B.10, B.11, B.14 and B.20 of section B were specifically discussed in more detail during the focus group interview.

4.3.3.5 *Section C:* Exclusive roles and responsibilities

C.1 New patient clinic

Radiation oncologist/radiation oncology registrar

C.1.1 Feedback

Guideline C.1.1
Informed consent for the brachytherapy procedure must be obtained by or under supervision of a licenced physician qualified to perform and familiar to the procedure.

The guideline was accepted without amendment by both focus groups.

Guideline C.1.2
Informed consent must be obtained and documented prior to the initiation of brachytherapy where conscious sedation will be administered.

The guideline was accepted without amendment by both focus groups.

Guideline C.1.3
A physician who is not fluent in the language of the patient should use the services of an interpreter who is fluent in the language the patient can understand and that of the physician.

The guideline was accepted without amendment by both focus groups.

Guideline C.1.4
Provide the patient with an opportunity to ask treatment related questions before signing the consent form. Encourage them not to be ashamed or to feel inadequate to ask questions.

The guideline was accepted without amendment by both focus groups.

Guideline C.1.5
Have consent forms available in alternative languages such as Sesotho, English and Afrikaans.

The guideline was accepted without amendment by both focus groups.

Guideline C.1.6
Ensure that the patient understands that brachytherapy is not an operation to the uterus, but radiation to the inside of the cervix.

The guideline was accepted without amendment by both focus groups.

Guideline C.1.7
Explain to the patient that she will receive conscious sedation to prevent discomfort and pain during treatment delivery. She will wake up in the recovery room after which she will be able to go home.

Focus group 1: The focus group reported that the second sentence of the guideline should be amended. The group stated that sedated patients, especially the outpatients, must be informed that they may not drive by themselves. A suggestion was made by the group to add to the guideline that there is a possibility that the patient will only wake up in the recovery room, because patients respond differently to the sedation medication.

Focus group 2: The guideline was accepted without amendment.

Guideline C.1.8
Provide the patient with understandable information on the possible side-effects of the treatment.

The guideline was accepted without amendment by both focus groups.

Guideline C.1.9

Discuss the aspect of sexual intercourse and childbearing with all the patients, irrespective of their age or marital status.

The guideline was accepted without amendment by both focus groups.

C.1.2 Availability of resources

The availability of resources was confirmed by both focus groups.

C.1.3 Additional/amended or omitted guidelines

- Additional guideline: Inform the patient that due to the sedation medication being administered during the treatment, driving home on her own is prohibited.
- Amended guideline: Inform the patient that the possibility exists that she might only wake up in the recovery room, because patients respond differently to the sedation medication. (Guideline C.1.7)

C.1.4 Summary

Focus group 1: The focus group agreed with the guidelines. It was noted by the group that many of the shared responsibilities mentioned in section B overlapped with some mentioned in section C. Having already allocated the shared responsibilities in section B to specific members of the multidisciplinary team, the group made the recommendation that these guidelines should be restructured. Guideline C.1.7 of this section was discussed in detail by the focus group.

Focus group 2: The focus group agreed with the guidelines in section C.1.

C.2 Brachytherapy unit

C.2.1 Radiation therapist

C.2.1.1 Feedback

Guideline C.2.1.1
Explain to the patient briefly the radiotherapy procedure that will take place and that the brachytherapy treatment delivery will be preceded by a CT scan procedure.

Focus group 1: The guideline was accepted without amendment.

Focus group 2: The focus group reported that although the patient is informed of the CT scan procedure that will precede the brachytherapy treatment delivery, mention should specifically be made to the patient about the movement of the bed before treatment delivery.

Guideline C.2.1.2
Show the new patient the inside of the treatment room and the treatment unit.

Focus group 1: The guideline was accepted without amendment.

Focus group 2: The focus group reported that this guideline should be shared by the radiation therapist and the oncology nurse as both members are responsible for showing the new patient the treatment room and unit.

Guideline C.2.1.3
Inform the patient that during treatment delivery, she can communicate with the personnel outside the treatment room via an intercom system and a video camera will provide visual communication with her.

Focus group 1: The guideline was accepted without amendment.

Focus group 2: The focus group reported that this guideline should be shared by the radiation therapist and the oncology nurse.

Guideline C.2.1.4 Inform the patient that there are safety mechanisms in place if machine breakage occurs and that the applicators can be removed, if necessary.

The guideline was accepted without amendment by both focus groups.

C.2.1.2 Availability of resources

The availability of resources was confirmed by both focus groups.

C.2.1.3 Additional/amended or omitted guidelines

- Additional guideline: Inform the patient that in emergencies the unit has an emergency strategy in place.
- Additional guideline: Provide information to the patient on infection control.
- Additional guideline: Explain to the patient that the sequence of patient treatment delivery will take place according to the scheduled treatment list.
- Amended guideline: Explain to the patient briefly the radiotherapy procedure that will take place and that the brachytherapy treatment delivery will be preceded by a CT scan procedure during which movement of the CT bed will occur. (Guideline C.2.1.1)
- Amended guideline: Show the new patient the inside of the treatment room and the treatment unit. (Guideline C.2.1.2). This guideline is to be shared with the radiation oncologist and oncology nurse and was moved to section B.
- Amended guideline: Inform the patient that during treatment delivery, she can communicate with the personnel outside the treatment room via an intercom system and a video camera will provide visual communication with her. (Guideline C.2.1.3). This guideline is not to be shared with the oncology nurse.

C.2.2 Oncology nurse

C.2.2.1 Feedback

Guideline C.2.2.1
Show the new patient the location of the dressing, waiting and recovery rooms.

The guideline was accepted without amendment by both focus groups.

Guideline C.2.2.2
Utilise the time spent in the waiting room to prepare the new patient emotionally for the treatment. Listen to her fears and concerns, especially the elderly.

Focus group 1: The guideline was accepted without amendment.

Focus group 2: The focus group reported that the word "*elderly*" should be omitted from the guideline. The group indicated that the guideline should be shared with the radiation therapist.

Guideline C.2.2.3
Provide the new patient with a detailed explanation of their role during the treatment procedure.

Focus group 1: The guideline was accepted without amendment.

Focus group 2: The focus group reported that the guideline should be shared with the radiation therapist and could be linked to the responsibility of the radiation therapist set out in guideline C.2.1.1 of section C.2.1.

Guideline C.2.2.4
Have nursing personnel present to assist the patient in the recovery room on her arrival from the treatment room.

The guideline was accepted without amendment by both focus groups.

Guideline C.2.2.5
Ensure that the ward patient has fully recovered, before sending her back to the ward.

Focus group 1: The focus group reported that it is not practical to wait for the ward patients to fully recover in the recovery room, because ward patients are sent back to the ward for post-brachytherapy care. A suggestion was made by the group to change the wording of the guideline to the following: "Patients should be transported in an adequate condition to the ward." The group stated that it is essential that personnel from the unit should communicate with the staff in the wards concerning the patient's medical condition before sending the patient back. The group reported that it would be good idea to provide the unit with a staff nurse to assist the patients in the recovery room.

Focus group 2: The guideline was accepted without amendment.

Guideline C.2.2.6
See to the well-being of each patient before she leaves the unit.

The guideline was accepted without amendment by both focus groups.

C.2.2.2 Availability of resources

Focus group 1: The focus group emphasized the importance of providing the unit with a staff nurse to assist the oncology nurse in attending to the patients. This was deemed feasible.

Focus group 2: The focus group reported that the resources of the department did not allow for the appointment of extra nursing staff to assist patients in the recovery room.

C.2.2.3 Additional/amended or omitted guidelines

- Amended guideline: Utilise the time spent in the waiting room to prepare the new patient emotionally for the treatment. Listen to her fears and concerns. (Guideline

C.2.2.2). This guideline is to be shared with the radiation therapist and was moved to Section B.

- Amended guideline: Patients should be transported in an adequately recovered condition to the ward. (Guideline C.2.2.5)
- Omitted guideline: Provide the new patient with a detailed explanation of their role during the treatment procedure. (Guideline C.2.2.3). Guideline is omitted as it is confusing in whose role should be explained, the patient's or that of the oncology nurse.

C.2.3 Radiation oncologist/radiation oncology registrar

C.2.3.1 Feedback

Guideline C.2.3.1
The attending radiation oncologist or radiation oncology registrar should introduce him/herself to the patient.

The guideline was accepted without amendment by both focus groups.

Guideline C.2.3.2
Provide the patient with an explanation of the procedure he/she will be performing.

The guideline was accepted without amendment by both focus groups.

Guideline C.2.3.3
Provide the patient with the choice of being treated by a female or male radiation oncologist or radiation oncology registrar.

Focus group 1: The focus group responded that it is not feasible to provide the patient with a choice of being treated by a female or male radiation oncologist or registrar. The group reported that it would only cause a logistical nightmare. The group suggested that the guideline be omitted.

Focus group 2: The focus group stated that they did not disagree with the guideline and that it would be ideal to implement. However, the group reported that it would be impractical to give patients a choice of being treated by a male or female radiation oncologist/registrar. The group stated that the department has an unequal gender distribution amongst the radiation oncologists and registrars and that implementing this guideline would be impractical, even in the private sector. It was suggested by the group that the guideline should not be omitted, but rephrased and that instead of providing the patient with a choice, rather to explain to the patient that the possibility exists that she will not be treated by a female doctor. The focus group suggested that this guideline should be included in section B as all members of the multidisciplinary team should share in this responsibility of informing the patient.

Guideline C.2.3.4
Ensure that each patient is treated weekly by the same radiation oncologist or radiation oncology registrar.

Focus group 1: It was reported by the focus group that although it would be the ideal for the patient to be treated by the same radiation oncologist/registrar, it would not be feasible to implement. The group stated that it would be a logistical nightmare with 13 registrars employed in the department. The group suggested that this guideline should be omitted.

Focus group 2: It was reported by the focus group that they did not disagree in principle with the guideline, but that it is not practical or feasible to implement. The group indicated that it would not be practical to have the same radiation oncologist/registrar doing the brachytherapy treatment weekly, because the radiation oncologists/registrars work according to a roster and have other responsibilities. It was stated by the group that the patients have to abide with the schedule.

Guideline C.2.3.5
Keep the patient sedated until her treatment is completed and the applicators have been removed.

Focus group 1: The focus group reported that the guideline should rather state the following: "Ensure that patients are adequately sedated".

Focus group 2: The guideline was accepted without amendment.

Guideline C.2.3.6
Documentation should be made of the sedation requirements during the procedure for future reference in following treatments.

Focus group 1: The guideline was accepted without amendment.

Focus group 2: The focus group reported that the guideline should be shared with the oncology nurse.

Guideline C.2.3.7
Individualise the sedation dosage.

The guideline was accepted without amendment by both focus groups.

C.2.3.2 Availability of resources

Focus group 1: The group mentioned that providing the patient with a choice of being treated by a male or female radiation oncologist/registrar could be accommodate at the new patient clinic, but not at the brachytherapy unit as resources were limited. It was stated that resources are limited not only in our department, but also elsewhere in the country.

Focus group 2: It was agreed by the focus group that due to logistical implementations, resources of the department will not allow for guidelines C.2.3.3 and C.2.3.4 to be implemented.

C.2.3.3 Additional/amended or omitted guidelines

- Additional guideline: Maintain professional conduct at all times and abstain from conversations over a sedated patient. (Additional comment that was made)
- Amended guideline: Explain to the patient that the possibility exists that she will not be treated by a female doctor. (Guideline C.2.3.3). Guideline to be moved to section C.1.

- Amended guideline: Documentation should be made of the sedation requirements during the procedure for future reference in following treatments. (Guideline C.2.3.6). Guideline to be shared with oncology nurse, but kept as the role of the radiation oncologist.
- Amended guideline: Ensure that patients are adequately sedated. (Guideline C.2.3.7)

C.2.4 Summary

Focus group 1: The focus group reported that they agreed with the proposed guidelines allocated to the radiation therapist in section C.2.1. Guideline C.2.2.5 allocated to the oncology nurse in section C.2.2 was discussed in detail by the focus group. The group disagreed with guidelines C.2.3.3 and C.2.3.4 being allocated to the radiation oncologist/radiation oncology registrar in section C.2.3. Guideline C.2.3.5 was also discussed in detail.

Focus group 2: Guidelines C.2.1.1 to C.2.1.3 allocated to the radiation therapist in section C.2.1 were discussed in detail by the focus group. Guideline C.2.2.2 allocated to the oncology nurse in section C.2.2 was discussed in detail by the group. The focus group disagreed with guidelines C.2.3.3 and C.2.3.4 allocated to the radiation oncologist/radiation oncology registrar in section C.2.3 and were discussed in detail.

4.3.4 Additional remarks

Focus group 1

The focus group mentioned that although the medical physicists at the brachytherapy unit do not interact with the patients, they are part of the multidisciplinary team and are indirectly involved in the management of the patients. The medical physicists are responsible for the brachytherapy dosimetry, treatment planning and delivery of the patients at the unit. However, the focus group concluded that medical physicists should not be included in the multidisciplinary team for this research study, because they do not have direct patient interaction.

The focus group indicated that the multidisciplinary team is lacking a key member, viz. a medically trained interpreter to assist them in providing understandable information to the patients. The following question was raised: "How ethical is it to use a cleaner to explain to the patient a complex treatment such as brachytherapy?" Resources in the department remain a problem and the focus group stated that it is more important to make a patient feel safe than to inform the patient exactly what will happen to her. The group felt that the patients' inability to grasp the concept of brachytherapy treatment is a third world problem and is related to the patients' education level.

The focus group additionally discussed the treatment schedule for patients that are HIV (Human Immunodeficiency Virus) positive. It was stated that it is an unwritten rule in the department to treat the HIV positive patients last on the list, even if some of them arrive early in the morning. It was indicated that these patients do not always understand the reason they are treated last on the list and might feel discriminated against. It was mentioned that the applicators are sterilised for each patient and the treatment schedule could therefore incorporate HIV positive between the other non-infected patients. The focus group concluded that it remains each member's responsibility to be careful when handling a HIV positive patient.

Focus group 2

Interpretation of the word "*management*" was confusing to some participants. Some participants felt that the medical physicists should not be excluded from the study as they play a major role in the treatment planning of the patients. However, it was noted that they have nothing to do with the handling of patients and the suggestion was made to change the word "*management*" to "*handling*" and thereby exclude the medical physicists from the study.

A comment was made that because HIV positive patients are always treated last on the list, for infection control reasons, the patients might notice that the sequence in which they are performed reflected on their HIV status. The focus group therefore decided that it was necessary to inform the patients concerning the sequence of treatment and that this should be incorporated in the consent form in the patient's file.

It was noted that although the patient experience was taken into account when formulating the proposed guidelines, the patients do not always realise the seriousness and clinical implications of some of their suggestions. It would be the ideal to implement all of the suggestions made, however resources, both financial and personnel, in the department are limited and were seen as a major restraining factor.

4.3.5 Amended guidelines

The original draft of the guidelines was formulated by integrating the findings of the participant experience (cf. 3.3.3.1), a literature search for related guidelines on patient management (cf. 3.3.3.2) and the researcher experience and familiarity with the brachytherapy environment of the department (cf. 3.3.3.3). In order to refine the original draft of the proposed guidelines, the researcher incorporated the suggested amendments made during the focus group interviews into the proposed guidelines. The amended guidelines are shown below.

GUIDELINES

Section A: Guidelines for the practice setting

1. Provide an environment that is clean, tidy and patient friendly and incorporate the following in the waiting room: for example - a muted television, books with information on the treatment, magazines and newspapers.
2. If unit layout permits: A bed in a separate room, in close proximity to the waiting room, where ward or ill patients could await their treatment under supervision/Ward or ill patients could await their treatment under supervision in the recovery room.
3. Patients are in a safe and secure environment by ensuring only one entrance to the recovery room.
4. Sufficient personnel to attend to patients in the recovery room, preventing adverse incidents from occurring.
5. Provide the patient with privacy in the recovery room by making use of partitioning.
6. A bell to ring in case of an emergency in the recovery room.

7. Water drink facilities available for the patients in the recovery room.
8. Wheelchairs for patients who are too weak to walk to their mode of transport.

Section B: Guidelines on collective roles and responsibilities

The members of the multidisciplinary team held responsible for the duties suggested are shown in brackets in cases where the guidelines are not applicable to all members of the team.

B.1 New patient clinic and brachytherapy unit

Concerning information given to the patient

1. All members of the team are responsible for the accuracy of the information given to the patients and to ensure that the information is understood by the patient.
2. Inform the patient about her disease and forthcoming treatment in her home language. *[Radiation oncologist/registrar or interpreter]*
3. Allocate a member/s of the multidisciplinary team to inform the new patient of her forthcoming brachytherapy treatment, preferably a day or two prior to the scheduled treatment. *[Radiation therapist or oncology nurse]*
4. Make use of information sessions, informative material such as booklets or pamphlets to inform patients of what brachytherapy entails.
5. Encourage the patient to direct treatment related questions to members of the unit when remarks made by fellow patients are confusing or contradicting.
6. Explain to the patient how the brachytherapy procedure will be incorporated into her six week treatment schedule. *[Radiation oncologist/registrar or radiation therapist]*
7. Inform the patient that she will receive information regarding her follow-up appointments at completion of her radiotherapy treatment schedule. *[Radiation oncologist/registrar or radiation therapist]*
8. Allocate a person/s to provide the new patient, who is unfamiliar with the hospital surroundings, with directions on where to register and to report for their first brachytherapy treatment. *[Oncology nurse or clerical staff working at the new patient clinic]*
9. Show the new patient the location of the unit and introduce her to the personnel. *[Clerical staff of the radiation department]*

10. Provide the patient with detailed instructions regarding her pre-treatment preparations on the evening and morning prior to receiving the brachytherapy. *[Oncology nurse or radiation therapist working at the accelerator]*
11. Show the new patient the inside of the treatment room and the treatment unit. *[Radiation therapist or the oncology nurse]*
12. Utilise the time spent in the waiting room to prepare the new patient emotionally for the treatment. Listen to her fears and concerns. *[Oncology nurse or radiation therapist]*
13. Provide the patient with an estimated waiting time. *[Oncology nurse or radiation therapist]*
14. Provide the patient with an estimated treatment time. *[Oncology nurse or radiation therapist]*
15. Provide the patient with an explanation if treatment has been delayed. *[Oncology nurse or radiation therapist]*
16. Maintain professional conduct at all times and abstain from conversations over a sedated patient.

Section C: Guidelines on exclusive roles and responsibilities

***C.*1 At the new patient clinic**

C.1.1 Role of the radiation oncologist/radiation oncology registrar

Informed consent

1. Informed consent for the brachytherapy procedure must be obtained by or under supervision of a licenced radiation oncologist/registrar qualified to perform and familiar to the procedure.
2. Informed consent must be obtained and documented prior to the initiation of brachytherapy where conscious sedation will be administered.
3. Inform the patient of the availability of the services of a medically trained interpreter.
4. A radiation oncologist/registrar who is not fluent in the language of the patient should use the services of an interpreter who is fluent in the language the patient can understand and that of the radiation oncologist/registrar.

5. When an interpreter is used, documentation should be placed in the patient's medical file, indicating the name of the person who acted as an interpreter.
6. Provide the patient with an opportunity to ask treatment related questions before signing the consent form. Encourage them not to be ashamed or to feel inadequate to ask questions.
7. Inform the patient that, due to logistical reasons, the possibility exists that she might be not be treated by the same radiation oncologist/registrar.
8. Consent forms and informative material should be available in at least Afrikaans, English and or the language spoken in the province by the majority of patients.

Information concerning the treatment procedure

9. Explain the nature of the proposed treatment by making use of diagrams or cartoons to describe to the patient what brachytherapy entails.
10. Ensure that the patient understands that brachytherapy is not an operation to the uterus, but radiation to the inside of the cervix.
11. Explain to the patient that she will receive conscious sedation to prevent discomfort and pain during treatment delivery.
12. Explain to the patient that patients respond differently to the sedation medication and she might only wake-up in the recovery room.
13. Provide the patient with understandable information on the possible side-effects of the treatment.
14. Discuss the aspect of sexual intercourse and childbearing with all the patients, irrespective of their age or marital status.

C.2 At the brachytherapy unit

C.2.1 Role of the radiation oncologist/radiation oncology registrar

1. The attending radiation oncologist/registrar should introduce him/herself to the patient.
2. Obtain consent from the patient before allowing medical or nursing students into the treatment room.
3. Provide the patient with an explanation of the procedure he/she will be performing.

4. Ensure that the patient is adequately sedated during treatment delivery, until removal of the applicators.
5. Documentation should be made of the sedation requirements during the procedure for future reference in following treatments.
6. The treatment progress of the patient should be noted in the patient's file (notes of clinical appearance).
7. Individualise the sedation dosage.

C.2.2 Role of the radiation therapist

1. Explain to the patient briefly the radiotherapy procedure that will take place and that the brachytherapy treatment delivery will be preceded by a CT scan procedure during which movement of the simulator bed will occur.
2. Inform the patient that during treatment delivery, she can communicate to personnel outside the treatment room via an intercom system and a video camera will provide visual interaction with her.
3. Inform the patient that there are safety mechanisms in place if machine breakage occurs and that the applicators can be removed, if necessary.
4. Inform the patient that the unit has an emergency strategy/resuscitation trolley in place.
5. Inform the patient concerning the sequence of treatment delivery.
6. Inform the patient of the outcome of the treatment and if necessary, provide her with a rescheduled date in case of treatment cancellation. The radiation therapist working at an accelerator should fulfil this role.
7. Inform the patient on a weekly basis of the timing of her next brachytherapy treatment. The radiation therapist working at an accelerator should fulfil this role.

C.2.3 Role of the oncology nurse

1. Show the new patient the location of the dressing, waiting and recovery rooms.
2. Have nursing personnel present to assist the patient in the recovery room on her arrival from the treatment room.
3. Allowance should be made for sufficient time for post treatment recovery.
4. See to the well-being of each patient before she leaves the unit.

5. Ensure that the ward patient is transported back to the ward in an adequate condition.
6. Personnel from the unit should communicate the patient's medical condition to the staff in the ward before the patient leaves the unit.
7. Allocate a person to escort the patient to her mode of transport or back to the ward. A student nurse or porter should fulfil this role.

4.4 DISCUSSION

This stage of the research provided multiple viewpoints, from members of the multidisciplinary team of the Department of Oncology, concerning the proposed guidelines that aim to provide guidance in order to ensure that quality patient management is delivered. The proposed guidelines proved to be clear and concise and structured and formulated in an explanatory and understandable manner that is easy to apply by all disciplines working at the new patient clinic and the brachytherapy unit. This finding is consistent with that of Booth *et al.* (2005) that stated that when recommendations are easy to follow and compatible with norms and values, the application of the recommendations will be facilitated. Rosen and Proctor (2003) reported that guidelines are intended to reduce variability in services, increase the reliability of practice behaviours and thereby increase the confidence of service users in the effectiveness of services rendered.

Most of the proposed guidelines for the practice setting were accepted by the focus groups. The patient-centred care approach of the proposed guidelines would ensure that the needs and expectations of patients are taken care of in providing an environment that embraces safety and security and presents amenities of care. Donabedian (1988) stated that amenities of quality care can include aspects such as convenience, comfort, quiet and privacy that are deemed necessary for the patient. Ensuring that the unit has sufficient personnel, especially nursing staff to see to the well-being of patients in the recovery room will be a constraining factor for implementation of the proposed guideline due to resource constraints. Including a guideline that adheres to the privacy and comfort of the patient in the recovery was deemed necessary as the recovery room is shared by more than one patient, pending on the patients scheduled for the day.

The proposed guidelines regarding the collective roles and responsibilities of members of the multidisciplinary team were accepted by the focus groups and the roles and responsibilities

where allocated to specific member/s of the multidisciplinary team. Thus, confusion amongst team members can be avoided regarding who does what? Delivery of cervical brachytherapy requires the collaboration of a multidisciplinary team that includes a radiation oncologist, medical physicist, radiation therapist and an oncology nurse (Morton *et al*. 2010). Morton *et al*. (2010) recognised that no one skill can be completely isolated or is absolute when dealing with people in a clinical context and a fluency in both technical and relational (interpersonal skills, communication) skills must be embedded into the delivery of brachytherapy for cervical cancer patients. However, although the medical physicists play an important role in the treatment planning and delivery of the patient in the Department of Oncology, for the purpose of the current study the medical physicists were excluded as they are not directly involved with the management or care of the patient at the new patient clinic or brachytherapy unit.

The proposed guidelines regarding the exclusive roles and responsibilities of the radiation oncologist/radiation oncology registrar, radiation therapist and the oncology nurse were widely accepted. These guidelines focus on communicating disease and treatment related information to the patient before, during and after brachytherapy treatment. Providing patients with sufficient and understandable information has been identified as an unmet need in stage one of the current study. Implementation of these guidelines is thus crucial as language barriers exist in the department and need to be address. It was indicated by the focus groups that it would be the ideal to appoint a medically trained interpreter to assist the radiation oncologist when he or she is not fluent in other languages spoken in the province. ACR (2012) stated that the underlying principle is that communication should be sincere and focused on the patient, taking into account cultural and language barriers, and individualized to the type of treatment offered. Currently the radiation oncologist at the new patient clinic makes use of nursing and cleaning staff to act as interpreters. ACR (2012) declared that patients that are not fluent in the language of the physician should have an interpreter who is fluent in a language they can understand and the language of the physician. ACR (2012) thus recommended that the facility has a policy for interpreter services that complies with applicable federal and state laws and hospital policies. However, due to resource constraints in the Department of Oncology, it may not possible to implement the guideline concerning the interpreter.

Patients receiving brachytherapy for cervical cancer face a wide range of psychological and physical challenges before, during and after treatment (Warnock 2005). The proposed guidelines of the current study suggest that booklets or pamphlets could be used by members of the multidisciplinary team in explaining brachytherapy treatment to the patient as it was proven to be a difficult concept to grasp by the patients (cf. 2.3.2.2). The focus groups acknowledged that the department does not provide patients with a booklet or a pamphlet on brachytherapy treatment and that this needs to be addressed. The focus groups had mixed feelings on using digital video display to inform patients on brachytherapy as it could be too graphic and unnerving for the patient, unless it is done not too graphically. Both focus groups therefore agreed that it would be good practice to use verbal dialogue and printed material such as cartoons, booklets or pamphlets to explain brachytherapy to the patient. This finding is consistent with that reported by ACR (2009) that stated verbal dialogue is the primary form of communication between physician and patient, but it may be enhanced through pertinent printed materials.

Overall, the proposed guidelines regarding the practice setting, collective and exclusive roles and responsibilities of members working at the new patient clinic and brachytherapy unit have been accepted by members of the multidisciplinary of the Department of Oncology. Resource constrains such as limited funding and shortage of personnel could prevent the full implementation of the proposed guidelines in the department.

4.5 LIMITATIONS

The audio recorded interviews only captured speech and although field notes were made during the interviewing process, some non-verbal communication and other contextual factors could have been missed.

The researcher was not present during the focus group interviews as an observer to document non-verbal communication, make field notes and experience the interviewing process.

Interpretation of the word "*management*" was confusing to some participants and should have been clarified in the preamble of the proposed guidelines that were reviewed.

4.6 CONCLUSION

Chapter 4 provided a multidisciplinary perspective on the proposed guidelines for implementation in the Department of Oncology. The opinions and views on the proposed guidelines by members who regularly interact with patients receiving high dose rate-intracavitary brachytherapy for locally advanced cervical cancer has narrowed the gap between research and practice, between the idealistic and the realistic. The scope of the original draft of the proposed guidelines has been refined by members of the multidisciplinary team.

In the next chapter, Chapter 5, National Perspectives and Formulation of Final Guidelines, the amended guidelines will be reviewed and refined by national heads or designated representatives of governmental and private brachytherapy units in South Africa. The final guidelines will be presented.

CHAPTER 5

NATIONAL PERSPECTIVES AND FORMULATION OF FINAL GUIDELINES

5.1 INTRODUCTION

Shekelle *et al.* (1999) advised that a guideline should receive external review to confirm content validity, clarity and applicability. It was thus necessary that the application and feasibility of the proposed guidelines needed to be reviewed by heads or designated representatives of governmental and private brachytherapy units in South Africa.

Chapter five provides a detailed description of the methods used to gather feedback on the proposed guidelines by participants from governmental and private brachytherapy units in the country. The findings will be reported and discussed. This chapter also presents the final guidelines to facilitate quality patient management in a multidisciplinary environment, followed by, limitations and a conclusion.

5.2 METHODOLOGY

The e-mail interviewing method was used for this stage of the research study as it has become a viable tool for qualitative research (Meho 2006). E-mail interviewing offered the researcher an opportunity to access, in an interactive manner, participants' thoughts and ideas in their own words (Meho 2006). Additionally, it is empowering to the participants, because it essentially allows them to be in control of the flow of the interview (Bowker & Tuffin 2004).

De Vos *et al.* (2011) and Meho (2006) encouraged the use of e-mail interviewing in qualitative research due to its benefits. E-mail interviewing is cost effective, as the cost involved is considerably less than with telephonic or face-to-face interviews (Meho 2006). This method requires no travelling, no hire or purchase of recording equipment and no transcribing costs (De Vos *et al*. 2011). Other benefits mentioned by De *Vos et al.* (2011) are that the e-mail interview enables both the interviewer and the participant to reflect on what has been said both in the short and long term. Both can scroll back in the script to any point.

This time for reflection enables deeper processing of information. The impersonal nature of the e-mail interview might encourage people to voice opinions they might not have voiced face-to-face. It also provides time for participants to construct a response to a particular question. The researcher and participant do not have to identify a mutually convenient time to talk to each other. Researchers can invite participation of large or geographical dispersed samples of people via e-mail messages (Meho 2006).

5.2.1 Selection and recruitment of participants

Key informant sampling was used for this stage of the research study to recruit national heads or designated representatives of governmental and private brachytherapy units in the country. Denscombe (2007) indicated that if the aim is to delve in depth into a particular situation with the view to explore the specifics, the emphasis will be on choosing key players in the field. The potential participants were identified on the basis of them being a head or designated representative of a brachytherapy unit utilising high dose rate-intracavitary brachytherapy for cervical cancer patients. Their experience and expertise in this particular field of brachytherapy proved them eligible in executing the review task.

The researcher utilised a list of contact details, provided by the supplier of brachytherapy sources and equipment in South Africa in order to recruit the potential participants (J Asevido 2013:Personal Communication, 24 November). The list of source installations included details of the location and contact details of individuals affiliated to specific brachytherapy units in the country. The abovementioned listed the contact details of medical physicists and or medical company representatives working at specific units in the country. These persons provided the researcher with the required contact phone numbers of the heads at their or other units. The list included both governmental and private hospitals of the following provinces: Western Cape, Eastern Cape, Kwazulu-Natal, Limpopo, North-West, Free State and Gauteng. In addition, the researcher performed an internet search for oncology units providing high dose rate-intracavitary brachytherapy as treatment modality. No additional units were identified. The head of the Department of Oncology in Bloemfontein was excluded from selection due to participation in the focus groups interviews (stage three) of the research study.

Thirteen heads of brachytherapy units in the country were contacted of which six were affiliated to governmental units and seven to the private sector. The thirteen potential participants were contacted telephonically, explaining in brief the study details and the reason for their required participation. It was also mentioned that it would be acceptable if he or she preferred to delegate a designated representative of their unit to participate. On acceptance of participation in the study, the researcher e-mailed the following documents to each participant: letters of invitation in English or Afrikaans (Appendices 24 and 25, respectively); background information in English or Afrikaans (Appendices 26 and 27, respectively) and consent documents in English or Afrikaans (Appendices 28 and 29, respectively). Hereby, the researcher provided the potential participants with detailed information regarding the research study they were being invited to participate in, thus ensuring they understood fully what participation would entail. It was stipulated to the potential participants that the proposed guidelines would only be e-mailed to them once the researcher had received the signed consent documents. The signed consent document could be sent to the researcher via e-mail or fax. To ensure sufficient participation, the researcher sent an e-mail reminder to participants who agreed to participate telephonically, but did not reply to the e-mail invitation. The researcher allocated a period of two to three weeks wherein to contact and recruit the potential participants.

5.2.2 Data collection

As in face-to-face and telephone interactions, most e-mail interview-based studies use an interview schedule for data collection (Meho 2006). The interview schedule in English (Appendix 30) was sent to each of the seven participants who agreed to participate in the study and who completed and returned the consent document. The interview schedule was sent as an e-mail attachment and participants were asked to respond within ten working days. The researcher designed an e-mail interview schedule that was semi-structured in nature and could be sent individually to several participants simultaneously. The e-mail interview schedule contained the following: the proposed guidelines for national review; general and specific questions following a logical sequence and lastly open ended questions that guided the interviewing process. The latter were self-explanatory and with a clear indication of the responses required (Meho 2006). Participants were requested to make amendments to specific guidelines by bracketing additions and or deletions.

5.2.3 Data analysis and presentation

Data from e-mail interviews are generated in electronic format and require little editing or formatting before they are processed for analysis (Meho 2006). The outcome of an e-mail interview can be downloaded directly on the computer, so there is no transcription time (FQS 2006). The aim of the data analysis was to integrate the electronic feedback from the heads or designated representatives into the final presentation of the guidelines to facilitate quality patient management in a multidisciplinary environment. The transcripts were analysed manually by the researcher by applying the following steps:

- Each e-mail interview schedule was downloaded and saved on the desktop of the PC. It was copied onto a CD and memory stick as backup. One master copy was placed in a secure place for safekeeping.
- Numbers were allocated to each of the participants to describe their profile.
- The transcripts were read in their entirety several times to familiarise the researcher with the text.
- Data were arranged according to the layout of the e-mail interview schedule.

The findings are presented as follows:

- According to the layout of the interview schedule.
- No distinction was made between the data received from a head or designated representative of a specific brachytherapy unit.
- Distinction was made between the data received from participants of governmental and private units when deemed necessary.
- Feedback from participants of governmental and private brachytherapy units were reported as the group's response to specific questions.
- Direct quotes were included where deemed necessary to support statements made by the participants.
- Additional comments and or suggestions relevant to the guidelines were reported.

5.2.4 Rigour

The overarching concept when considering rigour is trustworthiness (Letts *et al*. 2007). Trustworthiness can be defined as the extent to which the findings are an authentic reflection of the personal or lived experiences of the phenomenon under investigation (Curtin & Fossey 2007). Trustworthiness of this stage of the research study was established by considering the four criteria proposed by Lincoln and Guba (1985) which include credibility, transferability, dependability and conformability.

Credibility was ensured by obtaining feedback from national heads or designated representatives of both governmental and private brachytherapy units. Participants were informed that their participation was voluntary and that they had the right to withdraw from the study at any point. It was made clear to the potential participants that there were no right answers to the questions and they could therefore contribute their views and opinions without fear of losing credibility. Shenton (2004) reported that scrutiny of the research by peers and academics should be welcomed and therefore the review of the proposed guidelines by heads or designated representatives in the current study, contributed to the credibility of the overall findings of this stage.

Transferability was obtained by the external review of the national participants. Dependability was achieved by using e-mail interviewing as research method which has become a viable tool for qualitative research (Meho 2006). E-mail interviewing offered the researcher an opportunity to access, in an interactive manner, participants' thoughts and ideas in their own words. The e-mail interviewing method of data collection provided information volunteered by individual participants which was not shared with, viewed or influenced by other participants (Meho 2006).

Conformability was achieved in this stage of the research study as the findings were a reflection of the views, opinions and experiences of the participants, rather than the characteristics and preferences of the researcher.

5.3 FINDINGS

5.3.1 Participant profile

Alphanumeric coding (e.g. P1: Gov/Priv, Head/Rep) was used to refer to the profile of each participant when direct quotes were used or when suggestions were made (Table 5.1).

Table 5.1 Alphanumeric coding of national participants

Participant number	P1
Government	Gov
Private	Priv
Head	Head
Designated representatives	Rep

Seven of the thirteen invited heads or their designated representatives of brachytherapy units in the country were included in the study. The researcher received feedback from the seven participants within a period of fifteen working days. The sample size consisted of three heads of governmental units and four designated representatives of the private sector. The demographic details of the national participants are depicted in Table 5.2.

Table 5.2 Demographic details of national participants

Participant number	Occupation	Government/Private	Head/designated representative
1.	Radiation oncologist	Government	Head
2.	Radiation oncologist	Private	Designated representative
3.	Radiation oncologist	Private	Designated representative
4.	Radiation oncologist	Government	Head
5.	Radiation oncologist	Private	Designated representative
6.	Radiation oncologist	Private	Designated representative
7.	Radiation oncologist	Government	Head

The sample was representative of the following provinces in the country: Limpopo, Gauteng, Kwazulu-Natal and the Western Cape.

Six of the thirteen contacted or invited participants were excluded from the study for the following reasons:

(a) Two private heads were affiliated to brachytherapy units that did not treat gynaecological cancers.
(b) One head each from a governmental and a private unit did not respond to e-mails or telephone calls.
(c) One head of a governmental unit agreed to participate once she returned from leave. A designated representative could not be appointed in her place as she was the sole radiation oncologist in the hospital. The time schedule of the study prevented the researcher from including this potential participant in the study.
(d) One private designated representative signed consent to participate, but did not complete the interview schedule and could thus not be included in the findings of the study.

5.3.2 Participant feedback

The findings of the e-mail interviews with heads or designated representatives concerning the structure and overall opinion on the proposed guidelines for the practice setting, collective and exclusive roles and responsibilities are shown below.

5.3.2.1 *Layout and formulation of the proposed guidelines*

All participants accepted the layout and formulation of the guidelines. They reported that the guidelines were logical, concise and covered all aspects of patient management. Participants made the following comments:

> *Well compartementalised with well-defined mandates* (P1: Gov, Head)

> *...the guidelines are well formulated, as the information covers all the different aspects adequately and concise. (P5: Priv, Rep)*

> *…guidelines are logical and systematic (P6: Priv, Rep)*

> *…the structure of the guidelines is clear and easy to implement (P7: Gov, Head)*

5.3.2.2 *Overall opinion of the proposed guidelines*

Participants indicated that the guidelines could be implemented by their units. A participant of a governmental unit stated the following:

> *…a substantial amount could be implemented with some refining and focussing on what is already done in our context (P1: Gov, Head)*

Another participant from a governmental unit stated that from a point of treatment delivery, the guidelines would vary amongst units due to unit activities. One participant from a private and one participant from a governmental unit indicated that the guidelines could only be implemented partially due to the following reasons: (a) the layout of their units require different patient logistics, (b) a lack of equipment (Computed Tomography (CT) scanner) and (c) a shortage of staff (oncology nurses, doctors and radiographers).

However, a participant stated that the proposed guidelines could not be implemented in their unit, because of long waiting lists, numerous patients to treat, shortage of nurses, doctors and radiographers. The following comment was made by a participant from a governmental unit:

> *… the proposed guidelines are ideal for use in first world countries,… the proposed guidelines are too idealistic.* (P4: Gov, Head)

It was reported by both governmental and private participants that the guidelines would ensure a high quality of treatment in a patient-centred way and would improve patient comfort as they fully cover the needs of the patient. A participant of a private unit stated that the guidelines address the information given to the patient in detail and that a clear role definition is provided by the proposed guidelines. The following comments were made by three private participants:

> *Yes, the guidelines will help us strive toward an ideal, toward a better practice.* (P2: Priv, Rep)

> *Yes, would certainly allow us to ensure that we are following best practice and provide a framework to monitor the standard of care we are offering patients.* (P3: Priv, Rep)

> *…it focuses on the emotional aspects surrounding the treatment procedure. It does not cover the medical aspects of the treatment procedure.* (P5: Priv, Rep)

It was mentioned by a participant that even though the guidelines may not be implemented en masse, the fact that thought and planning had been given to the brachytherapy process and patient experience would lead to an improvement of quality assurance issues in their unit. It was also stated by a private participant that the guidelines should ensure that all members of the team understood their roles.

5.3.2.3 *Section A: Guidelines for the practice setting*

A.1 Feedback

Participants stated that they agreed with the guidelines in section A. The following comments were made by some of them:

> *Brachytherapy is an invasive and uncomfortable procedure and privacy is paramount to patients feeling safe and to ensure a positive experience.* (P2: Priv, Rep)
>
> *I agree with the guidelines as they are patient-orientated*. (P5: Priv, Rep)
>
> *I agree with the guidelines, because they entail basic standard of care that all healthcare facilities should be able to provide.* (P6: Priv, Rep)
>
> *I agree, because they are standard requirements/facilities for waiting rooms*. (P7: Gov, Head)

However, a participant of a governmental unit indicated that he disagreed with guidelines 5, 6 and 7 as they were not desirable due to the possibility of misuse and complications not being diagnosed for example: not recognizing patient complications due to the partitioning.

A.2 Availability of resources

Most of the participants reported that their resources did allow for the partial implementation of the guidelines in section A. It was mentioned by a participant of the private sector that even though their unit do not have a dedicated recovery room, only curtained-off area, the guidelines could be implemented to a large degree. Some participants reported that their resources did not allow for full implementation, because of limiting factors such as staff shortage and insufficient space for example: a recovery area was not incorporated in the final building plan. The following comment was made by one of them:

…nevertheless, I do feel that a recovery room is essential. (P2: Priv, Rep)

A.3 Additional/amended or omitted guidelines

- Additional guideline: Ensure that resuscitation and emergency trollies are at hand during the administration of sedation. *(P2: Priv, Rep)*
- Additional guideline: Provide the unit with a pulse oximetre. *(P4: Gov, Head)*
- Additional guideline: Provide post-brachytherapy observation by a nursing sister. *(P4: Gov, Head)*
- Additional guideline: Ensure well lighted waiting and treatment areas. *(P6: Priv, Rep)*
- Additional guideline: Ensure clean and discrete ablution facilities. *(P6: Priv, Rep)*
- Omitted guideline: Provide the patient with privacy in the recovery room by making use of partitioning. (Guideline 5). It would be more important to be able to see all the different patients to ensure their safety while they are recovering. *(P1: Gov, Head and P5: Priv, Rep)*

A.4 Additional comments

It was advised by a participant that units should practice more fluid communication and coordination between the brachytherapy activities and other facets of the treatment, especially the wards/nursing, administration and transport. He stated that this will facilitate adaptability and will prevent logistical and delivery problems. Another participant made the following comment:

Availability of these basic facilities would enhance comfort and safety to patients waiting to undergo a procedure. (P7: Gov, Head)

5.3.2.4 *Section B: Guidelines on collective roles and responsibilities*

New patient clinic and brachytherapy unit

B.1 Feedback

Most of the participants reported that they agreed with the guidelines set out in section B. A participant stated that the guidelines were noble and considerate. Another participant stated

that the guidelines clearly define the roles of different members of the team towards the patient's well-being. The following comments were made by the participants

> *I agree, because the experience will be a positive one if the patient is well informed.* *(P2: Priv, Rep)*

> *I agree, because of their comprehensiveness and patient-centredness…reduce fear and anxiety about the procedure* *(P3: Priv, Rep)*

> *…constitutes good clinical practice.* *(P6: Priv, Rep)*

Only one participant of a governmental unit disagreed and made the following comment:

> *I will agree to the guidelines if it was meant for first world settings… the lack of funding and resources has a negative impact on service delivery* (P4: Gov, Head)

B.2 Availability of resources

The majority of participants indicated that resources in their departments did allow for the implementation of the guidelines stipulated in section B. A participant mentioned that implementation is possible as all the members of their team are closely involved in ensuring that patients are kept well informed regarding their treatment. The following comment was made by a participant:

> *Yes, I think to a large degree we do provide… although not in such a formalised, structured way*. (P3: Priv, Rep)

However, participants from governmental units stated that resources in their units did not allow for implementation due to the lack of funding and sheer weight of patient numbers.

B.3 Additional/amended or omitted guidelines

- Additional guideline: Patients should see a social worker or psychologist. *(P2: Priv, Rep)*
- Additional guideline: Provide additional qualified staff. *(P4: Gov, Head)*
- Additional guideline: Explain that different doctors take slightly different approaches to treatment and that each patient's case should be individualised in order to get the best outcome for the patient. *(P6: Priv, Rep)*

- Additional guideline: Appointments should be made in writing and need to be presented on arrival at the unit. Include details such as the patient's name, hospital registration number and scheduled time. *(P6: Priv, Rep)*
- Amended guideline: Avoid using elaborate medical terminology and use simple language without losing the essence of the information. Guideline 2. *(P6: Priv, Rep)*
- Amended guideline: Address the psychological aspects of patients by providing them with additional information by means of pamphlets or a video presentation. Guideline 12. *(P5: Priv, Rep)*

B.4 Additional comments

One participant stipulated that there is a tendency to grossly overestimate what patients understand or perceive of brachytherapy treatment. It has less to do with educational background, but more with grasping the concept of cancer and its treatment. The participant felt that qualitative research needs to be done to ascertain what patients really understand. He reported that the clinician needs to work around that information even though it may be against his philosophical judgment and the existing legal requirements, as these do not take into account the practicalities of the situation. The participant said that this process may appear sub-optimal, but is formulated by his own experience. He stated that patients who have submitted to the other facets of the treatment regime generally submit well to the brachytherapy, even though less is understood about the procedure than professionals imagine they do or feel they should.

Another participant commented that providing the patient with sufficient information about their treatment greatly allays their level of anxiety and allows them to tolerate the treatment better. He stated that not talking over a sedated patient is important and concluded with the following remarks:

> *... providing the patient with sufficient information shows a high level of professionalism in health workers and also respect for the patient's right to be handled with dignity.* (P7: Gov, Head)

5.3.2.5 Section C: Guidelines on exclusive roles and responsibilities

C.1 At the new patient clinic

C.1.1 *Role of the radiation oncologist/radiation oncology registrar*

C.1.1.1 Feedback

All the participants reported that they agreed with the guidelines in section C.1. The following are some comments made by participants from governmental and private units:

> *These are more practical than section B.* (P1: Gov, Head)

> *…it covers the topic adequately. (P5: Priv, Rep)*

A participant said that she agreed with the guidelines, because the radiation oncologist is the first point of contact for the patients. She indicated that at their unit a rapport is established, during which the oncologist ensures that the patient fully understands and comprehends what she is signing for. Another participant stated that the radiation oncologists are the ones who decide on the need for brachytherapy and who administer it. He made the following comment:

> *…..are best placed to counsel patients and ensure the patient can give informed consent. (P3: Priv, Rep)*

C.1.1.2 Availability of resources

Participants reported that their resources do allow for the implementation of these guidelines. A participant of a governmental unit stated that their department has doctors available with sufficient experience to explain the procedure to the patient and that the services of an interpreter are also available, if necessary. The following comment was made by a participant from a private unit:

> *Yes, there are adequate time slots and personnel to ensure informed consent and information on the treatment is done according to the guidelines*. (P5: Priv, Rep)

Participants of private and governmental units indicated that due to funding constraints and a shortage of nursing staff, implementation might be inhibited. A participant made the following comment:

The only nursing staff provided is a nursing assistant from the day-ward. *(P6: Priv, Rep)*

A participant of a governmental unit indicated that their resources do not allow for implementation, because patient information and consent are incorporated in one form that is only written in English. He stated that translation is done by the oncologist, registrar, oncology nurse or medical officer and said the following:

…the staff is not fluent in all languages…non-South African citizens do not speak English. *(P7: Gov, Head)*

C.1.1.3 Additional/amended or omitted guidelines

- Additional guideline: Allow patients some time to process the information and to think about possible questions they may have. *(P2: Priv, Rep)*
- Additional guideline: Refresh information to the patient regarding the treatment due to long waiting periods before treatment delivery. *(P2: Priv, Rep)*
- Additional guideline: A qualified nursing sister should discuss the option and use of a dilator. *(P4: Gov, Head)*
- Additional guideline: Special emphasis should be placed on the prevention of late side-effects, in particular vaginal fibrosis and atrophy and the irreversible nature of vaginal ablation due to severe fibrosis. *(P6: Priv, Rep)*

C.2 At the brachytherapy unit

C.2.1 *Role of the radiation oncologist/radiation oncology registrar*

C.2.1.1 Feedback

Except for one participant, all the participants agreed with the guidelines in section C.2.1. The following comments were made by private and governmental participants, respectively:

…we practice similar guidelines. *(P2: Priv, Rep)*

…it is also what we apply at our unit. *(P7: Gov, Head)*

C.2.1.2 Availability of resources

Most of the participants stated that their resources do allow for implementation. A participant, who also agreed, stated the following:

… we are fortunate and privileged to have a dedicated theatre and anaesthetic slate. (P1: Gov, Head)

Participants of private units indicated that their resources do not allow for implementation, due to financial and staff constraints.

C.2.1.3 Additional/amended or omitted guidelines

• Additional guideline: Attention should be given to sedation as well as pain control. *(P5: Priv, Rep)*

C.2.1.4 Additional comment

It was mentioned by a participant that the role of the physicist should be mentioned and acknowledged. *(P4: Gov, Head)*

C.2.2 ***Role of the radiation therapist***

C.2.2.1 Feedback

Except for one participant, all the participants agreed with the guidelines in section C.2.2. A participant stated that he did not agree with guidelines 4, 5 and 6 in this section. The participant indicated that these guidelines may be unnecessary and perhaps even frightening for the patient.

A participant stated that she agreed with the guidelines, because the logistics need to be handled by the person organising the treatment schedule which is the radiation therapist.

C.2.2.2 Availability of resources

Participants indicated that their resources do allow for implementation of some of the guidelines. A participant reported that their radiation therapists generally have a good rapport with the patients receiving brachytherapy treatment. It was also mentioned by a participant that the radiation therapist generally assists the oncologist with the procedure and this covers the mentioned duties.

Some participants reported that their resources do not allow for full implementation due to shortage of staff and funding constraints. Although a participant indicated that their resources do not allow for full implementation, he mentioned the following:

> *…the rest is the same as stipulated in this section.* *(P7: Gov, Head)*

C.2.2.3 Additional/amended or omitted guidelines

- Additional guideline: The radiation therapist should ensure that the patient keeps as still as possible during the procedure. *(P5: Priv, Rep)*
- Additional guideline: The radiation therapist should confirm with the radiation oncologist that the sedation and pain control is adequate for each patient during procedure. *(P5: Priv, Rep)*

C.2.2.4 Additional comments

A participant made the comment that a person should be wary of information overload which may cause anxiety or lead to the patients failing to focus on core relevant issues. The following comment was made by the participant:

> *It is very important not to give information that may be altered or retracted at some stage in the future.* (P1: Gov, Head)

Another participant commented that communication is sometimes a problem and translators are not always available.

C.2.3 *Role of the oncology nurse*

C.2.3.1 Feedback

All the participants reported that they agreed with the guidelines in section C.2.3. A participant stated that she agreed with the guidelines, because oncology nurses are responsible for ensuring that the patients are stable before they are discharged home or to the ward. A participant said the following:

> *…would be appropriate in all cases where sedation is used.* *(P3: Priv, Rep)*

C.2.3.2 Availability of resources

Some participants indicated that their resources do allow for implementation. A participant of a private unit reported that their resources do allow for implementation as they do not use sedation and often cope perfectly well with the assistance of a radiation therapist only.

A few participants indicated that their resources do not allow for implementation. A participant of a private unit stated that they do not have an oncology nurse on their staff. Participants of private and governmental units stated the following:

> *…the role of the nurse is filled by the radiation therapist.* *(P2: Priv, Rep)*

> *…a shortage of key personnel makes it difficult to follow this guideline.* (P4: Gov, Head)

> *…due to funding constraints, the department does not have nursing staff to assist with conscious sedation…The only nursing staff provided is a nursing assistant from the day-ward.* (P6: Priv, Rep)

A participant of a governmental unit reported that their resources do not allow for implementation in their department due to shortage of nursing staff and no patients are accompanied back to the ward. He made the following comment:

> *If required, the patient is taken to the ward by a porter or accompanied to their hostel by a driver.* (P7: Gov, Head)

C.2.3.3 Additional/amended or omitted guidelines

• Additional guideline: Inform the patient of late complications with regards to vaginal fibrosis, painful intercourse (dyspareunia) etc. *(P4: Gov, Head)*

C.2.3.4 Additional comment

A participant commented that communication is not always effective between nurses, radiographers, ward sisters and oncology nurses.

5.4 FINAL GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT

The final guidelines were formulated to be used as a tool by members of multidisciplinary teams to facilitate quality patient management at their brachytherapy units. The guidelines address (a) the practice setting, (b) the collective roles and responsibilities of the radiation oncologist/radiation oncology registrar, the radiation therapist and the oncology nurse working at the new patient clinic and the brachytherapy unit, and (c) the exclusive roles and responsibilities of the abovementioned members of multidisciplinary teams. An overview of the final guidelines is depicted in Figure 5.1.

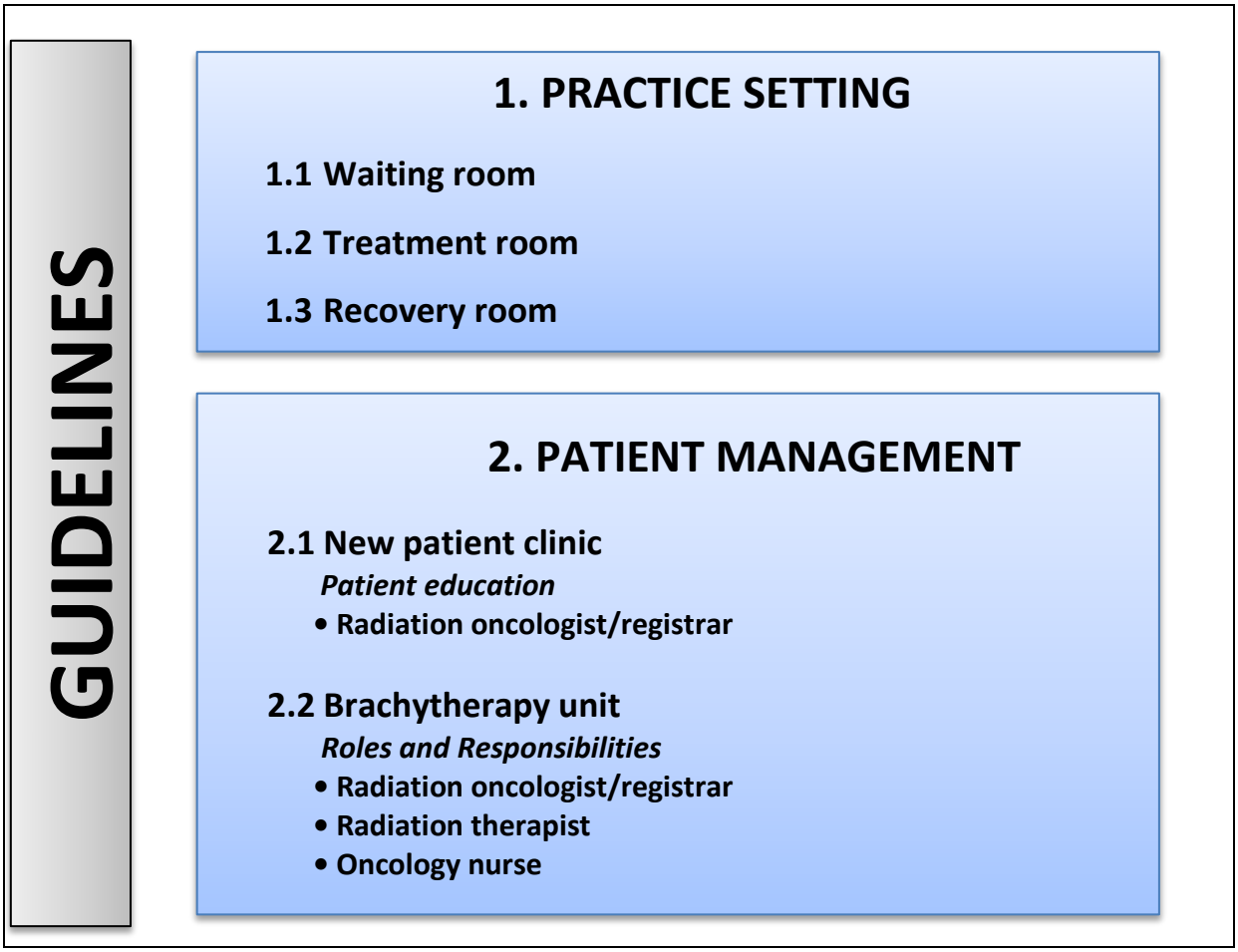

Figure 5.1 Overview of the final guidelines

BRACHYTHERAPY FOR CERVICAL CANCER:
GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT

PREAMBLE

The guidelines presented here are a means to aid or guide members of multidisciplinary teams in providing quality patient management for cervical cancer patients receiving high dose rate-intracavitary brachytherapy. It should be noted that although variations in terms of the practice setting, patient flow and availability of resources might occur, with some refining the guidelines can be adopted by any brachytherapy unit. The roles allocated to a specific member/s of the multidisciplinary team are not mutually exclusive, but depending on case load and facility preferences, they may be performed by different team members.

1. PRACTICE SETTING

This section of the guidelines addresses the logistical and safety issues deemed necessary to be in place during high dose rate brachytherapy procedure to ensure quality patient management.

1.1 Waiting room

- Provide an environment that is clean, tidy and patient friendly.
- Informative reading material regarding their disease and forthcoming treatment should be made available.
- Aids for the patient relaxation may include the following: a television (muted), newspapers, magazines, a radio, plants or flowers.
- Ensure well lighted waiting areas.
- Provide a bed in a separate room adjacent to the waiting room to accommodate ill or incapacitated patients awaiting their treatment.
- Provide clean and discrete ablution facilities/changing cubicle.
- Utilise time spent in the waiting room to prepare the new patient emotionally for the treatment. Listen to her fears and concerns.

1.2 Treatment room

- Ensure that a fully functional resuscitation trolley is available during administration of the sedation.
- Ensure well lighted treatment areas.

1.3 Recovery room

- Ensure patient safety, security and dignity by only having a single entrance to the recovery room.
- Provide sufficient trolleys or beds for transport of sedated patients between the treatment and recovery rooms to accommodate patient turnover.
- Provide sufficient personnel to monitor patients in the recovery room, in order to effectively prevent the occurrence of adverse incidents.
- Provide a bell for the patient to ring in case of an emergency in the recovery room.
- Provide water drink facilities for the patients in the recovery room.

- Provide wheelchairs for patients too weak to walk to their mode of transport.

2. PATIENT MANAGEMENT

This section of the guidelines addresses patient management, thereby ensuring patient satisfaction and delivery of a high level of quality, patient-centred care during the brachytherapy procedure.

Individual members of the multidisciplinary team held responsible for specific duties are shown in brackets in cases where these are not applicable to all members.

2.1 New patient clinic

2.1.1 ***Patient education***

- Information regarding the patient's disease and intended therapy should be given accurately and concisely without the use of technical medical terms while ensuring that the essence of the information is not lost.
- During this information session, informative material such as booklets or pamphlets and/or a video presentation could be employed to further enhance the patient's understanding of her therapy.
- Discuss the aspect of sexual intercourse with all the patients, irrespective of their age or marital status.
- Discuss the aspect of childbearing with patients that are peri-menstrual.
- Ensure that the patient understands that brachytherapy is not an operation to the uterus, but radiation to the inside of the cervix.
- Explain to the patient how the brachytherapy procedures will be incorporated into her six week treatment schedule. [Radiation oncologist/radiation therapist]
- Actively encourage the patient to direct treatment related questions to members of the multidisciplinary team, especially when remarks made by fellow patients are confusing and contradicting.
- Explain that different doctors may use slightly different approaches to treatment and that each patient's case is individualised in order to get the best outcome for the patient.

- Inform the patient that she will receive information regarding her follow-up appointments at completion of her radiotherapy treatment schedule. These appointments should be made in writing and need to be presented on arrival at the unit. [Radiation oncologist/registrar or radiation therapist]
- Address any obvious psychological issues the patient may have by referring her to a social worker or psychologist.
- Regarding the timing and preparation for the initial brachytherapy session, the patient should be informed of the exact timing of her forthcoming brachytherapy treatment, preferably a day or two prior to the scheduled treatment. The patient should also be provided with detailed instructions regarding her pre-treatment preparations on the evening and morning prior to receiving the brachytherapy. [Radiation therapist working at the accelerator or oncology nurse]
- Provide the new patient, unfamiliar with the hospital surroundings, with directions on where to register for and report to for her first brachytherapy treatment. Introduce her to the personnel and familiarize her with the inside of the treatment room and the treatment unit. [Radiation therapist or the oncology nurse]

2.1.2 ***Informed consent***

Radiation oncologist

- Informed consent for the brachytherapy procedure must be obtained by or under supervision of a licenced radiation oncologist qualified to perform and familiar with the procedure. Consent must be obtained, documented and signed prior to the initiation of brachytherapy where conscious sedation will be administered.
- A radiation oncologist not fluent in a language the patient understands should make use of the services of an appropriate interpreter. The patient should be informed of the availability of the services of an interpreter. When an interpreter is used, documentation of this should be available in the patient's medical file.
- Sufficient time must be given to allow the patient to assimilate and process the treatment information. Ample opportunity must be afforded to the patient to ask treatment related questions before signing the consent form. Patients should be encouraged not to be ashamed or to feel inadequate to ask questions.

- Inform the patient, that due to logistical reasons, the possibility exists that she might not be treated by the same radiation oncologist in subsequent brachytherapy sessions.
- Consent forms should be available in at least English and the languages spoken by the majority of patients in the province.
- Refresh information to the patient regarding the treatment due if long waiting times have elapsed before treatment delivery.
- All aspects related to the patient having to receive conscious sedation during the procedure must be discussed in detail at this stage. Explain that each patient responds differently to the sedation medication and that she might only wake-up in the recovery room. She will also be unable to drive herself home after the procedure.
- Provide the patient with understandable information on the possible side-effects of the treatment such as vaginal fibrosis and atrophy, the irreversible nature of vaginal ablation due to severe fibrosis and painful intercourse.

2.2 Brachytherapy unit (day of procedure)

2.2.1 ***Role of the radiation oncologist/radiation oncology registrar***

- The attending radiation oncologist/registrar should identify and introduce him/herself to the patient.
- Provide the patient with a brief explanation of the technical aspects of the brachytherapy procedure he/she will be performing.
- Obtain consent from the patient before allowing medical or nursing students to observe the procedure.
- Ensure that the patient is adequately sedated during the treatment delivery, up until removal of the applicators. Individualise the sedation dosage and document the sedation requirements for future reference in subsequent treatments.
- The treatment progress of the patient should be noted in the patient's file (macroscopic clinical appearance of the cancer) to inform the patient of the progress of therapy.
- Professional conduct should be maintained at all times and personnel should refrain from inappropriate conversations over a sedated patient.

2.2.2 ***Role of the radiation therapist***

- Explain to the patient briefly the brachytherapy procedure that will follow. Inform the patient that before the actual brachytherapy treatment will commence, the CT bed will automatically start moving as the treatment is preceded by a CT scan of the pelvis.
- The patient should be given a realistic estimate of her expected waiting time and expected duration of the treatment. The patient must be immediately informed of any unexpected delays in treatment.
- Inform the patient that there are safety mechanisms in place if machine breakage occurs and that the applicators can be removed, if necessary.
- Inform the patient that during treatment delivery, she is able to communicate with personnel outside the treatment room via an intercom system and a video camera will provide visual interaction with her.
- Impress upon the patient the need and importance for her to remain as still as possible during the procedure.
- Confirm with the radiation oncologist that sedation and pain control have been administered and are adequate before initiating therapy.
- Provide the patient with a rescheduled date in case of treatment cancellation. [Radiation therapist at the accelerator]
- Inform the patient on a weekly basis of the timing of her next brachytherapy treatment.

2.2.3 ***Role of the oncology nurse***

- Familiarize the new patient with the location of the dressing, waiting and recovery rooms.
- Have nursing personnel present to deliver immediate post-procedure care to the patient in the recovery room.
- Allowance should be made for sufficient time for post treatment recovery before ensuring that the ward patient is transported back to the ward in an adequate condition.
- Nursing personnel from the unit should communicate the patient's medical condition to the staff in the ward on arrival.
- Allocate a person to escort the patient to her mode of transport or back to the ward. [Student nurse or porter]

5.5 DISCUSSION

Findings of stage four of the research study provided a range of opinions on the proposed guidelines and have shown a level of consistency from the participants of both governmental and private brachytherapy units at a national level. The layout and formulation of the guidelines were accepted by all the participants as it was found to be well compartmentalised with well-defined mandates. It would be practical to implement at brachytherapy units as the layout and formulation of the guidelines are logical, clear and concise. However, due to variations in the layout of units and resource constraints it might be necessary to refine some of the guidelines to be adapted to the sequence of events and flow of patient management at a specific unit. It was acknowledged by the participants that the guidelines for the practice setting are patient orientated or patient-centred, because it entails basic standards of care that all healthcare facilities should be able to provide.

High dose rate-intracavitary brachytherapy is an invasive procedure for the patient and it is thus paramount to provide a practice setting where patients feel safe and secure and one where the patient's privacy is protected. Although patient privacy needs to be respected, it is necessary to provide a recovery room without partitioning as the sedated patients need to be observed by the oncology nurse for possible complications. Guideline 5 of this section (Provide the patient with privacy in the recovery room by making use of partitioning) was therefore omitted. Five additional guidelines were proposed and integrated into the existing guidelines. Resource constraints such as the shortage of personnel and limited space available for a dedicated recovery room could inhibit the full implementation of the guidelines for both governmental and private brachytherapy units. The importance of having an oncology nurse present in the recovery room to observe the patient post-brachytherapy should be emphasized as adverse incidents were reported by some patients interviewed during stage one of the research (cf. 2.3.2.4).

The majority of the participants agreed with the guidelines on collective roles and responsibilities. A multidisciplinary approach to inform the patient concerning her brachytherapy treatment constitutes good clinical practice. These roles allocated to a specific member/s of the multidisciplinary team are not mutually exclusive, but depending on case load and facility preferences, may be performed by different team members. High dose rate-intracavitary brachytherapy is a difficult concept to portray to patients, irrespective of their

educational background. There is a tendency to overestimate what patients are able to assimilate and perceive concerning their brachytherapy treatment. Efforts should focus on encouraging collaborative relationships with patients and their caregivers to ensure that necessary information is provided and understood, management options are clarified and patient needs are addressed in a timely fashion (ACR 2009). Such relationships maintain a patient-orientated perspective. This is consistent with the findings of the current study as the guidelines on collective roles proved to be patient-centred. Well informed and counselled patients are more likely to have reduced feelings of fear and anxiety; more likely to be compliant during treatment delivery and more likely their experience will be remembered as a positive one.

Providing patients with understandable treatment related information in their home language remains a challenge for most members of multidisciplinary teams in a country where eleven official languages are spoken. Participants of stage four of the study advised that if resources allow, the services of an interpreter should be incorporated in brachytherapy departments. Participants advised that the services of a social worker or psychologist could be used to allay fears, discuss potential social problems and assist with temporary disability grant applications if necessary. Although the sheer weight of patient numbers in a governmental setting and a lack of funding in a private unit were seen as implementation constraints, the majority of participants indicated that their resources do allow for these guidelines on collective roles and responsibilities to be implemented in their units. No guidelines were omitted from section B and five of the six proposed guidelines were integrated into the final set of guidelines.

Guidelines on the exclusive roles and responsibilities of the radiation oncologist working at the new patient clinic were accepted by all the participants. Effective communication between physicians and patients is a primary goal of the radiation oncologist in all clinical and treatment matters (ACR 2009). A smooth treatment transition for the patient is possible if the radiation oncologist ensures that the patient fully understands and comprehends her forthcoming treatment before signing consent. Consent is a communication process between the patient and a health care provider in which both parties have the opportunity to ask questions and exchange information relevant to the patient's diagnosis and treatment (ACR 2012). For this process to be effective, the authors stated that both parties must actively participate in the process and both parties share the responsibility for the accurate exchange of information. Physicians have legal and ethical duty to obtain informed consent from the

patient. The patient must therefore be given every opportunity to understand any treatment or procedure they are about to receive, to have all questions answered and to fully consent to treatments and procedures (ACR 2008; Bhatnagar, Land, Shogan, Rodgers, Heron & Flickinger 2007; Emanuel & Richter 1994).

Participants indicated that the role of the radiation oncologist at the new patient clinic needs to be emphasized as they are the initial ones to provide the patient with treatment related information. Information overload should be avoided. The implementation of the guidelines allocated to the radiation oncologist working at the new patient clinic was accepted by the majority of participants. However, due to resource constraints such as limited funding and a shortage of personnel (oncology nurse), full implementation of the guidelines was not possible. No guidelines were omitted form section C.1 and the four proposed guidelines were integrated into the existing guidelines.

Guidelines on the exclusive roles and responsibilities of the radiation oncologist, radiation therapist and the oncology nurse at the brachytherapy unit were accepted by the participants. Resource constraints such as limited funding, shortage of key personnel when conscious sedation is used and a lack of machines and equipment could prevent the full implementation of these guidelines. In some private units the role of the nurse is filled by a radiation therapist. No guidelines were omitted from section C.2. Two additional guidelines were proposed for section C.2.2 (the radiation therapist) and were integrated into the existing guidelines.

Participants of both governmental and private units acknowledged the significance of the guidelines. They would provide (a) a framework to monitor the standard of patient care or management, (b) ensure that all members of multidisciplinary teams understood their roles, (c) a motivation toward better practice, (d) ensure a positive patient experience and (e) ultimately improve quality assurance issues in brachytherapy units. The findings of the external review group confirmed the applicability and feasibility of the proposed guidelines, not only for members of the multidisciplinary team of the Department of Oncology, but also for those of governmental and private brachytherapy units in South Africa. Feasibility issues worth considering include the time, skills, staff and equipment necessary for the service providers to carry out the guidelines (Shekelle *et al*. 1999) in order to provide patient-centred care that will result in patient satisfaction with services rendered.

The researcher is of the opinion that the participants of this stage of the study provided a frank opinion of their experiences as health professionals at brachytherapy units. The findings have aided the researcher in refining the scope of the final guidelines to facilitate quality patient management in a multidisciplinary environment.

5.6 LIMITATIONS

Additional telephone calls to heads or designated representatives, who initially agreed to participate in the study and did not respond to e-mail reminders, could have increased the percentage of participation.

The national reviewers were all radiation oncologists. The input of national radiation oncology registrars, radiation therapists and oncology nurses, who are part of multidisciplinary teams, could have strengthened the value of this stage of the study.

A guideline under section C.1-new patient clinic (cf. 4.3.3.4) was accidently omitted from the information sent to the national participants. This guideline was included in the final set of the guidelines.

5.7 CONCLUSION

External review of the proposed guidelines by heads or designated representatives of governmental and private brachytherapy units in the country has confirmed content validity, clarity and applicability. This stage of the study addressed the four criteria of trustworthiness (cf. 5.2.4*)* to ensure research that is academically sound. The findings were integrated into the formulation of the final guidelines to facilitate quality patient management in a multidisciplinary environment. The final guidelines presented will make a valuable contribution to the field of knowledge on patient-centred guidelines to facilitate quality patient management.

In the next chapter, Chapter 6, Researcher Perspectives and Reflection, the researcher reflects on the contribution of the five stages towards formulation of the final guidelines, followed by the significance of the study, limitations, recommendations and concluding remarks.

CHAPTER 6

RESEARCHER PERSPECTIVES AND REFLECTION

6.1 INTRODUCTION

High dose rate brachytherapy is an essential component in the treatment schedule for women diagnosed with locally advanced carcinoma of the cervix. In order to facilitate quality patient management for this group of women, a multidisciplinary approach that is patient-centred is required. The US Institute of Medicine (IOM) report reinforces patient-centred care not only as a way of creating a more appealing patient experience, but also as a fundamental practice for providing high-quality care in the USA (Charmel & Frampton 2008).

Clear communication amongst all members of a multidisciplinary team is critical (Morton *et al*. 2010). Morton *et a*l. (2010) stated that such communication is made possible by the use of unambiguous documentation fully describing the treatment intent and delivery. Their advice is that written protocols and procedures for the treatment should be developed and the duties of each team member documented. Clinical practice guidelines are widely used as effective tools for improving the management of patients with cancer (Fevers *et al*. 2005).

The current study was conducted using a phenomenological approach, to formulate practice guidelines as a framework to facilitate quality patient management in a multidisciplinary environment. The patient-centred guidelines can be used as a tool to guide or assist members of multidisciplinary teams in providing quality patient management for patients with locally advanced cervical cancer treated at governmental and private brachytherapy units in South Africa.

This chapter provides an overview of the research study and presents my reflection on the findings. The significance and limitations of the study are discussed, followed by recommendations and concluding remarks.

6.2 OVERVIEW

An in-depth research study was initiated in 2012 on cervical brachytherapy as it was in this group of patients that I identified a specific need for improved patient management. It was my concern that technological advances in treatment planning and delivery at the brachytherapy unit of the Department of Oncology, Bloemfontein, might have compromised the quality of patient management delivered to patients with locally advanced cervical cancer. The research was thus guided by the following research question: What are the needs and expectations of women diagnosed with cervical cancer, receiving high dose rate-intracavitary brachytherapy at the Department of Oncology, Bloemfontein? The subsidiary questions flowing from this were the following:

• How do these patients conceptualize brachytherapy treatment?
• Is patient satisfaction achieved during treatment delivery?
• Is there a way of ensuring that the needs and expectations of the patients are adequately managed by members of a multidisciplinary team?

The department of Oncology provides oncology services to a vast geographical area including the Free State, Northern Cape and Lesotho. As the only facility in the Free State to administer high dose rate-intracavitary brachytherapy to this group of patients (private and academic), it was deemed necessary to investigate the needs and expectations of these patients with the aim to compile guidelines.

A comprehensive literature search for published guidelines on patient management for cervical cancer patients receiving high dose rate-intracavitary brachytherapy indicated that there are currently no guidelines available to assist or guide members of multidisciplinary teams to facilitate quality patient management for this group of women. The purpose of the current study was thus to establish guidelines to facilitate quality patient management in a multidisciplinary environment. It needs to be emphasized that although the medical physicists play an important role in the treatment planning and delivery of the patient, they were excluded from this study as they are not directly involved with the management or care of the patients. For the purpose of the study, the words "patient management" was defined as *the patient-centred care for cervical cancer patients receiving high dose rate-intracavitary brachytherapy.*

For the research questions to be adequately answered, a qualitative methodology was used as qualitative data takes the form of words (spoken or written). A phenomenological approach was thus chosen for the current study as it enabled me to explore the lived experiences of cervical cancer patients receiving high dose rate-intracavitary brachytherapy and it allowed me to capture participants' views and opinions on the proposed guidelines.

The study consisted of *five stages* that (1) integrated the patient experience, together with (2) findings in the literature and my aggregate experience to the formulation process of the proposed guidelines, (3) obtained the views and opinions of members of the multidisciplinary team of the Department of Oncology, regarding the proposed guidelines (4) gained the views and opinions on the amended guidelines from national heads or designated representatives of private and governmental brachytherapy units and (5) presented the final guidelines for implementation by brachytherapy service providers in South Africa.

Stage one of the research study provided me with an insight and a better understanding of patients' disposition toward brachytherapy treatment, informational needs and their psychological and physical experiences. Understanding the different ways cervical cancer patients experience the invasive procedure of high dose rate-intracavitary brachytherapy was fundamental for the development of the guidelines. Their reported experiences made a rich and valuable contribution to the development of the guidelines. In reflecting on stage one of the study, I felt it was appropriate for me not to be present during the interviewing process so as to maintain a non-biased approach. It is clear from my experience of service delivery at the unit that my presence as researcher could have inhibited information sharing by the participants due to my affiliation to the brachytherapy unit of the department and my familiarity with the participants. The decision to appoint a female interviewer not affiliated to our department, dressed in casual clothing and fluent in English, Afrikaans and Sotho added to the rich data collected during the interviews. It would have been ideal to video record the interviews to capture both verbal and non-verbal reactions, but due to my concern with how the patients would feel or react being videotaped I, in consultation with the research promoters, decided against this fairly intrusive form of interrogation. A precautionary step I took to counteract for non-verbal reactions not being documented was to simultaneously listen to the audio recordings while reading the transcripts and noting where participants' tone of voice emphasized certain important issues or topics discussed.

In *stage two* of the research, my knowledge and aggregate experience of 21 years of service delivery at the brachytherapy unit, together with topic related publications contributed to the guideline development process. The guidelines were formulated to be used as a tool to guide or address the following at the brachytherapy unit of the department (a) the practice setting; (b) the collective roles of members of a multidisciplinary team and (c) the exclusive roles of the radiation oncologist/radiation oncology registrar, the radiation therapist and the oncology nurse. In reflecting on stage two of the study, it was important for me to differentiate between idealistic and realistic requests made by the patients when formulating the proposed guidelines. My work experience in the unit was of value in differentiating between the two. It was my goal that the proposed guidelines are practical and easy to implement and therefore it was logical that the layout of the guidelines should follow the flow of patient management in our department.

In *stage three* of the research the original draft of the guidelines needed to be reviewed by members of the multidisciplinary team of the Department of Oncology to ensure that the proposed guidelines were appropriate, viable and sustainable for implementation in the department. The focus group interviews provided a broad range of opinions and views on the proposed guidelines. The majority of the guidelines were accepted and the suggested amendments were integrated to refine the scope of the guidelines. In reflecting on stage three of the study, I was at first apprehensive in recruiting twenty members of the multidisciplinary team of the department to take part in the focus group interviews that needed to be conducted on the same day. However, I am positive that my planning and organizational skills contributed to the successful outcome of the focus group interviews. Although I had no previous experience on arranging focus group interviews, I resorted to published literature on focus group interviews to assist me in planning the interviews. Once again I fulfilled the duties as an assistant facilitator so as to maintain a non-biased approach to the study.

Stage four of the study focussed on the external review of the guidelines by heads or designated representatives of governmental and private brachytherapy units in South Africa. It was necessary to establish the applicability and feasibility of the guidelines for national implementation. Their objective, critical and honest views and opinions provided me with rich data that made national implementation of the guidelines practicable. Content validity, clarity and applicability of the proposed guidelines were thus achieved through external review. In reflection on stage four of the study, this stage was intimidating for me having to

contact the heads of brachytherapy units in the country. However, I have found e-mail interviewing as method of data collection convenient, cost effective and it allowed me to include participants from all over the country.

Stage five of the study presented the final guidelines to facilitate quality patient management in a multidisciplinary environment. The scope of the guidelines was refined by all parties of stages three and four of the study and is a synthesis, with adaptation to brachytherapy units in South Africa. The guidelines are compatible with existing values and routines among members of the target group. Some guidelines need reaffirmation, while new guidelines have been identified. The practice guidelines which have a patient-centred care approach are feasible and applicable for implementation by governmental and private brachytherapy units in South Africa.

It is thus my conclusion that the guidelines will assist members of multidisciplinary teams to strive toward the ideal of better practice. Even if all the guidelines cannot be implemented en bloc due to resource constraints, it is my opinion that the guidelines will ultimately improve quality assurance issues in brachytherapy units and more importantly, enhance patients' experiences of services rendered.

6.3 SIGNIFICANCE OF THE RESEARCH STUDY

The study made a valuable contribution in providing a tool to be implemented by governmental and private brachytherapy service providers and members of multidisciplinary teams to facilitate quality patient management. The following values of this thesis are consistent with those reported by Perez *et al.* (2013):

The guidelines of the current study will minimize inappropriate practice variations, promote consistency and quality of management for this group of patients, provide reference points for education or practice, improve patient management or care, provide criteria for self-evaluation and set indicators for external quality review.

The guidelines address not only the collective and exclusive roles and responsibilities of members of multidisciplinary teams, but also the practice setting to ensure a safe and secure environment for the patient.

The research study highlighted the shortcoming of existing literature on the patient experience of receiving high dose rate-intracavitary brachytherapy as treatment modality. Exploring the patient experience of South African women receiving high dose rate-intracavitary brachytherapy is unique as it is the first time that their experiences have been voiced.

The strength of this study is the use of a combination of different qualitative methods (individual interviews, literature search, focus group interviews and e-mail interviews). In addition, the composition of the multidisciplinary focus group sessions, representing disciplines such as radiation oncologists/radiation oncology registrars, radiation therapists, oncology nurses, minimised bias towards a specific perspective. The sound research and methodology ensured the reliability and validity of the research.

6.4 STUDY LIMITATIONS

I recognise some limitations of the study as a whole:

The overarching limitation of the study was that I was not present as an observer during the patient and focus group interviews during which I could have made field notes and documented non-verbal communication and environmental factors.

Patients' experiences might have differed if resources of the Department of Oncology were not constraining factors in providing quality patient management to this group of patients.

The layout and activities of brachytherapy units might differ and therefore the guidelines may need adaptation before implementation.

6.5 RECOMMENDATIONS

It is recommended that the guidelines for quality patient management be submitted to the CEO of Universitas Academic Hospital for consideration and implementation by the Department of Oncology, Universitas Annex, Bloemfontein.

If resources permit, electronic versions will be most useful for the guideline users, accompanied by short paper publications, wall charts and pamphlets. The heads of national brachytherapy units will be contacted and informed of website details of the guidelines.

The guidelines should be published in English as health professionals should be fluent in English.

The results of this study have both theoretical and practical implications. Individuals responsible for educating future health professionals should promote the recognition of patient's needs and implementation of the guidelines. Findings of this study can help brachytherapy facilitators or members of a multidisciplinary team improve the quality of patient management of women undergoing brachytherapy for cervical cancer and tailor the way that patients are managed.

Producing an animation presentation of brachytherapy and what the treatment entails could assist the radiation oncologist/radiation oncology registrar in explaining the concept of brachytherapy treatment to the patient at the new patient clinic.

The guidelines could meet not only a local, but also a global need in providing quality patient-centred care to this group of patients.

The guidelines can be updated as soon as relevant new evidence on the patient experience of high dose rate-intracavitary brachytherapy is published.

The patient-centred approach of the guidelines could be implemented, with some refining, in brachytherapy units that treat other cancers.

Further research is encouraged to examine whether implementation of the guidelines at governmental and private brachytherapy units have made a difference to patient satisfaction with services rendered by members of multidisciplinary teams.

Further qualitative research in third world countries is encouraged to explore the patient experience of brachytherapy, investigating whether patients, irrespective of their educational background, truly grasp the concept of cancer and its treatment when signing consent.

6.6 CONCLUDING REMARKS

The research study has established guidelines to facilitate quality patient management for cervical cancer patients receiving high dose rate-intracavitary brachytherapy in a multidisciplinary environment. The patient experience has been integrated as qualitative evidence in guideline development. The guidelines provide a framework that defines the roles and responsibilities of each member of the multidisciplinary team. Members are encouraged to adhere to the guidelines to ensure that quality patient management is delivered. Acknowledging the limitations of this research process, it is my opinion that the research questions were answered appropriately and study objectives have been achieved. I am furthermore confident that the guidelines will positively influence the quality of patient management delivered by members of multidisciplinary teams who choose to implement these guidelines. I see this research as unique as it is the first time that voices and experiences of South African cervical cancer patients have been presented and included in guidelines formulated for quality patient management.

In the course of my research study I have developed knowledge and skills in my quest for professional, academic and personal growth. I have developed a detailed knowledge and understanding of phenomenology as a qualitative study design. I also acquired transferable skills such as time management, organisational, interpersonal and communication skills. My goal was achieved by formulating guidelines that have a patient-centred and not a treatment-centred approach. In the future, I look forward to pursue further research related to brachytherapy as treatment modality.

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APPENDIX 1:

APPROVAL LETTER FROM THE ETHICS COMMITTEE, FACULTY OF HEALTH SCIENCES, UNIVERSITY OF THE FREE STATE

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA
UFS UV

Research Division
Internal Post Box G40
☎(051) 4052812
Fax (051) 4444359

E-mail address: StraussHS@ufs.ac.za

Ms H Strauss/hv

2012-08-17

REC Reference nr 230408-011
IRB nr 00006240

MS D LONG
DEPARTMENT OF ONCOLOGY
NATIONAL DISTRICT HOSPITAL
BLOEMFONTEIN
9301

Dear Ms Long

ECUFS NR 97/2012
MS D LONG **DEPARTMENT OF ONCOLOGY**
PROJECT TITLE: BRACHYTHERAPY FOR CERVICAL CANCER: GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT.

- You are hereby kindly informed that the Ethics Committee approved the above study at the meeting on 14 August 2012 after the conditions have been met when the following was submitted:
  - ***The Information Leaflet and Informed Consent translated into Afrikaans and Sesotho***
- The Ethics Committee also approved the amendment to the criteria for the interviewer.
- Committee guidance documents: Declaration of Helsinki, ICH, GCP and MRC Guidelines on Bio Medical Research. Clinical Trial Guidelines 2000 Department of Health RSA; Ethics in Health Research: Principles Structure and Processes Department of Health RSA 2004; Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa, Second Edition (2006); the Constitution of the Ethics Committee of the Faculty of Health Sciences and the Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines.
- Any amendment, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.
- The Committee must be informed of any serious adverse event and/or termination of the study.

- A progress report should be submitted within one year of approval of long term studies and a final report at completion of both short term and long term studies.
- Kindly refer to the ECUFS reference number in correspondence to the Ethics Committee secretariat.

Yours faithfully

.....

PROF WH KRUGER
CHAIR: ETHICS COMMITTEE

APPENDIX 2:

APPROVAL LETTER FROM THE HEAD OF THE DEPARTMENT OF ONCOLOGY, UNIVERSITAS ANNEX, BLOEMFONTEIN

Acting Head & Principal Specialist
Department of Oncology, Universitas Annex, Bloemfontein, Free State

Tel.: (051) 405 2354
Sel no.: 073 745 3306
E-mail: deirdre.long6@gmail.com

16 May 2012

Personnel no. 12676063
Student no. 1988046486

Dr AC Bester
Acting Head & Principal Specialist
Department of Oncology
Universitas Annex
Bloemfontein
Free State

Dear Dr AC Bester

Re: Request for permission to conduct research study for Ph.D. degree at UFS

I, Deirdré Long, hereby request permission to conduct a prospective research study at the Department of Oncology, Universitas Annex, entitled: **Brachytherapy for Cervical Cancer: Guidelines to Facilitate Quality Patient Management in a Multidisciplinary Environment.**

This study is a descriptive study with the focus on qualitative investigation. The motivation for this research study arises from the attempt to identify and conceptualize the expectations and experiences of patients undergoing HDR-ICBT treatment. The guidelines compiled as a result of this study will be unique, as they will address the voiced needs and expectations of patients undergoing high dose-rate brachytherapy treatment in a developing country, giving due consideration to the Batho Pele principles.

The purpose of this study is to establish guidelines to facilitate quality patient management for cervical cancer patients undergoing brachytherapy treatment in a multidisciplinary environment. To achieve the purpose of the study, the following specific objectives were determined for the study:

- To asses 35 patients' experiences of health management, after undergoing three brachytherapy treatments. Data will be collected via in-depth interviews that will take approximately 45 minutes per interview.

- Preliminary guidelines for quality patient management will be formulated by the researcher, based on the outcomes of the patients' opinions surveys and the aggregate experience of the researcher.

• The preliminary guidelines will be reviewed and revised amongst 12 members of the multidisciplinary team working at the brachytherapy unit (Department of Oncology, Universitas Annex, Bloemfontein) with a minimum of one years' experience of service delivery. Data collection will be achieved via a single focus group interviewing session of 1-2 hours.

• Lastly, these guidelines will be reviewed by a panel of nine national experts in the field via e-mail interviewing. They will be given a two week deadline wherein to respond. Their e-mail feedback will be incorporated into revisions of the original draft of these guidelines.

Findings from this research can be utilised for designing and implementing patient centric programmes, promoting sensitive, caring and respectful communication through targeted professional education. The distribution of printed brochures/pamphlets before treatment can address patients' expectations and concerns. These guidelines can also assist brachytherapy facilitators to improve the physical environment of their units and to educate staff members on facilitating quality patient management.

The projected time schedule for the study is two years. The study protocol has been accepted by the Evaluation Committee of the University of the Free State and needs to be accessed by the Ethics Committee of the UFS for approval to conduct the research. Presentation and publication of the results of this thesis will be pending written approval from the CEO & Head of Clinical Services, Universitas Annex, Bloemfontein.

Promotor: Prof. H. Friedrich-Nel (Ph.D. HPE UFS)

(Associate Professor and Programme Head: Radiography and Dental Assisting – School of Health Technology, Central University of the Free State, Bloemfontein, South Africa)

Co-Promotor: Prof. G. Joubert (BA, MSc)

(Associate Professor & Head of the Department of Biostatistics, Faculty of Health Sciences, University of the Free State, Bloemfontein, South Africa)

Thanking you in anticipation.
Yours sincerely
Mrs D. Long
Assistant manager – Department of Oncology

Signature

16.5.2012
Date

DR AC BESTER M.Med
Prin Specialist Oncology
Mr:0175285 Tel: Nr:- 405 2646

Permission granted:

DR AC Bester (M.Med): Acting Head & Principal Specialist Oncology

Signature

16/5/12
Date

APPENDIX 3:

APPROVAL LETTER FROM THE CHIEF EXECUTIVE OFFICER AND HEAD OF CLINICAL SERVICES, UNIVERSITAS ACADEMIC HOSPITAL, BLOEMFONTEIN

health
Department of Health
FREE STATE PROVINCE

16 May 2012

Me. D Long
Assistant Manager
Department of Oncology
Universitas Hospital Annex

Dear Me Long

RESEARCH PROJECT: BRACHYTHERAPY FOR CERVICAL CANCER: GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT

Herewith permission for the mentioned project to be done at Universitas Annex Hospital on the following conditions:

1. The research should not expose the users and the Department to any avoidable harm.
2. Annual progress reports should be submitted and also a research report at the end of the research process.
3. Reporting of Adverse Events related to the research process must be done within 48 hours of discovery.
4. There shall be provision for obtaining informed consent from all patients/staff where appropriate.
5. Briefing sessions should be conducted with all stakeholders prior to commencement and at the end of the study to provide feedback where appropriate.
6. That approval is obtained from the Ethics Committee.

The Chief Executive Officer must be notified if the findings of the project will be published and a research report needs to be sent to the Head Clinical Services as soon as the study is completed.

Yours sincerely

DR NRJ VAN ZYL

DR NIC R J VAN ZYL
HEAD: CLINICALSERVICES
UNIVERSITAS ACADEMIC HOSPITAL

HEAD: CLINICAL SERVICES: DR NRJ VAN ZYL
Private Bag X20660, Bloemfontein, 9300. Tel. No. 051-4052666
Fax: 051-4053500, Room 1077, First Floor, Universitas Academic Hospital
Email: vanzylnr@universitas.fs.gov.za

2012 -05- 28

CLINICAL SERVICES
UNIVERSITAS ACADEMIC HOSPITAL

PATIENT INTERVIEWS

APPENDIX 4:

LETTER OF INVITATION TO PARTICIPATE IN THE RESEARCH STUDY

APPENDIX 4

ECUFS number: 97/2012

LETTER OF INVITATION TO PARTICIPATE IN THE RESEARCH STUDY

Dear Potential Participant

This is a letter to invite you to participate in a research study:

STUDY TITLE: **BRACHYTHERAPY FOR CERVICAL CANCER: GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT**

I, Deirdré Long, am doing research on the quality of patient management of women with cervical cancer, who are treated with internal radiation. Research is just the process to learn the answer to a question. In this study I want to learn more about your needs and wants, while you receive internal radiation. I want to write rules to improve patient management for women with cervical cancer for the future.

I am asking you to participate in this study that is being conducted at the Brachytherapy unit, Department of Oncology, Universitas Annex, Bloemfontein. By taking part in the study, you will help me to make rules that will improve the quality of patient care for women while undergoing the five weekly internal radiation treatments.

A female interviewer will have a conversation with you in the week preceding your fourth internal radiation treatment. The interviewer will ask you questions in order to hear how you have experienced some aspects of treatment delivery. The once off interview will be held in a private office at the brachytherapy unit of the department. I will let you know when and where the interview will take place and will fetch you at the treatment machine where you will be having your external radiation. The interview will last approximately 45 minutes and the questions will be asked in English. To make sure that we get your answers exactly as you say them, I will be audio recording the interview as a back-up for the interview.

Your participation in this study is voluntary and refusal to participate will not affect your treatment. You may with draw from this study at any time without penalty. However, there is no payment or awards for participating in this research study.

Efforts will be made to keep personal information confidential. What you say during the interview will be kept private. Your name will not be on the interview schedule and any reports or publications from this study will not identify you. The interview schedule and audio tape will be kept in a locked safe in the archive of the department. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law.

By signing the consent form you will give the researcher the right to present and publish the results of the study at congresses and in relevant medical journals, respectively. The findings of this study will be made available to you at completion of the study in the published thesis which will be available in the Frik Scott Medical Library, UFS, Bloemfontein.

If you have any questions or concerns, please do not hesitate to contact Ms D. Long at 073 745 3306 or deirdre.long6@gmail.com.

Contact details of Secretariat and Chair: Ethics Committee of the Faculty of Health Sciences, University of the Free State – for reporting of complaints/problems: Telephone number (051) 405 2812.

Thank you for your willingness to participate in this study.

Kind regards

Deirdré Long
Assistant-Director in Radiography: Department of Oncology
Universitas Annex
Bloemfontein
Free State

PATIENT INTERVIEWS

APPENDIX 5:

VERSOEKBRIEF OM DEEL TE NEEM AAN DIE NAVORSINGSTUDIE

APPENDIX 5

Ecufs nommer: 97/2012

VERSOEKBRIEF OM DEEL TE NEEM AAN DIE NAVORSINGSSTUDIE

Hierdie is ’n bief wat u versoek om deel te neem aan ’n navorsingsstudie.

STUDIETITEL: **BRAGITERAPIE VIR SERVIKSKANKER: RIGLYNE VIR OPTIMALE PASIËNTHANTERING IN ’n MULTIDISSIPLINÊRE OMGEWING**

Beste deelnemer/proefpersoon

Ek, Deirdré Long, is besig om navorsing te doen oor die kwaliteit van pasiënthantering vir vroue met servikskanker wat binne bestraling (bragiterapie) ontvang. Navorsing is slegs die proses waardeur die antwoord op ’n vraag verkry word. In hierdie studie wil ek meer uitvind oor u verwagtinge en ervarings wanneer u die binne bestraling kry. Ek wil daarvolgens riglyne saamstel wat die hantering van vroue met servikskanker vir die toekoms kan verbeter.

Ek nooi u dus uit om aan die navorsingstudie deel te neem wat by die Bragiterapie Eenheid, Departement Onkologie, Universitas Annex, Bloemfontein gedoen gaan word. U deelname aan die studie sal dit vir my moontlik maak om riglyne saam te stel om die kwalitieit van pasiënthantering tydens die vyf, weeklikse binne bestralings te verbeter.

Die gesprek sal gevoer word deur ’n vrou wat deur my aangestel is as onderhoudvoerder. Sy sal die onderhoud met u voer in die week voor u vierde binne bestraling. Tydens die onderhoud sal sy u vrae vra oor hoe u sekere aspekte van die behandeling ervaar het. Dit sal ’n eenmalige onderhoud wees in n privaat kantoor by die Bragiterapie Eenheid van die afdeling. Ek sal u vroegtydig laat weet wanneer en hoe laat sy met u die onderhoud sal voer en ek sal u by die versneller kom haal waar u die buite bestraling ontvang. Die onderhoud sal omtrent 45 minute duur en al die vrae sal in Afrikaans gevra word. ’n Bandopname sal tydens die onderhoud geneem word om seker te maak dat ek die inligting verkry soos u dit sê en terselfdertyd sal ook dien as kontrole vir die studie.

U deelname in hierdie studie is vrywillig, en weiering om deel te neem sal nie u behandeling beïnvloed nie. U kan enige tyd aan deelname onttrek sonder nadele. Daar is egter geensins geldelike vergoeding of toekennings verbonde aan u deelname in the navorsingstudie nie.

Daar sal probeer word om persoonlike inligting vertroulik te hou. Wat u tydens die onderhoud sê sal privaat gehou word. U naam sal nie op die vraelys verskyn nie en enige verslae of publikasies sal u nie identifiseer nie. Die vraelys en die bandopname van die onderhoud sal in ’n geslote kluis in die argief van die department gestoor word.Volkome vertroulikheid kan nie gewaarborg word nie. Persoonlike inligting kan bekend gemaak word as die wet dit vereis.

As u die toestemmingsvorm teken, gee u my die reg om die resultate van die studie by kongresse voor te dra en in mediese joernale te publiseer. Die bevindings van die studie sal tot u beskikking wees in die gepubliseerde tesis in die Frik Scott Mediese Biblioteek, UV, Bloemfontein.

Vir enige vrae met betrekking tot die studie, kan u my kontak.

Kontakbesonderhede: Me D. Long - 073 745 3306 or deirdre.long6@gmail.com.
Kontakbesonderhede van die Sekretariaat en Voorsitter: Etiekkomitee van die Fakulteit Gesondheidswetenskappe, Universiteit van die Vrystaat – vir rapportering van klagtes/probleme: Telefoonnommer (051) 405 2812.

Dankie vir u bereidwillighed om aan die studie deel te neem.

Vriendelike groete

Deirdré Long
Assistent-Direkteur in Radiografie
Departement Onkologie
Universitas Annex
Bloemfontein
Vrystaat

PATIENT INTERVIEWS

APPENDIX 6:

TOKOMANE YA TLHAHISOLESEDING YA MOKUDIE

Ecufs number: 97/2012

TOKOMANE YA TLHAHISOLESEDING YA MOKUDIE

Ho Wena Monkakarolo ya Hlomphehang ya ka Bang le Seabo

Thaetlele ya Phuputso: Radieishene ya ka hare ho mmele (Brachytherapy) bakeng sa Kankere ya Molomo wa Popelo: Ditataiso tsa ho Hlophisetsa Tshwaro ya Mokudi ya Boleng Sebakeng se Mafapha a Mangata

Nna, Deirdré Long, ke etsa patlisiso e mabapi le boleng ba tshwaro ya bakudi ba basadi ba nang le kankere ya molomo wa popelo, ba alafuwang ka radiesihene ya ka hare ho mmele (Brachytherapy). Patlisiso ke tshebetso feela ya ho ithuta karabo bakeng sa potso. Phuputsong ena ke batla ho ithuta haholwanyane mabapi le ditlhoko ditabatabelo tsa hao, ha o ntse o amohela radieishene ya ka hare ho mmele. Ke batla ho ngola ditataiso tse tla ntlafatsa tshwaro ya mokudi bakeng sa basadi ba tshwerweng ke bohloko ba kankere ya molomo wa popelo ka moso.

Ke o kopa ho nka karolo phuputsong ena e etswang ke ba Brachytherapy unit, Department of Oncology, Universitas Annex, Bloemfontein. Ka ho nka karolo phuputsong, o tla nthusa ho etsa melawana e tla ntlafatsa boleng ba tlhokomelo ya bakudi ba basadi ha ba le dikalafong tsa radieishene ya ka hare ho mmele tsa dibekeng tse ding le tse ding tse hlano.

Mmotsadipotso wa motho wa mme o tla o botsa dipotso bekeng e etellang pele kalafo ya hao ya bone ya radieishene ya ka hare ho mmele. Mmotsadipotso o tla o botsa dipotso e le ho utlwa hore na o bile le tse ding tsa dintlha tsa phano ya kalafo. Dipotso tsena tse tla ba hang feela di tla tshwarelwa sephiring ofising e yuniting ya “brachytherapy” ya lefapha. Ke tla o tsebisa hore na dipotso di tla ba hokae le neng mme ke tla o lata motjhining wa kalafo moo o tla beng o fumantshwa kalafo ya radieishene ya hao ya ka hare ho mmele. Dipotso tsena di tla nka nako ya metsotso e ka bang 45 mme dipotso di tla botswa ka Senyesemane. Ho etsa bonnete ba hore re fumana dikarabo tsa hao hantle ka moo o di boletseng ka teng, ke tla be ke hatisa lebanta la dipotso tsena ho etsa bekapo bakeng sa dipotso.

Bonkakarolo ba hao phuputsong ena ke ba boithaopo mme ho hana ho nka karolo ho ke ke ha ama kalafo ya hao. O ka nna wa ikgula phuputsong ka nako efe kapa efe ntle le kotlo. Leha ho le jwalo, ha ho tefo ya letho kapa dimpho bakeng sa ho nka karolo phuputsong ena ya boithuto.

Boikgathatso bo tla etswa ho boloka tlhahisoleseding ya hao sephiring. Seo o se buang nakong ya dipotso se tla bolokwa sephiring. Lebitso la hao le ke ke la ba tlhophisong ya dipotso mme ditlaleho dife kapa dife kapa diphatlalatso tse tswang phuputsong ena di ke ke tsa o tsebahatsa. Tlhophiso ya dipotso tsena le lebanta la kgatiso ya dipotso di tla bolokwa di notleletswe seifeng setsing sa dipolokelo sa lefapha. O ke ke wa fuwa tiisetso ya sephiri se feletseng ka hohlehohle. Tlhahisoleseding e mabapi le wena e ka hlahiswa haeba molao o hloka jwalo.

Ka ho saena foromo ena o tla fa mofuputsi tokelo ya ho teka le ho phatlalatsa diphetho tsa phuputso dibokeng le masedinyaneng a lokelehang a bongaka, ka tatelano. Ditshibollo tsa phuputso ena di tla fumaneha ho wena phethelong ya phuputso ena

sengolweng sa thuto e phahameng (thesis) se tla fumaneha ho Frik Scott Medical Library, UFS, Bloemfontein.

Haeba o na le dipotso dife kapa dife kapa dingongoreho, ka kopo se qeaqeye ho ikopanya le Mof D. Long ho 073 745 3306 kapa deirdre.long6@gmail.com. Dintlha tsa boikopanyo tsa Bongodi le Modulasetulo: Ethics Committee of the Faculty of Health Sciences, University of the Free State – bakeng sa ho tlaleha ditletlebo/mathata: Nomoro ya mohala ke (051) 405 2812.

Re o leboha ka boikemisetso ba hao ba ho nka karolo phuputsong ena.

Ka ditakaletso tse molemo

Deirdré Long
Motlatsi wa Mookamedi: Lefapha la Kalafo ya Kankere
Universitas Annex
Bloemfontein
Free State

PATIENT INTERVIEWS

APPENDIX 7:

CONSENT DOCUMENT

APPENDIX 7

Ecufs number: 97/2012

CONSENT DOCUMENT

Consent to participate in the research

STUDY TITLE: BRACHYTHERAPY FOR CERVICAL CANCER: GUIDELINES TO FACILITATE QUALITY PATIENT CARE IN A MULTIDISCIPLINARY ENVIRONMENT

You have been asked to participate in a research study.
You have been informed about the study by the researcher, Ms D. Long.

You may contact Ms D. Long at any time if you have questions about the research.

You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS at telephone (051) 405 2812 if you have questions about your rights as a research subject.

Your participation in this research is voluntary and that no potential risk of harm (physiological or psychological) can occur to you as a result of your participation in this study.

By signing this consent form you will give the researcher the right to present and publish the results of the study at congresses and in relevant medical journals, respectively.

If you agree to participate, you will be given a signed copy of this document as well as the participation information sheet, which is a written summary of the research.

The research study, including the above information has been verbally described to me. understand what my involvement in the study means and I voluntarily agree to participate.

_____	_____
Signature of Participant	Date
_____	_____
Signature of Witness (*Where applicable*)	Date
_____	_____
Signature of Translator (*Where applicable*)	Date

PATIENT INTERVIEWS

APPENDIX 8:

TOESTEMMINGSDOKUMENT

APPENDIX 8

Ecufs nommer: 97/2012

TOESTEMMINGSDOKUMENT

Toestemming tot deelname aan die navorsingstudie.

STUDIETITEL: BRAGITERAPIE VIR SERVIKSKANKER: RIGLYNE VIR OPTIMALE PASIËNTHANTERING IN ’n MULTIDISSIPLINÊRE OMGEWING

U is versoek om aan ’n navorsingstudie deel te neem.

U is oor die studie ingelig deur die navorser, Me D. Long.

U kan Me D. Long enige tyd kontak indien u vrae oor die navorsing het.

U kan die Sekretariaat van die Etiekkomitee van die Fakultiet Gesondheidswetenskappe, UV by telefoonnommer (051) 405 2812 kontak indien u enige vrae het oor u regte as ’n navorsingsdeelnemer.

U deelname aan hierdie navorsing is vrywillig en geen potensiële risiko (fisiologies of silekundig) kan met u plaasvind a.g.v deelname aan die studie.

Deur die teken van die toestemmingsvorm gee u die navorser die reg om die resultate van die studie by kongresse voor te dra en in mediese joernale te publiseer.

As u instem om deel te neem, sal ’n ondertekende kopie van hierdie vorm sowel as die deelnemerinligtingsdokument, wat ’n geskrewe opsomming van die navorsing is, aan u gegee word.

Die navorsingstudie, insluitend die bogenoemde inligting is verbaal aan my beskryf. Ek begryp wat my betrokkenheid by die studie beteken en ek stem vrywillig in om deel te neem.

_____	_____
Handtekening van deelnemer	Datum
_____	_____
Handtekening van getuie (*Waar van toepassing*)	Datum
_____	_____
Handtekening van Vertaler (*Waar van toepassing*)	Datum

PATIENT INTERVIEWS

APPENDIX 9:

TOKOMANE YA TUMELO

Ecufs number: 97/2012

TOKOMANE YA TUMELO

Tumelo ya ho nka karolo patlisisong

Thaetlele ya Phuputso: Radieishene ya Ka hare ho Mmele (Brachytherapy) bakeng sa Kankere ya Molomo wa Popelo: Ditataiso tsa ho Hlophisetsa Tshwaro ya Mokudi ya Boleng Sebakeng se Mafapha a Mangata

O kopilwe ho nka karolo projekeng ya phuputso ya boithuto.

O tsebisitswe mabapi le phuputso ke mofuputsi, Mof D. Long.

O ka nna wa ikopanya le Mof D. Long ka nako efe kapa efe haeba o na le dipotso tse mabapi le patlisiso.

O ka ikopanya le Secretariat of the Ethics Committee ya Faculty of Health Sciences, UFS nomorong ya mohala ya (051) 405 2812 haeba o na le dipotso mabapi le ditokelo tsa hao jwalo ka monkakarolo patlisisong.

Bonkakarolo ba hao patlisisong ena ke ba boithaopo mme ha ho menyetla ya kotsi ya tshenyo (ya mmeleng kapa kelellong) e ka hlahang ka lebaka la hore o nkile karolo phuputsong ena.

Ka ho saena foromo ena o tla fa mofuputsi tokelo ya ho teka le ho phatlalatsa diphetho tsa phuputso dibokeng le masedinyaneng a lokelehang a bongaka, ka tatelano.

Haeba o dumela ho nka karolo, o tla fuwa khopi e saennweng ya tokomane ena mmoho le leqephe la tlhahisoleseding ya monkakarolo, e leng kgutsufatso ya mongolo ya patlisiso ena.

Phuputso ena ya boithuto, ho kenyeletswa tlhahisoleseding e ka hodimo mona ke e hlaloseditswe ka puo. Ke utlwisisa se bolelwang ke bonkakarolo ba ka mme ke dumela ho nka karolo ka boithaopo.

_____	_____
Tshaeno ya Monkakarolo	Mohla
_____	_____
Tshaeno ya Paki (*Moo ho lokelehang*)	Mohla
_____	_____
Tshaeno ya Mofetoledi wa Puo (*Moo ho lokelehang*)	Mohla

PATIENT INTERVIEWS

APPENDIX 10:

INTERVIEW SCHEDULE

APPENDIX 10

Ecufs number: 97/2012

INTERVIEW SCHEDULE

Patient RT.no:	
Date of interview:	…. /…. /……
Age group:	1(30-45) 2(46-60) 3(≥61)
Language:	Afrikaans English Sesotho
Interview time:	

Thank you for meeting with me for this interview regarding your internal radiation at the brachytherapy unit and for taking part in this study. Your response will help improve the quality of patient management for women, diagnosed with cervical cancer in the future.

Feel free to take as much time as you need to answer the questions. Please answer them as completely and honestly as you can. Remember there are no right or wrong answers. If there are any questions you do not understand or things that you do not remember, please let me know. I want to remind you that everything you say will be kept confidential.

If you do not wish to answer a particular question, you may skip that question and that you may end the interview at any time.

Do you have any questions before we begin? Start time: _____h_____

Demographic details of participants:

1. Age group: 30-45
   46-60
   ≥61
2. FIGO Staging: Ib IIa IIb IIIa IIIb
3. Race/Ethnicity: Black White Coloured
   Asian Other_____
4. Home language: Afrikaans English Sesotho
   Other_____
5. Employment status: Employed Unemployed
6. Medical insurance Private Academic-out patient
   Academic-ward patient
7. Residence/Home: Bloemfontein Lesotho Qwa-Qwa
   Northern Cape Other_____
8. Residence during treatment: Katleho Olea
   Family/friends
   Other_____
9. Level of education: None
   Primary school
   Secondary school
   Completed secondary school
   Trade or apprenticeship
   Tertiary qualification

QUESTIONS

---

1. When you think or hear about "brachytherapy/inside radiation", what comes to mind?

Listen for her knowledge and perception of what brachytherapy entails.

- Probe: When you go for the inside radiation, what do you expect the doctor to do?
- Probe: Explore her perceptions – reference to treatment being understood as a single event or being part of a series of 5 treatments requiring her to return weekly for additional treatments.

The next question concerns the day you gave consent for the inside radiation, after the doctor explained the procedure to you

2. What made you decide to give consent for the inside radiation?

- Probe: What other possible treatment methods were discussed with you?
- Probe: What were you told regarding the side-effects of the inside radiation, during and after completion of the treatment?
- Probe: Were you informed about sexual intercourse?
- Probe: What happens after completion of the inside radiation? (follow-up appointments)
- Probe: Were you given an opportunity to ask questions?
- Probe: Did you talk to someone else about the inside radiation?
    - If yes, to whom? Why this specific person?
    - If no, would you have liked to discuss this treatment with someone before giving permission?
- Probe: Was the procedure of the inside radiation explained to you in English?

Let's talk about the day before you started with the inside radiation treatment

3. What did the doctor or nurse told you to do on the evening before you went for your first inside radiation treatment?

- Probe: Did you know why you had to do this?
    - If yes, did it make it worthwhile to do?
    - If no, how did it make you feel?

The next questions are about the day you arrived at the brachytherapy unit to receive your first inside radiation treatment

4. When you arrived at the brachytherapy unit, what was your first impression?

- Probe: Did you know beforehand where to go?
    - If yes, who told/showed you?
    - If no, how did it make you feel?
- Probe: Were you welcomed in a friendly manner by the staff on you arrival?
    - If yes, how did it make you feel?
    - If no, how did it make you feel?

- Probe: Did you speak to someone about your fears and worries before the treatment
    - If yes, to whom? (doctor/nurse/radiotherapist/fellow patient)
        - What were your fears/worries?
    - If no, would you have liked to speak to someone?
        - Why?
- Probe: Were you given another explanation on the day's procedure?
    - If yes, how did it make you feel?
    - If no, how did it make you feel?
- Probe: Were you given any pamphlets/brochures to read beforehand to explain the treatment and possible side-effects to expect afterwards?
    - If yes, how did it make you feel?
    - If no, how did it make you feel?
        Sub-probe: Will a pamphlet/brochure have helped you to understand everything better?
        - Why?

Let's talk about the time you spend in the waiting room, before you went into the treatment delivery room

5. How did you experience the time spent in the waiting room?

- Probe: Were you informed when you would receive your treatment that day?
    - If yes, did it made the wait more tolerable? Why?
    - If no, how did it make you feel?
- Probe: What did you do in the waiting room to keep yourself busy?
- Probe: Is there anything you can suggest that could make the time spent in the waiting room more pleasant?

The following questions are about the time you spend inside the room where you received the treatment

6. How would you describe your experience of the treatment delivery process inside the room?

- Probe: Think about the treatment and tell me if you had any thoughts or questions about going into the treatment delivery room.
    - If yes, can you share what those were?
- Probe: Was the inside radiation treatment what you had expected it to be?
    - If yes, how so?
    - If no, how so?
- Probe: How did you feel about the treatment?
    - Explore her reasons for experiencing either comfort/discomfort regarding the procedure itself, pain control and patient care.
    - Ask concerning the gender of the doctor performing the procedure.
        - Was the doctor male or female?
        - How do you feel about this?
- Probe: How could you have been better prepared for this treatment?
- Probe: Was there anything during your time spent in the treatment room that you did not like?
    - If yes, what was it?

Now let's talk about the time spent in the recovery room after your treatment

7. Describe how you experienced the recovery room, after you woke up.

- Probe: Was there someone to attend to you when you woke up?
    - If yes, how did it make you feel?
    - If no, how did it make you feel?
- Probe: How did you feel physically after the treatment?
    - Sub-probe: Did you feel dizzy and needed assistance to get your transport?
    - Sub-probe: Were you hungry/thirsty or felt faint?
    - Sub-probe: Would you have liked a refreshment?
        - Any suggestions?

8. Have you got any suggestions how the doctor and staff at the brachytherapy unit can make this treatment more pleasant for you?

- If yes, what will it be?

9. Would you recommend this brachytherapy unit to friends/family?

- If yes, why?
- If no, what is the reason?

Thank you for taking the time to participate in this interview. Your responses will certainly help improve health management for women undergoing brachytherapy treatment in the future.

If you have any questions about the study, please feel free to contact Ms D. Long, at 073 745 3306.

Thank you again.
Have a nice day.
End time: _____

PATIENT INTERVIEWS

APPENDIX 11:

ONDERHOUDSVRAELYS

Ecufs nommer: 97/2012

ONDERHOUDSVRAELYS

RT no. van Pasiënt:	
Datum van onderhoud:	…. /…. /……
Ouderdomsgroep:	1(30-45) 2(46-60) 3(≥61)
Taal:	Afrikaans Engels Sesotho
Tysduur van die onderhoud:	____h_____

Dankie dat u my toelaat om die onderhoud met u te voer met betrekking tot die binne bestraling by die bragiterapie eenheid. U deelname word baie waardeer. U antwoorde sal bydra tot die verbetering van pasiënthantering vir vroue met servikskanker vir die toekoms.

Daar is genoeg tyd om eers mooi oor elke vraag te dink, voordat u antwoord. Anwoord die vrae so volledig en eerlik as moontlik. Onthou, daar is geen regte of verkeerde antwoorde nie. As u ’n vraag nie heeltemal verstaan of iets nie mooi kan onthou nie, kan u my net sê. Ek wil u net weer herinner dat alles wat u my nou gaan meedeel vertroulik gehou sal word.

As u nie ’n spesifieke vraag nie wil beantwoord nie, kan ons dit uitlos en u mag die onderhoud tydens enige stadium beëindig.

Het u enige vrae voordat ons met die onderhoud begin? Begintyd: _____h_____

Demografiese besonderhede van die pasiënt:

1. Ouderdomsgroep: 30-45
   46-60
   61>
2. FIGO Stadiëring: Ib IIa IIb IIIa IIIb
3. Rassegroep: Swart Wit Kleurling
   Asiër Ander_____
4. Huistaal: Afrikaans Engels Sesotho
   Ander_____
5. Beroep: Werkend Werkloos
6. Mediese versekering: Privaat Akademiese buite pasiënt
   Akademiese saal pasiënt
7. Huis/Woning: Bloemfontein Lesotho Qwa-Qwa
   Noord-Kaap Ander_____
8. Huisvesting tydens bestraling: Katleho Olea Familie/vriende
   Ander_____
9. Opleiding: Geen
   Primêre skool
   Sekondêre skool
   Sekondêre skool voltooi
   Ambag
   Tersiëre kwalifikasie

VRAELYS

1. Wat verstaan u as u die woorde bragiterapie/binne bestraling hoor of daaraan dink?

Luister wat is haar kennis en persepsie van wat binne bestraling behels.

• Ondersoek: Wat het u verwag gaan die dokter doen as u vir binne bestraling gaan?
• Ondersoek: Ondersoek haar persepsies – verwysing na die behandeling as eenmalig of ’n reeks van 5 behandelings behels waarvoor sy weekliks moet terugkom.

Die volgende vraag handel oor die dag toe u toestemming tot die binne bestraling gegee het, nadat die dokter dit aan u verduidelik het

2. Wat het u laat besluit om toestemming te gee vir die binne bestraling?

• Ondersoek: Watter alternatiewe/ander behandelingmetodes is met u bespreek?
• Ondersoek: Wat is aan u vertel wat die newe-effekte van die binne bestraling gaan wees, tydens en na voltooiing van die behandeling?
  ◦ Was u ingelig oor seksuele omgang?
  ◦ Wat gebeur na voltooiing van die binne bestraling - opvolgafsprake?
• Ondersoek: Was u die geleentheid gegee om vrae te vrae?
• Ondersoek: Het u met iemand anders gepraat oor die binne bestraling?
  ◦ Indien ja, met wie? Hoekom met dié spesifieke persoon?
  ◦ Indien nee, sou u graag eers die behandeling met iemand wou bespreek voordat u toestemming gegee het?
• Ondersoek: Was die prosedure van die binne bestraling aan u verduidelik in Afrikaans?

Kom ons gesels oor die dag voordat jy met die binne bestraling behandeling begin het

3. Wat het die dokter of suster gesê moet u die aand voor die eerste binne bestraling behandeling doen?

• Ondersoek: Het u geweet hoekom u dit moes doen?
  ◦ Indien ja, het dit u gemotiveer om dit te voltooi?
  ◦ Indien nee, hoe het dit u laat voel?

Die volgende vrae handel oor die dag toe u aangemeld het vir u eerste binne bestraling behandeling by die bragiterapie eenheid

4. Toe u by die bragiterapie eenheid aangekom het, wat was u eerste indruk?

• Ondersoek: Het u vooraf geweet waar om te gaan?
  ◦ Indien ja, wie het vir u gewys of gesê?
  ◦ Indien nee, hoe het dit u laat voel?
• Ondersoek: Was u vriendelik verwelkom deur die personeel by u aankos?
  ◦Indien ja, hoe het dit u laat voel?

◦Indien nee, hoe het dit u laat voel?

• Ondersoek: Het u met iemand gepraat oor u vrese of bekommernisse voor die behandeling?
  ◦ Indien ja, met wie? (dokter/suster/radioterapeet/mede pasiënt)
    ▫ Wat was u vrese/bekommernisse gewees?
  ◦ Indien nee, sou u graag met iemand wou gesels het?
    ▫ Hoekom?
• Ondersoek: Was daar aan u weer ’n verduideliking gegee van die dag se prosedure?
  ◦ Indien ja, hoe het dit u laat voel?
  ◦ Indien nee, hoe het dit u laat voel?
• Ondersoek: Is daar vooraf ’n pamflet of inligtingsbrosjure aan u gegee wat die behandeling en moontlike newe-effekte daarvan aan u kon verduidelik?
  ◦ Indien ja, hoe het dit u laat voel?
  ◦ Indien nee, hoe het dit u laat voel?
    Sub-ondersoek: Sou ’n pamflet/brosjure u gehelp het om alles beter te kon verstaan?
    ▫ Hoekom?

Kom ons gesels oor die tyd wat u in die wagkamer moes deurbring voor u by die behandelingskamer in is

5. Hoe het u die tyd wat u in die wagkamer moes deurbring ervaar?

• Ondersoek: Was u ingelig oor wanneer u die behandeling daardie dag sou kry?
  ◦ Indien ja, was die wag dus meer aanvaarbaar?
    ▫ Hoekom?
  ◦ Indien nee, hoe het dit u laat voel?
• Ondersoek: Waarmee het u, u self besig gehou in die wagkamer?
• Ondersoek: Het u enige voorstelle hoe ons die tyd in die wagkamer vir u meer aangenaam kan maak ?

Die volgende vrae handel oor die tyd wat u binne die bestralingskamer vir u behandeling deurgebring het

6. Hoe sal u, u ervaringe van die behandelingsprosedure binne-in die kamer beskryf?

• Ondersoek: Dink aan die behandeling en sê vir my of u nog onsekerheid of vrae gehad het voordat u in die behandelingskamer ingestap het?
  ◦ Indien ja, wat was dit?
• Ondersoek: Was die behandeling vir die binne bestraling dit wat u verwag dit sou wees?
  ◦ Indien ja, hoe so?
  ◦ Indien nee, hoe so?
• Ondersoek: Wat is u gevoelens oor die behandeling?
  ◦ Vind meer uit oor haar ervaringe ten opsigte van gemak/ongemak tydens die prosedure, pynbeheer en pasiëntsorg.
  ◦ Vra haar opinie omtrent die geslag van die dokter wat die prosedure uitgevoer het.
    ▫ Was the dokter manlik of vroulik?
    ▫ Hoe voel u daaroor?

• Ondersoek: Hoe kon u beter voorbereid gewees het vir dié behandeling?
• Ondersoek: Was daar enigiets tydens die tyd wat u in die behandelingskamer deurgebring het waarvan jy nie gehou het nie?
    ◦ Indien ja, wat was dit?

Kom ons gesels nou oor die tyd wat u in die herstelkamer deurgebring het na die behandeling

7. Beskryf hoe het u die herstelkamer ervaar, nadat u wakker geword het?

• Ondersoek: Was daar iemand byderhand toe u wakker geword het?
    ◦ Indien ja, hoe het dit u laat voel?
    ◦ Indien nee, hoe het dit u laat voel?
• Ondersoek: Hoe het u fisies gevoel na die behandeling?
    Sub-ondersoek: Het u duiselig gevoel en hulp nodig gehad om by u vervoermiddel te kom?
    Sub-ondersoek: Was jy honger/dors/duiselig en sou graag ’n verversing wou nuttig?
        ▫Enige voorstelle?

8. Het u enige voorstelle hoe die dokter of personeel by die bragiterapie eenheid u behandeling meer aangenaam kan maak?

    ◦ Indien ja, wat sal dit wees?

9. Sal u dié bragiterapie eenheid aan familie/vriende aanbeveel?

    ◦ Indien ja, hoekom?
    ◦ Indien nee, wat is die rede?

Dankie vir u tyd wat u aan die onderhoud afgestaan het. U respons sal verseker bydra tot die verbetering van pasiënthantering vir vroue wat bragiterapie behandeling ontvang in die toekoms.

U kan Me D. Long, gerus kontak by 073 745 3306, indien u vrae oor die studie het.

Baie dankie.
Geniet u dag.
Tyd voltooi: ____h_____

PATIENT INTERVIEWS

APPENDIX 12:

TLHOPHISO YA DIPOTSO TSA BAKUDI

Ecufs number: 97/2012

TLHOPHISO YA DIPOTSO TSA BAKUDI

Nmr. ya RT ya Mokudi:	
Mohla dipotso:	…. /…. /……
Sehlopha sa dilemo:	1(30-45) 2(46-60) 3(≥61)
Puo:	SeAfrikanse Senyesemane Sesotho
Nako ya dipotso:	**---:---**

Ke o leboha ha o kopane le nna bakeng sa dipotso tsena tse mabapi le radieishene ya ka hare ho mmele ya hao yuniting ya "brachytherapy" le ka ho nka karolo phuputsong ena. Karabelo ya hao e tla thusa ho ntlafatsa boleng ba tshwaro ya bakudi bakeng sa basadi ba fumanweng ba na le bohloko ba kankere ya molomo wa popelo ka moso.

Ikutlwe o lokolohile ho nka nako e hlokwang ke wena ho araba dipotso tsena. Ka kopo di arabe ka botlalo le ka nnete ka moo o ka kgonang. Hopola, ha ho dikarabo tse nepahetseng kapa tse fosahetseng. Haeba ho na le dipotso dife kapa dife tseo o sa di utlwisiseng kapa dintho tseo o sa di hopoleng, ka kopo ntsebise. Ke batla ho o hopotsa hore dintho tsohle tseo o di boletseng di tla bolokwa sephiring.

Haeba o sa batle ho araba potso e itseng, o ka tlola potso eo mme hape o ka emisa dipotso ka nako efe kapa efe.

Na o na le dipotso dife kapa dife pele re ka qala? Nako ya ho qala: _____h_____

Dintlha tsa dipalopalo tsa monkakarolo:

1. Sehlopha sa dilemo: 30-45
   46-60
   ≥61
2. Mokgahlelo wa FIGO: Ib IIa IIb IIIa IIIb
3. Mmala/Morabe: Motsho Mosweu Wa mmala
   MoAsia O sele_____
4. Puo ya lapeng: SeAfrikanse Senyesemane Sesotho
   E sele_____
5. Boemo ba tsa tshebetso: O hirilwe Ha o sebetse
6. Inshorense ya bongaka sepetlele wa boithuto: Ya poraefete Mokudi wa kantle ho Mokudi wa wateng wa boithuto
7. Bodulo/Lapeng: Bloemfontein Lesotho Qwa-Qwa
   Kapa Leboya Ho sele_____
8. Bodulo nakong ya kalafo: Katleho Olea Ba lelapa/metswalle
   Ba sele_____
9. Boemo ba tsa thuto: Ha eyo
   Sekolo sa mathomo
   Sekolo se phahameng
   O qetile sekolo se phahameng
   Tshebetso kapa boithuti ba tshebetso
   Lengolo la thuto e phahameng

DIPOTSO

1. Ha o nahana kapa o utlwa ka "brachytherapy/radieishene ya ka hare ho mmele", ke eng se tlang kelellong ya haoi?

Mamela tsebo ya hae le monahano wa hore radieishene ya ka hare ho mmele e bolelang.

- Botsisisa: Ha o ya radieisheneng ya ka hare ho mmele, o lebeletse hore ngaka a etse eng?
- Botsisisa: Sibolla menahano ya hae – ho bua ka kalafo e utlwisiswang jwalo ka ketsahalo ya hang kapa karolo ya dikalafo tsa letoto tse 5 tse mo hlokang hore a kgutle beke le beke bakeng sa dikalafo tsa tlatsetso.

Potso e latelang e mabapi le letsatsi leo ka lona o faneng ka tumelo bakeng sa radieishene ya ka hare ho mmele, ka mora hore ngaka a o hlalosetse mokgwatshebetso, kliniking ya bakudi ba qalang ho tla

2. Ke eng se entseng hore o nke qeto ya ho fana ka tumelo bakeng sa radieishene ya ka hare?

- Botsisisa: Ke mekgwa efe e meng ya dikalafo tse ding tse ka kgonehang tse tshohlilweng le wena?
- Botsisisa: Ke eng seo o se jwetsitsweng mabapi le ditlamorao tsa radieishene ya ka hare ho mmele, nakong ya kalafo le ka mora phethelo ya kalafo?
  - Na o tsebisitswe mabapi le thobalano
  - Ho etsahala eng ka mora ho phethela radieishene ya ka hare ho mmele-diketelong tsa tshalomorao?
- Botsisisa: Na o filwe monyetla wa ho botsa dipotso tsa letho?
- Botsisisa: Na o buile le motho e mong hape mabapi le radieishene ya ka hare ho mmele?
  - Haeba karabo e le ee, le mang? Hobaneng e le motho eo ka ho kgetheha?
  - Haeba karabo ke tjhe, na o ka be o lakaditse ho tshohla kalafo ee le motho e mong pele o fana ka tumello?
- Botsisisa: Na o hlaloseditswe mokgwatshebetso wa radieishene ya ka hare ho mmele ka Senyesemane?

Ha re bue ka letsatsi le etellang pele leo o qadileng ka radieishene ya kalafo ya ka hare ho mmele

3. Ngaka kapa mooki o itse o etse eng ka phirimana e etellang pele letsatsi leo o ya ho fumana kalafo ya hao ya pele ya radieishene ya ka hare ho mmele?

- Botsisisa: Na o ne o tseba hore ke hobaneng o lokela ho etsa see?
  - Haeba karabo ke ee, na ho bile le molemo ho se etsa?
  - Haeba karabo ke tjhe, se entse hore o ikutlwe jwang?

Dipotso tse latelang di mabapi le letsatsi leo ka lona o fihlileng yuniting ya "brachytherapy" ho fumana kalafo ya hao ya pele ya radiesihene ya ka hare ho mmele

4. Ha o fihla yuniting ya "brachytherapy", maikutlo a hao a pele e bile afe?

- Botsisisa: Na o tsebile e sa le pele hore o lokela ho ya hokae?
    - Haeba karabo ke ee, ke mang ya o jwetsitseng/bontshitseng?
    - Haeba karabo ke tjhe, ho entse hore o ikutlwe jwang?
- Botsisisa: Na o amohetswe ka tsela e botswalle ke basebetsi ha o fihla?
    - Haeba karabo ke ee, ho entse hore o ikutlwe jwang?
    - Haeba karabo ke tjhe, ho entse hore o ikutlwe jwang?
- Botsisisa: Na o buile le motho e mong mabapi le matswalo a hao le matshwenyeho pele ho kalafo?
    - Haeba karabo e le ee, le mang? (ngaka/mooki/moalafi wa radiotherapi/mokudi e mong)
        - Matswalo/matshwenyeho a hao e ne e le afe?
    - Haeba karabo ke tjhe, na o ka be o lakaditse ho bua le motho e mong?
        - Hobaneng?
- Botsisisa: Na o fuwe tlhalosetso e nngwe ka mokgwatshebetso wa letsatsi leo?
    - Haeba karabo ke ee, ho entse hore o ikutlwe jwang?
    - Haeba karabo ke tjhe, ho entse hore o ikutlwe jwang?
- Botsisisa: Na o fuwe dipampitshana/diboroshara ho di bala pele hore di o hlalosetse kalafo le ditlamorao tse ka bang teng tseo o ka di lebellang ka morao?
    - Haeba karabo ke ee, ho entse hore o ikutlwe jwang?
    - Haeba karabo ke tjhe, ho entse hore o ikutlwe jwang?

      Potsisiso e nyane: Na pampitshana/boroshara e o thusitse ho utlwisisa dintho tsohle betere?
        - Hobaneng?

Ha re bue ka nako eo o e nkileng ka phapusing ya ho ema, pele o ya phapusing ya phumantsho ya kalafo

5. O bile le nako e jwang ka phapusing ya ho ema?

- Botsisisa: Na o tsebisitswe hore o tla fumana kalafo ya hao ka letsatsi lefe?
    - Haeba karabo ke ee, na see se entse hore ho ema ho mamellehe? Hobaneng?
    - Haeba karabo ke tjhe, ho entse hore o ikutlwe jwang?
- Botsisisa: O entse eng ho kganna nako ha o ntse o le phapusing ya ho ema?
- Botsisisa: Na ho na le letho lefe kapa lefe leo o ka le hlahisang le ka etsang hore nako e nkuwang ya ho ema e be hantle?

Dipotso tse latelang di mabapi le nako eo o e nkileng ka hare ho phapusi eo o fumaneng kalafo ho yona

6. O ka hlalosa nako eo o bileng le yona tshebetsong ya phumantsho ya kalafo ka phapusing e bile e jwang?

- Botsisisa: Nahana ka kalafo mme o mpolelle haeba o bile le menahano kapa dipotso tse mabapi le ho ya ka phapusing ya phumantsho ya kalafo.
    - Haeba karabo ke ee, na o ka arolelana ka tsona le rona?
- Botsisisa: Na kalafo ya radieishene ka hare ho mmele e bile ka moo o neng o lebeletse ka teng?
    - Haeba ho le jwalo, jwang?
    - Haeba karabo ke tjhe, jwang?

• Botsisisa: O ne o ikutlwa jwang mabapi le kalafo?
    ◦ Fumana mabaka a hae a ho ikutlwa a na le e nngwe ho boiketlo/makukuno mabapi mokgwatshebetso bowona, taolo ya bohloko le tlhokomelo ya mokudi.
    ◦ Botsa mabapi le bong ba ngaka e entseng mokgwatshebetso ona.
    ◦ Na ngaka e ne e le monna kapa mosadi?
        ▫ O nahana jwang mabapi le taba ee?
• Botsisisa: O ka be o itokisitse jwang betere ho feta bakeng sa kalafo ee?
• Botsisisa: Na ho bile le letho nakong eo o e nkileng ka phapusing ya kalafo leo o sa kang wa le rata?
    ◦ Haeba karabo ke ee, e ne e le eng?

Jwale ha re bue ka nako eo o e nkileng ka phapusing ya ho hlaphohelwa ka mora kalafo ya hao

7. Hlalosa ka moo o utlwileng ho le ka teng phapusing ya ho hlaphohelwa, ka mora hore o tsohe.

• Botsisisa: Na ho na le motho ya o thusitseng ha o tsoha?
    ◦ Haeba karabo ke ee, ho entse hore o ikutlwe jwang?
    ◦ Haeba karabo ke tjhe, ho entse hore o ikutlwe jwang?
• Botsisisa: O ne o ikutlwa jwang mmeleng ka mora kalafo?
    Potsisiso e nyane: Na o ne o ikutlwa o na le modikwadikwane mme o hloka thuso hore o fumane sepalwangwang sa hao?
    Potsisiso e nyane: Na o ne o lapile/nyorilwe kapa o ikutlwa o tsekela mme o batla setheohelang?
        ▫Na o na le ditlhahiso tsa letho?

8. Na o na le ditlhahiso tsa letho mabapi le ka moo ngaka le basebetsi ba yuniting ya "brachytherapy" ba ka etsang hore kalafo ee e be hantle?

9. Na o ka kgothaletsa yuniti ee ya "brachytherapy" ho metswalle/lelapa la hao, ba tshwerweng ke lefu la kankere ya popelo?

    ◦ Haeba o re ee, hobaneng?
    ◦ Haeba o re tjhe, lebaka ke lefe?

Re leboha ha o nkile nako ya hao ho nka karolo dipotsong tsena. Dikarabelo tsa hao di tla feela di thuse ho ntlafatsa taolo ya bophelo bakeng sa bophelo ba basadi ba fumantshwang kalafo ya radieishene ya ka hare ho mmele (brachytherapy) ka moso.
Haeba o na le dipotso dife kapa dife tse mabapi le phuputso ena, ka kopo ikutlwe o lokolohile ho ka ikopanya, Mof D. Long, ho 073 745 3306.

Ha ke o lebohe hape.
Eba le letsatsi le monate.
Nako ya phethelo: _____

FORMULATION OF THE GUIDELINES

APPENDIX 13:

CATEGORISED FINDINGS OF THE PATIENT INTERVIEWS

CATEGORISED FINDINGS OF THE PATIENT INTERVIEWS

1. Guidelines related to informational needs

A. Informed consent

A.1 Language of communication

- Patient should be addressed in their home language when the treatment procedure is explained to them.
- Use simple, home language to explain the treatment procedure as words such as "side-effects" are not understood.
- Include an interpreter when there is a language barrier between the informant and the patient.

A.2 *Opportunity for questions*

- *Encourage patients to ask questions.*

A.3 Reasons for signing consent

- *Obtain consent from the patient before allowing medical/ nursing students into the treatment room.*

B. Treatment related information

B.1 Treatment methods:

- An explanation has to be given to patients on how the brachytherapy treatment will be incorporated into the standard treatment schedule for cervical cancer over the six week period
- Inform the patients that brachytherapy treatment consists of five, weekly treatments
- Inform patients that brachytherapy is not an operation, but involves radiation
- Abstain from using words such as "burnt", "heat" and "slaughterhouse" when reference is made to brachytherapy treatment
- Inform the patients that on the day of their brachytherapy treatment, they will not receive chemotherapy or external beam radiotherapy

B.2 Side-effects:

- Patients need to be informed of the possible side-effects that can occur after brachytherapy treatment

B.3 Sexual intercourse:

- Sexual intercourse should be discussed with all patients, irrespective of their age or marital status
- Patients need to be informed of child-bearing possibilities after treatment

B.4 Pre-treatment preparations:

- Patients, including ward and private patients, need to be given detailed instructions regarding the pre-treatment preparations they have to follow on the evenings prior to and on the mornings before receiving their brachytherapy treatment as this can affect the outcome of the treatment delivery.
- Prescribe a sleeping tablet to patients that is scared or nervous for their first treatment
- Emphasize the importance of the pre-treatment preparation regarding the treatment outcome
- Be specific on what patients may eat and/drink prior to the treatment
- Inform the patients to abstain from food from 10pm on the evening prior to the treatment
- Provide the patients with laxatives they need to use prior to their five treatments

Explain to the patients the importance of taking a laxative on the day prior to their treatment as it is necessary to have an empty bowel system

B.5 Scheduled appointments:

- Schedule treatment times for private patients not before eight o'clock

Provide patients, including ward and private patients, weekly with information on when their next brachytherapy treatment is scheduled

B.6 Explanation of the procedure:

- Patients need to be given an opportunity to ask treatment related questions before signing the consent form
- Patients need to be encouraged not to be ashamed or to feel inadequate to ask questions
- Encourage patients not to listen to stories told by other patients, but to ask information from the personnel at the unit
- Provide patients with sufficient information that explains the brachytherapy treatment
- Inform patients that they will wake up in the recovery room and will be able to go home afterwards
- Inform the patients that if their treatment fails it needs to be repeated on another scheduled day

B.7 Pain management:

- Inform the patients that they will be given a sedative before treatment delivery that will help them not to experience pain during treatment delivery
- Inform patients that they will be given a sedative that will only last until the treatment delivery is finished
- Inform the patients that they will be given a sedative to prevent them from experiencing pain during the treatment

B.8 Follow-up appointments:

- Inform patients that they will receive instructions on their follow-up appointment at completion of their radiotherapy treatment schedule

C. Information format

- Provide patients with pamphlets or booklets on the disease, brachytherapy treatment procedure and possible side-effects
- Provide patients with informative material that is printed in their home language e.g. Sesotho, Afrikaans and English
- Hand out booklets or pamphlets on brachytherapy for patients to read at home
- Conduct information sessions for new patients. The following issues needs to be addressed during these sessions:
  - What can patients expect from the treatment?
  - What will be done to them? and
  - Will brachytherapy be a painful procedure or not? (Prompted)
- Provide additional information to new patients by means of information sessions that incorporates visual explanation via a DVD demonstration

2. Guidelines related to the multidisciplinary team

- Introduce patients to the personnel working at the brachytherapy unit
- Emphasize the role of the attending nurse in explaining the treatment procedure in detail to the patients before entering the treatment room
- Emphasize the role of the radiation therapists in explaining the treatment procedure a second time to patients when they are inside the treatment room
- Provide patients a choice of being treated by a female or male physician

- Ensure that each patient is treated weekly by the same physician
- Introduce the attending physician to the patients
- Make sure that the informed consent letters of patients have been signed before first treatment delivery
- Emphasize to personnel at the unit the importance of welcoming patients in a friendly manner
- Encourage professional appearance of personnel working at the unit
- Provide sufficient personnel to attend to patients in the waiting and recovery room and thereby preventing adverse advents from taking place
- Allocate someone specifically to inform all the new patients of the treatment procedure
- Allocate a health care worker to escort the patients to their mode of transport

3. Guidelines related to the environment and surroundings

- Showing the patients the brachytherapy treatment room a day in advance will assist in preparing them psychologically for the treatment
- Show patients the brachytherapy machine and the size of the applicators that is going to be used
- Provide an environment that is clean, tidy and patient friendly
- Ensure that patients are in a safe and secure environment by ensuring only one entrance to the recovery room.
- Familiarise patients with the location of the unit prior to their first treatment.
- Hand out leaflets to private patients with directions on where to register and to report for their first brachytherapy treatment

4. 1 Guidelines related to the waiting room

- Inform patients how long they need to wait before treatment delivery
- Inform the patients when treatment will commence
- Provide an explanation to the patients why treatment procedure is delayed
- Utilise the time spend in the waiting room to prepare the patients for the treatment and to encourage them

Make time to talk to new patients about their fears and concerns, especially the elderly patients

Obtain consent from patients before allowing medical or nursing students into the treatment room

Make the waiting room more welcoming by incorporating the following: Television, books with information on the treatment, newspapers, magazines, radio and flowers.

4.2 Guidelines related to the treatment room

Give patients a second explanation of the procedure inside the treatment room

Inform patients that a scan procedure will be performed before treatment delivery

Inform patients on how long the treatment would last

Inform the patients that there are safety mechanisms in place if machine breakage occurs

Individualise the dosage of sedative for each patient

Keep patients sedated until treatment is completed and applicators have been removed

Make a note in the patient's file when the dosage of the sedative was not enough to keep the patient from experiencing pain

Wait for the sedative to "kick-in" before inserting the applicators

4.3 Guidelines related to the recovery room

Have personnel present to assist the patients in the recovery room on their arrival from the treatment room

Provide supervision at all times in the recovery room in order to prevent adverse events

Provide a bell to ring in case of an emergency in the recovery room

Ensure that ward patients are fully recovered, before sending them back to the ward

Inform the patients in the recovery room of the outcome of the treatment

Provide water facilities for the patients in the recovery room

Provide patients with refreshments before they depart from the unit

See to the well-being of each patient before letting them go

Assist patients to their mode of transport

Transport ward and weak patients with wheelchairs to their destination

Provide patients, before they leave the unit, with a date for their next scheduled treatment

FOCUS GROUP INTERVIEWS

APPENDIX 14:

LETTER OF INVITATION TO PARTICIPATE IN A FOCUS GROUP INTERVIEW

APPENDIX 14

Ecufs number: 97/2012

LETTER OF INVITATION TO PARTICIPATE IN A FOCUS GROUP INTERVIEW

Date: 20 September 2013
Time: 12:00/13:30
Venue: Seminar room 2, Department of Oncology, Universitas Anex

Dear colleague

You are invited to participate in a focus group interview as part of a Ph.D. study with the title:

BRACHYTHERAPY FOR CERVICAL CANCER: GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT

The purpose of the study is to optimise the quality of patient management at the brachytherapy unit in the department. By means of the focus group interview the ideas, opinions and perceptions of all members of the multidisciplinary team regarding the proposed guidelines on quality patient management in a multidisciplinary environment will be obtained. It is an important part of the research to benchmark the guidelines with the opinions of professionals who regularly interact with the brachytherapy patients.

I hereby invite you to be part of the focus group interview. Participation is voluntary, and refusal to participate will involve no penalty. You may withdraw from this study at any time. However, there is no payment or awards for participating in this research study. Every effort will be made to keep personal information confidential.

The focus group interview will be audio recorded and will take a maximum of 90 minutes. It will be conducted in seminar room 2 of the Department of Oncology, Universitas Annex.

By signing the consent document you will give the researcher the right to present and publish the results of the study at congresses and in relevant medical journals, respectively. The findings of this study will be made available to you at the completion of the study in the published thesis, a copy of which will be provided to the department.

If you agree to take part in the focus group interview, you will be given a document with background information on the study. In addition, the proposed guidelines will be handed to you to review one week prior to the focus group interview. By signing the consent form you agree to refrain from discussing the proposed guidelines with the researcher or with any member of the multidisciplinary team before the focus group interview. The focus group interview will be conducted in a language decided on by the group to accommodate participants.

If you have any questions or concerns, please do not hesitate to contact Mrs D. Long at 073 745 3306 or deirdre.long6@gmail.com.

Contact details of Secretariat and Chair: Ethics Committee of the Faculty of Health Sciences, University of the Free State – for reporting of complaints/problems: Telephone number (051) 405 2812.

Thank you for your willingness to participate in this study.

Yours sincerely

Mrs D. Long
Assistant-Director in Radiography
Department of Oncology
Universitas Annex
Bloemfontein
Free State

FOCUS GROUP INTERVIEWS

APPENDIX 15:

VERSOEKBRIEF OM DEEL TE NEEM AAN Ǹ FOKUSGROEP ONDERHOUD

APPENDIX 15

Ecufs nommer: 97/2012

VERSOEKBRIEF OM DEEL TE NEEM AAN Ǹ FOKUSGROEP ONDERHOUD

Datum: 20 September 2013
Tyd: 12:00
Plek: Seminaarkamer 2, Departement Onkologie, Universitas Annex

Geagte kollega

U word versoek om deel te neem aan ʼn fokusgroep-onderhoud wat deel uitmaak van ʼn Ph.D. studie getiteld:

BRAGITERAPIE VIR SERVIKSKANKER: RIGLYNE OM KWALITEIT PASIËNT BESTUUR TE FASILITEER IN ʼn MULTIDISSIPLINÊRE OMGEWING

Die doel van die studie is om die kwaliteit van pasiënt bestuur by die bragiterapie eenheid van die departement te optimaliseer. Deur middel van die fokusgroep-onderhoud sal die idees, menings en sienings van al die lede van die multidissiplinêre span ten opsigte van die voorgestelde riglyne vir kwaliteit bestuur van pasiënte in ʼn multidissiplinêre omgewing verkry word. Dit is ʼn belangrike deel van die navorsing om die voorgestelde riglyne te toets teen die opinies van gekwalifiseerde personeel wat op ʼn gereelde basis interaksie het met pasiënte wat bragiterapie ontvang.

Hiermee nooi ek u uit om deel te wees van die fokusgroep-onderhoud. Deelname is vrywillig en u sal nie gepenaliseer word deur die versoek van die hand te wys nie. U mag enige tyd van die studie onttrek. Geen betaling of geldelike vergoeding word gegee aan persone wat aan die navorsingstudie deelneem nie. Pogings sal aangewend word om persoonlike inligting vertroulik te hanteer.

ʼn Klankopname sal van die fokusgroep-onderhoud gedoen word en die maksimum tydsduur sal 90 minute wees. Die onderhoud sal plaasvind in seminaarkamer 2 van die Departement Onkologie, Universitas Annex.

Deur die toestemmingsdokument te teken gee u die navorser die reg om die resultate van die studie by kongresse aan te bied en in toepaslike mediese joernale te publiseeer. Die resultate van die studie sal aan u bekend gemaak in ʼn gepubliseerde tesis waarvan ʼn kopie aan die departement voorsien sal word.

As u toestem om aan die fokusgroep-onderhoud deel te neem, sal u ʼn dokument ontvang met agtergrond inligting omtrent die studie. Bykomend sal u ʼn week voor die fokusgroep-onderhoud ʼn kopie ontvang van die voorgestelde riglyne. Deur die toestemmingsdokument te teken onderneem u om nie die voorgestelde riglyne met die navorser of met enige lid van die multidissiplinêre span te bespreek voor die fokusgroep-onderhoud nie. Die fokusgroep-onderhoud sal plaasvind in ʼn taal wat vasgestel word deur die groep om al die deelnemers te akkomodeer.

Indien u enige vrae of probleme het, kan u mev D.Long onverwyld kontak by 073 745 3306 of deirdre.long6@gmail.com.

Kontak besonderhede van die Sekretariaat en Voorsitter: Etiekkomitee van die Fakulteit Gesondheidswetenskappe, Universiteit van die Vrystaat – Telefoonnommer: (051) 405 2812.

Dankie vir u bereidwilligheid om aan die studie deel te neem.

Die uwe

Mev. D. Long
Assistent-Direkteur in Radiografie
Departement Onkologie
Universitas Annex
Bloemfontein
Vrystaat

FOCUS GROUP INTERVIEWS

APPENDIX 16:

CONSENT DOCUMENT

APPENDIX 16

Ecufs number: 97/2012

CONSENT DOCUMENT

Date_____

I, the undersigned, hereby give consent to participate in a focus group interview, which is scheduled to take place on_____, time_____, venue_____.

Please provide your particulars:
Surname:

_____

Full names:

_____

Contact number:

_____

E-mail address:

_____

Socio-demographic details:
Age:

_____

Race/Ethnicity

_____

Gender:

_____

Occupation:

_____

Highest qualification:

_____

_____ _____

Signature Date

I wish to assure you that your information will be treated in confidence and no reference will be made to your personal details. Please take note that the results from this research will be published.

Thank you in advance.

Yours sincerely

Mrs D. Long
Assistant-Director in Radiography
Department of Oncology
Universitas Annex
Bloemfontein
Free State

FOCUS GROUP INTERVIEWS

APPENDIX 17:

TOESTEMMINGDOKUMENT

APPENDIX 17

Ecufs nommer: 97/2012

TOESTEMMINGSDOKUMENT

Datum_____

Ek, die ondergetekende, gee hiermee my toestemming om aan die fokusgroep-onderhoud deel te neem wat geskeduleer is om op_____,
om_____ by die_____ plaas te vind.

Verskaf asseblief u persoonlike besonderhede:

Van:

_____

Volle voorname:

_____

Kontaknommer:

_____

E-posadres:

_____

Sosio-demografiese besonderhede:
Ouderdom:

_____

Rassegroep:

_____

Geslag:

_____

Beroep:

_____

Hoogste kwalifikasie:

_____

_____ _____

Handtekening Datum

Ek wil u verseker dat u inligting vertroulik hanteer sal word en dat daar geen verwysing na enige persoonlike besonderhede gemaak sal word nie. Neem asseblief kennis dat die resultate van die studie gepubliseer sal word.

By voorbaat dankie.

Die uwe

Mev D. Long
Assistent-Direkteur in Radiografie
Departement Onkologie
Universitas Annex
Bloemfontein
Vrystaat

FOCUS GROUP INTERVIEWS

APPENDIX 18:

INFORMATION LETTER

Ecufs number: 97/2012

INFORMATION LETTER

STUDY TITLE: BRACHYTHERAPY FOR CERVICAL CANCER: GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT

Background

Currently, there are many sets of guidelines to assist institutions to develop or optimise brachytherapy facilities regarding the treatment regimes, techniques, dose specification and treatment planning methods. However, a literature search has indicated that studies on patients' experiences while undergoing brachytherapy treatment are limited and were conducted in developed countries where women's experiences of treatment delivery and patient management may be different to those experienced by South African women. Therefore, to facilitate quality patient management in a multidisciplinary environment, specifically at a brachytherapy unit, it was deemed necessary to explore the patients' experiences and use the findings to formulate guidelines for quality patient management.

Research question

The research was guided by the following questions:

- What are the needs and expectations of women diagnosed with cervical cancer, while undergoing high dose rate brachytherapy treatment at the Department of Oncology, Bloemfontein?
- Is there a way of ensuring that their needs and expectations are adequately managed by members of a multidisciplinary team?

Purpose and objectives

The purpose of this prospective qualitative study was to formulate guidelines to facilitate quality patient management for cervical cancer patients undergoing high dose rate brachytherapy treatment in a multidisciplinary environment.

To achieve the purpose of the study, the following stages have been completed:

Stage one: Patient interviews

• Explore the patient experience, while undergoing HDR brachytherapy. This was done by conducting in-depth, semi-structured interviews with 28 purposively selected participants. In order to include women across the age spectrum into the study, the researcher purposively recruited ten patients as participants from each of the following three age groups: 30-45 years; 46-60 years and 61years and older. Each age group included at least one private and one local oncology patient. Hospitalised patients were also included in the study sample.

Stage two: Formulation of proposed guidelines

• Formulate preliminary guidelines for quality patient management that is based on the patient experience. This was done by using the findings of stage one, conducting a literature search on the topic and incorporating the aggregate experience of the researcher.

The focus group interviews will be stage 3.

Stage three: Focus group interviews

• To review and refine the proposed guidelines by means of two focus group interviews. The focus group will include all members of the multidisciplinary team working at the brachytherapy unit, with at least a year's experience of service delivery at the brachytherapy unit. The sample will include the following members of the multidisciplinary team: head of the department, radiation oncologists, radiation oncology registrars, radiation therapists and oncology nurses.

Thereafter stages four and five will follow.

Stage four: Review by heads or designated representatives

• To gather feedback on the proposed guidelines from heads/designated representatives of brachytherapy units in South Africa and to incorporate their advice, comments and opinions into revisions of these guidelines.

Stage five: Guidelines to facilitate quality patient management

• To formulate the final guidelines for quality patient management in a multidisciplinary environment.

FOCUS GROUP INTERVIEWS

APPENDIX 19:

INLIGTINGSBRIEF

Ecufs nommer: 97/2012

INLIGTINGSBRIEF

STUDIETITEL: BRAGITERAPIE VIR SERVIKSKANKER: RIGLYNE OM KWALITEIT PASIËNT BESTUUR TE FASILITEER IN 'n MULTIDISSIPLINÊRE OMGEWING

Agtergrond
Huidiglik is daar verskeie riglyne beskikbaar om diensverkaffers te help om bragiterapie fasiliteite te ontwikkel of te verbeter t.o.v. behandelingskedules, tegnieke, dosis spesifikasies en metodes van beplanning. 'n Literatuurstudie toon egter dat studies wat gefokus het op die ervarings van pasiënte tydens hul bragiterapie behandeling beperk is. Dié studies is uitgevoer in ontwikkelde lande waar vroue se ervarings van hul behandeling en pasiënt bestuur moontlik kan verskil van dié van Suid-Afrikaanse vroue. Dus, om te verseker dat kwaliteit pasiënt bestuur toegepas word in 'n multidissiplinêre omgewing, spesifiek by 'n bragiterapie eenheid, was dit nodig om pasiënte se ervarings te verken en die bevindings te gebruik om riglyne vir kwaliteit pasiënt bestuur te formuleer.

Navorsingsvraag
Die navorsing was gelei deur die volgende vrae:

- Wat is die behoeftes en verwagtinge van vroue, wat met servikskanker gediagnoseer is, tydens hul hoë dosis tempo bragiterapie behandeling in die Departement Onkologie, Bloemfontein?
- Is daar 'n manier om te verseker dat dié groep pasiënte se behoeftes en verwagtinge voldoende aangespreek word deur lede van 'n multidissiplinêre span?

Doel en doelwit
Die doel van hierdié prospektiewe kwalitatiewe studie was om riglyne te formuleer om kwaliteit pasiënt bestuur te fasiliteer vir sevikskanker pasiënte tydens hul bragiterapie behandeling in 'n multidissiplinêre omgewing.

Om die doel van die studie te bereik is die volgende fases voltooi:

Fase een: Onderhoude met pasiënte
• Verken die pasiënt se ervaringe tydens hoë dosis tempo bragiterapie behandeling. Dit was gedoen deur semi-gestruktueerde onderhoude met 28 doelgerig geselekteerde deelnemers te hou. Om 'n breë spektrum van pasiënte van alle ouderdomsgroepe by die studie in te sluit het die navorser tien pasiënte doelgerig geselekteer in die volgende drie ouderdomsgroepe:30-45 jaar; 46-60 jaar en 61jaar en ouer. Elke ouderdomsgroep het ten minste een privaat en een pasiënt van Bloemfontein ingesluit. Saalpasiënte was ook in die studie ingesluit.

Fase twee: Formulering van voorgestelde riglyne
• Formuleer voorgestelde riglyne vir kwaliteit pasiënt bestuur wat gebaseer is op die resultate van die pasiënt se ervaring. Dit was gedoen deur die bevindings van fase een te gebruik, 'n literatuurstudie oor die huidige onderwerp uit te voer en die saamgestelde werkservaring van die navorser by te werk.

Fase drie bestaan uit die fokusgroep onderhoude.

Fase drie: Fokusgroep onderhoude

• Om die voorgestelde riglyne te hersien en te wysig en te verfyn deur middel van twee fokusgroep-onderhoude. Die fokusgroep sal al die lede van die multidissiplinêre span werksaam by die bragiterapie eenheid met ten minste ‘n jaar ondervinding van dienslewering by die bragiterapie eenheid insluit. Die steekproef sal die volgende lede van die multidissiplinêre span insluit: departementshoof, stralingsonkoloë, kliniese assistente, stralingsterapeute en onkologie verpleegkundiges.

Daarna sal fases vier en vyf van die studie volg.

Fase vier: Hersien deur hoofde of afgevaardigde verteenwoordiges

• Om terugvoer te kry van hoofde/afgevaardigde verteenwoordiges van bragiterapie eenhede in Suid-Afrika oor die voorgestelde riglyne en om hulle advies, menings en opinies te inkorporeer in hersiening van hierdie riglyne.

Fase vyf: Riglyne om kwaliteit pasiënt bestuur te fasiliteer

• Om die finale riglyne vir kwaliteit pasiënt bestuur in ’n multidissiplinêre omgewing te formuleer.

FOCUS GROUP INTERVIEWS

APPENDIX 20:

PROPOSED GUIDELINES

PROPOSED GUIDELINES

Brachytherapy is an essential component in the treatment schedule for women diagnosed with locally advanced carcinoma of the cervix. The delivery of cervical brachytherapy requires the collaboration of a multidisciplinary team that includes radiation oncologists, radiation oncology registrars, radiation therapists and oncology nurses. Brachytherapy is an interdisciplinary procedure and the aim of the proposed guidelines is to provide team members with guidance to facilitate quality patient management as an essential component of patient satisfaction with services rendered.

The proposed guidelines address logistical matters of the practice setting, shared and exclusive roles and responsibilities of members of the multidisciplinary team at the new patient clinic and the brachytherapy unit of the department. The roles described below are not mutually exclusive, but depending on case load and facility preferences, they may be performed by different team members. It needs to be emphasized that some of the proposed guidelines are already in implementation in the department, either wholly or partially. Some need reaffirmation and in some cases additional resources may be required to implement the guidelines. The proposed guidelines are compatible with existing values and routines among members of the multidisciplinary team. All that should be expected is that members will follow a reasonable course of action based on current knowledge, available resources and the needs of the patient to deliver effective and safe medical care.

Please read through the proposed guidelines. In preparation for the focus group interview, circle the items you would like to discuss during the focus group interview. Please refrain from discussing the proposed guidelines with the researcher or any member of the multidisciplinary team. You are requested to bring this document with to the focus group interview, as it will be collected by the researcher after the discussion for the purposes of confidentiality.

A. Requirements in the practice setting

1. An environment that is clean, tidy and patient friendly by incorporating the following in the waiting room: television, books with information on the treatment, newspapers, magazines, radio and flowers.
2. A bed in a separate room, in close proximity to the waiting room, where ward or ill patients could await their treatment under supervision.
3. Patients are in a safe and secure environment by ensuring only one entrance to the recovery room.
4. Sufficient personnel to attend to patients in the recovery room, preventing adverse incidents from occurring.
5. A bell to ring in case of an emergency in the recovery room.
6. Water drink facilities for the patients in the recovery room.
7. Refreshments for the patients before they depart from the unit.
8. Wheelchairs for patients who are too weak to walk to their mode of transport.

Comments

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B. Shared roles and responsibilities

Information

1. All members of the team are responsible for the accuracy of the information and for making certain that the information is understood by the patient.
2. Inform the patient about her disease and forthcoming treatment in her home language.
3. Inform the patient of the availability of the services of an interpreter.
4. When an interpreter is used, documentation should be placed in the patient's medical file, indicating the name and qualification of the person who acted as an interpreter.
5. Explain the nature of the proposed treatment by making reference to brachytherapy as the inside radiation.
6. Avoid inappropriate terminology such as "burn", "heat" and "slaughterhouse".
7. Avoid using technical terms such as "side-effects".
8. Allocate a member of the multidisciplinary team to inform the new patient of her forthcoming brachytherapy treatment, preferably a day or two prior to the scheduled treatment.
9. Make use of information sessions, informative material such as booklets or pamphlets, or digital video display, to inform patients of what brachytherapy entails.
10. Informative material and a digital video display should be available in at least Afrikaans, English and Sesotho.
11. Discourage the patient from gaining treatment related information from fellow patients.
12. Questions should be directed to members of the unit.
13. Ensure that the informed consent letter of the patient has been signed before her first treatment delivery.
14. Obtain consent from the patient before allowing medical or nursing students into the treatment room.
15. Inform the patient on a weekly basis of the timing of her next brachytherapy treatment.
16. Explain to the patient how the brachytherapy procedure will be incorporated into her six week treatment schedule.
17. Inform the patient that she will receive information regarding her follow-up appointments at completion of her radiotherapy treatment schedule.

Directions

18. Allocate a person to provide the new patient, who is unfamiliar with the hospital surroundings, with directions on where to register and to report for their first brachytherapy treatment.
19. Show the new patient the location of the unit and introduce her to the personnel.

Pre-treatment preparation

20. Provide the patient with detailed instructions regarding her pre-treatment preparations on the evening and morning prior to receiving the brachytherapy.

Treatment procedure

21. Provide the patient with an estimated waiting time.
22. Provide the patient with an estimated treatment time.
23. Provide the patient with an explanation if treatment has been delayed.
24. Inform the patient in the recovery room of the outcome of the treatment and if necessary, provide her with a rescheduled date in case of treatment cancellation.
25. Allocate a person to escort patients to their mode of transport or back to the ward.

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C. Exclusive roles and responsibilities

C.1 New patient clinic

Radiation oncologist/radiation oncology registrar

Informed consent

1. Informed consent for the brachytherapy procedure must be obtained by or under supervision of a licenced physician qualified to perform and familiar to the procedure.
2. Informed consent must be obtained and documented prior to the initiation of brachytherapy where conscious sedation will be administered.
3. A physician who is not fluent in the language of the patient should use the services of an interpreter who is fluent in the language the patient can understand and that of the physician.
4. Provide the patient with an opportunity to ask treatment related questions before signing the consent form. Encourage them not to be ashamed or to feel inadequate to ask questions.
5. Have consent forms available in alternative languages such as Sesotho, English and Afrikaans.

Specifications for informed consent

During the process of obtaining informed consent, the physician should inform the patient of
the following:

Treatment procedure

6. Ensure that the patient understands that brachytherapy is not an operation to the uterus, but radiation to the inside of the cervix.
7. Explain to the patient that she will receive conscious sedation to prevent discomfort and pain during treatment delivery. She will wake up in the recovery room after which she will be able to go home.

Treatment effects

8. Provide the patient with understandable information on the possible side-effects of the treatment.
9. Discuss the aspect of sexual intercourse and childbearing with all the patients, irrespective of their age or marital status.

Comments

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C.2 Brachytherapy unit

Radiation therapist

1. Explain to the patient briefly the radiotherapy procedure that will take place and that the brachytherapy treatment delivery will be preceded by a CT scan procedure.
2. Show the new patient the inside of the treatment room and the treatment unit.
3. Inform the patient that during treatment delivery, she can communicate to personnel outside the treatment room via an intercom system and a video camera will provide visual communication with her.
4. Inform the patient that there are safety mechanisms in place if machine breakage occurs and that the applicators can be removed, if necessary.

Comments

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Oncology nurse

1. Show the new patient the location of the dressing- waiting and recovery rooms.
2. Utilise the time spent in the waiting room to prepare the new patient emotionally for the treatment. Listen to her fears and concerns, especially the elderly.
3. Provide the new patient with a detailed explanation of their role during the treatment procedure.
4. Have nursing personnel present to assist the patient in the recovery room on her arrival from the treatment room.
5. Ensure that the ward patient has fully recovered, before sending her back to the ward.
6. See to the well-being of each patient before she leaves the unit.

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Radiation oncologist/radiation oncology registrar

1. The attending radiation oncologist or radiation oncology registrar should introduce him/herself to the patient.
2. Provide the patient with an explanation of the procedure he/she will be performing.
3. Provide the patient with the choice of being treated by a female or male radiation oncologist or radiation oncology registrar.
4. Ensure that each patient is treated weekly by the same radiation oncologist or radiation oncology registrar.
5. Keep the patient sedated until her treatment is completed and the applicators have been removed
6. Documentation should be made of the sedation requirements during the procedure for future reference in following treatments.
7. Individualise the sedation dosage.

Comments

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FOCUS GROUP INTERVIEWS

APPENDIX 21:

INTERVIEW SCHEDULE: GROUP FACILITATOR

APPENDIX 21

ECUFS number: 97/201

INTERVIEW SCHEDULE: GROUP FACILITATOR

GROUP 1/2
Date: 20 September 2013
Time: 12:00/13:30
Venue: Seminar room 2, Department of Oncology, Universitas Annex, Bloemfontein

Appointed facilitator: Prof. H.S Friedrich-Nel
Assistant facilitator: Prof. G. Joubert

Welcome: Introduce study promoters: Hesta Friedrich-Nel and Gina Joubert. They will perform the duties of a facilitator and assistant-facilitator, respectively. The facilitator will guide the discussion and the assistant-facilitator will summarise the responses at the end of each section. Notes will be made for review by the researcher.

Mr Rod Campbell (Emergency Medical Care Unit, CUT) is busy with his master's degree and has asked to be present as an observer to learn more about focus group interviewing.

The topic is:
"Brachytherapy for cervical cancer: Guidelines to facilitate quality patient management in a multidisciplinary environment"

You have been selected to participate, because of your expertise and knowledge of patient management at the brachytherapy unit. I would like to emphasize that no person will be identified by name during the interview and only collective responses will be reported.

Guidelines: Before the session will commence, provide the focus group members with the following logistical aspects of the interviewing process:

- The focus group interview will be conducted in English as to accommodate participants. However, you can provide your responses in either Afrikaans or English. The facilitator will translate where applicable.
- There are no right of wrong answers, only different points of view and opinions.
- The interview will be audio recorded and members are advised to speak clearly and only allow one person to speak at a time.
- Let your voice and opinion be taken into account in establishing quality patient management in the department and do not feel intimidated by colleagues
- The formulation of the proposed guidelines was not based on patient numbers. However, patient numbers and quotes can be provided when deemed necessary to support statements made.
- The general agreement regarding each cluster of guidelines will be summarised.
- Please switch you cellular phones off during the interview.
- Talk to each other as your constructive feedback will be appreciated.

Opening questions:

1. In general, what is your opinion of the structure of the proposed guidelines?

• Layout
• Formulation

2. In general, what is your overall opinion concerning the proposed guidelines on the management if cervical cancer patients undergoing brachytherapy treatment in the department?

The following questions are directed to gather your feedback on the proposed guidelines on section A - requirements necessary in the practice setting:

3. Questions on section A:

• Do you agree with the guidelines in section A? If yes, Why? If no, Why not? • Do resources allow for the implementation of the guidelines? If yes, How? If no, Why not? • Is there anything else you would like to add to the proposed guidelines mentioned in this section? If yes, what would it be? • Summarise – Is everyone in agreement?

The following questions are directed to gather your feedback on the proposed guidelines on B- Shared roles and responsibilities of members of the multidisciplinary team:

4. Questions on section B:

• Do you agree with the guidelines in section B? If yes, Why? If not, Why not? • Are there any of the shared responsibilities that should be allocated to as specific person? If yes, why and to whom must it be allocated? • Do resources allow for the implementation of the guidelines? If yes, How? If not, Why not? • Is there anything else you would like to add to the proposed guidelines mentioned in this section? If yes, what would it be? • Summarise – Is everyone in agreement?

The following questions are directed to gather your feedback on the proposed guidelines on C.1- Exclusive roles and responsibilities of the radiation oncologist/registrar at the new patient clinic:

5. Questions on section C.1:

• Do you agree with the guidelines in section C.1? If yes, Why? If not, Why not? • Are the proposed guidelines exclusive to radiation oncologists or should some be shared? If not, why should it be shared and with whom? • Do resources allow for the implementation of the guidelines? If yes, How? If not, Why not? • Is there anything else you would like to add to the proposed guidelines mentioned in this section? If yes, what would it be? • Summarise – Is everyone in agreement?

The following questions are directed to gather your feedback on the proposed guidelines on C.2- Exclusive roles and responsibilities at the brachytherapy unit performed by the radiation therapist:

6. Questions on section C.2.1:

• Do you agree with the guidelines in section C.2.1? If yes, Why? If not, Why not? • Are the proposed guidelines exclusive to radiation therapists or should it be shared? If not, why should it be shared and with whom? • Do resources allow for the implementation of the guidelines? If yes, How? If not, Why not? • Is there anything else you would like to add to the proposed guidelines mentioned in this section? If yes, what would it be? • Summarise – Is everyone in agreement?

The following questions are directed to gather your feedback on the proposed guidelines on C.2- Exclusive roles and responsibilities at the brachytherapy unit performed by the oncology nurse:

7. Questions on section C.2.2:

• Do you agree with the guidelines in section C.2.2? If yes, Why? If not, Why not? • Are the proposed guidelines exclusive to the oncology nurse or should it be shared? If not, why should it be shared and with whom? • Do resources allow for the implementation of the guidelines? If yes, How? If not, Why not?

• Is there anything else you would like to add to the proposed guidelines mentioned in this section?
If yes, what would it be?
• Summarise – Is everyone in agreement?

The following questions are directed to gather your feedback on the proposed guidelines on C.2- Exclusive roles and responsibilities at the brachytherapy unit performed by the radiation oncologist/registrar:

8. Questions on section C.2.3:

• Do you agree with the guidelines in section C.2.3?
If yes, Why?
If not, Why not?
• Are the proposed guidelines exclusive to radiation oncologists or should it be shared?
If not, why should it be shared and with whom?
• Do resources allow for the implementation of the guidelines?
If yes, How?
If not, Why not?
• Is there anything else you would like to add to the proposed guidelines mentioned in this section?
If yes, what would it be?
• Summarise – Is everyone in agreement?

Is there anything else that needs to be added to the proposed guidelines on patient management in a multidisciplinary environment?

If yes, What will it be and why?

Conclusion

• Summarise with confirmation.
• Review the purpose of the focus group interview and ask if anything has been missed.
• Thanks and dismissal.

FOCUS GROUP INTERVIEWS

APPENDIX 22:

INTERVIEW SCHEDULE: ASSISTANT FACILITATOR

APPENDIX 22

ECUFS number 97/2012

INTERVIEW SCHEDULE: ASSISTANT FACILITATOR

GROUP 1/2
Date: 20 September 2013
Time: 12:00/13:30
Venue: Seminar room 2, Department of Oncology, Universitas Annex, Bloemfontein

Appointed facilitator: Prof. H.S Friedrich-Nel
Assistant facilitator: Prof. G. Joubert

Welcome: Introduce study promoters: Hesta Friedrich-Nel and Gina Joubert. They will perform the duties of a facilitator and assistant-facilitator, respectively. The facilitator will guide the discussion and the assistant-facilitator will summarise the responses at the end of each section. Notes will be made for review by the researcher.

Mr Rod Campbell (Emergency Medical Care Unit, CUT) is busy with his master's degree and has asked to be present as an observer to learn more about focus group interviewing.

The topic is:
"Brachytherapy for cervical cancer: Guidelines to facilitate quality patient management in a multidisciplinary environment"

You have been selected to participate, because of your expertise and knowledge of patient management at the brachytherapy unit. I would like to emphasize that no person will be identified by name during the interview and only collective responses will be reported.

Guidelines: Before the session will commence, provide the focus group members with the following logistical aspects of the interviewing process:

- The focus group interview will be conducted in English as to accommodate participants. However, you can provide your responses in either Afrikaans or English. The facilitator will translate where applicable.
- There are no right of wrong answers, only different points of view and opinions.
- The interview will be audio recorded and members are advised to speak clearly and only allow one person to speak at a time.
- Let your voice and opinion be taken into account in establishing quality patient management in the department and do not feel intimidated by colleagues
- The formulation of the proposed guidelines was not based on patient numbers. However, patient numbers and quotes can be provided when deemed necessary to support statements made.
- The general agreement regarding each cluster of guidelines will be summarised.
- Please switch you cellular phones off during the interview.
- Talk to each other as your constructive feedback will be appreciated.

Opening questions:

1. In general, what is your opinion of the structure of the proposed guidelines?

• Layout
• Formulation

Assistant facilitator: Notation of non-verbal attributes of participants

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2. In general, what is your overall opinion concerning the proposed guidelines on the management if cervical cancer patients undergoing brachytherapy treatment in the department?

Assistant facilitator: Notation of non-verbal attributes of participants

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The following questions are directed to gather your feedback on the proposed guidelines on section A - requirements necessary in the practice setting:

3. Questions on section A:

• Do you agree with the guidelines in section A? If yes, Why? If no, Why not? • Do resources allow for the implementation of the guidelines? If yes, How? If no, Why not? • Is there anything else you would like to add to the proposed guidelines mentioned in this section? If yes, what would it be? • Summarise – Is everyone in agreement?

Assistant facilitator: Notation of non-verbal attributes of participants

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The following questions are directed to gather your feedback on the proposed guidelines on B- Shared roles and responsibilities of members of the multidisciplinary team:

4. Questions on section B:

• Do you agree with the guidelines in section B? If yes, Why? If not, Why not? • Are there any of the shared responsibilities that should be allocated to as specific person? If yes, why and to whom must it be allocated? • Do resources allow for the implementation of the guidelines? If yes, How? If not, Why not? • Is there anything else you would like to add to the proposed guidelines mentioned in this section? If yes, what would it be? • Summarise – Is everyone in agreement?

Assistant facilitator: Notation of non-verbal attributes of participants

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The following questions are directed to gather your feedback on the proposed guidelines on C.1- Exclusive roles and responsibilities of the radiation oncologist/registrar at the new patient clinic:

5. Questions on section C.1:

• Do you agree with the guidelines in section C.1? If yes, Why? If not, Why not? • Are the proposed guidelines exclusive to radiation oncologists or should some be shared? If not, why should it be shared and with whom? • Do resources allow for the implementation of the guidelines? If yes, How? If not, Why not? • Is there anything else you would like to add to the proposed guidelines mentioned in this section? If yes, what would it be? • Summarise – Is everyone in agreement?

Assistant facilitator: Notation of non-verbal attributes of participants

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The following questions are directed to gather your feedback on the proposed guidelines on C.2- Exclusive roles and responsibilities at the brachytherapy unit performed by the radiation therapist:

6. Questions on section C.2.1:

• Do you agree with the guidelines in section C.2.1?
If yes, Why?
If not, Why not?
• Are the proposed guidelines exclusive to radiation therapists or should it be shared?
If not, why should it be shared and with whom?
• Do resources allow for the implementation of the guidelines?
If yes, How?
If not, Why not?
• Is there anything else you would like to add to the proposed guidelines mentioned in this section?
If yes, what would it be?
• Summarise – Is everyone in agreement?

Assistant facilitator: Notation of non-verbal attributes of participants

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The following questions are directed to gather your feedback on the proposed guidelines on C.2- Exclusive roles and responsibilities at the brachytherapy unit performed by the oncology nurse:

7. Questions on section C.2.2:

• Do you agree with the guidelines in section C.2.2?
If yes, Why?
If not, Why not?
• Are the proposed guidelines exclusive to the oncology nurse or should it be shared?
If not, why should it be shared and with whom?
• Do resources allow for the implementation of the guidelines?
If yes, How?
If not, Why not?
• Is there anything else you would like to add to the proposed guidelines mentioned in this section?
If yes, what would it be?
• Summarise – Is everyone in agreement?

Assistant facilitator: Notation of non-verbal attributes of participants

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The following questions are directed to gather your feedback on the proposed guidelines on C.2- Exclusive roles and responsibilities at the brachytherapy unit performed by the radiation oncologist/registrar:

8. Questions on section C.2.3:

• Do you agree with the guidelines in section C.2.3? If yes, Why? If not, Why not? • Are the proposed guidelines exclusive to radiation oncologists or should it be shared? If not, why should it be shared and with whom? • Do resources allow for the implementation of the guidelines? If yes, How? If not, Why not? • Is there anything else you would like to add to the proposed guidelines mentioned in this section? If yes, what would it be? • Summarise – Is everyone in agreement?

Assistant facilitator: Notation of non-verbal attributes of participants

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Is there anything else that needs to be added to the proposed guidelines on patient management in a multidisciplinary environment?

If yes, What will it be and why?

Conclusion

• Summarise with confirmation.
• Review the purpose of the focus group interview and ask if anything has been missed.
• Thanks and dismissal.

FOCUS GROUP INTERVIEWS

APPENDIX 23:

SUPPORTIVE DOCUMENT: ASSISTANT FACILITATOR

SUPPORTIVE DOCUMENT: ASSISTANT FACILITATOR

Additional information

A. Requirements in the practice setting

1. An environment that is clean, tidy and patient friendly by incorporating the following in the waiting room: television, books with information on the treatment, newspapers, magazines, radio and flowers.

[All 28 participants were impressed with the clean and tidy environment]

[15 of 28 participants suggested some improvements for the waiting room]

> *Maybe there could be a television in there where you can look at something, but not thinking about this radiation*; *So it's better to get something to take your mind off from it* (P6: 55, Aca, Ses, Eng, Kat, Sec)

> *…as daar miskien tydskrifte is of daar miskien net 'n radio kan wees* (…if there could be some magazines or maybe a radio) (P14: 41, Aca, Afr, Afr, :Loc, No)

2. A bed in a separate room, in close proximity to the waiting room, where ward or ill patients could await their treatment under supervision.

3. Patients are in a safe and secure environment by ensuring only one entrance to the recovery room.

> *…I was afraid of this door, because we come with this, this one here; And you are alone and there's no security…Come here and just stole your things* (P26: 48, Pr, Ses, En, :Loc, Ter)

4. Sufficient personnel to attend to patients in the recovery room, preventing adverse incidents from occurring – examples:

> *It's my problem that I saw that the staff is shortage now here, because when they put you here, ne, they go outside, You are alone; There's no one who's accompanying you this side* (P26: 48, Pr, Ses, Eng, Loc, Ter)

> *Dan's sy in en uit. Sy moet orals gaan. So dan is daar nie iemand wat daar by jou is nie"*(She goes in and out. She must be everywhere and therefore there is no-one with you) (P12: 50, Aca, Afr, Afr, Kat, Prim)

[1 of 28 participants fell off the bed in the recovery room-dizzy]

> *daar moet hulle altyd iemand hou daar of iemand laat kyk sodra jy uitkom. Want as jy wakker skrik…jy's deurmekaar. Jy weet nie waar jy is nie. Dan spring jy op en toe't ek nou die dag geval* (they must always have someone there, because when you wake up…you are confused. You don't know where you are. You jump up and I fell the other day) (P12: 50, Aca, Afr, Afr, Kat, Prim)

[1 of 28 participants witnessed a fellow patient falling of her bed]

Eendag toe sit ons in die wagkamer…. toe sien ek lat 'n pasiënt op die vloer val van bedwelmgeit. Toe roep ek die suster… (One day, we sat in the waiting room. I then saw a patient falling to the floor from being drugged. I then called the sister…) (P18: 41, Aca, Afr, Afr, Kat, Prim)

[2 of 28 participants left with syringes still intact]

…wat 'n probleem is, na die binne bestraling was daar twee mense wat die drippetjies wat hulle vir ons gee hier, dan vergeet hulle om daai drippetjie uit te haal en die mense het gegaan met hulle (..it is a problem, that after the inside radiation there were two people with drips which they give here to us, they forgot to remove those drips and the people left with it) (P12: 50, Aca, Afr, Afr, Kat, Prim)

5. A bell to ring in case of an emergency in the recovery room.

They are not around and there is not a bell. Something you can be able to ring them that side to say: Please help[!] (P26: 48, Pr, Ses, Eng, Loc, Ter)

6. Water drink facilities for the patients in the recovery room.
[10 of 28 participants felt thirsty – only tap facility in room]

Ek was, jy's baie dors. Jy's baie dors as jy daarvan af kom (I was, you are very thirsty. You are very thirsty when you come from there) *Gewoonlik drink ons maar sommer klaar hier, daar by die kraan.* (We usually drink there, from the tap) (P18: 41, Aca:, Afr, Afr, Kat, Prim)

Weet jy ek sal sê dit sal nogal 'n goeie ding wees as hulle dalk net vir mens soos water of iets net neersit in die recovery room. As jy wakker word, dat jy net so bietjie water kan drink (You know, I would say that it would be a good thing if they could put some water in the recovery room. That when you wake up, you could drink some water) (P4: 40, Aca, Afr, Afr, Ol, Sec)

7. Refreshments for the patients before they depart from the unit.
[7 of 28 were hungry- e.g. biscuit and energy drink]

So maybe after we received treatment, they can give something to eat or to drink (P21: 38, Pr, Ses, Eng, Ol, Ter)

…jy is baie honger, want jy't mos nie die oggend geëet nie. So jy is honger (…you are very hungry, because you did not eat anything in the morning. So therefore, you are hungry) (P4: 40, Aca, Afr, Afr, Ol, Sec)

Jy voel regtigwaar honger, want kyk jy eet mos nou ook nie. En jy eet ook nie eintlik goed, want jy's nou so op jou "nerves"…van daai slagpale… (You really are hungry, because you haven't been eating. And you don't eat well, because you are nervous…of the "slaughterhouse"…) (P12: 50, Aca, Afr, Afr, Kat, Prim)

8. Wheelchairs for patients who are too weak to walk to their mode of transport.
[19 of 28 participants felt dizzy when leaving the unit – sedation medicine]

There should be somebody here to take you in a wheelchair to where you need to be…to catch your transport (P7: 68, Aca, Ses, Ses, Kat, No)

B. Shared roles and responsibilities

Information

1. All members of the team are responsible for the accuracy of the information and for making certain that it is understood by the patient.

> *Toe sê ek vir haar, jy weet, ek weet nie wat is binne bestraling nie, want niemand het met ons dit bespreek nie. Ons het hiernatoe gekom, ons het uitgetrek en ons het gewag* (I then said to her, you know, I don't know what is inside radiation, because no-one discussed it with us. We came here, got undressed and then we waited) (P13: 64, Aca, Afr, Afr, Ol, Sec)

> *Toe sê ek nee, probeer dit huislik praat net in simple Afrikaans, dat ek kan verstaan* (I said no, rather speak in simple Afrikaans which I can understand) (P10: 57, Aca, Afr, Afr, Kat, Prim)

2. Inform the patient about her disease and forthcoming treatment in her home language.
[3 of 17 Sesotho speaking patients addressed in home language]

> *I could not understand as they were speaking in Afrikaans* (P9: 50, Aca, Ses, Ses, Kat, Sec)

> *…but I told them I would like to get the explanation in Setswane or Sesotho as well, because there other girls there who were training from the army and one of them came and explained everything to me* (P19: 56, Aca, Ses, Ses, Kat, Prim)

3. Inform the patient of the availability of the services of an interpreter.

4. When an interpreter is used, documentation should be placed in the patient's medical file, indicating the name and qualification of the person who acted as an interpreter.

5. Explain the nature of the proposed treatment by making reference to brachytherapy as the inside radiation.
[27 of 28 participants were not familiar with the word "brachytherapy"]

> *Ek het nie eens geweet mens noem dit Brachytherapy nie (I did not even know it is called Brachytherapy)* (P16: 69, Pr, Afr, Afr, Loc, Ter)

6. Avoid inappropriate terminology such as "burn", "heat" and "slaughterhouse"-examples:
[6 of 28 participants used the words "burn" or "heat"]

> *They are going to produce heat that will burn or heat the infection inside your womb*
> (P1: 47, Aca, Ses, Ses, Kat, Prim)

> *…want jy worry, hoe brand ek nou?* (…because one worries: how will I get burnt?) and "*Hoe gaan ek lyk nou as ek gebrand word?* (How will I look, after getting burnt?) (P11: 55, Aca, Ses, Afr, Kat, Prim)

[4 of 28 participants used the word “slaughterhouse”]

> *Hy was nie soos ek dit verwag het nie, want ek het gedink ’n mens word gesny…jy gaan slagpale toe* (It was not what I expected it to be, because I thought a person gets cut…you go to the slaughterhouse) (P12: 50, Aca, Afr, Afr, Kat, Prim)

> *I was expecting that maybe they are going to hang my feet there above and put something which is [very] big inside* (P26: 48, Pr, Ses, Eng, Loc, Ter)

7. Avoid using technical terms such as “side-effects”.

8. Allocate a member of the multidisciplinary team to inform the new patient of her forthcoming brachytherapy treatment, preferably a day or two prior to the scheduled treatment.

> *…daar is mos nou iemand voltyds. So elke tyd as daar nuwe mense kom, daar moet iemand voltyds altyd vir hulle sê: …Jy is by die binne bestraling. Dit werk so en met hulle gesels oor dit. Sodat mense kan gewoond raak. Sodat jy weet as jy na dié plek toe gaan, moet jy weet wat word spesifiek verwag* (…there is now someone full-time. So every time new patients arrive, there should be someone full-time, talking to them and say: You are at the inside radiation. It works like this and talk to them about it so that they can get used to it. Then you will know that when you go to this place, you must know exactly what to expect) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

> *So, voordat jy hom by die binne bestraling kry, moet jy eers vir hom miskien ’n dag of twee vat en sê: Môre is jou dag. Maar môre sal dit, dit gebeur en dit gebeur* (So, before you get the patient for the inside radiation, you must take a day or two and say the following: Tomorrow is your day. Tomorrow, this, this and that will happen to you) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

9. Make use of information sessions, informative material such as booklets or pamphlets, or digital video display, to inform patients of what brachytherapy entails.
[22 of 28 participants wanted informative material prior to their treatment]

> *…kan help as hulle ’n inligtingsessie gee wat om te verwag en hoekom doen hulle dit en wat is die gevolge…* (…could help if they give an information session on what to expect and why they do it and what are the consequences…) (P25: 37, Aca, Afr, Afr, Ol, Ter)

> *If you could just give us those pamphlets or the books so we can read and learn more and understand this radiation treatment* (P5: 33, Aca, Ses, Ses, Wrd, Loc, Sec)

10. Informative material and a digital video display should be available in at least Afrikaans, English and Sesotho.

11. Discourage the patient from gaining treatment related information from fellow patients.
[11 of 28 were scared of treatment due to information received from fellow patients]

> *I think, because when we get here we are very scared, because people say a lot of thing, but I realised that we get nervous over nothing really; No, it did not go the same way…after what most people told us we were very scared and thought about every bad thing under the sun we could think of, but when we got here, there it was totally the opposite of it* (P28: 61, Aca, Ses, Ses, Loc, Prim)

12. Questions should be directed to members of the unit.

13. Ensure that the informed consent letter of the patient has been signed before her first treatment delivery.

14. Obtain consent from the patient before allowing medical or nursing students into the treatment room.

> *Maar ek dink hulle moet mens net vroegtydig sê. Dan sal mens sommer wegbly, maar ek jok. Nee, ek dink hulle moet net oppas vir dit…* (But I think they should inform a person beforehand. Then one would stay away, but I lie. No, I think they must be careful of that…) (P16: 69, Pr, Afr, Afr, Loc, Ter)

15. Inform the patient on a weekly basis of the timing of her next brachytherapy treatment.
[4 of 28 participants did not know the scheduled date of treatment]

> *So I was sitting there and the nurse came and told me I was supposed to be at internal radiation. Then I just came here [Governmental hospital]* (P24: 36, Pr, Ses, Eng, Ol, Sec)

16. Explain to the patient how the brachytherapy procedure will be incorporated into her six week treatment schedule.

> *I never thought I have to go many times* (P6: 55, Aca, Ses, Eng, Kat, Sec)

> *You know, because the doctor didn't explain me anything about the treatment, it's everlasting or once-off. So really, I don't know* (P21: 38, Pr, Ses, Eng, Ol, Ter)

17. Inform the patient that she will receive information regarding her follow-up appointments at completion of her radiotherapy treatment schedule.
[20 of 28 participants were not informed about the follow-up appointment]

> *Maybe on the final day before they discharge me, that is when they might say something* (P5: 33, Aca, Ses, Ses, Wrd, Loc, Sec)

Directions

18. Allocate a person to provide the new patient, who is unfamiliar with the hospital surroundings, with directions on where to register and to report for their first brachytherapy treatment.
[27 of 28 participants did not know the location of the unit]

> *…Even to get to this room again…if it had not been of her, I would have been lost* (P23: 55, Pr, Ses, Ses, Ol, Prim)

> *Miskien kan hulle dit 'n bietjie verbeter en die pasiënt inlig vir as jy die eerste keer kom* (Maybe they can improve it a little bit and inform the patient, concerning coming for the first time) (P16: 69, Pr, Afr, Afr, Loc, Ter)

> *Moet jy nou daar wees of hierso?* (Must you be there or here?) (P16: 69, Pr, Afr, Afr, Loc, Ter)

[Private participants did not know where to register for their treatment]

> *…dit was goed gewees om nie te sukkel nie, want reeds mos nou bang* (It was good not to struggle, as I was already scared) (P4: 40, Aca, Afr, Afr, Ol, Sec)

19. Show the new patient the location of the unit and introduce her to the personnel.

Pre-treatment preparation

20. Provide the patient with detailed instructions regarding her pre-treatment preparations on the evening and morning prior to receiving the brachytherapy-examples:

[15 of 28 were not informed]

> *They never told me* (P15: 61, Aca, Ses, Ses, Kat, Sec)

> *Nee, hulle het niks gesê nie. Ek het gewonder of moet ek of nie. Maar ek het 'n stukkie toast geëet en tee gedrink* (No, they did not say anything. I was wondering, should I or not. But I ate a piece of toast and drank tee) (P16: 69, Pr, Afr, Afr, Loc, Ter)

Treatment procedure

21. Provide the patient with an estimated waiting time.

[21 of 28 participants were not given a waiting time]

> *The sister just tells me I must come here and then I'm going to wait. They say: Mother you are going to wait some couple of minutes. When you hear the bell rings, you must know somebody's finished there inside. Now it is you who's going to come* (P8: 52, Aca, Ses, Eng, Kat, Sec)

> *I did not know if it was going to be 5 minutes or 10 minutes. I just did not know* (P7: 68, Aca, Ses, Ses, Kat, No)

> *Here we did not have a clue how long were going to wait...* (P23: 55, Pr, Ses, Ses, Ol, Prim)

22. Provide the patient with an estimated treatment time.

> *Hey, it was nice for me* (P8: 52, Aca, Ses, Eng, Kat, Sec)

23. Provide the patient with an explanation if treatment has been delayed.

> *Ja, hy was aanvaarbaar…want ek is nou klaar gesê hoe laat die dokter kom* (Yes, it was acceptable, because I was already told how late the doctor would come) (P11: 55, Aca, Ses, Afr, Kat, Prim)

24. Inform the patient in the recovery room of the outcome of the treatment and if necessary, provide her with a rescheduled date in case of treatment cancellation.

25. Allocate a person to escort patients to their mode of transport or back to the ward.

> *…they should assist us to walk if we want to walk somewhere else and if we need to catch transport they should help us to get there as well* (P20: 51, Aca, Ses, Ses, Kat, Prim)

C. Exclusive roles and responsibilities

C.1 New patient clinic

Radiation oncologist/radiation oncology registrar

Informed consent

1. Informed consent for the brachytherapy procedure must be obtained by or under supervision of a licenced physician qualified to perform and familiar to the procedure.

2. Informed consent must be obtained and documented prior to the initiation of brachytherapy where conscious sedation will be administered.

3. A physician who is not fluent in the language of the patient should use the services of an interpreter who is fluent in the language the patient can understand and that of the physician.

> *It would have been nice if I got an explanation in Sesotho* (P23: 55, Pr, Ses, Ses, Ol, Prim)

4. Provide the patient with an opportunity to ask treatment related questions before signing the consent form. Encourage them not to be ashamed or to feel inadequate to ask questions.

[10 of 28 participants were not given an opportunity for questions]

> *There's some lot of things that I want to know* (21: 38, Pr, Ses, Eng, Ol, Ter)

> *I did not get a chance to ask all those questions* (P20: 51, Aca, Ses, Ses, Kat, Prim)

5. Have consent forms available in alternative languages such as Sesotho, English and Afrikaans.

Specifications for informed consent

During the process of obtaining informed consent, the physician should inform the patient of the following:

Treatment procedure

6. Ensure that the patient understands that brachytherapy is not an operation to the uterus, but radiation to the inside of the cervix.

[3 of 28 participants thought it to be a type of operation, while conscious]

> *I thought that when you get here, they begin operating you while you are still conscious…* (P9: 50, Aca, Ses, Ses, Kat, Sec)

> *I thought they were going to remove the womb and burn me* (P17: 30, Aca, Ses, Eng, Kat, Sec)

> *They told me that they were going to perform an operation on me using machines…* (P28: 61, Aca, Ses, Ses, Loc, Prim)

7. Explain to the patient that she will receive conscious sedation to prevent discomfort and pain during treatment delivery. She will wake up in the recovery room after which she will be able to go home.

[9 of 28 participants reported that the treatment was not a pleasant experience due to pain]

> *I became even more nervous when they told me that I was going to be sedated as well* (P23: 55, Pr, Ses, Ses, Ol, Prim)

> *…gaan ek reg wakker word?* (…am I going to wake-up properly?), *Hoe gaan ek voel van die sedasie?* (How will I feel after the sedation?) (P25: 37, Aca, Afr, Afr, Ol, Ter)

> *So I was scared that maybe I'm going not to be wake up* (P26: 48, Pr, Ses, Eng, Loc, Ter)

> *Is it painful?* (21: 38, Pr, Ses, Eng, Ol, Ter)

> *So I was worried I'm going to get hurt* (P24: 36, Pr, Ses, Eng, Ol, Sec)

Treatment effects

8. Provide the patient with understandable information on the possible side-effects of the treatment.

[16 of 28 participants were not informed of the possible side-effects]

> *...ek het nou nie eintlik regtig 'n "clue" daarvan nie* (…I actually have no clue) (P12: 59, Aca:Afr, Afr, Kat, Prim)

> *They never told me. They only said to me that when they are done with me, I will experience pains, but I should not take anything for them. I will be fine* (P19: 56, Aca, Ses, Ses, Kat, Prim)

9. Discuss the aspect of sexual intercourse and childbearing with all the patients, irrespective of their age or marital status.

[15 of 28 participants were not informed of sexual intercourse]

> *I would ask about sex* and *will I still be able to give birth though?* (P5: 33, Aca, Ses, Ses, Wrd, Loc, Sec)

> *But, it can be possible to have children. After the radiation* (P17: 30, Aca, Ses, Eng, Kat, Sec)

C.2 Brachytherapy unit

Radiation therapist

1. Explain to the patient briefly the radiotherapy procedure that will take place and that the brachytherapy treatment delivery will be preceded by a CT scan procedure.

> *…as hulle dit net vir die pasiënt ook kan sê. Ons gaan jou elke keer eers deursit en dan die bestraling doen. Dan weet mens wat om te verwag* (…if they can tell this to the patient. We are going to put you through and then give the radiation. Then one knows what to expect) (P16: 69, Pr, Afr, Afr, Loc, Ter)

2. Show the new patient the inside of the treatment room and the treatment unit-examples:

[5 of 28 participants were scared of the treatment unit]

Ja, as ek net gesien het wat sou gebeur het, dan was ek miskien nie so bang nie, want ek was vreeslik gespanne (Yes, if only I could see what would happen. I would have not been so scared, because I was very tense) (P13: 64, Aca, Afr, Afr, Ol, Sec)

…dis seker die groot iets wat hulle indruk, ek weet nie en dan plug hulle hom in…en dan sit hulle die elektrisiteit aan (…it's probably something bit they push in, I don't know and then they plug it in…and switch the electricity on) (P13: 64, Aca, Afr, Afr, Ol, Sec)

3. Inform the patient that during treatment delivery, she can communicate to personnel outside the treatment room via an intercom system and a video camera will provide visual communication with her.

4. Inform the patient that there are safety mechanisms in place if machine breakage occurs and that the applicators can be removed, if necessary.

Oncology nurse

1. Show the new patient the location of the dressing- waiting and recovery rooms.

2. Utilise the time spent in the waiting room to prepare the new patient emotionally for the treatment. Listen to her fears and concerns, especially the elderly-examples:
[14 of 28 participants had a fear for the unknown]

…they make sure that you understand very well so that you do not become scared and want to run away
(P15: 61, Aca, Ses, Ses, Kat, Sec)

[15 of 28 participants wanted to talk about their fears and concerns]

I think if they would encourage us and speak to us, try to make us feel calm and relaxed, because you know people are different. Some became more nervous than others (P19: 56, Ses, Ses, Kat, Prim)

3. Provide the new patient with a detailed explanation of their role during the treatment procedure.

So, by the time when I went in, I was prepared, because I knew what was going to take happen (P15: 61, Aca, Ses, Ses, Kat, Sec)

4. Have nursing personnel present to assist the patient in the recovery room on her arrival from the treatment room- example:
[14 of 28 participants had no-one assistance in the recovery room]

Please, when we come in here, you should always keep an eye on us to see how everyone is doing and make sure that we are all right… (P23: 55, Pr, Ses, Ses, Ol, Prim)

5. Ensure that the ward patient has fully recovered, before sending her back to the ward.

There was never been a time I find myself waking up in here (P5: 33, Aca, Ses, Ses, Wrd, Loc, Sec)

6. See to the well-being of each patient before she leaves the unit-examples:
[14 of 28 participants left the recovery room without anyone seeing to their well-being]

> *I'm waiting for you to tell me whether I can go* (P26: 48, Pr, Ses, Eng, Loc, Ter)

> *Whether it was out of that door or out of this door, I don't know. I was still a little bit dizzy* (P6: 55, Aca, Ses, Eng, Kat, Sec)

Radiation oncologist/radiation oncology registrar

1. The attending radiation oncologist or radiation oncology registrar should introduce him/herself to the patient.

2. Provide the patient with an explanation of the procedure he/she will be performing.

3. Provide the patient with the choice of being treated by a female or male radiation oncologist or radiation oncology registrar.
[10 of 28 participants wanted to be treated by a female physician]

> *…as hulle dalk kan kyk dat net vrouens dalk die binne-bestraling kan doen* (…if they can see to it that only female doctors perform the inside radiation) (P4: 40, Aca, Afr, Afr, Ol, Sec)

> *Ag, jy weet, ons hou nie daarvan nie, maar ons moet dit maar aanvaar. Ek meen, hulle is dokters* (You know, we do not like it, but we have to accept it, because they are doctors) (P13: 64, Aca, Afr, Afr, Ol, Sec)

> *You know I prefer it if it is a female doctor, because a female doctor understand all the female parts* (P9: 50, Aca, Ses, Ses, Kat, Sec)

> *So, toe dink ek, ai, soms tyd like ons nou nie mansmense nie (So, I was thinking, oh, certain times, we don't like men)* (P12: 50, Aca, Afr, Afr, Kat, Prim)

4. Ensure that each patient is treated weekly by the same radiation oncologist or radiation oncology registrar-example:

> *…dit is nice want dan, jy bou soort van 'n verhouding". So jy ken die dokter en jy's gemaklik met die dokter* (…it is nice, because you built on a relationship. You know the doctor and you feel comfortable with the doctor) (P25: 37, Aca, Afr, Afr, Ol, Ter)

5. Keep the patient sedated until her treatment is completed and the applicators have been removed-examples:

> *Ek weet net ek het vir hulle geskree: Julle skroei my van binne [!] Want dit was erg* (I only know that I screamed at them: You are burning me on the inside [!] It was terrible) (P13: 64, Aca, Afr, Afr, Ol, Sec)

> *I felt it when they were putting their stuff inside me; …I never experienced that much pain;* Because *I was awake, I could see and feel everything that they were doing and I could even feel the pain* (P1: 47, Aca, Ses, Ses, Kat, Prim)

6. Documentation should be made of the sedation requirements during the procedure for future reference in following treatments-examples:

Hulle moet 'n manier kry om dit minder pynvol te maak (They must make a plan to make it less painful) (P1: 47, Aca, Ses, Ses, Kat, Prim)

Die pynbeheer is nie vir my baie goed nie "(The management of pain is not very good for me) (P25:37:Aca:Afr:Afr:Ol:Ter)

7. Individualise the sedation dosage-example:

…*daai narkose, hy maak my niks* (…that anastetic, it did nothing to me) (P22: 35, Aca, Afr, Afr, Wrd, Sec)

NATONAL REVIEW

APPENDIX 24:

E-MAIL INVITATION TO PARTICIPATE IN THE RESEARCH STUDY

APPENDIX 24

ECUFS number: 97/2012

E-MAIL INVITATION TO PARTICIPATE IN THE RESEARCH STUDY

Dear Prof/ Dr/ Mr/ Ms

You are invited to participate in a research study that is being conducted by me, Deirdré Long (Assistant-director in Radiography) at the Brachytherapy unit, Department of Oncology, Universitas Annex, Free State, Bloemfontein. This prospective research study forms part of a Ph.D. study with the title:

BRACHYTHERAPY FOR CERVICAL CANCER: GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT

The purpose of this study is to establish guidelines to facilitate quality patient management for cervical cancer patients, undergoing high dose-rate – intracavitary brachytherapy treatment. The aim of the study is to optimise the quality of patient management at brachytherapy units in governmental and private institutions. By means of the electronic mail (e-mail), your feedback on the guidelines on quality patient management in a multidisciplinary environment is requested. This is an important part of the research to benchmark the guidelines with the opinions of professionals who regularly interact with cervical cancer patients, undergoing brachytherapy.

As head of a brachytherapy unit, you are kindly invited to participate in this research study. If, however, you would rather designate another representative in your brachytherapy unit to participate in this study, it will also be acceptable. I have forward background information and a letter of consent (to be signed by you/designated representative) to you by e-mail. Once I have received your written consent via e-mail or fax, I will forward the proposed guidelines to you. The document contains a list of preliminary guidelines (*sections A-C*), allowing you to respond to the open-ended questions, to make amendments and to notate your opinions and views on the guidelines. Due to the time schedule of the study, I would appreciate it if you could respond and return the feedback schedule to me within two weeks (10 working days).

Participation is voluntary, and refusal to participate will involve no penalty. You may withdraw from this study at any time. However, there is no payment or awards for participating in this research study. Every effort will be made to keep personal information confidential. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law. By signing the consent form you will give the researcher the right to present and publish the results of the study at congresses and in relevant medical journals, respectively. The findings of this study will be made available to you at completion of the study in the published thesis which will be available in the Frik Scott Medical Library, UFS, Bloemfontein.

If you have any questions or concerns, please do not hesitate to contact Mrs D. Long at 073 745 3306 or deirdre.long6@gmail.com.

Contact details of Secretariat and Chair: Ethics Committee of the Faculty of Health Sciences, University of the Free State – for reporting of complaints/problems: Telephone number (051) 405 2812.

Thank you for your willingness to participate in this study.

Yours sincerely

Mrs D. Long
Assistant-Director in Radiography
Department of Oncology
Universitas Annex
Bloemfontein
Free State

NATIONAL REVIEW

APPENDIX 25:

E-POS VERSOEK OM DEELNAME AAN DIE NAVORSINGSTUDIE

APPENDIX 25

ECUFS nommer: 97/2012

E-POS VERSOEK OM DEELNAME AAN DIE NAVORSINGSTUDIE

Geagte Prof/Dr/Mnr/Me

U word versoek om deel te neem aan ’n navorsingstudie wat deur my, Deirdre Long (Assistant-direkteur in Radiografie) gedoen word by the Bragiterapie eenheid van die Onkologie Departement, Universitas Annex, Bloemfontein. Hierdie prospektiewe navorsingstudie maak deel uit van ’n Ph.D. studie getiteld:

BRAGITERAPIE VIR SERVIKSKANKER: RIGLYNE OM KWALITEIT PASIËNT BESTUUR TE FASILITEER IN ’n MULTIDISSIPLINÊRE OMGEWING

Die doel van die studie is om riglyne saam te stel om kwaliteit pasiënt bestuur te fasiliteer vir pasiënte met servikskanker wat hoë dosis tempo – intrakavitêre bragiterapie behandeling ontvang. Die studie poog om die kwaliteit van pasiënt bestuur by bragiterapie eenhede van staatsdepartemente en dié van die privaatsektor te optimaliseer. Deur gebruik te maak van elektroniese pos (e-pos) sal u terugvoer ten opsigte van die voorgestelde riglyne vir kwaliteit bestuur van pasiënte in ’n multidissiplinêre omgewing verkry word. Dit is ’n belangrike deel van die navorsing om die voorgestelde riglyne te toets teen die opinies van gekwalifiseerde personeel wat op ’n gereelde basis interaksie het met servikskanker pasiënte wat bragiterapie ontvang.

As hoof van ’n bragiterapie-eenheid word u vriendelik versoek om aan die navorsingstudie deel te neem. Indien u dit verkies om ’n afgevaardigde van die bragiterapie eenheid te laat deelneem aan die studie, sal dit in orde wees. Ek het ’n dokument met agtergrondsinligting saam met die toestemmingsdokument aan u gestuur wat deur u of die afgevaardigde persoon geteken moet word. Sodra ek die getekende toestemmingsdokument terug ontvang via e-pos of faks, sal ek die voorgestelde riglyne aan u stuur. Die e-pos dokument bevat die voorgestelde riglyne (*Afdelings A-C*) wat u sal toelaat om te reageer op die vrae, verandering aan te bring en u opinie/kommentaar te gee. Dit sal 30 -40 minute neem om die terugvoerskedule te voltooi. Om by die tydskedule van die studie te hou, sal ek dit waardeer as ek u terugvoer kan verkry binne twee weke (10 werksdae) nadat u die voorgestelde riglyne ontvang het.

Deelname is vrywillig en u sal nie gepenaliseer word deur die versoek van die hand te wys nie. U mag enige tyd van die studie onttrek. Geen betaling of geldelike vergoeding word gegee aan persone wat aan die navorsingstudie deelneem nie. Pogings sal aangewend word om persoonlike inligting vertroulik te hanteer. Konfidensialteit kan nie gewaarborg word nie. Persoonlike inligting mag bekend gemaak word indien die wet dit vereis. Deur die toestemmingsdokument te teken gee u die navorser die reg om die resultate van die studie onderskeidelik by kongresse aan te bied en in toepaslike mediese joernale te publiseeer. Die bevindinge van die gepubliseerde tesis sal beskikbaar gestel word in die Frik-Scott Mediese Biblioteek van die UVS, Bloemfontein.

Indien u enige vrae of probleme het, kan u mev D.Long onverwyld kontak by 073 745 3306 of deirdre.long6@gmail.com.

Kontak besonderhede van die Sekretariaat en Voorsitter: Etiekkomitee van die Fakulteit Gesondheidswetenskappe, Universiteit van die Vrystaat – Telefoonnommer: (051) 405 2812.

Dankie vir u bereidwilligheid om aan die studie deel te neem.

Die uwe

Mev. D. Long
Assistent-Direkteur in Radiografie
Departement Onkologie
Universitas Annex
Bloemfontein
Vrystaat

NATIONAL REVIEW

APPENDIX 26:

E-MAIL INFORMATION LETTER

APPENDIX 26

ECUFS number 97/2012

E-MAIL INFORMATION LETTER

STUDY TITLE: BRACHYTHERAPY FOR CERVICAL CANCER: GUIDELINES TO FACILITATE QUALITY PATIENT MANAGEMENT IN A MULTIDISCIPLINARY ENVIRONMENT

Background

Currently, there are many sets of guidelines to assist institutions to develop or optimise brachytherapy facilities regarding the treatment regimes, techniques, dose specification and treatment planning methods. However, a literature search has indicated that studies on patients' experiences while undergoing brachytherapy treatment are limited and were conducted in developed countries where women's experiences of treatment delivery and patient management may differ from those experienced by South African women. Therefore, to facilitate quality patient management in a multidisciplinary environment, in a brachytherapy unit, it was deemed necessary to explore the patients' experiences and use the findings to formulate guidelines for quality patient management.

Research question

The research was guided by the following questions:

- What are the needs and expectations of women diagnosed with cervical cancer, while undergoing high dose rate brachytherapy treatment at the Department of Oncology, Bloemfontein?
- Is there a way of ensuring that their needs and expectations are adequately managed by members of a multidisciplinary team?

Purpose and objectives

The purpose of this prospective qualitative study was to formulate guidelines to facilitate quality patient management for cervical cancer patients undergoing high dose rate brachytherapy treatment in a multidisciplinary environment.

To achieve the purpose of the study, the following stages have been completed:

Stage one: Patient interviews

• Explore the patient experience, while undergoing HDR brachytherapy. This was done by conducting in-depth, semi-structured interviews with 28 purposively selected participants. In order to include women across the age spectrum into the study, the researcher purposively recruited ten patients as participants from each of the following three age groups: 30-45 years; 46-60 years and 61years and older. Each age group included at least one private and one oncology patient from Bloemfontein. Hospitalised patients were also included in the study sample.

Stage two: Formulation of proposed guidelines

• Formulate preliminary guidelines for quality patient management that is based on the patient experience. This was done by using the findings of stage one, conducting a literature search on the topic and incorporating the aggregate experience of the researcher.

Stage three: Focus group interviews

• To review and refine the proposed guidelines by means of two focus group interviews. Each focus group consisted of members of the multidisciplinary team working at the brachytherapy unit, with at least a year's experience of service delivery. The sample included the following members of the multidisciplinary team: head of the department, radiation oncologists, radiation oncology registrars, radiation therapists and oncology nurses.

Stage four: Review by heads or designated representatives

• To gather feedback on the proposed guidelines from heads/designated representatives of brachytherapy units in South Africa and to incorporate their advice, comments and opinions into revisions of these guidelines.

Stage five: Guidelines to facilitate quality patient management

• To formulate the final guidelines for quality patient management in a multidisciplinary environment.

NATIONAL REVIEW

APPENDIX 27:

E-POS INLIGTINGSBRIEF

ECUFS nommer: 97/2012

E-POS INLIGTINGSBRIEF

STUDIETITEL: BRAGITERAPIE VIR SERVIKSKANKER: RIGLYNE OM KWALITEIT PASIËNT BESTUUR TE FASILITEER IN 'n MULTIDISSIPLINÊRE OMGEWING

Agtergrond

Huidiglik is daar verskeie riglyne beskikbaar om diensverkaffers te help om bragiterapie fasiliteite te ontwikkel of te verbeter t.o.v. behandelingskedules, tegnieke, dosis spesifikasies en metodes van beplanning. 'n Literatuurstudie toon egter dat studies wat gefokus het op die ervarings van pasiënte tydens hul bragiterapie behandeling beperk is. Dié studies is uitgevoer in ontwikkelde lande waar vroue se ervarings van hul behandeling en pasiënt bestuur moontlik kan verskil van dié van Suid-Afrikaanse vroue. Dus, om te verseker dat kwaliteit pasiënt bestuur toegepas word in 'n multidissiplinêre omgewing, spesifiek by 'n bragiterapie eenheid, was dit nodig om pasiënte se ervarings te verken en die bevindings te gebruik om riglyne vir kwaliteit pasiënt bestuur te formuleer.

Navorsingsvraag

Die navorsing was gelei deur die volgende vrae:

- Wat is die behoeftes en verwagtinge van vroue, wat met servikskanker gediagnoseer is, tydens hul hoë dosis tempo bragiterapie behandeling in die Departement Onkologie, Bloemfontein?
- Is daar 'n manier om te verseker dat dié groep pasiënte se behoeftes en verwagtinge voldoende aangespreek word deur lede van 'n multidissiplinêre span?

Doel en doelwit

Die doel van hierdié prospektiewe kwalitatiewe studie was om riglyne te formuleer om kwaliteit pasiënt bestuur te fasiliteer vir sevikskanker pasiënte tydens hul bragiterapie behandeling in 'n multidissiplinêre omgewing.

Om die doel van die studie te bereik is die volgende fases voltooi:

Fase een: Onderhoude met pasiënte

• Verken die pasiënt se ervaringe tydens hoë dosis tempo bragiterapie behandeling. Dit was gedoen deur semi-gestruktueerde onderhoude met 28 doelgerig geselekteerde deelnemers te hou. Om 'n breë spektrum van pasiënte van alle ouderdomsgroepe by die studie in te sluit het die navorser tien pasiënte doelgerig geselekteer in die volgende drie ouderdomsgroepe:30-45 jaar; 46-60 jaar en 61jaar en ouer. Elke ouderdomsgroep het ten minste een privaat en een pasiënt van Bloemfontein ingesluit. Saalpasiënte was ook in die steekproef ingesluit.

Fase twee: Formulering van voorgestelde riglyne

• Formuleer voorgestelde riglyne vir kwaliteit pasiënt bestuur wat gebaseer is op die resultate van die pasiënt se ervaring. Dit was gedoen deur die bevindings van fase een te gebruik, 'n literatuurstudie oor die huidige onderwerp uit te voer en die saamgestelde werkservaring van die navorser by te werk.

Fase drie: Fokusgroep onderhoude

• Om die voorgestelde riglyne te hersien en te wysig en te verfyn deur middel van twee fokusgroep-onderhoude. Elke fokusgroep het bestaan uit lede van die multidissiplinêre span, werksaam by die bragiterapie eenheid met ten minste ‘n jaar van dienslewering. Die steekproef het die volgende lede van die multidissiplinêre span ingesluit: departementshoof, stralingsonkoloë, kliniese assistente, stralingsterapeute en onkologie verpleegkundiges.

Fase vier: Hersien deur hoofde of afgevaardigde verteenwoordiges

• Om terugvoer te kry van hoofde/afgevaardigde verteenwoordiges van bragiterapie eenhede in Suid-Afrika oor die voorgestelde riglyne en om hulle advies, menings en opinies te inkorporeer in hersiening van hierdie riglyne.

Fase vyf: Riglyne om kwaliteit pasiënt bestuur te fasiliteer

• Om die finale riglyne vir kwaliteit pasiënt bestuur in ’n multidissiplinêre omgewing te formuleer.

NATIONAL REVIEW

APPENDIX 28:

E-MAIL CONSENT DOCUMENT

APPENDIX 28

ECUFS number 97/2012

E-MAIL CONSENT DOCUMENT

I, the undersigned, hereby give consent to participate in the research study.

Please tick the appropriate box:
Head of a brachytherapy unit - government□ Head of a brachytherapy unit - private□
Designated representative – government □
Designated representative – private □

Please provide your particulars:
Surname:

_____

Full names:

_____

Contact number:

_____

E-mail address:

_____

Socio-demographic details:
Age:

_____

Race/Ethnicity

_____

Gender:

_____

Occupation:

_____

Highest qualification:

_____

Years of experience at the unit

_____

_____ _____

Signature Date

I wish to assure you that your information will be treated in confidence and no reference will be made to your personal details. Please take note that the results from this research will be published.

Thank you in advance.

Yours sincerely

Mrs D. Long
Assistant-Director in Radiography
Department of Oncology
Universitas Annex, Bloemfontein
Free State

NATIONAL REVIEW

APPENDIX 29:

E-POS TOESTEMMINGSDOKUMENT

APPENDIX 29

ECUFS nommer: 97/2012

E-POS TOESTEMMINGSDOKUMENT

Ek, die ondergetekende, gee hiermee my toestemming om deel te neem aan die navorsingstudie.

Maak asseblief 'n regmerk by die toepaslike boks:

Hoof van die bragi-eenheid – staat □ Hoof van die bragi-eenheid – privaat □
Afgevaardigde verteenwoordiger- staat □
Afgevaardigde verteenwoordiger – privaat □

Verskaf asseblief u persoonlike besonderhede:
Van:

_____

Volle voorname:

_____

Kontaknommer:

_____

E-posadres:

_____

Sosio-demografiese besonderhede:
Ouderdom:

_____

Rassegroep:

_____

Geslag:

_____

Beroep:

_____

Hoogste kwalifikasie:

_____

Aantal jare ervaring by die eenheid

_____

_____ _____
Handtekening Datum

Ek wil u verseker dat u inligting vertroulik hanteer sal word en dat daar geen verwysing na enige persoonlike besonderhede gemaak sal word nie. Neem asseblief kennis dat die resultate van die studie gepubliseer sal word.

By voorbaat dankie.

Die uwe
Mev D. Long
Assistent-Direkteur in Radiografie
Departement Onkologie, Universitas Annex
Bloemfontein, Vrystaat

NATIONAL REVIEW

APPENDIX 30:

E-MAIL INTERVIEW SCHEDULE

APPENDIX 30

ECUFS number 97/2012

E-MAIL INTERVIEW SCHEDULE

GUIDELINES

Brachytherapy is an essential component in the treatment schedule for women diagnosed with locally advanced carcinoma of the cervix. The delivery of cervical brachytherapy requires the collaboration of a multidisciplinary team that includes radiation oncologists, radiation oncology registrars, radiation therapists and oncology nurses. Brachytherapy is an interdisciplinary procedure and the aim of the proposed guidelines is to provide team members with guidance to facilitate quality patient management as an essential component of patient satisfaction with services rendered.

The proposed guidelines address the following: (i) logistical matters of the practice setting; (ii) collective roles and responsibilities which are shared amongst members of the multidisciplinary team and (iii) exclusive roles and responsibilities of the radiation oncologist/registrar, radiation therapist and the oncology nurse at the new patient clinic and the brachytherapy unit, respectively. The roles described below are not mutually exclusive, but depending on case load and facility preferences, they may be performed by different team members. It needs to be emphasized that some of the proposed guidelines are already in implementation in the department, either wholly or partially. Some need reaffirmation and in some cases additional resources may be required to implement the guidelines. The proposed guidelines are compatible with existing values and routines among members of the multidisciplinary team. All that should be expected is that members will follow a reasonable course of action based on current knowledge, available resources and the needs of the patient to deliver effective and safe medical care.

INSTRUCTIONS TO PARTICIPANTS:

Please read through each section of the proposed guidelines (*Sections A-C*) and:

(i) Indicate any amendments made by you to specific guidelines by bracketing additions and/or omissions;

(ii) Answer the related questions following each section.

GUIDELINES

Section A. Guidelines on requirements in the practice setting

1. Provide an environment that is clean, tidy and patient friendly and incorporate the following in the waiting room: for example - a muted television, books with information on the treatment, magazines and newspapers.
2. If unit layout permits: A bed in a separate room, in close proximity to the waiting room, where ward or ill patients could await their treatment under supervision/Ward or ill patients could await their treatment under supervision in the recovery room.
3. Patients are in a safe and secure environment by ensuring only one entrance to the recovery room.
4. Sufficient personnel to attend to patients in the recovery room, preventing adverse incidents from occurring.
5. Provide the patient with privacy in the recovery room by making use of partitioning.

6. A bell to ring in case of an emergency in the recovery room.
7. Water drink facilities available for the patients in the recovery room.
8. Wheelchairs for patients who are too weak to walk to their mode of transport.

The following questions are directed to gather further feedback on the proposed guidelines on *section A* - Requirements in the practice setting:

Questions:
• Do you agree with the guidelines in *section A*?
If yes,
Why?_____
_____
If no, Why
not?_____
_____
____
• Do resources in your department allow for the implementation of the guidelines?
If yes,
How?_____
_____
____
If no, Why
not?_____
_____
_____
• Is there anything else you would like to add to the proposed guidelines mentioned in this
section?_____
If yes, what would it
be?_____
_____
_____
• Comments or suggestions?
_____
_____
_____
_____

Section B. Guidelines on collective roles and responsibilities
The members of the multidisciplinary team held responsible for duties delivered are shown in brackets in cases where it does not apply to all members.

B.1 New patient clinic and brachytherapy unit
Concerning information given to the patient
1. All members of the team are responsible for the accuracy of the information given to the patients and to ensure that the information is understood by the patient.
2. Inform the patient about her disease and forthcoming treatment in her home language. *[Radiation oncologist/registrar or interpreter]*

3. Allocate a member/s of the multidisciplinary team to inform the new patient of her forthcoming brachytherapy treatment, preferably a day or two prior to the scheduled treatment. *[Radiation therapist or oncology nurse]*
4. Make use of information sessions, informative material such as booklets or pamphlets to inform patients of what brachytherapy entails.
5. Encourage the patient to direct treatment related questions to members of the unit when remarks made by fellow patients are confusing or contradicting.
6. Explain to the patient how the brachytherapy procedure will be incorporated into her six week treatment schedule. *[Radiation oncologist/registrar or radiation therapist]*
7. Inform the patient that she will receive information regarding her follow-up appointments at completion of her radiotherapy treatment schedule. *[Radiation oncologist/registrar or radiation therapist]*
8. Allocate a person/s to provide the new patient, who is unfamiliar with the hospital surroundings, with directions on where to register and to report for their first brachytherapy treatment. *[Oncology nurse or clerical staff working at the new patient clinic]*
9. Show the new patient the location of the unit and introduce her to the personnel. *[Clerical staff of the radiation department]*
10. Provide the patient with detailed instructions regarding her pre-treatment preparations on the evening and morning prior to receiving the brachytherapy. *[Oncology nurse or radiation therapist working at the accelerator]*
11. Show the new patient the inside of the treatment room and the treatment unit. *[Radiation therapist or the oncology nurse]*
12. Utilise the time spent in the waiting room to prepare the new patient emotionally for the treatment. Listen to her fears and concerns. *[Oncology nurse or radiation therapist]*
13. Provide the patient with an estimated waiting time. *[Oncology nurse or radiation therapist]*
14. Provide the patient with an estimated treatment time. *[Oncology nurse or radiation therapist]*
15. Provide the patient with an explanation if treatment has been delayed. *[Oncology nurse or radiation therapist]*
16. Maintain professional conduct at all times and abstain from conversations over a sedated patient.

The following questions are directed to gather further feedback on the proposed guidelines on *section B* - Collective roles and responsibilities of members of the multidisciplinary team.

Questions:

• Do you agree with the guidelines in *section B*?

If yes,

Why?_____

_____

_____

If no, Why not?_____

_____

• Do resources in your department allow for the implementation of the guidelines?
If yes,
How?_____
_____
____
If no, Why
not?_____
_____
• Is there anything else you would like to add to the proposed guidelines mentioned in this section?_____
If yes, what would it
be?_____
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• Comments or suggestions?
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Section C. Guidelines on exclusive roles and responsibilities

***C*.1 At the new patient clinic**

C.1.1 Role of the radiation oncologist/radiation oncology registrar

Informed consent

1. Informed consent for the brachytherapy procedure must be obtained by or under supervision of a licenced radiation oncologist/registrar qualified to perform and familiar to the procedure.
2. Informed consent must be obtained and documented prior to the initiation of brachytherapy where conscious sedation will be administered.
3. Inform the patient of the availability of the services of a medically trained interpreter.
4. A radiation oncologist/registrar who is not fluent in the language of the patient should use the services of an interpreter who is fluent in the language the patient can understand and that of the radiation oncologist/registrar.
5. When an interpreter is used, documentation should be placed in the patient's medical file, indicating the name of the person who acted as an interpreter.
6. Provide the patient with an opportunity to ask treatment related questions before signing the consent form. Encourage them not to be ashamed or to feel inadequate to ask questions.
7. Inform the patient that, due to logistical reasons, the possibility exists that she might be not be treated by the same radiation oncologist/registrar.
8. Consent forms and informative material should be available in at least Afrikaans, English and or the language spoken in the province by the majority of patients.

Information concerning the treatment procedure

9. Explain the nature of the proposed treatment by making use of diagrams or cartoons to describe to the patient what brachytherapy entails.
10. Ensure that the patient understands that brachytherapy is not an operation to the uterus, but radiation to the inside of the cervix.

11. Explain to the patient that she will receive conscious sedation to prevent discomfort and pain during treatment delivery.
12. Explain to the patient that patients respond differently to the sedation medication and she might only wake-up in the recovery room.
13. Provide the patient with understandable information on the possible side-effects of the treatment.
14. Discuss the aspect of sexual intercourse and childbearing with all the patients, irrespective of their age or marital status

The following questions are directed to gather further feedback on the proposed guidelines on *section C.1* - Exclusive roles and responsibilities of the radiation oncologist/registrar at the new patient clinic.

Questions:

• Do you agree with the guidelines in *section C1*?

If yes,

Why?_____

_____

____

If no, Why not?_____

_____

_____

• Do resources in your department allow for the implementation of the guidelines?

If yes,

How?_____

_____

____

If no, Why not?_____

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____

• Is there anything else you would like to add to the proposed guidelines mentioned in this section?_____

If yes, what would it be?_____

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• Comments or suggestions?

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_____

C.2 At the brachytherapy unit

C.2.1 Role of the radiation oncologist/radiation oncology registrar

1. The attending radiation oncologist/registrar should introduce him/herself to the patient.
2. Obtain consent from the patient before allowing medical or nursing students into the treatment room.
3. Provide the patient with an explanation of the procedure he/she will be performing.
4. Ensure that the patient is adequately sedated during treatment delivery, until removal of the applicators.
5. Documentation should be made of the sedation requirements during the procedure for future reference in following treatments.
6. The treatment progress of the patient should be noted in the patient's file (notes of clinical appearance).
7. Individualise the sedation dosage.

The following questions are directed to gather further feedback on the proposed guidelines on *section C.2.1* - Exclusive roles and responsibilities at the brachytherapy unit performed by the radiation oncologist/registrar.

Questions:

• Do you agree with the guidelines in *section C.2.1*?

If yes,

Why?_____

_____

____

If no, Why not?_____

_____

____

• Do resources in your department allow for the implementation of the guidelines?

If yes,

How?_____

_____

____

If no, Why not?_____

_____

• Is there anything else you would like to add to the proposed guidelines mentioned in this section?_____

If yes, what would it be?_____

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• Comments or suggestions?

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C.2.2 Role of the radiation therapist

1. Explain to the patient briefly the radiotherapy procedure that will take place and that the brachytherapy treatment delivery will be preceded by a CT scan procedure during which movement of the simulator bed will occur.
3. Inform the patient that during treatment delivery, she can communicate to personnel outside the treatment room via an intercom system and a video camera will provide visual interaction with her.
4. Inform the patient that there are safety mechanisms in place if machine breakage occurs and that the applicators can be removed, if necessary.
5. Inform the patient that the unit has an emergency strategy/resuscitation trolley in place.
6. Inform the patient concerning the sequence of treatment delivery.
7. Inform the patient of the outcome of the treatment and if necessary, provide her with a rescheduled date in case of treatment cancellation. The radiation therapist working at an accelerator should fulfil this role.
8. Inform the patient on a weekly basis of the timing of her next brachytherapy treatment. The radiation therapist working at an accelerator should fulfil this role.

The following questions are directed to gather further feedback on the proposed guidelines on *section C.2.2* - Exclusive roles and responsibilities at the brachytherapy unit performed by the radiation therapist.

Questions:

• Do you agree with the guidelines in *section C.2.2*?

If yes,

Why?_____

_____

_____

If no, Why not?_____

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____

• Do resources in your department allow for the implementation of the guidelines?

If yes,

How?_____

_____

____

If no, Why not?_____

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____

• Is there anything else you would like to add to the proposed guidelines mentioned in this section?_____

If yes, what would it be?_____

_____

• Comments or suggestions?

_____

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C.2.3 Role of the oncology nurse

1. Show the new patient the location of the dressing- waiting and recovery rooms.
2. Have nursing personnel present to assist the patient in the recovery room on her arrival from the treatment room.
3. Allowance should be made for sufficient time for post treatment recovery.
4. See to the well-being of each patient before she leaves the unit.
5. Ensure that the ward patient is transported back to the ward in an adequate condition.
6. Personnel from the unit should communicate the patient's medical condition to the staff in the ward before the patient leaves the unit.
7. Allocate a person to escort the patient to her mode of transport or back to the ward. A student nurse or porter should fulfil this role.

The following questions are directed to gather further feedback on the proposed guidelines on *section C.2.3* - Exclusive roles and responsibilities at the brachytherapy unit performed by the oncology nurse.

Questions:

• Do you agree with the guidelines in *section C.2.3*?

If yes,

Why?_____

_____

____

If no, Why not?_____

_____

_____

• Do resources in your department allow for the implementation of the guidelines?

If yes,

How?_____

_____

If no, Why not?_____

_____

____

• Is there anything else you would like to add to the proposed guidelines mentioned in this section?_____

If yes, what would ibe?_____

_____

• Comments or suggestions?

_____

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_____

_____

In general, what is your opinion of the structure of the proposed guidelines?
• Layout

_____
_____
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• Formulation

_____
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_____

What is your overall opinion concerning the proposed guidelines on the management if cervical cancer patients undergoing brachytherapy treatment?

_____
_____
_____
_____
_____
_____

Lastly, could these guidelines be used by your unit to facilitate quality patient management in a multidisciplinary environment? Please motivate.

_____
_____
_____
_____
_____
_____
_____

This feedback schedule must be mailed or faxed to the following:
E-mail:
deirdre.long6@gmail.com
Fax:
O51 447 5029

Thank you for your time and effort.

Yours sincerely
Deirdré Long