Southern African Journal of Gynaecological Oncology 2016; 8(2)
http://dx.doi.org/10.1080/20742835.2016.1212968

South Afr J Gynaecol Oncol
ISSN 2074-2835 EISSN 2220-105X

RESEARCH

Brachytherapy for cervical cancer: guidelines to facilitate patient-centred care in a multidisciplinary environment

Deirdré Long[a]*, Hester Sophia Friedrich-Nel[b] and Georgina Joubert[c]

[a]*Department of Oncology, Universitas Annex, Roth Avenue, Bloemfontein, South Africa*
[b]*Faculty of Health & Environmental Sciences, Central University of Technology, Bloemfontein, South Africa*
[c]*Faculty of Health Sciences, University of the Free State, Bloemfontein, South Africa*
**Corresponding author, email: deirdre.long6@gmail.com*

Objective: To establish patient-centred guidelines to assist multidisciplinary members in providing quality care for cervical cancer patients receiving brachytherapy.
Design: A qualitative research design.
Main measures: This prospective research study was conducted from July 2012 to March 2014 and constituted five stages. Stage 1: 28 one-to-one semi-structured patient interviews were conducted, stage 2: development of the proposed guidelines, stage 3: two focus group reviews of the proposed guidelines, stage 4: refinement of these guidelines by review by national heads of brachytherapy units and stage 5: presentation of the final guidelines.
Results: Four main themes with sub-themes were identified from the patient interviews. Patients' perspectives of care were integrated into the development process of the proposed guidelines. Guidelines were developed to address the practice setting and define the collective and exclusive roles and responsibilities of the radiation oncologists, radiation therapists and oncology nurses. Content validity, clarity and applicability of the guidelines were confirmed.
Conclusion: Guidelines were established integrating the patient experience into the development process. They provide a framework that clearly defines the roles and responsibilities of each member of the multidisciplinary team. Members are encouraged to implement the guidelines to ensure that quality patient-centred care is delivered, rendering patient satisfaction.

Keywords: brachytherapy, cervical cancer, guidelines, multidisciplinary team, patient-centred approach

Introduction

Guidelines have been a cornerstone of professional decision support in the past 30 years and play an important role in routine clinical practice.[1] Systematically produced guidelines for social work and social care practice are relatively recent in their provenance.[2] Gould stated that guidelines are typically assessment or intervention protocols developed by practitioners, academics and increasingly including service users.[2] Bastian was one of the first authors to draw attention to patients' participation in guideline development.[3] Bastian argued that if consumer involvement is to successfully raise the standard of health care guidelines, then the standard of consumer participation itself needs to be raised. The Australian National Guidelines' development programme goes even further by placing consumer participation at the level of a guiding principle, making it a mandatory element of the process.[4] If guidelines are to promote consistency and quality of care, the development process must incorporate the perspectives and expertise of consumers.[5,6]

Currently, there are various sets of brachytherapy-related guidelines to assist institutions in developing or optimising brachytherapy facilities regarding treatment regimes, techniques, dose specification and treatment planning methods.[7] Viswanathan and Thomadsen reported that the updated 2012 recommendations of the American Brachytherapy Society also address image-guided treatment planning and delivery and recommended reporting parameters for quality assurance.[8] However, these 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 (HDR)-intracavitary brachytherapy (ICBT) treatment delivery. It is apparent that, currently, there is little evidence available to suggest that the patient's perspective and experiences of undergoing HDR-ICBT have been integrated into any guideline development process. In addition, patients' experiences of receiving HDR-ICBT treatment and care in developing countries and especially South Africa have not previously been published.

In the Free State province, with a population of over 2 786 800 inhabitants, the brachytherapy unit of the Department of Oncology, Universitas Annex, Bloemfontein, is currently the only facility in the province to administer this specialised treatment for women diagnosed with locally advanced cervical cancer.[9] This service is also utilised to treat patients referred from four private oncology practices. Cervical cancer is the most prevalent gynaecological cancer in the Department of Oncology and standard therapies in the treatment of locally advanced cancer of the cervix include radiotherapy, surgery and platinum-based chemotherapy.

The purpose of this research was to explore the experiences of South African women receiving HDR-ICBT for locally advanced cervical cancer and to formulate guidelines that consciously embrace the patients' perspective of their management.

Methods

Study design

A qualitative approach was selected for this research study as it enabled the researcher to both explore the 'lived experiences' of the patients and obtain the views and opinions on the proposed guidelines of members of the multidisciplinary team of the

Table 1: Structure of the proposed guidelines

• Section A:
Guidelines on collective roles and responsibilities
A.1 New patient clinic and brachytherapy unit
• Section B:
Guidelines on exclusive roles and responsibilities
B.1 At the new patient clinic
B.1.1 Role of the radiation oncologist/registrar
• Informed consent
• Information concerning the treatment procedure
B.2 At the brachytherapy unit
B.2.1 Role of the radiation oncologist/registrar
B.2.2 Role of the radiation therapist
B.2.3 Role of the oncology nurse
• Section C:
Guidelines for the practice setting
C.1 Waiting room
C.2 Treatment room
C.3 Recovery room

Department of Oncology, Universitas Annex, Bloemfontein, Free State as well as heads or designated representatives of governmental and private brachytherapy units in South Africa.

Ethical considerations

Permission to conduct the study was obtained from the Chief Executive Officer and Head of Clinical Services Universitas Academic Hospital, the Head of the Department of Oncology, Universitas Annex, Bloemfontein and the Ethics Committee of the Faculty of Health Sciences, University of the Free State. All participants were provided with an oral explanation and written information document. Participants were assured that confidentiality would be preserved. Written informed consent was given by all participants.

Guideline development process

The study comprised five stages: (1) patient interviews, (2) development of the proposed guidelines, (3) focus-group interviews, (4) national review and (5) presentation of the final guidelines.

Stage one: patient interviews

A phenomenological approach was chosen as the framework for stage one. From July 2012 to December 2012, 28 one-to-one, semi-structured patient interviews were conducted with purposively selected patients between the ages 30 to 73 years. The interviews were conducted by a female, multilingual social worker who is not affiliated to the department. Her 11 years of experience as a social worker and her fluency in Sesotho, Afrikaans and English confirmed her eligibility as an interviewer. Demographic and medical details (age, staging of cancer, race/ethnicity, home language, language interviewed, private/governmental patient status, residence during treatment, educational level and employment status) were collected in order to describe participants' characteristics. The sample size for this study was determined by saturation of the data. The order of questions of the interview schedule was designed to simulate the path of events that each participant had gone through at the department (from the new patient clinic until treatment delivery). All the interviews were audio-recorded.

The verbatim data were transcribed and where necessary translated into English. Findings were analysed according to the phenomenological method described by Giorgi (1985), whereby essential themes and sub-themes were identified.[10]

Stage two: development of the proposed guidelines

The guideline formulation process comprised the following three steps:

(1) Patients' experiences in stage one were categorised according to the following:
   a. informational needs;
   b. multidisciplinary team;
   c. environment and surroundings; and
   d. waiting, treatment and recovery room.

(2) A literature search was conducted on guidelines for patient care for cervical cancer patients receiving HDR-ICBT by using the following key words: guidelines, patient care, brachytherapy, cervical cancer. The following databases were used: Pubmed Clinical Queries, The Cochrane Library, Trip database, ProQuest, NRF, Medline (Ovid), Africa-Wide, CINAHL, PsycARTICLES, PsycEXTRA, PsycINFO, PsycTESTS.

(3) The first author's knowledge and 22 years of clinical experience at the brachytherapy unit of the department were incorporated.

The structure of the proposed guidelines is depicted in Table 1.

Stage three: focus-group interviews

In September 2013, two focus-group interviews obtained multiple viewpoints on the proposed guidelines by 20 of the 21 members of the multidisciplinary team of the brachytherapy unit of the department. Each group of 10 participants was compiled in such a way that they were comparable regarding professional category

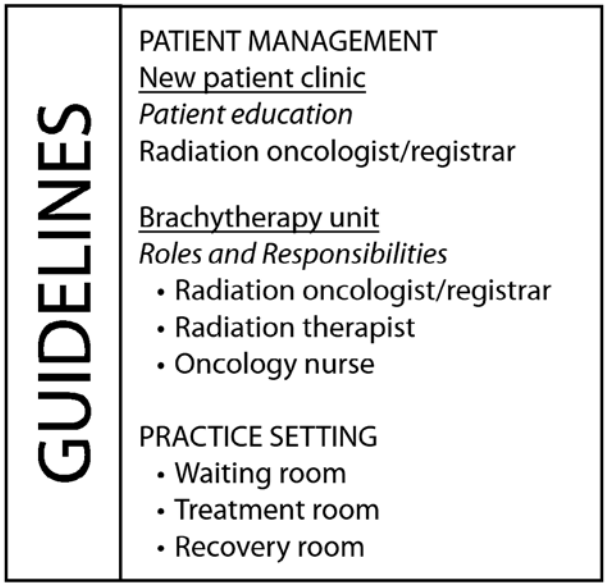

Figure 1: Overview of the final guidelines.

and years of experience. In total, seven radiation oncologists, six radiation oncology registrars, five radiation therapists and two oncology nurses took part in the focus-group interviews. Although the medical physicists play a major role in the treatment planning and delivery for these patients, they were excluded from the study as they are not directly involved with the care of patients in the department.

The opinions of the participants concerning the proposed guidelines were collected by using an interview schedule, audio-recordings and field notes. The facilitation team consisted of the group facilitator (second author) who made use of an interview schedule to elicit the focus group's responses and opinions. The duties of assistant facilitators were fulfilled by the first and third authors. Non-verbal behaviours were noted on the interview schedule and field notes were incorporated. Findings were analysed manually by the first author and amendments were integrated into the original draft of the proposed guidelines.

Stage four: national review

In March 2014, electronic mail questionnaires were used to gather the views and opinions on the amended guidelines of stage three by national heads or their designated representatives of governmental and private brachytherapy units in the country. Key informant sampling was used for this stage of the research study to recruit participants.

A list of contact details, provided by the supplier of brachytherapy sources and equipment in South Africa, was used in order to recruit the potential participants. 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 13 potential participants were contacted telephonically, indicating that it would be acceptable if the head 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, background information and consent documents. It was stipulated that the proposed guidelines would only be e-mailed to the potential participants once the researcher had received their signed consent documents.

Seven of the 13 invited participants agreed to participate. Six of the 13 invited participants were excluded from the study as (a) 2 private heads were affiliated to brachytherapy units that did not treat gynaecological cancers; (b) 2 heads did not respond to e-mails or telephone calls; (c) 1 head of a governmental unit was on leave as sole radiation oncologist in the hospital and (d) 1 private practitioner did not complete the interview schedule and could thus not be included in the findings of the study.

The group of national reviewers consisted of three heads of governmental and four designated representatives of private brachytherapy units, respectively. Findings were analysed manually by the first author and suggestions were integrated to present the final guidelines.

Rigour

Trustworthiness of the research study was established by considering the four criteria proposed by Lincoln and Guba (1985), which include credibility, transferability, dependability and conformability.[11]

Credibility was ensured by peer debriefing with authors, and feedback from patients and members of multidisciplinary teams. Transferability was obtained by the national review of heads and/or designative representatives. Dependability and conformability were enhanced by a rigorous audit trail of data and procedures.

Results

The final guidelines were formulated for use as a tool by members of multidisciplinary teams to facilitate quality patient-centred care at their brachytherapy units. The guidelines address: (a) 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 (b) the exclusive roles and responsibilities of the above-mentioned members of multidisciplinary teams and (c) the practice setting. An overview of the final guidelines is depicted in Figure 1.

Guidelines to facilitate quality patient-centred care in a multidisciplinary environment

(1.) 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.

(1.1) New patient clinic

(1.1.1) 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 premenopausal.
- Ensure that the patient understands that brachytherapy is not an operation, 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 contradictory.
- 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]

(1.1.2) Informed consent

Radiation oncologist

- Informed consent for the brachytherapy procedure must be obtained by or under supervision of a licensed 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 when asking questions.
- Inform the patient that, for 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 English and the official languages spoken in the area.
- Provide information to the patient regarding the proposed treatment if long waiting times have elapsed before treatment delivery.
- All aspects related to the patient receiving 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.

(1.2) Brachytherapy unit (day of procedure)

(1.2.1) 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 to 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.

(1.2.2) 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 informed immediately 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.

(1.2.3) Role of the oncology nurse

- Familiarise 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.
- Allow 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]

(2.) Practice setting

This section of the guidelines addresses the logistical and safety issues deemed necessary to be in place during the high dose rate brachytherapy procedure to ensure quality patient management.

(2.1) 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 patient relaxation may include the following: a television (muted), newspapers, magazines, a radio, plants or flowers.
- Ensure well-lit 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.

(2.2) Treatment room

- Ensure that a fully functional resuscitation trolley is available during administration of the sedation.
- Ensure well-lit treatment areas.

(2.3) 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-drinking facilities for the patients in the recovery room.
- Provide wheelchairs for patients too weak to walk to their mode of transport.

Discussion

The guidelines presented here address (1) patient management at the new patient clinic and the brachytherapy unit and (2) the practice setting, respectively. The guidelines on the exclusive roles and responsibilities of the radiation oncologist working at the new patient clinic were accepted by all the participants of stages three and four. Effective communication between physicians and patients is a primary goal of the radiation oncologist in all clinical and treatment matters.[12] 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.[13] For this process to be effective, both parties must actively participate in the process and both parties share the responsibility for the accurate exchange of information. Physicians have a 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 she is about to receive, to have all questions answered and to fully consent to treatments and procedures.[14–16]

Participants indicated that the role of the radiation oncologist at the new patient clinic needs to be emphasised as he/she is the initial one to provide the patient with treatment-related information. Information overload should be avoided. The guidelines allocated to the radiation oncologist working at the new patient clinic were 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 may not be possible.

A multidisciplinary approach to inform the patient concerning her brachytherapy treatment constitutes good clinical practice. The exclusive 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 between 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.[12] Such relationships maintain a patient-orientated perspective. 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 it is 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 11 official languages are spoken. Participants in 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.

Guidelines on the exclusive roles and responsibilities of the radiation oncologist, the radiation therapist and the oncology nurse at the brachytherapy unit were accepted by the participants of stages three and four. 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.

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. 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-treatment) should be emphasised as adverse incidents were reported by some patients interviewed during stage one of the research. It was acknowledged by the participants in stages three and four that the guidelines for the practice setting are patient orientated or patient centred, because they entail basic standards of care that all healthcare facilities should be able to provide.

The layout and formulation of the guidelines were accepted by all participants in stages three and four as the guidelines were found to be well compartmentalised with well-defined mandates. The guidelines would be practical to implement at brachytherapy units as the layout and formulation 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.

Participants in both governmental and private units acknowledged the significance of the guidelines. They would (a) provide a framework to monitor the standard of patient care or management, (b) ensure that all members of multidisciplinary teams understood their roles, (c) provide a motivation towards 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 brachytherapy unit of the Department of Oncology, but also for those working at 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 in order to provide patient-centred care that will result in patient satisfaction with services rendered.[17]

The guidelines are in keeping with the Batho Pele principles (*Putting people first*) that were introduced in South Africa by the Mandela Administration in October 1997.[18] These principles are aligned with the following constitutional ideals: (a) promoting and maintaining high standards of professional ethics; (b) providing service impartially, fairly, equitably and without bias; (c) utilising resources efficiently and effectively; (d) responding to people's needs; (e) encouraging citizens to participate in policy-making and (f) rendering an accountable, transparent and development-oriented public administration.

Acknowledging the limitation that the input of national radiation oncology registrars, radiation therapists and oncology nurses could have strengthened the value of this research, all members are encouraged to adhere to the guidelines to ensure that quality patient care is delivered.

Conclusion

Guidelines were established to facilitate quality patient-centred care for South African women 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 to define the roles and responsibilities of each member of the multidisciplinary team. The results have both theoretical and practical implications. Further qualitative research in developing countries is encouraged to explore the patient experience of brachytherapy, investigating whether, irrespective of their educational background, patients do truly grasp the concept of cancer and its treatment when signing consent.

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Received: 18-01-2016 Accepted: 12-07-2016