

Article

Patients' informational needs while undergoing brachytherapy for cervical cancer

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Abstract

Objective: To identify informational needs of South African women receiving intracavitary brachytherapy for locally advanced cervical cancer as part of a process to develop guidelines for quality patient-centred care.

Design: A prospective, qualitative study with a phenomenological approach.

Setting: Brachytherapy Unit, Department Oncology, Universitas Hospital, Bloemfontein, South Africa.

Participants: Purposive sampling was utilized to recruit patients undergoing brachytherapy for cervical cancer from July to December 2012.

Main Outcome Measures: Semi-structured, one-to-one interviews were conducted, guided by a theme list. Audio-recorded interviews were conducted in Sesotho, Afrikaans and English by an unaffiliated, multilingual interviewer. The interviews were transcribed, translated and thematic analysis performed.

Results: Data saturation was achieved having interviewed 28 participants, aged 30–73 years. Four themes with sub-themes were identified: (i) informational needs, (ii) patient disposition towards treatment, (iii) psychological experience and (iv) physical experience. Findings on patients' informational needs were the overarching theme and form the focus of this article. These informational needs included: providing patients with disease- and treatment-related information in their home language; adequate information concerning possible side-effects, sexual intercourse and pre-treatment preparation; and providing patients with informative material as standard procedure.

Conclusion: The article has identified women's informational needs providing a focus for patient-centred care. Providing patients with sufficient and understandable information could lessen feelings of fear and anxiety towards treatment delivery. Guidelines with a patient-centred approach could thus be developed to be used as a tool to assist members of multidisciplinary teams in providing quality care to this group of women.

Key words: brachytherapy, cervical cancer, patient experience, informational needs, phenomenology, qualitative study

Introduction

The Global Burden of Cancer [1] estimated that worldwide, annually 528 000 women are newly diagnosed with cervical cancer and that 266 000 women die from the disease. Sub-Saharan Africa is the region with the highest incidence of cervical cancer in the world [2], accounting for 22.2% of all cancers in women as well as being the most common cause of cancer death among women [3]. The most recent age-standardized 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 [4]. South Africa is the only country in this region with a national cytology-based screening program since 2001, but coverage remains poor and the impact on invasive cervical cancer is unknown [5].

The American Brachytherapy Society endorses the use of brachytherapy as an integral component of the treatment for locally advanced cervical cancer [6]. Although this invasive procedure of high-dose rate intracavitary brachytherapy has advantages such as a lower dose to the normal tissues [7], the procedure presents patients with a wide range of physical and psychological challenges [8]. There is growing recognition of the importance of addressing the psychological, emotional and physical needs of cancer patients at various stages of their cancer journey [9]. Information about cancer diagnosis, treatment and its possible effects can effect health outcomes, reduce anxiety and increase feelings of control [10].

Research into women's experiences of receiving high-dose rate brachytherapy has been limited, especially on the African continent. Jenkinson *et al.* [11] 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 are a first step toward planning and improving the care women receive [12].

Bastian was one of the first authors to draw attention to patients' participation in guideline development [13]. 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. Currently, there are various sets of brachytherapy-related guidelines to assist institutions to develop or optimize brachytherapy facilities regarding treatment regimes, techniques, dose specification and treatment planning methods [14]. However, these guidelines for service providers and members of multidisciplinary teams (radiation oncologists, medical physicists, radiation therapists and oncology nurses) are limited to the organizational and technical aspects of high-dose rate intracavitary brachytherapy treatment delivery. It is apparent that currently, there is little evidence available to suggest that the patient's perspective and experiences of undergoing brachytherapy have been integrated into any guideline development process.

The purpose of this article was thus to identify the informational needs of South African women receiving high-dose rate intracavitary brachytherapy for locally advanced cervical cancer as part of a process to develop guidelines for quality patient-centred care.

Methodology

Study design

A prospective, qualitative study with a phenomenological approach described by Giorgi [15] was chosen as the framework for the study. A phenomenological approach allowed the researcher 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 [16], allowing the essence to emerge [17]. Leedy and Ormrod [18] 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.

As part of a process to develop guidelines with a patient-centred approach, a qualitative research design would also enable the researcher to explore the views and opinions of members of multidisciplinary teams on the proposed guidelines, confirming content validity, clarity and applicability.

Target population and sampling

In order to include the opinions of women across the age spectrum into the study, the first author purposively recruited participants from each of the following three age groups: 30–45; 46–60 and 61 years and older. Each age group included governmental and private oncology patients. Although hospitalized patients were included, the majority of participants received their treatment as outpatients. 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 6-week period. The department, in association with the Cancer Association of South Africa, 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 5–8 km radius of the department and patients are transported daily to the radiation department for their radiotherapy.

The inclusion and exclusion criteria for these participants are depicted in Table 1.

The sample size was determined by saturation of the data, which was reached after 28 interviews. The sample consisted of 18 black, 6 white and 4 mixed race participants. Seventeen of the 28 participants' home language was Sesotho and the remaining 11 participants' home language was Afrikaans. Twenty-two of the 28 participants of this study were classified as governmental participants and 6 of the participants were private patients. Two participants had no formal education, 10 received primary schooling, 11 completed secondary schooling and 5 participants completed their tertiary education.

Data collection

Interviewer

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. The majority of the patients treated at this facility are fluent in at least one of these languages.

Interview schedule

An open-ended questionnaire in English, Afrikaans and Sesotho was designed by the first author as an interview schedule and used as a tool to determine the direction of the conversation. The interview schedule provided the interviewer with a set of predetermined questions that guided the semi-structured interviewing process. Probes were used to address issues that did not come from asking the open-ended questions. The interview schedule was pilot tested for face validity with three participants from each language group. 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.

The order of questions of the interview schedule simulated the path of events that each participant had gone through, from the new patient clinic up until treatment delivery. Because the brachytherapy unit in the department is currently the only facility in the Free State to administer this specialized treatment, this service is also utilized to treat patients referred from four private oncology practices, three locally and one situated in another province. The private patients receive their radio-chemotherapy at private oncology practices, where after they are sent to the Department of Oncology, Universitas Academic Hospital Complex for their brachytherapy treatment. The management and sequence of events of governmental and private patients, receiving high-dose rate intracavitary brachytherapy, in the department is depicted in Fig. 1.

Table 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 Academic Hospital Complex, Bloemfontein, Free State.
2. Private and governmental patients.
3. Patients who receive a combination of radiotherapy and chemotherapy.
4. Patients who have received three of the five high-dose rate brachytherapy treatments.
5. Patients who receive EBRT and high-dose rate brachytherapy over a 6-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.

Patient interviews

Data were collected between July and December 2012. The interviews were conducted with patients who had received three of their five brachytherapy treatments. The date, time and locale for the interviews were arranged so as to not inconvenience the participant and were therefore scheduled to coincide with their external beam radiotherapy treatment.

The interviews were conducted in the participant's language of preference (English, Afrikaans or Sesotho), in a locale conducive for private conversation at the brachytherapy unit and were audio recorded. The verbatim data were 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.

Ethical considerations

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

Data analysis and presentation

The transcribed data were analysed manually by the first author according to the phenomenological method described by Giorgi [15]. The steps were as follows:

- The transcripts were read and reread in order to familiarize the researcher with the text.
- Since phenomenology is interested in meanings, the first author 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 28 transcribed interviews were purposively selected by the second and third authors to check for variation in

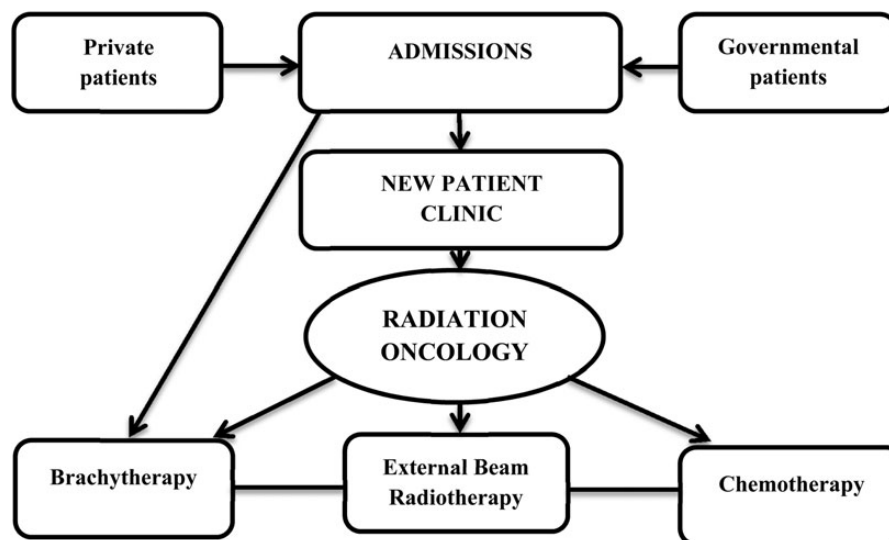


Figure 1 The flow of patients at the Department of Oncology: sequence of events.

interpretation, thus ensuring the credibility and dependability between the data and the findings made by the researcher.

- Meaning units were identified from the participants' descriptions of their experiences.
- The meaning units were transformed into conceptual language and those with shared characteristics were grouped together to build categories.
- Categories of experiences were summarized into related statements and theme titles allocated. Sub-themes covering different aspects within each theme were identified.

Alphanumeric coding (e.g. P1: 47, Aca, Ses, Ses, Kat, Prim) was used to describe the profile of each participant when direct quotes were used (Table 2).

Direct quotes were translated into English for publication purposes and used to inform the explanation. It was indicated whether the suggestions made by the participants were prompted or not. The quotes were not edited, thus English grammar may not be correct.

Rigour

The issues of rigour were dealt with using Lincoln and Guba's [19] criteria which include credibility, transferability, dependability and conformability. In this study, credibility was ensured by peer debriefing (second and third authors). Transferability of the findings was achieved through the rich description of women's experiences obtained during the audio-recorded interviews, while dependability and conformability were enhanced by rigorous audit trail of data and procedures.

Findings

Four themes with sub-themes were identified from the data and are depicted in Fig. 2.

Informational needs was the overarching theme, emanating from the interviews and therefore forms the focus of this article.

Informational needs

A. Informed consent

New patient clinic

A.1 Language of communication

The 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. The following remarks were made by them:

Yes, I did understand very well what was said. She explained a lot of things to me . . . she really motivated me and made me to be strong (P2: 73, Aca, Ses, Ses, Kat, Prim)

. . . 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)

Most of the Sesotho speaking participants received an explanation of the treatment procedure in English. A participant made the following comment:

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

However, a few Sesotho speaking participants, addressed in English, indicated that they did not fully comprehend what was explained to them. These were some of their remarks:

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

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

The Sesotho speaking participants, who were informed of their brachytherapy treatment in Afrikaans, reported that they did not understand what was explained to them. The following remarks were made by 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)

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. (P19: 56, Aca, Ses, Ses, Kat, Prim)

On request of the participant, a Sesotho speaking member of the multidisciplinary team was found to provide her with an explanation of the procedure in her home language.

A.2 Opportunity for questions

The participants were asked to state whether they were granted an opportunity to ask questions to the radiation oncologist before signing consent for the brachytherapy treatment. Most of the participants reported that they were given an opportunity to ask questions to 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)

Some of the participants said that they had no questions, because they were adequately informed. The following remarks were made:

. . . 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)

They supply adequate information. They are approachable and willing to listen. (P25: 37, Aca, Afr, Afr, Ol, Ter)

However, a few participants reported that although they were given an opportunity to ask questions, they were unclear what questions to ask and made the following remarks:

. . . you know a person feels stupid. You're scared. You don't know which questions to ask. (P13: 64, Aca, Afr, Afr, Ol, Sec)

I was thinking that if I was to ask a question, I might ask something unnecessary. (P10: 57, Afr, Afr, Kat, Prim)

I honestly do not know why I never asked . . . I was much stressed. (P23: 55. Pr, Ses, Ses, Ol, Prim)

. . . but sometimes you want to see for yourself. (P20: 51, Aca, Ses, Ses, Kat, Prim)

Only a few participants reported that they were not given an opportunity to ask questions. A ward participant made the following comment:

I didn't get an opportunity to ask questions. I felt too presumptuous to ask. It feels as if I would waste their time. (P22: 35, Aca, Afr, Afr, Wrd, Sec)

Another participant stated that she wanted to ask 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)

Table 2 Alphanumeric coding used to describe 28 participants' profiles

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	Prim
	Secondary	Sec
	Tertiary	Ter

A.3 Reasons for signing consent

Most of the participants said that they had come to the hospital for help, because they had concerns for their future health and well-being. 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. (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 41-year-old participant reported the following:

I just want to get healthy as I have children. (P14: 41, Aca, Afr, Afr, Loc, No)

Participants gave consent for the brachytherapy treatment, because they were told that surgery was not an option and brachytherapy was part of the advised treatment. The following statement was made by a participant:

. . . 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)

B. Treatment-related information

Participants were questioned during the interviews on the following treatment-related information conveyed to them: (i) brachytherapy as treatment method; (ii) side-effects; (iii) sexual intercourse; (iv) pre-treatment preparation; (v) scheduled appointments and (vi) explanation of the treatment procedure.

B.1 Treatment method

Participants reported that they had received information regarding brachytherapy as treatment method, from the informing doctor.

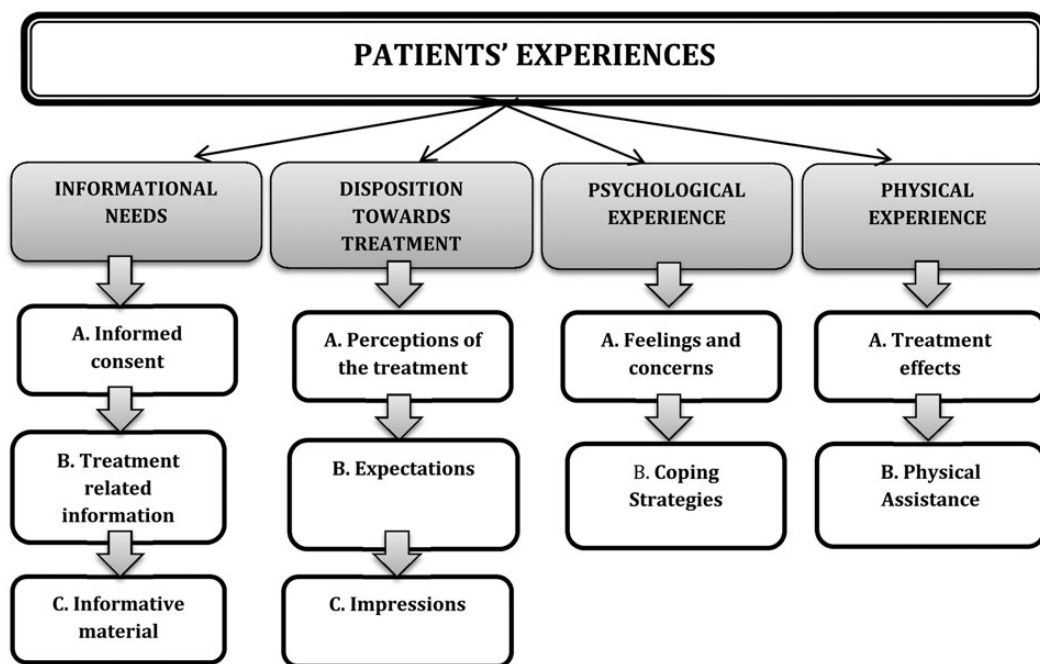


Figure 2 Identified themes and sub-themes of patients' experiences.

A participant said that she was told that after the ‘machine’ (radiotherapy), she needed to go for the ‘inside radiation’ (brachytherapy) 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)

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. The following comments were made:

. . . 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)

. . . it is just a small thing. (P26: 48, Pr, Ses, Eng, Loc, Ter)

B.2 Side-effects

Less than half of the participants reported that they were informed about the possible side-effects they might experience, while undergoing brachytherapy treatment. The following remarks were made by participants who said that they were not informed of the side-effects of the inside radiation:

. . . I do not actually have a clue about it. (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 it. I will be fine. (P19: 56, Aca, Ses, Ses, Kat, Prim)

Expected side-effects such as infection, nausea, diarrhoea, burning of urine, pain, swelling and shrinkage of the cervix were mentioned to some participants. The following comment was made by a participant:

I will experience diarrhoea and vomiting and swelling. (P17: 30, Aca, Ses, Eng, Kat, Sec.)

B.3 Sexual intercourse

Most participants reported that they were not informed about sexual intercourse, while undergoing brachytherapy treatment. One participant said that she intended to ask the doctor about it as she was a married woman. A 48-year-old participant reported the following:

They didn’t say anything, because the thing which I said to them; I told them I don’t have a partner now. I’m a single parent. So they didn’t go deeper with it. (P26: 48, Pr, Ses, Eng, Loc, Ter)

An elderly participant made the following statement:

They did not say anything to me. Maybe they only talk about it with young people . . . those they believe could still be sexually active. (P28: 61, Aca, Ses, Ses, Loc, Prim)

The following remarks were made by participants who were informed about sexual intercourse during treatment:

I should continue to have sexual intercourse with a male partner to assist the lower part of the womb to open . . . it is necessary for me to engage in sexual intercourse. (P1: 47, Aca, Ses, Ses, Kat, Prim)

They told me I have to do it, but to use a condom. (P17: 30, Aca, Ses, Eng, Kat, Sec)

B.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. The following remarks were made:

I was not told. I was not told to prepare myself. (P24: 36, Pr, Ses, Eng, Ol, Sec)

They did not tell me anything. (P22: 35, Aca, Afr, Afr, Wrđ, Sec)

No, they did not say anything. I was wondering, should I or not. But I ate a piece of toast and drank tea. (P16: 69, Pr, Afr, Afr, Loc, Ter)

Participants who did receive pre-treatment instructions stated the following:

I must not eat in the morning, because my stomach must be empty. (P8: 52, Aca, Ses, Eng, Kat, Sec)

I have to make sure that my stomach is clean so that it won’t fail. If there’s faeces in there, it might be a problem . . . the machine won’t work. (P6: 55, Aca, Ses, Eng, Kat, Sec)

B.5 Scheduled appointments

Although the majority of the participants reported that they were informed of the specific date that they were going to receive their brachytherapy treatment, there were some who were not informed and made the following comments:

I did not even know that it was my day for inside radiation. (P25: 37, Aca, Afr, Afr, Ol, Ter)

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

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)

One participant said that she was traumatized by not being informed on which day she was scheduled to go for her first brachytherapy treatment and 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)

B.6 Explanation of the treatment procedure

The majority of the participants reported that they received a second 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 radiation oncologist. A participant said that although she was 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. She made the following comment:

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)

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.

C. Informative material

It is not standard procedure in the department to provide new patients with informative material on their disease and brachytherapy treatment. Therefore, 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:

Yes, I think lots of people will read it and see. . . It will be good. (P12: 50, Aca, Afr, Afr, Kat, Prim)

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:

. . . I did not get a pamphlet here and so I did not know what to expect. (P13: 64, Aca, Afr, Afr, Ol, Sec)

However, there were a few participants who preferred not to be given any type of informative material. The following comments were made by them:

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)

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

D. Patients' suggestions and final remarks

At the end of each interview, participants were asked whether they had any suggestions that could improve aspects of care in the department. The following suggestions were made:

- Provide easily understood information in the patient's home language. It would have been nice if I got an explanation in Sesotho. (P23: 55, Pr, Ses, Ses, Ol, Prim)
I said: rather speak in simple Afrikaans which I can understand. (P10: 57, Aca, Afr, Afr, Kat, Prim)
- Provide patients with information about sexual intercourse and the possibilities of subsequent childbearing.
- Provide patients an opportunity to ask questions.
- Information sessions prior to treatment. (Prompted)

. . . 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, Wrđ, Sec)

It 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:
 - What patients can expect from the treatment?
 - What will be done to them? and
 - Will brachytherapy treatment be a painful procedure or not?
- Provide patients with pamphlets or booklets with disease and treatment-related information in their home language. (Prompted)

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, Wrđ, Loc, Sec)

Patients' 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, Wrđ, 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)

Discussion

The findings revealed participants' shared and unique experiences of receiving high-dose rate intracavitary brachytherapy for locally advanced cervical cancer. Patients' informational needs were the overarching theme and therefore form the focus of this article. The data analysis confirmed the importance of providing patients with disease and treatment-related information in their home language before signing consent. 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—one of the main languages in the region, only a few were informed of their brachytherapy treatment in their home language. Providing patients with understandable treatment-related information in their home language remains a challenge for members of multidisciplinary teams in a country in which there are 11 official languages. If resources allow, the services of an interpreter should be enlisted. Participants who received detailed information of their subsequent treatment in their home language felt that this helped to reduce their feelings of fear and anxiety. Kamer *et al.* [20] reported 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 [21]. Some of the participants reported that, according to them, treatment-related information was not discussed with them. The following unmet informational needs were identified: treatment-related information concerning the side-effects of brachytherapy, sexual intercourse, pre-treatment preparation and scheduled appointments. However, some of these unmet needs 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 [22]. In areas of wide social and racial diversity, full consideration of the differing cultural concerns needs to be acknowledged.

Although the participants indicated that they had an opportunity to ask questions before signing consent, some reported that they considered it presumptuous to voice their questions, 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. Kavanagh and Broom [23] commented 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 side-effects women might experience as well as encouraging questions to explore other issues the women thought important. This could be done on an ongoing basis and to test the patient's understanding of information received by asking them to explain it in their own words.

Second to information from healthcare providers (mostly radiation oncologists), participants wanted to receive conventional printed materials (booklets or pamphlets) on the disease, treatment and possible side-effects. Providing patients with informative material, information sessions and a video presentation prior to treatment delivery in their home language, could reduce anxiety and used by many as a coping strategy. Stewart *et al.* [24] stated that although most women preferred to receive information from their physician or healthcare 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. Warnock [8] reported that all the interviewed patients from their study stated that being shown the treatment room had played a positive role in preparing them for brachytherapy [8].

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 in developing guidelines to facilitate quality patient-centred care for this group of women.

Limitations

The limitation of using only audio recording to capture data is that it only captures speech and not non-verbal communication and environmental factors. 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 [25] deterred the researcher from applying it.

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 and could not be included in the results of the study.

Patients' experiences might have differed if resources of the Department of Oncology, Universitas Annex were not constraining factors in providing quality patient care to this group of patients.

Conclusion

This study has highlighted the importance of providing patients with information on the disease, treatment and its possible effects in their home language as this could reduce feelings of fear and anxiety towards their forthcoming brachytherapy treatment. Published studies regarding the patient experience of receiving high-dose rate intracavitary brachytherapy for locally advanced cervical cancer are limited.

The information communicated in this article is unique as it is the first time that the informational needs of African women treated for cervical cancer are voiced, thereby narrowing the gap in the literature.

Based on these findings, guidelines to facilitate quality patient-centred care in a multidisciplinary environment were developed. Once implemented, these guidelines could become a tool to guide members of multidisciplinary teams in providing quality patient-centred care for this group of women.

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