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Patient-centered care during gynaecological brachytherapy in terms of Batho Pele principles

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Abstract

Background: Patient-centred care means that healthcare systems are there to serve the people. The Batho Pele principles “Putting People First” were established in 1997 by the Mandela administration of South Africa and these service delivery principles are to be adhered to by government institutions. The principles are applicable to radiation therapy treatment aspects mainly to sustain, but also to improve on the quality of patients’ experiences while undergoing treatment.

Purpose: The aim of the study was to establish the standard of patient-centred care by exploring and describing gynaecological cancer patients’ expectations, experiences and understandings prior, during and post HDR brachytherapy treatment procedures.

Methodology: A qualitative research design with a descriptive phenomenological research approach was followed. Recruitment entailed using purposive sampling. To obtain rich insights into respondents’ lived experiences, data were acquired through semi-structured interviews, incorporating the Batho Pele principles.

Findings and conclusion: A gap in communication between the healthcare provider and cancer patient respondents was exposed. This caused them to be lost regarding the brachytherapy treatment processes and procedures. They expressed their desire for information and seemed to be mostly submissive to what was being done to them. Findings indicated partial compliance with Batho Pele in terms of courtesy, redress and access; there was insufficient compliance with regard to consultation, service standards, information, openness and transparency.

Keywords redress, openness and transparency, service delivery

INTRODUCTION AND BACKGROUND

Patient-centred care means that healthcare systems are there to serve the people.^[1] The Batho Pele principles “Putting People First” were established in 1997 by the Mandela administration of South Africa and these service delivery principles are to be adhered to by government institutions.^[2] The principles are applicable to radiation therapy treatment aspects, mainly to sustain and also to improve the quality of patients’ experiences while undergoing treatment.^[2]

The referral process for high dose-rate (HDR) brachytherapy treatment starts at a radiation oncology new patient clinic when a patient agrees to undergo radiation therapy treatment.^[3] It was observed that at a public sector tertiary hospital, information on radiation treatment methods and side effects are provided to patients by radiation oncologists. Informed consent forms however only convey general radiation therapy information and lack treatment specific information. As HDR brachytherapy treatment is such a sensitive and invasive procedure, and high quality

patient care is of utmost importance, the researcher questioned whether the available information is adequate for a patient to fully understand the HDR brachytherapy treatment.^[4-7]

As there was a dearth of literature on the subject,^[3,8-10] a research study was deemed necessary. The research question was: What are the gynaecological cancer patients’ expectations, experiences and understandings of the HDR brachytherapy treatment procedure? The aim of the study was to establish the standard of patient-centred care by exploring and describing gynaecological cancer patients’ expectations, experiences and understandings prior, during and post HDR brachytherapy treatment procedures. To encapsulate care and service provision, healthcare supervisors (heads of departments of radiotherapy), providers (nursing staff, oncologists, radiotherapists), patients and families should work together within the framework of the Batho Pele principles,^[2] to support the patient, reduce costs and enhance the quality of healthcare;^[11] this involves inter alia the below principles.

- **Consultation** – patients should be

informed about the treatment they will receive, how it will be conducted and the side effects

- **Service standards** – patients should be informed about the level and quality of service they will be receiving to ensure that their expectations and experiences are aligned with the standard of services of the profession and the institution
- **Access** – the general public should have equal right of entry to the services, in this case radiation therapy treatment
- **Courtesy** – patients should be cared for with courtesy, thoughtfulness and kindness
- **Information** – patients are entitled to receive accurate and comprehensive information about their treatment and the services rendered to them
- **Openness and transparency** – patients should be informed about the treatment risks and side-effects
- **Redress** – valid comments and

complaints from patients should be received positively and addressed in an appropriate manner.

MATERIAL AND METHODS

A descriptive, qualitative, phenomenological strategy was used to obtain thick and rich descriptions of the patients' expectations, experiences and understandings of the brachytherapy treatment procedures: their "life world" pre, during and after undergoing a sequence of brachytherapy gynaecological cancer treatments.^[12]

This study was conducted in a radiation oncology department of an urban tertiary hospital's brachytherapy unit, in Gauteng. The Research Ethics Committee of the University of Pretoria and Faculty of Health Sciences Ethics Committee approved the study. Potential participants were required to sign an informed consent before enrolment in the study. The population and sampling were determined by the entries in the register of patients undergoing radiation treatment. At the time of the study, and according to the records over a three-month period, 43 patients received gynaecological HDR brachytherapy treatment. Purposive sampling was utilised to obtain information-rich potential participants;^[12] patients of diverse cultures were included in the study to obtain a holistic

patient spectrum (Table 1). Ten participants were interviewed before data saturation^[13] was reached.

Three sets of semi-structured interviews, guided by Long's^[3] approach, were conducted: a pre-brachytherapy interview, post-brachytherapy interview, and an exit interview. The interview schedule included respondents' demographics such as age, education, race, language and culture, to determine their diversity. Each interview lasted 20-40 minutes.

The initial interview was conducted prior to the potential participants' first HDR brachytherapy treatment to explore expectations and anticipated experiences. There were four questions.

- Why are you here today?
- What were you told about the treatment that you are about to receive?
- What are you expecting of this treatment?
- What do you think will happen here?

A post-treatment interview was conducted immediately after the first treatment to explore the respondents' experiences of the HDR brachytherapy treatment. The following questions were asked.

- How did you come to know of this treatment?
- Was it as you expected it to be?
- Describe the treatment.
- What was your experience regarding the treatment you underwent?

The final interview was conducted once all the HDR brachytherapy treatments were completed. The purpose was: to establish whether the respondents' expectations and experiences had altered; to give them an opportunity to share new experiences; to verify their previous expectations; and to gain the knowledge and understandings that they had obtained during the treatment process. They were asked two questions.

- What are you experiencing now after the treatment?
- How do you think we can improve on making your experience better?

Trustworthiness of the study was ensured by providing verbatim accounts of the respondents' expectations, experiences and understandings. The collected data should give adequate information to a reader, to allow evaluation of the credibility of the results. Use was made of fieldnotes and notes on personal observation and feel-

Table 1. Patient interviews: respondents' profile and demographics

PARTICIPANT	DIAGNOSIS	PROCEDURE	AGE	RACE	BELIEF	EDUCATION	LANGUAGE	LANGUAGE INTERVIEWED
P1	CaCx iB2	Ring and Tandem	54	African	Christian	Gr10	Seswati/English	English
P2	CaCxiiiB	Ovoid and Tandem	42	African	Christian	Gr11	Sepedi/Sotho/Tswana/English/Afrikaans	English
P3	CaCxiiB	Ring and Tandem	42	African/Black	Christian	Gr5	Shana	Shana (interpreter)
P4	CaCxiiiB	Ring and Tandem	49	African	Christian	Gr12	Swazi/English	English
P5	Endometrium iiiB	Y-applicator	66	Black	Christian	No	Swazi/Afrikaans	Afrikaans
P6	CaCxiiiB	Ovoid and Tandem	71	African	Christian	Gr8	Northern Sotho/Sepedi/English	English
P7	CaCxiiiB	Ovoid and Tandem	34	Black	Christian	Gr11	Sepedi/English/Venda/Zulu	English
P8	CaCxiiiB	Ring and Tandem	73	Black/African	Christian	No	Tsonga/English/Afrikaans	English
P9	Endometrium iiB + Hysterectomy	Sorbot	46	White	Christian	Gr12 + Tertiary	Afrikaans	Afrikaans
P10	CaCxiiA	Ring and Tandem	27	Black	Jehovah's witnesses	Gr12	Zulu/English	English

ings, to assist in reflexivity.^[14] An audit trail was kept; bracketing was done throughout the study to ensure dependability and confirmability.^[14,15] Member checking ensured further credibility and accuracy of data capturing and interpretation.^[16] During data analysis, the cyclic process, as described by Kemmis,^[17] namely plan » act » observe » reflect (and then again plan » etc.) was adhered to.^[17,18] This cycle aided in responsiveness which assisted in obtaining research rigour. The early cycles helped to identify the content of the later cycles, and in the later cycles the interpretations were tested, challenged and refined.^[18] Each cycle consisted of critical reflection through which the researcher recollected and critiqued the occurrences in each step.^[18]

FINDINGS

Interpretation commenced with the profile of the respondents and to provide insight on their socio demographic characteristics (Table 1). Since this was a qualitative study, the data strengthened the rigour of the study and assisted in transferability.^[19,20] The data also demonstrated the variety of cancer stages, procedures, ages, races, education and languages of the respondents. Ten females who were about to undergo two to three brachytherapy treatments consented to participate in the study. They were given an option to participate in their preferred language. The data collected from the transcribed interviews were incorporated in the Batho Pele principles^[2] to explore the respondents' perspectives on the standard of the services they had received. Their verbatim responses are presented in italics.

• Perspectives on information and service standards

Although the respondents might have seen the treatment as a source of hope, the following responses from the initial interview revealed that they felt lost regarding the treatment process.

I don't know, they just took me that side, they say I must come this side, I don't know... I don't know what is happening this side. They didn't tell me anything. (Pt-4PreB:16-17)

I didn't get information about brachy, I only got information about the radiation treatment. The other treatment, but brachy I don't have any clue. (Pt7PreB:18)

I don't know; that's the problem. No-one told me anything. Not anyone tell me. I just heard the brachy is sore, I don't know. (Pt-8PreB:22-23)

During the post-treatment interview, they indicated further uncertainty.

They didn't tell me. I want to know what is going on, what they found. I want to know what's going on. (Pt1PostB:17-18)

I don't know what they going to do, I don't know if I should be scared, because I don't know what they are going to do. I shouldn't be scared. I'll just see. (Pt5Post:29-30)

There seemed to be very few instances of them obtaining information from nurses, oncologists and radiotherapists during treatment. Only two obtained information, which formed knowledge prior to the brachytherapy treatment and, in recollection, only one was satisfied with the information. The respondents did not want to be influenced by negative talk from other patients, but still seemed to listen to them. Their knowledge of brachytherapy, which they had assembled during the treatment procedures, was gathered from other patients' descriptions of the treatment, or they had constructed their own interpretation of it. They shared the fears that they experienced due to the brachytherapy treatment, which was mostly because of a gap in communication or inadequate information. Some were informed to a certain extent, but a shortfall in terms of the Batho Pele principles' information and service standards was identified.

• Perspectives on access and consultation

At the hospital where the study was conducted, gynaecological cancer patients' access to treatment is affected by the period between the first appointment with the radiation oncologist and the commencement of the actual HDR brachytherapy treatment, which, according to appointment bookings, is approximately six to eight weeks. These patients have access only to a certain extent because of the extended time-delays, and equal right of access to services is thus only partially adhered to. Consultation does take place, but from a patient perspective, is lacking in depth as is implied in the following statement about a respondent's consultation with the radiation oncologist.

No, not a lot, he just ask me how I'm doing, I didn't get any information from him. He didn't tell me anything; he just asked me what my problem is. I just tell him about that pain. (Pt1Tele:17-19)

• Perspectives on courtesy

Overall, the respondents seemed to be submissive. They accepted the treatment procedures just as they were. Taking control of their situation did not come naturally for all; some had complete confidence in their doctors and supposed that the doctor would have told them what they needed to know.^[4] Most comments concerning healthcare providers were positive.

They treat me very well. (Pt-6PreB:18)

Maar verder, die mense, die radioterapeute, hulle was almal vriendelik. En dit was eintlik vir my snaaks hoe die dokter was. (translation: the radiotherapy staff, they were all very friendly, it was strange for me how the doctor was.) (Pt9Exit:53)

The staffs were so lovely, so friendly, they were so comforting. I just think that they did their best, I was so thrilled with their service, and they very friendly. (Pt10Exit:32-33)

Healthcare providers act as a support structure to a patient, a sense of comfort.^[4] The respondents were appreciative of gestures, such as kindness and friendliness shown by the healthcare providers; it calmed them or helped them feel better; and had no necessary connection to the information provided to them by healthcare providers.^[4] According to the respondents' perspective, the healthcare providers treated them with courtesy. The Batho Pele principle is in part fulfilled at the research site.

• Perspective on openness and transparency

The respondents' understanding of brachytherapy, in retrospect, was described according to their knowledge, which was obtained from information received from the healthcare providers; some were possibly informed by other patients, and one saw what was happening prior to her own brachytherapy procedure.

I'm just scared, because I saw people in there, eish. There is no nice here, the machine is put under

you. It's not good. I'm just scared, but I don't know. (Pt6PreB:14-16)

The brachytherapy procedure was also described by the respondents' own experiences, which involved a description of instruments being used during the procedure.

They just put me some instrument in my vagina. (Pt4PostB:8)

The doctor put that thing inside. (Pt8PostB:11-12)

One was concerned about reproductive

related matters and was not informed that she would not be able to bear children after receiving the treatment.

But I want to know about the sex, can I still have sex? Will I still get the children? (Pt3Exit:14-15)

One expressed disappointment about the comment of a radiation oncologist who said the following about a Sorbot applicator procedure (a simpler procedure, performed on patients who had hysterectomies).

It won't be bad. (Pt9Exit:7)

She found the procedure to be very traumatic and was disappointed because the radiation oncologist was not emphatic and made it out as:

Nothing. (Pt9Exit: 21)

They sedated me for the second treatment, but it was still terrible. They used the smaller sorbot apparatus, the first one's head was very big. (Pt9Exit: 23-24)

They coped with the treatments because of hope they had in their hearts. In some there was a sense of disappointment and

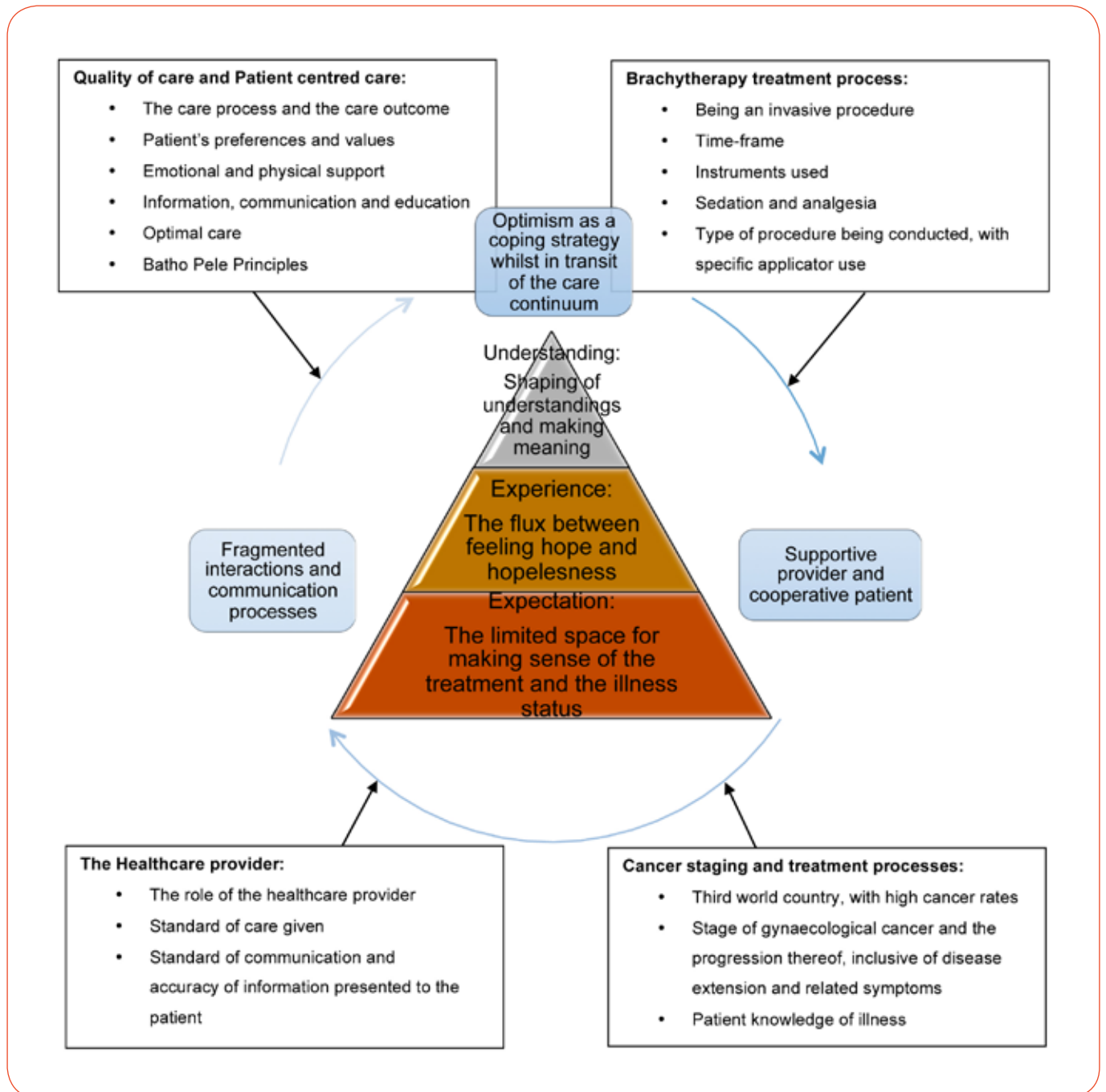


Figure 1. Conceptual framework illustrating the Brachytherapy encounter.^[19]

others held onto their faith. They did not know what to expect of the brachytherapy treatment procedure and were unsure throughout the processes. Thus, from respondents' perspective there seems to be a lack in adherence to the Batho Pele principles of openness and transparency.

• *Perspective on redress*

The respondents were probed as to whether they thought that they could make any recommendations to improve the brachytherapy treatment procedures. Only four made recommendations; the rest were content with the way the treatments were conducted by the healthcare providers.

The following improvements were suggested: provide easily-understood information in the patients' home language; give information prior to treatment and repeat it once inside the treatment room; provide patients with pamphlets/booklets on the disease, treatment and side-effects; show patients the treatment room and apparatus prior to treatment; utilise time spent in the waiting room to prepare patients psychologically for their forthcoming treatment; inform patients that they will receive a sedative prior to their treatment; administer adequate sedation for optimal pain control and complete the treatment as quickly and sufficiently as possible.

These suggestions address the shortcomings that were identified in terms of the Batho Pele principles and by implementing the suggested improvements the quality of patient-centred care could be improved.

DISCUSSION

The discussion of the findings is guided by: When we see the world we experience essences.^[21] The phenomenon under investigation is given a common understanding by describing the concepts and essences thereof.^[14] We work with the different meanings that are present in the descriptions and we try to discover a pattern of meanings that is partly made up of

differences and similarities amongst these meanings.^[21] The respondents' experiences were shaped by their expectations, which in turn shaped their understandings and their overall outlook on their treatment continuum, as shown in Figure 1. The framework was adopted from Hall et al^[22] and adapted as it was most appropriate to capture gynaecological cancer patients' expectations, experiences and understandings within a patient quality-of-care context of brachytherapy processes and procedures. The arrows in Figure 1 show the influence that four factors have on the brachytherapy patients' life-world. Each overarching theme has a unique influence on patients' expectations, experiences and understandings. The cyclic figure was adapted into a pyramid, which represents the life-world of brachytherapy patients, inclusive of their brachytherapy treatment processes and procedures expectations, experiences and understandings.

The overarching themes in Figure 1 have an inter-relating influence, directly/indirectly on the themes of the pyramid. To a healthcare provider, the treatment processes and procedures are a daily familiarity, but for a patient it is a complex process to comprehend. The framework was developed from a patient's perspective, based on the descriptions shared and ranging from machines to procedures, envisaged outcomes, and coming to terms with what has happened.^[22]

The factors affecting the gynaecological cancer patients' expectations, experiences and understandings are all linked. The quality of patient-centred care, brachytherapy treatment process, healthcare provider, and cancer staging all influence the essences of optimism as a coping strategy, communication, the supportive provider and the cooperative patient. Gynaecological cancer patients want help with finding a sense of meaning in their lives; they are dealing with pain, loss and death sooner and more intensively than most people.^[23]

CONCLUSION

Health systems are there to serve the people^[1] and the Batho Pele principles provide effective guidelines to explore patients' perspectives of service delivery standards.^[2] The strength of this study lies in its contribution to the scientific knowledge using the Batho Pele principles in terms of perspectives of service delivery regarding HDR brachytherapy standards. A limitation is the very small sample size; findings cannot be generalised. Future studies are suggested to include multiple institutions to allow generalisation and a wider demographic profile of participants.

The findings indicated partial compliance with Batho Pele in terms of courtesy, redress, and access. There was insufficient compliance with regard to consultation, service standards, information, openness and transparency. These findings are comparable to other similar studies.^[3-5,8,10,24-28] The findings, in a South African context, could be used by healthcare providers for self-assessment purposes to ultimately improve quality and standards of care as explained in the Batho Pele principles.

CONTRIBUTIONS OF AUTHORS

AE was the main researcher and was responsible for the data collection, capturing and presentation of the results. CRM assisted with interpretation and analysis of the results until agreement was reached. Both contributed equally to writing the manuscript.

CONFLICT OF INTEREST

None

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