

Experiences of women receiving high dose rate brachytherapy for cervical cancer at an academic hospital

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The objective of this study was to present a descriptive summary of the experiences of women treated with high dose rate brachytherapy for cervical cancer. A qualitative descriptive design was used and 16 women treated at an academic hospital in Gauteng were purposively selected. Qualitative interviews were conducted and thematic analysis was used to analyse the data, from which two themes arose: the treatment experience and experiencing emotional distress. Being treated with brachytherapy was a negative experience causing fear, pain and humiliation. The participants feared the procedure, before receiving the first treatment and even after having had one. Pain was a major problem, as the preventative medication participants received did not protect them from experiencing pain. Having to open and hang their legs was a humiliating experience aggravated by the presence of observers and the rotation of doctors. Their belief in God comforted them and gave them courage to endure the treatment, whilst caring staff comforted and supported them. In addition to individualised patient education, nurses should assess the level of pain women experience before, during and after receiving brachytherapy and advocate for the revision of pain management protocols.

Keywords: brachytherapy, cervical cancer, experiences, South Africa

Background of the study

Cervical cancer is a health problem of the developing world, as approximately 84% of all women diagnosed with this disease live in developing regions.¹ According to Denny,² it is estimated that 78 897 women living in Africa will be diagnosed with cervical cancer annually, whilst 61 671 (78%) will die from this disease. Late presentation and lack of treatment facilities contribute to the high death rate.³ In South Africa, cervical cancer is the second most common cancer in women but the most common in black women.⁴ According to the 2010 Cancer Registry,⁴ the highest percentage (30.02%) of all black women newly diagnosed with cancer suffered from cervical cancer, compared with 6.37% in Asian and 4.24% in Caucasian women.

According to the International Atomic Energy Agency (IAEA)⁵ brachytherapy is mandatory for the curative treatment of all women with invasive cervical cancers. The standard treatment for women diagnosed with Stage IIB to IVA disease consists of external beam radiation and brachytherapy with or without concurrent chemotherapy. Brachytherapy is most commonly administered intracavitary and is therefore an intrusive procedure involving lithotomy position, the insertion of uterine and vaginal applicators, a urinary catheter and a rectal retractor. High dose rate brachytherapy has the benefit of shorter treatment times resulting in several advantages, such as less exposure to nursing staff, administering treatment on an outpatient basis, not exposing patients to prolonged periods of bed rest thus reducing the risk for thromboembolism, reduced risk for the displacement of the applicators and packing during the treatment and using a tandem with a smaller diameter compared with the one used for low dose brachytherapy. The overall treatment time, which is the time from the first radiotherapy treatment to the last radiotherapy treatment, plays

an important role in the outcome of the patient treated with radiotherapy and the entire course, including external beam radiation and brachytherapy, should not exceed eight weeks.

Little is known about the experiences of women receiving high dose rate brachytherapy in South Africa, as qualitative investigations of this phenomenon does not seem to be available. Our study reflects on these experiences and provides baseline data focusing on this knowledge gap.

Method

Setting and sample

The setting was an academic hospital in Gauteng Province. The hospital offers specialist inpatient and outpatient services and serves as referral hospital for a number of regional hospitals. Approximately one-third of the patients treated at the Department of Radiation Oncology suffer from gynaecological cancer. Most patients referred to the department are treated on an outpatient basis; those who are too ill to come to the hospital on a daily basis are admitted to the ward. In addition, patients who live far from the hospital and are not able to afford transport costs to and from their homes are temporary lodged at interim homes run by non-governmental organisations.

Our sample consisted of 16 women, who were receiving high dose rate brachytherapy at an academic hospital in Gauteng. Participants were between 32 and 54 years old, with an average of 42.2. Most were single, had more than two children and lived in urban communities. The majority (12 of 16) had never been screened for cervical cancer. Women had to be 18 years and older, had to have received at least one brachytherapy treatment and had to be able to speak Basic English to participate in the study.

Methods

We used a qualitative descriptive design, which allowed us to present an accurate account of the meanings participants ascribed to specific events.⁶ This design was applicable to our study as it allowed us to present a descriptive summary of women's experiences of high dose rate brachytherapy. Purposive sampling, a recognised measure to improve the transferability of the findings and usually used in qualitative research,⁷ was employed to select the sample. Data saturation, the point where no new information emerges from the data,⁸ determined the sample size.

After obtaining ethical clearance and permission from the university and hospital, we approached eligible women scheduled for brachytherapy and invited them to participate in the study. Participation was voluntary and informed consent, in writing, was obtained from the volunteers. Unstructured interviews, used to determine individuals' perceptions and opinions,⁹ were conducted in English in a private room, with only the researcher and participant present, for an average of one hour. One question was asked: *Please tell me what it is like for you to get brachytherapy?* Sixteen interviews, followed by an additional eight to clarify issues, were conducted during August and September 2014. Probes and prompting questions⁹ were used to encourage participants to expand on their experiences and member checks¹⁰ enhanced the credibility of the findings. In addition, we used Shenton's¹⁰ guidelines to enhance the rigour of the study and applied the principles of confirmability, transferability, dependability and credibility throughout the study.

Data analyses

Data gathering and analysis occurred concurrently. The interviews were transcribed verbatim and an Excel® spreadsheet (Microsoft Corp, Redmond, WA, USA) was used to capture the demographic information. We analysed the data using thematic analysis, a flexible approach that minimally organises data, reports themes within data and allows a rich description of the data.⁶ We familiarised ourselves with the data by reading and re-reading the transcribed interviews; initial ideas were written in the margins. We coded interesting features across the entire data set, organised it into emerging themes, checked it against the data set and named the themes. We used reflexivity during the data analyses to be self-aware of who we are, our privileged position and any preconceptions we hold^{11,12} and how this might affect the study findings.

Results

Two themes arose from the data: the treatment experience and experiencing emotional distress.

Receiving the treatment: 'the worst experience ever'

The participants agreed that brachytherapy was a dreadful experience and described it in terms of 'terrible,' 'horrible' and the 'worst experience ever'. Pain was a major issue for most and participants were overwhelmed by the 'hell' they experienced during the procedure, especially when the applicators were inserted. However, for some the removal of the applicators was equally painful; others even preferred to die from cervical cancer than to undergo another treatment. One participant explained: 'When applying their thing, it's like somebody who is cutting your nails ... each treatment through the vagina feels like it's been through a meat grinder...'. A second participant said: '... they were shoving stuff in your vagina ... painful, painful stuff... I'd rather die of cervical cancer than going through the procedure ... like something cutting through the soft skin in your vagina ...

a sharp knife ... pain ... worse when they are taking it out ... just when you think it is over, they tell you it's over, and they are still going to take out and the pain gets just even worse...'

Participants reacted differently when they experienced severe pain; some called out whilst others wept or kept quiet. One participant said '... ah! I screamed, I screamed, I could not take the pain ... for me it was like I could rip the thing out ... it was so horrible...'. Another explained: 'It was very sore ... it was very, very sore but I didn't cry ... I can't scream because it's my culture...'

Many participants compared the pain with childbirth, a process they preferred to brachytherapy. Some were of the opinion that childbirth only lasts for one day compared with the various brachytherapy treatments scheduled for them. One participant explained: '... you feel the pain worse, worse, worse than childbirth ... in short I'd rather have 20 more kids than have one brachytherapy'; another added '... it's painful ... even having a baby is much better really because ... these things, they are metals ... that they put it in you...'

The participants agreed the pain they experienced during the treatment was because the analgesia they received did not work well and was not 'strong' enough. One participant said: '... they told me that this tablet and this injection will keep you not feeling the pain but it didn't work that way... I felt exactly everything, like you tying a knot inside of me ... it was so very sore...'. Another added, 'Eish! I feel so very painful because that pill and injection didn't drug me...'

Participants did not only experience pain during the treatment but also reported unrelieved pain lasting for hours and even days after the procedure. Having dysuria added to the pain, which they described as having a 'hot' vagina and 'hot' urine. In addition, having to pass urine was so painful that some tried to retain their urine, whilst others screamed and cried when having to urinate. One participant explained, '... the vagina is still hot, yes still hot and painful ... two days, three days then afterwards you get normal again'. Another said, '... yoo! It's too painful when you go to the toilet if you finish doing the brachytherapy, for the first time when you go to the toilet it's too painful ... like the hot water, you see the fire when you burn... I was screaming and crying.'

Brachytherapy was a negative experience characterised by severe pain. The analgesia participants received prior to the procedure did not prevent pain. Some experienced pain for days after the treatment and the pain resulting from dysuria added to their suffering.

Experiencing emotional distress: 'they make me to open my legs'

Participants experienced emotional distress before, during and after having brachytherapy. They feared the procedure even before having had it and the rest of the treatment after having had the first. One participant explained, '... I couldn't sleep ... I'm thinking of the agony I'm gonna go through'. Another described how terrified she was during the procedure, '... it makes me scare ... to see the doctors get something inside of you ... this doctors is going to kill me...'. A third participant described her fear for the follow-up treatment, '... even for your next appointment you remember precisely ... like I am right now, so scared I have been since yesterday ... I keep thinking ... I can do nothing but thinking...'

Having to 'open' and 'hang' their legs demeaned participants and added to their emotional distress. One participant said, '... you

open your legs wide ... the way you lie down ... they see through you ... you don't feel good...'. A second participant added, '... look, my legs were tied up, am on my back yeah ... humiliating ... the less I talk about it the better because if I talk about it, it hurts me because it brings back...'

Not having the same doctor, and having observers present caused helplessness and added to participants' humiliation. One participant said, 'I was surrounded by other nurses and doctor ... yah there was four of them and a doctor and they were all standing next to me and watching hmm ... yah I felt like everybody watching me.... I felt helpless because I didn't know what to do...'. Another added, '... every time it's somebody else, you feel that shyness err ... always other faces of the students coming in and out so for me it's a bit of humiliating.... I think it's more humiliating for the patient as you might think....'

Most participants did not feel prepared for the treatment and felt nothing was explained to them during the procedure. In addition, some were of the opinion that the healthcare professionals did not display a caring attitude towards them. Two participants explained their experience, '... (I) am here at the hospital because am sick you know, yeah ... he is not (to) treat me like the dog ... treat me like ... yeah like human...'; the second participant said: '... doctor must try to ... explain to you and tell you; you are going to do this and this.... I was expecting them to tell me what they are going to do to me this side.... I felt so sad, so bad even if someone told me before what is going to happen there, maybe I will have prepared myself....'

Despite not feeling prepared for the procedure, some participants found the healthcare professionals supportive and caring. One participant described her experience as positive: '... I find the doctor and introduce herself ... I felt comfortable ... they say you must relax you will be OK'. Another added, '... the nurses they make you comfortable, relax ... they help you to go and lie down in the bed ... they were friendly, loving, helping even the doctors everybody...'

Religion served as a source of comfort and hope and participants trusted God to help them get through the treatment. One participant explained, '... oh God ... I went through it and then it was finished and I said thank you God that it was finished...'. Another added, '... hope and pray in faith because so yah I know its only faith that gets us through this...'

Brachytherapy was a humiliating experience, a procedure feared by participants and for which they felt unprepared. They found having to open their legs demeaning and not having the same doctor inserting the applicators and having observers present added to their emotional distress. Having faith in God assisted them to tolerate the procedure, whilst caring staff promoted comfort.

Discussion

Receiving brachytherapy, the 'worst ever' experience, is not easy. Some participants felt unprepared and uninformed and experienced the health professionals as uncaring. In addition, having more than the essential staff present when they were at their most vulnerable, lying on their backs with their legs 'wide open', added to their emotional distress. Velji and Fitch,¹³ who investigated the experiences of Canadian women who received brachytherapy, found the information that women received prior to the treatment and the care they received from nurses during the procedure shaped their experience positively or negatively. In addition, Brand¹⁴ found a significant relationship between the fear and anxiety women experience before

brachytherapy and unmet information needs. Considering these factors, it is not surprising that the women in our study feared brachytherapy and considered it a negative experience. However, to conclude that the negative experiences of the participants were caused by their unmet information needs and the lack of care they expected would be over-simplifying a complex issue and should be investigated before definite deductions can be made. In contrast with the findings of Velji and Fitch,¹³ who found that the treatment modality itself did not play an important role in how women experience this treatment, the nature of the procedure expressed as 'shoving stuff in your vagina' played a major role in how our participants experienced brachytherapy.

The participants experienced both physical and emotional pain. Participants feared the procedure before they had been treated and even the follow-up treatments. Andersen, Karlsson, Anderson and Tewfik,¹⁵ when exploring survivorship issues in women diagnosed with gynaecological cancer, found levels of anxiety and distress in women remained high before, during and after brachytherapy. Kwekkeboom, Dendaas, Straub and colleagues¹⁶ found that pre-treatment distress was significantly higher than that experienced before the second brachytherapy. It is unclear whether the distress levels of women in the current study decreased after the first treatment as the number of treatments was not taken into consideration and distress levels were not measured. However, distress after the first treatment was still a reality for the women in our study.

The severe pain participants experienced, described as 'cutting' and 'I could not take the pain', added to their suffering. According to Arnold, Lee and Stuart¹⁷ and Chapman,¹⁸ pain is a common symptom amongst persons receiving any form of cancer treatment and is a reality for about 50–53% of patients at all disease stages and about 62–88% of patients with advanced disease. Nail¹⁹ found most women diagnosed with gynaecological cancer experience varying degrees of pain during brachytherapy, which, according to Kwekkeboom, Dendaas, Straub *et al.*¹⁶ ranges from mild to moderate. In addition, Rollison and Strang²⁰ found more than half (13 of 20) of the patients in their study experienced moderate to severe pain during this procedure. Although the current study did not assess the levels of pain, it provides evidence of the experience of severe pain during brachytherapy procedures. As evident by 'that pill and injection didn't drug me', the conscious sedation participants received did not prevent them from experiencing pain. The way pain is managed does not seem to be best practice as, according to Puntillo, Wild, Morris *et al.*²¹ and Gordon, Dahl, Miaskowski and colleagues,²² unlike other forms of cancer pain, procedural pain can be anticipated and prevented.

As described by 'I couldn't sleep, I'm thinking of the agony I'm gonna go through', women experienced high levels of anxiety. Warnock,²³ on investigating experiences of gynaecological cancer patients treated with brachytherapy, found a relationship between pain and anxiety and difficulty coping during the procedure. However, it was unclear whether the pain was raised by the anxiety or the anxiety resulted in pain. The emotional pain of having to lie in the lithotomy position with your legs wide open adds to the complexity of the pain experience. In addition, it was interesting to find the participants preferred childbirth, described by Simkin²⁴ as the ultimate painful, emotionally distressing, vulnerable and exhausting event in a woman's life, to having to undergo brachytherapy. It can only be concluded, as supported by Velji and Fitch¹⁴ and Kwekkeboom Dendaas, Straub and colleagues,¹⁶ that brachytherapy is a very unpleasant and uncomfortable procedure.

Participants' belief in God brought comfort and hope, as supported by 'It's only faith that gets us through this'; participants trusted God to provide them with strength to tolerate the treatment. According to Wachholtz and Pearce,²⁵ people rely on their religious faith to cope with any kind of life challenges. Furthermore, spirituality and religion have the ability to reduce stress, whilst prayer has the ability to distract from pain. It was positive to find that nurses and doctors supported participants as some experienced the staff as caring and comforting. Attree²⁶ found patients considered good quality care as patient-focused, individualised care based on their needs, provided in a humane manner by means of a caring relationship. As illustrated in the current study, being with the participants was also experienced as good care. Providing good quality of care gives patients the feeling of being the focus and being genuinely cared for, which enables the development of trust and confidence – something desperately needed when being treated with brachytherapy.

Our study has limitations. A single study focusing on women treated in the public healthcare sector might not be sufficient to gain insight into what women receiving high dose rate brachytherapy experience. Further research is needed to gain a deeper understanding of this phenomenon.

Conclusion

Being treated with brachytherapy was a negative experience causing fear, pain and humiliation. The participants feared the procedure, before receiving the first treatment and even after having had one. Some felt unprepared and uninformed and experienced the staff as uncaring. In addition, having more than the essential staff members present when they were at their most vulnerable – lying on their backs with their legs wide open – was a humiliating experience. The pain participants experienced was so severe some could not help but cry out, as the preventative medication they received did not protect them. The dysuria they experienced after the treatment added to their suffering. However, their belief in God comforted them and gave them courage to endure the treatment, whilst caring staff also comforted and supported them.

Patients should receive individualised education regarding the procedure, and the rotation of doctors and presence of observers could be minimised. In addition, doctors could explain the procedure and inform patients what the next step would be so that they are prepared for what would be happening to them. Nurses should assess the level of pain women experience before, during and after receiving brachytherapy and, based on the findings, advocate for the revision of pain management protocols. Non-drug options used in pain management could also be considered to complement pharmacological interventions.

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