

# Experiences of Women Receiving Multifraction High Dose-Rate Brachytherapy for Cervical Cancer: A Prospective Qualitative Study

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## Abstract

**Objective:** The aim of this study was to establish cervical cancer patients' expectations and experiences during high dose-rate (HDR) intracavitary brachytherapy procedure, as part of a process to develop guidelines for quality patient-centered care. **Methodology:** A prospective, qualitative study with a descriptive phenomenological approach was used. Purposive sampling was carried out to recruit 31 women undergoing HDR brachytherapy for cervical cancer from June to August 2020 at the National Institute of Oncology in Rabat. Semi-structured, one-to-one interviews guided by a theme list were conducted by a female radiation oncologist in Arabic before, during and after treatment. The following aspects were discussed: expectations, experiences in the waiting room, in the treatment room, and suggestions for improvement. Data was transcribed, translated and thematic analysis performed. **Results:** Most of the patients felt unprepared and did not have a clear understanding of brachytherapy. Brachytherapy was a difficult experience causing fear and anxiety throughout treatment. Most women dreaded the procedure, before receiving the first treatment and even after having had one. Pain was a major problem for the participants. Some women compared this pain to childbirth, a process they preferred to brachytherapy. Patients agreed that the preventative medication received was not efficient to relieve the pain. Despite these negative experiences, patients were left with a positive outlook. Dialogue with the healthcare professionals, support from their family and fellow patients, envisaged outcomes and desires to heal were used to cope, whilst faith and spirituality gave them strength to endure the procedure. **Conclusion:** Women undergoing uterovaginal brachytherapy for cervical cancer experience pain and emotional distress. Providing patients with adequate information, more

sensitive support during the procedure and debriefing afterwards could lessen feelings of fear and anxiety. Our findings advocate for the revision of pain management protocols. Further studies should be carried out to define patient-centered recommendations and provide quality care to this group of women.

## Keywords

Brachytherapy, High Dose-Rate, Cervical Cancer, Qualitative Study, Experiences

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## 1. Introduction

Cervical cancer is a major cause of female mortality throughout the world and the second cancer in women in Morocco [1]. The treatment of choice for patients with locally advanced cervical cancer is definitive radiotherapy combined with chemotherapy, including intracavitary brachytherapy [2].

Brachytherapy is an intrusive procedure involving lithotomy position, insertion of uterine and vaginal applicators and a urinary catheter. It is a stressful experience for cancer patients and may cause a broad range of physical, emotional and psychosocial difficulties [3]. Little is known about the experiences of women receiving high dose-rate brachytherapy, as qualitative investigations of this phenomenon are limited.

Our study reflects on these experiences and provides baseline data focusing on this knowledge gap. A better understanding of the unique experiences of this particular group of patients could help healthcare professionals to provide better support and appropriate patient education programs to meet their needs.

The aim of this study was to explore the expectations and experiences of women undergoing internal radiation for cervical cancer at the brachytherapy unit of the Radiation Oncology Department of the National Institute of Oncology in Rabat, Morocco.

## 2. Methodology

A prospective, qualitative study with a descriptive phenomenological approach was used.

After obtaining ethical approval and permission from the university and hospital, we approached eligible women scheduled for high dose-rate (HDR) brachytherapy and invited them to participate in the study. Informed consent was obtained for patients wishing to participate.

Purposive sampling, a recognized measure to improve the transferability of the findings and usually used in qualitative research, was employed to select the sample. Data saturation, the point where no new information emerges from the data, determined the sample size and was reached after 93 interviews.

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

The sample consisted of 31 cervical cancer patients, aged between 27 and 70 years (median 49.6 years), requiring HDR brachytherapy with uterine (tandem) and vaginal (ring/ovoid) applicators, recruited between June and August 2020. Five were divorced or separated at the time of collection, 5 were widows, while the remaining 21 were married. Most women had more than three children and lived in urban communities. Twenty participants had never been to school, 4 received primary schooling, 5 completed secondary schooling and 2 completed their tertiary education. Twenty-two were housewives and 9 had low-paying jobs (kitchen helper, housekeeper, seamstress). All women were Muslim.

Applicator placement was completed in the operating room under spinal anesthesia and analgesia to alleviate the pain and help the patients relax. After CT-guided brachytherapy planning, the patients received two treatments for one theatre procedure with one overnight stay, then repeated a week later. Patients were treated to a total dose of 28 Gy in four fractions of 7 Gy.

Between two sessions of treatment, patients were hospitalized in a single or double room and were required to have full bed-rest in a supine position in order to keep the applicators in situ overnight. Subsequent analgesia consisted of intravenous paracetamol and oral anti-inflammatory analgesics as needed for the duration of the hospital stay.

The interviews were conducted by a female radiation oncologist affiliated to the department in Arabic.

An open-ended questionnaire 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. Semi-structured

**Table 1.** Inclusion and exclusion criteria of cervical cancer patients undergoing high dose-rate brachytherapy treatment.

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**Inclusion criteria:**

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- Histologically proven cervical cancer, FIGO Stages I-IVA, treated at the Department of Radiation Oncology, National Institute of Oncology, IBN SINA Teaching Hospital of Rabat, Morocco.
  - Completion of concurrent chemo-radiation.
  - Referral for intracavitary (tandem applicator with either ring or ovoids) brachytherapy at our institution.
  - Ability to communicate in French or Arabic and to understand scores.
  - Informed consent.
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**Exclusion criteria:**

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- Patients who had a hysterectomy before radiotherapy.
  - Patients who are part of other trials who receive treatment other than the standard treatment protocol.
  - Prior intracavitary or interstitial brachytherapy.
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interviews, were conducted in a private room, with only the researcher and participant present, for an average of 20 minutes. For each patient, 3 interviews were conducted before, during and after the HDR brachytherapy treatment process.

- The initial interview schedule was conducted prior to the patients' first HDR brachytherapy treatment procedure to probe their expectations and anticipated experiences.
- The post treatment interview schedule was done directly on completion of the first treatment to establish the patients' experiences of the HDR brachytherapy treatment they had undergone.
- The exit interview schedule was done following completion of all the HDR brachytherapy treatments, to explore patients' impressions and suggestions.

The following aspects were addressed by the interview schedule: treatment-related information given and understood, participants' perceptions, expectations, impressions, waiting room, treatment room and recovery room experiences and suggestions for improvements.

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 information. We analyzed the data using thematic analysis and organized it into emerging themes. Direct quotes were translated into English for publication purposes and used to inform the explanation.

### 3. Findings

Four themes with sub-themes arose from the data: 1) expectations and informational needs, 2) psychological experience, 3) physical experience and 4) coping strategies. Women's expectations, physical experience, emotional distress and coping strategies form the focus of this article.

#### 1) Patients' expectations

During the interviews, patients recognized that brachytherapy was the last event in the treatment chain lying ahead of them. However, they demonstrated very limited knowledge of the upcoming brachytherapy treatment procedure, describing it as some sort of "cleansing of their uterus". A woman commented:

"I don't know much. This is the last step of my treatment; I just want it to be over."

To the question "what do you expect from this treatment", "healing" was the most given answer. Most participants shared their desire to recover and carry on living as normal people:

"I just hope to be cured from this disease."

A 27-year-old participant reported:

"I just want to get healthy as I have children, they need me".

However, other patients weren't clear about their expectations:

"I really don't know what to expect. I'll have to see for myself."

#### 2) Physical experience

The participants agreed that brachytherapy was a dreadful experience and described it in terms of “terrible”, “hard” and the “worst experience ever”.

**Pain** was a major issue for most once the anesthesia wore off, and participants reported unrelieved pain lasting for hours and even days after the procedure.

Participants were overwhelmed by the “hell” they experienced when the applicators were inserted. One participant explained:

“...it’s like something cutting through the soft skin in your vagina with a sharp knife.”

The pain was excruciating for some:

“I was in a lot of pain, so very sore”.

“I could feel that thing inside my vagina when I moved even slightly”.

A woman added: “I could feel that thing inside, burning me”.

Most of the participants indicated that being restricted to “**complete bed-rest**”, applicator in situ overnight, without moving the lower part of the body, was the most difficult experience, making comments such as:

“It was so uncomfortable. I could not move and needed to stay totally still, all night.”

“It was too long; I couldn’t wait for them to take it off.”

However, for some the **removal** of the applicators was equally painful. A participant said:

“It was worse when they were taking it out...just when you think it is over, and the pain gets even worse...”

For some patients, **back pain** was the most unbearable symptom during internal radiation. One commented:

“My back felt so uncomfortable, like it was broken.”

Some participants claimed that their back pain was even worse right after the treatment.

“It was hard to get out of bed for days after treatment”.

Most patients reported having **dysuria** added to the pain, with burning sensation when urinating. One participant explained:

“It burned every time I had to pee...but two or three days after you get normal again”.

Participants reacted differently to pain; some called out and complained whilst others kept quiet. One participant said:

“... ah! I could not take the pain ... I wanted to rip the thing out and leave”.

Another explained:

“It was very sore, but I didn’t scream or cry... I had to be resilient, I prayed, it’s my culture...”

Participants described their experiences according to some past experiences of what they were familiar. Many participants compared the pain to childbirth, a process they preferred to brachytherapy. The following comments were made:

“...it’s worse than childbirth... I’d rather have 3 more kids than go through this again”

“...Having a baby only lasts one day...but this treatment hurts for days”

Other physical symptoms experienced by participants included diarrhea (n = 16), nausea and vomiting (n = 4), loss of appetite (n = 17), sleep disturbance (n = 20) and tiredness (n = 28).

Some participants did not want to eat during brachytherapy. One participant remarked:

“I had diarrhea after eating, so I did not eat”.

“Oh, I felt so ashamed because I had diarrhea all night but I couldn’t even move to clean myself.”

Patients were asked how they felt about the procedure and whether they were satisfied with the degree of pain control. All participants declared that spinal anesthesia prevented them from pain during the procedure in the OR, however they agreed that the medication they received afterwards was not efficient enough. One participant said:

“...they said the medication would ease the pain but it didn’t work...”

Another added:

“Eish! I feel so very painful, that pill and injection isn’t strong enough...”.

### 3) Psychological experience

Participants experienced emotional distress **before, during and after** the brachytherapy procedure.

Throughout the process, the treatment outcome was a recurring concern for the participants:

“Is the treatment working? Is the cancer gone?”

“I’m afraid that the disease won’t go away, is the disease still here?”

Most women felt **anxious and scared before starting brachytherapy**. They **feared** the procedure, possible pain and side-effects, and even anesthesia:

“I couldn’t sleep... I kept thinking of the pain I’m going to go through”.

“I’m afraid of the unknown. Is it going to hurt?”

“I don’t really know what they’re going to do to me. I’m scared.”

“I’m afraid of anesthesia, it’s my first time in an OR.”

“I’m anxious, I think about a lot of things. I think of my children.”

In the environmental context, women also suffered **influences of people** who have undertaken the procedure. This type of interference occurred in the exchange of experiences among **other patients and their families in the waiting room**. Most reported that the conversations held before the brachytherapy made them even more anxious and scared, before the negative reports of some patients:

“I’m scared. A woman said it’s very painful, even worse than giving birth they said!”

“[...] While we waited, the girls talked and each one said something different.”

“I heard women say it was horrible. I’ll have to see for myself”.

In the operating room, most women experienced an increase in distress and

fear of the unknown treatment.

“Every time I went there, I was cold, my hands sweated and I was shaking.”

“In the OR, my heart was racing and I felt nauseous”.

“I was so nervous; I didn’t know what was going to happen in there.”

Furthermore, we found that being observed by professionals of the opposite sex, and at times by trainees, while remaining in gynecological position, added to their emotional distress and embarrassment. Some participants described:

“...my legs were tied up, I had to lie there... I felt ashamed.”

“A woman my age... I felt so embarrassed”.

“I was surrounded by nurses and doctors... I felt like everybody was watching me...”

For the follow-up treatment, most women still feared the procedure, even after receiving the first treatment:

“...even for your next appointments, you keep thinking...”

“Now I know, but I’m still nervous about it, I can do nothing but thinking...”

The unavailability of companions and family made women feel lonely which caused discomfort in the socio-cultural context:

“[...] I came alone. I’m divorced, I have no one.”

Moreover, women felt that being in a single room made the treatment more difficult to bear than if they had been able to interact with other patients. Their feeling of loneliness was reflected in the following statements:

“I was on my own. I couldn’t move, I couldn’t talk to anyone. It was hard!”

“It was very difficult and painful. It felt like a punishment”.

#### **4) Coping strategies:**

While participants suffered various forms of distress during the treatment process, most indicated that they had no alternative. A sense of helplessness was reflected by their acceptance that nothing could be performed to relieve the symptoms, and that they merely hoped the treatment would be finished as quickly as possible.

The desire to be cured of the disease and the will to continue living provided power to patients, and helped them complete the therapy.

On the other hand, some participants commented that “being positive” helped them to cope with the ordeal of the treatment. A few women showed a positive attitude:

“I’m here to get better, it’s a good thing! Why would I be afraid?”

“I feel serene. I’m only afraid of god the all mighty and I accept whatever he gives me.”

“I’m fine. It can’t be worse than what I’ve already been through! The hardest part is behind me. Right?”

Similarly, emotional support had a significant effect on women’s experiences during brachytherapy. Participants valued every face-to-face interaction with family members, healthcare professionals and patients. Women felt comforted by having support of their family and friends. A participant was delighted with

the presence of her family.

“[...] I always went there with my husband, sometimes with my sister... I can't imagine going through this on my own.”

A participant appreciated a nurse who was very caring. She recalled:

“A nurse chatted with me and comforted me. I felt thankful.”

Moreover, participants in double rooms suggested that it was helpful to have a person in a similar situation to accompany them during the treatment period:

“We reassured each other and set a common goal: it would be finished soon and we would go back home.”

“...Another woman was with me. It made me feel better not to go through this alone”

Religion served as a source of comfort and hope. Participants trusted God to help them get through the treatment. The following statements were made:

“...I know only God can get us through this...”

“I just pray God to help me with it;”

“I just hold onto my faith and accept whatever God brings my way”

“I pray god to heal me so I can go back to normal.”

#### **5) Patients' impressions and suggestions:**

Most participants felt unprepared for the treatment they had just gone through.

“If someone told me, I will have prepared myself...”

“It was so much harder than I expected.”

“I thought radiotherapy and chemotherapy was the hardest part, but it's not”.

However, despite the negative experiences, participants demonstrated contentment and gratitude. The following were the comments made by participants at the exit interview, having completed all 4 brachytherapy treatments:

“I feel much better. The bleeding has stopped. I'm so grateful.”

“I'm happy and relieved everything went well.”

“I am glad it's over. I put my faith into it and I was brave, and I feel better now.”

“It was hard but everything was great, the nurses, the doctors. I'm very happy.”

“Everything I went through is fine. I just want to be cured. Thank you very much.”

At the end of the exit interview, participants were asked whether they had any suggestions that could improve aspects of care in the department. Two main issues were mentioned by most of the patients: insufficient information and preparation, and pain management.

## **4. Discussion**

Published studies regarding the patient experience of receiving high dose-rate intracavitary brachytherapy for locally advanced cervical cancer are limited, especially in Morocco [4]. This study explored cervical cancer patients' expecta-



tions and experiences prior to, during and after the brachytherapy procedure. The aim was to provide insights on how they shaped their understandings and how they mentally, emotionally and physically processed the brachytherapy procedure as part of the cancer treatment continuum.

The design of the study allowed us to understand this phenomenon in the participants' own terms and therefore to provide a description of human experience as it is experienced by the patients, allowing the essence to emerge [5] [6]. The data analysis allowed describing the experiences lived in the different phases of the therapeutic route of the participants.

Women in our study considered brachytherapy a negative and difficult experience. Most participants felt unprepared and uninformed. Velji and Fitch [7], who investigated the experiences of Canadian women who received brachytherapy, found the information that women received prior to the treatment shaped their experience positively or negatively. The importance of sharing appropriate information cannot be overstated, since too much or too little, or even inaccurate information may generate negative energy. For example, we found that hearing negative stories from fellow patients in the waiting rooms could be a source of anxiety. In addition, Brand [8] found a significant relationship between the fear and anxiety women experience before brachytherapy and unmet information needs.

The data revealed participants' emotional experiences of undergoing high dose-rate brachytherapy. As described by "I couldn't sleep", women experienced high levels of anxiety. Participants feared the procedure before they had been treated and even the follow-up treatments. They were anxious because of the potential pain and side-effects and about their ability to tolerate the treatment. The embarrassment of having to lie in the lithotomy position added to the complexity of the emotional experience. Women felt vulnerable and exposed, and found having more than the essential staff present disempowering and intrusive. Fear of the future was also very present, women worried about the treatment outcome and effectiveness. Patients have to live with the possibility that the disease won't go away or that their cancer might return [9].

The psychological distress reported by our participants' echoes that reported in other studies. In a recent systematic literature review, of ten studies regarding psychological issues, nine reported that:

Brachytherapy caused anxiety and distress for most women [4].

The findings also confirmed that brachytherapy is an invasive and painful procedure. All participants mentioned some form of pain when asked about their brachytherapy experience, described as "cutting", "I felt sore", and "I was in so much pain". The experience of being confined to bed applicator in situ for hours without being able to move added to their suffering. The applicator removal turned out to be equally painful. Other symptoms, such as back pain, diarrhea, dysuria, nausea, anorexia, extreme weakness and sleep disturbance were also reported. The symptoms reported by our participants were similar to those

in other studies conducted with patients receiving brachytherapy for cervical cancer [4] [7] [10] [11].

Some patients were traumatized by the pain, whilst others were resilient. Most participants indicated that they had no alternative but to endure the suffering and unbearable symptoms. Confinement to bed was a part of the treatment, and treatment-induced symptoms were unavoidable. They tried to get through this difficult period by accepting the suffering as part of the treatment. Some participants tried to manage their symptoms by self-imposed restricted diets or by refraining from eating.

Women linked their experiences to previous familiar experiences, such as the pain of giving birth, described as the ultimate painful, emotionally distressing, vulnerable and exhausting event in a woman's life [12] [13]. In addition, it was interesting to find the participants preferred childbirth to having to undergo brachytherapy.

As evident by "It didn't work", "the medication wasn't strong enough", the analgesics participants received afterwards did not prevent them from experiencing pain. These findings are consistent with data reported in other studies, and advocate for the revision of pain management protocols. In a study from South Africa, the authors recommended better pain management strategies and non-drug options to complement pharmacological management [13].

When focusing on women behavior to face this challenging experience, multiple coping strategies have been identified. Participants fed on their internal and external assets to acclimatize to brachytherapy treatment and its side effects.

First, patients presented with the ability to endure and tolerate the suffering involved because of the hope the treatment provides them. Hope is an intricate, multidimensional, dynamic empowering state of being and prevailing factor in healing, coping, and quality of life [14] [15]. On the other hand, "being positive", "being brave" and taking some control of their circumstances by wanting to see for themselves, helped patients to cope. Several studies also indicate that "being positive" is an effective coping strategy for relieving symptom distress [3].

Adequate environment can also play a vital role in maintaining a positive attitude towards overcoming the suffering. We found that the psychological support of healthcare professionals, family and fellow-patients was crucial in shaping women's experience of brachytherapy. Participants felt more comfortable when they were able to interact with others. They valued the time spent debriefing with healthcare professionals after treatment, to enable recognition of positive gains, as well as to process the stresses of the experience. Our findings are consistent with those of Chan *et al.* who also identified the importance of support from healthcare professionals, family and friends [16].

Women also found that sharing their room with fellow-patients receiving the same treatment to be a valuable support as they were able to comfort each other. Therefore, there may be benefits in delivering therapy to two women in adjacent beds [3].

Last but not least, participants relied heavily on faith, as supported by “...only God can get us through this”; they trusted God to provide them with strength to tolerate the treatment. Putting themselves in the hands of God brought comfort and hope. According to Wachholtz and Pearce, people rely on their faith to cope with any kind of life challenges, as spirituality and religion have the ability to reduce stress, whilst prayer has the ability to distract from pain [13] [17].

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. The findings may not be applicable to patients in different healthcare settings or from different cultural backgrounds. The generalizability of the study findings is therefore limited. Further research is needed to gain a deeper understanding of this phenomenon.

## 5. Conclusions

Women undergoing uterovaginal high dose-rate brachytherapy for cervical cancer experience fear, anxiety and both physical and emotional pain.

Psychological support of healthcare professionals, family and fellow patients and “being positive” helped patients to cope, whilst their belief in God and the hope of healing gave them courage to endure the suffering.

Adequate preparation before the procedure, more sensitive support during the procedure and debriefing afterwards could lessen feelings of fear and anxiety towards treatment. The presence of observers could be minimised. Close monitoring of pain levels before, during and after the procedure seems necessary to provide better pain management.

Further studies should be carried out to define patient-centered recommendations and provide quality care to this group of women.

## Conflicts of Interest

The authors declare no competing interests.

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