

# Informational Needs in Women Undergoing Multifraction High Dose-Rate Brachytherapy for Cervical Cancer: A Prospective Qualitative Study

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## Abstract

**Objective:** To identify the informational needs of Moroccan women receiving intracavitary brachytherapy for locally advanced cervical cancer as part of a process to develop guidelines for quality patient-centered care. **Methodology:** A prospective, qualitative study with a phenomenological approach was carried out at the Brachytherapy unit of the National Institute of Oncology in Rabat, Morocco. Purposive sampling was used to recruit 31 patients undergoing high dose-rate brachytherapy for cervical cancer from July 2020 to August 2020. Semi-structured, one-to-one interviews were conducted by a female radiation oncologist in Arabic, guided by a theme list. The interviews were translated and a thematic analysis was performed. **Results:** Data saturation was achieved having interviewing 31 participants, aged 27 - 70 years. Findings on patients' informational needs were the overarching theme and form the focus of this article. The informational needs included: providing patients with disease- and treatment-related information in their home language; adequate information concerning pre-treatment preparation, possible side-effects, and sexual intercourse; and providing patients with informative material adapted to their needs as standard procedure. **Conclusion:** This study has identified unmet women's informational needs during brachytherapy for cervical cancer. Providing patients with sufficient and understandable information, adequate preparation before the procedure, more sensitive support during the procedure, and debriefing afterward could lessen feelings of fear and anxiety towards treatment delivery. Guidelines with a patient-centered

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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.

## Keywords

Brachytherapy, Cervical Cancer, Informational Needs, Qualitative Study

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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 standard of care for women diagnosed with locally advanced disease is external beam radiation with concurrent chemotherapy followed by intracavitary brachytherapy. Although this invasive procedure of intracavitary brachytherapy has advantages such as a lower dose to the normal tissues [2], the procedure presents patients with a wide range of physical and psychological challenges [3].

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 [4]. Information about cancer diagnosis, treatment, and its possible side effects can affect health outcomes, reduce anxiety and increase feelings of control [5].

Research into women's experiences of receiving high-dose-rate brachytherapy has been limited, especially in Morocco. Understanding the cervical cancer patients' experiences and the extent to which needs are being met by the existing services are the first step toward planning and improving the care women receive [6].

Currently, there are various sets of brachytherapy guidelines to assist institutions to develop or optimize brachytherapy facilities regarding treatment regimes, techniques, dose specification, and treatment planning methods [7] [8]. However, these guidelines are limited to the organizational and technical aspects of intracavitary brachytherapy treatment delivery.

The purpose of this study was thus to identify the informational needs of women receiving high-dose-rate (HDR) intracavitary brachytherapy for locally advanced cervical cancer as part of a process to develop guidelines for quality patient-centered care.

## 2. Methodology

This study was set in the Brachytherapy unit of the National Institute of Oncology in Rabat, Ibn Sina Teaching Hospital, Morocco.

A prospective, qualitative design with a descriptive phenomenological approach was used [9], which 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.

After obtaining ethical approval and permission from the university and hospital, we approached eligible women scheduled for HDR brachytherapy and in-

vited them to participate in the study. The inclusion and exclusion criteria for the participants are depicted in **Table 1**. All participants were provided with an oral explanation and were assured that confidentiality would be preserved. Informed consent was given by all 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 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 2020 and August 2020. Five women 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.

The interviews were conducted by a female radiation oncologist affiliated to the department, in Arabic and French, as most of the patients treated at this facility are fluent in at least one of these languages.

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 interviewing process.

Semi-structured 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 procedures.

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

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**Inclusion criteria:**

- Histologically proven cervical cancer, FIGO Stages I-IVA, treated at the Brachytherapy Department, 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.
- Informed consent.

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**Exclusion criteria:**

- 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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- The initial interview schedule was conducted prior to the patients' first HDR brachytherapy treatment to explore their expectations, anticipated experiences and understanding of the procedure. The first question was: Why are you here today? What it is like for you to get brachytherapy? Then probes and prompting questions were added to encourage participants to expand on their 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.

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<sup>®</sup> 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.

The purpose of this study was to establish the information needs of cervical cancer patients undergoing brachytherapy; 2) identify the gap between the information they currently receive and the information they want 3) establish information sources and the patients' preferences for them.

### **3. Results**

The findings revealed women's unique experiences of receiving multifraction HDR intracavitary brachytherapy for locally advanced cervical cancer. Four themes with sub-themes arose from the data: 1) informational needs, 2) psychological experience, 3) physical experience and 4) coping strategies. Patients' informational needs were the prevailing theme and therefore form the focus of this article. Informational needs were the overarching theme emanating from the interviews and form the focus of this article.

#### **3.1. Reason for Giving Brachytherapy Consent**

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 statements were made:

"I have to...my doctor told me it's necessary."

"I would rather have my uterus removed but I don't have a choice."

#### **3.2. Reason for Being There That Day**

When patients were asked about the reason for being at the hospital on that cur-

rent day, they immediately acknowledged and referred to their illness. These are some of their comments:

“I’m here to get treatment for the cancer.”

“I’m here today because I’m sick and desperate to receive help!”

“I came here today to get my treatment and get back on my feet.”

### 3.3. Opportunity for Questions

The participants were asked to state whether they were granted an opportunity to ask questions to the radiation oncologist. Most of the participants reported that they were given an opportunity to ask questions to the informing doctor before the brachytherapy treatment. Some participants reported asking the following questions:

“How does it work? Does it hurt? Are there side effects?”

“Am I going to spend the night at the hospital?”

“Will I still be able to give birth?”

Some of the participants said they had no questions, because they trusted their doctor. The following remarks were made:

“...I didn’t have any question, I just did what the doctor said, he knows best.”

However, a few participants reported that although they were given an opportunity to ask questions, they did not for various reasons and made the following remarks:

“I didn’t know what questions to ask.”

“I honestly do not know why I never asked...I was scared.”

“I was too exhausted after the chemotherapy to ask questions.”

“I didn’t ask questions. Sometimes you just want to see for yourself.

“I heard other patients in the waiting rooms sharing their experience.”

“I did my research on the internet.”

“I wanted to ask about sex but I felt ashamed.”

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

“I didn’t get an opportunity to ask questions. There wasn’t enough time.”

“I felt like I would waste their time.”

### 3.4. Treatment-Related Information

Participants were questioned during the interviews on the treatment-related information conveyed to them.

#### 1) Brachytherapy as a treatment method

Participants reported that they had received information regarding brachytherapy from the doctors, but also by talking to other patients sharing their own experience in the waiting rooms.

The terms “brachytherapy” or “inside radiation” were commonly used amongst the patients. Most of the participants indicated they knew that a device was going to be inserted into them, however, they didn’t have a clear understanding

of the treatment procedure. Patients often described that device as “a light bulb”, “some instrument inserted in my vagina”, or “the doctor put that machine inside”. Others described it as some form of cleansing: “cleaning the dead cells”, “cleaning the womb”.

#### 2) 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 and the radiation oncology resident were mostly responsible for informing the patients of the treatment procedure. The following comments were made:

“They told me it’s a small procedure, under anesthesia, and that I’ll have to spend the night at the hospital.”

“I was told that was the final step of the treatment.”

Some participants, however, preferred not to be informed about the brachytherapy treatment and made the following comment:

“...in fact, I didn’t want to know anything. I will have to see for myself.”

“I didn’t want to know anything. I leave it to god the almighty.”

#### 3) Anesthesia

Most of the participants knew that the procedure would take place in the operating room under anesthesia. Here are some of their comments:

“It’s like a little surgery, they put a needle in the back.”

“Yes, they said half of my body would go to sleep.”

#### 4) Side-effects

Only a third of the participants reported that they were informed about the possible side-effects they might experience while undergoing brachytherapy treatment. Expected side-effects such as pain, diarrhea, swelling and shrinkage of the cervix were mentioned to some participants. The following comment was made by a participant:

“They said I’m going to experience pain, but they’ll give me painkillers for it.”

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 have a clue about it. What is it?”

“They never told me anything about side effects. It is serious?”

“Can I still have children?”

#### 5) Sexual intercourse

Most participants reported that they were not informed about sexual intercourse. The following remarks were made:

“I intended to ask about sex, as I’m a married woman. What should I tell my husband?”

“They didn’t say anything about sex. Can I still sleep with my husband?”

“I haven’t slept with my husband since I got sick anyway, I’m too scared.”

A 48-year-old participant reported the following:

“I guess they didn’t say anything, because I told them I’m divorced.”

Some of the elderly participants made the following statements:

“They did not say anything to me. Maybe they only talk about it with young people...”

“I don’t care about sex anymore; my husband is like a brother to me now. I just want to get better.”

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

“The nurse said that I should continue to have sexual intercourse to avoid vaginal shrinkage.”

“They told me I have to do it, but to be safe and use a condom.”

#### 6) Pre-treatment preparation

Most of the participants did receive pre-treatment instructions and stated the following:

“I must not have breakfast, because my stomach must be empty.”

“They said I have to follow a diet and take pills to make sure that my stomach is empty so that it won’t fail.”

Some of the patients 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 had no idea. I was not told to prepare myself.”

“They did not tell me anything. They just said I should come early.”

“No, they did not say anything. I was wondering if I could eat? I had dinner last night.”

#### 7) 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 treatments, some women made the following comments:

“I did not know. They just told me to come today. So I’m here.”

“No one explained to me that I will be going for the treatment today.”

“No one told me I had to spend the night at the hospital. I didn’t even bring my stuff. I wasn’t prepared.”

### **3.5. Informative Material**

It is not standard procedure in our 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, it could help us know what to expect.”

“...I can’t read, but my children could help me understand.”

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

“It’s better not to know anything. I leave it to god.”

“I’d rather see for myself.”

“No, I never went to school, I can’t read.”

### 3.6. Patients’ Impressions

After completing all 4 brachytherapy fractions, most patients felt they were not prepared for what they had just gone through. The following comments were made during the exit interview:

“It was so much more difficult than I expected. Very painful and uncomfortable.”

“I thought the hardest part was over with the chemotherapy, but the brachytherapy was the hardest.”

“It was so long and painful. I didn’t think it would be this hard.”

“It was so stressful not knowing what was going to happen to me in there.”

Despite the negative experiences, they demonstrated contentment:

“I feel happy and relieved everything went well.”

“I am really happy with this treatment. 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.”

“I’m happy it’s over. Everything you have done to me is fine. I just want to be cured. Thank you.”

### 3.7. Patients’ Suggestions and Final Remarks

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: the information quality and the pain management. The following conclusions were reached:

- It was suggested to set information sessions prior to treatment and provide patients an opportunity to ask questions, to address the following issues:
  - o What patients can expect from the treatment?
  - o What will be done to them?
  - o Will brachytherapy treatment be a painful procedure?
  - o What are the possible side-effects of this treatment, with a special focus on sexual intercourse and fertility.
- Providing patients with pamphlets or booklets with disease and treatment-related information in their home language, using illustrations and symbols could help the illiterate patients understand.
- Use the time spent in the waiting room to prepare the patients psychologically for their forthcoming treatment.
- Give patients a second explanation of the treatment procedure inside the treatment room.
- Take the time to debrief and update the patients regularly and reassure them that the procedure is going well.



- Administer adequate medication necessary for better pain control.
- Complete treatment as quick and sufficient as possible.

#### 4. Discussion

Studies have identified that cancer patients have many informational needs that vary with gender, age, type and stage of disease [10]. Providing cancer patients with information prepares them for treatment and helps them cope with adverse effects associated with it, reduces anxiety and depression, increases satisfaction with treatment, improves communication with family and improves quality of life [11]. Patient education and meeting patients' information needs is therefore a fundamental aspect of patient-centered care [12].

During the interviews, our patients demonstrated very limited knowledge of their illness, but realized that they were sick and needed treatment for their cancer. The acknowledgement of their disease was a big step for most women; they had come that far through their treatment journey [13].

Patients recognized that brachytherapy was the last event in the treatment chain lying ahead of them at that stage. However, the upcoming brachytherapy treatment procedure was unfamiliar territory to them. Most women had a very rudimentary understanding of this treatment, describing it as some sort of "cleansing of their uterus". The following unmet informational needs were identified: treatment-related information concerning pre-treatment preparation and scheduled appointments, possible acute and late side-effects of brachytherapy, sexual intercourse and fertility. Some of the participants reported that, according to them, treatment-related information and side effects was not discussed with them. Others simply didn't know what question to ask or mentioned they were uncomfortable asking questions because they did not want to waste the radiation oncologist's time. However, some of these unmet needs could be the outflow of receiving too much or little information on the day of giving consent for brachytherapy. This might be due to time constraints during the consultation process that limit the amount of information and support that can be provided [14].

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 [15]. For instance, we observed that hearing negative stories from fellow patients in the waiting rooms could influence the participants and be a source of anxiety. Our findings are consistent with the data in the literature. Kavanagh and Broom commented that practitioners should spend time informing patients and answering their questions. Doubts concerning the procedure must be clarified. It is important that women are informed of the details of the procedure, the number and frequency of sessions and the side-effects they might experience. The staff should encourage questions to explore any other issues that women deem im-

portant. Moreover, updating the patients regularly during the procedure might be essential to alleviate their anxieties [16]. Kamer *et al.* reported that patients need to be given adequate information before the brachytherapy application to reduce anxiety [17]. Warnock 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 [3].

Each patient's timing of desire for information varies, as does the level of detail and context [18]. Although most of the participants indicated that they had an opportunity to ask questions before giving consent, a few patients pointed out that they weren't ready to ask questions at the time, given their exhaustion after chemoradiation, and preferred to be informed at a later stage. Besides, patients want the information they receive to be of positive value and generally tend to avoid too detailed information [19]. We found that a few participants preferred not to be burdened with too much information. These patients frequently used defense mechanisms to protect themselves and adjust to this new experience. Many women relied on religion, wanted to put themselves in the hands of god and used their faith as a coping strategy. In other cases, they tried to be brave and were taking some control of their circumstances by wanting to see for themselves. These actions gave them hope and strength to endure the procedure [20]. It is important that the caregivers be sensitive to the patient's mental state and adapt teaching interventions as needed.

Sexuality was a delicate subject to discuss openly for most women, demonstrating the complexities and challenges in dealing with this topic. Cultural values and beliefs definitely come into play, especially in the Moroccan context. Patients also tend to prioritize questions about curing the disease and managing treatment side-effects. Other possible reasons may be due to alteration in body image, side effects of treatment and emotional distress caused by the disease and its treatment [21] [22].

It is therefore important to assess patients to find out whether they have any concerns with any aspect of sexual care, identify barriers to communication about such issues and deliver the information in accordance to patients' needs.

Finding the most suitable approach to deliver information concerning the disease and its treatment for patients with cervical cancer is clearly important. Informing patients in a way they preferred could reduce anxiety and be used as a coping strategy [23] [24]. Data in the literature confirmed the importance of providing patients with understandable disease and treatment-related information in their home language before giving consent. Long *et al.* focused entirely on informational needs and reported that 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. They concluded that information should be delivered both verbally and written in the patient's home language in pamphlets/booklets [18]. According to Stewart *et al.* [25], second to information from healthcare providers (mostly radiation oncologists), participants

wanted to receive conventional cancer-specific printed materials such as pamphlets and brochures, general print books, broadcast media, videotapes, telephone information lines, audiotapes, Internet and CD-ROMs. These authors found that preoperative HDR brachytherapy educational hand-outs that clarified the nature of the procedure and its possible side-effects helped the patients to be less anxious.

In areas of wide social and educational diversity, full consideration of the differing cultural concerns needs to be acknowledged. In our context, providing patients with understandable written treatment-related informative material remains a challenge, as Morocco records high rates of illiteracy, and public hospitals mainly treat patients from disadvantaged socio-economic backgrounds. In our study, 20 out of 31 women (64.5%) had no former education and couldn't read. Therefore, offering women adequate informative material such as illustrated brochures, videotapes and audiotapes in their home language can be an interesting alternative.

Our study has limitations. Different ages, stages, and education ranges types were included in this study; however, it was still a small sample size. 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.

Our study focused on women treated in the public healthcare sector. The findings might not be applicable to patients in different healthcare settings or from different cultural backgrounds. Further research should be undertaken to gain a deeper understanding of this phenomenon.

## 5. Conclusions

Cervical cancer patients undergoing brachytherapy are faced with physical, psychological, and social challenges [3]. Our findings indicate that cervical cancer patients undergoing brachytherapy show a need for more information about their disease, preparation for treatment, the treatment itself, side effects, fertility, and sexual intercourse. Considering more efficient methods for providing information to ensure all information needs are met is important. This includes the creation of educational materials and communication tools specific to cervical cancer patients, such as illustrated pamphlets or audio/video presentations in their home language prior to treatment delivery.

Based on these results, guidelines can be implemented as standard procedures and become a tool to help members of multidisciplinary teams in providing quality patient-centered care for this group of women.

## Conflicts of Interest

No potential conflict of interest relevant to this article was reported.

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