

Patients' Experiences of Preparation for Radiation Therapy: A Qualitative Study

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This research was funded by a Strategic Research Partnership Grant (CSR 11-02) from the Cancer Council New South Wales [NSW] to the Newcastle Cancer Control Collaborative (NEW-3C) and by infrastructure funding from the University of Newcastle and Hunter Medical Research Institute. Forshaw was supported by a University of Newcastle Postgraduate Research Scholarship. Carey was supported by a National Health and Medical Research Council Translating Research into Practice Fellowship (APP1073031). Boyes was supported by Early Career Fellowships from the National Health and Medical Research Council (APP1073317) and Cancer Institute NSW (13/ECF/1-37).

Forshaw, Hall, Boyes, and Carey contributed to the conceptualization, design, and analysis. Forshaw and Hall completed the data collection and provided statistical support. All authors contributed to the manuscript preparation.

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Submitted March 2016. Accepted for publication May 29, 2016.

Keywords: radiation; patient education; informed consent issues; ethics

ONF, 44(1), E1-E9.

doi: 10.1188/17.ONF.E1-E9

Purpose/Objectives: To explore patients' experiences of and preferences for preparation for radiation therapy.

Research Approach: Qualitative study.

Participants: 26 individuals who recently received radiation therapy for cancer.

Setting: One Australian radiation oncology clinic located within a tertiary referral hospital in New South Wales.

Methodologic Approach: Semistructured interviews were conducted and analyzed based on a qualitative descriptive approach and content analysis of the transcribed interviews.

Findings: Four main themes related to preparation techniques were identified: (a) psychological preparation (frame of mind, downward comparison, coping mechanisms, and reassurance); (b) information preparation (format, content, and knowledge from patients' own or others' experiences); (c) quality of health care; and (d) social support. Two themes related to outcomes of preparation were identified: feeling psychologically prepared and knowing what to expect. Overall, participants' accounts of preparation for radiation therapy revealed that provision of information was satisfactory. Some participants would have liked more information and support primarily in relation to side effects and the practicalities of what would happen during treatment.

Conclusions: The information gained in this study indicates what strategies may best prepare patients for radiation therapy.

Interpretation: Providing patients with information that creates a realistic expectation of what radiation therapy involves both before and after treatment seems particularly important in helping them feel prepared.

Radiation therapy is one of the three major cancer treatment modalities (Tait & Hardy, 2006), with about 50% of all patients with cancer recommended to receive it (Barton et al., 2013). Radiation therapy is used to treat cancer itself (curative) or to relieve symptoms (palliative). For many, curative radiation therapy is a time-intensive treatment, which is often undergone five days per week for as many as eight weeks (New South Wales [NSW] Department of Health, 2010). Palliative radiation therapy usually involves fewer treatments given during a specified time. Although the physical and psychological impacts of radiation therapy can vary, short-term effects commonly include skin changes and fatigue, and long-term side effects include secondary tumors, cognitive impairment, or infertility, depending on the site and dose of treatment. Poor psychological outcomes, such as anxiety and depression, are also common among people receiving radiation therapy (Hess & Chen, 2014; Reilly et al., 2013).

To meet ethical and legal obligations, healthcare providers must adequately prepare patients for medical procedures, including radiation therapy (Wu, Nishimi, Page-Lopez, & Kizer, 2005). Obtaining informed consent is a complex process (Kinnersley et al., 2013) that requires a patient to understand the procedure, including its risks, benefits, and alternatives (Lupton, 2005; Schenker, Fernandez, Sudore, & Schillinger, 2010). Preparation of patients for medical interventions has been reported to increase patient satisfaction and knowledge and improve physical and psychological outcomes (Devine & Westlake, 1995; National Breast Cancer Centre [NBCC] & National Cancer Control Initiative [NCCI], 2003; Waller, Forshaw, Bryant, & Mair, 2014). Although information needs for individual patients vary (Royal Australian and New Zealand College of Radiologists [RANZCR], 2012; Tait & Hardy, 2006), numerous studies have shown that most patients prefer to be fully informed (Zeguers et al., 2012). Inadequate preparation can lead to negative patient outcomes, such as anxiety, dissatisfaction with care, uncertainty, and psychological distress (Halkett et al., 2012; Porocho, 1995).

A tailored patient-centered approach to preparing and informing patients for proposed procedures is recommended (RANZCR, 2010; Shabason, Mao, Frankel, & Vapiwala, 2014; Zeguers et al., 2012). A number of evidence-based recommendations (National Health and Medical Research Council, 2004) and guidelines (NBCC & NCCI, 2003; RANZCR, 2010) detail how healthcare providers can assist in adequately preparing patients for procedures such as radiation therapy. However, the current recommendations are broad, providing only basic suggestions on how to facilitate communication with patients. In addition, radiation oncology departments vary in how they prepare patients for procedures (RANZCR, 2012). Patient information about radiation therapy is also inconsistent, uncomprehensive, and too technical (RANZCR, 2012), and lack of treatment-related knowledge and misinformation has been reported as causes of patient fear and anxiety as they commence radiation therapy (Halkett et al., 2012). Lack of information can result in patients misinterpreting the significance of their side effects and may affect patients' treatment decisions (Halkett et al., 2012; Porocho, 1995; RANZCR, 2010). Reports have revealed a need to improve patient education on and preparation for radiation therapy (Shabason et al., 2014).

A number of studies have examined patient experiences and satisfaction with radiation therapy and receiving information related to radiation therapy (Gamble, 1998; Hinds, Streater, & Mood, 1995; Long, 2001). The findings have indicated that most patients want to receive full details about their treatment and that preconceived perceptions of radiation therapy

influence how well patients feel prepared for treatment. Several studies have assessed the effects of intervention strategies to improve patient preparation for radiation therapy (Johnson, 1996; Porocho, 1995; Thomas, Daly, Perryman, & Stockton, 2000). Results have indicated that educating patients on what to expect during radiation therapy leads to reduced treatment-related anxiety, stress, and fear.

Although these studies highlight the importance of preparing patients for radiation therapy, most were conducted in the 1990s or early 2000s. Since that time, healthcare practices have changed, particularly with the increased recognition and importance of patient-centered care (Institute of Medicine, 2001). Consequently, gathering up-to-date data about patients' experiences of preparation for radiation therapy is necessary. Understanding how patients are prepared and what they find useful will inform the most appropriate methods for preparing them for radiation therapy. The current study aimed to explore patients' experiences and perceptions of preparation for radiation therapy, and to identify factors that are perceived to assist with preparation.

Methods

This qualitative substudy was part of a larger mixed-methods study that aimed to develop a standardized, psychometrically rigorous measure to assess the perceived level of preparation of patients receiving radiation therapy. The aim of the substudy was to assess patient experiences of preparation for radiation therapy. The qualitative component consisted of in-depth semistructured interviews with a subsample of patients undergoing radiation therapy from the larger study. The results of the substudy were used to inform the development of the items used to measure patient preparation. This study was approved by the NSW Population and Health Service Research Ethics Committee and the University of Newcastle Human Research Ethics Committee.

Setting and Participants

A purposive sample of participants was recruited for the substudy from one Australian radiation oncology clinic located within a tertiary referral hospital that provides public hospital services. Additional patients from this and other hospitals were recruited for the larger study using the same or similar recruitment methods. The cost of radiation therapy was fully covered by Medicare or Veteran Affairs (publicly funded healthcare schemes in Australia). The radiation oncology clinic had five linear accelerator machines to deliver radiation.

Eligible patients for both the substudy and the larger study were aged 18 years or older, diagnosed

with cancer, attending at least their second consultation at the radiation oncology unit, receiving radiation therapy at the time of recruitment, able to read and speak English, and were considered physically and mentally capable of participating in the study by clinic staff.

Data Collection

Data collection took place from November 2014 to April 2015. Patients waiting for their treatment appointment were approached consecutively by clinic staff who assessed their eligibility and initial interest in the study. Clinic staff introduced interested patients to a research assistant (RA) located in the waiting area. The RA provided patients with an information statement and sought written informed consent for their participation. Within two weeks following recruitment, one RA called participants at their preferred time to discuss their experience of radiation therapy in a free and open manner. A telephone interview was deemed most appropriate because it allowed participants to complete the interview in the comfort of their own home at a time most suitable for them. This approach contributed to the rigor of the data, as it allowed patients with different commitments to take part. Participants were not required to travel or to complete the interview during business hours. The short time frame between patient recruitment and interviews helped ensure that their experiences were still fresh in their minds. All interviews were conducted by a single experienced researcher who was neither involved in recruiting participants nor part of the patient care team.

Each interview was audio-recorded upon patient consent. Open-ended questions were used to guide the interview and elicit detailed information on the patients' preparation for radiation therapy, including the type of information they received, satisfaction with their preparation, additional information they would have liked to have received, and the factors they perceived as most important in preparing them for radiation therapy. Participants were encouraged to speak openly and freely about their experiences. The interview guide was designed to be flexible, with questions amended based on the participants' responses. In addition, the length of each interview was determined by the individual participant.

Rigor

The following four constructs were used to ensure the rigor of the study data: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

Reflexivity and peer checking were used to establish credibility (Thomas & Magilvy, 2011). The researcher

conducting the interviews used a reflective approach, recording preconceptions, reflections, and ideas after each interview. The coding process was reviewed by another author who also reanalyzed a sample of the data. The author who performed peer checking was selected based on her knowledge of the study as well as her experience in conducting psychosocial research in cancer populations.

Transferability was addressed through the provision of detailed descriptions of the study sample and setting. Dependability was ensured by keeping a decision audit trail via recording the decision points and by peer involvement in the analysis process. Peers who represented a range of relevant skills and expertise relevant to this study were chosen, including experts in research on patients with cancer, psychosocial research, and clinical care and radiation therapy. Confirmability was established through the use of the reflective approach, peer involvement in discussions, and clarifications about data interpretation.

Data Analysis

A qualitative description approach was used to discover themes in the data to provide descriptions of patients' experiences in wording similar to their own. This research approach is particularly suitable for obtaining firsthand knowledge of patients' experiences with a particular topic (Neergaard, Olesen, Andersen, & Sondergaard, 2009).

Each interview audio-recording was transcribed verbatim. NVivo software, version 10, was used to manage data and to assist with analysis. Content analysis involved a systematic process of coding and identifying themes or patterns to extract categories from the data (Cho & Lee, 2014; Hsieh & Shannon, 2005; Thomas, 2006). Specifically, a general inductive approach to content analysis was employed, whereby codes, categories, or themes were directly drawn from the data (Cho & Lee, 2014). A sample of the transcripts (N = 3) was coded by two researchers independently, and the findings were compared. A coding frame was developed, and then all transcripts were coded by one researcher. The coding frame was adapted as new codes emerged, and all transcripts were recoded against this frame. A constant comparison method was used to assess whether coding had been appropriately assigned. This involved comparing text to segments that had been previously assigned the same code. With this method, existing codes were refined and new codes were identified, resulting in the code structure evolving inductively (Bradley, Curry, & Devers, 2007). A sample of the data was then reanalyzed by a second researcher. After discussion, the researchers conceptualized all

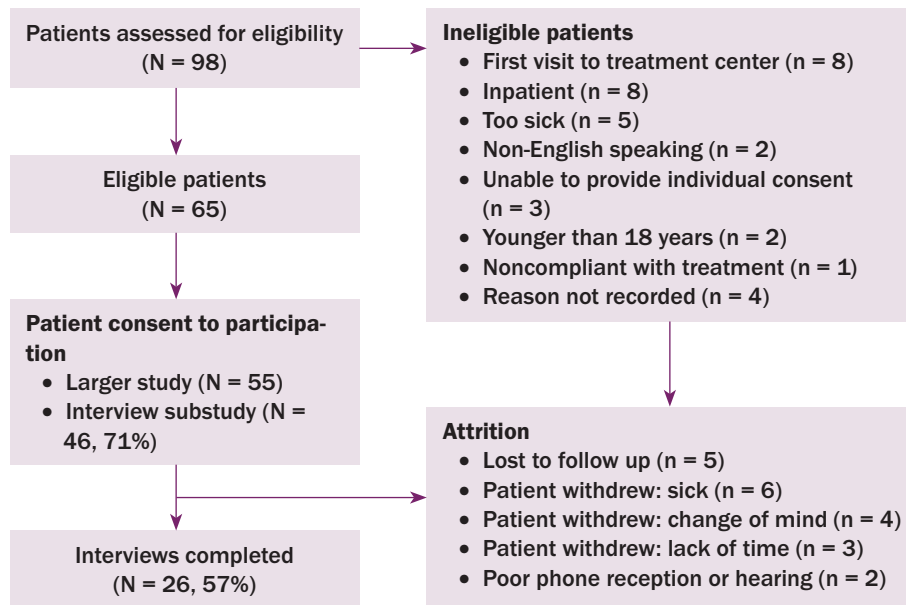


FIGURE 1. Participant Recruitment and Interview Participation

the resulting codes into broad categories or themes (Thomas, 2006). Saturation of the data was reached when information relating to the preparation experience became redundant and no new concepts were identified in subsequent interviews.

Results

Participant recruitment is described in Figure 1. Sixty-five eligible patients were identified, of which 55 consented to the larger study and 46 (71%) also consented to the substudy. A total of 26 patients (57%) completed the interview. Participants were aged 43–77 years and had a variety of cancer diagnoses (see Table 1). Interviews ranged from 5–25 minutes (\bar{X} = 14 minutes, SD = 5.7 minutes), including one interview that was terminated early because the patient was feeling sick. Participants were recruited until data saturation occurred.

Four main themes related to preparation techniques were identified: psychological preparation, informational preparation, social support, and quality of health care. Two themes related to the outcomes of preparation were identified: feeling psychologically prepared and knowing what to expect.

Psychological Preparation

Four subthemes emerged: frame of mind, downward comparison, coping mechanisms, and reassurance.

Frame of mind: Participants' view of their circumstances and radiation therapy seemed to affect their level of preparation for radiation therapy. Participants who viewed their radiation therapy as something

they just had to accept felt more prepared. Responses included:

Yeah, I sort of accepted, all right, well, it was my lot. . . . Some things you just got to accept and go with it, the flow, and learn yourself.

I'm myself, my own make up, I'm a realist . . . and I realized that . . . for my better health, I had to have [radiation therapy], and I looked at it in a positive way, which I still do today.

I think it's a case of personally accepting things the way they are, and you've got to go ahead and do it.

Downward comparison:

Some participants compared their circumstances to other people's or other treatments, which made them feel prepared.

Compared to what I could have been like after surgery, I was able to lead a normal life because there was no need for catheters or healing of wounds—that sort of thing.

But the actual ray treatment is only about one minute, if you know what I'm saying, and you don't even know it's going on. So the actual treatment itself [laughs], it's not like getting a needle or someone cutting your toe off—it's, it's nothing.

I'd probably be more worried about it if I had, you know, a brain tumor or lung cancer or something like that.

Coping mechanisms: Participants described a range of coping mechanisms they were informed about or used to help get through radiation therapy, which included listening to music, breathing techniques, distraction by talking to healthcare professionals, counting numbers, and meditation. All participants reported that the mechanism they used helped them cope with treatment.

Yeah, you just listen to the music and breathe through your nose slowly and surely, and you know it is going to finish in a minute.

The staff were really good, and they put music on that I liked, so it was just a case of sit back and enjoy.

Reassurance: When patients were informed about the effectiveness of the treatment, they felt more prepared.

So I think patients need an assurance that what they are having for that large amount of time is going to be successful.

Informational Preparation

Three subcategories related to informational preparation were identified: information format, information content, and knowledge gained from patients' or others' experiences.

Information format: Information provision was the main strategy used by healthcare providers to prepare patients for radiation therapy. A variety of formats were used, and participants' views of the usefulness of the different formats varied. Verbal and written information were the most commonly used formats.

It was always followed up with written . . . booklets, pamphlets—that was after it [had been] explained.

The verbal explanations were so much more clearer [than written material]. They could tell me exactly what I didn't understand.

DVD and online information were also provided, but to a much lesser extent.

Information content: Receiving information on the following topic areas were identified as important in feeling prepared: radiation therapy-related side effects, the practicalities of treatment (e.g., what radiation therapy does, what is involved); what the treatment machine looked like and how it worked; and what the patient would feel during treatment. The following quotes illustrate the importance of receiving such information.

Really . . . the only information I wanted to know was . . . what the side effects were. You know what to expect.

I think it's very much the detail of what's going to happen so that, you know, you don't get any surprises. . . . That was very important.

Make sure they understand that therapy is not going to hurt you and it's zap, zap—gone.

Knowledge gained from patients' or others' experiences: Participants' perceived knowledge and understanding of radiation therapy seemed to significantly affect their level of preparation. For instance, participants who felt that they knew what to expect based on previous experiences of radiation therapy or other similar medical procedures or the experience of

others who had received radiation therapy indicated a high level of preparation.

This lymphoma was a relapse from four years ago, and I had radiation at that time as well. . . . I think I was pretty well prepared for it this time . . . like after the previous thing. I knew—I more or less knew what would happen.

Since April last year, I've had a lot of scans, and . . . I'm used to getting under a lot of machines. . . . The concept of going under another machine didn't bother me at all—so, yeah, I was just excited.

I would say I was more fortunate than a lot of people. . . . Because of my wife's experience and being so closely involved with that, I was very well prepared.

Social Support

A number of patients found a support person helpful, as he or she was able to provide support and encouragement, keep track of information and scheduling, and attend treatment appointments with them. Healthcare providers' active involvement of the support person in the preparation process was also beneficial.

TABLE 1. Participant Characteristics (N = 26)

Characteristic	\bar{X}	Range
Age (years)	63.8	43–77
Education (years)	10.4	9–16
Characteristic	n	
Gender		
Female	7	
Male	19	
Marital status		
Married or living as married	16	
Divorced, separated, or widowed	8	
Missing	2	
Insurance status		
Private health insurance	10	
No private health insurance	14	
Missing	2	
Primary cancer type		
Breast	4	
Prostate	12	
Other (colorectal, gynecologic, head and neck, Hodgkin lymphoma, lung, melanoma, pancreatic)	9	
Missing	1	
Treatment status at time of interview		
Currently receiving radiation therapy	14	
Finished radiation therapy	11	
Missing	1	

They were brilliant, they let my wife come in and have a look at the gear, the treatment, you know, and told her how it worked.

Having someone to talk to, whether support people or staff at the radiation therapy clinic, also helped patients feel prepared.

You've got to have someone that you can talk to.

It was good to chat with [the staff] with two-way conversations.

Quality of Health Care

Half the participants revealed that their trust in their healthcare provider helped them feel prepared for radiation therapy. Many revealed that they viewed their healthcare provider as an expert and were happy to receive the suggested treatment. "I just put my trust in them and just let them do what they felt was necessary." Many participants explained how the friendliness and professionalism of the treatment center staff was very important to their overall preparation for treatment.

All I can say is they are a wonderful team and they just made it almost a pleasurable experience.

You know their full concern is you. You know, they are just smiling at you, calling you by your first name.

[The staff] made the day worthwhile, going there and having the treatment, cause I was looking forward to the next day to go along, having a bit of a chat [with] the people there.

Receiving additional assistance from healthcare providers also helped patients prepare for radiation therapy, which included information on how to treat side effects (e.g., skin care, mouth/throat washes); regular appointments with a specialist, doctor, or nurse; assisted parking; community transport; flexible appointment scheduling; dietary advice; and accommodation.

They give you like these creams . . . to use and things like that. So they prepare you for what's going to happen each week by week.

The actual best part was being given a swipe key so I could park the car under the building nearby.

Two subcategories were identified in relation to preparation outcomes: feeling psychologically prepared and knowing what to expect.

Feeling psychologically prepared: About half the participants indicated that they were not worried about receiving radiation therapy, were actually looking forward to treatment, and were keen to start

it. For example, one participant explained, "I had no feelings of anxiety or anything like that. I was quite looking forward to all the treatment." Conversely, about a quarter of the participants described how they felt apprehensive, anxious, worried, or terrified about beginning treatment. One participant shared,

[I was] a little bit apprehensive to start with, I suppose with something different, something new and something that's, you know, going to affect your health one way or the other.

Of those participants, most indicated that they felt anxious or apprehensive because they had to wait to start treatment, or they feared what would happen if the radiation therapy did not work and another treatment was required.

Knowing what to expect: The majority of participants perceived that they were well informed and had received the right balance, thoroughness, or amount of information, as reflected in their comments.

Well, they were absolutely perfect. They didn't underdo it, they didn't overdo it, they got the balance just right.

I can say that both verbally and written word were fully explained to me and [that] even an idiot like me knew what to expect.'

The radiation therapist told me in quite good detail what the exact procedure would be, and, you know, when the machine would go "click," when it would move and all that. So it was quite reassuring to know what was going to happen every minute, and nothing was out of place. . . . Again, I think it's very much the detail of what's going to happen so that, you know, you don't get any surprises. . . . That was very important and, as I thought, done very well.

However, three participants indicated that they would have preferred to receive additional information.

He did explain to me what was going to happen . . . but . . . to be honest, even though [the] Cancer Council material was reasonable, it was just very generalized.

A lack of understanding or uncertainty about radiation therapy and what was going to happen seemed to have a negative effect on some participants, who described treatment as a daunting process for them at first, feelings which often resolved after their first treatment.

The feelings of just . . . not really knowing what it's going to be like, what to expect when you go into that room. You're a bit, like, nervy, but once you've had your first treatment, I mean, there was nothing to be worried about.

I think every patient is very nervous because, like I said, it's the fear of the unknown. No matter how much you explain to them, it is still really hard to comprehend what is going to happen in there.

I've never been in one of those rooms, so . . . you didn't know what to expect when you went in. Or exactly how the rays, you know, if you'll see a beam coming toward you or anything like that.

Discussion

The findings provide a new understanding of the overall preparation experience of patients for radiation therapy and what most helped them feel prepared. This information can guide future interventions to prepare patients for receiving radiation therapy. Based on these findings, some suggestions follow on how to improve patient preparation.

Patient Perceptions of Radiation Therapy

The importance of assessing patient beliefs and feelings about radiation therapy was revealed in this study. In addition to participants' actual level of understanding of radiation therapy, frame of mind and uncertainty appeared to be the main factors that contributed to patients feeling prepared. Participants' perceptions of their circumstances also influenced their level of preparation. For example, participants who accepted their circumstances seemed most prepared. A number of participants also identified that receiving assurance and information about their treatment contributed to them feeling prepared for radiation therapy. Previous research has identified that similar concepts, such as outcome benefits (Sundaresan et al., 2014) and the preservation of hope (Gamble, 1998), are important factors in preparing patients for radiation therapy. Even for the participants who felt apprehensive or worried, most indicated that this was because they wanted to get started with treatment or they feared that the treatment would be unsuccessful. This finding is consistent with other studies that have reported existential anxiety as patients' primary concern (Egestad, 2013). To help ensure the delivery of information and support to those who need it most, healthcare providers should assess patients' frame of mind related to radiation therapy. Such assessments may help them identify additional information and support patients may need to feel prepared for radiation therapy.

Dispelling Uncertainty and Providing an Expectation of Outcomes

The authors found that the patients had a high degree of satisfaction with the care and information

they received about radiation therapy, similar to the findings in other studies (Gamble, 1998; Halkett & Kristjanson, 2007). However, most participants preferred to be informed of the specific practicalities of radiation therapy, including what to expect during the procedure as well as possible side effects. The results of the current and previous studies reveal that familiarizing patients with what is involved in treatment and potential side effects is imperative in preparing them for radiation therapy (Gamble, 1998; Halkett & Kristjanson, 2007). The importance of developing patient awareness about the details of radiation therapy is further emphasized by the findings, which revealed that uncertainty was a main inhibitor to patient preparation and that an in-depth understanding of what to expect was a major aid to preparation. Although most participants seemed to benefit from or wish for specific, practical information, not all participants wanted it. This finding is congruent with those of other qualitative studies, which have identified the importance of delivering information in line with individual patient needs (Worster & Holmes, 2008). Discussion among healthcare providers and patients about how much information the patients want and how they want to receive it is recommended.

Offering Support

Consistent with other research (Becker-Schiebe et al., 2015; Egestad, 2013; Gamble, 1998; Halkett & Kristjanson, 2007; Long, 2001), this study revealed that healthcare professionals who exhibit friendly and caring attitudes positively affect participants' experiences. Almost all participants stated that the friendliness and professionalism of the staff was very important to their overall preparation for treatment, as was trust in their healthcare providers. Participants also gained a great deal of benefit from the involvement of support people. Some guidelines (NBCC & NCCI, 2003) acknowledge that the presence of a support people can increase patient understanding, recall, and satisfaction with care. The findings of the current study indicate that patients value not only support people but also when their healthcare providers' actively engage them in their care. Therefore, healthcare providers should actively assess each patient's need and preference for the involvement of support people and encourage and incorporate their involvement accordingly.

Limitations

The majority of participants were English-speaking men diagnosed with prostate cancer. Consequently, the generalizability of the findings to the broader population of patients receiving radiation therapy may be limited. In addition, low response rates and recruitment from only one treatment center may further limit the generalizability of the findings.

Knowledge Translation

- Providing patients with information on the specific practicalities of radiation therapy and the possible side effects seems particularly pertinent in helping them feel prepared.
- Actively engaging patients' support people in the preparation process for radiation therapy seems to help them feel more prepared for the procedure.
- Uncertainty about radiation therapy seems to contribute to patients' uneasiness in undergoing the procedure.

However, the final sample size was sufficient to obtain data saturation, and the findings were strengthened through the stringent methods used to ensure that study rigor was met. Other characteristics such as length of time receiving radiation therapy and treatment aim (palliative versus curative) may affect patients' perceptions of their preparation for treatment. In addition, these factors were not explicitly assessed in this study; therefore, future research should examine the influence of such factors on patients' level of preparation. The aim of this study was to gain an overall understanding of patients' experiences with preparation for radiation therapy. Future research should assess patients with other characteristics (e.g., cancer types).

Implications for Nursing

The results of this study can be used to inform nursing practice regarding useful strategies for preparing patients for radiation. Specifically, the results indicated that informing patients about what to expect from the actual radiation therapy procedure and possible side effects were particularly important in preparing them for radiation therapy. When informing patients, healthcare providers should first assess their current knowledge and experience of radiation therapy and/or similar healthcare procedures. They should use patients' own knowledge and expectations as a platform to help explain what will happen and what to expect from radiation therapy. This method may be particularly useful in reducing uncertainty or misperceptions about radiation therapy, which seem to be barriers to patient preparedness. In addition, delivering such information in line with patients' preferences is essential. Actively involving patients' support people in the preparation process should also be considered and explored with patients. If a patient wishes to involve a support person in the preparation process, healthcare providers should encourage active participation by involving the support person in discussions about

what to expect from the procedure, as well as suggesting how he or she may assist the patient in coping with the impacts of radiation therapy before, during, and after treatment.

Conclusion

This study provided important insights into how to enhance patient preparation for radiation therapy. Informing patients about the actual procedure and possible side effects seems particularly important in preparing them for radiation therapy. However, healthcare providers should ensure that they deliver such information according to patient preferences. The aspects and indicators of preparation identified in this study should be explored in larger quantitative studies.

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