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Patients' experiences of preparation for radiotherapy: a qualitative study

Short title: Patients' experiences of preparation for radiotherapy

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Abstract

Objective: It is essential that patients are provided with adequate information and support to optimise their preparation for medical interventions, including cancer treatments. This qualitative study explored patients' experiences of and preferences for preparation for radiotherapy.

Research Approach: Qualitative study.

Participants: Semi-structured interviews were conducted with individuals who had recently received radiotherapy for cancer.

Methodologic Approach: Interviews were analysed based on a qualitative description approach and content analysis of the transcribed interviews.

Findings: Twenty-six participants with a variety of cancer diagnoses were interviewed. Four main themes related to preparation techniques were identified: 1) psychological preparation (frame of mind, downward comparison, coping mechanisms and reassurance); 2) information preparation (format, content, and knowledge from own or other's experiences); 3) quality of healthcare; and 4) social support. Two themes relating to outcomes of preparation were identified: 1) feeling psychologically prepared and 2) knowing what to expect. Overall, participants' accounts of preparation for radiotherapy suggest that provision of information was satisfactory. Some participants would have liked to receive more information and support, primarily in relation to both side effects, and the practicalities of what would happen during treatment.

Conclusions: The information gained in this study provides an indication of what strategies may best help to prepare patients for radiotherapy treatment.

Interpretation: Providing patients with information that creates a realistic expectation of what radiotherapy involves, both before and after treatment, seems to be particularly important to helping patients feel prepared.

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

Knowledge translation

- Providing patients with specific information on the actual procedure and possible side effects of radiotherapy seems particularly pertinent to helping patients feel prepared.
- Actively engaging patient's support persons in the preparation process of radiotherapy seems to assist patients in feeling more prepared for the procedure.
- Uncertainty about radiotherapy seems to contribute to patients feeling unprepared to undertake the procedure.

Radiotherapy is one of the three major cancer treatment modalities (Tait & Hardy, 2006), with approximately 50% of all cancer patients recommended to receive it (Barton et al., 2013). It can be used to either treat the cancer (curative) or to relieve symptoms (palliative). For many, curative radiotherapy is a time-intensive treatment, which is often undertaken five days per week, for up to eight weeks (NSW Department of Health, 2010). Palliative radiotherapy usually involves a few treatments given over a few days. While the physical and psychological impacts of radiotherapy can vary, short-term effects commonly include skin changes and fatigue (Bennenbroek et al., 2003); while long-term side effects can include: secondary tumours, cognitive impairment or sterility depending on the site and dose of treatment (Bennenbroek et al., 2003). Poor psychological outcomes such as anxiety, depression (Bennenbroek et al., 2003) and uncertainty are common among people having radiotherapy (Bennenbroek et al., 2003).

It is an ethical and legal imperative that patients are adequately prepared for medical interventions, including radiotherapy (National Quality Forum (NQF), 2005). Informed consent is a complex process (Kinnersley et al., 2013) that requires a patient to understand the intended procedure including the potential risks, benefits, and alternatives (Lupton, 2005; Schenker, Fernandez, Sudore, & Schillinger, 2011). The 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 and National Cancer Control Initiative, 2003; Suls & Wan, 1989; Waller, Forshaw, Bryant, & Mair, 2014). Whilst information needs for individual patients are variable (Royal Australian and New Zealand College of Radiologists, 2012; Tait & Hardy, 2006; Zeguers et al., 2012), numerous studies have shown that most patients prefer to be fully informed (Zeguers et al., 2012). Inadequate preparation can have a negative effect on patient outcomes (Poroch, 1995) such as pain, anxiety, satisfaction with care (Poroch, 1995), uncertainty and psychological distress (Halkett et al., 2012).

A tailored patient-centred approach to preparing and informing patients of the proposed medical procedure is recommended (Shabason, Mao, Frankel, & Vapiwala, 2014; The Royal Australian and New Zealand College of Radiologists, 2010; Zeguers et al., 2012). There are also a number of evidence-based recommendations (NHMRC, 2004) and guidelines (National Breast Cancer Centre and National Cancer Control Initiative, 2003; The Royal Australian and New Zealand College of Radiologists, 2010) on how healthcare providers can assist in adequately preparing patients for a potentially threatening procedure such as radiotherapy. However, the current recommendations are broad, providing only basic suggestions on how to facilitate communication with patients.

Consequently, radiation oncology departments vary in terms of how they prepare patients for their procedure (Royal Australian and New Zealand College of Radiologists, 2012). It has also been suggested that patient information about radiotherapy is inconsistent, uncomprehensive and too technical (Royal Australian and New Zealand College of Radiologists, 2012). Lack of treatment-related knowledge and misinformation have been reported as reasons why patients often commence radiotherapy with fear or anxiety (Halkett et al., 2010). Lack of information can also result in patients misinterpreting the significance of side-effects they experience, (Poroch, 1995; The Royal Australian and New Zealand College of Radiologists, 2010) and may also impact on patients' treatment decisions (Halkett et al., 2012). A need to improve patient education and preparation about what to expect during and after radiotherapy has been reported (Shabason et al., 2014).

There are a number of studies that have examined patient experiences and satisfaction with radiotherapy and receiving information related to radiotherapy (Gamble, 1998; Hinds, Streater, & Mood, 1995; Long, 2001). Findings of these studies indicate that most patients want to receive full details of their treatment (Gamble, 1998), and that preconceived perceptions of radiotherapy influence the extent to which patients feel prepared for treatment (Long, 2001). Several studies have assessed the effect of intervention strategies to improve patient preparation for radiotherapy (Johnson, 1996; Poroch, 1995; R. Thomas, Daly, Perryman, & Stockton, 2000). Results of these studies indicate that educating patients about what to expect during radiotherapy results in reduced treatment-related anxiety, stress and fear (Johnson, 1996; Long, 2001; Poroch, 1995; R. Thomas et al., 2000). While these studies highlight the importance of preparing patients for radiotherapy, as well as shedding light on some of the factors that are important to preparing patients, most were conducted in the 1990s or early 2000s. Since that time health care practice may have changed, particularly with the increased recognition of the importance of patient-centred care as a component of high quality health care (Institute of Medicine, 2001). Consequently, there is a need to gather up-to-date data about patients' experiences of preparation for radiotherapy. Understanding how patients are prepared and what they find useful or not will help to inform the most appropriate methods for preparing patients for radiotherapy. This study aimed to explore patients' experiences and perceptions of preparation for radiotherapy, and to identify factors that are perceived to assist with preparation.

METHOD

Study Design

This was a qualitative sub-study of a larger mixed methods study. The aim of this sub-study was to assess cancer patient experiences of preparation for radiotherapy. The larger study aimed to develop a standardised, psychometrically rigorous measure to assess the perceived level of preparation of cancer patients receiving radiotherapy treatment. This qualitative component used in-depth semi-structured interviews with a sub-sample of cancer patients undergoing radiotherapy from the larger study. The results from this sub-study were used to inform the development of the items included in the measure of patient preparation.

Setting and Participants

For this sub-study a purposive sample of participants was recruited from one Australian radiation oncology clinic, located within a tertiary referral hospital that provides public hospital services. For the main study additional patients from this and other hospitals were recruited using the same or similar recruitment methods. The cost of radiotherapy was fully covered by Medicare or Veteran Affairs (publicly funded health care schemes in Australia). The radiation oncology clinic had five linear accelerator machines delivering radiation treatment.

Eligible patients for both this sub-study and the main study were: aged ≥ 18 years; diagnosed with cancer; attending at least their second consultation at the radiation oncology unit; currently receiving radiation therapy at the time of recruitment; able to read and speak English; and 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. Consenting participants were contacted by the researchers within two weeks following recruitment to complete the phone interview. Participants were telephoned at their preferred time to discuss in a free and open manner, their experience of having radiotherapy. A telephone interview was deemed most appropriate as it reduced the burden experienced by participants who could complete the interview in the comfort of their own home at a time that was most suitable to them. This approach contributed to the rigour of the data as it allowed a diversity of patients, with different commitments, to take part. Participants were not required to travel and were not restricted to completing the interview during business hours. The

short timeframe between recruitment and patient interview was to help ensure that the experience was still fresh in the minds of participants. All interviews were conducted by a single researcher (KF), a PhD candidate with a Bachelor degree in Medical Science (Pathology), a Master's degree in Public Health and three years' experience as a research assistant. The researcher was not involved in recruitment of the participants, nor part of the patient care team.

With patient consent, each interview was audio-recorded. Open-ended questions were used to guide the interview and elicit detailed information on specific areas of patient's preparation with radiotherapy, 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 to preparing patients for radiotherapy. Participants were encouraged to speak openly and freely about their experience of being prepared for radiotherapy. The interview guide was designed to be flexible, with questions amended based on the direction of the participant's responses. The length of each interview was determined by the individual participant.

Ethical approval

This study was approved by the NSW Population & Health Service Research Ethics Committee and the University of Newcastle Human Research Ethics Committee.

RIGOUR

The following four constructs (Lincoln & Guba, 1985) were used to ensure the rigour of this study's data:

1. *Credibility*: Reflexivity and peer checking were used to establish credibility (Thomas & Magilvy, 2011). The researcher conducting the interviews (KF) used a reflective approach, recording preconception reflections, and ideas after each interview. The coding process used was also reviewed by another author (AH), and a sample of the data analysed by the first author was re-analysed by another author (AH). The author (AH) 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.
2. *Transferability*: was addressed through the provision of detailed descriptions of the study sample and setting, the details of which are described above.
3. *Dependability*: was ensured by keeping a decision audit trail via recording the decision points made, and through peer involvement in the analysis process. Peers that represented a range of relevant skills and expertise relevant to this study were chosen, including experts in: cancer patient

research (AH, AB, MC and JM), psychosocial research (AH, AB and MC), clinical care and radiotherapy (JM).

4. *Confirmability*: was established through use of the reflective approach and peer involvement in discussions and clarifications about the interpretation of the data, the procedures of which are further described below.

DATA ANALYSIS

A qualitative description approach was used, which involves themes being discovered in the data, and results in a description of patients' experiences in wording similar to their own (Neergaard, Olesen, Andersen, & Sondergaard, 2009). This approach is particularly suitable for research seeking to obtain first-hand knowledge of patients' experiences with a particular topic (Neergaard et al., 2009).

Each interview audio-recording was transcribed verbatim. NVivo software program was used for data management and to assist with the analysis. Content analysis, whereby a systematic process of coding and identifying themes or patterns (Hsieh & Shannon, 2005) (Cho & Lee, 2014; Thomas, 2006) was used to extract categories from the data. 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) were coded by two researchers (KF & AH) independently and the findings compared. A coding frame was developed and all transcripts were then coded by one researcher (KF). 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. Through this method existing codes were refined and new codes identified, resulting in the code structure evolving inductively (Bradley, Curry, & Devers, 2007). A sample of the data was then re-analysed by the second researcher (AH). After discussion (KF and AH), all resulting codes were then conceptualised into broad categories or themes (Thomas, 2006). Saturation of the data was considered to have been reached when information relating to the preparation experience became redundant and no new concepts relating to patient preparation for radiotherapy 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 main study, and 46 (71%) to this sub-study. A total of 26 patients (57%)

completed the interview. Participants were aged from 43 to 77 years with a variety of cancer diagnoses (see Table 1). Interviews ranged in length from 5 to 25 minutes (mean 14 minutes, SD 5.7 minutes), including one interview which was terminated early due to the patient feeling unwell. Participants were recruited until data saturation occurred.

Four main themes related to preparation techniques were identified. These included psychological preparation; information preparation; quality of healthcare; and social support. Two themes relating to outcomes of preparation were identified: feeling psychologically prepared and knowing what to expect.

Preparation techniques

1. Psychological preparation

Four sub-themes relating to psychological preparation were identified: frame of mind, downward comparison, coping mechanisms and reassurance.

Frame of mind

How participants viewed their circumstances and radiotherapy seemed to impact on their level of preparation for radiotherapy. For the majority of participants, viewing their radiotherapy as something they just have to accept significantly impacted on them feeling prepared. Common phrases included:

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

“... and the fact that I’m myself, my own make up, I’m a realist ...and I realised that...for my better health I had to have it 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 or other treatments to help them feel prepared. For example:

“...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 1 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 tumour or lung cancer or something like that”.

Coping mechanisms

Participants described a range of coping mechanisms that they were informed about or utilised to help them get through radiotherapy. These included: listening to music; breathing techniques; distraction by talking to healthcare professionals; counting and meditation. All participants reported that the mechanism used made them feel more able to cope with treatment. For example:

“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

Being informed about how effective the treatment was expected to be also resulted in a number of participants feeling 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”.*

2. Informational preparation

Three sub-categories relating to informational preparation were identified: format of information, content of information, and knowledge gained from one’s own or others’ experiences.

Format of information

Information provision was the main strategy used by healthcare providers to help prepare patients for radiotherapy. A variety of formats were used, with participants varying in their views on the usefulness of the different formats. Verbal and written information were the most commonly used formats. *“It was always followed up with written, and I was given booklets, pamphlets -that was*

after it was explained...". "If there was anything written and I had no one beside me...that's why the verbal explanations were so much more clearer. They could tell me exactly what I didn't understand". DVD and online information were also provided or accessed, but to a much lesser extent.

Content of information provided

Receiving information on the following topic areas were identified as important for being prepared: radiotherapy-related side effects, the practicalities of treatment e.g. what radiotherapy does, what is involved in treatment; what the treatment machine looks like and how it works; and information on what pain may be felt during treatment. Quotes that illustrate the importance of receiving such information include:

"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 its zap, zap gone".

Knowledge gained from own or others' experiences with radiotherapy or other medical procedures

Participants' perceived knowledge and understanding of radiotherapy seemed to have a significant impact on how prepared they felt. For instance, participants who felt they knew what to expect based on either their own previous experience of radiotherapy, or other similar medical procedures, or knowing someone else who had received radiotherapy, indicated a high level of preparation. For example:

"This lymphoma was a relapse from 4 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".

"Because...since April last year I've had a lot of scans and...I'm used to getting under a lot of machines. That 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, having, because of my wife's experience and being so closely involved with that I was very well prepared yeah".

3. Social support

Having a support person available was helpful for a number of patients, as they were able to provide support and encouragement, keep track of information and scheduling and attend treatment appointments. Healthcare providers' active involvement of the support person in the preparation process was also beneficial. For example:

"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 was also revealed as important to patient's preparation. This included the ability to talk to both support persons and staff at the radiotherapy clinic. *"....You've got to have someone that you can talk to". "The socialisation created by the staff. ... it was good to chat with them with two-way conversations..."*

4. Quality of healthcare

Half of the participants revealed that their trust in their healthcare provider helped them feel prepared for having radiotherapy. Many revealed that they viewed their healthcare provider as the expert and were happy to receive the treatment they suggested: *"I just put my trust in them and just let them do what they felt was necessary".* Friendliness and professionalism of the treatment centre staff was also emphasised by many participants as being very important to their overall preparation for having treatment:

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

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

"... I think the fact that all the staff and that made you feel sort of... it 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 to the people there..."

Receipt of additional assistance from healthcare providers also helped patients prepare for having radiotherapy. This included being given additional information on how to treat side effects (e.g. skin care or mouth/throat washes); having regular appointments with their specialist, doctor or nurse;

assisted parking; community transport; flexible appointment scheduling; receiving dietary advice; and accommodation. For instance:

"...so they give you like these creams and that 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".

Preparation outcomes

Two sub-categories were identified in relation to outcomes of preparation: feeling psychologically prepared and knowing what to expect.

1. Feeling psychologically prepared

Approximately half of the participants seemed well prepared for radiotherapy by indicating that they were not worried about having radiotherapy, were looking forward to treatment and were keen to start it. For example *"I had no feelings of anxiety or anything like that. I was quite looking forward to all the treatment"*. Conversely, about a quarter of participants described feeling apprehensive, anxious, worried, or terrified about beginning treatment. One participant described their feelings as *"a little bit apprehensive umm 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 the main reason they felt anxious or apprehensive was because they wanted to get treatment started, or feared what would happen if the radiotherapy did not work and another treatment was required.

2. 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. This was reflected in comments including: *"Well they were absolutely perfect. They didn't under do 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 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. For

example: *“He did explain to me what was going to happen like, but, well then to be honest, even though Cancer Council material was reasonable, it was just very generalised”.*

A lack of understanding or uncertainty about radiotherapy and what was going to happen, seemed to have a negative impact on some participants. These participants described treatment as a daunting process for them at first, feelings which often resolved after having their first treatment. For example:

“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”.

“But 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”.

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

DISCUSSION

The current findings provide new understanding of the overall experience of how participants were prepared for radiotherapy, and what most helped them to feel prepared. This information can provide guidance on what may best help prepare radiotherapy cancer patients for receiving their treatment. Based on these findings, some suggestions for how patient preparation could be improved are summarised below.

Patient perceptions of radiotherapy

The importance of assessing patient beliefs and feelings about radiotherapy was revealed. In addition to participants actual level of understanding of radiotherapy, frame of mind and level of uncertainty appear to be the main factors that distinguished whether a patient felt prepared or not. Participants’ perceptions of their circumstances had a particular impact. 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 radiotherapy. Previous research has identified that similar concepts such as outcome benefit (Sundaresan et al., 2014) and the preservation of hope (Gamble, 1998) are important to

preparing patients for radiotherapy. Even for the patients who felt apprehensive or worried, most indicated this was because they wanted to get treatment started, or feared radiotherapy being unsuccessful. This finding is consistent with other studies which have reported existential anxiety as being patients' primary concern (Egestad, 2013). To help ensure the delivery of information and support to those who may need it the most, healthcare providers may benefit from assessing patients frame of mind in relation to having radiotherapy. Such an assessment may help identify additional information and support that patients may need to feel prepared for having radiotherapy.

Dispelling uncertainty and providing an expectation of outcomes

Similar to other studies of radiotherapy patients (Gamble, 1998; Halkett & Kristjanson, 2007) our study found a high degree of satisfaction with care and information received. However, most participants indicated a preference for being specifically informed of the practicalities of radiotherapy, both in terms of what to expect during the procedure as well as possible side effects. Based on the current results and previous studies (Gamble, 1998; Halkett & Kristjanson, 2007), ensuring patients are aware of what is involved in treatment and potential side effects, seems to be an imperative to preparing patients for radiotherapy. The importance of developing patient awareness of what is involved in radiotherapy is further emphasised by the findings that uncertainty was a main inhibitor to patient preparation, while an in-depth understanding of what to expect was identified as an enabler. Whilst most participants seemed to benefit from or wish for specific, practical information, not all participants wanted such detailed information. This finding is congruent with other qualitative studies, which have identified the importance of delivering information in line with patient's individual needs (Worster & Holmes, 2008). Discussion between the healthcare provider and patient about how much detail the patient would like to receive and how, is recommended.

Offering support

Consistent with other research (Becker-Schiebe et al., 2015; Egestad, 2013; Gamble, 1998; Halkett & Kristjanson, 2007; Long, 2001), this study found that health professionals who exhibited a friendly and caring attitude positively impacted on participants' experiences. Friendliness and professionalism of staff was emphasised by almost all participants as being very important to their overall preparation for treatment, as was trust in their healthcare provider. Participants also gained a great deal of benefit from the involvement of their support persons. It is currently acknowledged in some guidelines (National Breast Cancer Centre and National Cancer Control Initiative, 2003) that the presence of a support person can increase patient understanding, recall and satisfaction with

care. The findings from this study indicate that it is not just the presence of a support person that is valued by patients, but also their healthcare provider's active engagement of their support person in their care and support. It is therefore suggested that health care providers actively assess each patient's need and preference for support person involvement; and encourage and incorporate the involvement of support persons as the patient wishes.

Limitations

The majority of participants were English speaking males diagnosed with prostate cancer. Consequently the ability to generalise these findings to the broader population of radiotherapy cancer patients may be limited. In addition, low response rates and recruitment from only one treatment centre may further limit the generalisability of the findings. However, the final sample size was sufficient to obtain data saturation and the findings of this study are strengthened through the stringent methods followed to ensure study rigour was met. Other characteristics such as length of time receiving radiotherapy and treatment aim (palliative vs. curative) may affect patient's perceptions of their preparation for treatment. However, these factors were not explicitly assessed in this study, thus future research should examine the influence of such factors on patient's level of preparation. Furthermore, the aim of this study was to gain an overall understanding of patients' experiences with preparation for radiotherapy. Thus it was outside the scope of this study to assess differences in experiences of receiving radiotherapy across different characteristics such as cancer type. Future research should explore possible differences.

IMPLICATIONS FOR NURSING

The results from this study can be used to inform nursing practice with regards to what strategies may be useful for preparing patients for radiation treatment. Specifically, results indicate that informing patients about what to expect from the actual procedure of radiotherapy and possible side effects is perceived by patients as particularly important to feeling prepared for radiotherapy. When informing patients about what to expect, health care providers should first assess patients' current knowledge and experience of radiotherapy and/or similar health care procedures. Health care providers should use patients' own knowledge and expectations to help explain what will happen and what to expect from radiotherapy. Using patients' prior knowledge base as a platform to informing patients about what to expect may be particularly useful in reducing any uncertainty or misperceptions that patients may feel with regards to their radiotherapy treatment, which seem to be barriers to patients feeling prepared. However, attempts to deliver such information in line with patients' preferences is essential. Actively involving the patient's support person in the preparation

process should also be considered and explored with patients. If patients wish to involve their support persons in the preparation process, health care providers should encourage their active participation. This can be done by involving them in the discussions about what to expect from the procedure, as well as providing support persons with suggestions on how they may assist the patient to cope with the impacts of radiotherapy, before, during and after the procedure.

CONCLUSION

This study provides important insights into how patient preparation for radiotherapy may be enhanced. Providing patients with specific information on the actual procedure and possible side effects seems particularly pertinent to helping patients feel prepared for radiotherapy. However, ensuring such information is delivered in line with patient's preferences is essential. The aspects and indicators of preparation as identified in this study need to be explored in larger quantitative studies.

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Figure 1
Flowchart of participant recruitment and interview participation

Table 1**Demographic and disease characteristics of participants (n=26)**

Patient characteristics	n (%)
Sex	
Male	19 (73.1%)
Age (years)	
Mean (min, max)	63.8 (43-77)
Education (years)	
Mean (min, max)	10.4 (9-16)
Marital status	
Married or living as married	16 (66.7%)
Divorced, separated or widowed	8 (33.3%)
Insurance status	
Private health insurance	10 (41.7%)
No private health insurance	14 (58.3%)
Primary Cancer Type	
Breast	4 (15.4%)
Prostate	12 (46.2%)

Other (colorectal, gynaecological, head and neck, Hodgkin's lymphoma, lung, melanoma, pancreatic)	9 (38.4%)
Treatment status at time of interview	
Currently receiving radiotherapy	14 (56.0%)
Finished radiotherapy treatment	11 (44.0%)

*Observations within each variable may not add to total sample size due to missing values

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FIGURE 1: Flowchart of the inclusion and exclusion process based on Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines[54]

APPENDIX A: Search terms from Medline (extracted 10/11/15)

Search term	Matches
1 exp Informed Consent/	<u>37347</u>
2 (Informed adj2 (consent or decision* or choice*)).tw.	<u>31149</u>
3 (Consent* adj (process or form* or document*)).tw.	<u>3263</u>
4 ((improv* or understand*) adj2 consent).tw.	<u>312</u>
5 risk communication.tw.	<u>1417</u>
6 1 or 2 or 3 or 4 or 5	<u>60963</u>
7 exp Decision Making/	<u>134347</u>
8 decision making.tw.	<u>70102</u>
9 ((patient* or consumer* or personal or individual) adj1 (decision* or choice or preference or participation or involvement)).tw.	<u>13865</u>
10 (patient-cent* or 'quality of care' or satisfaction or experience).tw.	<u>549120</u>
11 exp Quality Indicators, Health Care/	<u>15122</u>
12 (quality adj3 (care or healthcare)).tw.	<u>50238</u>
13 exp Patient-Centered Care/	<u>12904</u>
14 exp "Process Assessment (Health Care)"/	<u>3321</u>
15 exp Quality Improvement/	<u>9741</u>
16 exp Program Evaluation/	<u>60814</u>
17 exp Health Services Research/	<u>135350</u>
18 (patient* adj3 (experience* or opinion* or perspective* or perception or perceive*)).tw.	<u>101799</u>
19 exp Patient Satisfaction/	<u>68581</u>
20 (patient adj3 satisfaction).tw.	<u>23336</u>
21 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20	<u>990868</u>
22 exp Patient Education as Topic/	<u>74475</u>
23 exp Health education/	<u>143623</u>
24 (preoperative adj3 (information or prepar*)).tw.	<u>3492</u>
25 (psychological adj3 prepar*).tw.	<u>396</u>
26 ((sensory or procedural) adj3 information).tw.	<u>5388</u>
27 (prepar* adj3 (treatment* or test* or procedure* or surgery)).tw.	<u>19543</u>
28 22 or 23 or 24 or 25 or 26 or 27	<u>171647</u>
29 exp data collection/ or exp health care surveys/ or exp interviews as topic/ or exp questionnaires/ or exp self report/	<u>1636265</u>
30 ((develop* scale* or measure* or survey* or instrument* or tool*) adj5 (psychometric* or reliability or validity or validation or acceptability)).tw.	<u>32706</u>
31 exp Psychometrics/	<u>59482</u>
32 29 and 31	<u>25126</u>
33 30 or 32	<u>53016</u>
34 exp Specialties, Surgical/	<u>170401</u>
35 exp Surgical Procedures, Operative/	<u>2583494</u>
36 surgery.tw.	<u>782652</u>
37 (threat* or invasive) adj3 procedure*.tw.	<u>16559</u>
38 exp anesthesia/	<u>165926</u>
39 exp Radiotherapy/	<u>151019</u>
40 exp chemoradiotherapy, exp chemotherapy, adjuvant/ or exp consolidation chemotherapy/ or exp induction chemotherapy/ or exp maintenance chemotherapy/	<u>40042</u>
41 exp diagnostic Imaging	<u>1879100</u>
42 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41	<u>4638263</u>
43 6 or 21 or 28	<u>1173205</u>
44 33 and 43	<u>10337</u>
45 42 and 44	<u>1156</u>