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The breast cancer patient's experience of making radiation therapy treatment decisions

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Abstract Women who are diagnosed with breast cancer have many decisions to make during the course of their treatment. The aims of this paper are to describe the women's experience of making radiation therapy treatment decisions for early breast cancer and to explore how women feel about receiving radiation therapy. An in-depth understanding of the women's experience was developed using a qualitative research approach underpinned by hermeneutic phenomenology. In-depth interviews were conducted with 18 women who had completed treatment for early breast cancer. The themes that emerged from the data were: being challenged, getting ready, beyond control, regaining a sense of control and getting through it. This study provides health professionals with an initial understanding of the women's perspective of the experience of making radiation therapy treatment decisions for early breast cancer. This study concludes by suggesting that further research needs to be conducted to gain an understanding of how other patients feel about treatment decision-making and radiation therapy.

Introduction

Breast cancer is the most common cancer in females in many countries including Australia, the United States of America and the United Kingdom.¹ The Australian Institute of Health and Welfare² reported that one in 11 women in Australia will develop breast cancer in their lifetime. When women receive their diagnosis they are confronted with a range of difficult challenges and decisions relating to themselves, their lives and their treatment options. One decision that they make relates to whether they will receive radiation therapy or not.

Treatment decisions may be made by the medical practitioner, shared between the medical practitioner and the patient, or made independently by the patient.^{3,4} Factors that have been found to influence women's treatment decisions include: geographical location, culture, personal choice, family members and medical practitioner's recommendations.⁵⁻⁷ Women may also select particular treatment options because they believe that a particular treatment will provide them with a better chance of surviving the disease⁸ or because they are concerned about the effect treatment will have on their body and body image.⁹

Hammick *et al.*¹⁰ reported that patients have varying levels of understanding of radiation therapy and what it is used for. This finding is supported by Johnson¹¹ and Hunt¹² who found that some patients have little understanding of radiation therapy, fear its use and/or doubt its effectiveness. Although there is evidence that cancer patients fear radiation therapy, there is a paucity of published research examining the impact of the patient's knowledge and understanding of radiation therapy on the experience of making radiation therapy treatment decisions. The aims of this paper are to describe the women's perspective of the experience

of making radiation therapy treatment decisions for early breast cancer and to explore how women feel about receiving radiation therapy as a component of their treatment. The responses provided by women in the context of this paper emerge from a broader study that was designed to describe the women's perspective of the phenomenon of making treatment decisions for early breast cancer. This study provides health professionals with an opportunity to gain an improved understanding of the women's perspective of the experience of making radiation therapy treatment decisions for early breast cancer. Health professionals who have a greater understanding of the women's radiation therapy experiences may be able to empathise and support patients more effectively during treatment decision-making and throughout their radiation therapy treatment.

Methodology

A qualitative research method was used for this study because qualitative research methodology acknowledges the existence of multiple social realities. Qualitative research approaches provide researchers with methods that can develop an in-depth understanding of how people feel and what the experiences are like for them.¹³ Hermeneutic phenomenology was used to underpin the qualitative approach because it provides a way of interpreting and understanding the subject's lived experiences. A more detailed explanation of the methodology that was used in this study is provided in Halkett *et al.*¹⁵

Ethics approval for the research was obtained from the University of South Australia and other institutions that assisted in recruitment. Women provided written informed consent prior to participating in the study. To preserve anonymity each woman

was assigned a subject (S) number.

In-depth, open-ended interviews were conducted with 18 women who had completed treatment for early breast cancer. The women were asked to describe the period from when they were diagnosed until after treatment completion. Interview prompts were used to encourage women to focus on describing the experience of making treatment decisions. Two interviews were conducted with each individual so that it was possible to gain a rich description of their experiences. The second interview was used to further explore the women's experiences and provided the opportunity to ask further questions and clarify the meaning of what was discussed in the first interview. All interviews were conducted in 2003 and were within one year of the completion of their prescribed treatment. Interviews were tape-recorded and field notes were also taken during the interviews. Full transcripts of the interviews were constructed and analysed using thematic analysis.

Findings

The themes that emerged are described below.

Being challenged

This theme sets the scene and demonstrates how women felt when they initially received their breast cancer diagnosis. Women felt severely affected by their diagnosis and experienced feelings of shock, surprise and terror when they realised that their understandings of the world and their lives were challenged and that they could no longer take the world for granted. For example, one subject said:

"I was absolutely stunned. I mean you just don't think that it is going to happen to you. I couldn't say anything at the time because I didn't know what to say, I was so stunned, I couldn't believe it." S7

Women perceived their diagnosis as a challenge to their existence, their sense of self, their future goals and their values. They found it difficult to discuss their treatment options and take in all of the information that their medical practitioners provided during this period. For example, one subject said:

"I did feel at one stage that I could stick my head in the sand and get my husband to sit over here and discuss with the doctor about it all, like it was all too much . . . you are in shock and you need time to digest the information and many times I came home and I would say to my husband 'What did the doctor say about . . .' You can't take it in, you need time to take it in . . ." S2

Women initially tried not to think about breast cancer and experienced feelings of denial because they could not believe that they had been diagnosed with this condition and were not ready to make changes to their understandings of themselves and their lives. They also found it difficult to communicate with the medical practitioners and did not take in all of the information that was provided because they could only cope with small amounts of information at a time. The women's reactions to their diagnosis are consistent with research by Janoff-Bulman¹⁶ who reported that individuals experience involuntary feelings of denial and 'emotional numbing' which help to protect them from the information that they receive. Janoff-Bulman¹⁶ reported that denial processes allow people to 'shut down the system' and deal with small amounts of information when they are ready.

Getting ready

After women received their diagnosis they tried to get into a state of readiness and prepare themselves for the events that may

follow their diagnosis. Some women were told that they should consider radiation therapy when they were discussing surgery options and others did not realise that it was an option until after they had received surgery and were advised that they needed to meet with a radiation oncologist.

One participant explained that she felt prepared for radiation therapy because she was initially informed that she would need radiation therapy after her surgery. However, other women felt unprepared and overwhelmed when they were told they needed radiation therapy. For example, one woman said:

"I had been handling everything okay, very methodically . . . once they said you have got to have radiation that just tipped me over. I hadn't factored that into my whole network of thinking and that I found really hard, to think 'There is another thing'." S3

This participant felt overwhelmed and realised that her thinking needed to also accommodate the idea of radiation therapy.

Another woman felt unprepared for radiation therapy and explained that she felt she did not know enough about it before she went for treatment:

"I had no idea with the radiation, I had no idea what happens. It was scary, not scary, it is overwhelming. When you have your treatment you don't know what to expect and you don't know how it is going to affect you." S5

Some participants learned more about radiation therapy when they discussed their treatment options with their medical practitioners. One woman was told that she was having radiation therapy to reduce the risk of recurrence:

"I knew exactly what was going to happen, he told me that more than likely they would get all of it when they did the operation, but he said there was always a chance you leave a couple behind and that is why I had the radiation." S9

Another woman knew little about radiation therapy and was relieved when she was told that she would not lose her hair:

"I said 'I don't want to lose my hair' and he said 'You are not having chemo, you are only having radiation'." S10

Women tried to learn more about radiation therapy to prepare themselves so that they felt less overwhelmed and were no longer scared or frightened by the thought of radiation therapy. Some women felt prepared before treatment while others did not feel comfortable with the thought of radiation therapy until they went for treatment in the radiation therapy department.

Beyond control

When women received their diagnosis they realised that they could not control all aspects of their lives and began to feel that their lives and existence were beyond their control. A number of women explained that they took on a less active role in making treatment decisions because they lacked confidence in themselves and believed that they did not have enough knowledge to make the right treatment decisions.

One woman described the lack of control she felt:

"The surgeon had already mapped it out, it was already set in place, I would be having chemo, ray treatment, tablets. There wasn't really any discussion on my part. He said it was vital that I have this treatment and he read off what I was having. So they had already had their case conference and decided what the treatment would be. I more or less had to agree with it." S2

This participant believed that the decisions regarding her life were temporarily beyond her control. Although she did not feel she had control, she remained confident because her medical practitioner had taken responsibility and provided

her with some direction.

Another woman also took a passive role and consented to radiation therapy because she felt that it might increase her chances of survival:

"Well I didn't decide that myself, I agreed to have it. I thought it was a bit of a hassle but if it was going to help why not have it and I think that sort of treatment is the best that they have for now, there will be perhaps other treatments and better ones, but for now we accept what they have." S4

This woman felt poorly informed about radiation therapy, but she willingly accepted treatment because she wanted to follow the medical practitioner's recommendations and needed to feel like she was actively fighting the disease.

A third participant also perceived that her treatment decisions were beyond her control:

"The radiotherapy, I said 'How does that go, because I get heart palpitations and I had chest injuries before. . . ?' They said more or less 'Well if you don't go and get it done well bad luck', because they wouldn't be responsible if it came back."

"They more or less tell you straight away that 99% of patients have radiotherapy. You are put in a position where you take that risk of the radiation therapy treatment when you have it done, but then if you don't get it done, there is always a bigger chance that you might get cancer back again, so that is what you have got in your mind when they tell you this." S5

Subject 5 believed that she needed to accept that her decisions were beyond her control because she wanted medical practitioners to take responsibility for her treatment and continue to provide her with support in the future. She therefore followed her medical practitioner's recommendations and consented to treatment.

The exemplars above demonstrate that some women who participated in the current study took on a less active role in treatment decision-making because they perceived that their treatment decisions were beyond their control and they wanted medical practitioners to take responsibility for their decisions. Women also accepted a less active role because they felt that their medical practitioners would not provide continuing support if they chose to deviate from the recommended treatment regime.

Regaining a sense of control

After women had accepted their diagnosis and received surgery they began to take responsibility for their lives and were able to regain a sense of control. One woman was able to regain a sense of control when she took responsibility for her radiation therapy treatment decision and decided not to receive treatment:

"As I thought about it and read more about it and I felt in myself more I actually worked out the statistics, I just felt the collateral damage, even though modern techniques are so much better than they used to be, weren't worth it for me. Given my prognosis I felt really confident that the sort of post trauma treatment I was getting with my doctor was fine and I was happy to go that way and look after myself and be mindful of what I had to do alternatively." S6

Subject 6 gained a greater sense of control when her family doctor supported her treatment decisions and encouraged her to pursue treatment options that she believed in:

"He said 'That is part of the treatment, doing what you believe in and you have to feel okay about it all and if it makes you feel safer that is good'." S6

Women who regained a sense of control began to feel more confident within themselves and were able to positively

reconstruct their understandings of the world. Those who took responsibility for their treatment decisions sought reassurance from their medical practitioners and support people. Positive reassurance helped women to feel more confident and in control and enabled them to determine whether other people respected their actions and decisions.

Sharing the challenge with others

Women shared the experience of making decisions and receiving treatment because they found their diagnosis difficult to deal with and believed that they needed support from others. The majority of women found that the staff in the radiation therapy department (radiation therapists, radiation oncologists and nurses) were supportive and provided them with personalised care.

One woman displayed some concerns about her radiation therapy experience:

"It was kind of like living on another planet, you go in and get your treatment, you are radiated, very frightening, that would be a difficult job for the radiation nurse I feel. The one thing they don't do is to just console you. You are trying to be brave but inside of you, you are scared if the treatment isn't right."

However, the exemplars below demonstrate that other women were pleased with the individualised care that they received during their radiation therapy treatment:

"They are lovely people in the radiation department. Very caring. They treat you as a person not a number." S8

"The staff in the radiation department were wonderful, happy, cheerful. And because they see you every day it is like old friends, how are you today . . . plenty of cheek and very reassuring . . ." S2

The exemplars presented in this theme demonstrate that some women coped with their treatment well, while others found the experience uncomfortable and confronting. Women realised that the radiation therapy department was busy and many were pleased when staff in the radiation therapy department took time to treat them as an individual and find out how they were feeling during their treatment. Some women also found that the staff in the radiation therapy department provided them with comfort, reassurance and understanding.

Getting through it

Radiation therapy treatment generally lasted five to six weeks. Some women highlighted that they struggled to maintain the routine of going for daily treatment. Women who experienced side effects felt that they just had to tolerate the side effects and somehow find a way to get through the remaining treatment.

One woman explained that she found it difficult to remain positive throughout her treatment:

"The hardest part is hanging in there while you are having the radiation treatment and trying to visualise the cancer out. I ended up with blisters across my breast . . ." S1

This participant could see that the radiation was affecting her skin, but she was unsure if the radiation was also killing her cancer and questioned whether she could make it through till the end of treatment.

A second woman highlighted that it was an effort to go for treatment every day. However, she was able to deal with it when she compared it to what it was like when she was working:

"I used to think to myself I used to do this was like when I was working. But the people there were very nice. That's the main thing if you've got pleasantries when you get there then you don't mind. And the bus stop was right outside the hospital which helps. And there is also shopping, but you didn't feel like shopping sometimes." S11

A third woman highlighted that she struggled to get through treatment because she began to feel extremely tired:

"The feeling of just unbelievable tiredness. The first three weeks I was fine, I thought okay, I can handle this, this is not affecting me one little bit, even though I had to walk 15 minutes every day to the bus stop and catch two buses and all that sort of thing. It didn't worry me, but the last three weeks toward the end, from the middle of the week to the end of the week I was getting to the point where I didn't want to do it anymore. I had never experienced such tiredness, it really knocks you out. That was the radiation so I would hate to think what the chemo would be like." S9

Women had little understanding of what to expect before they commenced radiation therapy. However, once treatment started they gained an understanding of what it was like and got into a routine. Women felt that they needed to continue receiving treatment and put up with any side effects that they experienced.

Discussion

This study provides health professionals with an initial understanding of the women's perspective of the experience of making radiation therapy treatment decisions for early breast cancer. Although radiation therapy is a common treatment for breast cancer, it is still feared by people who lack understanding of it and know little about it.^{11,12} A number of women who participated in the current study expressed that they felt poorly informed about radiation therapy prior to their diagnosis. Medical practitioners tried to inform women about treatment after they received their diagnosis, however this was a somewhat difficult task because women felt challenged by their diagnosis and were still dealing with the fact that they could no longer take their lives for granted. Many of the women were only able to take in small amounts of information because they were not ready to deal with all of the information that the medical practitioners initially provided.

The data demonstrates that some women tried to prepare themselves and find out more about radiation therapy because they did not like feeling overwhelmed and wanted to reduce their fears about the thought of radiation therapy. Gamble¹⁷ reported that women may benefit from access to a range of different information sources. The current study complements research by Gamble¹⁷ and reports that women felt more confident and less frightened when their medical practitioners informed them and helped them to prepare for treatment.

When women received their diagnosis they began to feel like their lives were temporarily beyond their control. This finding is consistent with research by Shaha and Cox¹⁸ who reported that people with colorectal cancer realised that they could no longer control their lives and believed that they needed to pursue an external locus of control. A number of women who participated in the current study took on a less active role in making treatment decisions and relied on medical practitioners to take responsibility for their care. Some women took on a less active role because they felt poorly informed and were not ready to take responsibility for their decisions. Owens *et al.*¹⁹ similarly reported that some patients with cancer of the prostate did not participate in decisions about radiation therapy because they felt poorly informed. Other women who participated in the current study took a less active role because they believed that they would not receive continuing support if they did not follow the medical practitioner's recommendations. Verhoef and White²⁰ similarly found that some cancer patients felt that their medical practitioners used 'scare tactics' and led them to believe that they would not receive continuing care if they did not accept the recommended treatment.

Some women felt that they needed to regain a sense of control after surgery was complete. Arman and Rehnselfdt²¹ similarly reported that patients want to regain independence and a sense of control. One participant in the current study began to regain a sense of control when she developed her understanding of treatment and independently took responsibility for her radiation therapy treatment decisions.

Most women found that they were able to share the challenge of breast cancer with health professionals who worked in the radiation therapy department. Although one woman was disappointed with her experiences in the radiation therapy department, other women who had radiation therapy were pleased that the radiation therapists treated them as individuals and provided them with reassurance during treatment.

Some women found that the experience of receiving radiation therapy was different to what they expected. Women felt that they had to get through treatment and put up with any side effects that they experienced. Women developed ways of coping with changes in their routine and found that the experience was bearable because they had things to look forward to and knew that their treatment would eventually end.

Conclusion

Findings from the current study provide health professionals with an initial understanding of the women's experience of making radiation therapy treatment decisions for early breast cancer. Additional research that is being conducted by the authors will provide an in-depth understanding of the women's perspective of the whole phenomenon of making treatment decisions rather than focusing only on radiation therapy treatment decisions.

This study provides a starting point for further research that explores the patient's perspectives and the perspectives of other people who are involved in the experience of making treatment decisions. Further research is required to determine the patients' perspectives on other decision-making processes and on their treatment experiences. Additional studies should also continue to explore whether patients feel adequately informed about radiation therapy and evaluate new methods of informing newly diagnosed cancer patients about radiation therapy.

Acknowledgements

This research was partially funded by a research scholarship granted by the Professional Accreditation and Education Board of the Australian Institute of Radiography.

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