

“I Made All Decisions Myself”: Breast Cancer Treatment Decision-Making by Receivers and Decliners

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ABSTRACT

Objective: Many women with breast cancer refuse adjuvant treatments. How they arrive at their respective decisions and whether they are passively or actively involved in making decisions is less known. We explored the different decision-making behaviors of women who received treatments (receivers) after being diagnosed with breast cancer and those who refused (decliners). **Methods:** Seven women (four receivers and three decliners) were recruited from the Breast Cancer Integrative Oncology Study. We conducted an inductive content analysis based on in-depth semi-structured interviews with open-ended questions. **Results:** Receivers reported that doctors and family members influenced their decision-making. Decliners perceived their doctors as supportive of their decisions and reported that the experience of adjuvant therapy of family and friends, the

results of Oncotest, and concerns about side effects influenced their decision-making. Receivers expressed discomfort about their decisions, relied on books, whereas decliners used various sources to find information. Both receivers and decliners believed that they had made the decisions themselves. However, receivers were somewhat negative about doctors' advice. Receivers also reported that, sometimes, the decision-making process was lacking and reported discomfort with the treatment process. **Conclusions:** Women with breast cancer need support in understanding the care they are prescribed and getting essential care.

Key words: Adjuvant chemoradiotherapy, breast cancer, decision-making, therapy, treatment

Introduction

In the United States, more than 3.5 million women have breast cancer.^[1] Among these women, approximately 6%–13.8% willingly declined recommended chemotherapy;^[2-4] 9% declined radiotherapy,^[5] and 14% declined hormone therapy.^[6] The increase of approximately 281,550 newly diagnosed breast cancer cases in the United States during 2021^[1] is alarming.

Previous studies^[3,4,7] found that women received or declined the recommended treatments for clinical reasons. On the one hand, the motives for receiving chemotherapy or radiotherapy among people with cancer include trusting their conventional oncologist and perceiving chemotherapy as a beneficial treatment for a prolonged life. Comorbidity or potential side effects were not major factors that influenced

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the decisions.^[7,8] On the other hand, people who declined adjuvant treatments were more likely to perceive their conventional oncologist as uncaring, insensitive, and unnecessarily harsh.^[9,10]

In addition to clinical factors, other factors related to receiving or declining treatments include people's evaluation of the treatment burden (e.g., length of the treatment and hospital stay, invasiveness of the intervention, extent of testing, comorbidity, and side effects) and treatment outcomes (e.g., quality of life and rate of survival with and without treatment have been reported to be predictors).^[7-9,11,12] People's decisions about treatment were also influenced by other people's experiences, involvement of family members, and information received.^[7,8] Use of complementary and integrative medicine (CIM) among women with breast cancer has also been related to declining recommended treatments.^[4,7,10,13,14]

Despite the previous studies that have examined factors related to receiving or declining recommended treatment, not much is known about *how* these women arrived at their respective decisions and *whether* they were passively or actively involved in making their own decisions. By analyzing in-depth personal interviews with women diagnosed with breast cancer, this study aimed to explore differences in adjuvant cancer treatment decision processes between women who received all recommended breast cancer treatment (hereinafter receivers) and those who did not (hereinafter decliners).

Methods

Data and study sample

The data for the current study were gathered from March 2018 to August 2018 in the greater Seattle area. Seven women (four receivers and three decliners) were recruited from the participants of the Breast Cancer Integrative Oncology Study. A total of 585 women were originally recruited through integrative oncology clinics (integrative oncology cohort) and the Cancer Surveillance System (CSS) registry in Western Washington State (usual cohort). The inclusion criteria of the original study were: (1) being 18 years of age or older and (2) a diagnosis of breast cancer or ductal carcinoma *in situ* verified by biopsy pathology. Three of the women who were interviewed came from the integrative oncology cohort of the study and sought care from an integrative oncology physician within 2 years of initial diagnosis. The other four women who were interviewed came from the usual cohort of the study group who were recruited from the CSS registry. Standish *et al.*^[15] discuss the recruitment procedures in detail.

Among the 585 women, 427 (379 receivers and 48 decliners) had medical records that clearly indicated

that they had received surgery and had received at least one recommendation for adjuvant treatments (i.e., chemotherapy, radiotherapy, or hormone therapy) from their doctors and were receiving or declining that treatment.^[16] Among the 427 women, 24, including women from both the integrative naturopathic oncology and usual care cohorts who were receivers and decliners of adjuvant therapy, were contacted by mail. The inclusion criteria of the current study were (1) women who gave permission to be contacted for future studies, (2) women who were at Stage 2 or 3 at diagnosis, and (3) women who were either receivers or decliners. The recruitment letter included a return postcard so that the women could mark "yes" or "no" for an interview.

Among 24 women, seven marked "yes" for an interview, two marked "no" for an interview, 11 did not respond, and four letters were returned. Written consent forms were obtained from the seven women who marked "yes" for the interview. The first author visited the women at their home or office for the face-to-face interview using the measures described below, which took 45 min to 2 h. Each interview was audiotaped and transcribed, and the accuracy of transcription was checked by listening to the interviews and reading the transcript before data analysis.

Measures

During the interview, all participants provided their demographic characteristics and clinical characteristics. To assess the level of involvement in treatment decision-making, the Involvement in Treatment Decision-Making questionnaire had two questions.^[17] This questionnaire is a self-report measurement that assesses participants' perceived *Level of Involvement* and *Participation Congruence* in making cancer treatment decisions.^[17] The original questionnaire includes six "Level of Involvement" items regarding participants' perceived level of involvement in making decisions about their overall cancer treatment and specific treatment including surgery, chemotherapy/radiotherapy, additional tests, complementary treatments, and lifestyle changes (e.g., How much do you feel you were involved in making a decision about your treatment overall?). Responses to the level of involvement items are rated on a three-point Likert-type scale and the scores range from 0 "much less involved;" 1 "a fair bit;" 2 "very involved;" and 9 "not applicable." Two "Participation Congruence" items ask about the correspondence between preferred and actual involvement in overall and conventional treatment decision-making (e.g., Would you have preferred to be more or less involved in making decisions about your conventional treatment for cancer?). Responses to the Participation Congruence items are rated on a five-point Likert-type scale with scores ranging from

1 “much less involved” to 5 “much more involved.” In this study, the following two questions were used:

- How much do you feel you were involved in making decisions about your treatment overall? (Answer choices: not involved at all – others made a decision for you; a fair bit; very involved; not applicable – in my case, there were few or no decisions to be made by me or my doctor)
- Would you have preferred to be involved in making decisions about your treatment? (Answer choices: much less involved; less involved; fairly involved; more involved; much more involved).

In-depth interviews, which were audiotaped and transcribed for data analysis, were conducted by the first author using the following open-ended questions:

- Which treatments did you receive/decline?
- What factors did you consider when you made your treatment decisions?
- Who made the final decisions?
- How did you feel while you made treatment decisions?

Statistical analysis

ATLAS.ti 8.4 was used to conduct an inductive content analysis to extract content-related common themes that share the same meaning.^[18] Following Weber’s suggestion,^[19] two authors independently read the transcripts several times to gain a broad understanding of the text, highlighted key quotations and identified key codes related to each research question. As the author carefully read the coded quotations from all participants, major themes were identified by putting common key-coded quotations together. After another author felt that she had identified the major themes, the two authors met and reviewed the major themes together and engaged in active dialog to resolve any discrepancies. After extensive discussions, both authors agreed on the themes. Finally, the authors read the interview transcripts again to validate the themes.

Ethical approval

The Institutional Human Subjects Review Committee of the Bastyr University and Fred Hutchinson Cancer Research Center approved the original study and written consent was obtained from each subject before participation (Approval No. 00001798). For the current study, the committees from Bastyr University, Fred Hutchinson Cancer Research Center, and the University of Washington have approved that women, who have given permission, may be contacted for future studies.

Results

Characteristics of study participants

Tables 1 and 2 present the demographics, clinical characteristics, level of involvement in treatment

decision-making, and the use of CIM by receivers [Table 1] and decliners [Table 2]. All participants were Caucasian women between 47 and 70 years old with some college education or beyond. All participants used some type of CIM.

I made all decisions myself

All participants stated that they were very involved in their treatment decision-making and perceived their involvement as fair. All women had surgery after being diagnosed with breast cancer. Both receivers and decliners reported that having surgery was an easy decision. They all underwent surgery for the same reason, which was summarized by one of the participants as “to take the tumor out.” Both receivers and decliners responded that they had made the final decision about receiving or declining adjuvant cancer treatment for themselves; they perceived that their level of involvement was fair.

Reasons for receiving adjuvant treatments

Following doctor’s recommendations

Although all participants indicated that they had made the final decision themselves, all four receivers followed the recommendations of their doctors who were considered as experts. Two receivers reported that they “just followed” the doctor’s recommendations. For example, one receiver said, “*I didn’t really think – I just did what I was supposed to do. I didn’t think a lot about it. I would just go and do it.*” Another participant also did not want to find out more about cancer treatment and indicated that she just followed her doctor’s recommendation. “*I said, “Do it.” She [the doctor] said, “Don’t you want to read up on it?” “Nope. No, I don’t care. Just do it.”* Another participant said that the main reason for her receiving the full treatment was that her husband strongly wanted her to listen to her doctor’s recommendation. She described that her decision to have chemotherapy was hard because she got so much pressure from her “family (husband and parents) and society.” She felt that the “proactive process” of decision-making was lacking in her case:

And then... so... when you, you know, you didn’t want to get chemo but while your, you know, oncologist was pushing and then your family wanted to get treatment, how do you decide? You know, finally you decide to get chemo, but what was the process?

In fact, this participant believed that she was “cancer free” after removing the tumor and positive nodes. Therefore, she wanted to postpone it to do more research on her own about alternative treatment. However, her doctor pushed her to get chemotherapy right away. She said, “...

Table 1: Characteristics of receivers

Characteristics				
Demographic characteristics				
Age (years)	55	49	73	47
Education	Graduated college or beyond	Some college	Graduated college or beyond	Some college
Race/ethnicity	White Caucasian	White Caucasian	White Caucasian	White Caucasian
Marital status	Married	Married	Domestic partnership	Married
Employed	Yes	Yes	Retired	Yes
Household income	>\$100k	>\$100k	<\$25,000	>\$100k
Clinical characteristics				
Age at diagnosis (years)	47	42	67	42
Stage	2	3	3	3
Side	Left	Right	Right	Left
Estrogen receptor	Positive	Positive	Positive	Negative
HER2	Positive	Negative	Positive	Positive
Surgery	Yes	Yes	Yes	Yes
Chemo	Yes	Yes	Yes	Yes
Radiation	Yes	Yes	Yes	Yes
Hormone	Yes	Yes	Yes	Yes
Recurrence	No	Yes - bones	Yes	Yes - brain
CIM use				
CIM types	Massage Dietary supplement	Naturopathy Chiropractic Acupuncture Dietary supplement	Acupuncture Meditation Dietary supplement	Naturopathy Dietary supplement

CIM: Complementary and integrative medicine; HER2: Human epidermal growth factor receptor 2

Table 2: Characteristics of decliners

Characteristics			
Demographic characteristics			
Age (years)	55	70	63
Education	Graduated college or beyond	Graduated college or beyond	Graduated college or beyond
Race/ethnicity	White Caucasian	White Caucasian	White Caucasian
Marital status	Married	Divorced	Married
Employed	Yes	Yes	Retired
Household income	>\$100k	\$25,000-50,000	\$50,000-100,000
Clinical characteristics			
Age at diagnosis	47	65	57
Stage	2	3	3
Side	Left	Right	Right
Estrogen receptor	Positive	Positive	Positive
HER2	Negative	Negative	Negative
Surgery	Yes	Yes	Yes
Chemo	No	No	No
Radiation	Yes	No	No
Hormone	Yes	Yes	No
Recurrence	No	No	No
CIM use			
CIM types	Dietary supplement	Naturopathy Massage Chiropractic Acupuncture Dietary supplement	Naturopathy Massage Dietary supplement

CIM: Complementary and integrative medicine; HER2: Human epidermal growth factor receptor 2

they just wanted to overtreat me, and I just left there feeling, like, way worse.” Consequently, she doubted if she would make the same decision if she had to decide again.

Statistical analysis

One receiver reported that a high chance of recurrence impacted her decision to follow the full treatment:

Well, and that's another reason I had a hard time deciding to do it is because the number she gave me, about it coming back, that even if I go through chemo, the chance of it coming back was still, like, 40%.

Reasons for declining adjuvant treatments

Chemotherapy

Decliners had different reasons for undergoing specific adjuvant treatments after surgery. Two of the three decliners reported that their decision for declining chemotherapy was influenced by having a sister or a friend who had breast cancer and who received the full treatment. For example, one decliner said, *"The reason I declined; so my sister got breast cancer 3 years before me and she went through chemo. Chemo's really nasty."* Another decliner said, *"It's also very dangerous. For the nurses that deliver the chemo, they end up with higher rates of cancer because of their exposure to the drug. I really didn't want chemo at all."*

Radiotherapy

One participant declined radiation because she felt that the treatment was not individualized for each patient, saying, *"I found out there were not any variables. It didn't matter what your skin tone was, how big you are, or whatever."* The other participant who refused radiation mentioned that she was worried about the potential side effects of having radiation around her heart area.

Hormone therapy

One decliner said she did not receive hormone therapy despite her doctor's recommendation because she had two friends who had taken it and were very uncomfortable with the treatments' side effects on their joints.

Patient–doctor relationships in decision-making

One receiver perceived that her doctor is the expert, which ultimately led her to follow the doctor's recommendations. While this participant performed "the best student" role to follow her doctor's "straightforward, long, and aggressive plan," another participant complained about her oncologist being too pushy, saying, *"Well, my oncologist was really pushing it. She was really pushing a lot of drugs."* She perceived that her doctor did not really care about her as a patient, which resulted in her being "overtreated." The third receiver was satisfied with her doctor, while the fourth receiver pointed out how disappointed she was with her doctor's attitude toward her treatment:

At first the doctor, my oncologist... I felt very important and special and like, she was taking care of me and everything, and then she started to lose interest because something else bigger and better came along, or something and I was getting forgotten, and I wasn't getting in for the tests I needed, and I just felt like I wasn't a priority anymore.

In contrast, two out of three decliners indicated that their doctors spent time on their cases, provided all the necessary information, and were very supportive of their decisions on whether to receive all cancer treatments or not. One participant said:

She was wonderful. She spent, like, 45 min talking with me and so she gave me a lot of information and that's what I wanted, and so I took someone with me to take notes so I was very clear about the decision.

Most decliners indicated that their doctors were not "pushy," which allowed them to read and conduct their own research on side effects of adjuvant treatments. One said that she was grateful that she could trust her doctor because her doctor did not "push" her either way.

Sources of information in making treatment decisions

Receivers and decliners used different sources to search for cancer treatment information. Overall, receivers heavily relied on books as their main source of information for cancer treatment. They commented that there was a "definitive book about breast cancer" that captures balancing hormones and alternative cancer treatments. One receiver described it as follows:

Well, the first thing a girlfriend of mine and I did was go out and buy the latest edition of Christiane Northrup—is that her name?—the breast book. Do you know it? It's sort of the definitive book about breast cancer. It talks about different kinds of cancer: positive estrogen, negative estrogen, treatments, and different kinds of chemo. So, it really spells the whole thing out.

One receiver raised concerns about the reliability of cancer treatment information on the Internet: "... of course you get on the Internet and that is awful." Other receivers raised concerns about using the Internet as a source of information. There was a receiver whose oncologists told her to "stay off the Internet." Another woman said:

I went to the library and got a bunch of books and started reading them and said, "There's so much information you get on the Internet and you're up until 3:00 in the morning and you're reading stuff, and you're, like, "Don't do it."

In contrast, decliners more actively searched for information from various sources, mostly from the Internet and materials provided by doctors. One participant even attended a cancer conference to find the most current information available.

Emotional aspects of making treatment decisions

At the time of diagnosis of breast cancer, both receivers and decliners felt fear, shock, confusion, and panic, which were difficult emotions to experience. Yet, they showed different types of emotions regarding their decision-making

on cancer treatment. Most receivers expressed negative emotions while making their decisions. One receiver said, “I was so shocked and so uncomfortable with everything that I was – I was uncomfortable with making the decision.” Another receiver expressed her emotion about the treatment (i.e., Gamma Knife due to metastasis to the brain) schedule: “I was mad. I was mad, I was hurt, I was scared. I thought I was important. I thought they wanted me to live, and now they wanted me to wait 2 months.”

Overall, decliners were satisfied with not receiving any cancer treatment. They all expressed contentment with their decisions. One said, “Nothing would’ve helped me to receive it all and I wouldn’t have wanted to. I’m happy with my choices.” One decliner said that a diagnosis of cancer itself was frightening, but she felt more frightened when she thought about the side effects of chemo and radiation:

The diagnosis of cancer is very frightening because there’s indefinite, unclear kinds of cures, and no cures, so I think emotionally it was very difficult to go through that, but then I also wanted to have a lot of choices about what I did postsurgery because the side effects of chemotherapy and of radiation are very intense so that scared me I think more than the surgery. It was more frightening.

Discussion

The current study contributes to the limited amount of research conducted to explore decision-making among women with breast cancer who were recommended to receive conventional adjuvant treatments after surgery. In addition to the factors related to treatment decisions, this study examined whether they were allowed to freely make their own choices about adjuvant treatments.

Both receivers and decliners perceived that they were involved, that they made all final treatment decisions by themselves, and that their involvement was adequate. This is important since studies have found that involvement in treatment decision-making has been related to the quality of life among women with breast cancer.^[17] It was also found that participating more or less than preferred has been related to decisional regret.^[20]

However, in this study, receivers’ decisions seemed to be somewhat contradictory to what they perceived their involvement in treatment decision-making should be. Their decisions turned out to be heavily influenced by pressure from their doctors and family members. Some indicated that they just followed the doctors’ recommendations, and some were uncomfortable making decisions that contradicted their physicians’ advice. Some felt that they had received aggressive treatment or were overtreated. These findings are similar to recent findings that cancer patients mainly decide on chemotherapy or radiotherapy based on their

trust in oncologists and systemic adjuvant treatments as a means to prolong their lives.^[8,21] Otherwise, they referred to excessive diagnosis and treatment of breast cancer.^[22] Approximately 18% of women in the United States have referred to overtreatment of breast cancer.^[23]

Compared to receivers, different reasons were underlying the decisions of decliners. They described concerns about the side effects of treatment, having observed the struggle of their family, and friends receiving chemotherapy or hormone therapy, and one woman relied on the results of the Oncotest. Decliners were happy not to receive any cancer treatment and feared the side effects of chemotherapy and radiation. These findings are similar to previous findings that the most frequent motivations for or against therapy included the wish to survive or avoid recurrence, clinician’s recommendation, side effects, and treatment duration.^[7,9]

The current study highlights the differences in doctor–patient relationships. Receivers perceived that their doctors were definitive and pushy, whereas decliners indicated that their doctors spent time providing all the needed information, although they actively searched for further information themselves using various sources. They were allowed to conduct their own research on side effects of adjuvant treatments and their doctors were supportive of their decisions not to receive any cancer treatments. This finding is different from previous findings that people who decline adjuvant treatments were more likely to perceive their oncologist as insensitive and unnecessarily harsh.^[9,10] This discrepancy may be related to the recent movement to make the integration of supplemental medicine services more accessible to patients.^[24]

The findings of this study are similar to those of a previous study,^[25] which suggested five empirical indicators of treatment decision-making among women with breast cancer: (1) perceived salience of alternatives, (2) decision conflicts, (3) information seeking, (4) risk awareness, and (5) deliberation. Applying these five indicators, receivers, and decliners in this study did not differ much on the first (perceived salience of alternatives) and the final indicators (deliberation); every woman in this study used some sort of CIM such as dietary supplements, naturopathic doctor, chiropractic, acupuncture, and massage, and all made their own final decisions. However, they differed on decision conflict, information seeking, and risk awareness. Decliners had less decision conflict and more support from their doctors and family members. They more actively sought cancer treatment information by themselves using various information sources including books, Internet websites, and even conferences. They were more aware of the risk of receiving adjuvant cancer treatment based on their indirect experience

through family and friends who had already undergone the treatment. Thus, although they made all decisions themselves, their complicated decision-making processes need to be thoroughly understood.

Limitations

The primary limitation of this study is that the sample was small and all participants were White American women who had some college education or beyond. The study was conducted over 6 months and was limited to women in a large American city. This study has strengths as well, including the similarities among women diagnosed with breast cancer, as analyzed through in-depth personal interviews. In future, repeating the study with more women with diverse ethnic and cultural backgrounds will be important.

Conclusions

The analysis of in-depth personal interview data indicates that receivers and decliners differed on decision-making processes, information sources, relationship with doctors, and emotions about their decisions. We hope that health-care providers can use these findings to understand why some women decline adjuvant breast cancer treatment. Receiving good education, observing the difficulty of receiving chemotherapy, and having doctors who were not “pushy” may be the reasons why some women decline adjuvant breast cancer treatment. Supporting and guiding women during the process of making difficult treatment decisions is vitally important because they are agents in their care by making choices that influence their disease prognosis. In addition, it is important to examine what decliners do to manage their cancer. Finally, survival, recurrences, hospitalizations, adverse effects, and complications in each group of patients need to be compared.

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Conflicts of interest

There are no conflicts of interest.

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