RESEARCH ARTICLE

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Time-Related Characteristics of Medical and Psychosocial Decisions in Japanese Women with Breast Cancer: Results of a Web-Based Open-Ended Response

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Abstract

Background: This study aimed to articulate chronological characteristics of decisions made by Japanese women with breast cancer (BC) since their diagnosis. **Methods:** Open-ended questions were asked using an Internet-based cross-sectional survey method. Qualitative content analysis was performed on 1,158 free descriptive responses obtained from 549 participants, which were categorized according to the content of decisions. Furthermore, 994 text data from 433 respondents to the quantitative questions were categorized according to the decisions' timing and examined in relation to medical and sociodemographic factors. **Results:** Whereas more than 60% of medical decisions, except chemotherapy, were made before initial treatment, approximately more than one-third of sociopsychological decisions were made only after the initial treatment. In decisions regarding medical care, only surgical decisions showed an association between timing and the participants' decision-making style. Meanwhile, in decisions regarding sociopsychological matters, socioeconomic status at the time of diagnosis, such as marital and employment status, along with the perceived importance of what was to be determined, were associated with the timing of decision-making related to employment, attitudes toward life with BC, family matters and financial affairs. **Conclusion:** Women make various decisions depending on the amount of time since the diagnosis of BC. Generally, medical decisions are made prior to initial treatment, while these temporal characteristics are not observed for decisions relating to sociopsychological matters. Furthermore, socioeconomic status influences the timing of decision-making regarding sociopsychological matters. This finding can illustrate the manner in which to go through life with BC, and thus, help women who are unexpectedly diagnosed with BC to be more prepared.

Keywords: Breast cancer- decision-making- Japan

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Introduction

Cancer has been the leading cause of death in Japan for over 40 years. Based on the 2018 cancer incidence data, 50.2% of Japanese women will be diagnosed with cancer throughout their lifetime, and 10.9% will be diagnosed with breast cancer (BC), the most common type of cancer (Japan TEBotCSi, 2022). In response to this situation, the Japanese government implemented cancer control measures according to the Phase 3 Basic Plan to Promote Cancer Control Programs, implemented by the Cabinet in March 2018 (Japan TEBotCSi, 2022). The three areas of this control program are "prevention," "improvement of cancer care," and "coexistence with cancer." In the process of coexisting with BC, women often have to make many decisions regarding their medical and psychosocial matters. Prior studies have investigated the role of Japanese women with BC in making decisions regarding their overall medical treatment and pharmacotherapy (Nakashima et al., 2012; Shimizu et al., 2019; Japan TEBotCSi, 2022). Social difficulties and decisions related to these difficulties, including reproductive function, informing their children about their illness, whether to resign from their jobs, body image, and sexual function, have suggested that Japanese cancer patients have to make several types of psychosocial decisions after being diagnosed (Adachi et al., 2007; Yoshida et al., 2010; Saito et al., 2014; Hisamura et al., 2018; Furui et al., 2019a; Furui et al., 2019b). We previously showed that one-third of Japanese women with BC who participated in an Internet survey had to make both medical and psychosocial decisions (Yamauchi et al., 2021). Women with BC, especially younger survivors, need age-appropriate information or help (Thewes et al., 2004; Bu et al., 2022), and their needs may vary over a prolonged period following diagnosis (Akechi et al., 2015; Lu et al., 2020). However, to our knowledge, few studies have explored the temporal changes in the needs of

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women with BC, and furthermore, no consensus has been reached regarding the same. Hence, this study articulated the chronological characteristics of decisions made by Japanese women with BC since their diagnosis.

Materials and Methods

In this study, data from a previous study that conducted a cross-sectional anonymous Internet survey using a convenience sample of Japanese female BC survivors registered with an online marketing research company (Rakuten Insight Inc. Osaka, Japan) were analyzed. Details of this Internet survey described in a previously published article and are reviewed herein (Yamauchi et al., 2021). For the current study, first, 1,158 free descriptive responses from 549 participants were analyzed and categorized according to the content of their decisions.

Of the 1,158 text data, 994 were responses to quantitative questions from 433 participants, and these were analyzed in this study.

Measurements

Sociodemographic and clinical characteristics

The sociodemographic variables included age, marital status, final education level, household income, and parental status at diagnosis. The clinical variables included family history of BC, BC stage primarily diagnosed, surgery they had received as BC treatment, presence of recurrence/metastasis of BC, and whether survivors had received radiation, chemotherapy, or hormone therapy.

Perceived decisions

The participants were asked to recount their decisions after being diagnosed with BC through the following survey item: “From the time you were diagnosed with breast cancer to the present, please list up to three decisions that you have made because of your diagnosis and that have remained in your mind, regardless of whether or not they were directly related to your treatment.”

Timing of decisions

The participants were asked to choose one of three timings in relation to each decision they made: 1) between their diagnosis and the start of their initial treatment, 2) within one year of the start of their initial treatment, and 3) more than one year after their diagnosis. As the number of decisions made more than 12 months after diagnosis was small, timings 2) and 3) were combined for analysis as “after the initial treatment.”

Decision style

The style adopted for each decision was elicited based on the final decision-maker being mentioned. The styles included: [active], “myself”; [collaborative], “me and my physician together” or “me and my family together”; and [passive], “physician” or “my family.”

Importance of the decision

The degree of importance of each participant’s decision was assessed. Participants rated each decision they made on a numerical rating scale from not important at all (0) to very important (10). The variable was dichotomized based on its importance (very important vs. not very important).

Analysis

For decisions with a frequency of 40 or more, Chi-squared tests were performed to examine any associations between the timing of the decision and participants’ characteristics (sociodemographic and clinical characteristics, decision style, and perceived importance of the decision). Statistical analyses were performed using SPSS Version 24 (IBM Corp., Armonk, NY, USA).

Results

Participants’ characteristics

In terms of socioeconomic status, the study’s participants tended to be married (72%), have children (63%), have a job (59%), be educated beyond high school (72%), and have a household income of less than 5 million yen (59%) (Table 1). In terms of clinical background, they tended to be 40 years or older with a diagnosis of BC (80%), diagnosed with BC at stage II or less (77%), have no family history of BC (74%), had no recurrence or metastasis of BC (86%), received radiation (55%) and/or hormone therapy (71%), and did not receive chemotherapy (57%).

Timing of decisions made

The participants made decisions regarding medical care and sociopsychological matters following their BC diagnosis (Table 2). Irrespective of whether the decisions involved treatment selection, 63–90% of the medical decisions unrelated to chemotherapy were made before the initial treatment. Among pre-treatment decisions, decisions on the type of surgery, timing of surgery and inclusion of reconstructive surgery had the highest frequencies (n=119). One-third of women made these decisions. Among the decisions made after the initial treatment began, the number of decisions related to chemotherapy (n=28) was the highest. Of these, approximately 30% were decisions to discontinue or not undergo chemotherapy. It is noteworthy, subsequent to being diagnosed with BC, 11 women decided on whether to undergo an examination that included genetic testing, which is not covered by Japan’s universal health insurance.

Similar to the decisions regarding medical care, more than two-thirds of the decisions regarding family (86%) and financial matters (71%), informing others of their BC (72%), obtaining information (77%), and seeking help (67%) were made before the initial treatment began. Following their diagnosis, 163 women made attitude-related decisions. More than 80% of their attitudes toward BC or BC treatment were determined before the start of the initial treatment, whereas the attitudes of more than half of them regarding living with BC were formed after commencement of their treatment. Approximately 60% of the decisions involving a lifestyle change were made after their treatment began, one-third of which were to change eating habits (n=14). Only three participants mentioned changes related to exercise. Three women quit smoking

Table 1. Characteristics of the Study Participants (n=433)

Characteristics	(n, %)	
Age at diagnosis (in years)		
≤ 39	85	(19.6)
40–49	198	(45.7)
≥ 50	150	(34.6)
Marital status at diagnosis		
Single	108	(24.9)
Married	396	(71.7)
Other	19	(4.4)
Education		
≤ High school	120	(27.7)
> High school	313	(72.3)
Household income at diagnosis		
< ¥5,000.000	211	(58.7)
≥ ¥5,000.000	222	(41.3)
Employment status at diagnosis		
Regular employment	116	(26.8)
Other than regular employment	139	(32.1)
Other	178	(41.1)
Child at diagnosis		
No child	162	(37.4)
With a child (or children)	271	(62.6)
Family history of breast cancer		
No	320	(73.9)
Yes	113	(26.1)
BC stage		
0	70	(16.2)
I	149	(34.4)
II	116	(26.8)
≥ III	52	(12.0)
Other (do not remember, etc.)	46	(10.6)
Surgery		
Total mastectomy	192	(44.3)
Breast conserving surgery	205	(47.3)
Other	36	(8.3)
Recurrence/metastasis of BC		
No	371	(85.7)
Yes	62	(14.3)
Radiation therapy		
No	197	(45.5)
Yes	236	(54.5)
Chemotherapy		
No	247	(57.0)
Yes	186	(43.0)
Hormone therapy		
No	125	(28.9)
Yes	308	(71.1)

between their diagnosis and commencement of initial treatment. Some women prepared for matters after their death before the treatment in case the treatment did not work, and after the treatment in case the cancer returned.

Association between timing of decisions and characteristics of participants

Statistically significant associations between decision timing and participant characteristics are presented in Table 3. Women who made a surgical decision after the initial treatment began, tended to perceive themselves as final decision-makers. Single women were more likely to make decisions regarding employment before their initial treatment and to form an attitude toward life with BC after the commencement of treatment; married women did not exhibit this trend. Women who placed less emphasis on their attitude toward life with BC tended to form such an attitude after the start of the initial treatment, while this was not the case for women who considered it to be crucial. Contrastingly, those who placed great importance on financial matters tended to make related decisions before the treatment, while this was not the case for women who attached less importance to financial matters. This result indicates that a participant's employment status at diagnosis may have affected the timing of decisions on family matters. The percentage of respondents who had decided, after the start of the initial treatment, how they would care for children and/or older parents and whom they would ask to take care of them, appeared to be higher among those who had a job, irrespective of whether they represented regular employment.

Discussion

The information that women with BC seek depends on the time since their diagnosis (Lu et al., 2020). This suggests that they have to make various decisions at different stages of their BC journey. Therefore, the present study analyzed Japanese women's opinions using open-ended questions to articulate the chronological characteristics of decisions about BC since diagnosis. Among the decisions that women have to make post their BC diagnosis, it was noted that medical decisions tended to be made prior to the initial treatment, while it was not the case with sociopsychological matters. It was found that socioeconomic status at diagnosis, such as marital and employment status, and whether a decision on the matters was seen as important may influence the timing of non-medical decisions.

According to the results of previously published questionnaire surveys in Asia and the West, the most common unmet needs for women with BC were in the psychological domain, and the most common item was related to fear of cancer metastasis or recurrence (Akechi et al., 2011; Akechi et al., 2015; Brennan et al., 2016; Edib et al., 2016; Ellegaard et al., 2017; Chae et al., 2019; Vuksanovic et al., 2021; Bu et al., 2022). This raises the question of how and when women decide to confront cancer recurrence. In the current study, the women stated the following about their decisions made at or just after their diagnosis: "I decided to learn about BC and choose my own treatment," "I decided to consult with the doctors until I was satisfied," and "Cancer is a long-term disease, so I decided to choose a treatment that made

Table 2. Decisions Made by Women with BC Following Diagnosis by Timing after Diagnosis (n=365)

Categories of decisions	Total n	Between diagnosis and start of initial treatment n (%)	Within one year from the start of initial treatment n (%)	More than one year after diagnosis n (%)
I. Decisions regarding medical care				
1. BC treatments	273	189 (69.2)	66 (24.2)	18 (6.6)
1-a. Surgery (including reconstructive surgery)	143	119 (83.2)	14 (9.8)	10 (7.0)
1-b. Reconstructive surgery	51	32 (62.7)	12 (23.5)	7 (13.7)
1-c. Chemotherapy	49	21 (42.9)	26 (53.1)	2 (4.1)
2. Medical care other than treatments	92	76 (82.6)	15 (16.3)	1 (1.1)
II. Decisions regarding sociopsychological matters				
3. Mindset	163	85 (52.1)	62 (38.0)	16 (9.8)
3-a. Attitude toward life with BC	123	52 (42.3)	58 (46.3)	14 (11.4)
3-b. Attitude toward BC and/or BC treatment	40	33 (82.5)	5 (12.5)	2 (5.0)
4. Employment	132	83 (62.9)	42 (31.8)	7 (5.3)
5. Family matters	120	103 (85.8)	16 (13.3)	1 (0.8)
6. Financial matters	75	53 (70.7)	20 (26.7)	2 (2.7)
7. Lifestyle modification	44	18 (40.9)	20 (45.5)	6 (13.6)
8. Informing others about BC	25	18 (72.0)	6 (24.0)	1 (4.0)
9. Pregnancy/childbirth	14	7 (50.0)	7 (50.0)	0 (0.0)
10. Preparing for one's death	24	13 (54.2)	8 (33.3)	3 (12.5)
11. Appearance	13	7 (53.8)	5 (38.5)	1 (7.7)
12. Obtaining information	13	10 (76.9)	3 (23.1)	0 (0.0)
13. Marriage/divorce	7	3 (42.9)	2 (28.6)	2 (28.6)
14. Seeking help	6	4 (66.7)	2 (33.3)	0 (0.0)

sense to me," indicating that women decided to choose the treatment they would receive rather than to prepare for a recurrence. Before the initial treatment started, they prepared themselves psychologically for the BC treatment they would receive: "I was prepared to accept any treatment recommended by the doctor," "I decided to receive treatment as a [means to attain] complete cure," and "I decided to be proactive in receiving treatment." After the initial treatment started, the number of women who had determined attitude toward BC or BC treatment, decreased. However, some women decided to prepare themselves in case the treatment failed: "I will not have any treatment if I have cancer recurrence" and "Even if I have metastasis or recurrence, I will not be pessimistic about undergoing treatment." Furthermore, 24 women took time to prepare themselves for matters after their death if the treatment failed or if the cancer recurred after treatment. In the present results, the support needs for fear of cancer recurrence were not always high, which seems to be inconsistent with prior studies. However, only a few longitudinal studies have been conducted in this field, and a consensus about the chronological characteristics of decision-making has not yet been reached. For example, prior studies found that Taiwanese women's greatest needs from diagnosis to three months later were information about whether their cancer was under control or diminished (Liao et al., 2012). Contrastingly, the most frequent unmet need immediately after treatment and at six months after treatment for patients with various types of cancer in England was fear of recurrence (Armes et al., 2009). The results of the above-mentioned prior studies and those of the present one suggest that the psychological needs of BC patients may depend on the timing after diagnosis, and support for fear of cancer recurrence and metastasis may be more efficient if it is received a few months after diagnosis. Additionally, we found that women in the current study had determined their attitudes about living as BC survivors: "Life is limited, so I should make the most of the present," "I decided to keep a smile on my face and cry with my heart especially in front of children," and "I put myself first. I decided to do what I want to do, and if I do not like something, including relationships, I will say no." Women who were single and did not think it was important to prepare themselves for living with BC, were more likely to make decisions about how to live as BC survivors after the start of initial treatment. Among the participants, 14 made this decision more than one year after diagnosis. Similarly, in a previous study, the psychological needs of Japanese women with BC remained for longer than one year, although they were significantly less than what was found within one year of diagnosis (Akechi et al., 2015). The psychological needs of women diagnosed with BC may change from preparedness for treatment to how to live with it, including the case of recurrence, and could persist for a year or more after diagnosis.

The chronological characteristics of the medical decision shown in this study were that decisions related

Table 3. Frequencies of Decisions Made by Women with BC Following Diagnosis by Timing of Decision Made and Characteristic of Participants.

[Decision] Factor	Total n	Between diagnosis and start of initial treatment n (%)	After the start of initial treatment n (%)	P
[Surgery]				
Decision style				
Active	92	71 (77.2)	21 (22.8)	0.032
Collaborative	46	43 (93.5)	3 (6.5)	
Passive	5	5 (100.0)	0 (0.0)	
	143	119 (83.2)	24 (16.8)	
[Employment]				
Marital status at diagnosis				
Single	50	38 (76.0)	12 (24.0)	0.021
Married	77	41 (53.2)	36 (46.8)	
Other	5	4 (80.0)	1 (20.0)	
	132	83 (62.9)	49 (37.1)	
[Attitude toward life with BC]				
Marital status at diagnosis				
Single	30	9 (30.0)	21 (70.0)	0.032
Married	86	37 (43.0)	49 (57.0)	
Other	7	6 (85.7)	1 (14.3)	
	123	52 (42.3)	71 (57.7)	
Importance of the decision				
Very important	90	46 (51.1)	44 (48.9)	0.001
Not very important	33	6 (18.2)	27 (81.8)	
	123	52 (52.3)	71 (57.7)	
[Family matters]				
Employment status at diagnosis				
Regular employment	22	15 (68.2)	7 (31.8)	0.001
Other than regular employment	35	27 (77.1)	8 (22.9)	
Other	64	61 (96.8)	2 (3.2)	
	120	103 (85.8)	17 (14.2)	
[Financial matters]				
Importance of the decision				
Very important	47	37 (78.7)	10 (21.3)	0.047
Not very important	28	16 (57.1)	12 (42.9)	
	75	53 (70.7)	22 (29.3)	

to chemotherapy continued after the start of the initial treatment. In this study, more than 50% of chemotherapy-related decisions were made after initial treatment started, and approximately 30% of those decisions were to discontinue or refuse chemotherapy. However, only a few studies have focused on the patients' decision to refuse chemotherapy. Interviews of women with BC revealed that they refused to receive chemotherapy because of their acquaintances' or relatives' experience with chemotherapy or the prospected impact of the same and the risk of recurrence, side effects, and reduced QOL; they were satisfied with their decision to refuse chemotherapy (Kim et al., 2021; Karuturi et al., 2022). These studies indicated the factors that influenced the refusal of chemotherapy, but they did not indicate when these women refused chemotherapy. Our study added time-related information to the support for women with BC regarding chemotherapy, which is needed not only after diagnosis but also after the start of initial treatment.

In this study, most of the decisions regarding employment were not about resignation, but about continuing to work, how long to take leave of absence, and when to start work after treatment. Among those who participated, single women were more likely to decide to continue working before starting the initial treatment. This result is inconsistent with those of previously published studies of Japanese cancer patients: a study conducted in 2015 showed that approximately 21% of patients changed employment status after their diagnosis and the female sex and being in non-regular employment were factors associated with job loss (Takahashi et al., 2018; Tsuchiya et al., 2020). The three areas of the Phase 3 Basic Plan to Promote Cancer Control Programs, as implemented in Japan after the 2015 study was conducted, are "prevention," "improvement of cancer care," and "coexistence with cancer". Social problems, including the employment status of cancer patients, comprise one of the measures included in "coexistence with cancer," and there is a possibility that this measure has enabled Japanese women to continue working even once they are diagnosed with BC. In the current study, we did not ask the women why they wanted to continue working. Since medical expenses are a financial burden for women (Martin et al., 2014; Takahashi et al., 2018), further investigation into why women continue to work should be conducted. Furthermore, with regard to decisions about balancing work and medical treatment, women in this study decided how to take care of their children, husbands, or older parents, and whom to ask for help during hospitalization. Participants who had a job tended to make these decisions after the start of the initial treatment, regardless of whether they were in regular employment. Delays in making these decisions may be associated with work-related factors, such as the duration of sick leave. To practice "coexistence with cancer," further study should be thus conducted to clarify the association between issues related to sick leave and family problems.

This study has several limitations. First, it has selection bias because it uses a web-based self-administered survey, and generalization of the findings is not possible. Second, the consequences of the decision were not investigated; therefore, the different levels of importance associated with each decision were not clear. To prioritize the issues that women face when they are diagnosed with BC, the consequences of their decisions should be investigated. Third, multivariate analysis was not performed because of the small sample size. Multivariate analysis in a study with a large sample size is thus necessary to understand the factors that influence decision-making over time.

Author Contribution Statement

KY participated in the study design, coordination of data collection, analysis and interpretation of the data, and drafting of the manuscript. M Nakashima participated in the study design, data analysis and interpretation of the data. M Nakao participated in proofreading the final submission. All authors have reviewed the results and approved the final version of the manuscript.

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Consent for Publication

Not applicable.

Ethical Declaration

This study was approved by the Clinical Ethical Review Board of Kurume University's, School of Medicine (approval number: 13138). Prior to the investigation, participants were provided with explanations via the Internet regarding the purpose and method of the study. They were also given information regarding the handling of the results. The study was conducted upon receiving the participants' signed consent online.

Data Availability

Datasets used and analyzed during the current study are available from the corresponding author upon reasonable request.

Conflict of Interest

The authors declare that they have no competing interests.

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