

Decisional Support throughout the Cancer Journey for Older Women Diagnosed with Early Stage Breast Cancer: A Single Institutional Study

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Abstract To determine if older women with early stage breast cancer have sufficient decisional support during their breast cancer journey, a questionnaire-based study was conducted at the Sunnybrook Odette Cancer Centre, in Toronto, Ontario, Canada. Women with stages I and II breast cancer, ≥ 60 years,

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were contacted upon completion of their adjuvant treatment. A questionnaire was developed based on focus groups, the literature, and consultation with patients and a multidisciplinary team of experts. The questionnaire was divided into six domains as follows: (1) information support surrounding diagnosis, (2) impact of cancer diagnosis on the patient, (3) quality of interaction with healthcare team, (4) decisional support from the healthcare team, (5) additional information needs surrounding treatment decision, and (6) information support during radiation treatment. Ninety-two of 137 patients approached were included in the analysis. Ninety percent were >60 years at the time of diagnosis and 65 % had stage I invasive breast cancer. The majority of women received adequate decisional support during their cancer journey. Approximately 90 % of women indicated that they received a high level of support during their cancer diagnosis. We found no significant differences in overall decisional support based on age at diagnosis, education level, ethnicity, or the presence of co-morbidities. However, participants desired additional educational resources such as a worksheet, consultation summary, or workbook to assist in making a treatment decision. The majority of participants felt that they had sufficient support while making a treatment decision for breast cancer.

Keywords Older Women · Breast Cancer · Treatment Decision · Decisional Support

Introduction

For early breast cancer (stage I or II), breast conserving surgery (lumpectomy) followed by adjuvant radiation therapy (RT) is similar to mastectomy in terms of breast cancer

recurrence rate and overall survival [1]. Despite the fact that breast RT post-lumpectomy reduces the recurrence rate from 9 to 2 % at 10 years, the lack of overall survival benefit, its logistical issues, patients' co-morbidities, and treatment side effects, all of which may impact quality of life should be considered when making treatment decisions [2, 3]. With the evolution of multi-modality breast cancer treatment, physicians must effectively transfer their treatment knowledge to their cancer patients to help them make an informed treatment decision. However, when it comes to the patient–physician interaction, older women often feel that oncologists have limited time to spend addressing their questions and concerns [4]. This has led to a more complex treatment decision process when counseling older women with breast cancer, particularly those who are ≥ 70 years of age regarding adjuvant treatments post lumpectomy.

Decisional support is a multi-faceted process that helps patients prepare for their treatment decisions and discussions with their health care teams. Many forms of decisional support exist, such as audio recordings or written summaries of the patient–physician consultation [5, 6], prompt sheets [7], and patient decision aids to help patients understand the risks and benefits of therapy and to promote more active participation in the decision-making process [8–10]. At the Sunnybrook Odette Cancer Centre (SOCC), Toronto, Ontario, the decisional support process available to patients faced with a decision about post-lumpectomy RT is varied. It is a standard practice that all patients receive a RT information booklet; however, site-specific and treatment-specific decisional support is inconsistent.

Given the variety of decisional support practices at our center, the primary objective of this study was to determine if women, 60 years and older (at the time of interview) with early invasive breast cancer, felt that they had sufficient support while preparing to make a decision for adjuvant breast cancer treatment. Our secondary objective was to determine if the degree of decisional support was correlated with various demographic factors such as age, education level, ethnicity, and co-morbidities.

Methods and Procedures

Questionnaire Development

To assess patients' decisional support throughout the breast cancer journey, a questionnaire was developed using a multi-step process. Initially, a previously conducted needs assessment by our group, which involved a focus group, was used to identify the informational needs of our target population [11]. Additionally, a review of the literature was performed and a multidisciplinary team of experts treating breast cancer was consulted, which included radiation oncologists, medical

oncologists, psychologists, radiation therapists, nurses, and experts in cancer patient education in order to identify factors affecting decisional support among older women. Through this process, a list of questions was developed and reviewed by both patients and health care providers. Based on our prior needs assessment and feedback from health care professionals and patients, the final questionnaire was divided into six domains as follows: (1) information support surrounding diagnosis (6 questions), (2) impact of diagnosis on patients' lives (3 questions), (3) quality of patient interactions with the healthcare team (7 questions), (4) decision support from the healthcare team (14 questions), (5) additional information needs surrounding treatment decision (10 questions), and (6) information support during radiation treatment (6 questions). These questions were rated on a 4-point Likert scale as “1—not at all,” “2—a little,” “3—quite a bit,” or “4—very much,” with a numeric value assigned to each answer option. We also included a question for patients to rate their overall decisional support during their treatment, which was rated on a 5-point scale. The final questionnaire is outlined in Appendix I.

Participants and Procedure

Women 60 years of age or older, post lumpectomy treated for stage I or II, primary invasive breast carcinoma, who spoke and read English and who completed adjuvant treatment within 2 years of interview were eligible. Written consent was obtained from all patients prior to enrollment in the study. Following Research Ethics Board approval, patients were approached for participation in the radiation oncology or medical oncology follow-up clinics once they had completed their adjuvant chemotherapy and/or RT. At the SOCC, it is standard practice for patients to be followed up by their medical and/or radiation oncologist following the completion of their adjuvant treatment, rather than discharging directly to their family physician. This allowed for the recruitment of patients who had completed their adjuvant treatment within the past 2 years. Patients either completed the questionnaire independently, or with help from of a research assistant in the follow-up clinic. Patients were also given the option to take the questionnaire home to complete and return it at their next follow-up appointment or via mail.

Data Analysis

Descriptive statistics were performed for variables of interest. Continuous measures were summarized using means and standard deviations, whereas categorical measures were summarized using frequency counts and percentages. The primary outcome was expressed as a proportion based on patients' overall decisional support rating. Additionally, participant responses were grouped into low (“1—not at all” and “2—a little”) and high (“3—quite a bit” and “4—very much”) response categories, and

proportions were determined for each category. Together, these measures were used to determine the proportion of patients who received sufficient support while preparing to make a decision for adjuvant breast cancer treatment.

To evaluate our secondary outcome, a total score for the questionnaire was created by summing response options on their original numeric scale, and similarly, subsection scores were determined for the six domains of the questionnaire. Cronbach's alpha statistics were performed for both the overall questionnaire and each of the six subsections to assess internal consistency. The mean total score and subsection scores for sections with sufficient internal consistency were correlated with age at diagnosis (<65 vs. ≥65 years), level of education (≤ high school vs. post-secondary), ethnicity (White, non-Hispanic vs. Asian, Hispanic, African American), and presence of co-morbidities using a two-sample two-sided *t* test at the 5 % confidence level. All analyses were performed using SAS Version 9.1 (SAS Institute, Cary, NC, USA).

Results

Internal Consistency

Overall, our questionnaire was found to have a high degree of internal consistency (Table 1). Similarly, domains 1, 3, 4, and 5 displayed sufficient internal consistency; however, domains 2 and 6 were not internally consistent and were not included in the subsection correlations.

Patient Demographics

Patient demographics and characteristics are outlined in Table 2. A total of 137 eligible patients were approached, of whom 97 patients (71 %) consented and completed the questionnaire. Reasons for non-participation included language barriers (*n*=3), memory loss (*n*=1), failure to return questionnaire when taken home (*n*=13), lack of time (*n*=5), lack of interest (*n*=11), and unspecified reasons (*n*=7). Five patients with stage III/IV cancer were excluded from the analysis. Participants were approximately 70 years of age at the time

of interview; the majority was not living alone, and lived greater than 5 km from the cancer treatment center. Approximately half of the participants had completed a post-secondary education or higher, and the majority of participants were white, non-Hispanic women. Nearly all participants received radiation therapy and just over half suffered from additional chronic health conditions, including hypothyroidism, cardiovascular disease, and diabetes.

Decisional Support

Overall, the vast majority of women indicated that they experienced a high level of decisional support during their breast cancer treatment decision-making process. A very small proportion of participants felt that their overall decisional support was inadequate, and the majority indicated that it was excellent (Table 3). Specifically, during their diagnosis, the vast majority of participants felt that they received a high level of support. Only a small proportion of women felt a low level of assistance from their healthcare team in terms of making a decision regarding their adjuvant breast cancer treatment. Furthermore, nearly all patients expressed a high level of comfort voicing their needs or concerns with their healthcare team. Related to their treatment, the majority of participants experienced a high level of improvement in their knowledge after consultation with their health care team, and only a few wanted to ask more questions after leaving their consultation, indicating that the consultation process was adequately addressing most of the patients' information needs. Furthermore, the majority of women expressed a high level of active participation in making their final treatment decision; however, approximately half of participants felt that they were not given choices for different adjuvant treatment options, while some felt that they were unable to make their final treatment decision on their own.

Women also expressed the need for additional information surrounding their radiation treatment decision. Specifically, women valued educational materials such as information sheets, pamphlets, and/or booklets, and as well as being given a chance to ask questions or receiving explanations from their healthcare team. Just over half of the participants expressed a high level of agreement that a worksheet would be beneficial

Table 1 Internal consistency

Questionnaire component	No. of items	Cronbach's α
Overall questionnaire	46	0.89
Domain 1: information support surrounding diagnosis	6	0.73
Domain 2: impact of diagnosis on patients' lives	3	0.60*
Domain 3: quality of patient interactions with the healthcare team	7	0.77
Domain 4: decision support from the healthcare team	14	0.77
Domain 5: additional information needs surrounding treatment decision	10	0.81
Domain 6: information support during radiation treatment	6	0.63*

*Insufficient internal consistency to perform subscale analyses

Table 2 Participant demographics ($N=92$)

	Number (%)
Age at interview (years)	
Mean	68
Range	60–86
Current living arrangement	
Living alone	25 (27.2)
Living with spouse	43 (46.7)
Living with other family members	22 (23.9)
Other	2 (2.2)
Distance from cancer center	
≤5 km	17 (18.5)
>5 km	75 (81.5)
Highest level of education	
High school or less	46 (51.1)
Post-secondary	44 (48.9)
Income	
Less than \$10,000	6 (6.7)
\$10,000–20,999	10 (11.1)
\$21,000–29,999	9 (10.0)
\$30,000–39,999	8 (8.9)
\$40,000 or more	38 (42.2)
Unknown	19 (21.1)
Age at diagnosis (years)	
<65	35 (38.0)
≥65	57 (62.0)
Stage at diagnosis	
Stage I	60 (65.2)
Stage II	32 (34.8)
Ethnicity	
White, non-Hispanic	67 (73.6)
Asian, Hispanic, African American	24 (26.4)
Additional chronic health conditions	
Present	38 (42.7)
Absent	51 (57.3)
Treatment(s) received	
Chemotherapy	22 (23.9)
Hormone therapy	56 (60.9)
Radiation therapy	89 (96.7)

in helping them make a list of questions for the health care team during the treatment decision-making process. The majority of participants felt that a written summary of the points discussed during consultation with their healthcare team would be beneficial. However, approximately half demonstrated a low level of agreement that being provided with a list of useful internet websites would be beneficial. Finally, the vast majority expressed a high level of agreement that a workbook with information tailored to help patients make a treatment decision would be useful.

We correlated the mean total score and total subsection score for each participant with age at diagnosis, education, ethnicity, and the presence of co-morbidities. The mean subsection score for information support surrounding diagnosis ($t(89)=-2.04$, $p=0.04$) and the quality of patients' interaction with the healthcare team ($t(89)=-2.61$, $p=0.01$) were significantly higher for Caucasian participants. Also, those with a post-secondary education or higher had significantly higher mean subsection score for additional information needs surrounding treatment decision-making ($t(88)=-2.40$, $p=0.02$). The remaining subsection analyses did not show any statistically significant differences according to any of the demographic factors.

Discussion

Overall, the majority of women recalled experiencing a high level of decisional support surrounding their decision to undergo adjuvant breast cancer treatment. Age at diagnosis, education level, ethnicity, or the presence of additional chronic health conditions was not associated with the overall perception of decisional support, but well-educated women expressed a greater need for additional information surrounding treatment decision making. Additionally, Asian, African American, and Hispanic women experienced significantly lower informational support during their diagnosis and experienced a lower quality of interaction with their healthcare team during the breast cancer decision-making process. As a result, these women may require additional support during their diagnosis and consultations in order to optimize the treatment decision-making experience. There is a gap in the delivery of treatment information to breast cancer patients from minority groups and ethnic minority women may comprehend this information differently [12]. The feeling of inadequate support during diagnosis and a low-quality interaction with the healthcare team may result from disparities in communication by healthcare workers to patients of different ethnicities. For instance, Gordon et al. found that African American women received less information regarding medical treatments than white women [13]. Ultimately, improved communication, cultural competency, and delivery of culturally and ethnically appropriate information and support by healthcare providers is necessary to reduce disparities in support based on ethnicity [12, 14, 15].

Despite literature describing that some women feel passive when making treatment decisions [4] our study found that nearly three-quarters of older women felt that they actively participated in the treatment decision-making process. Our findings are consistent with Hawley et al. who found that 39 % of breast cancer patients made their surgical treatment decision on their own, and 38 % shared the treatment decision with their surgeon [16]. In addition, compared to younger women, older women were more likely to report active participation by

Table 3 Select participant responses

	“Low” <i>n</i> (%)	“High” <i>n</i> (%)
Domain 1—information support surrounding diagnosis		
6. Did you feel that you received enough support during your diagnosis?	10 (10.9)	82 (89.1)
Domain 3—quality of patient interactions with the healthcare team		
13. Were you comfortable with voicing your needs or concerns to your health care team?	4 (4.4)	87 (95.6)
15. Did you feel that the members of the health care team provided enough support to assist you to make a treatment decision?	10 (11.0)	81 (89.0)
Domain 4—decision support from the healthcare team		
21. Did you feel your knowledge about your illness improved after the consultation?	17 (18.5)	75 (81.5)
23. Did you feel you wanted to ask more questions after leaving the consultation?	79 (85.9)	13 (14.1)
25. Did you actively participate in making your final treatment decision?	34 (26.4)	67 (73.6)
26. Were you given choices for different treatment options?	44 (48.9)	46 (50.1)
27. Were you able to make the final treatment decision yourself?	23 (25.6)	67 (74.4)
Domain 5—additional information needs surrounding treatment decision		
34. To be given a worksheet to make a list of questions to ask the health care team to answer during the meeting?	38 (41.3)	54 (58.7)
35. To be given a written summary of the points discussed with your physicians (surgeon, medical oncologist, radiation oncologist) after the consultation?	32 (35.2)	59 (64.8)
36. To be given a list of useful internet websites?	48 (53.9)	41 (46.1)
37. To be offered a workbook that included treatment information, benefits, and side effects tailored to help guide you towards a treatment decision?	23 (25.6)	67 (74.4)
Overall support		
47. Overall, I would grade my decisional support during my treatment:	Satisfactory <i>n</i> (%)	Excellent <i>n</i> (%)
	26 (28.3)	63 (68.5)
	Unsatisfactory <i>n</i> (%)	Neutral <i>n</i> (%)
	0 (0)	1 (1.1)
	Inadequate <i>n</i> (%)	
	2 (2.2)	

sharing their breast cancer treatment decision with their surgeon, rather than allowing their surgeon to make the treatment decision on their own [16]. Furthermore, although the older women in our study felt that they actively participated, nearly half felt that they were not provided with a choice when it came to different treatment options. This is consistent with qualitative studies, which have shown that older women feel that they are not given a choice during the treatment decision-making process [4, 17]. However, this anomalous finding may be a result of older women feeling that receiving information from their physicians and making a treatment decision in consultation with their oncologist is a form of participation while still feeling that the physician should choose the most appropriate treatment option [18]. Therefore, women can feel both a sense of participation in the treatment decision-making process, while still feeling that they did not have a choice for their ultimate course of treatment.

The majority of women felt that their knowledge improved after consultation with their healthcare team, and only a few wanted to ask more questions after leaving their consultation. Despite subjective reports of increased knowledge, it may be necessary to use assessments of understanding in order to determine if physicians' communication efforts with their patients have been effective [19–22]. Assessments of understanding may be particularly important when the health topic is complicated, such as the case for adjuvant breast cancer treatment [19]. Studies that have evaluated early stage breast cancer patients' knowledge about treatment have revealed low knowledge of survival and recurrence rates for surgical interventions [23, 24]. It may be important to incorporate objective measures of patient knowledge following consultation to ensure that patients have an adequate understanding of their breast cancer treatment options, and are truly making an informed decision about their treatment. The use of a decision aid with assessment questions may be a feasible option to provide patient education about treatment options, and objectively evaluate knowledge following consultation with the healthcare team.

Limitations

Our study has some limitations. We included patients who were less than 60 years of age at the time of diagnosis ($n=9$); however, these patients comprised a small proportion of our study population, and all women who were interviewed were 60 years of age or older, so we were still able to capture the perspective of older women in the treatment decision-making process. In addition, our study was conducted within a single institution, and as an academic centre, the decisional support experienced by our study population may not be same as that of patients from community hospitals. Furthermore, the concept of decisional support is subjective in nature, and may vary among patients depending on their points of view and personal experiences. Our study was also limited to patients

who could speak and read English, of whom the majority was white and non-Hispanic. The decisional support needs of specific ethnic/racial minority groups may differ from those observed in our study. Finally, our study was questionnaire based, and although we included an open-ended question for participants to provide additional comments, the subjective nature of the decisional support process may warrant a qualitative approach. Given that we were interested in patients' satisfaction with their decisions regarding post-lumpectomy radiation therapy, inclusion of patients who decided not to have radiation therapy would strengthen the generalizability of our study results; however, given the nature of our accrual process, inclusion of this comparison group was not feasible.

Conclusions

The majority of women in this study felt that they actively participated in the treatment decision-making process; however, approximately half felt that they were not given a choice of treatments. Despite an overall high level of support, the need for additional informational support exists, especially among women with a higher level of education. Additional information needs can be addressed by providing patients with educational materials, a worksheet, consultation summary, or a decision aid workbook. Among older women from ethnic/racial minority groups, there may be a particular need to improve informational and overall support during diagnosis, as well as the quality of the patient–healthcare professional interaction. This may warrant the use of specific educational materials at the time of diagnosis, and a more culturally sensitive approach by healthcare professionals.

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