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Characterizing Informational Needs and Information Seeking Behavior of Patients with Breast Cancer

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Abstract

Background: Appropriate information may facilitate adjustment to cancer diagnoses. Our study aims to characterize informational satisfaction in breast cancer patients and assess resources used by patients to gain information.

Methods: Newly diagnosed Stage 0-III breast cancer patients seen at an academic medical center between May and September 2020 received questionnaires assessing information satisfaction. Patients indicated resources used to obtain information along with satisfaction with information received in various topics. A subset of questionnaire respondents completed semi-structured interviews.

Results: Fifty-two (35%) patients completed the questionnaire. Patients received information from physicians (96%), the internet (81%), nurses (79%), and fellow breast cancer patients (54%). Interview participants preferred receiving information from providers when making medical decisions but found patient forums and social media to be important adjuncts for receiving information.

Conclusion: Patients are satisfied with information received about diagnosis and treatment, but finances, sexual health, and fertility are less frequently discussed.

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Introduction:

Patients undergoing treatment for breast cancer routinely seek high quality sources of information regarding their disease. Recent studies suggest that individuals whose informational needs are not met may experience increased anxiety [1, 2]. Furthermore, up to 85% of breast cancer patients queried at their outpatient oncology appointments reported wanting additional information about their disease [3]. Certain populations including young breast cancer patients and those with limited health literacy may be especially vulnerable to unmet informational needs [4–8]. Many patients are unsatisfied with the information they have received regarding prognosis of their disease, symptom management, and cosmetic outcomes of surgery, which are important factors to consider when making decisions about their cancer treatment [8–10]. Studies have found that high quality information facilitates shared-decision making, which in turn may increase decisional satisfaction and decrease decisional regret [11–13]. Understanding gaps in how information is currently delivered may improve quality of care by providing patients with the information they want in the format they prefer and at the time they desire. To build on the current literature, in-depth perspectives from breast cancer patients regarding their experiences with receiving information about their cancer may be beneficial in constructing a holistic account of what patients need from their providers during their diagnosis and treatment course.

Thus, in this study, we aimed to 1) characterize informational satisfaction in breast cancer patients with Stage 0-III disease, and 2) assess resources currently used by individuals to gain information related to their cancer and its treatment(s). Additionally, we probed further into patients' informational preferences with semi-structured interviews, exploring the type of information patients sought from each of these resources and their experiences.

Material and Methods:

With institutional review board approval, all newly diagnosed, Stage 0-III breast cancer patients seen at an academic medical center between May and September 2020 were eligible for inclusion. At our institution, newly diagnosed invasive breast cancer patients meet their oncology providers – an advanced practice provider, their medical oncologist, surgical oncologist, and radiation oncologist – during a single-day multi-disciplinary clinic appointment. They meet with a multidisciplinary clinic advanced practice provider first who discusses their diagnosis, followed by visit with one of three of our breast surgical oncologists who review imaging results and potential surgical management. After this, they meet with one of seven of our medical oncologists and one of three of our radiation oncologists in no specific order who discuss their respective recommendations. During the visit, patients are provided with a packet of informational pamphlets for cancer patients outlining potential imaging studies, chemotherapy, radiation therapy, psychological resources, and sexual health and fertility. Patients with ductal carcinoma in-situ meet their

surgical oncologist preoperatively and then meet with radiation oncology and medical oncology post-operatively. After their visit, eligible persons received invitations by email to complete a questionnaire, which was adapted by the research team from questionnaires developed in two previous studies on informational needs in breast cancer patients [8, 14]. They received weekly reminder emails after their appointment to complete the questionnaire. The questionnaire (Supplement 1) asked patients to self-report demographic data including age, diagnosis, highest level of education obtained, and annual household income. Additionally, the questionnaire asked individuals to report their satisfaction with the information they had received from all information sources utilized across six domains: diagnosis, treatment, activities of daily life, self-image and disease acceptance, family life and sexual health, and survivorship. Sources of information including physicians, nurses, internet, handouts or pamphlets, friends, family, other breast cancer patients, and support groups—were also assessed. Responses were scored on a five-point Likert scale with the following choices: not discussed, not at all satisfied, somewhat satisfied, very satisfied, or completely satisfied. Descriptive statistics were used to summarize questionnaire data.

Patients who completed the questionnaire and indicated interest in completing a short phone interview to discuss this topic further were contacted by the research team. Participants completed semi-structured interviews which included open-ended questions about their diagnosis and treatment received, sources of information about their diagnosis and treatment, and satisfaction with information sources. One researcher (VH.) interviewed the participants via phone. Interviews lasted approximately 30 minutes. All interviews were audio recorded, and participants provided verbal consent prior to the interviews. Interviews were conducted until thematic saturation was achieved.

Interview transcripts were developed from the audio recordings. Data were analyzed using thematic analysis, a qualitative method for identifying, analyzing, and reporting themes. Two researchers (VH, AL) randomly selected transcripts (n= 3) to review independently and generate a list of codes based on the emerging themes. These lists were amended and refined through discussion between the researchers until a single coding rubric was agreed upon. Once the coding rubric was agreed upon, the two researchers (VH, AL) then independently coded the remaining interviews to identify every occurrence of themes in each transcript.

Results:

Questionnaire:

Fifty-two patients completed the questionnaire out of 147 who received it (35% completion rate). Table 1 summarizes the patient characteristics. Notably, 51% of patients who completed the questionnaire had been diagnosed with invasive breast cancer, 69% were greater than 45 years of age, 73% had completed at least a bachelor's degree, and 60% had an annual household income greater than \$70,000. Questionnaires were completed a median of 82.5 days after their multidisciplinary clinic visit (range = 2-236).

Forty-four (44) percent of participants indicated having a family history of breast cancer. Ninety-four (94) percent reported wanting all available information about their illness,

whereas 6% wanted only limited or positive information about their illness. However, all patients reported that they would like to be involved in all decisions about their illness.

Patients received information from a variety of sources. The most reported information sources were physicians (96%), the internet (81%), and nurses (79%). Eight percent of patients identified sources of information not listed in the questionnaire including cancer survivors and groups on social media, social workers, scientific literature, and their own previous breast cancer experience.

Figures A.1 and A.2 show patient satisfaction with information received about the different topics assessed on the questionnaire. The vast majority of patients were very or completely satisfied with information received about the cause of disease (88%), symptoms of disease (83%), stage of disease (90%), treatment types (94%), benefits of treatment (85%), effect of disease on day-to-day life (81%), how to be active during the process of treatment (83%), and prognosis (83%). The topics most infrequently discussed were effects of breast cancer and its treatment on breastfeeding ability (75%), fertility (69%), sexual health (50%), alternative treatment options if first treatment fails (52%), and financial costs of treatment (56%). However, among patients under age 45 (N = 16), 4 (25%) reported that effects of illness on fertility were not discussed, and 5 (31%) reported that effects on breastfeeding ability were not discussed.

Semi-Structured Interviews:

Twelve patients completed semi-structured phone interviews and provided further insights on the information topics, information sources, preferred timing of information, and the volume of information they received during day of consultations with the multi-disciplinary oncology team. At the time of the qualitative interviews, seven (7) patients had completed all treatments except hormonal therapy, and five (5) individuals were still receiving chemotherapy or radiation. Interviews were conducted a median of 57.5 days after survey completion (range = 9–175). Most frequently discussed themes are shown in Figure B. Representative quotes of most frequently discussed themes are included in Table 2.

Information Topics—Patients described seeking general information about their diagnosis as well as specific information such as hormone receptor status. They also wanted information on outcomes of treatment and their risk of breast cancer recurrence. Many patients encountered challenges when searching for information on diagnostic and pathology tests, including information about their pathology report and their genetic testing results. They also wanted additional information on treatment options, including surgery, chemotherapy, radiation, and hormonal therapy as well as the side effects of each of these treatment options. In particular, patients discussed wanting additional information on the cosmetic outcomes of breast cancer surgery as well as breast reconstruction, including before and after pictures.

Additionally, patients were concerned with learning more about what changes in quality of life they might expect during survivorship, along with garnering more information about what challenges they might encounter and how to actively prepare for them.

Preferred Information Sources—Patients described receiving information from an array of sources including, healthcare providers, websites, online support groups / forums, family and friends, breast cancer survivors, academic journals, pamphlets/handouts received in at the Breast Cancer Center, and social media. Notably, patients described their providers as being their primary source of information in making their medical decisions, but sources like websites, electronic medical record messaging systems, social media, and breast cancer forums were also favored.

Patients described the limitations of some of the resources they used to obtain information, particularly regarding information that was not specific to their diagnosis received in pamphlets or on the internet or provided them with misleading details as was brought up with internet sources.

Volume of Information During Initial Consultation—At our institution, all patients with a new diagnosis of invasive breast cancer are seen for a day long visit with our multi-disciplinary team including surgical, medical and radiation oncologists as well as nurse practitioners, and nurse navigators. While the vast majority of patients interviewed felt that the volume of information they received during their initial multi-disciplinary oncology consultation day to be appropriate, a minority of patients found the volume of information presented during their visit to be overwhelming.

Discussion

The results of this mixed-methods study indicate that patients are generally satisfied with the information they have received about their breast cancer diagnosis and highlight some opportunities for improvement. We found that most patients find the volume of information received on their multidisciplinary clinic day to be appropriate. Additionally, our results suggest that most patients find their oncology providers to be their most trusted source of information, and they supplement what they learn from their providers using the internet, breast cancer forums, and social media. Patients are generally satisfied with information they receive about their disease, including its cause, symptoms, stage, and treatment. Topics such as effects of breast cancer on fertility, sexual health, and financial aspects of breast cancer treatment were least frequently discussed. Thus, there are opportunities to develop, disseminate and evaluate additional informational materials for these topics. In interviews, patients discussed a desire for specific, personalized information about their disease as well as the potential cosmetic outcomes of breast cancer surgery and reconstruction.

Our results are similar to those at other institutions which have found that providers, materials provided by the hospital, and other patients are popular sources of information [15]. Studies investigating informational needs have also found that patients report needing information about diagnosis and treatment and treatment side effects and that information provided about fertility and sexual health is not adequate, which is further supported by our similar results [16]. Improving information provided to patients is crucial as some studies have identified relationships between health literacy and health information and levels of depression and anxiety in their populations [17].

Studies have found that many breast cancer patients experience adverse financial consequences from their breast cancer treatment and that some populations may be more vulnerable to financial toxicity – with variations by race, education, comorbidity, and insurance status, among others [18–20]. With over half of our patients reporting that the financial consequences of breast cancer treatment were not discussed, our results provide an impetus to improve communication about financing treatment and provide support to patients who may be at risk for financial toxicity.

Notably, interviews demonstrated the profound impact internet and social media has for some patients – particularly for connecting breast cancer survivors and sharing the results of breast surgery and reconstruction. Previous work has shown that up to 95% of patients use the internet to obtain information on breast reconstruction and information gleaned from the internet influenced procedure decisions for nearly a quarter of patients [10]. Additionally, the growth of social media has made it a particularly useful tool for breast cancer information dissemination as well as connecting breast cancer patients and survivors through breast cancer social networks [21–24]. There may be limitations of social media and websites as informational sources for cancer patients, as internet sources may contain misleading information, which were brought up as concerns by patients in our interviews. Studies investigating the quality of YouTube videos on breast cancer found that many videos were misleading and not useful [25–27]. A qualitative study investigating how health related internet information impacts the patient-provider relationship found that providers are often required to put internet information in context and that misleading interpretations can at times cause conflict during consultations [28].

Recent studies have explored ways to personalize information provided to breast cancer patients. Personalized decision aids for breast cancer patients can increase their understanding of their disease and available treatments and promote shared decision making [29, 30]. The integration of these tools may help satisfy patients' desires for personalized information about their disease and improve their satisfaction with information. In addition, personalized information related to fertility options, sexual health, and navigating the range of additional physical and psychosocial survivorship challenges across the breast cancer experience may minimize adverse outcomes, empower patients, and promote their overall well-being and quality of life.

There are several limitations of our study. First, we had a relatively low number of respondents from a single breast cancer center, making us unable to perform sub analyses. Furthermore, these respondents were predominantly well-educated, of high socioeconomic status groups, and were older. These factors may limit the generalizability of our results to the broader population, especially those with low health literacy. Additionally, the outcomes assessed in this study were self-reported by patients, which introduces subjectivity and potential bias. However, the major aim of this study was to assess patient satisfaction and resources used to gain information at the time of diagnosis, so patient perspectives and experiences were the most appropriate outcome measures. Finally, our study is limited by recall bias given the variation in the timing of survey and interview completion.

Conclusions

In conclusion, breast cancer patients at our institution are largely satisfied with the information they receive about their disease, but received less information on changes in sexual health, fertility, and financial issues through cancer treatment. Patients utilize the internet, social media, and other breast cancer patients as key adjuncts to information received from their providers, especially for information on the patient experience and survivorship. Areas for improvement identified in our study provide an impetus to tailor informational resources based on current patient need. Further studies should include developing and piloting personalized information materials on disease, treatment, sexual health, fertility, financial issues, and survivorship.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure A.1: Select Questionnaire Responses Related to Diagnosis.

Newly diagnosed breast cancer patients seen at an academic medical center between May and September 2020 completed questionnaires assessing information satisfaction. Figure includes data from questionnaire responses for satisfaction with information topics related to diagnosis. Topics are ordered from least to most discussed, with least discussed being at the top and most discussed being at the bottom.

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Figure A.2: Select Questionnaire Responses Related to Impacts of Illness and Treatment. Newly diagnosed breast cancer patients seen at an academic medical center between May and September 2020 completed questionnaires assessing information satisfaction. Figure includes data from questionnaire responses for satisfaction with information topics related to impacts of illness and treatment. Items are ordered from least to most discussed, with least discussed being at the top and most discussed being at the bottom.



Figure B: Frequently discussed themes.

Newly diagnosed breast cancer patients seen at an academic medical center between May and September 2020 completed semi-structured interviews. Figure depicts most frequently discussed themes identified in qualitative analysis of interviews.

Table 1:

Patient Characteristics

Characteristic	Cohort (N=52) n (%)	
Age		
Young (<45)	16 (30.77%)	
Middle (45–64)	23 (44.23%)	
Elderly (>64)	13 (25.00%)	
Highest Level of Education Received		
Never received high school diploma / GED	1 (1.92%)	
High school diploma / GED	3 (5.77%)	
Some college level credits or Associate's degree	6 (11.54%)	
Trade / technical / vocational training	3 (5.77%)	
Bachelor's degree	19 (36.54%)	
Master's degree	14 (26.92%)	
PhD or other advanced degree	5 (9.62%)	
Unknown	1 (1.92%)	
Diagnosis		
Ductal carcinoma in situ (DCIS)	18 (34.62%)	
Invasive breast cancer	27 (51.92%)	
Other	5 (9.62%)	
Unknown	2 (3.85%)	
Annual Household Income		
\$10,000–30,000 / year	9 (17.31%)	
\$30,001–60,000 / year	8 (15.38%)	
\$60,001-90,000	11 (21.15%)	
Greater than \$90,000 / year	23 (44.23%)	
Unknown	1 (1.92%)	

Table 2:

Most Frequently Identified Themes with Representative Quotes.

Code	Sub-Code	Representative Quote(s)
Information Topics	Diagnosis	"Just learning more about invasive ductal carcinoma pretty much, and what that means"
	Treatment (General Options, Expectations)	[on surgical options] "I didn't know what type of procedure I wanted to have – if I should go through lumpectomy and radiation or if I should do massive unilateral or bilateral mastectomy" [on hormonal therapy] "It was a difficult decision to make, whether to take the drugs, which one to take. Maybe not to take any of the drugs, but I do feel that I'm struggling with that, and I am having trouble getting the information I need"
	Outcomes / Recurrence	"I was less interested in learning about the specific cancer and more about learning how to move forward treatment, mortality rates, things like that, as morbid as that is"
Information Sources	Healthcare Providers	"I was always asking the doctors my follow-up questions on that research"
	Websites / Internet	"I first went to the American Cancer Society and what I was more curious about was, especially from American Cancer Society was, what kind of treatments are done for breast cancer and then I stopped looking. So for me, what I did was I wanted to be generally prepared and mostly educated, but having gone down the cancer path before, which wasn't pleasant, I didn't want to follow any rabbit holes that were gonna give me wrong information, because that's clearly super possible on the internet"
	Breast Cancer Survivors	"I also have, as it turns out, a number of friends who have had breast cancer before, so they were a resource also"
Preferred Information Sources	Healthcare Providers	"I prefer talking to the people who are going to be doing the procedures I think you gain more from assessing the individuals that are going to be working with you or on you than you do from a lot of other sources"
	Websites / Internet	"The internet was a great resource because you're off doing something, and your mind wanders back to something that's going on with your treatment and then a question pops into your head. And you instantly want an answer for that question"
	EMR Messaging	"I would personally prefer specific communication from [electronic portal messaging] with embedded links in it"
Volume of Information MDC	Appropriate	"For me it was appropriate even had I not had any knowledge about it prior to my appointment, I would almost rather get everything, get information one day and then go home and think about it, than having to make two or three different appointments. So, I really liked that aspect of it, and I liked how well the team work together"
	Overwhelming	"It was a little overwhelming at first. It took a couple of days to go sort through it all, but they gave you everything basically in writing. So, I had no trouble getting through it once, and then I was fine. But you do have to go through the materials after the fact."