

The need for decision and communication aids: a survey of breast cancer survivors

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Background Qualitative studies have identified barriers to communication and informed decision making among breast cancer survivors making treatment decisions. The prevalence of these barriers is unknown.

Objective To quantify the need for decision support among breast cancer survivors.

Methods We surveyed 2,521 breast cancer survivors participating in an online registry hosted by the Cancer Support Community to find out what proportion of breast cancer patients: made decisions during their first visit with a specialist; received satisfactory information before that visit; asked questions and received responses; and endorsed expanded use of decision support.

Results We received 1,017 (41%) responses and analyzed 917 surveys from women who lived in the United States. Most of the respondents recalled making treatment decisions during their first visit (52%). A minority (14%) received information before the first specialist visit. At least 25% of respondents rated their satisfaction below 7 on a scale of 10 for decision-making, information, and questions asked and answered. Respondents endorsed the need for assistance with obtaining information, listing questions, taking notes, and making audio-recordings of visits.

Limitations The respondent sample skewed younger and had higher-stage cancer compared with all breast cancer survivors. Responses were subject to recall bias.

Conclusions Cancer survivors expressed gaps in their care with respect to reviewing information, asking questions, obtaining answers, and making decisions. Implementing decision and communication aids immediately upon diagnosis, when treatment decisions are being made, would address these gaps.

A person's journey through breast cancer diagnosis and treatment involves complex deliberations and decisions.¹ One key dynamic of interest is that newly diagnosed patients often receive their diagnosis in the form of biopsy results, then schedule a meeting with a specialist to discuss treatment options and outcomes.² We and others have found evidence of the patient need for information while they are waiting for their specialist visits.³⁻⁶ For example, one study of needs found that breast cancer survivors complained of too much, too little, or conflicting information while they waited.⁷ That assessment also found that survivors remembered "freezing up" upon seeing their specialist. This resulted in patients forgetting to ask questions, and in the specialist's advice and information "going in one ear and out the other." These phenomena are especially problematic because breast cancer patients often make decisions in their first visits.⁸ The implication is that they may be making those decisions without having asked all the questions they want to ask, and without having

absorbed critical information.

Indeed, recent studies of breast cancer have found knowledge gaps among patients making treatment decisions. Sepucha and colleagues surveyed 35 mostly college-educated women with early-stage breast cancer who had made surgery decisions at 2 academic medical centers in Boston.⁹ They found that 44% of the women did not know that breast cancer survival was equivalent for mastectomy compared with lumpectomy plus radiation. Five years later, the authors replicated this finding among 440 survivors from 4 academic medical centers, among whom 55% did not know that critical fact.¹⁰ Other authors have reported 51% of 1,132 patients in Detroit and Los Angeles¹¹ and 58% of 107 women in Ontario Canada¹² had this knowledge. Researchers have found similar results for other breast cancer treatment decisions. Lee and colleagues surveyed 84 survivors from 4 academic medical centers about reconstruction decisions and found participants answered only 38% of questions correctly on a reconstruction-specific knowledge quiz that asked about the various

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options and their outcomes.¹³ In another study, Lee and colleagues surveyed 352 survivors at 4 academic medical centers and found respondents answered only 40% of questions correctly on a chemotherapy-specific knowledge quiz of options and outcomes.¹⁴

Researchers have identified efficacious strategies for addressing patient needs for information and involvement, including decision aids for orienting patients to their condition and the treatment options and outcomes;¹⁵ question-prompting, question-listing, and question-coaching for assuring that patients ask their questions;¹⁶ and consultation summaries and audio-recordings for assuring that patients can remember what their providers have told them.¹⁷ These strategies have been implemented in academic and community settings as both individual and integrated interventions.¹⁸⁻²² Broader adoption of this approach to providing treatment decision support may require further evidence of need.

To our knowledge, there is not a recent, quantitative estimate of the prevalence of these specific information and communication needs. Without quantifying the extent of these needs, it is not clear how urgently to deploy known strategies that may add effort and cost to patient visits. Therefore, we formulated the following study questions to address this gap in knowledge:

- What proportion of patients made decisions during their first visit with a specialist, and what was their satisfaction with the decision process and outcome?

- What proportion of patients got information prior to their first visit? How many were satisfied with that information?
 - What proportion of patients asked all their questions during that visit and how satisfied were they with their questions?
 - How satisfied were patients with physician discussions of risks and benefits of treatment options?
 - What is patient guidance about implementing support strategies such as decision aids and question-coaching?
- To answer these questions, our study team analyzed survey responses from women who had joined the Cancer Support Community's registry of breast cancer survivors.

Methods

Study population

In 2010, the Cancer Support Community launched a breast cancer survivor registry, recruiting volunteer registrants through public relations and marketing campaigns. The Cancer Support Community's registry differs from others in that it focuses on tracking the psychosocial impact of breast cancer. From time to time, the Cancer Support Community surveys registrants who have previously agreed to be contacted for research purposes. At the time of this survey, 2,521 registrants comprised the study's target population.

Design

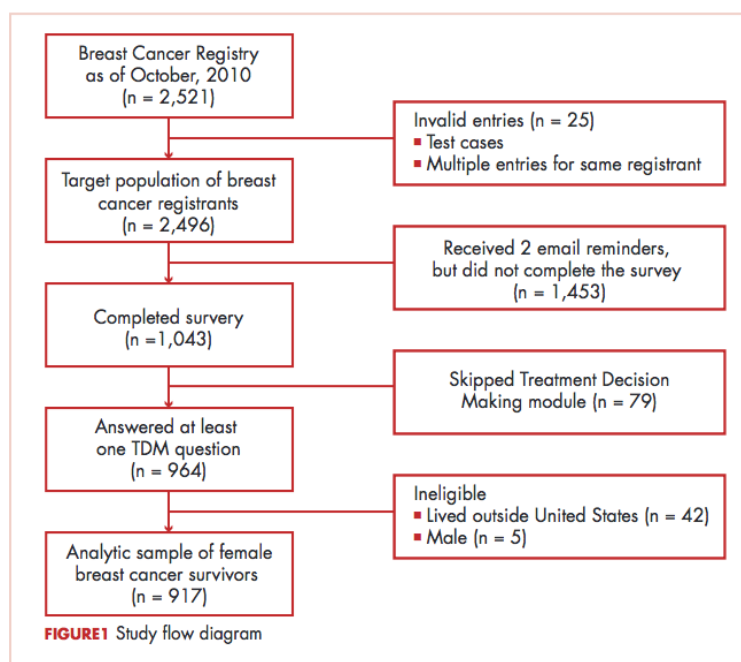
Cancer Support Community (CSC) conducted a cross-sectional survey of registrants in October 2010. (Figure 1) The study design was therefore a prospectively planned, cross-sectional, retrospective survey of survivor perceptions regarding various psychosocial issues. CSC contracted with Patient Crossroads, a for-profit private corporation that specializes in patient registries, to host the survey and collect and de-identify the data.

Ethics statement

An independent institutional review board, Ethical and Independent Review Services (E&I, Independence, MO), conducted an ethics review before the survey and approved the study. Survey respondents provided consent through an online process.

Sampling plan and recruitment of survey respondents

In October 2010, Patient Crossroads generated e-mails to 2,496 eligible registrants containing an invitation to log



on to their registry account and answer 18 items in the information, communication, and decision-making module (see Appendix). Ten days later, Patient Crossroads sent a reminder e-mail to 2,150 nonresponders; and 2 weeks after that, a third and final e-mail reminder to 1,754 nonresponders.

Survey items

Based on previous needs assessments⁷ the research team identified or created survey items to address the study questions as follows (see Appendix).

To quantify the prevalence of immediate, as opposed to more deliberate, decision-making, we asked registrants to recall their first visit to a specialist after diagnosis; indicate what type of specialist they saw (surgeon, medical oncologist, radiation oncologist, or other); and recall whether they arrived at a decision during that first visit (Yes, No, or Don't remember). We also asked how satisfied they were with how they arrived at a decision; their participation in the treatment decision; and the outcome of the treatment(s) taken, all on a categorical scale of 0-10, where 0 = minimum satisfaction and 10 = maximum satisfaction.

We also knew from prior work that people with breast cancer value receiving information upon diagnosis, and prefer to receive information from their physicians.²⁵ We asked whether the first specialist provided any information materials to the registrant prior to the first visit (Yes, No, or Don't remember), and respondent satisfaction with such materials (on the same scale of 0-10).

Patients commonly express freezing up and forgetting to ask questions. Making a list of questions is known to mitigate this risk.^{22,26} We asked registrants to respond Yes, No, or Don't remember about whether they brought a list of questions; asked any questions; and forgot to ask any questions. We also asked them to rate their degree of satisfaction (0-10), with the content of the questions they did ask.

Previous studies have shown physicians spend more time discussing benefits than risks of treatment options.^{13,27,28} We sought to assess whether patients rate these behaviors differently in terms of their satisfaction (0-10).

To guide development of new support programs for patients, we asked registrants to rate the importance of receiving assistance with gathering information (0-10; 0 = minimum importance and 10 = maximum importance) prior to a first visit to a surgeon or oncologist; developing a written list of questions for that visit; getting notes during the first visit; and making an audio-recording.

We also asked respondents for their age, sex, education, income, health insurance coverage, and race or ethnicity. Mutually exclusive racial or ethnic groups included Latino, non-Latino white, non-Latino African American,

American Indian or Alaskan Native, and Asian or Pacific Islander. Respondents who reported more than one race or ethnicity were classified with the category they reported identifying with the most, or if they did not have a category with which they most identified, they were considered multiethnic.

Eligibility and analysis plan

We included in the analytic data set all female respondents residing in the United States who had been treated for breast cancer and answered at least one question about information, communication, and decision-making needs and behaviors. We calculated descriptive statistics, tabulated the nominal responses, and plotted the distributions of the quantitative ratings. Authors MM and JB performed the analyses using Stata, version 11.1 (Stata Corp, Austin, Texas), including the *turnip* plot graphics function.²⁹

Results

Sample characteristics

A total of 1,043 registrants responded to at least 1 item on the overall survey within a 6-week period from October 6, 2010 through November 17, 2010 for an overall response rate of 41% (Table 1). Among the 1,043 registrants who completed the online survey, 964 answered at least 1 question from the module on information, communication, and decision-making. From the 964, we excluded 42 registrants who lived outside the United States and 5 male breast cancer survivors, which gave an analytic dataset of 917 female breast cancer survivors who started the survey and addressed at least 1 question. Among those 917, the item completion rate varied from a minimum of 86% to a maximum of 99%.

This sample was 88% white. The median age was 55 years. Most respondents (71%) had at least a college degree. The median time since diagnosis was 3.8 years (median age at diagnosis, 49 years). More than half were stage II or higher at diagnosis, and 13% had a recurrence. By way of comparison, when we checked the population of breast cancer survivors, we found that 88% are white,³⁰ with a median age of 61 years, and 38% have stage II or higher cancer at diagnosis.³¹ Therefore, compared with the population, this sample was similar in race, but skewed younger, and had higher stage of disease.

Answers to study questions

What proportion of registrants made decisions during their first visit and what is their satisfaction with the decision, their participation, and the outcome?

Most of the respondents (80%) recalled seeing surgeons first and making a treatment decision during that first visit (52%; Table 2). The respondents reported a median rating of 9 (0 = minimum satisfaction, 10 = maximum satisfac-

TABLE 1 Analytic sample characteristics (N = 917)

Characteristic	No. of patients (% of sample; % of those who answered)	Characteristic	No. of patients (% of sample; % of those who answered)
Age, y (median, 55; range, 28–84)		Disease stage at diagnosis	
<45	116 (13; 13)	0	82 (9; 9)
45 – <55	340 (37; 37)	I	303 (33; 34)
55 – <65	322 (35; 35)	II	353 (39; 39)
≥65	139 (15; 15)	III	126 (14; 14)
Race and/or ethnicity		IV	22 (2; 2)
Non-Hispanic white	769 (84; 84)	I don't know/remember	30 (3; 1)
Black/African American	52 (6; 6)	Missing	1 (<1; –)
Hispanic or Latino	21 (2; 2)	Recurrence	
Asian or Pacific Islander	9 (1; 1)	No	801 (87; 87)
Multiple	10 (1; 1)	Yes	116 (13; 13)
Other	5 (<1; <1)	Hormone receptor positive	
Missing	51 (5; –)	No	197 (21; 23)
Education		Yes	592 (65; 69)
Some high school or less	21 (2; 3)	I don't know	63 (7; 7)
High school or GED	215 (23; 26)	Missing	65 (7; –)
College degree	304 (33; 37)	HER2 status	
Graduate or professional degree	276 (30; 34)	Positive	161 (18; 19)
Missing	101 (11; –)	Negative	477 (52; 57)
Employment status		I don't know	197 (21; 24)
Full time	381 (42; 49)	Missing	82 (9; –)
Part time	111 (12; 14)	Triple negative	
Retired	191 (21; 24)	No	482 (53; 66)
Not employed	99 (11; 13)	Yes	132 (14; 18)
Missing	135 (15; –)	I don't know	117 (13; 16)
Household income, US\$		Missing	186 (20; –)
<40,000	83 (9; 16)	Self-reported depression	
40,000 – <60,000	77 (8; 15)	No	671 (73; 75)
60,000 – <80,000	75 (8; 15)	Yes	220 (24; 25)
80,000 – <100,000	76 (8; 15)	Missing	26 (3; –)
≥100,000	196 (21; 39)	Comorbidities (excl depression)	
Refused to answer/Didn't know	223 (24; –)	None	442 (48; 50)
Missing	187 (20; –)	At least 1	449 (49; 50)
Age at diagnosis, y		Missing	26 (3; –)
<40	139 (15; 15)	Treatment	
40–<50	346 (38; 38)	Chemotherapy	631 (69)
50–<60	313 (34; 34)	Radiation	576 (63)
≥60	116 (13; 13)	Lymph node removal	567 (62)
Missing	3 (<1; –)	Hormone therapy	555 (61)
Time from diagnosis, y		Lumpectomy	529 (58)
<1	90 (10; 10)	Mastectomy	452 (49)
1 – <2	157 (17; 17)	Targeted therapy	115 (13)
2 – <5	315 (34; 34)	Prophylactic mastectomy	104 (11)
≥5	352 (38; 39)		
Missing	3 (<1; –)		

tion) for satisfaction with their decision-making, participation, and outcome. One-quarter of respondents reported ratings less than 7 for those items. Although the distributions in Figure 2A are skewed toward the upper end of the scale, they also show responses at every level of satisfaction, including 0.

What proportion of registrants got information prior to their first visit? How many were satisfied with that information?

The doctor provided information materials in advance of the visit in 14% of cases. Among 124 respondents who got information materials, the median satisfaction was 5, and the 25th percentile rating was 0. The distribution in Figure 2B shows an almost uniform number of ratings across the full range of possible with responses, with slight ceiling and floor effects at 0 and 10.

What proportion of registrants asked all their questions during the first visit, and how satisfied were they with their questions?

Almost all of the respondents reported asking questions at their first visit (786 or 92%). Among the 762 who also provided ratings, the median satisfaction with question-asking was 7, and the 25th percentile was 5. The distribution in Figure 2B for satisfaction with questions asked shows responses for every level of satisfaction, including 0. Half (50%) of the respondents brought a question list with them to the appointment. One-third (33%) forgot to ask questions (Table 2).

How satisfied are registrants with physician discussions of risks and benefits of treatment options?

Respondents rated the explanations of benefits with a median of 8 and a lower quartile of 6; and rated explanation of risks at a median of 8 with a lower quartile of 5 (Figure 2B).

What is registrant guidance about implementing support strategies such as providing information materials, and assisting with question lists, note-taking, and audio-recording?

Respondents rated information materials, listing questions, and visit notes at a median importance of 10 (0-10; 0 = minimum importance, 10 = maximum importance). For information and question-listing, the lower quartile was 8; and for visit notes, it was 9. The median rating for audio-recordings was 9 with a lower quartile of 6 (Figure 2C).

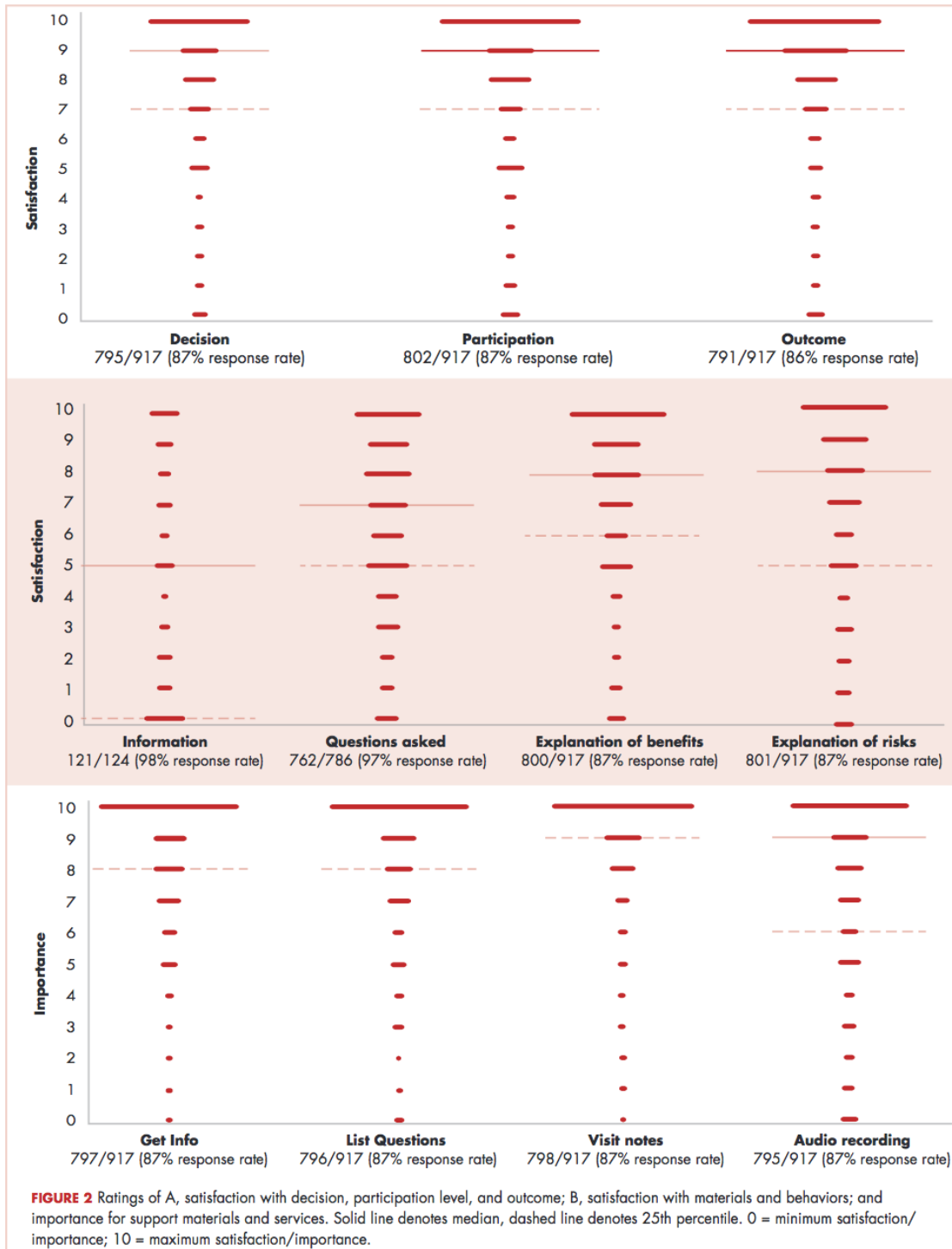
Discussion and conclusions

A majority of respondents said they arrived at a decision about their treatment during the first visit. The standard of care is to inform patients that breast cancer is not a medical emergency; that the decisions should be responsive to informed patient preferences, and that most patients need not rush to make a decision about their course of treatment.²

TABLE 2 Patient experience with the first meeting with the doctor (N = 917)

Responses to questions	No. of patients (% sample; % those who answered)
First specialist seen to discuss treatment decisions after breast cancer diagnosis	
Surgeon	731 (80; 80)
Medical oncologist	149 (16; 16)
Radiation oncologist	11 (1; 1)
Other	21 (2; 2)
Missing	5 (1; 1)
Arrived at a treatment decision during the first visit with the doctor	
Yes	418 (46; 52)
No	376 (41; 46)
I don't remember	16 (2; 2)
Missing	107 (12; —)
Doctor provided information materials before first meeting	
Yes	124 (14; 14)
No	713 (78; 80)
Don't remember	57 (6; 6)
Missing	23 (3; —)
Asked doctor questions on the first visit	
Yes	786 (86; 92)
No	32 (4; 4)
Don't remember	37 (4; 4)
Missing	62 (7; —)
Questions she forgot to ask or wished she had asked, in the 24 h after the visit	
Yes	265 (29; 33)
No	243 (27; 31)
Don't remember	285 (31; 36)
Missing	124 (14; —)
Brought a written list of questions to the first meeting with their doctor	
Yes	389 (42; 50)
No	334 (36; 43)
Don't remember	59 (6; 8)
Missing	135 (15; —)

This standard seems not to have been met. The respondents generally expressed satisfaction with their decision, participation, and outcome, although a quarter rated their satisfaction level as lower than 7 (0 = minimum satisfaction, 10



= maximum satisfaction). We interpret this result as reflecting a perceived opportunity for improvement in decision-making among one-quarter of respondents.

Registrants' responses to the questions about receiving information before their first visit with a specialist suggested that physicians did not generally send the patient orienting information before the visits, which was concordant with findings from our previous qualitative work.⁷ When they did provide information, half of the respondents who received that information were dissatisfied, rating the quality of information below 5 on a scale of 0-10. Other studies suggest that patients highly value information from their physicians.^{25,32} Specialists, especially surgeons (who see breast cancer patients to discuss treatment options after a diagnosis) are missing an opportunity to address key information needs. One option for providing information to patients in advance of a specialty visit is to send them decision aids, which have been found to be highly satisfying as well as effective in improving knowledge in breast cancer.³³

Respondents reported asking questions, and half said they brought a question list, yet one-third forgot to ask questions and one-quarter rated their satisfaction with their questions at below 5 out of 10. We noted with interest that many brought question lists yet forgot to ask questions. Concurrently, members of our research team conducted a separate study in which we learned that most patients in the sample (63 of 78 patients, or 81%) wrote a question list when invited to do so, but only 14 of 61 (23%) actually showed them to their physician.²⁶ We speculate that the same dynamic may have played out with the registrants surveyed: bringing a question list may not stimulate question-asking if it stays in the purse or pocket.

The number of patients who omitted questions and were dissatisfied with their questions echoes previous research findings suggesting that patients face barriers to raising questions with specialists.³⁴⁻³⁶ Several evidence-based interventions are available for assisting patients with question-asking. Patients can circle "frequently asked questions" on prompt sheets, or add their own questions.^{37,38} Members of our study team have also implemented a question-coaching intervention in which patients make a list of questions with a health coach, who types them for clarity and convenience²⁰ and sends or e-mails them to the physician in advance of the visit. This mitigates the risk that a patient will list questions but not refer to them or show them to the physician during the appointment. These interventions are satisfying to patients and are associated with increased question-asking.^{18-20,22,24}

With regard to physician explanations of risks and benefits of the treatment options, other studies have found that patients tend to be more satisfied with explanations of benefits rather than risks.^{13,27,28} The proposed mechanism

is that physicians may believe that benefits are more likely than risks so they deserve more time and attention. Conversely, although risks may be rare, they can be very harmful, and may therefore deserve the same quality of attention as benefits. However, in our sample, satisfaction was similar, showing adequate median scores of 8, but also room for improvement as the lower quartile ratings were 6 (for benefits) and 5 (for risks). This finding points to the opportunity identified in study question 2: physicians can improve their risk communication by providing written or audiovisual materials to patients in advance of the visit. This would allow physicians to use packaged visual aids shown to be effective across a spectrum of health literacy and numeracy, and would allow patients extra time to review the information and absorb it.

Respondents strongly endorsed the need for assistance with gathering information, listing questions, taking notes during the consultation, and making audio-recordings of the consultation. Although recordings were highly rated, they were less attractive compared with consultation summaries. This finding contradicts the finding by another research group in which 46% of patients ranked recordings highest and 21% preferred written summaries.³⁹ In other investigations, we have found that summaries and recordings serve different purposes.^{20,40} Patients value the written summaries because they are easy to review as a means of getting the gist of the consultation. Recordings are valuable because they allow patients and family members to review details – they are a definitive record of what was said and done during visits. It may be that recordings are less popular because patients perceive these as intrusive or are concerned that their doctors may consider it intrusive.

Study quality

There are a number of challenges to conducting this type of research. Although the CSC was able to recruit and follow survivors over time, there are cohort factors, such as changes in health care delivery and availability of treatment options, which may affect the data. In addition, the data collected are self-reported and difficult to verify without the benefit of medical records, although other studies have found similar patient populations to be accurate in reporting data.⁴¹ The response rate of 41% means that we were learning the views of a minority of registrants. Finally, as the data is collected completely online, it is limited to those with Internet access. This factor tends to skew the results by attracting a younger and more educated demographic.

Conclusions and implications for practice, policy, and research

Overall, we found quantitative evidence that many patients need and value assistance with gathering information,

asking questions, and absorbing information as they consult with specialists after a diagnosis of breast cancer. Our study found that many patients embarked on treatment decisions as of their first meeting with a surgeon. Patient support organizations wishing to support patients during the decision-making phase of their care must find ways of intervening immediately after a patient is diagnosed. For example, as a result of this study, the Cancer Support Community is testing various mechanisms, including how to embed its services in existing hospitals and clinics, or establish direct referral agreements with specialists who diagnose cancer. For those patients who are referred, or who self-refer, within the window of active decision-making, the Cancer Support Community now offers a service called Open To Options, which helps patients brainstorm and write a list of questions for upcoming appointments. This service is available free of charge by telephone, nationwide, in English and Spanish. It is also available in person at many of the Cancer Support Community's affiliate locations.

Given the opportunities for improvement we found with patient perceptions of information materials, healthcare providers and patient advocates should expand distribution of decision aids describing treatment options and outcomes. A key implication of our study is that patients need these materials before they attend decision-making visits.

Regarding consultation summaries and recordings, health care providers and patient advocacy organizations should consider providing audio-recording devices or referrals to smartphone applications that facilitate the process whereby patients can record their consultations for later review. As a matter of policy and advocacy, such organizations should also support initiatives to encourage patients to obtain and review physician summaries, such as the Open Notes initiative.⁴² Members of the study team are also implementing a national initiative, the Patient Support Corps, to provide trainees as patient companions and note-takers.

Our study also raised issues that remain unresolved in the research literature. Why do patients who bring question lists still regret not asking all of their questions? What are the barriers to effective use of question lists? Why do patients rate consultation recordings as less helpful than written summaries? We plan to pursue these and other questions in follow-up research. In addition, the Cancer Support Community has redesigned the registry to include other cancers, which will allow for the exploration of issues related to information, communication, and decision making in a more diverse audience of individuals affected by cancer.

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References

1. Belkora J. Promoting critical reflection in breast cancer decision-making. In: Edwards A, Elwyn G, eds. Shared decision-making in health care: achieving evidence-based patient choice. 2nd ed. Oxford: Oxford University Press; 2009:xviii, 414 p.
2. Love SM, Lindsey K. Dr Susan Love's breast book. 5th ed. Cambridge: Da Capo Press; 2010.
3. Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting, Board on Health Care Services, Institute of Medicine. Adler NE, Page A, eds. Cancer care for the whole patient: meeting psychosocial health needs. Washington, DC: National Academies Press; 2008.
4. Hack TF, Degner LF, Parker PA, Team SC. The communication goals and needs of cancer patients: a review. *Psychooncology*. 2005;14:831-845; discussion 846-837.
5. Hughes K. Decision-making by patients with breast cancer: the role of information in treatment selection. *Oncol Nurs Forum*. 1993;20:623-628.
6. Rees CE, Bath PA. The information needs and source preferences of women with breast cancer and their family members: a review of the literature published between 1988 and 1998. *J Adv Nurs*. 2000;31:833-841.
7. Belkora JK. Mindful collaboration: prospect mapping as an action research approach to planning for medical consultations [PhD dissertation]. Stanford, CA: Department of Engineering-Economic Systems & Operations Research, Stanford University; 1997.
8. Janz NK, Wren PA, Copeland LA, Lowery JC, Goldfarb SL, Wilkins EG. Patient-physician concordance: preferences, perceptions, and factors influencing the breast cancer surgical decision. *J Clin Oncol*. 2004;22:3091-3098.
9. Sepucha K, Ozanne E, Silvia K, Partridge A, Mulley AG, Jr. An approach to measuring the quality of breast cancer decisions. *Patient Educ Couns*. 2007;65:261-269.
10. Lee CN, Chang Y, Adimorah N, et al. Decision making about surgery for early-stage breast cancer. *J Am Coll Surg*. 2012;214:1-10.
11. Hawley ST, Fagerlin A, Janz NK, Katz SJ. Racial/ethnic disparities in knowledge about risks and benefits of breast cancer treatment: does it matter where you go? *Health Serv Res*. 2008;43:1366-1387.
12. Whelan T, Levine M, Willan A, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. *JAMA*. 2004;292:435-441.
13. Lee CN, Belkora J, Chang Y, Moy B, Partridge A, Sepucha K. Are patients making high-quality decisions about breast reconstruction after mastectomy? [outcomes article]. *Plast Reconstr Surg*. 2011;127:18-26.
14. Lee CN, Wetschler MH, Chang Y, et al. Measuring decision quality: psychometric evaluation of a new instrument for breast cancer chemotherapy. *BMC Med Inform Decis Mak*. 2014;14:73.
15. Stacey D, Bennett CL, Barry MJ, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2011;CD001431.
16. Kinnersley P, Edwards A, Hood K, et al. Interventions before consultations for helping patients address their information needs. *Cochrane Database Syst Rev*. 2007;3:CD004565.
17. Pitkeethly M, MacGillivray S, Ryan R. Recordings or summaries of consultations for people with cancer. *Cochrane Database Syst Rev*. 2008(3). DOI: 10.1002/14651858.CD001539.pub2.
18. Belkora J, Katapodi M, Moore D, Franklin L, Hopper K, Esserman L. Evaluation of a visit preparation intervention implemented in two rural, underserved counties of Northern California. *Patient Educ Couns*. 2006;64:350-359.
19. Belkora JK, Loth MK, Chen DF, Chen JY, Volz S, Esserman LJ. Monitoring the implementation of consultation planning, recording, and summarizing in a breast care center. *Patient Educ Couns*. 2008;73:536-543.
20. Belkora JK, Loth MK, Volz S, Rugo HS. Implementing decision and communication aids to facilitate patient-centered care in breast cancer: a case study. *Patient Educ Couns*. 2009;77:360-368.

21. Hacking B, Wallace L, Scott S, Kosmala-Anderson J, Belkora J, McNeill A. Testing the feasibility, acceptability and effectiveness of a 'decision navigation' intervention for early stage prostate cancer patients in Scotland - a randomised controlled trial. *Psychooncology*. 2013;22:1017-1024.
22. Belkora J, Miller M, Crawford B, et al. Evaluation of question-listing at the Cancer Support Community. *Transl Behav Med*. 2013;3:162-171.
23. Belkora J, Edlow B, Aviv C, Sepucha K, Esserman L. Training community resource center and clinic personnel to prompt patients in listing questions for doctors: Follow-up interviews about barriers and facilitators to the implementation of consultation planning. *Implement Sci*. 2008;3:6.
24. Belkora JK, Teng A, Volz S, Loth MK, Esserman LJ. Expanding the reach of decision and communication aids in a breast care center: a quality improvement study. *Patient Educ Couns*. 2011;83:234-239.
25. Hesse BW, Nelson DE, Kreps GL, et al. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Arch Intern Med*. 2005;165:2618-2624.
26. Volz S, Moore DH, Belkora JK. Do patients use decision and communication aids as prompted when meeting with breast cancer specialists? [Published online ahead of print January 7, 2013]. *Health Expect*. doi: 10.1111/hex.12042.
27. Hoffman RM, Lewis CL, Pignone MP, et al. Decision-making processes for breast, colorectal, and prostate cancer screening: the DECISIONS survey. *Med Decis Making*. 2010;30(5 Suppl):53S-64S.
28. Pass M, Belkora J, Moore D, Volz S, Sepucha K. Patient and observer ratings of physician shared decision making behaviors in breast cancer consultations. *Patient Educ Couns*. 2012;88:93-99.
29. How to use the Turnip Graph Engine in STATA. http://www.vaoutcomes.org/downloads/Turnip_README.pdf. Accessed June 6, 2013.
30. Howlader N, Noone A, Krapcho M, et al. SEER Cancer Statistics Review, 1975-2010, National Cancer Institute. http://seer.cancer.gov/csr/1975_2010/. Accessed April, 2013.
31. American Cancer Society. Cancer Treatment and Survivorship Facts & Figures 2012-2013. Atlanta: American Cancer Society; 2012. <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-033876.pdf>. Accessed 1/5/2014.
32. Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Educ Couns*. 2005;57:250-261.
33. Waljee JF, Rogers MA, Alderman AK. Decision aids and breast cancer: do they influence choice for surgery and knowledge of treatment options? *J Clin Oncol*. 2007;25:1067-1073.
34. Frosch DL, May SG, Rendle KA, Tietbohl C, Elwyn G. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012;31:1030-1038.
35. Roter DL. Patient participation in the patient-provider interaction: the effects of patient question asking on the quality of interaction, satisfaction and compliance. *Health Educ Monogr*. 1977;5:281-315.
36. Roter DL. Patient question asking in physician-patient interaction. *Health Psychol*. 1984;3:395-409.
37. Butow PN, Dunn SM, Tattersall MH, Jones QJ. Patient participation in the cancer consultation: evaluation of a question prompt sheet. *Ann Oncol*. 1994;5:199-204.
38. Dimoska A, Butow PN, Lynch J, et al. Implementing patient question-prompt lists into routine cancer care. *Patient education and counseling*. 2012;86:252-258.
39. Tattersall MH, Butow PN, Griffin AM, Dunn SM. The take-home message: patients prefer consultation audiotapes to summary letters. *J Clin Oncol*. 1994;12:1305-1311.
40. Belkora JK, Volz S, Teng A, Pass M, Moore DH, Esserman L. Five years of integrating decision and communication aids into routine breast cancer care: an implementation report. *International Shared Decision Making Conference Proceedings*. Maastricht, Netherlands 2011.
41. Cohen E, Belkora J, Tyler J, et al. Adoption, acceptability, and accuracy of an online clinical trial matching website for breast cancer. *J Med Internet Res*. 2012;14:e97.
42. Leveille SG, Walker J, Ralston JD, Ross SE, Elmore JG, Delbanco T. Evaluating the impact of patients' online access to doctors' visit notes: designing and executing the OpenNotes project. *BMC Med Inform Decis Mak*. 2012;12:32.