Original Article

Adapting the Breast Cancer Surgery Decision Quality Instrument for Lower Socioeconomic Status: Improving Readability, Acceptability, and Relevance

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Abstract

Introduction. Breast cancer is the second most common malignancy in women. The Decision Quality Instrument (DQI) measures the extent to which patients are informed and involved in breast surgery decisions and receive treatment that aligns with their preferences. There are limited data on the performance of the DQI in women of lower socioeconomic status (SES). Our aims were to 1) examine (and if necessary adapt) the readability, usability, and acceptability of the DQI and 2) explore whether it captures factors important to breast cancer surgery decisions among women of lower SES (relevance). **Methods.** We conducted semistructured cognitive interviews with women of lower SES (based on insurance status, income, and education) who had completed early-stage breast cancer treatments at three cancer centers. We used a two-step thematic analysis with dual independent coding. The study team (including Patient Partners and a Community Advisory Board) reviewed and refined suggested changes. The revised DQI was presented in two focus groups of breast cancer survivors. **Results.** We conducted 39 interviews. Participants found most parts of the DQI to be helpful and easy to understand. We made the following suggested changes: 1) added a glossary of key terms, 2) added two answer choices and an open text question in the goals and concerns subscale, 3) reworded the treatment intention question, and 4) revised the knowledge subscale instructions since several women disliked the wording and were unsure of what was expected. **Discussion.** The readability, usability, acceptability, and relevance of a measure that was primarily developed and validated in women of higher SES required adaptation for optimal use by women of lower SES. Further research will test these adaptations in lower SES populations.

Keywords

acceptability, breast cancer surgery, decision making, decision quality, lower socioeconomic status, readability

Date received: June 24, 2018; accepted: October 6, 2018

Nearly one in eight women will be diagnosed with breast cancer in their lifetime.[1,2] Despite significant overall improvements in breast cancer survival, disparities in care experiences and outcomes persist.[3,4] Women of lower socioeconomic status (SES) diagnosed with early-stage breast cancer (stages I to IIIA) report poorer

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communication with their health care providers, lower knowledge of breast cancer surgery, and higher receipt of mastectomy rather than breast conserving surgery (BCS), compared with women of higher SES.[3–11] They are also likely to experience worse health outcomes and increased mortality compared with women of higher SES.[3,12,13]

While BCS is recommended to treat early-stage breast cancer, research demonstrates equivalent survival between mastectomy and BCS.[14–19] Both options are offered routinely, but patients value the harms and benefits of each treatment option differently.[3,20] Since clinical equipoise exists, this breast cancer treatment decision is considered preference-sensitive, warranting patient involvement in decision making.[21,22] According to the Institute of Medicine, patient participation in decision making should be promoted to improve the quality of health care, particularly for cancer care.[23] All women

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diagnosed with early-stage breast cancer should be supported in making high-quality breast cancer surgery decisions that are informed by adequate knowledge of breast cancer treatment options, and aligned with their values and preferences, regardless of SES.[24,25] However, across all socioeconomic strata, only 44% to 51% of women with early-stage breast cancer achieve the degree of participation in decision making they desire, and women commonly report poor knowledge of breast cancer surgery.[5,6,26–29] Women of lower SES with early-stage breast cancer are more likely to have lower knowledge of breast cancer surgery, to play a passive role in decision making, to have higher decision regret, and to have lower satisfaction with treatment decision making compared with women of higher SES.[4,5,8,9,11]

In the context of preference-sensitive decisions such as early-stage breast cancer surgery, the quality of the treatment decision cannot be determined by clinical factors only.[30,31] In 2006, an international consensus process was used to define decision quality as the extent to which 1) patients are informed and 2) choose treatments that match what is most important to them.[32] This definition guided the development of the Decision Quality Instrument (DQI) for early-stage breast cancer.[33] The DQI measures the extent to which patients are informed about and involved in medical decision making and receive surgery that is aligned with their goals and preferences.[34] The DQI includes three sections and produces three scores: 1) decision-specific goals and concerns to examine the extent to which patients received treatment that is aligned with their goals (goals and concerns subscale), 2) decision-specific knowledge to assess patient understanding of the options and outcomes (knowledge subscale), and 3) the extent to which patients are meaningfully involved in the decision-making process with their health care provider (decision process subscale).[34]

The DQI was primarily developed and evaluated in women of higher SES. Of the 35 breast cancer survivors who were involved in developing the measure, 77% had received some college education or a college degree, and 97% were Caucasian.[33] In the validation study ($n = 440$ patients), 87.5% had received some college education or a college degree, 83% were Caucasian, and 86.6% reported an annual income of more than $30,000.[34] In 2010, a cross-sectional survey featuring the DQI was mailed to Latina breast cancer patients to examine the quality of surgical decision making in this group.[35] The sample included a sizeable proportion of women of lower SES. Of 97 Latina breast cancer survivors, 58.8% did not receive a college education and 50.5% reported an annual income of $30,000 or less. The study response

rate was low (42%); this was attributed to staff turnover and variable adherence to the protocol. Furthermore, Sepucha and colleagues suggested that the low response rate may also be due to a lack of acceptability of the survey among Latina respondents, about half of whom seemed to report lower income and lower educational attainment than survivors who had previously completed the DQI.[33,34] However, there was no comprehensive assessment of the readability, usability, and acceptability of the DQI in English-speaking women of lower SES of varying race and ethnicity.[36] It is, therefore, unclear whether the DQI is readable, usable, and acceptable to women of lower SES. It is also uncertain whether the current validated version of the DQI captures the factors (including potential barriers) that are important to women of lower SES when deciding about early-stage breast cancer treatments. There is limited evidence regarding the values and preferences of women of lower SES considering surgical treatments for early-stage breast cancer.[37]

Our aims were to 1) examine (and if necessary adapt) the readability, usability and acceptability of the DQI in women of lower SES and 2) explore whether the goals and concerns subscale captures the factors that are important to them when deciding about early-stage breast cancer treatments. This study is the first to specifically explore the readability, usability, acceptability, and relevance of the DQI to people of lower SES.

Methods

We conducted a cross-sectional qualitative study of the readability, usability, acceptability, and relevance of the DQI among women of lower SES diagnosed with early-stage breast cancer who had completed treatments in the past 3 years. We used semi-structured cognitive interviews integrating verbal probing techniques. This study was designed and conducted according to the consolidated criteria for reporting qualitative research (COREQ) (see Supplemental File 1 for checklist).[38]

Study Population

We used purposive sampling and targeted women of lower SES who had completed treatments for early-stage breast cancer in the past 3 years at Dartmouth-Hitchcock Medical Center (DHMC) in Lebanon, New Hampshire; Montefiore Medical Center in the Bronx, New York; and Joanne Knight Breast Health Center in St. Louis, Missouri.

We used the following inclusion and exclusion criteria. Inclusion criteria were the following: 1) assigned female at birth; 2) between 18 and 74 years of age; 3) low SES using insurance status (uninsured or on Medicaid or Medicare without supplemental insurance), educational attainment, annual household income, and information provided by the social worker and care team; 4) completed treatments for early-stage breast cancer (stages I-IIIA) within the past 3 years (so that they could reflect on their full care path and not have the burden of currently undergoing treatment); and 5) had at least a basic command of spoken English. Exclusion criteria were the following: 1) transgender men and women, 2) women who had undergone prophylactic mastectomy, 3) women >74 years of age, 4) women with visual impairment, and 5) women with inflammatory breast carcinoma.

We intended to recruit up to 15 eligible participants at each of our three sites or recruit participants until data saturation was reached and no new themes emerged.[39]

Data Collection

Subject Recruitment. To screen for eligible participants, research assistants at Montefiore Medical Center and Joanne Knight Breast Health Center reviewed medical records for eligibility using the aforementioned inclusion and exclusion criteria. Social workers and relevant care team members were consulted as necessary to confirm participants' eligibility. At DHMC, the oncology social worker of the Comprehensive Breast Program performed the initial screening, spoke to patients, and transferred the contact information of eligible and interested patients to the research assistant using a password-protected file. At each site, research assistants contacted eligible patients by sending a study information sheet and an introduction letter in the mail. The information sheet (Supplemental File 2) first described the purpose of the interview and the characteristics of the participants. The information sheet integrated pictures and used plain language (readability: seventh-grade level). It was developed iteratively to improve readability and understanding, with input from our patient partners, several of whom are breast cancer survivors. A series of frequently asked questions appeared on page two of the information sheet. The contact information of the research coordinator, principal investigator, and institutional review board office was provided on the last page (Supplemental File 2).

Cognitive Interviews. The research assistants who contacted eligible patients (JS: female research assistant; NM: female research assistant; TDG: male research

assistant) were those who conducted the interviews. All research assistants had prior experience conducting qualitative interviews with patients. However, not all research assistants had conducted cognitive interviews in the past. Prior to starting data collection, the study principal investigator (M-AD) and research project coordinator (RWY) trained all research assistants in conducting cognitive interviews following verbal-probing techniques.[40–43] After reviewing each DQI question together, the interviewer asked for other specific information related to the question or to the answer given. The principal investigator has experience using these techniques.[44–47] In order to ensure quality control and standardization of the data collection methods across all sites, the principal investigator and research project coordinator read the first and fifth interview transcripts received from each site and provided timely feedback on each interview, so necessary changes could be implemented for subsequent interviews.

After screening for eligibility, the research assistants followed-up with a telephone call to discuss the study and schedule a time to conduct the interview via phone or in person. No relationship with the participants had been established prior to study recruitment. When possible, the research assistants met the patients when they came to the clinic for a follow-up appointment. If the patient preferred to schedule an interview on the phone, the research assistant mailed the materials and called the patients at the scheduled time. All interviews were audio recorded. Before the interview began, the research assistants introduced themselves, gave participants an opportunity to review the study information sheet, to ask any questions, and obtained verbal consent.

First, research assistants asked participants to complete the DQI as if they had recently received a new breast cancer diagnosis and needed surgical treatment. Research assistants left the room or waited silently on the phone for a few minutes to give participants an opportunity to read the DQI and make any notes. Second, after participants had finished reading the DQI, the research assistants began semistructured interviews following a cognitive-interviewing script that focused on readability, usability, and acceptability of all instructions and questions (see Supplemental File 3). Interviewers gathered general impression about the worksheet, inviting any comments, including negative ones, on the instructions appearing on the first page. Participants were asked to explain, using their own words, what the instructions and items meant. The research assistant subsequently covered each subscale to focus on the instructions and items, one by one. For the goals and concerns subscale, interviewers asked additional questions about factors that mattered most to participants when deciding between mastectomy and lumpectomy (relevance).

After the interview ended, participants were asked to complete a demographics survey consisting of 15 questions: 1) time since breast cancer diagnosis, 2) time between diagnosis and surgery, 3) health insurance at the time of diagnosis, 4) health insurance coverage of breast cancer treatment, 5) current insurance, 6) country of birth, 7) English proficiency, 8) gender, 9) race, 10) ethnicity, 11) age, 12) highest educational attainment, 13) employment status, 14) household income, and 15) Chew's Single Item Literacy Screener.[48] Participants were given the option of completing the questionnaire on paper, verbally over the phone, or electronically (i.e., via tablet). After completing the questionnaire, all participants received a $15 gift card. No field notes were made. No repeat interviews were carried out.

Data Analysis

A HIPAA-compliant company transcribed the interview recordings. We used a two-step thematic analysis, assisted by the computer software ATLAS-ti.[49–51] Three reviewers coded the transcripts independently, one reviewer coded all transcripts (JS), and two reviewers split the full set due to staffing changes (AW and PS). First, the reviewers coded the transcripts to identify DQI items and instructions that required adaptation, as well as factors that matter to women when deciding about breast cancer surgery. The coders convened after independently coding five transcripts to review and agree on the themes and codes that had emerged in order to create a codebook, which was used to code all remaining interview transcripts. In a second and more detailed analysis, we coded the interview transcripts according to all the themes discussed in the interviews, including spontaneously emerging themes. The raters discussed discrepancies with the principal investigator of the study (M-AD) until consensus was reached. We developed the emerging themes into specific set of changes for the DQI. We typically considered themes that appeared at least five unique times in the interviews for the revised DQI (DQI-R). We subsequently discussed the list of codes and preliminary findings with Dr. Sepucha (measure developer of the DQI), our patient partners (LW, EC, SJ, AB), our Community Advisory Board, and the broader study team. After consensus on appropriate changes from these study groups, we developed and reviewed the DQI-R. We subsequently presented it in two focus groups of breast cancer survivors of varying

SES. Each focus group went through and provided feedback (i.e., acceptable or recommended changes) for each section of the DQI-R.

Results

Participants

Over 3 months, we identified 102 potentially eligible patients and confirmed eligibility for 75. We contacted these 75 women and interviewed 39: 12 at DHMC, 14 at Montefiore Medical Center, and 13 at Washington University in St. Louis. The remaining 36 either did not respond to the researcher or did not agree to take part. We reached thematic saturation where no new themes were emerging after conducting 38 interviews and stopped data collection (after interview 39). All but one participant completed the demographic survey. Not all questions were answered by all participants (see Table 1). On average, participants had been diagnosed with early-stage breast cancer 2.4 years prior to being interviewed. Participants' mean age was 52.6. Half of the sample were Caucasian. The majority of participants (22/39) did not have a college degree, were in receipt of Medicaid or uninsured at the time of diagnosis (31/39), and reported a household income of $35,000 or less (24/39). Less than half were employed part-time or full-time time. Interviews lasted between 9 and 93 minutes, with an average of 42.60 minutes. Most women (24/39) reported adequate health literacy (see Table 1 for more details).

Thematic Analysis

The independent coders agreed on a codebook of 25 codes. Two major themes emerged from the interviews, in alignment with the interview guide: 1) what matters most to women when choosing early breast cancer treatment and 2) readability, usability, and acceptability of the DQI (including suggestions for improvement) (see Table 2).

Theme 1: What Matters Most When Choosing Breast Cancer Surgical Treatments. When asked about what mattered to them in making a surgery decision, half of the sample (*n* = 20) reported not being given an explicit choice between mastectomy and BCS to treat their early-stage breast cancer.

> They didn't give me much options and I just told them do whatever they have to do because I just wanted to live. (Transcript 16, age 48)

When discussing what mattered most in choosing their surgical treatment, the most prevalent subtheme was the importance of survival, recurrence, and cure (*n* = 31). Women mentioned "[being] cancer-free," "the chances of it spreading," and "wanting to live." Most women were able to make a distinction between survival and recurrence, and seemed to understand that their surgery choice would not affect their overall survival. However, a minority of women talked about choosing the type of surgery that would maximize survival, thus pointing to a gap in knowledge.

> You know, what's important to me is basically overall survival. You know, yes my breast is important but, you know, given the choice between one or the other, I'm going to choose survival. (Transcript 6, age 58)

Nineteen participants expressed the importance or influence of other people in making a surgery decision.

> My husband, my spouse, had influence in the decision making (. . .) you know, listening to the pros and the cons for me being, you know, another opinion. I would like to have another voice there, so I found that to be very helpful. (Transcript 10, age 37)

Effects or side effects of surgery, including recovery time and ability to maintain pre-cancer lifestyle, were also important (*n* = 15).

> I'm very active, I wouldn't want to have a procedure that would ultimately render me not able to do things like swimming or kayaking, you know things like that. (Transcript 36, age 60)

> Recovery time. Because of my job, because of work. Responsibility at work. (Transcript 39, age 44)

> I'm a very independent person and I didn't want that [weak] feeling. (Transcript 35, age 63)

Patients felt that the trust in and relationship with their doctor (*n* = 15) played a significant role in their decision-making process.

> I had to fully trust my surgeon. (Transcript 42, age 42)

For some of those patients, boundless trust in their doctors occasionally meant following the doctor's recommendation, thus overriding their own decisional power.

> So, I decided, you know, whatever the doctors thought was the right procedure, you know, I just told them, go ahead you know what you're doing, I trust you, you know. It is

Table 1 Demographic Characteristics (*n* = 37[a])

Characteristics and Categories	*n*
Age, mean (range)	52.6 (31–70) years
How long ago, mean (range), were you diagnosed with breast cancer?	2.4 (0.25–5) years
Time between diagnosis and surgery, mean (range)	10 (1–54) weeks
Race/ethnicity	
American Indian or Alaska Native	1
Asian	1
Black or African American	13
Hispanic	3
White or Caucasian	20
In what country were you born?	
USA	34
US Virgin Island	1
Dominican Republic	1
Jamaica	1
Puerto Rico	1
Roughly how old were you when you learned English?	
0–5 years old	37
16–20 years old	1
Education	
Professional degree	4
4-year degree	4
2-year degree	8
Some college, no degree	12
High school diploma or equivalent	5
No high school diploma	4
Not reported	1
Health insurance[b] at time of treatment	
Medicaid or other state-sponsored	22
Medicare	8
Private Insurance	7
Uninsured	1
Health insurance covered all or part of breast cancer treatment	
Yes	31
No	2
Not reported	5
Current health insurance	
Medicaid or other state-sponsored	23
Medicare	8
Private insurance	7
Working status at time of interview	
Part-time work (15–34 hours per week)	4
Full-time work	10
On temporary leave	1
Full-time student	1
Not working at the moment	7
Retired	7
Other	5
Annual household income, US$	
Less than $20,000	19
$20,000 to $34,999	5
$35,000 to $49,999	7
$50,000 to $74,999	4
Not reported	3
How confident are you in filling out medical forms by yourself?	
Extremely	24
Quite a bit	6
Somewhat	1
A little bit	1
Not at all	1
Not reported	5

[a]One participant did not complete the demographic survey. Some participants did not answer one or several questions within the demographic survey.
[b]Some participants selected multiple insurance categories.

Table 2 Themes and Subthemes Identified in Interviews

Themes	Subthemes
1. What matters most to women	• Survival, elimination of cancer, recurrence • Avoiding radiation • Relationship with the doctor • Ability to maintain independence and lifestyle • Support system • Concern for family • Cost
2. Readability, usability, and acceptability of the Decision Quality Instrument	• Good readability, usability, and acceptability overall • Suggested modifications to improve readability

good that I found a brave surgeon, a person who I trust, and who made me feel confident. (Transcript 38, age 48)

Talk with your doctor and hear their suggestions and then you decide and if you're not comfortable, get a second opinion. (Transcript 35, age 63)

For others ($n = 14$), "avoid having radiation" was important due to fears regarding pain, scar tissues, and side effects. Participants also mentioned that their personal characteristics and medical history ($n = 13$), such as "what stage I was in" or "the grade of cancer" mattered to them in making a surgical treatment decision. Others mentioned concerns for family and others ($n = 12$).

The first thing I thought of was when I was diagnosed, the thing that popped in my head is, I have children. And my children need to be raised by a mom, and you know, a mom and a dad. And so, my thought was that what mattered most to me was my family. (Transcript 39, age 44)

Waiting time between diagnosis and surgery was important to some participants ($n = 10$).

I preferred to have [the surgery] done immediately. The faster you attack something, the better for you. The better you know outcome for you to live. (Transcript 11, age 47)

I think what gets most cancer patients down, no matter what type of cancer it is, probably more so the breast cancer, is that it's the hurry up and wait. (Transcript 41, age 70)

In this study population, women were more likely to report that keeping their breast was not essential ($n = 12$) compared with those who felt it was important to their treatment decision ($n = 10$). Some stated that cost was not a factor in making a treatment decision ($n = 18$), although a sizable proportion took cost into account ($n = 11$). Interviewees mostly referred to the monetary cost of treatment (health care bills and

out-of-pocket expenses) but did not specify whether cost influenced them to choose one surgery over the other. Of the 11 patients who mentioned the importance of cost in their decision-making process, 9 were receiving Medicaid or other state-sponsored insurance, or Medicare without supplemental insurance at the time of diagnosis.

While the codes and their respective occurrence provided important insights into the factors that mattered most to women of lower SES when making early-stage breast cancer treatment decisions, not all codes were relevant to the adaptation of the concerns and goals subscale of the DQI. In order to explore whether the DQI can determine whether the treatment decision is aligned with patients' goals and concerns, we focused on informed preferences and aimed to integrate factors that would influence a patient's decision toward either surgery option. For instance, a majority of participants mentioned the importance of survival and eliminating cancer. However, this prominent concern for any woman diagnosed with early-stage breast cancer would not be a driver in their surgical decision as both mastectomy and BCS have similar outcomes in terms of survival. Cost was considered an important part of the decision-making process for 11 out of 39 patients.

Theme 2: Readability, Usability, and Acceptability of the Original DQI. Almost all participants ($n = 37$) considered that the overall DQI instructions were clear and easy to understand.

I think it's pretty self-explanatory. (Transcript 8, age 48)

[Directions are] very understandable. (Transcript 32, age 53)

They are all straightforward, easy. (Transcript 1, age 57)

Nearly half of participants ($n = 19$) reported positive reactions to the DQI. They found it to be "very helpful" and "important."

It would have helped me out a lot in coming up with my decision. (Transcript 33, age 43)

I thought it was pretty thorough in asking the questions and the questions were good questions on it. (Transcript 8, age 48)

I think this helps you determine whether or not you know, how much do you yourself know, and how much this doctor know. (Transcript 41, age 70)

Fewer participants ($n = 10$) expressed their concern about the timing of administration of the measure:

That's the big issue at the beginning. It is—it is—this is overwhelming. (Transcript 20, age 44)

For someone who is just finding out like for me, no. I wouldn't have a peace of mind because like in that moment, it's like, I have to sit there and think, oh my God, like I'm going to be actually without breast for the remaining of my, you know, life like. . . . Maybe come to me when everything is done, you know. (Transcript 10, age 37)

Sixteen participants felt that certain phrases were confusing or suggested revisions to improve comprehension.

It's saying early breast cancer. I want to know what's considered early. (Transcript 19, age 64)

Some of the questions are worded a little strange. . . . I don't know how to answer that because I'm not trying to avoid a treatment, you want to avoid the disease you know. (Transcript 27, age 47)

Nine participants suggested revising the instructions.

Yeah, or maybe saying you know yeah, we're asking you (. . .) about the average breast cancer case. I think that make it clearer that that's what you're asking I guess. (Transcript 4, age 52)

Maybe I would say these are questions about some facts that are important to patients to know all right and maybe just please do your best to answer each question to the best of your knowledge or something what works to that effect. (Transcript 15, age 63)

Many participants did not understand that the knowledge questions included facts that are accurate for an average early-stage breast cancer patient ($n = 21$). Participants also felt that the knowledge subscale was difficult to answer or felt like a test ($n = 17$). Several suggested additional items that may be beneficial to include, such as questions about chemotherapy, reconstruction, or an open text response ($n = 10$).

It didn't really say a whole bunch about chemo on this. (Transcript 35, age 63)

This seems like this could be at this point, some kind of a, maybe an open-ended question (. . .) a little essay question. (Transcript 4, age 52)

Several women found the DQI difficult to understand because of the medical terms such as mastectomy or radiation that may be difficult to process when hearing those terms for the first time, during the initial diagnosis.

I didn't know what questions to ask because I didn't know technically what breast cancer even was, other than the word. (Transcript 18, age 43)

You have a lot of questions asking me the same thing so I have to exactly, in my head, I have to exactly understand which word means what. Do you understand what I'm saying? So, I don't know the difference of this. I don't know that. (Transcript 11, age 47)

Changes and Adaptations to the DQI in Response to Participant Feedback

In response to the analyses, several modifications were made to revise the DQI for this population. First, in response to feedback about the medical terminology, we added a short glossary to define key terms used on the first page: early-stage breast cancer, lymph nodes, lumpectomy, breast reconstruction, mastectomy, and radiation therapy (see Supplemental File 4).

Second, aligned with Theme 1, we made changes to the goals and concerns subscale. We added two questions to the section: "How important is it to you to . . ." First, "Have reconstruction to make a breast shape?" and, second, "Avoid more surgery?" To improve understanding, we revised the question, "Which treatment do you want to do to treat your early-stage breast cancer?" to "At the moment, what option are you leaning toward to treat your early-stage breast cancer?" In order to capture any other factors that patients may consider or want to share, we also added an open-ended question, "Is there anything else that is important to you that we have missed?"

Third, to address the concern that the knowledge subscale felt like a quiz, we revised the instructions to read, "We would like to check if we have done a good job at giving you information about breast cancer. Please answer the following questions using what you have read and heard from your care team so far." No changes were made in the response options or in the last subscale, decision process.

The study team, including Dr. Sepucha, our Community Advisory Board, and patient partners who have completed all breast cancer treatments, reviewed the final version of the DQI and found all changes acceptable (see DQI-R in Supplemental File 4). The focus groups, conducted in Lebanon, New Hampshire, and St. Louis, Missouri, were attended by 7 and 15 women, respectively. We received no suggestions for amendments to the DQI-R from either focus group. All attendees found the DQI-R to be readable, usable, and acceptable.

Discussion

This study was the first to interview people of lower SES to determine the readability, usability, acceptability, and relevance of the DQI. Overall, participants considered most parts of the DQI to be helpful and easy to understand. However, several aspects of the measure proved challenging or incomplete for a sizeable proportion of our lower SES sample, justifying revisions to two out of three DQI subscales. After reviewing all comments and consulting Dr. Sepucha, author of the DQI, modifications to improve the readability, usability, acceptability, and broad relevance of the DQI were made. In the goals and concerns subscale, we added two questions using the "Not at all important" to "Extremely Important" scale and an open-ended question to capture factors that matter most to women and may not be captured elsewhere. The last question was revised to assess their treatment intention more explicitly. The instructions in the knowledge subscale were revised to clarify the reference point and to reassure patients that the purpose was to assess the care team's effectiveness in communicating information. A glossary was added. The DQI-R was deemed readable, usable, and acceptable; this was confirmed by the patient partners and by 22 breast cancer survivors who attended two separate focus groups and requested no further changes.

The strengths of this study lie in the diversity of the study participants, careful training, and ongoing feedback provided to all research assistants conducting the interviews. We interviewed women in three geographically diverse areas of the country (Lebanon, New Hampshire; Bronx, New York; and St. Louis, Missouri) in order to improve the generalizability of our findings. Former breast cancer patients of various educational backgrounds, income, age, and race/ethnicity provided comments and suggestions for improvement, which were reviewed by M-AD, JS, RWY and Dr. Sepucha, to make this instrument more appropriate for women of lower SES. The fact that half of the sample reported not being given a choice between lumpectomy and mastectomy may be considered a limitation of the study. It also points to the need for improved decision support in this population. Furthermore, a small proportion of our sample reported having private health insurance ($n = 7$) although we actively targeted women of lower SES who were uninsured or on Medicaid or Medicare without supplemental insurance. During the screening process, it was not always possible to know the patient's insurance status ahead of time. So, all other information available and the social workers' and other care team members' assessments were used to determine the estimated SES of the potential participant. Another limitation is the relatively high health literacy level reported by 24 participants in our sample (61.5%), as measured using Chew's Single Item Literacy Screener. Social desirability bias could have affected the responses participants provided on the health literacy scale. This bias may have led some participants to respond to those questions based on social expectations. Furthermore, only English speakers were invited to take part in the study.

A prior study has demonstrated feasibility and reliability of a previous version of the DQI in a sample that was mostly Caucasian with high education and high annual income.[34] In this highly educated sample, three goals were significantly associated with surgery choice: desire to keep breast, remove breast for peace of mind, and avoid radiation. In our sample, desire to keep breast was not considered essential. However, fear of recurrence and survival (remove breast for peace of mind) and avoiding radiation were important factors. Fear of recurrence has previously been reported as a determining factor in early-stage breast cancer surgery decisions among low-income women.[8]

Other factors that were not captured in Sepucha's higher SES sample[34] emerged in our lower SES sample and led to the addition of two goals and one open-ended question: have reconstruction to make a breast shape, and avoid more surgery. The goal of avoiding more surgery could be related to financial considerations, although there is limited evidence regarding the impact of limited financial resources on breast cancer surgery decision making.[8,52] The open-ended question was created to capture other factors that were important to women of lower SES but that may not always be a driver in their surgical decision (such as cost, or trust in their doctor).

Trust in their doctor and how much control the doctor exerted over the decision-making process has been shown to be an important factor in breast cancer surgery decision making among women of lower income and lower SES. McVea and colleagues[8] interviewed 25 women of lower income diagnosed with early-stage breast cancer about their experiences deciding between surgical

treatment options. The physician's style, and specifically the degree to which she/he permitted or encouraged patient participation in decision making, strongly influenced the treatment choice. In McVea's sample, 10 out of 25 lower income women (40%) reported not being offered a choice between mastectomy and lumpectomy with radiation. This is consistent with our lower SES sample where 51% of participants reported not being given a choice between surgical treatments for early-stage breast cancer. Existing literature confirms that patients of lower SES are more likely to play a passive role in decision making.[4,6,7,9,10] Consistent with previous studies among lower SES patients, it is likely that differences in SES between patients and health care professionals alter communication patterns to potentially foster physician's control over decision making.[8,11,53]

Although many participants considered cost relevant in deciding between surgical treatments, research indicates no overall long-term cost difference between mastectomy and lumpectomy.[54] Lumpectomy seems to have higher short-term costs but lower long-term costs than mastectomy. Costs 1 year post surgery are also more likely to be influenced by the use of adjuvant therapy than by the type of surgery.[54] Therefore, despite the importance of cost in the overall decision-making process for 11 out of 39 patients, it does not clearly enable interpretation of which option patients should logically choose if they are particularly concerned about cost. Consequently, cost was not included in the DQI-R.

Another study examined the quality of surgical decisions in Latina breast cancer patients and suggested that some adaptations may be needed to increase acceptability in the Latina population.[35] That study concluded that the different aspects of decision quality did not vary by level of acculturation.[35] As our study sample included a diverse racial/ethnic makeup and varying levels of education and income, this adapted version of DQI may be beneficial in assessing the decision quality in women across socioeconomic strata and cultural backgrounds. It is worth noting that the DQI is used across clinical domains for a wide variety of decisions and with diverse populations.[55–58] This work is relevant in the context of other versions of the DQI. Aspects of the questionnaire that were challenging for early-stage breast cancer patients may be relevant to patients diagnosed with other cancer types or medical conditions (e.g., addition of a glossary).

Conclusions

Although the DQI was found to be broadly acceptable and usable, our findings suggest that women of lower SES may have different goals and concerns compared with the higher SES samples with whom this measure had been previously developed and evaluated. Avoiding additional surgery may be related to financial considerations, a concern that did not seem prominent in women of higher SES who contributed to the development and validation of the DQI. The addition of a glossary to facilitate understanding of key clinical terms is an important contribution to improving the usability of the measure. The proposed revisions to the DQI will be evaluated in a large randomized controlled trial with a diverse patient population to determine their performance. If the results show strong reliability and validity in this population, this revised version of the DQI will have broad applicability and could be used across SES groups, following a proportionate universalism approach.[59]

Author Contributions

M-AD planned and designed this study, supported by GE, RWY, JS, BV, MP, AT, KS, EC, SJ, and AB. JS and NM were research assistants/research coordinators collecting data at two of the participating cancer centers, supported by MP, SD, KR, and JM. BV, KS, EO, and SPL have provided expertise and advice on the study design and data collection procedures. PS, JS, and AW coded all data. JS and M-AD drafted the manuscript. All authors have reviewed and approved the final version of this manuscript.

Supplemental Material

The online supplementary materials for this article are available on the *Medical Decision Making Policy & Practice* website at http://journals.sagepub.com/home/mpp.

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