Defer, Share, or Drive the Decision

Empowering Patients With Varied Preferences to Engage in Decision-making (an Analysis From Alliance A231701CD)

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Objective: To understand how breast cancer patients experience the surgical decision process and identify strategies surgeons can employ to empower patients to engage in decision-making.

Background: Patient engagement in decision-making is associated with improved patient outcomes. Although some patients prefer that their health care provider drive the decision, the benefits of engaging in decision-making hold true even for patients who prefer to defer to their provider.

Methods: We performed semi-structured interviews with patients who experienced low engagement in clinical trial A231701CD (n = 30). We used qualitative content analysis to analyze data and organize it into overarching themes that represent experiences with decision-making.

Results: Patients could be grouped based on their experiences with the decision process into those who wanted to defer, share, or drive the decision. Three domains differentiated patients between groups: (1) overall disposition toward the surgeon, (2) tendency to exchange information and ask questions, and (3) attitudes toward how their preferences should shape the treatment decision. We identified surgeon behaviors that could optimize patient engagement. These opportunities were observed across all patients, regardless of their experience with the decision process.

Conclusions: Surgeons can empower patients to engage in decision-making by getting to know patients as individuals, ensuring all treatment options are presented, and integrating patient preferences into the decision process. Through these actions, surgeons can help patients with varied preferences for decision-making engage in making high-quality decisions that reflect patients' priorities. These suggestions may have the greatest impact on socially disadvantaged patients and help to reduce disparities in care.

Key Words: breast cancer, decision making, engagement, surgery

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Patient engagement in decision-making is important in every medical decision.[1,2] Engagement is associated with improved patient experiences with treatment decision-making, including decisional satisfaction, quality of life, and perceived quality of care and physician communication.[3–5] Patient involvement, through sharing preferences and asking questions, helps patients feel good about the decision process, confident in their health care provider, and more comfortable with the treatment decision. However, some patients prefer their health care provider to drive the decision. Many factors contribute to this preference, including patients' limited knowledge of the medical topic (relative to the health care provider), perceptions that they have limited capacity to influence the decision, or fear of making the "wrong" choice.[6–10] This is a challenge because the benefits of engaging in decision-making hold true even for patients who prefer their health care provider to drive the decision.[3–5]

Alliance for Clinical Trials in Oncology A231701CD was a clinical trial that evaluated the effectiveness of a web-based decision aid at increasing patient engagement in decision-making.[11] This study was conducted in 10 clinics within the NCI Community Oncology Research Program. We intentionally selected clinics that cared for a high proportion of socioeconomically disadvantaged patients. Socioeconomically disadvantaged patients disproportionately experience barriers to engagement in decision-making, and a shared decision-making intervention that increases patient engagement may reduce disparities in care. The trial also collected data on barriers to engagement that patients experience with the goal of identifying opportunities to improve the quality of care delivery.

In this study, we interviewed patients with breast cancer participating in A231701CD who had a low engagement in their surgical consults to understand how they experienced the surgical decision process.[12] Breast cancer surgery is an especially appropriate setting for this research, as the decision for breast conservation or mastectomy is highly dependent on patient's preferences.[13,14] As most women are candidates for both procedures, patients' values and preferences should drive decision-making. A secondary goal of the study was to identify strategies that surgeons can

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employ to empower their patients to engage in the decision process.

METHODS

Study Context

We performed semi-structured interviews with patients with breast cancer enrolled in a randomized clinical trial testing a decision aid's (DA) effectiveness in increasing patient engagement in decision-making (Alliance for Clinical Trials in Oncology A231701CD, NCT03766009).[12] The trial assessed patient engagement and measured various preparatory and interactional barriers to engagement.[11,12,15,16] We asked patients before their surgical consultation to identify their general preferred role in decision-making using the Control Preferences Scale (CPS).[17]

Interview Participants

Patients were eligible for interviews if they were randomized to the intervention DA arm, had low engagement during their surgical consultation (defined as the lowest tertile on either engagement outcome), and had at least 1 measured barrier to engagement. We used maximum variation sampling to recruit patients across participating clinics to ensure different perspectives and experiences were represented. Overall, 77 patients were eligible. Forty-seven patients were approached, of whom 30 (64%) completed the interview. The remaining 30 eligible patients were never approached because we reached informational redundancy.

Data Collection

A trained qualitative researcher interviewed the patients by phone or via video call between July and December 2022. All interviews were conducted after the patient had completed their surgical treatment for breast cancer. Interviews lasted, on average, 1 hour and followed an interview guide. Interviews aimed to understand patients' hopes or expectations for how the treatment decision would be made, what their surgeon did to make them feel part of the decision, and what the surgeon did to help them feel comfortable asking questions and sharing their thoughts or feelings about surgery (Appendix 1, Supplemental Digital Content 1, http://links.lww.com/SLA/F394). The interviews were audio recorded, transcribed verbatim, and de-identified before importing into Nvivo to manage data and facilitate analysis.

Data Analysis

Data collection and analysis were performed concurrently using qualitative content analysis.[18,19] Three team members (M.S., N.J., and H.N.) independently analyzed initial interviews, compared themes, and reached a consensus to develop a list of conceptual codes. As subsequent interviews were coded and new concepts emerged, the codebook was revised and applied to earlier interviews. We used visual mind maps and written memos to organize the data into overarching themes.

Participants provided informed consent for participation. The NCI Central Institutional Review Board approved this study.

RESULTS

Table 1 summarizes the characteristics of the interview participants. Most were White (63%) and had early-stage breast cancer. Although our participants were all assessed as having low engagement in the consultation, the majority (n = 22/30) indicated that they preferred to make decisions for treatments together with their doctors.

TABLE 1. Characteristics of Interview Participants

	N = 30
Age (y) mean, range	62 (38–72)
Race, n (%)	
White	19 (63)
Black	9 (30)
Asian	2 (7)
Area deprivation index	5 (1–10)
T stage, n (%)	
T0	5 (17)
T1/T2	20 (67)
T3/T4	5 (16)
N stage, n (%)	
N0	22 (73)
N1/N2/N3	6 (20)
Nx	2 (7)
Type of breast surgery, n (%)	
Mastectomy	12 (40)
Breast Conservation	18 (60)

Patients could generally be placed into 3 groups based on their experiences with the decision process (Fig. 1): those who wanted to defer to the surgeon's recommendation (n = 8), those who wanted to share decision-making with the surgeon (n = 18), and those who wanted to drive the treatment decision (n = 4). We discerned 3 domains that generally differentiated patients between groups: (1) their overall disposition toward the surgeon in terms of expertise and trust, (2) their tendency to exchange information and ask questions, and (3) their attitudes toward how their preferences should shape the treatment decision. We expand on the domains that characterize each group in the text that follows. We then describe patient examples of surgeon behaviors that could optimize patient engagement in the consultation.

Patients' Experiences With the Surgical Decision Process

Deferring Decisions

Patients who wanted to defer treatment decisions to their surgeon expressed an inclination to defer even before they had met the surgeon or heard the treatment recommendation because "they are the expert." One patient said, "I trust the team entirely, whatever they say, I will do" (patient 5). When asked where that trust comes from, she responded, "I felt that I was going to die and I thought that, 'Well, this is what they see on a daily basis, they see so many patients, so they know best for me.'"

For some of these patients, trust and confidence in the surgeon seemed to reduce their desire to hear comprehensive information about breast cancer and ask questions. One patient implied that she only wanted information about the option recommended by the surgeon: "To me, it seems like a waste of time for them to go through all the details of every option, when they already know what they want to do, and you already know what they want you to do" (patient 1). Patients with a high level of trust in the provider also tend to ask fewer questions, even when prompted by the surgeon. One patient who recalled not understanding parts of the conversation said she did not ask for clarification: "She

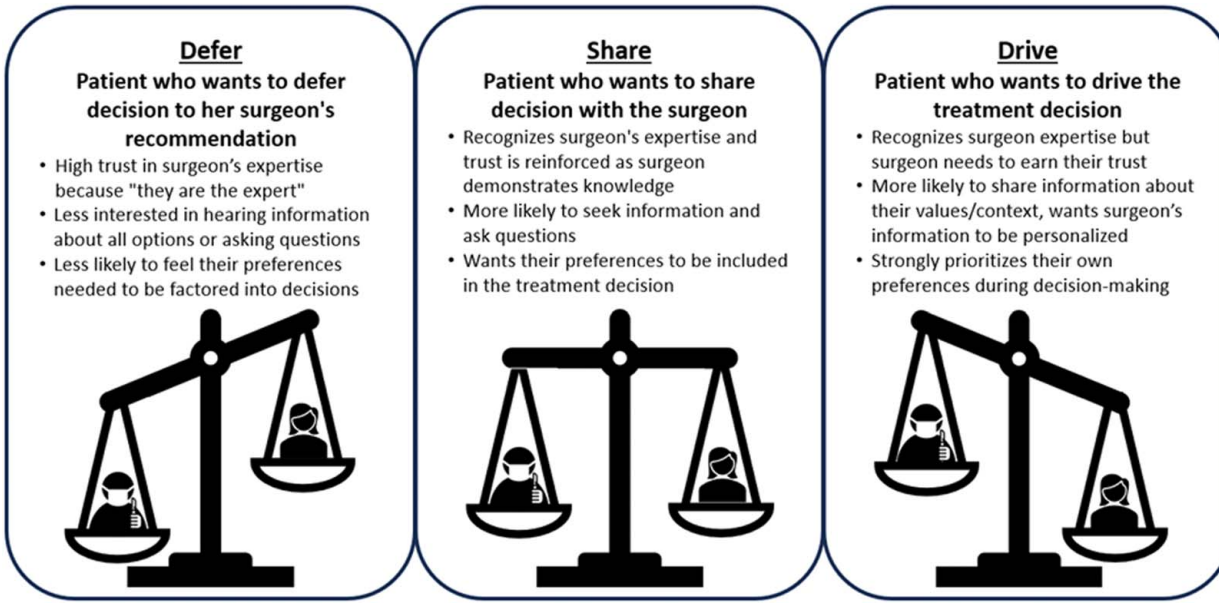

FIGURE 1. Overview of patient experiences with the decision process.

asked me, 'Do you have some questions? and I'm thinking, I was like, 'No.' Because the only thing in my mind is she knows what she's doing. And I'm good with that" (patient 8).

Patients who wanted to defer decisions did not necessarily feel their own preferences needed to be factored into the treatment decision. "I always make the doctor make the decision. Even though they give me options…I have no idea what's right for me or what's wrong for me—so I always ask them to do what they think is best" (patient 8). In some cases, the patient accepted the recommendation without sharing any of her preferences for treatment:

> *You just told me that I'm going to need a mastectomy, so at this point I don't feel like I have anything else to say about that. Like I wasn't like, "well, can we just try for this?" …I didn't really see it as me feeling like my opinion needed to be taken into consideration…she made the recommendation, and I had made the decision to trust that. (Patient 4)*

This pattern was especially common in clinical scenarios where the surgeon's recommendation aligned with the patient's preferences.

Sharing Decisions

Patients who wanted to share the decision with the surgeon acknowledged the surgeon's expertise. As the surgeon demonstrated their knowledge and clinical reasoning over the course of the consultation, patients' confidence was reinforced. When asked what helped her feel like she could trust her surgeon, one participant responded, "She explained it very well. So I just felt comfortable with her" (patient 16).

Patients in the share group tended to be relatively confident in their own knowledge and ability to ask questions. These patients spoke up when they needed clarification: "If I didn't understand the answer, I stopped and I asked, 'I'm sorry, I'm not understanding you'" (patient 18). These patients' level of engagement depended on the concordance between the surgeon's discussion of the options and the patients' own perspectives of their treatment choices. For example, 1 patient who expected a recommendation for breast conservation based on her own research did not engage significantly in the discussion:

> *When I sat down at that meeting, it was pretty much 'this is what we recommend.' I trusted the team and I thought, "Ok, that sounds reasonable." …I don't feel like I got a lot from the team as much as I did on my own, but I didn't ask as many questions because I had done some things on my own. (Patient 14)*

Patients who wanted to share the decision recognized the importance of their own perspective within the decision process and were willing to share their preferences for treatment. These patients wanted to hear the surgeon's information and recommendation and then make the decision together, rather than just accepting a recommendation for treatment: "At the end it was my choice, my decision, but I wanted to gain all the clarity I could from her [surgeon] and from the team of professionals that were around" (patient 15).

Driving Decisions

Patients who wanted to drive the decision tended to come into their surgical consult needing the surgeon to earn their trust, despite recognizing that the surgeon had expertise. One patient said, "I was headstrong, I had done my research and I know what I need to do, so let's do it" (patient 9). These patients were still open to hearing what the surgeon had to say, but some seemed to anticipate that the surgeon would not support their preference: "Before going in there I knew I was going to have a double mastectomy. I knew they were going to try to sell me on a lumpectomy, and I knew I need to stand firm" (patient 12).

Patients in the drive group felt that imparting their own preferences and values to the surgeon was just as important as receiving information from the surgeon. However, they were still open to hearing the surgeon's perspective: "I was

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leaning towards the mastectomy because of that [mother's recurrence] and because of my age and because of the age of my daughters, but I wanted to see what the doctors thought of it" (patient 22). At the same time, these patients wanted the surgeon's information to be personalized to reflect their life circumstances and preferences:

> *Obviously, the doctor knows what they're talking about. But there needs to be that sense of, "I feel like you've taken interest in me and you've taken the time to explain it to me so that I'm comfortable in my decision." (Patient 22)*

Patients who wanted to drive the decision strongly prioritized their own perspectives during decision-making. They were less likely to be receptive to surgeons' treatment recommendations when they felt that the recommendations were not tailored to them, and strongly valued a surgeon who they perceived considered them as an individual. One patient who went into her consult preferring a mastectomy felt that the surgeon did not entertain mastectomy as a reasonable option: "I kind of felt like she went into it thinking this [lumpectomy] was the best option for me in her opinion, and wasn't really taking the rest of my life into consideration" (patient 22). This patient decided to seek out other opinions "because this team is not on board what I think is the best option for me."

Opportunities for Surgeons to Empower Their Patients to Engage in Decision-making

Through the interviews, we were able to identify surgeon behaviors that could optimize patient engagement in the consultation. These opportunities for surgeons to empower their patients were observed across all patients, regardless of their experiences with the decision process. These behaviors included (1) treating patients as individuals, (2) sharing information about all treatment options, and (3) integrating patient preferences into the decision process. We expand on these in the section that follows.

Treating Patients as Individuals

Despite widely varied experiences with how they worked with the surgeon to reach a decision about breast surgery, patients all expressed some degree of wanting to feel like they and the surgeon were working toward the same goals. Surgeons helped patients feel this way by taking the time to get to know the patient as an individual, asking about their concerns, listening actively, and validating the patients' personal reasoning around the decision before making a recommendation (Table 2). These actions reassured patients that the surgeons were considering their priorities and what was best for their individual situation rather than treating them like generic patients, and made patients more willing to partner with the surgeon in deciding treatment.

Sharing Information About All Treatment Options

While patients differed in how much information they wanted from their surgeon, patients across all groups perceived transparent communication to be beneficial. This includes at least a brief description of options and time for the patient to ask questions (Table 3). Several patients who perceived that they received limited information about the options also wondered why surgeons made the recommendation they did and had lingering questions even at the time of their interview, months after their surgery; this included patients who were recommended breast conservation as well as patients in the defer group. In contrast, 1 patient in the drive group who initially had a strong preference for mastectomy appreciated that the surgeon took time to convey information about all options. Importantly, this patient perceived the surgeon was focused on making sure the patient understood the information about her options rather than on dictating the treatment decision.

Integrating Patient Preferences Into the Treatment Decision

Patients across all groups appreciated when their perspective was reflected in the treatment decision, even if the recommendation or choice was clear. Surgeons used variable approaches to accomplish this (Table 4). One patient said her surgeon explicitly asked her how she would like to make the decision, which allowed her to decide how much input from the surgeon she would like. Another patient's surgeon encouraged her to make the initial surgery decision and then took the extra step of validating her choice; this reinforced to the patient that she was making a good decision. Some surgeons provided a treatment recommendation with a rationale personalized to the patient's situation when the patient asked for more guidance. Finally, some surgeons had the practice of providing an initial recommendation; in this case, patients valued when the surgeons asked them for their thoughts about the recommended treatment.

DISCUSSION

In this study, we described key features of patients' experiences with the decision process for breast cancer surgery. Breast cancer is seen as the quintessential situation for shared decision-making, with 2 surgical options that have similar survival and recurrence, but different patient-centered outcomes.[1,2,13,14] Numerous benefits to patient engagement in decision-making exist, including improved patient satisfaction, quality of life, and decision quality.[3–5,20]

TABLE 2. Patient Quotes Supporting the Strategy of "Treating Patients as Individuals"

Seeing patients as individuals	"I felt like they cared for me. Not just, 'she's another patient. Let's get her in and out,' you know? No, I felt like they cared for me." (Patient 20)
Soliciting information and actively listening	"She listened and she asked questions, not just surface-level questions.…And she seemed to be taking those answers into consideration when determining what we should do about my breast cancer situation… [at the other institution] no one else took notes, no one else really seemed to be listening… it seemed as if folks were waiting for me to stop talking so that they could share what they thought I should do. And she didn't do that. She was listening." (Patient 26)
Validating patients' perspectives	"[The surgeon] said, 'Yeah that makes sense. You have young kids. You're young for breast cancer. Your mom's been through this.' …not in a 'yes ma'am' kind of way, but they were able to kind of see it from my perspective." (Patient 22)

TABLE 3. Patient Quotes Supporting the Strategy of "Sharing Information About All Treatment Options"

Sharing clear information to help patients understand treatment options	"She elaborated and made sure that I understood what she was saying to the best of her ability, like, you know, elementary style. So that made me feel comfortable knowing that she's really trying to help me understand and help me get it so I can make the absolute best decision for me." (Patient 21)
	"She wasn't being mean or not paying attention to what I wanted, it was more like letting me know, 'you can have that option [mastectomy], but you don't have to,' you know? 'We can do this [lumpectomy],' but if I wanted [mastectomy], she let me know I could if that's what I wanted." (Patient 9)
Encouraging and allowing time for questions	"And what it makes me feel better is that the doctor took the time to answer each question and make sure that I understood each of my questions. So it gave me assurance that everything is going to be ok." (Patient 5)
Providing an explanation for recommendation	"I really appreciated that [explanation of options] because I think if she would have just said 'we're going to have to do a mastectomy,' I would have been sitting there wondering why." (Patient 6)

Despite the benefits of engagement, patient participation in breast cancer surgery decision-making is variable.[21,22] Our participants largely indicated on their survey before their consultation that they wanted a shared approach between themselves and their doctors for medical decision-making.[17] Despite this stated preference, all of our participants were quantitatively assessed as having low engagement in the decision process[12] and a substantial proportion of our participants had described wanting to defer the treatment decision entirely during our interviews.

Challenges within the surgical consultation mean that patients are often not involved in treatment decision-making to the extent they prefer.[6,8,23,24] Heightened emotions, combined with the perceived urgency to make a decision and progress with treatment, may lower patients' confidence to engage meaningfully in treatment decisions.[9,25–27] Breast cancer treatment is complex, making patients dependent on the surgeon's expertise.[27] This vulnerability, reflected in our study through the frequent use of words such as "confidence" and "trust," can exacerbate the power imbalance in the patient-surgeon relationship.[10,26] Prior studies have found that patients with cancer or other life-threatening conditions tend to have higher trust because the higher stakes of their illness lead patients to feel they have no choice but to trust their physician to survive.[9,25,26] While patients' high confidence or trust in their surgeon can be positive, patients with higher trust in their doctors also tend to be more passive or less involved in medical decision-making.[28–30] This deference to "medical experts" has been associated with poorer quality of life, higher decisional role regret, and worse perceptions of decision quality, care quality, and physician communication.[3–5,20]

In recognition of these challenges, we offer suggestions for surgeons to empower all patients to participate more fully in decisions about their care (Appendix 2, Supplemental Digital Content 2, http://links.lww.com/SLA/F395). Although these recommendations are derived from our interviews with patients who had low engagement in decision-making, we believe that they are applicable regardless of patients' preferred roles.

First, surgeons should take time to learn about the patient as an individual with the goal of making patients feel that this consultation and any decision made is personalized to them. Surgeons have acknowledged that their recommendations tend to be based on their perceptions of patients' feelings, rather than explicit discussions of patient preferences and values.[31] In our study, patients across all groups appreciated when their surgeon asked questions to understand their individual context and priorities when it came to treatment. Importantly, this simple step of eliciting input can have the effect of making patients feel like they and their surgeon have the same goals for treatment, which is valuable regardless of who drives the final decision. These practices are consistent with previous studies about optimal physician-patient communication in cancer care.[22,25,26,30,32–36]

TABLE 4. Patient Quotes Supporting the Strategy of "Integrating Patient Perspectives Into Treatment Decisions"

Offering support during deliberation	"Dr. [NAME] told me I have two options… I could either get my breasts removed or just have the tumors removed. And she basically said 'we can make this decision together, you can make the decision with your family, or it could just be you.'" (Patient 10)
Validating the patient's treatment preference	"She went very carefully over the mastectomy route and the lumpectomy route, and she says, 'I'll give you a little time to think about it, and what direction you would like to go'… when I told her lumpectomy, afterward I said 'if this was you, what would you have chosen?' And she said, 'I would have chosen what you chose.' So, that's what made me feel a lot better at that point." (Patient 6)
Providing an individualized recommendation	"She kept asking, 'These are the options, what do you want?' ….And I said, "Well what would you recommend?" And she said, 'Well, it's your decision, but because it was caught so early…[lumpectomy] would be easier.' …She explained what she thought, but she left it up to me." (Patient 18)
Eliciting patients' perspectives about a provided recommendation	"I feel like once he explained it [rationale for lumpectomy], he made sure I understood, and he asked me what I thought." (Patient 11)
	"She didn't say, 'you have to get this [mastectomy] done.' But she did say, 'I can't recommend a lumpectomy'….she asked if I was OK with that, and I said, 'yeah, I am fine with it.'" (Patient 4)

Second, surgeons should present at least a brief summary of all treatment options.[13,14,35,37] Increasing patients' awareness of the options can increase patients' willingness to participate in the decision process.[29,38] Most women have at least some opinion regarding mastectomy versus breast conservation given the significant differences in body image, sexuality, postoperative recovery, and need for radiation.[35,37] Neglecting to discuss a patient's preferred option can lead to patient disengagement in the conversation and contribute to patients seeking care elsewhere. Further, it may cause patients to have uncertainty regarding the rationale underlying any treatment recommendation, leading to lower patient satisfaction with care. Based on our data, we recommend that surgeons provide clear information about all options and create opportunities for patients to voice any feelings about the options.

Third, surgeons should make an effort to integrate patient preferences into the treatment decision and support deliberation. Although patients often ask for recommendations,[21,22,24,35,38] giving recommendations early in the consult before exploring patient priorities may inhibit discussion[21,35,36] and overtly influence patients to choose treatments that they did not initially prefer.[39,40] If making a recommendation, providing a rationale that reflects that patient's values and circumstance may help the patient feel that the recommendation is individualized to them, and encourage discussion between the patient and the surgeon.[21,22,24,35,38] An additional step to encourage engagement could be to ask patients for their perspectives about any recommendation made.[36] If a patient conveys a preference, surgeon validation of that choice using elicited patient information is beneficial.

Although the provision of knowledge about treatment options is a critical component of all surgical consultations, surgeons must also empower patients to share their own goals and treatment preferences so that these can be integrated into treatment decisions.[6,10] Surgeons can use the suggestions we have outlined here to engage any patient. However, these suggestions may have the greatest impact on socially disadvantaged patients and help to reduce disparities in care. Analyses of audiotaped consults have shown that physicians tend to be more verbally dominant and less patient-centered with Black patients than with White patients.[41,42] Black women also tend to have more disempowering, paternalistic interactions than White women.[43] By engaging patients, the actions described in this manuscript may help to address implicit bias and power dynamics that may exist due to race and other factors.

Limitations

A strength of our study is that it includes concrete examples from patients' experiences that can guide surgeons in supporting patients facing the surgical decision for breast cancer. There are a few limitations to this study. First, our study was designed to specifically focus on patients with low engagement in their surgical consult,[12] and our sample could be influenced by any measurement error associated with these outcomes. However, the opportunities we describe for surgeons to empower patients apply to all patients regardless of their level of engagement, minimizing the impact of this limitation. This study has the usual limitation associated with participation bias, given that participants in our interviews may differ from those who decline. Finally, the interviews occurred after treatment was complete, raising the potential for recall bias. However, the interviews were rich in detail, minimizing this risk.

CONCLUSIONS

Breast cancer surgery decisions should be evidence-based and consider patient's preferences. Engaging patients in the decision-making process is critical to achieving this goal. The overload of cancer information combined with the strong emotions that accompany a cancer diagnosis makes it challenging for some patients to engage in the decision, leading them to rely on their surgeons to make treatment decisions. Based on our interviews with women with low engagement, we offer suggestions for ways surgeons can empower patients to participate more fully in decisions about their care. To reduce the impact of this physician-patient power imbalance, surgeons should get to know patients as individuals, ensure all treatment options are presented, and encourage patients to participate in their consultations to the extent that they feel comfortable. Through these actions, surgeons can help patients engage in making high quality decisions in which the treatment decision reflects the patient's individual context and preferences.

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