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Factors Affecting Surgical Decisions in Newly Diagnosed Young Women with Early-Stage Breast Cancer

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Given that young women with breast cancer often have concerns and priorities attributable to their life stage, we conducted a series of interviews to better understanding the surgical decision-making experience among women diagnosed at age ≤ 40. Women spoke of how the potential effect of an extended recovery was affecting their decision and, in some cases, contributing to decisional conflict. Several women described their worry of leaving cancer cells behind; others cited the need for continued surveillance as a consideration. Attention to situational anxiety and concerns about recurrence are warranted to ensure that decisions are made in a supportive and patient-centered setting.

Keywords: breast cancer, surgery, decision making

Introduction

In the United States, more than 12,000 women under the age of 40 are diagnosed with breast cancer each year.[1] While treatment decisions for breast cancer patients of all ages are affected by multiple factors, young women with breast cancer often have concerns and priorities accentuated by their life stage (e.g., fertility, impact on a young family, starting a career, body image) that may influence their surgical treatment considerations differently than older women.

With more young women with unilateral breast cancer choosing to have contralateral prophylactic mastectomies (CPM), there has been increased attention to this trend. A recent analysis of a nationally representative sample of over 1 million women reporting that the percentage of women who had CPM nearly tripled between 2004 (10.5%) and 2012 (33.3%).[2] CPM decreases the risk of developing a contralateral breast cancer, however, for the majority of women (e.g., those without a cancer pre-disposing mutation, such as BRCA1 or BRCA2) this 5-year risk is estimated to be 2%–3%.[3–5] In addition, the risk of distant recurrence is the same no matter what breast cancer surgical procedure is chosen, with breast conserving surgery and mastectomy (including CPM) conferring equivalent survival outcomes.[6,7]

Given recent surgical trends in young women with breast cancer, we conducted a series of key informant interviews to gain an in-depth understanding of how newly diagnosed young women approached decisions about breast cancer surgery.

Methods

Between February and October 2016, we screened Dana-Farber Cancer Institute (DFCI) clinic lists and approached newly diagnosed women with nonmetastatic (Stage 0–III) breast cancer diagnosed at age 40 and younger who had not yet undergone surgery and invited them to participate in a one-time interview study. Interested women who were eligible were interviewed either in person or via phone. After obtaining informed consent (written for in-person, verbal for phone), interviews were conducted in English except for a single interview conducted in Spanish with the aid of a DFCI institutional interpreter.

A semistructured interview script (Appendix A1) was developed to explore different aspects of the surgical decision-making process. Topics included sources of information about surgical options, pros and cons of each option, struggles with the surgical decision, physician recommendations, expectations around recovery, genetic testing, and sources of assistance with the decision process. In addition, women were asked for sociodemographic information, clinical stage of disease (if known), and a single question about their preferred medical decision-making style.[8] Interviews were expected to take ~ 20 minutes. Participants received a $25 gift card in appreciation of their time. Interviews were recorded and transcribed with identifiers removed. Following the creation of a preliminary codebook, transcripts were coded by two researchers (S.M.R. and M.L.G.) using NVivo software v11 (QSR International, Burlington, MA). Initial codes

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were classified into preliminary themes and grouped in larger domains using thematic content analysis. Preliminary themes related to the created domain, ''factors affecting the surgical decision process,'' were subsequently reclassified under broader themes and are presented here. Transcripts also were reviewed for information related to the sources of information and support utilized, and the women's stage of the decision process at the time of the interview, including whether a participant indicated they had or had not yet made a decision and choice of surgery (if the decision had been made). This research study was approved by the DFCI Institutional Review Board.

Results

Among 20 participants, 20% (4/20) identified as Hispanic or nonwhite; almost all (18/20) were partnered; median age at interview was 37 (Table 1). At the time of the interview, 50% (10/20) of women reported knowing their clinical stage, with most having Stage 1 or 2 disease (9/10, 90%). A shared decision-making process around surgery was preferred by 45% (9/20) of women; one participant preferred to make the decision about surgical treatment on her own, while 40% (8/20) indicated they preferred making the decision on their own while seriously considering their doctor's opinion.

At the time interview, 60% (12/20) of women indicated that they had made a decision about surgery; of these 12, 4 women said their plan would change if their genetic testing came back positive (Table 2). Among women who had not yet made a decision ($n=8$), two were leaning toward mastectomy, two were undecided with no preference indicated, and four were waiting for results of their genetic tests before deciding.

Analyses identified six primary themes: (1) postsurgical and survivorship concerns; (2) emotional factors (3) local therapy concerns; (4) reconstruction; (5) recommendations about surgery from providers, family, and friends; and (6) family history and genetics. Themes and corresponding subthemes are presented in Table 3 together with illustrative quotes.

Table 1. Study Population Characteristics ($N=20$)

Median age (range), years	37 (27–40)
Race, *N* (%)	
White	16 (80)
Other or unknown	4 (20)
Hispanic or Latina, *N* (%)	
Yes	2 (10)
No	18 (80)
Married/partnered, *N* (%)	
Yes	18 (90)
No	2 (10)
Clinical stage, *N* (%)	
0	1 (5)
1	3 (15)
2	6 (30)
Unknown or unsure	10 (50)
Education, *N* (%)	
Less than college degree	3 (15)
College/graduate degree	17 (85)

Table 2. Decision-Making Around Surgery ($N=20$)

	N *(%)*
Preferred medical decision-making style	
I prefer to make the decision about which surgical treatment I will receive	1 (5)
I prefer to make the final decision about my surgical treatment after seriously considering my doctor's opinion.	8 (40)
I prefer that my doctor and I share responsibility for deciding which surgical treatment is best for me	9 (45)
I prefer that my doctor make the final decision about surgical treatment but seriously consider my opinion/I prefer to leave all decisions regarding surgical treatment to my doctor	2 (10)
Decision made at time of interview ($N=12$)[a]	
Lumpectomy	5 (42)
Bilateral mastectomy	3 (25)
Unilateral mastectomy	4 (33)
Decision not made at time of interview ($N=8$)	
Leaning toward lumpectomy	2 (25)
Waiting for genetic test results before deciding	4 (50)
Not yet decided	2 (25)
Sources of support and/or information[b]	
Doctors and other providers	20 (100)
Partner	13 (65)
Family, friends, and colleagues	10 (50)
Other women with breast cancer (including internet-based support)	14 (70)

[a]4/12 said plan would change if genetic testing came back positive.
[b]Responses not mutually exclusive.

Postsurgical and survivorship concerns

Future ability to breast feed was a factor for some women in the decision process. Several women cited concerns about how an extended recovery would affect caring for young children and returning to work, and in some cases, contributed to decisional conflict. For example, one woman spoke of how the hardest thing she struggled with regarding her decision was ''… trying not to be over reactive in the moment when the decision I make is long-term.'' In weighing the pros and cons of different types of surgery, one participant spoke of wanting to ''choose the easiest, less invasive … that would be the fastest for me to be able to be back to my children'' while also acknowledging that a lumpectomy ''doesn't feel like … sufficient surgery.'' Another described how she ''worried initially … about the recovery time with the double mastectomy because I do have young kids so that was … daunting.''

Emotional factors/local therapy concerns/reconstruction

The need for peace of mind and concerns about recurrence and contralateral breast cancer also were cited by some women as affecting their decision. Several women spoke of their worry that cancer cells would be left behind after surgery, while others cited the need for continued surveillance. Anxiety surrounding frequent mammograms and lack of trust in imaging were also considerations during the decision process. While issues related to appearance and image were cited

Table 3. Factors Affecting Surgical Decisions: Themes and Subthemes

Theme	*Quote*
Postsurgical/survivorship concerns	
Cosmesis and self-image	''It would be traumatic … to lose your breasts … I know there's reconstruction but … I don't feel the answer is just to go ahead and do a bilateral mastectomy no matter what.''
Need for surveillance	''I would still need MRIs. I would still need mammograms, and I said why? Why go through all of that if, in the same procedure … I can just be done with it.''
	''Doing the imaging is not a concern for me … what's more concerning is that I don't have any faith in it …''
Employment	''I've been working through this, and I have to work … continue to work all the way through it. … So for me, that's a big consideration …''
Length of recovery	''I was worried initially a lot about just the recovery time with the double mastectomy because I do have young kids … I think the lumpectomy I could kind of wrap my head around and say, '… They take out the bad part … I'll recover. It's no big deal.' Whereas the double mastectomy was extremely daunting … a lot longer recovery time …''
Breastfeeding	''I want to have children … I thought about how I would like to be able to breast feed my child … that was one thing that I was a little bit concerned about …''
Emotional factors	
Worry about recurrence/contralateral breast cancer	''They said my risk of recurrence with a mastectomy or a lumpectomy is the same … Mentally, I can digest that. Emotionally … I think if you remove a whole lot of breast tissue obviously there is less of a place where it could recur …''
Peace of mind	''… mastectomy is also an option … the pros are obviously that you know there's a lesser chance of recurrence … I know that it's not that much lesser than lumpectomy and radiation but it is a lesser chance … and it may bring a little but more of a peace of mind to me and kind of help me with my anxiety … I'm also considering a double mastectomy … because … again there's just some sort of instinctual thing …''
Need it out	''… given the intensity of some of the reconstruction … I just really feel like I need to focus right now on getting the cancer out of my body.''
Local therapy concerns	
Minimizing surgery	''… lumpectomy with radiation … that seems to be … the least invasive, and … the easiest to recover from so those are … the pros of that surgery.''
Fear of leaving cancer cells behind	''Even knowing that there could have been anything left behind by trying to spare the nipple during the surgery was enough to make me not want to do that …''
Radiation	''… with the lumpectomy, I will definitely have to have radiation … so I'd rather not have radiation …''
Reconstruction	''One of the things that scares me a lot about implants is that they're not a forever thing, and so I try to picture myself at sixty with implants …''
Recommendations	
Input from providers (including second opinions)	''I feel like I've talked to … those doctors there, and then I came up here … between the oncologist and plastic surgeon and … breast surgeon, I feel like I've gotten different information from each … you get different perspectives.''
Input from family and friends	''A lot of … friends or family are just like, 'Well, you should just have both your breasts taken off, and that way you never have to worry about it again,' and I think they don't understand how traumatic that could be for somebody.''
Family history and genetics	''… if I hadn't had this gene mutation purely for the sake of saving it for breast feeding purposes when I do eventually start a family … that was the only reason why I considered a unilateral mastectomy.''

MRI, magnetic resonance imaging.

as considerations for many women, for others it was not a factor. One woman articulated that she was ''not concerned if I'm gonna look ugly … the only concern is my health. But if they give me the opportunity to have reconstructive surgery, of course, I will do it.''

Recommendations from providers, family, and friends

Women shared that they received advice or recommendations from a range of sources, including from providers, friends, and family members. One woman described feeling ''pressure from my husband to go the lumpectomy route,'' while another acknowledged ''my husband wants me to do them both … I'm just not sure what I want.'' Women cited doctors and other providers as being primary sources of information regarding surgical treatment options, while partners, other women with breast cancer, family, friends, and colleagues were identified as being common sources of support or information following diagnosis and during the decision process (Table 2).

Family history and genetics

At the time of the interview, some women had already undergone genetic testing and knew their results, while others did not yet know their results or had not yet been tested. For many women, knowing the results of their genetic testing—whether positive or negative—did influence surgical decisions, especially whether or not to choose to have a CPM.

Discussion

For young women with recently diagnosed early-stage breast cancer, practical concerns are often weighed in combination with emotional factors when making decisions about surgical treatment. As more young women have chosen to have bilateral mastectomies,[6,7] understanding the implications of extensive surgery, including returning to work and childcare, is essential during the decision-making process. Several young women brought up these concerns when talking about the pros and cons of their surgical options, stressing the importance of these issues. While concerns about the length and intensity of recovery following surgery were reasons for some to consider less extensive surgery, apprehension around the future need for surveillance, worry about recurrence, and peace of mind were reasons some women were considering (and in some cases already had chosen) bilateral mastectomy. Anxiety and worry about recurrence have been found previously to be associated with greater likelihood of overestimation of breast cancer associated risks, including recurrence and contralateral breast cancer, among both women with invasive breast cancer and ductal carcinoma *in situ*.[9–11] Our group and others have previously reported that women cite decreasing their risk of recurrence and contralateral breast cancer, and improving survival as reasons for choosing mastectomy.[12–16] The relationship between anxiety and inaccurate risk perceptions as well as the evidence that these factors appear to affect decision-making further underscore the need to account for the role of emotions during a time that can be particularly challenging given that there are other treatment-related decisions that are being made. For younger women, this can often include decisions around fertility preservation as well.

Relative to older survivors, younger cancer survivors have been found to have more concerns about recurrence,[17] further highlighting the importance of attention to these issues when young women are diagnosed with breast cancer and considering treatment options. While almost half of the women interviewed noted a preference for shared decision-making, an equal number said they preferred to make their surgical decision on their own, although most would consider their doctor's opinion. These findings suggest that even among women who clearly view the decision as their own, providers still play an influential role in the decision process. This should include not only helping women understand the risks and benefits of different types of breast cancer surgery but also addressing concerns about recurrence and anxiety that may be hindering optimal decision-making.

Conclusion

This was a select population of women who were seen or treated at a comprehensive cancer center and therefore generalizability may be limited. However, while findings from these interviews may not reflect all experiences, they provide insights and add to the available research examining the experiences of young women with breast cancer. In particular, these findings highlight the tension between seemingly conflicting individual priorities and underscore how surgical decisions can be complex for young women with breast cancer due to factors specific to their life stage affecting decision-making.

Developing novel, targeted interventions that deliver relevant information and address situational anxiety as well as concerns about recurrence may reduce both decisional conflict and distress. Specifically, breast cancer treatment decision aids have been shown to be effective in increasing knowledge and decreasing decisional conflict and are generally well received by patients.[18–21] In addition, these tools can assist providers with the communication of the pros and cons of different surgical options, including the short- and long-term physical and emotional effects of surgery. One recently developed internet-based decision aid for women thinking about CPM also included strategies to help manage concerns about recurrence as well as concerns related to mammographic surveillance, which were two issues that emerged in our study as affecting decisions.[22] Given that concerns about recurrence and cancer worry have been found to be associated with choosing CPM in prior studies,[23,24] addressing anxiety around diagnosis and prognosis in the context of the decision process may help ensure that surgical decisions are both informed and are made in a supportive and patient-centered setting.

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Disclaimer

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Author Disclosure Statement

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(Appendix follows →)

Appendix

Appendix 1. Improving Surgical Decision-Making in Young Women with Breast Cancer—Patient Interview

Intro: Thanks again for taking the time to talk about your experiences. I know this is a very stressful time for you. I am going to try to keep this brief. I'm going to start off with a few quick questions about you.

1. How old are you?
2. Are you currently single or married or living with a partner?
3. What is your race?
4. Are you Hispanic or Latina?
5. What is the highest grade or level of school you have completed?
6. What is your clinical stage of disease?
7. Which of the following best describes your preferred medical decision-making style?
   - ☐ I prefer to make the decision about which surgical treatment I will receive.
   - ☐ I prefer to make the final decision about my surgical treatment after seriously considering my doctor's opinion.
   - ☐ I prefer that my doctor and I share responsibility for deciding which surgical treatment is best for me.
   - ☐ I prefer that my doctor make the final decision about surgical treatment but seriously consider my opinion.
   - ☐ I prefer to leave all decisions regarding surgical treatment to my doctor.

Thanks for that information. Now I'd like to start with some questions about how you are currently approaching your decision about which breast cancer surgery to have. There are no right or wrong answers and if there's a question you'd rather not answer, that's fine too.

1. Where are you getting information about your surgical treatment options?

Prompts: friends, your partner, other family members, other people you know who had breast cancer, doctors (which type of doctor? surgeon, medical oncologist, plastic surgeon), other provider (genetic counselor, nurse), breast cancer books/pamphlets, internet, other sources?

Now, thinking about those sources of information, which one do you think has been the most helpful or useful for you?

2. Whether or not you have decided about which surgery you are going to have, what have you considered doing? What are the pros (''good things'') and cons (''bad things'' of each surgical option for you?

Prompts: Are there advantages to having lumpectomy for you? What do you view the downsides of lumpectomy to be? What about mastectomy? Pros and cons for you? Have you considered a double mastectomy? If you have, what are pros and cons for you? If you have not, why not? What has your care team told you about these choices?

- Prevention of local recurrence/second cancer, recovery time, cosmetic outcome, and least invasive surgery, did a family history of breast cancer (or other cancer) play a role, worry, or anxiety surrounding mammograms

3. Have you struggled with the decision about surgery?
- If yes: What has been hard?
- If no: What has made the decision easy?

Prompts: Do you feel like you are getting enough information to make a decision? Is there too much information out there (''information overload'' from this and other treatment decisions)? Is it hard to understand the risks and benefits of each choice? Do you feel like you have enough time to decide or feel rushed about deciding? Do you feel pressure from friends/family to make a particular decision?

If you have decided, have there been moments of indecision where you wondered whether you chose the right thing? Fears about the choice you made?

4. Did you feel your doctor(s) made a strong recommendation about one surgery over another?

Prompts: Did your doctor try to talk to you into or out of one surgery or another? Did your doctor explain his/her reasoning if this was the case?

5. Did talking to your doctor(s) raise new issues or concerns that you have not anticipated about surgical options?

Prompts: previously unknown risks of surgeries? benefits? hassles? cosmetic issues?

6. What do you expect the recovery to be like from surgery?

Prompts: recovery time, complications, reconstruction-specific issues, need for physical therapy, need for radiation

7. Recognizing you may have more than just surgical issues to deal with, what are you most concerned about related to your surgery, AFTER your surgery?

Prompts: How long it will take until you feel ok/better, how you will look, how this will affect your sex life, worries that the cancer will come back, reconstruction-specific issues, concerns about mammography (in follow-up); issues related to kids

8. Are you concerned about any particular site of the cancer coming back and has this affected your surgical decisions?

9. Have you been tested?/Will you be tested for a genetic mutation before your surgery? This includes BRCA 1 or 2 mutations and might also include testing for other alterations or mutations.

10. If yes, will the results influence (or have they influenced) your decision about surgery?

Prompts: If you test positive for a BRCA mutation, would you have a lumpectomy mastectomy, or consider a double mastectomy? If you test negative, would you have a lumpectomy, mastectomy, or a double mastectomy?

11. Is there someone helping you with the decision? Is there anybody not helping?

Prompts: friend, family member, support group, doctors on your oncology care team, other health care providers

12. Have you made your surgical decision(s) yet? If so, what are they currently?

13. Is there anything else that you want to tell me about how you are thinking about your breast surgery?

Thank you again for your time.