

“It’s Like We Don’t Exist”: Tailoring Education for Young Women Undergoing Surgery for Early-Stage Breast Cancer

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PURPOSE: The implications of a diagnosis and consequent surgical treatment for breast cancer may be different for young women compared to older women. This study investigated the information requirements of young women to support their treatment decision making at diagnosis.

PARTICIPANTS & SETTING: A purposeful sample of 20 women diagnosed with breast cancer aged 40 years or younger who had undergone surgery and had participated in a large cohort study in the United Kingdom.

METHODOLOGIC APPROACH: Audio recordings of semistructured interviews were used to reveal information received at the time of surgical treatment.

FINDINGS: Themes identified were types of breast cancer, surgical treatments, nonsurgical treatments, fertility, and surgery and after surgery. Participants felt that information required throughout treatment was influenced by individual life circumstances, such as children or plans for children, relationships, and career intentions. Participants felt information was lacking on the effects of treatment on body image, reconstructive surgery, and genetic predisposition to breast cancer.

IMPLICATIONS FOR NURSING: Knowledge of the information requirements of young women diagnosed with breast cancer allows nursing staff to provide tailored support at times identified as most useful.

KEYWORDS breast cancer; young women; information needs; breast cancer surgery; decision making

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In the United Kingdom, about 20% of breast cancer cases are diagnosed in young women. With about 1,100 deaths each year, it is the leading cause of cancer death for women aged younger than 50 years (Cancer Research UK, n.d.). Characteristics of breast cancer in young women as compared to older women include increased risk of recurrence, higher proportion of triple-negative cancers, and higher mortality rates, which present challenges to the treatment of breast cancer in this age group (Narod, 2012).

Randomized, controlled trials have demonstrated equivalent survival in suitable patients between those treated with mastectomy and breast conservation (lumpectomy and radiation therapy) (Fisher et al., 2002), and this appears to be no different in young women (Maishman et al., 2017), providing some women with a choice of surgical intervention to treat breast cancer. When presented with a surgical choice, however, women may struggle to make a decision because of lack of knowledge, individual decisional preferences, or emotional state after diagnosis (Molenaar et al., 2004; Nold, Beamer, Helmer, & McBoyle, 2000; Staradub et al., 2002). The difficulties of weighing pros and cons of different treatment options experienced by young women is counterbalanced by evidence suggesting that greater involvement in treatment decisions decreases decisional conflict and regret (Brown et al., 2012; Hack, Degner, Watson, & Sinha, 2006) and increases satisfaction with the decision (Janz et al., 2004). In addition, being informed about diagnosis and treatment can result in a positive impact on quality of life, greater satisfaction with choices, and improved ability to cope during and after treatment (Keating et al., 2010).

Elements involved in the treatment decision-making process include having sufficient information

about treatment options, being aware of risks involved in the choices offered, understanding the information received, and being clear about how the outcomes correspond with individual values (Whelan et al., 1999, 2004). Health professionals are required to provide relevant and useful information and to support patients in understanding treatment and reaching decisions that might have long-term effects on the patient's quality of life (Barnato et al., 2007; Hawley et al., 2017; Montazeri, 2008).

Patient decision aids are tools that assist patients in making treatment decisions by providing tailored information (e.g., to condition, to age) and outcomes on treatment choices available for specific health conditions (O'Connor et al., 2009). To create useful and relevant patient decision aids, health professionals and researchers need to know the information needs of patients because deficits still exist in healthcare providers' understanding of the decision-making processes framing the surgical treatment of breast cancer. This is exemplified by a lack of understanding of the trend observed in young women choosing more extensive surgery for the treatment of breast cancer over breast conservation (Bellavance & Kesmodel, 2016).

Evidence shows that the concerns of younger patients offered a surgical choice between mastectomy and breast-conserving surgery for the treatment of early-stage breast cancer differ from those of older women. A systematic review on the information requirements of women undergoing surgical treatment for breast cancer who were diagnosed at age 50 years or younger (Recio-Saucedo, Gerty, Foster, Eccles, & Cutress, 2016) highlighted key problems faced and the information needs that would support them while making a surgical decision to treat breast cancer. Overall, the studies included in the review found the following:

- Younger women require more information regarding sexuality and impact of treatment on body image.
- Younger women prefer to participate in treatment decisions to their desired level, with some patients preferring to leave the final decision to their surgeons and others opting for a shared decision-making approach.
- Younger women require more information on what breast cancer is and options of treatment regardless of their preference for participation in the decision-making process.
- Younger women express greater needs to receive as much information as possible regarding treatment

effects on fertility and genetic predisposition to develop breast cancer.

The review also highlighted the paucity of evidence of the specific needs of younger patients with cancer, which is detrimental to the provision and quality of care available to this population (Hammond, 2017; Katz, 2015a, 2015b). The studies highlight the importance of understanding the information and support requirements of younger patients (Dunn & Steginga, 2000; Fitch, Gray, Godel, & Labrecque, 2008; Grosser, 2003; Muñoz, 2010).

This qualitative study addresses the reported underrepresentation of young women in studies of cancer (Young Survival Coalition, 2017) by exploring information that would allow them to better understand their diagnosis and treatment options.

Methods

Aims and Research Questions

The aim was to gain a detailed understanding of the information requirements of young women (aged 40 years or younger) diagnosed with invasive breast cancer and to understand the ways in which information (e.g., medical evidence related to survival) supports treatment and decision making. Interviews were considered to be the most appropriate method of capturing in-depth factors that influenced women's decision making because it provided them with an opportunity to talk about their experiences in depth. As a result, the study adopted a qualitative approach. Detailed analysis of the participants' responses allowed the authors to identify underlying views that were influential to decision making. Women's retrospective recall of decision-making experiences, information searched and received, and the ways in which information was used to support decisions were explored through two key research questions:

- What information do young women with breast cancer require to support their surgical and treatment decisions?
- How does the information received support treatment decision making?

This study received ethical approval (MREC 10/HO504/87) from Southampton and South West Hampshire NHS Research Ethics Committee (B). All participants provided written informed consent to take part in semistructured interviews.

Participants

Potential participants were sought from the Prospective Study of Outcomes in Sporadic Versus Hereditary Breast Cancer (POSH) (Copson et al., 2013)

in a two-stage process of identification and invitation. First, principal investigators from six local centers participating in the POSH study identified and selected potential participants according to their demographic and treatment situations (i.e., receiving neoadjuvant chemotherapy, mastectomy and breast-conserving surgery, with and without family history, known high-risk gene mutations, urban versus rural location, and ethnicity). Of 67 patients identified from the POSH study, 9 were not suitable to approach because of clinical reasons (e.g., treatment for recurrence). Consequently, a research nurse posted 58 interview invitation letters, of which 21 replies were received (36% response rate). Details of the responses were sent to a researcher experienced in qualitative methods, who contacted the 21 women by phone to provide further details of the study and arrange an interview. Twenty of 21 women agreed to participate in the study. Medical records were reviewed to collect treatment information. All women received at least one adjuvant treatment (chemotherapy, radiation therapy, hormonal therapy). Interviews took place in the location that was most convenient to the participant. Written consent was signed before the interview started, and participants were reminded of their right to withdraw at any point of the study. All interviews were audio recorded and transcribed verbatim. The average length of the interviews was 70 minutes. Sociodemographic data, including age, ethnicity, marital status, and educational background, were self-reported by participants.

Interview Guide

A list of preliminary interview questions was compiled, and the study steering group was formed by academics, clinicians, and patients. Three patient representatives agreed to run a pilot of the interview and provided feedback to improve the structure and the sequence of the questions. The refined interview guide is presented in Figure 1.

Framework Approach

Interview data analysis was guided by the framework approach, a qualitative method explicitly developed in the context of applied policy research that has been widely adopted in health services research (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie & Spencer, 2002). This approach reduces data through summarization and synthesis while retaining links to the original source. Its strength lies in the opportunity it provides to conduct a comprehensive analysis and create outputs that closely reflect the views of the participants.

FIGURE 1. Semistructured Interview Questions

Initial Questions

- Can you tell me anything about the type of surgical treatment you had for your breast cancer?
- Did you feel there was a decision to be made either by you or the surgeon?
 - How did you feel about this at the time?
 - How do you feel about this now?
 - Did you feel involved in the decision (if there was a decision to make)?

Depending on response to the previous question:

- What was important to you in making your decision?
- What do you think was important to the surgeon in making the decision?

Decision Process and Decision Involvement Preferences

- Can you tell me about any difficulties around making the decision about your surgery?
- Do you remember anything else that was happening at the time that may have influenced the choice that may not have been related to the breast cancer itself?
- Do you feel like someone or something influenced your surgical choice?

Surgeon

- Did the surgeon explain what he/she thought was important in deciding on the type of surgery?
- Did the surgeon recommend the surgery type?
- Did you feel as though you had received enough information and support before your surgery?
- Is there anything you would have liked around that time to prepare you for the surgery?
- Is there anything else you want to mention about that time that hasn't been talked about yet?

Consequences of the Decision

- Have you had any further procedures (e.g., surgery, reconstruction)?
- Can you tell me about your experiences after your initial surgery?
- How do you feel now about having had breast-conserving surgery/mastectomy?
- If you were giving advice or supporting someone in a similar situation, what would you suggest?

Information Sources

- What information sources did you use, if any (e.g., printed materials, websites, videos)?
 - Did you find those sources useful?

Concluding Question

- Is there anything else that might be important for us to consider when developing a resource for young women facing surgery for breast cancer?

Data analysis used the computer-assisted qualitative data analysis software QSR International NVivo, version 9.0. Transcriptions uploaded on NVivo underwent the five stages of the framework approach: familiarization with the data (reading and notating transcriptions to highlight patterns and variations); thematic framework (representation of the categories of information emerging from the data); indexing (coding of transcriptions against the framework); charting (organization of the findings); and reporting (presentation of findings).

The first iteration of data analysis resulted in a preliminary thematic framework, which was reviewed and agreed upon with members of the team. It included broad categories of information that patients need, such as medical information on surgical procedures and other treatments used in breast cancer. The transcriptions were then coded against the preliminary framework. In this process, new themes were added until all transcriptions, in units of sentences or paragraphs, were entirely analyzed and coded. Two researchers developed the thematic framework, which was reviewed by a third researcher. Findings were validated, and discrepancies were resolved through iterative discussions and reviewing the transcriptions and framework until saturation was reached and no new information emerged from the data (Fusch & Ness, 2015) (see Figure 2).

Results

Of the 20 women who participated in the interviews, 19 reported an ethnicity of White/Caucasian. At diagnosis, the average age was 35 years (median = 37, range = 23–40), 4 were single, 11 had children, and 6 reported having family history of breast cancer. Seven of the women had a lumpectomy (breast-conserving surgery), and 13 had a mastectomy, of which 10 had reconstruction. Three were diagnosed when they were aged younger than 30 years, and 17 were diagnosed when they were aged younger than 40 years. Nineteen were working, and 14 reported having gone to college or having higher education.

Thematic Framework

Analysis of the interview transcripts resulted in five categories of information that young women required throughout the treatment pathway and to inform their initial treatment decision making: types of breast cancer, surgical treatment, nonsurgical treatments, fertility, and surgery and after surgery (i.e., practicalities about undergoing surgery and going home). These findings addressed the first

question of the study: What information do young women with breast cancer require to support their surgical and treatment decisions? The level of detail in some categories of information was influenced by individual life circumstances, including if women were single or in a relationship, had or planned to have children, or had started a professional career. Except for those women who were offered neoadjuvant chemotherapy, fertility was not immediately relevant to the surgical decision, but it was an aspect discussed at diagnosis because women wanted to have a clear idea of the long-term implications of various treatments. The five categories of information are illustrated with excerpts from the interviews. Names accompanying quotes are pseudonyms, and age reported is at diagnosis.

Types of breast cancer: Young women reported that a component of understanding treatment was to first know their diagnosis. Breast cancer in young women is rare, and young women indicated a need to know about incidence figures for the type of tumor and the differences in survival rates associated with their specific diagnosis. Some women investigated this information by typing in a search engine the definition of the tumor taken from their medical

FIGURE 2. Categories of Information That Young Women Identify as Required During Treatment for Breast Cancer

Types of Breast Cancer

- Hormone-receptor negative
- Hormone-receptor positive
- Triple-negative tumors

Surgical Treatments

- Mastectomy
- Lumpectomy (breast-conserving surgery)
- Reconstruction (immediate or delayed)

Nonsurgical Treatments

- Radiation therapy
- Chemotherapy
- Hormonal therapy

Fertility

- Effects of breast cancer treatment on fertility
- Fertility preservation options

Surgery and After Surgery

- In-hospital concerns
- Nutrition and exercise
- Everyday concerns after surgery

report. However, using medical terminology returned complex information, which created confusion. The purpose of searching for specific types of tumor was to understand the full extent of their particular diagnosis. The following excerpt illustrates this:

Well, that would have been interesting to have actually had some information on this particular type of tumor, yes. And what sort of proportion of people get it and just some idea of how serious it was, how easy it was to treat, what, you know, other places in the body where it's been found before, possible causes of it. (Ellie, age 37 years)

Surgical treatment: With regard to the outcomes of surgery, young women discussed the need for visual materials (photographs) of different surgical procedures, particularly showing women in their age group. Participants emphasized the impact that the thought of the surgical procedure had on their self-image and why they felt unprepared to deal with it because the images available to them were mostly of older women, whose range of surgical procedures did not match theirs.

And also, as I say, my grandmother had had a mastectomy, but I had no idea what it looked like, never seen her without any clothes on. And the only picture they showed me was of a really old lady, so it would be quite nice to have somebody a bit younger. (Megan, age 39 years)

Women expressed the need to understand how effective one type of surgery would be over another and whether a more conservative surgical procedure, such as breast-conserving surgery, would be enough to ensure non-recurrence.

They weren't sure whether to do a partial removal or a full mastectomy . . . and I said to him that I wanted the thing that meant I would survive. I wanted the long-term solution, so if that meant cosmetically, we had to go for a full mastectomy, then as far as I was concerned, losing the breast compared to having a longer chance of living was a good trade-off. (Stacey, age 39 years)

Reconstructive surgery was a recurring topic among the participants. There was great interest in learning about the different types of surgery and the criteria to determine which technique was best for them based on their age, lifestyle, and preferences.

Other concerns regarding this surgery included the best time to have it and the different cosmetic outcomes associated with each type of surgery.

Then just more information: if you have this type of surgery, this is the result. Luckily, the surgeon that I ended up having was very clear on the fact that, if I chose to have reconstruction with an implant, for instance, because I was only 38 [years old], and you generally have to change implants every 10 years, I would be having quite a few surgeries, you know, hopefully, in my lifetime. That's something I didn't know until he said. I just assumed they put an implant in, and you were done. (Julia, age 38 years)

Nonsurgical treatments: The effects of nonsurgical procedures (chemotherapy, radiation therapy, and hormonal therapy) were an issue that these young women wanted to be informed about from the beginning, even though not all women would require all treatments.

One option was to get rid of it [the tumor] first and then have the chemotherapy, which was what I decided to do. . . . It wasn't something I had to think about because to me, that was common sense, because in my mind, if you did it the other way 'round, even though the [neoadjuvant] chemotherapy might shrink it, it's still there, so the risk of it spreading gets even worse. (Rose, age 40 years)

At the end of the day though, you've just got to make a decision, and when I decided that I'd go for the hormonal treatment rather than the chemotherapy, I didn't really know whether that was the right decision, but then you could go on for weeks and weeks saying, "Shall I? Shan't I? Shall I do this? Shall I do this?" You've just got to a point to make a decision and just, just take, you know, what it, it was all there. It was all there and available for you. (Pam, age 37 years)

Women also reported a need to know common side effects of treatment and the reasons underlying the side effects.

[It was] never explained to me that it wasn't the tablet I was reacting to; it was the removal of estrogen I was reacting to. I thought I was having a side effect. It was the side effect of the tablet, not

the treatment, so I didn't realize when they stuck me on Arimidex® [anastrozole] that I was going to just as likely have the same. If I'd have known that Arimidex robs your body of estrogen in the same way the tamoxifen does it, I wouldn't have let them put me on Arimidex. (Stacey, age 39 years)

Fertility: The effects of nonsurgical treatments, such as chemotherapy, on fertility are known (Peate, Stafford, & Hickey, 2017; Royal College of Obstetricians and Gynaecologists, 2011). Although not directly related to making a surgical choice, the decisions associated with accepting treatment included understanding the long-term implications on family planning for the young women in this study.

Once you start having the treatment, it's too late then, because it does affect, you know, so I think especially young girls, I think they should know, should be told that it will affect their fertility, and they might have a choice of doing something then before they have their treatment. (Trish, age 34 years)

They also explained that I would very probably go through the early menopause as a result of the chemo and all the rest of it, but . . . what could the implications be for future fertility? (Emilia, age 38 years)

Surgery and after surgery: Young women in this study were less likely to have had surgery or have had the experience of being in the hospital. They felt that being prepared for this experience was necessary, particularly in relation to what would happen and when.

[They could] potentially produce, like, a flow chart to say, you know, on the day of surgery, this is where you know you're going to have to turn up at this time, and to actually have a bigger picture not just of, you know, from the doctor's side. That flow chart would include the surgical procedure side, but then also to include kind of, like, the emotional support side within that flow chart to say, OK, this is the time that whoever's coming with you, they can spend with you, and then this is the time that they need to leave . . . this kind of stuff. (Mia, age 34 years)

Once you've been for your preop[erative] assessment, maybe then they could give you some

information and say, right well, when you wake up, you are going to have this, and you will have to have this after you've been discharged, and things like that. You know, you have to have this bag that you carry around for 10 days or whatever, even while you're at home. (Megan, age 39 years)

The response to the second research question (How does the information received support treatment decision making?) emerged from the analysis of the interview transcriptions in discussions with the research team. The response to this question does not follow the themes identified in question 1. Instead, the narrative highlights the way that information requirements, in terms of type and depth of information, was influenced by two factors: stage of treatment and personal circumstances.

Ongoing Need for Information

Regarding the process of treatment decision making, the various moments at which women had to make decisions or come to terms with the decisions made by the healthcare professionals were complex and involved multiple aspects of their lives. For those patients who had surgical treatment, the period of time between receiving a diagnosis and undergoing a mastectomy or breast-conserving surgery was not longer than two weeks. Within this period, starting with the discovery of an abnormality in the breast and an appointment with their general practitioner, women found themselves immersed in a process where multiple decisions had to be made regarding tests (e.g., mammograms, needle biopsies, ultrasounds, magnetic resonance imaging), surgery, and the immediate management of postsurgical treatment (highly dependent on the choice of surgery made).

It would have been like nice to [have] time to, you know, think about, potentially think about things, been given a bit of time to go away and say, "OK, have a think. We're going to run through a treatment plan in a bit." . . . I don't know, maybe have a list of things that they want the patient to consider. (Mia, age 39 years)

Overall, women strongly felt the need to be informed before making decisions when choices were available.

But if I wasn't like that then, I think that they should have said, "You've got two routes: you can go right, you can either have that done first or

that done first.” And explain the reasoning, why they leave that decision to you, why that route would be best, why that other route would be best, and then allow you to make a decision. But that wasn’t how it was. It was, “Right, those are the decisions you’ve got to make.” (Rose, age 40 years)

Participants expressed the need to know aspects of their diagnosis and treatments but at different levels of detail, rendering some information irrelevant at the appointment when the diagnosis was given and when surgical treatment was discussed.

It wasn’t, like, all in one go because, even with my own experience, I would not have taken it all in on that day if it had been all in one go, because I had my list of questions that I wanted covered there and then and at that point, you just, you don’t hear what they’re saying anyway. You only hear what you want to hear. (Sam, age 37 years)

Information and Individual Circumstances

As days went by and diagnosis was assimilated, other aspects of treatment and consequences to the women and their families became more relevant, making other types of information (e.g., fertility, nonsurgical treatments, schedules) more relevant. Women reported that individual circumstances (e.g., impact of treatment on self-image, relationship status, working life, family) influence and even compete with different aspects of treatment decisions. Information required was linked to those circumstances.

I had wanted to do anything I could to save my life, mainly for my children because they were only 2 and 3 [years old] at the time. (Ellie, age 37 years)

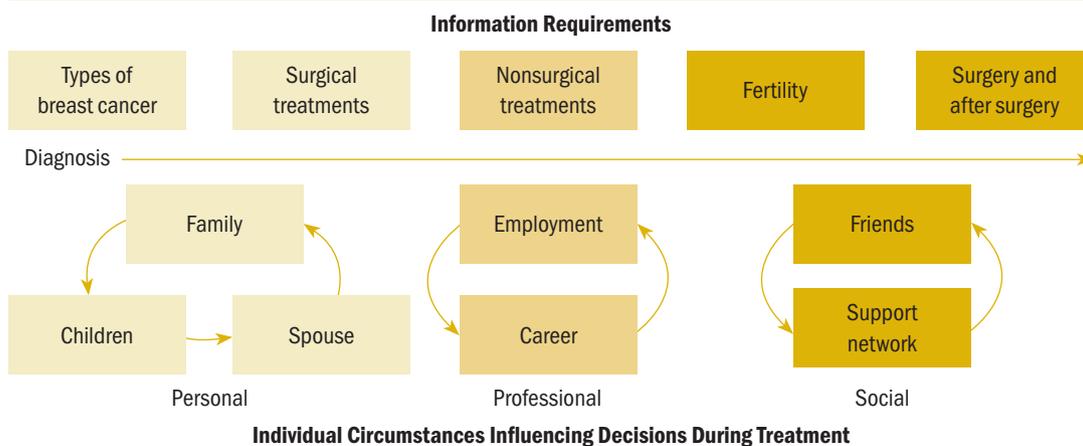
The young women also expressed a strong desire to keep control of the effect that having treatment would have on their professional and financial lives, observed, for example, in how radiation therapy was scheduled around the working week to minimize disruption caused by fitting in appointments.

They said they recommended more treatment, and I said, “Is it really necessary?” And I explained my reasons, why I was reluctant to, because I didn’t want to take months off work, which in hindsight sounds ridiculous, but it was something that was really worrying me because how are you going to manage financially? (Megan, age 39 years)

Work [was] really good, which was nice, but then, I only used to take the day off that I was having chemotherapy. It was always on a Thursday. Friday’s always my day off, and then I’d work again on Saturday and, no matter what, I had it in my head I was only going to take the Thursday off, and that would be it. (Jane, age 29 years)

The information requirements and decisions made were specific to the individual circumstances of women, creating a tension that started at diagnosis and expanded throughout treatment. The changing information requirements throughout treatment are represented in Figure 3.

FIGURE 3. Information Requirements in the Context of Individual Circumstances According to Semistructured Interviews



Discussion

In this study, young women reported the information that was relevant to them at the time of making a decision regarding surgical treatment for breast cancer, as well as information required about other types of treatment following surgery. Although some of the information categories reported in this study may be relevant to women in other age groups (e.g., practicalities of being in the hospital), some aspects are more relevant to younger women (e.g., how treatment affects professional life or family planning). The current authors note that this study did not aim to compare the needs of women in different age groups, but rather to report the experiences of young women (aged 40 years or younger) making decisions regarding treatment for breast cancer at an age when this diagnosis is not likely to be expected. Participants in this study expressed needs to receive information related to all aspects of treatment, not only surgical, even if the relevance of this information varies from the time of making or participating in surgical decisions to later stages of treatment.

Through the analysis of the narratives, an interaction between the information required and the individual circumstances of the women was also identified. Information required at each stage of the treatment pathway were specific to the life circumstances of each young woman, resulting in a decision-making process where young women assessed the urgency of recovering health against the disruption to life caused by the treatment received. The interplay of individual circumstances involving family, social, and professional aspects of young women's lives that influenced the decisions about treatments offered affected the information that women required at different stages in the treatment pathway. Although type of surgery for primary treatment and the consequences and risks of each procedure were more relevant at diagnosis, other aspects of treatment (e.g., how attending radiation therapy sessions affects family or working life) gained precedence as treatment progressed. The constant tension between deciding the best course of treatment according to individual circumstances lasted through the course to recovery.

Women reported clear awareness of the complexities of having a finalized treatment plan before the primary surgical procedure was received. This did not seem to affect their psychosocial or emotional status because it was never mentioned when the women were asked about their feelings regarding their decisions or medical treatments.

KNOWLEDGE TRANSLATION

- Young women diagnosed with early-stage breast cancer require information at different time points along the treatment trajectory. Information needs are influenced by individual circumstances (e.g., marital status, career, children).
 - The types of information more useful to young women at the time of diagnosis and surgical treatment included clinical and practical aspects of their diagnosis and treatment.
 - The long-term effects on quality of life of a breast cancer diagnosis and treatment highlight the importance of ensuring that young women are well informed of the consequences and risks of the different treatment options.
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Health organizations and charities have created resources aimed at providing information tailored to young women diagnosed with breast cancer (Breast Cancer Care, 2017; Centers for Diseases Control and Prevention, 2016; CoppaFeel!, 2017). Regardless of these efforts, the women who participated in this study felt that there was not enough information available to them with respect to surgical procedures for primary treatment breast cancer, adjuvant treatments, practical aspects of having a surgery, postsurgical care, and long-term effects of treatment (premature menopause and changes to body image). Their views are consistent with studies that indicate that the psychosocial effect of cancer in younger people (Zebrack, 2011) and the long-term impact of cancer treatment on the quality of life of younger women (Geue et al., 2014) is not represented adequately in research. Addressing the effects of the latter has been identified as essential to improving the quality of life of young women with breast cancer (Fobair et al., 2006), particularly in a population where the impact of treatment expands over decades (Gilbert, Ussher, & Perz, 2010; Kinamore, 2008). In addition, researchers identified that, even when information is available, a need exists to develop mechanisms that allow the information to reach relevant patient groups (National Institute for Health and Care Excellence, 2013). Patient information packages aimed at younger populations must include short- and long-term effects of treatment and be available in multiple formats, which can more easily reach patients in this age group.

Familial predisposition to developing breast cancer and impact of treatment on fertility were two of the aspects that young women in this study identified as requiring special attention, similar to Australian studies of fertility-related concerns of young women

diagnosed with breast cancer (Peate et al., 2011; Peate, Meiser, Hickey, & Friedlander, 2009).

Patient decision aids have the potential to deliver information in a timely and useful way. From the women's reports on the effect of receiving a cancer diagnosis and the need to put the diagnosis in the context of their lives, the authors identified an important element for a decision aid. Decisions are not only about facts and figures, but also about how young women think and feel about which option to choose and the effect that their choices are likely to have on their lives. The young women in this study expressed the need to receive tailored information that takes into consideration the needs associated with the stages in life when families are being planned or raised and careers are being developed.

Limitations

Recognizing the limitation of the research that results from the sample size, it is important to restrict the applicability of the findings to populations that meet the study inclusion criteria. The current findings cannot be generalized. However, the participants in this study were recruited from one cohort study that randomly selected more than 2,900 young women aged 40 years or younger with a diagnosis of breast cancer. A subsample from such a large cohort is likely to provide an accurate representation of the views of young women. A second limitation results from the retrospective design of the study in which participants were asked to remember their treatment experiences at diagnosis; therefore, recall bias must be considered. The consequence of bias may be that women were offered detailed information on the aspects that they reported not to have been offered, but the completeness of their recollections may not have been comprehensive.

Implications for Nursing

Findings from this study can be used to promote shared decision making. In the healthcare context, the essence of shared decision making is a collaboration among clinicians, nursing staff, and patients to reach a decision about treatments. Shared decision making requires that patients are well informed of their options. The categories of information reported in this study can be used by nursing staff to guide conversations in presurgical assessment clinics, ensuring that patients understand treatments, risks, and implications of different surgical procedures.

In addition, recognition of the changing requirements for information as treatments progress can

help staff to tailor the structure and sequence of patient decision aids, booklets, and information packages in ways that are most helpful to the patient.

Conclusion

The specific informational needs of young women are not currently supported. Additional factors were identified by this group to support their shared surgical decision making. Priority of these factors was largely influenced by each patient's circumstances; however, consensus existed regarding informational requirements. Resources to deliver information in a timely manner to young women at the time of breast cancer diagnosis need to be developed.

Patients with access to the most relevant information at the time of making a treatment decision feel better informed about treatment and, as a result, have less decisional conflict and a likely positive effect on quality of life. At diagnosis, clinicians may be required to provide patients with a supportive atmosphere in which women feel more prepared to voice their concerns, values, and preferences regarding the treatment path chosen.

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All authors contributed to the conceptualization and design. Gerty completed the data collection. Recio-Saucedo, Gilbert, Gerty, Cutress, and Foster provided the analysis. Recio-Saucedo, Gilbert, Gerty, Cutress, Eccles, and Foster contributed to the manuscript preparation.

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