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In the Moment: Women Speak About Surgical Treatment Decision Making Days After a Breast Cancer Diagnosis

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A diagnosis of breast cancer will affect the lives of one of every eight women in the United States (American Cancer Society, 2007), launching them into a stressful period of uncertainty and rapid, life-changing decision making (Hewitt, Herdman, & Holland, 2004). Most women diagnosed with early-stage breast cancer are candidates for the equally efficacious treatments of lumpectomy and radiation or mastectomy with or without reconstructive surgery (Fisher et al., 2002). Studies of women's surgical treatment decision making have shown that, when offered a choice between these options, women vary in their desired preferences for information and the degree to which they wish to participate in the decision-making process. In general, younger and more educated women desire more information and participation in decision making than older and less educated women (Beaver, Luker, Owens, Leinster, & Degner, 1996; Bilodeau & Degner, 1996; Hawley et al., 2007; Petrisek, Laliberte, Allen, & Mor, 1997; Wallberg et al., 2000), although individual variation among women exists (Degner et al., 1997; Hack, Degner, & Dyck, 1994). These studies also identified that, regardless of age, women often participate in the decision-making process more or less than they desire.

Identifying which women desire more or less involvement in surgical treatment decision making and matching that degree of involvement, although difficult (Hawley et al., 2007), may increase women's satisfaction and decrease decision regret (Lantz et al., 2005). Active participation, however, regardless of women's preferences for involvement, also has been found to support better psychosocial outcomes for women (Deadman, Leinster, Owens, Dewey, & Slade, 2001; Hack, Degner, Watson, & Sinha, 2006). Others argue that, regardless of women's preferences, they may not have adequate knowledge with which to make informed surgical treatment decisions (Fagerlin et al., 2006).

Lack of consensus among previous studies may be in part the result of solicitation of women's preferences

Purpose/Objectives: To explore the pretreatment thoughts and behaviors of women newly diagnosed with breast cancer regarding their surgical treatment decision-making experience.

Research Approach: Qualitative, descriptive.

Setting: A multispecialty breast center in the midwestern region of the United States.

Participants: 18 English-speaking women, aged 37–87 years, mean of 12 days postdiagnosis of clinical stage 0–II breast cancer.

Methodologic Approach: Open to semistructured interviews were conducted during the period following surgical consultation but prior to surgical treatment. Transcribed interviews, originally analyzed to identify the psychological processes of women in response to breast cancer diagnosis, were additionally analyzed using directed content analysis focusing on women's thoughts and behaviors related to their surgical treatment decision-making process.

Main Research Variables: Breast cancer surgery and decision making pretreatment.

Findings: Women's pretreatment thoughts and behaviors related to surgical treatment decision making were characterized by information processing, contemplating options, and interacting with others. Breast cancer information was used by women before the surgical consultation and after treatment decisions had been made. Treatment options were contemplated and preferences formed often before the initial surgical consultation. Women associated having options with a better prognosis. Age was a factor primarily in the type of information women desired.

Conclusions: Most women made their own surgical treatment decisions with ease, supported by the confidence instilled by their surgeons and oncology nurses.

Interpretation: The findings provide oncology nurses with insight regarding women's desire for and use of information and their contemplation of surgical options, therefore suggesting areas on which to focus clinical assessment and to test tailored interventions.

for information and participation in decision making months to years after their decisions had been made. The time that elapsed between women's diagnoses and data collection in the studies raises questions about

whether the women were able to accurately recall their preferences at the time of their decision-making experiences and to what extent decision regret confounded their views. Additionally, most of the studies used a structured response format, therefore limiting women's responses about their experiences.

In a review of the literature, Kiesler and Auerbach (2006) noted a lack of prospective research on patients' treatment decision making. With regard to breast cancer, only one previous study (Pierce, 1993) has qualitatively explored women's thoughts regarding surgical treatment decision making within the context of the pretreatment period (between diagnosis and surgery). Pierce identified three styles of decision making—deferring, delaying, and deliberating—with women who used the deferring style tending to be older.

Because the experience associated with surgical treatment decision making may be more related to women's long-term satisfaction (Katz, Lantz, & Zemencuk, 2001; Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002; Lantz et al., 2005), psychological well-being (Deadman et al., 2001), and quality of life (Hack et al., 2006) than the choice made, research should focus on the period of time during which the experience occurs. Through a greater understanding of women's thoughts and behaviors during the pretreatment period, clinical assessment and intervention may be tailored to facilitate improved satisfaction and well-being. Therefore, this article presents a qualitative content analysis of women's thoughts and behaviors associated with breast cancer surgical treatment decision making, captured in the women's own words during the pretreatment period.

Methods

Data for the current study were originally collected and analyzed with grounded theory methodology (Glaser, 1978, 1992, 1998, 2005; Glaser & Strauss, 1967) to identify the pretreatment cognitive-emotional processing women perform in responding to the traumatic event of a breast cancer diagnosis. The grounded theory analysis identified a basic social psychological process of acclimating that was defined as the mental work (e.g., guarding, meaning making, introspecting) women engage in to respond to the loss or potential loss of self-integrity initiated by the experience of being diagnosed with breast cancer (Lally, 2006). Surgical treatment decision making is a task performed by women during the pretreatment period while in the midst of acclimating to the experience of being diagnosed. Therefore, women shared their thoughts and behaviors during the interviews related to decision making in addition to their thoughts related to the experience of being newly diagnosed. Because the grounded theory analysis focused on the cognitive-emotional processing of the diagnosis itself and not the task of decision making,

an additional qualitative content analysis (Sandelowski, 2000) of the interview data was performed to describe the decision-making thoughts and behaviors expressed by these women during the pretreatment period. The findings of the qualitative content analysis are the focus of this article.

Analysis

Eighteen transcripts were analyzed through qualitative content analysis, with a directed approach (Hsieh & Shannon, 2005). Analysis was performed in two steps. First, the transcripts were read with a focus specifically on identifying instances of surgical treatment decision-making-related thoughts and behaviors (e.g., information gathering). Next, each decision-making-related instance was coded and categorized with either predetermined codes and defined categories from the initial grounded theory analysis or, if predetermined codes or categories did not fit particular incidences, new codes or categories. Newly created codes were compared to existing codes and categories to determine whether additional categories were needed or, rather, the new codes served to more fully define and subcategorize the predetermined categories (Hsieh & Shannon). Coding the interview data with a focus on decision-making-related incidents additionally contributed to and expanded the definition of three predetermined categories (information processing, contemplating options, and interacting with others) beyond what had been done during the initial coding for the grounded theory analysis. No new categories were required to fit the data. Figure 1 provides examples of coding within the three categories. Throughout the analysis, the researcher also wrote memos allowing for further elaboration of how factors such as age, for example, might influence the decision-making behaviors identified among the women interviewed.

An audit trail of interviews, coding, categories, and memos was maintained during the analysis. Nurse researcher colleagues reviewed and provided feedback to the researcher regarding agreement or disagreement with the final categorization of the data.

Setting and Sample

Setting: Interview data were obtained at a large, urban, multispecialty breast center in the midwestern region of the United States where two advanced oncology certified nurses (AOCNs[®]) play a central role in the care of women with breast cancer. Women were recruited by the nonresearcher AOCN[®] from her patient population.

Routine care was not altered for this study. An AOCN[®] informed women of their breast cancer diagnosis and provided immediate support, information, and care coordination by phone. Women met with the AOCN[®] for 30–45 minutes immediately prior to their surgical

Information Processing

- Preparing for appointments
- Too much information to absorb
- Surrogate information gathering
- Learning experience
- Information needs met
- Information decreased fears
- Information increased fears

Contemplating Options

- Decision correctness contemplated
- Age influences decision.
- Treatment better nowadays
- Strong reason or need is required for a mastectomy to occur.
- Mastectomy ends worry.
- Contemplating treatment choices
- Seeking finality

Interacting With Others

- Others not imposing beliefs
- AOCN® provided information.
- Physician influenced by information.
- Staff instills confidence.
- Confidence eliminates need for opinions.
- Decision concordance with others
- Surgeon gave surgical options.

Figure 1. Example of Coding Within the Decision-Making Categories

consultations to discuss the biopsy pathology as well as surgical and adjuvant therapies. Consultations occurred 0–8 days ($\bar{X} = 4.8$ days) following notification of diagnosis, with the exception of one woman (14 days) who received her initial diagnosis elsewhere. Educational and supportive information and resources were provided to each woman. Immediately following the surgical consultation, the AOCN® again met with each woman to answer questions and coordinate the plan of care, including additional consultations. Women were informed about the study at this time. The AOCN® continued to be available to these women throughout treatment. A resource library and support services also were available.

Sample: The study was approved by the institutional review boards of the researcher's academic institution and the agency where data were collected. Women were eligible who had been diagnosed within the prior three weeks with their first clinical stage 0–II breast cancer, had undergone surgical consultation with one of four general surgeons or a surgical oncologist, had been presented with surgical options, had not yet undergone surgical treatment, were able to speak and understand English, and were physically and psychologically able to participate in an interview. Recruiting women with an initial diagnosis of early-stage breast cancer who were eligible for either a mastectomy or lumpectomy ensured that the sample of women interviewed would have common experiences in the course of their initial care, including the task of surgical treatment decision making, about which to describe their thoughts and behaviors.

During the initial grounded theory analysis, women's age was identified as a factor that modified their cognitive-emotional processing of the diagnosis experience. Therefore, interviews were obtained from women varying widely in age to contribute to the developing theory.

Interviews

The researcher conducted open to semistructured interviews ranging in length from 25–90 minutes (following informed consent) from March through August 2005. Women were encouraged to tell their postdiagnosis stories, prompted with

Please think back to the day you were diagnosed . . . where you were, who was with you, what you were doing when you got the call [with the diagnosis]. Then tell me what the experience of being diagnosed with breast cancer has been like so far.

Additional probes were added as needed to expand on stories of decision making and surgical consultation. Four women were accompanied by a significant other, who, except for one instance, did not contribute to the interview. Interviews were audiotaped, professionally transcribed, and verified by the researcher.

Findings

The sample consisted of 18 women, aged 37–87 years, who were 6–21 days postdiagnosis ($\bar{X} = 12$ days) at the time of the interview. All of the women were Caucasian. The majority were college educated ($n = 12$) and married ($n = 13$). Table 1 provides data regarding age, disease stage, and surgical treatment choices. Surgical treatment decision making by women in the pretreatment period was characterized by information processing, contemplating options, and interacting with others.

Information Processing

Overall, the women felt that information about breast cancer was important, plentiful, and readily available and that their needs were met. Women wanted just enough information to satisfy themselves (which, for a few, was little to none) and attempted to manage the amount and timing of information to avoid becoming overwhelmed. One younger woman stated that

It seems like that first week was really information overload, we were in shock, and disbelief. . . . The information was good, but it was very bombarding. It wasn't really stressful, but it was overwhelming.

Another woman explained managing information.

If I don't like what I'm reading, I don't read it. If I don't want to know the side effects of a drug, I don't read it. . . . If I have to take it, I have to take it. I'll deal with it as I'm taking it.

Information also could increase fears.

I go to the surgeon, then he always goes into the worst case scenario, which you're just like, "Whoa! Wait a minute now. I thought that this was contained and, you know, it hasn't escaped or it hasn't spread." . . . So then you kind of take a couple of steps back.

Although the Internet, books, and friends were used for information, many sought little information beyond what was provided by the physician and AOCN®. Those using the Internet wanted information from reputable sites and limited their use to avoid overload.

I haven't done more than go to WebMD®, breast cancer, and read the five pages on it. . . . I thought, until I read all this, I'm not going to go on reading other things; I just have to prioritize, because you can really spend a lot of time online. Not that I wouldn't want to know, but that WebMD was a nice summary.

In some cases, women sought information for others who had higher information needs than themselves. Conversely, several women relied on others with higher information needs to be surrogate information gatherers. Some women were simply comforted knowing that others were gathering information, whereas other women also benefited through receiving information from their family and friends.

My first thought was, what if I do nothing. It's fine. It's just this tiny, tiny problem that's very confined. And, so then, of course, my dear daughter-in-law . . . found me a [Web] site. . . . Sometimes those are scarier than not knowing, I think. But, they were also very helpful and also told me that it would be foolish to think that I could just go along and do nothing.

If women gathered and used information on their own, they tended to do so at two primary times. The first was in preparation for the surgical consultation.

[We learned] apparently there were decisions to be made between surgeries and reconstruction. I don't think we read too much on radiation and [chemotherapy], but it was a good overview of everything, from the lymph nodes, all of that. . . . So we read that before we came in.

The second was when women described waiting to have a period of calm prior to surgery to read information from the clinic and others, although most often they had already made a treatment choice by that time. Three days after making her treatment decision at the surgical consultation, one woman stated

I've just started going through the pamphlets and such that I've gotten from the breast center. . . . I can

Table 1. Clinical Stage and Women's Surgical Treatment Decisions

Stage	Lumpectomy		Mastectomy ^a		Bilateral	
	n	Age Category ^b	n	Age Category ^b	n	Age Category ^b
0	2	Middle	–	–	1	Middle
I	2	Younger	1	Younger	1	Younger ^c
	5	Middle	–	–	1	Middle ^d
	1	Older	–	–	–	–
II	1	Middle	–	–	1	Younger
	2	Older	–	–	–	–
Total	13	–	1	–	4	–

N = 18

^aWith breast reconstruction unless otherwise noted

^bYounger is aged 44 years or less (n = 5), middle is aged 46–68 years (n = 10), and older is aged 78 years or more (n = 3).

^cSurgical decision not determined at time of interview

^dWithout breast reconstruction

see where I'm going to have more questions but I really think that the initial information that I've gotten, it's pretty overwhelming but I need to sit down and take the time to read through it and focus on it.

Age was not a defining factor in how much information women wanted or whether they used what was provided. One older woman preferred to receive information in person and gained most from "listening" during her appointments to set straight "horror stories" she had heard about breast cancer over the years. Another older woman, however, desired minimal information and put the clinic information folder out of her sight so as not to be reminded of her cancer. Younger women also exhibited a range of behaviors from extensive information seeking to wanting little information at all. Women of all ages used information that answered their questions and avoided information that upset them emotionally. Older women desired information about surgical recovery and maintaining their independence, whereas younger women were already looking ahead for information about postoperative treatment.

Contemplating Options

Surgical treatment decision making for early-stage breast cancer typically involves making a choice between lumpectomy or mastectomy with or without breast reconstruction.

Choosing a surgical treatment: Women often arrived at the surgical consultation with either a strong preference for mastectomy or lumpectomy or the belief that they may be required to have one over the other. Women derived their preferences or anticipations about treatment options in one of three ways: research done

before the surgical consultation, perceived knowledge and beliefs about breast cancer treatment, or a feeling that lumpectomy or mastectomy would simply suit their needs better.

I thought about it before I came in and talked to the [AOCN®] and the surgeon. . . . That happened to my mom many years apart, I don't want to, 10 or 20 years from now, have cancer in the other breast and then have to have that one removed when I'm elderly. So I don't know, I guess I thought [bilateral mastectomy] is the easiest way to do it.

Women sometimes found that they had anticipated the need for mastectomy incorrectly.

In the consultation with the surgeon, I went in thinking I was having a mastectomy. You know, that's what I had planned on, based on the reading I had done. I mean, I knew it was a decision that needed to be made, but I also didn't have all the facts. . . . I knew it didn't sound like he would make the decision, but I'm sure if it needed to lean one way versus the other, based on the specific situation, I'm sure we would know about it [from the surgeon].

Women typically did not share their initial preferences or the recommendation they anticipated from the surgeon early in the surgical consultation, if at all, but rather as the consultation unfolded, women mentally compared their initial preferences against the information and options they heard from the surgeon.

Motivations for choice: Women's surgical treatment decisions were motivated by several factors: the desire to eliminate future inconvenience and worry about cancer balanced by avoiding mastectomy unless medically required, maintaining physical function and appearance, and rapid recovery.

Women indicated that they would have agreed to undergo mastectomy if their surgeons had made that recommendation. However, when no recommendation was made, some women saw mastectomy as an option that might bring them peace of mind. Most of the women, however, felt that mastectomy should be reserved only for the worst breast cancers or when recommended out of medical necessity. A younger woman, looking for finality, described her thoughts.

She [a survivor] had the mastectomy—both sides. That helped a little bit because I was thinking the same things that she was thinking. She was 36 . . . she didn't want to go through it again. She's been cancer-free ever since. . . . I'm young. I don't want to go through this again. I don't want to experience this again. I know there's a chance of it.

Another younger woman felt differently.

[An acquaintance] told me she thought it would be better to have a mastectomy because then I wouldn't

have to worry and go through the radiation. I told her she was crazy. I can't do that. Unless I have to, I want to keep all my body parts. That just didn't make sense to me. Why would I want to do that if I don't have to?

Older women saw advanced age as an advantage. Age protected them from worrying about recurrence or being greatly concerned over loss of their breasts; however, they still elected lumpectomy.

If I were young, I would really want the lumpectomy. . . . I prefer the lumpectomy, but if they find out I need a mastectomy, okay. And I think my age has to do with that.

Breast appearance was mentioned as a concern for both lumpectomy and mastectomy, but only by a few women. Maintaining and returning quickly to previous physical function was of, perhaps, equal or greater concern for women of all ages when making their surgical treatment decisions. One younger woman, deciding whether to undergo breast reconstruction, stated

I guess my biggest thing is my function. Because I'm so active and my biggest fear is like the lymphedema and all that, you know . . . so that scares me more than the cosmetic.

Decision-making ease: Women expressed varying degrees of difficulty when making their surgical treatment decisions, but mostly felt that it was "easy." All but one woman had made a surgical treatment decision at the time of the interview and most had declared their decisions days earlier at the first surgical consultation. As one woman who desired control in her treatment decision said,

I didn't know I was going to have a choice. I thought you [providers] were going to tell me what I had to do. That was the easiest decision I've had to make in a long time.

Most women seemed quite comfortable and certain about their decisions; however, some continued to revisit their choices.

So, there's been the thought in my mind, did I make the right decision [lumpectomy] and I think I did. But, I also have a tendency to try to go back and agonize over decisions. But, I do keep coming back to the same spot, [which is] that I think I made the right decision.

Another woman, yet undecided about her choice despite extensive information gathering, was concerned about making the "correct decision" and understanding as much as possible.

It's been overwhelming . . . trying to make a decision, the best decision of what's going to happen. . . . What are my options? What's the plastic surgery? I didn't

understand there are four types of mastectomy. I didn't know that until my sister pointed that out to me. . . . I didn't understand all that, and I still don't understand everything.

Interacting With Others

Women experienced multiple interactions with healthcare providers and family and friends who affected their decision making through provision of information and options, as well as support of their decisions.

Healthcare providers: Most women felt satisfied with the manner in which information and options were provided by their surgeons, the AOCN[®], and other care team members. As one woman expressed,

I really appreciated [the surgeon]. My husband did, too, because he just talked right to you, not past you. Sometimes people just kind of tell you something, and they don't care if you don't understand. He makes you understand. "Do you have any questions you want to ask me? How do you feel about it? Are you okay?" Most people aren't that way.

She also described that the surgeon's demeanor made her feel cared for and instilled trust, which, in turn, helped her decide to choose the surgical option toward which she believed the surgeon was leaning.

Surgeons presented women with all surgical options but rarely provided a firm recommendation for either lumpectomy or mastectomy. Some women were ambivalent, wishing for a recommendation but recognizing choice as a positive prognostic sign.

Sometimes it's better to just have someone say, "Here's what you should do." . . . It's important for me to know what choices there are and what do I need to know in order to make this choice. . . . So, I like being able to have some choices even though there's a part of me that doesn't. . . . I like things that are clear; here's the way we're going to go. But, if that were the case, then it would be worse; my situation would be worse.

Women of all ages expressed surprise that their surgeons did not make a recommendation but drew confidence from the surgeons' support of their choices.

I was in the mindset of thinking the surgeon's going to read the biopsy report and he's going to come up with recommendations . . . when in reality, it's my decision. I didn't know that . . . it's like, "Oh, wow! Okay, I don't feel that I need a mastectomy and I want a lumpectomy." . . . And, I looked at [the surgeon] and I said, "Now, if you said that I would need a mastectomy then I would probably look at you and say I want a second opinion."

The women in this study made their own decisions, whether they felt the surgeon had agreed with their

choices or they had opted for the implied choice of the surgeon. Most felt comfortable in decision making, aided by the confidence they felt in their surgeons, the AOCN[®], and other team members. This confidence reduced women's desire for a second surgical opinion.

I had one friend that said to get a second opinion. . . . A second opinion? I've had three pathologists read this report. . . . I am well satisfied with what they're doing, and I believe I'm all taken care of.

Family, friends, and others: The women used prior knowledge of other women's past surgical treatment experiences and comparable risk factors when making their own surgical decisions, even if they had never met these other women. Women also strategized about who should be told about the diagnosis to avoid potentially unwanted treatment advice, which appeared successful because most of the women received support from their families and friends regarding their surgical choices, regardless of the option chosen. One woman described how her mother and sisters offered their opinions when requested.

I asked my mom, "If you were my age, what would you do?" She goes, "I'd probably do the mastectomy because you do have a lot of life. You can get rid of it, take care of it, and get it done now." My other two sisters haven't said anything, but my one sister said, "It's basically up to you what you decide. I can see you going either way." So they're basically leaving it up to me, but my mom did let me know.

Women made it clear that the surgical treatment decision was their own decision to make. While married women consulted their spouses, husbands' input was primarily supportive and not directive in nature. According to the women, their husbands were mainly focused on whether the surgery chosen would be the most likely to cure the cancer and wanted their wives to feel comfortable with the surgical decision regardless of whether the choice was lumpectomy or mastectomy.

Discussion

Eighteen women with clinical stage 0–II breast cancer were interviewed 6–21 days postdiagnosis, following surgical consultation but prior to treatment, to better elucidate the thoughts and experiences of women during the pretreatment period. All women received the clinic's usual education and support services of an AOCN[®] who met with women before and after surgical consultation. A directed content analysis of the interview data was performed to describe the thoughts and behaviors of these women related to their surgical treatment decision-making experiences. Both the pretreatment timing of the interviews, while women were in the midst of the decision-making experience, and use of open to semistructured interviews contributed to

capturing data that provide new insights regarding when and how women make surgical treatment decisions and use breast cancer treatment information.

The findings of the current study support earlier findings indicating that older women may prefer more information focused on self-care (Bilodeau & Degner, 1996; Degner et al., 1997) and that variations exist among women regarding the amount of information about breast cancer that they desire (Degner et al.; Hack et al., 1994). An interesting finding was that women in the current study who used breast cancer informational resources described doing so at two time points—before the surgical consultation to prepare for the appointment or days after the surgical consultation—although, in most cases, the surgical treatment decision had been made. The first point is not entirely surprising because people undergoing cancer treatment often gather information in preparation for physician appointments (Dickerson, Boehmke, Ogle, & Brown, 2006). In the current study, however, women described gathering information to become knowledgeable about breast cancer and treatment options even before hearing the surgeon's initial explanation of the new diagnosis and treatment options. There seemed to be a need among some women to appear knowledgeable and avoid being surprised by new information during the initial consultation.

Other women in this study did not review informational materials in preparation for their surgical consultations and also reported having not done so even a week after the consultation. This finding highlights the importance of the information conveyed to women by surgeons and nurses during the initial surgical consultation. In addition, the information conveyed during the surgical consultation appears even more significant when considering that the majority of women in this study declared their surgical treatment choices before leaving the surgeon's office. In other words, many women obtained most of the information on which they based their surgical choices from the interactions with the AOCN® and surgeon on the day of the surgical consultation and only later reviewed informational materials to further educate themselves. This finding differs from other studies that indicate women use a wide variety of information sources to make their surgical treatment decisions (Bilodeau & Degner, 1996; Fagerlin et al., 2006). Except for one woman in the current study, women did not delay making their surgical decisions to use a variety of informational resources. When women in the earlier studies were asked about information used in their decision-making process, they may have defined the process for themselves as extending beyond actually declaring a choice (Lam, Fielding, Chan, Chow, & Or, 2005). This seems to be the case in the current study because many women used informational resources to add to their breast cancer treatment knowledge after they had made their treatment decisions and when they

had a greater opportunity to assimilate and reflect upon the information and the decisions they had made.

Fagerlin et al. (2006) proposed that a lack of time taken by women to obtain and process accurate information before making a treatment decision may result in women making uninformed surgical treatment decisions. This did not seem to be the case in the current study. Although women's breast cancer knowledge was not measured in this study, the women reported having sufficient information and indicated that their ability to reach a surgical treatment decision was enhanced by the manner in which information was provided by the AOCN® and surgeon. Family and friends also were used by women in this study to gather and filter information for them when they wished to protect themselves from being overwhelmed. Therefore, the ability to call upon informed people, from the time of diagnosis, may have assisted many women to make what they felt were informed treatment choices immediately following the surgical consultation, without using additional informational resources. This finding supports that of an earlier study that found personal resources of information were more valued by women than written materials (Bilodeau & Degner, 1996).

An additional insight provided by the current study is that women contemplated treatment options and developed preferences for (or assumptions about) their surgical treatment before options were presented at the surgical consultation. Women, however, did not always share their preferences and assumptions with their surgeons. Clinically, this finding is important because patients with cancer often do have treatment preferences (Deadman et al., 2001; Till, Sutherland, & Meslin, 1992), but successful physician-patient communication results when the needs of both parties are shared (Hack, Degner, & Parker, 2005). Although patients report sharing or collaborating (Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Sepucha, Ozanne, Silvia, Partridge, & Mulley, 2007), *shared decision making* remains inconsistently defined and confounded with *informed decision making* (Moumjid, Gafni, Bremond, & Carrere, 2007), a one-way communication by the physician with the patient making the decision (Charles, Gafni, & Whelan, 1999).

In the current study, women's lack of sharing their preferences with their surgeons and the surgeons' lack of making treatment recommendations resulted in what was more likely *informed* than *shared* decision making. Nevertheless, many women in this study reported feeling at ease with making a treatment decision. The current study findings support earlier studies in which women were able to easily make their surgical treatment decisions based on their values when provided with treatment options (Stanton et al., 1998). An interesting finding of the current study, however, is that women considered the fact that they were presented with options and had control over their

choices to be a positive prognostic indicator. The support women gained from feeling positive about their prognosis helped balance their surprise at needing to take an active role in their treatment decision making when their surgeons did not provide a definitive treatment recommendation.

Previous research has examined women's satisfaction with the decision-making process based on whether women's preferences for participation in decision making were matched by their actual participation (Lantz et al., 2005). Role preference was not assessed, nor was usual care altered in the current study; therefore, the degree to which taking an active role in treatment decision making matched these women's preferences is unknown. Based on the interviews, however, it can be concluded that women felt they were presented with surgical options and understood that the surgical treatment decision was their own to make. Whether women felt their surgeons had agreed with their predetermined preferences, women changed their preferences upon hearing information presented at the surgical consultation, or women chose what they presumed to be the implied recommendation of the surgeon, most did not express dissatisfaction with the process.

Although making a treatment decision may not have been the preferred role of every woman in the study, the women reported gaining confidence in their decision-making role through the confidence and support they felt from their surgeons, the AOCN®, and clinic staff. Friendliness and supportiveness shown by surgeons has been shown to benefit patient satisfaction and adjustment (Kiesler & Auerbach, 2006; Roberts, Cox, Reintgen, Baile, & Gibertini, 1994), as has patients playing an active decision-making role (Hack et al., 2006) and selecting their treatment (Deadman et al., 2001) despite decisional-role preference. Therefore, a question for future research is whether the varying success with which decisional-role preferences of women are actually matched in clinical practice (Hawley et al., 2007) may be compensated for by the confident and supportive demeanor of surgeons, nurses, and clinic staff, as the findings of this current study seem to suggest.

Most women in the current study chose to undergo lumpectomy, but several women did choose mastectomy or bilateral mastectomy. Previous studies have identified similar results (Katz et al., 2005) and shown that women may make treatment decisions based on their desire to avoid radiation therapy associated with lumpectomy (Sepucha et al., 2007). The current study also identified that women of all ages and stages of disease who chose lumpectomy viewed mastectomy as having the potential to reduce their fears of recurrence but believed that mastectomy should be reserved for breast cancers that were more advanced than their own. Although many women who chose lumpectomy indicated that choosing

mastectomy would be an over-reaction to their current fears and a choice they may later regret, women who chose mastectomy had just as firm of a conviction that their decision fit with their knowledge of themselves, what they knew of other women's experiences, and their values.

Conclusions and Implications

Women in this study were found to differ in their acquisition and use of breast cancer information during the pretreatment period. Many of the women had a preference for either mastectomy or lumpectomy before they met with their surgeons, but did not always share their thoughts. Women wanted to be informed of the surgical treatment options and the surgeon's recommendation. Given treatment options and a feeling of confidence conveyed by their surgeons and breast center staff, most women easily made a surgical treatment decision before leaving the surgeon's office.

Because women may have obtained breast cancer information varying in quantity and quality before the surgical consultation, assessment of women's prior knowledge and treatment preferences during the surgical consultation, or by an advanced practice nurse within the period between diagnosis and consultation, may reduce women's misunderstandings about treatment options, promote discussion of women's values, and build the confidence women found valuable in supporting their decision making. Nurses also should assess women's preferences for the amount, timing, and sources of information desired and not make assumptions based on age alone. It also is important for nurses to recognize that women may not be their own information gatherers and to support the people in women's lives who fulfill that role. Finally, women should be supported in decision making and allowed sufficient time during the pretreatment period to continue gathering and reviewing information, even if they appear to have already made a treatment choice.

The current study is one of the few to explore the thoughts and behaviors of women related to surgical treatment decision making within the pretreatment period and contributes to nurses' ability to assess and design tailored interventions to address women's needs during this period. A limitation of this study, however, is that the data were originally collected with a focus other than woman's surgical treatment decision making. Additionally, the study did not include minority women or women who had not received care from an AOCN®. Therefore, future studies focusing on the decision-making needs of women during the pretreatment period while addressing the limitations of this study should be performed to add to the knowledge of this important time in the lives of women with breast cancer.

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References

- American Cancer Society. (2007). *Breast cancer facts and figures 2007–2008*. Atlanta, GA: Author.
- Beaver, K., Luker, K.A., Owens, R.G., Leinster, S.J., & Degner, L.F. (1996). Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nursing*, 19(1), 8–19.
- Bilodeau, B., & Degner, L.F. (1996). Information needs, sources of information, and decisional roles in women with breast cancer. *Oncology Nursing Forum*, 23(4), 691–696.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Social Science and Medicine*, 49(5), 651–661.
- Deadman, J.M., Leinster, S.J., Owens, R.G., Dewey, M.E., & Slade, P.D. (2001). Taking responsibility for cancer treatment. *Social Science and Medicine*, 53(5), 669–677.
- Deber, R.B., Kraetschmer, N., Urowitz, S., & Sharpe, N. (2007). Do people want to be autonomous patients? Preferred roles in treatment decision making in several patient populations. *Health Expectations*, 10(3), 248–258.
- Degner, L.F., Kristjanson, L.J., Bowman, D., Sloan, J.A., Carriere, K.C., O'Neil, J., et al. (1997). Information needs and decisional preferences in women with breast cancer. *JAMA*, 277(18), 1485–1492.
- Dickerson, S.S., Boehmke, M., Ogle, C., & Brown, J.K. (2006). Seeking and managing hope: Patients' experiences using the Internet for cancer care [Online exclusive]. *Oncology Nursing Forum*, 33(1), E8–E17. Retrieved July 22, 2009, from <http://ons.metapress.com/content/c21318332p085456/fulltext.pdf>
- Fagerlin, A., Lakhani, I., Lantz, P.M., Janz, N.K., Morrow, M., Schwartz, K., et al. (2006). Breast cancer patients and their knowledge about treatment. *Patient Education and Counseling*, 64(1–3), 303–312.
- Fisher, B., Anderson, S., Bryant, J., Margolese, R.G., Deutsch, M., Fisher, E.R., et al. (2002). Twenty-year follow-up of a randomized trial comparing total mastectomy, lumpectomy, and lumpectomy plus irradiation for the treatment of invasive breast cancer. *New England Journal of Medicine*, 347(16), 1233–1241.
- Glaser, B.G. (1978). *Advances in the methodology of grounded theory: Theoretical sensitivity*. Mill Valley, CA: Sociology Press.
- Glaser, B.G. (1992). *Emergence versus forcing: Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.
- Glaser, B.G. (1998). *Doing grounded theory: Issues and discussions*. Mill Valley, CA: Sociology Press.
- Glaser, B.G. (2005). *The grounded theory perspective III: Theoretical coding*. Mill Valley, CA: Sociology Press.
- Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine de Gruyter.
- Hack, T.F., Degner, L.F., & Dyck, D.G. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Social Science and Medicine*, 39(2), 279–289.
- Hack, T.F., Degner, L.F., & Parker, P.A. (2005). The communication goals and needs of cancer patients: A review. *Psycho-Oncology*, 14(10), 831–845.
- Hack, T.F., Degner, L.F., Watson, P., & Sinha, L. (2006). Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psycho-Oncology*, 15(1), 9–19.
- Hawley, S.T., Lantz, P.M., Janz, N.K., Salem, B., Morrow, M., Schwartz, K., et al. (2007). Factors associated with patient involvement in surgical treatment decision making for breast cancer. *Patient Education and Counseling*, 65(3), 387–395.
- Hewitt, M., Herdman, R., & Holland, J. (2004). *Meeting psychosocial needs of women with breast cancer*. Washington, DC: National Academies Press.
- Hsieh, H.F., & Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288.
- Katz, S.J., Lantz, P.M., Janz, N.K., Fagerlin, A., Schwartz, K., Liu, L., et al. (2005). Patient involvement in surgery treatment decisions for breast cancer. *Journal of Clinical Oncology*, 23(24), 5526–5533.
- Katz, S.J., Lantz, P.M., & Zemencuk, J.K. (2001). Correlates of surgical treatment for women with noninvasive and invasive breast cancer. *Journal of Women's Health and Gender-Based Medicine*, 10(7), 659–670.
- Keating, N.L., Guadagnoli, E., Landrum, M.B., Borbas, C., & Weeks, J.C. (2002). Treatment decision making in early-stage breast cancer: Should surgeons match patients' desired level of involvement? *Journal of Clinical Oncology*, 20(6), 1473–1479.
- Kiesler, D.J., & Auerbach, S.M. (2006). Optimal matches of patient preferences for information, decision making, and interpersonal behavior: Evidence, models, and interventions. *Patient Education and Counseling*, 61(3), 319–341.
- Lally, R.M. (2006). Theory of acclimation in newly diagnosed breast cancer patients. *Dissertation Abstracts International-B*, 67(04). Retrieved July 30, 2009, from <http://www.lib.umi.com/dissertations/fullcit/3212062>.
- Lam, W.W.T., Fielding, R., Chan, M., Chow, L., & Or, A. (2005). Gambling with your life: The process of breast cancer treatment decision making in Chinese women. *Psycho-Oncology*, 14(1), 1–5.
- Lantz, P.M., Janz, N.K., Fagerlin, A., Schwartz, K., Liu, L., Lakhani, I., et al. (2005). Satisfaction with surgery outcomes and decision process in a population-based sample of women with breast cancer. *Health Services Research*, 40(3), 745–767.
- Moumjid, N., Gafni, A., Bremond, A., & Carrere, M.O. (2007). Shared decision making in the medical encounter: Are we all talking about the same thing? *Medical Decision Making*, 27(5), 539–546.
- Petrisek, A.C., Laliberte, L.L., Allen, S.M., & Mor, V. (1997). The treatment decision-making process: Age differences in a sample of women recently diagnosed with nonrecurrent, early-stage breast cancer. *Gerontologist*, 37(5), 598–603.
- Pierce, P.F. (1993). Deciding on breast cancer treatment: A description of decision behavior. *Nursing Research*, 42(1), 22–28.
- Roberts, C.S., Cox, C.E., Reintgen, D.S., Baile, W.F., & Gibertini, M. (1994). Influence of physician communication on newly diagnosed breast patients' psychologic adjustment. *Cancer*, 74(Suppl. 1), 336–341.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334–340.
- Sepucha, K., Ozanne, E., Silvia, K., Partridge, A., & Mulley, A.G., Jr. (2007). An approach to measuring the quality of breast cancer decisions. *Patient Education and Counseling*, 65(2), 261–269.
- Stanton, A.L., Estes, M.A., Estes, N.C., Cameron, C.L., Danoff-Burg, S., & Irving, L.M. (1998). Treatment decision making and adjustment to breast cancer: A longitudinal study. *Journal of Consulting and Clinical Psychology*, 66(2), 313–322.
- Till, J.E., Sutherland, H.J., & Meslin, E.M. (1992). Is there a role for preference assessments in research on quality of life in oncology? *Quality of Life Research*, 1(1), 31–40.
- Wallberg, B., Michelson, H., Nystedt, M., Bolund, C., Degner, L.F., & Wilking, N. (2000). Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. *Acta Oncologica*, 39(4), 467–476.