The Experience of Using Decisional Support Aids by Patients With Breast Cancer

Margaret D. Lacey, PhD, RN, AOCN®

Purpose/Objectives: To explore the lived experience of patients with breast cancer using decisional support aids during the prediagnosis, diagnosis, and treatment phases of their disease.

Research Approach: Descriptive, phenomenologic.

Setting: Community-based.

Participants: 12 women, ages 38–68, diagnosed with and treated for breast cancer.

Methodologic Approach: Audiotaped interviews were transcribed and analyzed according to Colaizzi’s method.

Main Research Variables: Use of decisional support aids.

Findings: Six major themes were identified: being too stressed and overwhelmed to make a decision, feeling an internal sense of urgency to have the breast cancer managed quickly, trusting the opinion and advice of physicians about treatment decisions, appreciating the importance of support from family and friends in decision making, finding nurses were unavailable or uninvolved in decision making initially, and missing out on the benefits of a multidisciplinary approach.

Conclusions: Being presented with the diagnosis of breast cancer evokes a range of feelings and emotions. By identifying, explaining, and expressing their accounts, participants revealed their lived experience and its meaning. The description of this phenomena may assist nurses to discover the lived experience and the meanings and essential structure of that experience.

Interpretation: Oncology nurses need to be aware of and understand the issues surrounding the decision-making process of patients with breast cancer. Gaps clearly exist in the information and support provided to these participants. Nurses must target areas that are insufficient in providing decisional support aids and plan for partnerships to ensure a multidisciplinary approach in this process.

Key Points . . .

- The complexity of treatment options and the emotional impact of the diagnosis present patients with breast cancer with overwhelming anxiety that requires definitive, supportive interventions.

- Healthcare providers, particularly oncology nurses, are important decisional supports throughout the treatment process. Oncology nurses, physicians, psychologists, social workers, and other healthcare team members need to understand more about the dynamics of the decision-making process.

- The availability of decisional support aids (e.g., written materials, videos) in physician’s offices, smaller community agencies, and surgicenters that lack the expertise of an oncology nurse would lend support to women prior to diagnosis.

Breast cancer is a serious healthcare problem and a major public health challenge in the United States and countries throughout the Western Hemisphere (Mettlin, 1999). The American Cancer Society (2002) estimated that 203,500 new cases of breast cancer will be diagnosed and about 39,600 will die from the disease in the United States in 2002.

A great deal of research has been generated about the psychosocial impact of breast cancer diagnosis and treatment, as well as methods to enhance adjustment to the disease. In their comprehensive review, Glanz and Lerman (1992) cited a number of factors that mediated the psychosocial implications of breast cancer. They identified information and participation in decision making as problematic for women and suggested that more research was needed to facilitate women’s decision-making abilities. Thus, the purpose of this study was to explore and describe the lived experience of patients with breast cancer using decisional support aids during the prediagnosis, diagnosis, and treatment phases of their disease. Decisional support aids were defined as educational programs and literature (e.g., written resources, audio and video materials, the Internet), individual counseling, informed and unbiased (i.e., not promoting or valuing one treatment modality over another) physicians and nurses, multidisciplinary healthcare teams, and patient and family involvement in the decision-making process. A descriptive, phenomenologic approach (Colaizzi, 1978) was used for this study. This research method draws on participants’ accounts to discover the lived experience and the meanings and essential structure of that experience.

Background

Research pertaining to decision making and patient participation in medical treatment evolved out of the discipline

Margaret D. Lacey, PhD, RN, AOCN®, is a chair and an associate professor in the Department of Nursing at Eastern University in St. David’s, PA. This study was funded by an ONS Foundation research grant, supported by Chiron Therapeutics. (Submitted October 2001. Accepted for publication March 28, 2002.)

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of health education. Roter (1977) discussed the philosophy of health education as the science of self-help; health-education tenets strive for client self-sufficiency by assisting patients and consumers to assume responsibility for their own bodies, health, and actions. Roter labeled this philosophic approach “patient activation.”

Roter (1977) applied Green and Lewis’ (1986) PRECEDE model of educational diagnosis to a health-education problem. In this model, enabling, predisposing, and reinforcing are pertinent to patient-provider communication. Roter used an experimental design to assess the effectiveness of a patient-education intervention to increase patient participation during a medical visit. She talked with patients in a waiting room to determine the problems and questions they were unlikely to discuss with their physician. Roter recorded the patients’ questions and encouraged them to ask these questions when examined by physicians. Roter used Lewin’s model because it demonstrates the relationship between new information and the roles of others in decision making. The results of Roter’s study revealed a statistically significant increase in the number of direct questions asked by the experimental group over the control group.

Barrere (1992) described a psychosocial model for patient decision making as the goal-directed communication between the nurse provider and client. The five techniques for this type of communication were rephrasing, personalizing, gentle confrontation, refocusing, and facilitating. Barrere suggested that nurses give optimal psychosocial support and guidance to every woman undergoing a biopsy for breast cancer regardless of the results. Furthermore, she suggested that ambulatory surgery nurses should direct clients with positive results to an oncology clinical nurse specialist who can answer questions about complex treatment options.

Lauver and Angerame (1993) interviewed 40 women from the ages of 26-73 with no history of breast cancer about the factors that precipitate women to seek or avoid prompt care for breast cancer symptoms. Although the findings were multidimensional regarding clients’ perceptions as they related to outcomes, the importance of client-physician interaction in the care-seeking process was identified. Lauver and Angerame suggested that providers, especially those in ambulatory settings, can reinforce clients’ accurate perceptions and clarify inaccurate perceptions about the care-seeking process. The researchers recommended that providers acknowledge and empathize with clients’ anxieties while providing psychosocial support.

Hughes (1993) investigated decision making in women with breast cancer. In the study, the relationship between information about treatment alternatives and patients’ treatments choices was examined. Using a 26-item observer checklist, the amount and nature or manner in which clinical information was presented during an initial clinic visit at a large tertiary medical center were recorded. The findings suggest that the amount and manner of information given was not related to treatment selection. However, treatment decisions were related to information given prior to the initial visit. Hughes recommended that nurses consider determining what patients already have been told about breast cancer and the various treatment modalities and correct any misconceptions before providing additional information.

Neufeld, Degner, and Dick (1993) developed a nursing intervention strategy to provide decisional support for patients with cancer who want to participate in medical treatment decisions. Their framework for understanding decision making was based on the concepts of commitment and control. They explained these concepts as they related to human behavior or action. The intervention was pilot-tested on women with breast or gynecologic cancer. The nursing intervention strategy was described in detail and emphasized nurses’ role as a catalyst, prompting people to action that, under most circumstances, they would not have initiated themselves. Neufeld et al. determined that this intervention strategy showed that nurses could incorporate decisional support into their practice in busy oncology clinics.

Neill, Armstrong, and Burnett (1998) interviewed 11 women about the reasons that influenced their decision to have reconstructive surgery after mastectomy. The researchers used an exploratory, descriptive, qualitative research method and noted that reconstruction diminished the negative effects of breast cancer and its treatment for these women. “Getting my life back” was the dominant goal expressed by the women, with contributing themes identified as information seeking, talking it over, and seeking normality.

**Methods**

**Design**

The current study used a descriptive, phenomenologic research design to explore and describe the experience of patients with breast cancer who used decisional support aids during the prediagnosis, diagnosis, and treatment phases of breast cancer. The phenomenologic approach is a philosophy and research method that investigates human experience (Russell, 1999). This method of research describes, in retrospect, a detailed analysis of a conscious lived experience. A lived experience is defined as real and true everyday occurrences of an individual (Russell). Phenomenology, when used as a qualitative research method in clinical practice, far exceeds describing patients’ experiences. This approach is a relentless search for the true meaning of phenomena from patients’ perspectives (Pulikakathyil & Morgan, 1991).

Colaizzi’s (1978) method of phenomenologic research, a style whose goal is obtaining the essence of the phenomena through the lived experience of the subject, was used in the current study. Participants were interviewed about their experiences to determine the meaning and essence of those experiences.

**Sample and Setting**

A purposive sample of 12 women diagnosed and treated for breast cancer, who were disease free, was solicited from a radiation oncology center of a tertiary care hospital in a suburb of a large metropolitan area. The institutional review boards of the researcher’s academic institution and the participating hospital granted approval for the study.

Criteria for inclusion specified women who were diagnosed with breast cancer without distant metastasis, had completed treatment, and were deemed disease free.

A printed overview explaining the study was given to the coordinator of the radiation oncology unit. The coordinator asked women who met the study’s criteria if they were interested in participating. If a woman expressed interest, the coordinator gave the researcher her name and telephone number and a convenient time for contact. Following
the initial contact, the investigator provided additional information and clarification about the study and scheduled a time and place for a personal interview. Twenty women expressed interest in the study. After being contacted by the researcher, 12 women agreed to be interviewed.

Procedure

After participants provided telephone consent to the interview, the researcher scheduled a date, time, and location that were convenient for each subject. Participants signed an informed consent before the start of the interview, which lasted 30–75 minutes. All the interviews were audiorecorded and conducted in the privacy of the participants’ homes. The participants guided the interviews, and the researcher allowed sufficient time for each phase of their disease to be adequately recalled and described. The researcher probed only for clarification. Each audiotape was given an identification letter and was dated and stored in a file cabinet in the researcher’s home office. Saturation, the point at which no new or different interpretations are uncovered, was reached with the 12 interviews.

Instrumentation

The researcher asked each participant the following questions to elicit responses framed around decisional support aids used during the stages of prediagnosis, diagnosis, and treatment of breast cancer.

- Please tell me what it was like when you were given the diagnosis of breast cancer.
- Please tell me your experience using decisional support aids that were made available to you when you were first diagnosed with breast cancer.
- Please tell me your experience using decisional support aids that were made available to you when you were faced with the possibility of having breast cancer.
- Please tell me about your experience using decisional support aids that were made available to you during treatment.
- Please tell me anything else that you thought about during this time.
- Is there anything you would like to add to our talk or conversation today?

Data Analysis

The researcher reduced the verbatim transcripts to certain patterns and themes using Colaizzi’s method as described by Wolf (1991). Wolf’s procedural steps follow.

1. The researcher gained familiarity by reading and rereading the description transcripts to acquire a feeling for them and make sense of them. The investigator also listened to the audiotapes two to three times to sensitize herself to manifest and latent meanings.
2. The researcher extracted significant statements to identify the thematic structures of the experience and listed structures and indicators.
3. The researcher formulated meanings by reflecting on the significant statements of each participant’s transcript. Meanings were identified throughout the analysis.
4. By grouping themes with related meanings, the researcher organized the aggregate formulated meaning into clusters of themes to achieve unity of meaning. The researcher searched for themes that fit together under major theme categories.
5. The researcher validated the clusters of themes and indicators to create an exhaustive description of the patients’ lived experience of using decisional support aids.
6. The researcher reflected on clusters of themes and indicators to create an exhaustive description of patients’ lived experiences using decisional support aids.

To establish rigor (Burns & Grove, 1999), a follow-up questionnaire and the formulated themes from the exhaustive descriptions were mailed to participants. The researcher encouraged comments to establish credibility of the findings from the participants’ point of view. Participants were asked to agree or disagree with major themes and clarify the meanings of the descriptions. According to the returned questionnaires (N = 7), the findings reflected their experience.

Auditability, also known as a decision trail, was developed and maintained in explicit detail, and bracketing contributed to its process (Russell, 1999). The current study’s researcher set aside any preconceived knowledge, ideas, and biases about the research phenomena under study (Gillis & Jackson, 2002; Russell). Each transcription was coded using the identification letter on the audiotape and placed in a three-ringed binder. The researcher used colored tabs to separate each interview. When significant statements were extracted from an interview, the statements were categorized by subject identification letter and page number of the transcription to facilitate easy accessibility for other researchers. Clusters of themes and meanings were organized around indicators (i.e., significant statements) and arranged in a threecolumn table that listed themes, indicators, and meanings. Thirty-one pages of the three-column table listing significant statements were extracted from 252 pages of transcribed data; as a result, exhaustive descriptions emerged.

Another researcher used the study’s data and concurred with its themes. Two experienced, qualitative researchers reviewed the data and decision trails independently and agreed with the findings.

Findings

The study’s participants (N = 12) ranged in age from 38–68 years (X = 54.3). Four of the participants were African American, and eight were Caucasian. Ten of the participants were married, one was single, and one was widowed. The time since their last treatment ranged from 3–21 months. Treatments included combinations of two or three modalities: surgery, radiation therapy, and chemotherapy. Table 1 presents the demographic characteristics of the participants.

Six major themes were identified from the study’s data: (a) being too stressed and overwhelmed to make a decision at first, (b) feeling an internal sense of urgency to have the breast cancer managed quickly, (c) trusting the opinion and advice of physicians about treatment decisions, (d) appreciating the importance of family and friends’ support in decision making, (e) finding nurses were unavailable or uninvolved in initial decision making, and (f) missing out on a multidisciplinary approach. Table 2 represents the clusters of themes identified under the six theme categories gathered and organized around indicators (significant statements).
Being Too Stressed and Overwhelmed to Make a Decision When First Diagnosed

Women’s stress and the emotional impact of the breast cancer diagnosis influenced their ability to make a decision. They were too overwhelmed to consider making a decision when first given the diagnosis. A sense of fear and dread overpowered them, thus incapacitating their decision-making ability. Women described their initial reaction to the diagnosis as “devastating, shocking, and overwhelming.”

I was dumbfounded, worst day of my life. I kind of went into a shell. I did not want anyone to bother me. Anything anyone said went right through my head. People were trying to be nice to me, and I just would not let them near me.

It was the worst possible thing they could have told me. I was hysterical. The best way I could describe it is that I was so out of control that like I was going to jump out of my skin. I just did not know what to do.

I felt like I lost everything, kind of lost my mind, kind of devastated me.

I was scared to death because my mother died at 56 of breast cancer; I figured I was going to die too.

On the follow-up questionnaire, one participant commented, A diagnosis like breast cancer does knock you for a loop; however, knowing it was caught in the early stages and the treatment plan was radiation seemed to make the stress a little easier.

Feeling an Internal Sense of Urgency to Have the Breast Cancer Managed Quickly

Few related that they had any literature or knowledge about breast cancer treatment options prior to their diagnosis. However, once the diagnosis was confirmed and patients recovered somewhat from the initial shock, an internal sense of urgency to get the breast cancer managed as soon as possible took over.

Table 1. Demographics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Diagnosis</th>
<th>Treatment</th>
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</thead>
<tbody>
<tr>
<td>A</td>
<td>44</td>
<td>Caucasian</td>
<td>Infiltrating ductal carcinoma</td>
<td>Mastectomy, chemotherapy, radiation</td>
</tr>
<tr>
<td>B</td>
<td>51</td>
<td>Caucasian</td>
<td>Infiltrating ductal carcinoma</td>
<td>Lumpectomy, chemotherapy, radiation</td>
</tr>
<tr>
<td>C</td>
<td>68</td>
<td>Caucasian</td>
<td>Infiltrating ductal carcinoma</td>
<td>Lumpectomy, radiation</td>
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<tr>
<td>D</td>
<td>61</td>
<td>Caucasian</td>
<td>Infiltrating lobular carcinoma</td>
<td>Lumpectomy, radiation</td>
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<tr>
<td>E</td>
<td>50</td>
<td>African American</td>
<td>Ductal carcinoma in situ</td>
<td>Lumpectomy, radiation</td>
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<tr>
<td>F</td>
<td>47</td>
<td>African American</td>
<td>Infiltrating ductal carcinoma</td>
<td>Lumpectomy, radiation</td>
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<tr>
<td>G</td>
<td>68</td>
<td>African American</td>
<td>Infiltrating lobular carcinoma</td>
<td>Mastectomy, radiation</td>
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<td>H</td>
<td>41</td>
<td>African American</td>
<td>Infiltrating ductal carcinoma</td>
<td>Lumpectomy, radiation</td>
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<td>I</td>
<td>38</td>
<td>Caucasian</td>
<td>Infiltrating ductal carcinoma</td>
<td>Lumpectomy, radiation</td>
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<td>Caucasian</td>
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<td>Lumpectomy, radiation</td>
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<td>Caucasian</td>
<td>Ductal carcinoma in situ</td>
<td>Lumpectomy, radiation</td>
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Table 2. Summary of Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Theme Clusters</th>
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<tbody>
<tr>
<td>Being too stressed and overwhelmed to</td>
<td>Sense of fear and dread at the diagnosis of cancer; feeling devastated and</td>
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<tr>
<td>make a decision when first diagnosed</td>
<td>wanting to withdraw from reality</td>
</tr>
<tr>
<td>Feeling an internal sense of urgency to</td>
<td>Little or no literature prediagnosis; initial choice of lumpectomy made on</td>
</tr>
<tr>
<td>have breast cancer managed quickly</td>
<td>limited knowledge; told to make a decision right there; wanted to make a</td>
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<tr>
<td></td>
<td>decision quickly; internal sense of urgency made option of second opinion</td>
</tr>
<tr>
<td></td>
<td>not important</td>
</tr>
<tr>
<td>Trusting the opinion and advice of</td>
<td>Physicians had all the expertise and knowledge; physicians gave all the</td>
</tr>
<tr>
<td>physicians about treatment decisions</td>
<td>options and made suggestions.</td>
</tr>
<tr>
<td>Appreciating the importance of family</td>
<td>Husbands’ response to mastectomy considered in decision making; family and</td>
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<tr>
<td>and friends’ support in decision</td>
<td>friends did most of the information seeking; sought opinions of other family</td>
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<tr>
<td>making</td>
<td>members and friends with breast cancer; ultimately is “my decision and</td>
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<tr>
<td></td>
<td>responsibility.”</td>
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<tr>
<td>Finding nurses were unavailable or</td>
<td>Lots of written and some video information given but not until chemotherapy</td>
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<tr>
<td>uninvolved in initial decision making</td>
<td>and/or radiation started; surgeon and oncologist most influenced decisions;</td>
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<tr>
<td></td>
<td>did not seek nurses’ input; sporadic interactions with chemotherapy and</td>
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<tr>
<td></td>
<td>radiation oncology nurses</td>
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<tr>
<td>Missing out on a multidisciplinary</td>
<td>No referral to other resources, such as Reach for Recovery, support groups,</td>
</tr>
<tr>
<td>approach</td>
<td>or social workers; no referral to oncologists; additional surgeries needed</td>
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<td></td>
<td>because of lack of teamwork.</td>
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I went right head-on into it, to get it done. To get it taken care of. I mean, I was going to go for a second opinion, but it was there. You know, as someone said, “why don’t you go for a second opinion,” but then when I went back and she showed us the pathology reports [the cancer is] there.

My brother kept saying to get two more opinions, but I just wanted to get it taken care of.

**Trusting Physician’s Opinion and Advice About Treatment Decisions**

Women needed to trust the opinion of their physicians regarding recommendations about treatment. Many viewed physicians as the ones with all the expertise and knowledge. Consequently, they trusted and needed physicians to make the decisions for them. Trusting their physicians and the women’s overwhelming sense of the seriousness of their disease made seeking a second opinion unimportant and irrelevant.

Dr. X gave me the choice, but we kinda had to make the decision right there. So, I did depend on him 100%.

And I told [the physician] that I could only put my faith and trust in him because I know nothing about it. I’m sure there are choices, but I know nothing about it, and I would need his expertise to guide me along. So, I went with whatever he set up for me.

Well, [the physician] gave me all the possibilities of what it possibly could be and if this is cancer, how he would recommend that we would take care of it. He just made me feel real comfortable.

Once I had made the decision to go with [my surgeon], I just trusted that she would be the right doctor.

One participant wanted the physicians to be more forthcoming in their opinions and what decision to make.

I just wished that [physicians] would give me an opinion. I mean, you know, like, say, if it was my mother, I would do, you know, I would do it this way. But, they didn’t. That had me a little nervous.

**Appreciating the Importance of Support From Family and Friends in Decision Making**

As the women faced complex treatment choices, they received support from family and friends. The support acted to buffer and filter stress. Many of the women expressed how their families and friends did most of the information seeking for them. Some women sought the opinions of other family members and friends with breast cancer. The support and caring of family and friends helped women diagnosed with breast cancer tolerate their situations from diagnosis through the post-treatment phases of their disease.

It was mainly my one daughter. She went with [my husband and I] because [when] you’re upset, you don’t hear what they’re [the doctors] saying.

I talked to my sister who had been diagnosed with breast cancer prior to me and kind of talked to friends who had gone through something similar. My husband was very supportive . . . and I have a daughter, and everybody was really supportive.

I discussed it with my husband . . . would he still love me if I lost a breast. I didn’t have nobody [sic] to really talk to. No groups there [at the hospital] that you could go and talk to and vent. So, it was the Lord, my husband, my mother, and close friends rallied around me.

In the follow-up questionnaire, one participant commented on this formulated theme.

Yes, family support was important, but bottom line it was my final responsibility to myself, and comments by my family didn’t deter me.

Two participants disagreed with this theme on the follow-up questionnaire. One explained, “It was my decision to make. My husband was supportive in whatever I decided, but I knew what I had to do.” The other woman clarified her disagreement by describing her husband and daughter as supportive but she said, “I couldn’t deal with their anxiety and take care of myself, as well. It was my body after all.”

**Finding Nurses Were Unavailable or Uninvolved in Initial Decision Making**

Many women received a great deal of information in the form of written materials, such as pamphlets, booklets, and videos, from nurses and other healthcare members but not until chemotherapy or radiation was started.

[Nurses] flood you with the booklets for radiation and the chemotherapy and the eating habits and the exercise. It was after the surgery and before the chemotherapy that I was given a lot of material to read.

Women shared that they did not seek nurses’ advice and only experienced sporadic interactions with chemotherapy and radiation oncology nurses.

This was true. It was the surgeon and the oncologist who most influenced my thinking and led me to chemo and then radiation.

One participant said,

I didn’t ask for any input from nurses. However, all the people involved in the radiation treatments were very thoughtful and considerate and answered any questions I had about radiation.

Another woman stated,

I don’t believe the nurses became involved until I began with the radiation treatment plan.

One woman discussed her experience with radiation therapy: “Radiation, they really did not tell me much about it except that it would only take a minute.” Subsequent to her radiation treatments, she developed severe sloughing of her skin with cellulitis that required IV antibiotic therapy. She described the visiting nurse as “not worth a diddly lick . . . she would put the IV in and leave.” Another woman stated,

[The nurse] said the doctor was not telling me the right thing to do. I was in tears several times because of her, because she kept, every other time she would say, “you still might lose your breast.”

The women’s perspective illustrated nurses’ peripheral involvement not only initially, but also throughout their illness trajectory. Unfortunately, most times, the women did
not know whether they were interacting with a nurse at all. When they were receiving radiation treatment, it was difficult to distinguish nurses from other healthcare personnel.

**Missing Out on the Benefits of a Multidisciplinary Approach**

Being cared for by a multidisciplinary team approach was lacking according to women’s perspectives. Woven throughout their accounts was a breakdown in communication among the medical oncologists, general and plastic surgeons, radiation oncologists, and advanced practice nurses. Participants noted a lack of referrals to other resources, such as Reach for Recovery, support groups, psychologists, and social workers.

[The healthcare providers] never got me in touch with support groups. A social worker came from the hospital one day to visit. But that was when I was already released from everything, and she said there was no real reason for her coming anymore.

There is not enough support. And I think when they see on them films or whatever that it’s a problem; someone should be right there.

One participant did not become involved in a support group. She stated,

I never quite knew how to do that. I also never went to see a regular oncologist because no one referred me until I asked if I should be taking tamoxifen.

Another woman said,

They fell down on this, I think when you talk about interrelated team. There wasn’t good teamwork in this one. Because what happened was, she did the implant at that time of the surgery and everything went very nicely and I was going down to her office regularly. And, low and behold, after I started chemo, well into the chemo, somebody came up with the bright idea that I should have radiation after the chemo. Well, you can’t do that with an implant. So, it caused me to have two more surgeries, which shouldn’t have happened.

**Essential Structure of the Experience of Using Decisional Support Aids**

Identifying the essential structure of the phenomena of using decisional support aids entails comparing and contrasting individual transcripts to construct an essential structure (Gillis & Jackson, 2002; Russell, 1999). The essential structure embodied facing a devastating diagnosis of breast cancer and relying on the self, physicians, and family to make prudent treatment choices without the support of nurses and a team of providers skilled in breast cancer. The emotional impact of the diagnosis precluded any thought of using decisional support aids. The women needed some time to absorb the diagnosis and comprehend its implications. Once they coped with the diagnostic phase, a sense of urgency to have their breast cancer managed quickly followed. The women described how they had little or no information prediagnosis. Trusting their physicians’ opinions and advice about treatment decisions followed the diagnostic phase. The women viewed their physicians as experts and described how they relied heavily on their expertise and knowledge as the primary source of decisional support. Women related how the support of family and friends in the decision-making process was valuable. They also discussed the decisions made by other family members and friends with breast cancer.

The participants found that nurses were unavailable or uninvolved in their decision making initially. They reiterated that the surgeons and oncologists influenced their decisions most. The women were given a great deal of information during the treatment phase of their breast cancer; however, after treatment started, the women’s interactions with nurses were sporadic and support at this phase was lacking. An overall multidisciplinary approach to decision making was missing at all phases of the women’s disease trajectory.

**Discussion**

**Limitations**

The study participants were solicited from one radiation oncology center in a tertiary care institution outside a large metropolitan city. The descriptions of their lived experiences with using decisional support aids were contingent on their ability to recall their experience after a 3–21 month period. Some of the participants had more extensive treatments than others, which may have made their experiences more complex.

Analysis of the participants’ lived experience with decisional support aids provides insight into this phenomena and suggests application to clinical settings. The complexity of treatment options and the emotional impact of the diagnosis present patients with breast cancer with overwhelming anxiety that requires definitive, supportive interventions. The social support of family and friends is important to patients in the decision-making process. However, family support does not preclude the need for nurses and other healthcare providers to provide effective decisional support aids that facilitate the decision-making process. Decision aids, as defined by Pierce and Hicks (2001), are tools that help the patient learn about the decision problem by explicating alternatives, assessing the likelihood of outcomes, and clarifying values (p. 271).

Healthcare providers, particularly nurses, are important decisional supports throughout the treatment process. Oncology nurses, physicians, psychologists, social workers, and other healthcare team members need to understand more about the dynamics of the decision-making process. In a study about the decision-making process of women considering participation in a breast cancer prevention trial, participants trusted nurses and staff who provided emotional and informational support (Schaefer, Ladd, Gergits, & Gyauh, 2001). Along with this finding was the importance of the advocacy role of nurses in assisting women through the decision-making process (Schaefer et al.).

Personal interactions with healthcare providers, as described by this study’s participants, were vital and either positively or negatively viewed. The time before, during, and after the breast cancer diagnosis was critical in providing the type of care that advocates, supports, and sustains women through a time of extreme anxiety and fear. Flooding patients with written materials, videos, and other information is not sufficient. Truly informing, clarifying, and supporting is necessary and comprises decisional support (i.e., the latent mean-
ing) in the women’s accounts especially at the time of diagnosis. Oncology nurses can be instrumental in providing a systematic approach for the study of decision making in a clinical context. Pierce and Hicks (2001) believed this method would enhance knowledge of the complex process of making decisions.

A multidisciplinary approach should be the gold standard for patients with cancer throughout the continuum of their disease from the acute to the survivorship phase. According to Pelusi (1997),

The challenge for the multidisciplinary team is to explore the survivorship phenomenon. Survivorship planning must take place at the time of diagnosis and continue through the entire life of the individual (p. 1353).

The lack of psychosocial support and access to community or hospital resources for continuing assistance during and after the treatment phases of the breast cancer trajectory was alarming. In breast cancer treatment centers, oncology nurses must meet women’s needs from prediagnosis to post-treatment. The expanded use of decisional support aids in the form of written materials and videos in physician’s offices, smaller community agencies, and surgicenters that lack the expertise of oncology nurses would lend some support to women prior to diagnosis. However, at a time when patients are expected to work their way through an intricate managed care system and nurses are dealing with critical shortages, the challenge to implement a plan of action is daunting.

Pierce and Hicks (2001) posited that the most pressing aspect of patient decision-making research is uncovering how healthcare providers can best support the decision process. Nurses are in the best situation to give patients the support needed to make informed decisions.

The development of decision-making models should be a priority for further research. Research is warranted to identify specific types of decisional support aids that can limit and reduce the psychological burden of making decisions. Additional research should provide more information and insight into whether psychosocial support during the decision-making process enhances and improves outcomes.

Author Contact: Margaret D. Lacey, PhD, RN, AOCN®, can be reached at mlacey@eastern.edu, with copy to editor at rose_mary@earthlink.net.

References


For more information . . .

➤ Breast Cancer Online
www.bco.org

➤ National Breast Cancer Coalition
www.natlbcc.org

➤ Detailed Breast Cancer Risk Calculator
www.halls.md/breast/risk.htm

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.