Experiences of Non-Navigated Women Undergoing Breast Diagnostic Evaluation

Mariann M. Harding, RN, MSN, CNE, and Susan McCrone, PhD, RN, PMHCNS-BC

During the diagnostic period, women need appropriate, timely information regarding tests and procedures. Nurse navigator programs were developed to combat the negative effects on survival that are caused by delays in the diagnosis of breast cancer and lack of support from the healthcare team. Nurse navigators decreased barriers to care, increased patient satisfaction, and lowered anxiety in women undergoing diagnostic evaluation. However, although patient navigation programs have become a presence in oncology centers, those programs and the accompanying support are not offered at every facility that provides components of diagnostic evaluation. Therefore, the purpose of the current study was to explore the experiences of women who underwent a breast diagnostic evaluation without any accompanying navigation services.

Most women report experiencing immediate, intense fear after discovering a lump in their breast (Demir, Donmez, Ozsaker, & Diramali, 2008; Liao, Chen, Chen, & Chen, 2007). The uncertainty regarding potential diagnoses may lead to psychological distress that persists throughout the diagnostic period until a diagnosis is given, even if it is one of malignancy (Shaw, Wilson, & O’Brien, 1994). That distress can interfere with women’s ability to obtain necessary follow-up care, possible resulting in higher mortality after a confirmed cancer diagnosis (Allen, Shelton, Harden, & Goldman, 2008). Experiences during the diagnostic period are believed to influence treatment outcomes once diagnoses are confirmed (Harding & McCrone, 2011). Perceptions of decreased support from the healthcare team may lessen women’s satisfaction with their health care and increase distress in the immediate postdiagnosis period (Ferrante, Chen, & Kim, 2008; Witek-Janusek, Gabram, & Mathews, 2007).

Women’s interactions with their healthcare teams are highly influential on the experience of undergoing a breast evaluation. Women who perceived being informed adequately about the process experienced less psychological distress, coped better with the possibility of having cancer, and had a greater degree of trust in their healthcare team (Lebel et al., 2003; Pineault, 2007). Having a specific professional for women to contact with questions or clarifications and promptly giving women explanations regarding diagnostic results may lessen their distress (Liao et al., 2007; O’Mahony, 2001). Unfortunately, most women reported feeling like they received inadequate information or preparation for diagnostic procedures (O’Mahony, 2001). That insufficiency has two results: women spend time actively seeking outside information to fulfill this need (Allen et al., 2008) and, in hindsight, often feel that they were inadequately prepared for what were later described as painfully gruesome procedures (Thorne, Harris, Hislop, & Vestrup, 1999). Women have reported that connecting with others who also had undergone breast diagnostic experiences was beneficial as it provided specific information about the biopsy experience (Benedict, Williams, & Baron, 1994; Thorne et al., 1999). A lack of information also drove women to attempt...
interpreting the information they did possess for diagnostic cues, including estimating the risk for a malignancy, evaluating physicians’ descriptions of a suspicious lesion, or inferring the speed of referral times (Poole & Lyne, 2000; Shaw et al., 1994). Those interpretations may lead to invalid perceptions of the situation as 36% of patients with breast cancer are diagnosed from nonurgent referrals (Hanna, Muneeer, & Khalil, 2005) and 75% overestimate their risk for breast malignancy (Lebel et al., 2003).

The general attitude of healthcare providers is important. According to O’Mahony (2001), women desired compassion and support in interactions with healthcare providers and needed to feel that they were being treated with respect and care during the diagnostic process. Women expressed that they felt dehumanized by the diagnostic process, they were not treated as individuals, or the significance of the experience to them personally was not recognized by the healthcare team (Northouse, Tocco, & West, 1997). Being told not to worry was not comforting, but appeared patronizing to feelings that women experienced (O’Mahony, 2001).

Methods

To provide rich data, the current study used a qualitative, descriptive design with focus group methodology. Focus groups are advantageous as a method of data collection because they provide researchers with rich information that cannot be garnered from surveys, as well as an in-depth understanding of the health and wellness needs of specific constituencies (Nardi & Petr, 2003).

Following institutional review board approval, the principal researcher sent potential participants a letter explaining the purpose of the focus group and asking them to contact the principal researcher if they were interested or had additional questions. When a potential participant contacted the researcher, they were provided with a description of the focus group and given the opportunity to either accept or decline participation. Inclusion criteria were women aged 18 years or older, English-speaking, who had undergone breast diagnostic evaluation with a definitive diagnosis of breast cancer. No women were included if they were pregnant at the time of cancer diagnosis.

The focus group took place in a multipurpose conference room at a local church, a familiar place that allowed for a relaxed setting. Participants signed an informed consent statement at the beginning of the session and agreed to be audio recorded. The principal researcher conducted the group and informed participants that they only had to answer the questions with which they felt comfortable.

The women sat in a circle and introduced themselves by first name. After using an icebreaker to open discussion, the researcher asked a set of trigger questions aimed at determining information and support needs, identifying deficits in currently available services, and seeking ideas for ways that needs could be better met (see Figure 1). The participants also were encouraged to identify effective and ineffective interventions during the diagnostic experience. The session lasted approximately 90 minutes.

A content analysis was performed that focused on identifying and categorizing each participant’s comments. Notes taken immediately after the focus group pertained to nonverbal communications, as well as the thoughts and feelings of the participants. The principal researcher transcribed and proofed the audio, read the transcription, coded the data in the margin of the transcript as appropriate, and organized the responses into possible categories to determine essential themes from the focus group. The researcher then reanalyzed the data-clarified categories. The co-researcher, an expert in qualitative data analysis, verified categories.

Results

Six participants attended the focus group. Participants were Caucasian and ranged in age from 39–58 years. All reported full-time employment, healthcare coverage, and a minimum high school education. Four participants had children at home younger than age 18 when they were diagnosed. The content analysis revealed three categories related to supportive care: information, navigation, and communication.

Information

Interactions with the healthcare team were highly influential on participants’ experiences undergoing a breast evaluation. All participants described dissatisfaction with the information received from their healthcare providers; they felt that they were either not given the appropriate information or the information they received was not at the level or amount of knowledge they desired. Consequently, most felt they were not prepared as they should have been for diagnostic procedures.

The biopsy procedure I underwent was terribly painful. All I was told before was that it would not be too uncomfortable and to wear a bra that would let me ice the area. What a lie. Having a wire in my breast was extremely painful, and I could not move my arm for two days.

Someone could have told me what to [better expect] for the biopsy. It was way worse than what they said it would be.

All I got for a stereotactic biopsy was, “Don’t eat after midnight, wear a bra, and be there at 10.” What a joke.

During that period, healthcare teams seemed to have lost a degree of participants’ trust. Some participants described asking questions despite the fear of being labeled as a difficult patient; others did not ask questions at all. Few felt that the members of the healthcare team were receptive to their need for information.
I don’t know if [doctors] prefer [that] patients generally be kept in the dark, but that approach was not what I needed or wanted at that point, and it made the whole experience more stressful than it needed to be.

I found it very frustrating that I was told almost nothing about the procedures I would be undergoing, why those procedures were necessary, or what the possible outcomes might be.

They, doctors especially, seemed extremely annoyed with all of my questions.

To fulfill their unmet need for information, every woman turned to the Internet as a major source of information about breast cancer and the diagnostic tests that they were undergoing; however, all stated that the information available was limited.

I looked online for information, too, about tests, cancer itself, and what my test results mean. Nothing was too helpful. No one said anything at all about how [stressful] that time was.

Does the Internet count as a person? I searched for some correlation between my symptoms and some diagnosis. Even that was kind of useless.

I read stories other women posted and tried to see if any were like mine, but nobody’s was.

The doctor probably did not like it, but I actually went to the Internet, too. I was on for hours, reading about what the ultrasounds meant, signs, what calcifications were, and all the stuff about the biopsy.

Many participants sought out other women who had undergone the experience and described them as valuable sources of information.

Someone who had been through it was the single most helpful person to me at that time. This person gave me accurate knowledge regarding the diagnostic tests, the possible results, and the treatment implications, and was calm and supportive. In other words, emotional support that was backed up by specific and accurate information was extremely helpful.

The women also verbalized displeasure with healthcare providers asking them to make treatment decisions when they felt that they lacked the knowledge to do so in an informed manner.

I went to the doctor who looked at me the day I was diagnosed, and [the doctor] said I could have a mastectomy or a lumpectomy. He wanted me to decide then, and I had no clue what to do. They just asked me to make this major decision with no information.

Navigation

The current study’s focus group discussed the difficulty of navigating the healthcare system. Each described receiving services from three to four different members of the healthcare team during this time. Numerous complaints were voiced about the length of time between procedures, healthcare providers not having test results at the time of visits, and frank miscommunication among the healthcare team. One woman said, “Losing films, losing reports, then having to change appointments. Nobody tells you anything.” Another found difficulty with “extended waiting to schedule more tests without a word on what the recent results were.”

Participants stated that they coordinated their own care and, subsequently, had difficulty in accessing care. They did not know where to go to receive treatment when a referral was necessary, found their own provider through friend referrals or the Internet, or did not realize that they had a choice in selecting a treatment provider.

I was told I could go to a surgeon of my choice; but I did not know anyone, so I just went to [who the doctor] referred me to. I did not like [the surgeon] at all, but really did not know where else to go.

We found my surgeon from the Internet, looked at [the hospital’s] Web site and physician information, and looked at their profiles while making the appointment.

Communication

Participants described overwhelming support from family and friends, but, overall, felt let down by the healthcare team. Most were dissatisfied by the communication with the healthcare team, including the receipt of letters, telephone calls, and personal interactions. Participants also were disappointed that they were not provided with any information on who to call with questions or concerns.

The staff at my doctor’s office basically did nothing beyond a secretary calling to tell me that a potential abnormality had been detected on my mammogram and that I needed to schedule a biopsy.

No one really told me anything specific ever. There was never anyone to call with questions.

I loved getting the letter on Friday saying there is a problem and you can’t call until Monday.

All participants were dissatisfied that no one acknowledged that these were stressful times for them. One woman said, “They forget how it is for me. They see it all the time. No one seemed to care that I was stressed.” Another stated that, “All the healthcare people just acted like it was no big deal. Which, to them, maybe it wasn’t, but to me it was.” However, the most unsettling report from participants was that most stated they were told not to worry and false reassurances were at the level of frank dishonesty.

I was not fine, I had stage IIA breast cancer. Since when is that fine? I had, still have, a right to worry.
Clinical Journal of Oncology Nursing • Volume 17, Number 1 • Experiences of Women Undergoing Diagnostic Evaluation

Implications for Practice

- Women need appropriate information regarding diagnostic tests, including the type of information the test provides and any procedural-related care.
- Women must be given assistance with navigating the healthcare system and obtaining referrals for breast care services.
- Healthcare teams should acknowledge the stress associated with the evaluation as unique to each woman and provide information in an honest manner without false reassurances.

The frequent blind reassurances that “everything will be fine” were a lie.

The doctor said not to worry; but . . . the report said that there were calcifications, and I had a family history. [What the doctor said] was not good.

Limitations

Several factors limit the current study’s generalizability. The study captured limited variability in the experiences reported by the participants. Because the women came from the same geographic area, the limited variability in the experiences reported by the women may have reflected local healthcare practices. More variability may have been discovered if more than one focus group was conducted or if participants were recruited from the community at large. The participants were similar in age and ethnicity, which is not reflective of the general population. In addition, the retrospective design may have introduced recall bias.

Implications for Nursing

Although much attention focuses on the care of women who are in the active treatment phase of breast cancer (Nardi & Petr, 2003), the current group of women expressed dissatisfaction with the healthcare team stemming from their experiences at the beginning of the cancer trajectory during the diagnostic phase. They recalled immediately encountering difficulties including lack of information, not knowing how to navigate the healthcare system, and dissatisfaction with the communication they received. The women verbalized displeasure with making treatment decisions when they felt that they lacked the knowledge to do so in an informed manner.

Although patient-navigation programs have become an expected presence in many oncology centers, the current group of women underwent diagnostic testing at facilities that did not offer access to navigation services, particularly with regard to providing appropriate information or assisting with referrals, including breast surgeons. The challenge for healthcare teams is how to provide support to all women undergoing breast diagnostic testing. To do that, changes in clinical practice need to be made. Healthcare providers need to deliver appropriate, timely information to women undergoing breast diagnostic evaluation. Women need to be given written information regarding diagnostic tests, including how to prepare for the test, the type of information the test provides, and any postprocedure care needed. Every center that provides components of the diagnostic evaluation should ensure that a phone number is available to call with questions or concerns. Women also should be told when, how, and from whom they will receive their test results.

None of the women reported contact with a nurse during the evaluation period. Because nurses traditionally are known for their role in providing supportive care, changing current practice to place nurses in the critical role of providing information and emotional support possibly would promote a more positive experience for women beginning the breast cancer trajectory. Other interventions could focus on patients seeking out information, how to mediate that information, and Internet-navigation needs such as identifying credible and helpful sites. The current study’s participants supported the suggestion of a Web site devoted specifically to women undergoing the evaluation process, which not only would include this information, but would validate the stress associated with the experience and interventions to deal with the stress. The results of the study suggest a need for improvement in the delivery of information without false assurances. Providers need to give clear and consistent messages and results while being cognizant of the fact that the experience is significant to each woman. Healthcare providers may feel that diagnostic evaluations are a typical procedure; however, for women undergoing the experience, it must be recognized that the experiences are anything but routine (Harding & McCrone, 2011).

References


Receive Continuing Nursing Education Credits

Receive free continuing nursing education credit* for reading this article and taking a brief quiz online. To access the test for this and other articles, visit http://evaluationcenter.ons.org/Login.aspx. After entering your Oncology Nursing Society profile username and password, select CNE Tests and Evals from the left-hand menu. Scroll down to Clinical Journal of Oncology Nursing and choose the test(s) you would like to take.

* The Oncology Nursing Society is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center’s COA.