Information Needs Prior to Breast Biopsy

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Biopsy is the definitive diagnostic procedure for breast cancer. The fear of cancer may make the breast biopsy itself a distressing experience for women and their significant others. Information seeking is believed to be a primary mode of coping with distressful events. The purpose of this study was to describe the information needs of women and their significant others prior to a breast biopsy and to explore the influence of information on the breast biopsy experience. Semi-structured, audiotape-recorded interviews with 11 women and 8 significant others were conducted prior to breast biopsy, and categories arising from the data were developed. The primary information need identified by the participants was to know "Is it cancer?" Participants' uncertainty regarding the outcome of the biopsy led to feelings of distress. The major strategy used to reduce distress was information management, in which the amount and type of incoming information was controlled. Nursing interventions based on the study findings are presented.

Information Needs Prior to Breast Biopsy

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Breast biopsy is the definitive diagnostic procedure for cancer of the breast, the most common type of cancer in women (Boring, Squires, & Tong, 1993). Approximately 20% of the women undergoing a breast biopsy will have a malignant lesion (Parbhoo, 1990). Because over 182,000 women are diagnosed

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with breast cancer each year, an estimated 700,000 women undergo a breast biopsy annually (American Cancer Society, 1993).

Research on women, and their significant others, who experience this diagnostic procedure is limited. The majority of studies focus on the women's responses after the diagnosis of cancer and the treatment options for breast cancer (Hughes, 1993; Scott & Eisendrath, 1986; Wainstock, 1991; Ward, Heidrich, & Wolberg, 1989; Wong & Bramwell, 1992).

Consistent among the studies of women undergoing breast biopsy is that it is a distressing experience (MacFarlane & Sony, 1992; Scott, 1983). In a study of 85 women undergoing breast biopsy, Scott (1983) concluded that the women's general reasoning ability was decreased, and anxiety levels were extremely high prior to biopsy, compared to 6 to 8 weeks after discharge. MacFarlane and Sony (1992) found that women, when interviewed within 1 week of hospital discharge, reported high levels of anxiety prior to breast biopsy. Personal journals written by women diagnosed with breast cancer also revealed a high level of distress surrounding the breast biopsy experience (Lorde, 1980; Webb, 1986; Underwood, 1990).

A commonly used nursing intervention with persons undergoing a diagnostic procedure is information giving or patient education. The purpose of information giving is to help the person prepare for a stressful event and to decrease anxiety. Cohen and Lazarus (1979) identified information seeking as one of the major means of coping with stressful events. Research on patients undergoing surgery demonstrates that providing information in advance of a stressful event influences the person's sense of control and coping mechanisms (Abramson, Garber, & Seligman, 1980; Degner & Russell, 1988; Dennis, 1990; Johnson & Leventhal, 1974). Despite the documented benefits of patient education, the amount and type of information desired and evaluated as helpful by women undergoing breast biopsy is not known.

Significant others are affected by a woman's diagnosis of breast cancer (Northouse, 1987; Wilson, 1991), and a woman's response is subsequently influenced by how a significant other is able to support her. Research on patients undergoing surgery has shown that the response of family members and significant others influences the person's efforts to take control of the
event (Dziurbejko & Larkin, 1978; Hymovich, 1978; Mishel, 1983). Understanding the experience from the perspective of both the woman and her significant other will enable nurses to design interventions to make this event less stressful.

The purpose of this study was to describe the information needs of women and their significant others prior to a breast biopsy and to explore the influence of information on the breast biopsy experience. The specific research questions were the following: (a) What are the information needs of women prior to breast biopsy? (b) What are the information needs of significant others of women undergoing breast biopsy? and (c) How does information influence the breast biopsy experience?

**METHOD**

**DESIGN**

A qualitative, descriptive approach was used to explore the information needs of women undergoing breast biopsy and those of their significant others. The naturalistic, or qualitative, paradigm was used because it provides guidelines for conducting research consistent with the humanistic, nonreceived worldview (Lincoln & Guba, 1985). In addition, this approach is appropriate when the phenomena in question have not been thoroughly explored.

**SAMPLE**

Eleven women and 8 significant others comprised the study sample. The participants were obtained from one tertiary care center. Convenience sampling was used to select the participants. Data collection continued until no new categories of data were obtained. Criteria for inclusion of women in the study were the following: (a) have no history of prior breast cancer; (b) be over 18 years of age; (c) be able to speak and to read English; (d) be oriented to time, place, and person; and (e) not currently be undergoing psychiatric treatment. The significant other was whoever the woman identified as a primary support person and was at least 18 years of age; oriented to time, place, and person; and able to speak and to read English.
The participants ranged in age from 35 to 72 years with a mean age of 55.9 years. The sample was homogeneous with respect to cultural and religious background, and education. Eight of the women were married, 2 had never been married, and 1 was widowed. Of the 8 significant others, 7 were husbands, and 1 was a female friend. All participants indicated a Christian religious preference, with the exception of 1 participant who did not indicate any religious affiliation. The women’s level of education ranged from 12 to 22 years (mode = 12 years), whereas the education level of the significant others ranged from 10 to 18 years (mode = 16 years). Five of the women had had a prior negative breast biopsy.

**PROCEDURE**

The names of women who were to undergo a breast biopsy within the coming week were obtained, every few days, from the surgical schedule of a large, private, tertiary care hospital. Human subjects' approval was obtained from Marquette University and the hospital involved. Women were contacted by telephone and asked to participate in the study. Written informed consent was obtained prior to the interview. Interviews were conducted prior to biopsy and took place in the women’s homes or in the hospital.

A significant other was also interviewed in 8 of the 11 cases. One woman in the sample did not name a significant other, and another did not want her significant other to know she was having a biopsy. A third woman’s significant other initially agreed to be interviewed but was unavailable during the planned interview time.

Semistructured, audiotaped interviews were conducted with all participants. Interviews lasted 40 to 60 minutes and were conducted by the primary investigators. Exemplar questions included the following: “What is important, or not important, for you to know at this time?”; “Why is it important to know that?”; and “What information is helpful, or not helpful?” Field notes were recorded at the time of interview or immediately thereafter. Demographic data were obtained from study participants.
DATA ANALYSIS

Audiotaped interviews and field notes were transcribed verbatim to increase the reliability of the raw data. A team approach to data analysis was employed to increase the credibility and dependability of the analysis process (Lincoln & Guba, 1985). All transcripts were read independently by each of the researchers and initial substantive coding categories were developed from concepts that rose from the data. The coding categories were discussed by the research team and a consensus was reached on the categories to be used. The transcripts were then independently recoded by the researchers using the agreed-on coding categories. Consensual agreement was reached on the final coding. Themes were developed from the coded data by the research team. The small sample size allowed for richness of data collection and emphasis on depth of analysis rather than generalizability of findings.

STUDY FINDINGS

The information needs described by the participants and the influence of these needs on their experiences are represented in Figure 1. This model represents the experiences of both the women and the significant others and is discussed below.

PRIORITY INFORMATION NEED

The major information need identified by both the women and the significant other was to know “Is it cancer?” This was the most pressing concern, as one participant’s words illustrated: “Is it cancer or isn’t it? That’s all I want to know.”

Because this question could not be answered immediately, the participants experienced considerable uncertainty. Waiting for the biopsy to take place and for results to be known was distressing, especially for the women. As one woman stated: “The timespan is the hardest thing to deal with... It’s the waiting before the biopsy. It would be nice to know. I don’t want to wait for the biopsy. I want to know now.” To decrease this uncertainty, the respondents looked for clues that might pre-
dict the results of the biopsy. They did this by focusing on the meaning of the woman's symptoms. Some pondered whether a specific symptom or proposed biopsy technique made them more or less likely to have breast cancer. For example, one woman commented: "Are there any clues before you get to this point of biopsy? . . . My cysts are not palpable, the fact that I have to have general anesthesia, does that mean anything?"

One area of difference between the women and the significant others was that the women were "present oriented." They wanted to know the result of the biopsy rather than the treatment options and indicated that focusing on breast cancer and its treatment was anxiety producing.

In contrast, although the significant others wanted to know the result of the biopsy, many had needs for information that were future oriented. For example, 6 of the 8 significant others wanted to know possible treatment options for breast cancer. As one man stated: "I would like to hear more about what are all the options and what he (surgeon) considers the best option to go with if this should be positive."
EMOTIONAL RESPONSES

The emotional responses engendered by the need to know if the women had cancer or not varied in intensity. The participants, especially the women, experienced feelings of shock, anxiety, fear, powerlessness, and fatalism. All of the women expressed some level of distress, as illustrated in the following three quotations: "At this point, you're 100% worried." "No matter how slight the chance, as far as I'm concerned right now I'm positive until proven negative." "There is nothing I can do about it, I just have to wait for it to happen."

FACTORS INFLUENCING EMOTIONAL RESPONSES

The types and intensity of the participants' feelings were influenced by past experiences and the information the individuals had received concerning the upcoming biopsy. Those women who had had a prior negative breast biopsy and their significant others stated that they were not experiencing high levels of emotional distress. Women without prior breast biopsy experience tended to describe greater distress.

The participants' emotional responses were also influenced by the information received. The primary source of information was usually the woman's surgeon. The surgeon not only provided information on the biopsy procedure but also influenced the intensity of the emotional reaction. Physicians who maintained a positive attitude and verbally indicated that the lesion was "probably nothing" reduced the woman's emotional distress. A woman who claimed to be experiencing very little distress stated, "He said several times he didn't think it was a malignancy, but it's just time to check it to be sure."

The women usually did not request information from the physician. Some women indicated that they did not seek information after learning they needed a biopsy because they were "too shocked" and could not think of any questions. Others stated that they did not know enough to ask questions, that their physician would tell them what it was they needed to know, or that they simply did not want to know too much. The following series of quotations demonstrate the variety of attitudes: "When you're first learning about something, sometimes you don't have enough information to ask questions." "I guess I felt, oh well, they'll tell me what I need to know."
“Sometimes, I don’t think—maybe it’s good not to know everything. You sit and worry about it when there’s nothing you can do about it anyway.”

It should be noted that none of the significant others had the opportunity to speak directly to the physician. They received information from the women. Some indicated a desire to have contact with the surgeon, whereas others stated that, because it was the woman who was undergoing the procedure, they were comfortable with receiving information through her. Several of the significant others felt that they were not an integral part of the woman’s experience. One significant other described this feeling as follows: “I’m like an outsider. It’s like my wife is on the other side of that glass and I’m over here just observing what’s going on.”

The significant others were more likely to express needs to have detailed information about the actual surgical procedure, the postoperative appearance, and possible treatment for breast cancer. One significant other described his need for more information than his wife required as follows: “I think because us men, we’re sitting on the other side of the door, and we want to know what’s going on. Whereas, the women having it and watching it, they don’t want to know.”

Other sources of information included doctor’s office staff who provided information regarding arranging for the biopsy, nurses at the hospital who described the actual procedure, and other women who had biopsies. The latter was a trusted source of information on breast biopsy: “I know quite a few people and have talked to different people that had had biopsies—and I don’t know anybody who didn’t come through it good.” Only one of the women actively sought reading material to provide information. This woman read the life story of an actress who had had breast cancer.

**INFORMATION MANAGEMENT**

The distressing feelings engendered by the need to know the diagnosis led the participants to employ common coping strategies. A major coping strategy used was the management of information. The conceptualization of this coping strategy differs from the strategy described by Lazarus and Folkman (1984) as “information seeking.” Rather than actively seeking
information, the respondents controlled the amount and type of incoming information.

Because the respondents were not able to have their most important information need, to know if it is cancer, met until after the biopsy, they focused on information that was within their grasp. The women preferred that the information be concrete, but not too detailed, and that simple terminology be used. They focused on procedural information. For example, they wanted to know how to make arrangements for the biopsy, the temporal sequence of events, and the actual procedure for localization and biopsy. Examples of the information desired are illustrated in the following quotations: “I’d like information about the procedure. Just real basic though . . . not too detailed.” “I think if you dwell on specific things it might make you more susceptible to pain in some ways, or it just might make you more anxious about everything.” The women also desired that the information be given to them over a period of time as given below: “I don’t think I’d want to know the whole ball of wax at one time because then I’d be upset.” “If you get scared and then you’d be afraid to go and have it done. So you probably don’t want too much information at one time.”

Other coping strategies influenced the management of information. Some women used suppression. They did not ask for more information because they were trying not to think about the potential of breast cancer. One woman stated, “I don’t want to deal with it. If I could hide in denial for a while, I’d be the happiest.” The women also focused on staying busy and normalizing their days so that they would not have time to think about the biopsy.

Women also coped by putting faith in God and in their health care providers. These women did not need more information because they trusted that they would be taken care of either by God or their doctor. As one respondent commented, “I trust my doctor, that he’s going to do it . . . so no questions. I know he’s busy, he told me I have to have it and that’s it.”

**DISCUSSION**

In this study, the need to know if the breast lesion was malignant was the major information need experienced by the
women and their significant other, and it was the primary cause of the participants' distress. Waiting for results was described as being especially distressing. This distress, which was identified as anxiety in previous studies by Scott (1983) and MacFarlane and Sony (1992), was described by respondents in this study as feelings of shock, fear, anxiety, powerlessness, and fatalism.

In contrast to the high anxiety that has been reported in previous studies (MacFarlane & Sony, 1992; Scott & Elsendrath, 1986), the emotional responses of participants in this study varied in both type and intensity. Past experience with a negative breast biopsy tended to reduce distress. Women reported less emotional distress when their physicians informed them about the need for biopsy in a positive, reassuring manner.

Instead of coping through “information seeking” (Cohen & Lazarus, 1979), a process of “information management” was used as a coping strategy. The respondents, especially the women, put limits on the amount and depth of information that they would accept at any one time. Information that described the biopsy procedure in basic, simple terms with an optimistic attitude reduced distress and was desired by the women participants. The significant others concurred, but tended to feel more detached from the experience, and sought future-oriented cancer treatment information that would help them support the women if cancer was present and treatment required.

The timing of information was important. Many women were not able to readily absorb information or to ask questions in the surgeon's office immediately after learning that they needed a breast biopsy. They were reticent to contact their surgeons later to have questions answered. The relationship between the woman and the individual surgeon was commonly one of short duration, usually one office appointment prior to surgery.

In addition to coping through information management, the women used a variety of other coping strategies. The coping strategies such as faith in God and health professionals, keeping busy, and normalizing behaviors were identified by the participants as beneficial.

This study has expanded the body of nursing knowledge related to women's experience with breast biopsy. It is unique
in looking at information needs as they evolve prior to the biopsy procedure. The investigators also explored the information needs of significant others, an area often neglected in other studies. However, the generalizability of this study is limited by several factors. The sample size is small and represents a homogeneous group of fairly well-educated individuals from one large tertiary care center.

**IMPLICATIONS**

Further research is needed to explore the many implications suggested by this study. However, based on the study findings, several recommendations can be made for nursing practice. Nurses may assist women undergoing breast biopsy and their significant others by providing individualized information about the procedure in simple terms, by recognizing that the timing of information is important, and by realizing that women and significant others will vary in their readiness to receive information. It is important for nurses to assess the variety of feelings experienced by women and their significant others so that interventions that address individual needs and specific emotions can be formulated. Providing examples of strategies used by women who have had a previous biopsy may also be beneficial.

Specific care delivery mechanisms that may enhance the care provided to this population include providing the opportunity for clients to access a nurse by phone, both before and after the biopsy experience, and scheduling follow-up calls prior to biopsy to ascertain whether additional information is needed. In addition, separate information sessions for significant others may be advantageous, because the discussion of breast cancer and its treatment was helpful to significant others, but was reported to be distressing to the women undergoing biopsy. Health care providers should be sensitive to the woman's need to know the results of the biopsy and communicate the results as soon as they are available.

Study findings indicated that women undergoing biopsy, because of the uncertainty and stress involved with the procedure, put limits on the amount and depth of information that they would accept at this time. Therefore, increasing the knowl-
edge base of the general public regarding breast biopsy prior to the need for the procedure may enable women and significant others to more successfully cope with the breast biopsy experience.

Further research that uses more diverse populations is indicated. An intervention study exploring the use of follow-up telephone calls and the impact on emotional distress may provide additional insight into this phenomenon.

REFERENCES


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