9 Assessing marital responses to the threat of breast cancer

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OVERVIEW

The discovery of a breast lump or other abnormality has implications for the individual that ripple through the marital and family systems. Evidence suggests that this is a stressful time, with the fear of breast cancer a major concern. This chapter proposes that early assessment of the woman and her partner during the prediagnosis phase may have a prophylactic effect, reducing both individual distress and family disruption. An interview guide based on the Calgary Family Assessment Model (CFAM) suggests specific questions to ask the couple. The importance of creating an opportunity for partners to express emotional concerns and receive accurate information is emphasized.

> I have not been sleeping well. In the middle of the night I keep thinking "What if...?" and I just go crazy. In the daytime I can just say I am not going to think about it and I don't. But at night it is harder not to think about it because you are just lying there. (woman, age 48)

A woman's discovery of a lump or other abnormality in her breast often triggers thoughts of breast cancer and raises a multitude of fears about dying, disfigurement, and abandonment by her partner. This intensely emotional response is well documented in the popular and scientific literature. The most stressful stage of the breast cancer experience seems to come immediately after discovery of the lump (Jamison et al., 1978), yet health professionals have given relatively little attention to this prediagnosis period.

This chapter reviews what is known about the impact of the breast cancer threat and identifies a nursing assessment framework for working with the marital subsystem before biopsy. While breast cancer is known to occur in males, female breast cancer is the focus here.

NURSING PROCESS

Assessment

The health problem: Breast cancer. Breast cancer, the most common female malignancy, strikes approximately 1 in every 11 women. It is the leading cause of death of women aged 35 to 54. The American Cancer Society predicted that, in 1985, 119,000 women would be newly diagnosed as having breast cancer and 38,400 of all women with breast cancer would die from it (Silverberg, 1985). Although concern about the alarming increase in the incidence of this disease continues to grow, 80% of abnormal breast conditions, including tumors, are benign (National Institutes of Health [NIH], 1982). Surgical removal of breast tissue for biopsy is commonly used to make an accurate diagnosis.

Among the factors associated with increased breast cancer risk are aging, family history of breast cancer, a high-fat diet, and high socioeconomic status (Helmrich et al., 1983; NIH, 1982).

Family implications. Empirical studies and clinical observations of female breast cancer reported in the literature have focused almost exclusively on individual patients in the postdiagnosis treatment phase. Women's psychological adjustment following breast cancer diagnosis and surgical breast removal (mastectomy) has received wide attention in the literature (Ervin, 1973; Lewis and Bloom, 1978–79; Morris, 1983; Morris et al., 1977; Scott, 1983b). However, little is known about individual experience during the critical prediagnosis period when the *possibility* of breast cancer is the primary concern.

Scott (1983a) interviewed 85 women with benign tumors at the prebiopsy phase and at 6 to 8 weeks postbiopsy to determine their anxiety levels and critical thinking ability. Patient anxiety levels prior to knowledge of diagnostic results were extremely high; 6 weeks later, anxiety was significantly reduced. Scott made no attempt to involve family members.

Maguire (1976) included prebiopsy measures in his study of 95 mastectomy and 65 benign breast disease patients. On admission to the hospital for the biopsy procedure, 40% of the women rated themselves as very anxious or depressed. Again, data were not collected from any other subsystems.

How does the psychological distress related to the threat of breast cancer affect the marital system? No empirical evidence could be found describing marital or family subsystem experience during the prediagnosis period; this is not surprising because in most settings where women receive breast care, the partner is involved only peripherally, if

at all. Furthermore, there is usually little provision for partner involvement in patient education or in the selection of treatment. A comprehensive listing of breast cancer services identified only one program that offered women *and their families* prebiopsy education sessions with a nurse (NIH, 1982).

The impact of a confirmed breast cancer diagnosis and mastectomy on the marital and whole family systems has also received limited attention. One of the few relevant studies found that husbands involved in presurgical decision making reported greater postsurgical sexual satisfaction than those who were less involved. A significant number of men in the sample also reported psychosomatic and psychological reactions, including sleep disorders, appetite loss, and work disruption, during their partner's diagnosis and surgery (Wellisch et al., 1978).

Further justification for including the partner in breast cancer assessment is provided by Cooper (1984), who found that lung cancer diagnosis affected the openness of a married couple's communication. Most spouses reported not sharing their fears and concerns with the patients, and more spouses than patients reported signs of stress and isolation.

Obviously, the male partner appears affected by a woman's breast cancer experience. Yet he is largely neglected in present health care delivery and research efforts.

Taylor et al. (1985) reported that the more disfiguring the breast cancer surgery, the more likely it is that the patient will report a decline in marital affection and sexual behavior. Spiegel et al. (1983) found better patient adjustment to breast cancer in families that encouraged open discussion of feelings and problems. These observations further strengthen the importance of including the partner in prediagnosis assessment.

Theoretical bases. Traditional disease models have centered on the dualism of mind vs. body and individual vs. context, recognizing no relationship between the parts. The systems perspective clearly demonstrates the fallacy of such a dichotomy. This chapter offers an assessment tool based on systems theory; it postulates that the world comprises complementary, hierarchical components (von Bertalanffy, 1950). Living systems contain levels ranging from the biological to the societal, with each level being organizationally distinct but communicating with others. Therefore, change at one hierarchical level effects change at other levels.

This theory modifies conventional views of illness in several ways. First, it suggests that illness affects the patient's psychological *and* organic subsystems. Moreover, it suggests that illness has an impact on several subsystem levels, as well as on interactions between levels

(Beavers, 1983). This challenges nurse clinicians and researchers to examine illnesses in context and to look beyond the individual when planning nursing assessment and intervention.

Nurses in any setting who wish to include the partner or significant other in the critical prediagnosis assessment can use this framework. The assessment provides a unique opportunity for marital partners to share their concerns through the presence of a third party. Questions invite expression of feelings and concerns and allow the couple to broach sensitive issues that they might otherwise have been reluctant to explore. In this way open marital communication can be enhanced and future adjustment difficulties prevented.

Herz (1980) suggests that, in addition to open emotional communication, another factor affects family responses to illness: the nature of the illness itself. This finding is especially significant for those facing the threat of breast cancer because of the breast's association with nurturing, femininity, and sexuality (Goin, 1982). Added to this is cancer's widespread image as a cause of pain, suffering, and death. These associations may vary with individual or cultural values, but they speak eloquently to the sensitive nature of the illness and the importance of including the marital/sexual partner in assessment.

Why perform a prediagnostic nursing assessment? As suggested by the literature, this phase is critical (Scott, 1983b); although four out of five breast biopsies are benign, the patient and family will feel in limbo until the results are known. As one woman remarked, "I felt I could not plan for next month or next year until I knew." Often the prediagnosis phase consists of waiting—for an appointment with a surgical oncologist, for mammogram results, and for biopsy scheduling. This phase can take anywhere from a few days to several weeks, creating what Welch (1981) calls the "worry and waiting syndrome."

Lambert and Lambert (1985, p. 71), although concentrating on implications, support nursing involvement during the prediagnosis phase. They define the nurse's role in prediagnosis as

> ...assisting the individual in obtaining appropriate medical evaluation; dealing with the impact that the detection of a lump has upon one's life; being cognizant of the possible ramifications of a mastectomy, and utilizing appropriate support systems.

The assessment process. A prediagnostic assessment provides information and support as it encourages anticipatory coping. As such, it may also reduce distress and family disruption.

The assessment tool contains several questions that may be used as a guide during a joint interview with the woman and her partner. By

using Wright and Leahey's CFAM (1984), questions can be developed to assess specific areas of family structure, development, and function. A home interview allows the nurse to see the couple in their physical and social environment, thus enriching the data collected; however, the session can be conducted in any quiet and private setting.

Family structure. Involving the couple in preparing a genogram or diagram of the family constellation (Wright and Leahey, 1984) helps begin the interview and engage their interest. To enhance engagement efforts, it is best to begin with the male partner, and then ask parallel genogram questions of the woman. These questions are usually willingly and enthusiastically answered, and it is amazing to watch the degree of rapport that develops when the nurse interviewer conveys genuine interest in family information. After the genogram has been constructed, the couple can be shown their "family map" as evidence that important and valued information has been shared.

Besides eliciting information about the family's structure, the questions used to generate the genogram can illuminate such other important issues as previous experience with illness, family history of breast cancer, the quality and quantity of supportive relationships, and even self-fulfilling health prophesies.

Research comparing various methods of obtaining family information found that the semistructured genogram interview was useful and efficient, yielding four times as much information as the informal health interview. Ninety-six percent of all patients respond favorably to its use (Rogers and Durkin, 1984).

Family development. The timing of the illness in the family life cycle also needs to be assessed. Because breast cancer tends to be a "middle-aged" illness, such developmental tasks as relinquishing parental control and reinvesting energies in the marital relationship and individual pursuits (McCullough, 1980) may influence and be influenced by the illness. The genogram provides the information needed to determine the family's developmental stage and identify related tasks. Additional questions, such as "How does what you're doing to face this illness now compare with what you would have done 10 years ago (or 10 years from now)?" may also elicit useful information about the illness's impact on family development.

Family functioning. Assessment of family functioning must encompass the following topics (see also Table 9.1):

Beliefs. This area explores the couple's knowledge of breast lump diagnosis and treatment. Lazarus and Folkman's (1984) theoretical work emphasized that some situations have the potential to create threat, harm, and challenge, depending on a dynamic interaction between sev-

eral personal and situational factors. Individual interpretations of an illness or the possibility of illness might be related to previous experience with the illness itself; exposure to media or personal reports about the condition; uncertainty about how the illness will develop or respond to treatment, or the mental confusion that comes from having to consider several possible outcomes; the length of the anticipation time; and timing of the illness in relation to other life events. All of these factors may contribute to or diminish the perceived threat.

An exploration of family beliefs (see Table 9.1) not only assesses the couple's perceived threat but also identifies information deficits. Seeking information about the illness, its treatment, and the probable outcomes is an important skill in coping with acute health crisis (Moos, 1982). However, anxiety, uncertain diagnosis, and lack of partner involvement in discussions of treatment alternatives can hinder information processing and result in an incomplete and unclear understanding of the health crisis. Nurses can provide necessary patient education in such specific areas as diagnostic testing procedures (for example, the mammogram); expectations and sensations associated with various types of biopsies (including when results are expected); and general health care, such as management of postoperative pain, swelling, bruising, and fatigue.

Table 9.1 Assessing Family Function in Potential Breast Cancer

Area Assessed	Appropriate Questions
Beliefs (Perception of threat)	• What do you understand will be done about the breast lump? • What previous experience do you have with major illness/surgery? • What does the word "cancer" mean to you? • Do you know someone who has or has had cancer? What happened to that person? • What other major events are happening in your life right now?
(Information deficit)	• What do you want to know about your illness, diagnosis, and/or treatment?
Emotional communication	• What concerns you most about the possibility of breast cancer? • What changes have you noticed in your partner since you were told about the need for a biopsy? • Who seems to be most affected by this situation?
Problem solving	• What have you as a couple found to be most helpful in dealing with your current situation? What else would help you cope? • What do you need most from your partner at this time?

It is crucial that the nurse allow the couple to guide the education process by asking what *they* want to know. Research suggests that a need *not to know* may serve a protective function (Bean et al., 1980; McIntosh, 1974). Learner readiness is an important aspect of any health teaching and one that nurses are frequently least sensitive to in their eager attempts to help clients.

The client couple may also ask the nurse, "What if they find cancer?" Recent media attention and an abundance of conflicting information about breast cancer treatment make this a question that must be dealt with carefully and accurately. Several publications might be recommended to interested couples (Kushner, 1984; Morra and Potts, 1980; NIH, 1982).

Emotional communication. Even in well-functioning families, the ability to express thoughts and feelings may be threatened by the intensity and duration of the illness (Herz, 1980). The nurse must encourage the couple to communicate openly, even about emotional concerns that are difficult to discuss.

In most cases, the woman facing a possible breast cancer diagnosis is concerned primarily with the biopsy and the likelihood of a positive diagnosis. Knowing this allows the nurse to probe empathetically for more specific fears about pain, breast loss, and death. The partner is generally most concerned about his wife's health and the possibility of her death; he may feel that the potential breast loss is less important or not important at all. Sharing his feelings with the patient may allay her concerns about sexual attractiveness and abandonment. In this way, assessment of emotional communication may, in a sense, become intervention by initiating ventilation and verbal intimacy.

Another useful strategy is to ask each partner for information about the other, thereby acknowledging and normalizing behavior changes that, while normal in the context of coping with the breast cancer threat, may be causing anxiety for one or both partners.

Wright and Leahey (1984, p. 107) suggest that "clarification of differences between individuals is a significant source of information about family functioning." By allowing partners to share their concerns and behaviors in relation to the threat of illness, the nurse can facilitate a clearer understanding of their present experience and encourage mutual support.

Problem solving. The nurse should encourage the couple to consider what problem-solving approaches they will use to deal with the threat of breast cancer. Focusing specifically on marital subsystem solution patterns will at least demystify current patterns and may encourage consideration of new coping techniques.

Planning

Should breast cancer be diagnosed, several interventions, based on the prebiopsy assessment, will require planning. Information deficits noted in the prediagnosis phase may direct the nurse to explore what the couple wants to know about cancer treatment alternatives, so she can plan appropriate education. The nurse might also encourage more specific emotional communication about the cancer diagnosis and examine problem-solving methods used to compensate for differing communication styles.

CASE STUDY

The following are excerpts from an interview with Susan and Dave Rennie. After the surgeon suggested a biopsy of Susan's breast lump, a nurse called and arranged to see the couple in their home a few days before the test. When constructing the genogram (Figure 9.1), the nurse learned that the Rennie family consisted of the father, Dave (43), an accountant, and the mother, Susan (41), a part-time sales clerk. Their children were Michelle, 14, and Todd, 11—students in grades 8 and 5, respectively. The couple has been married 19 years. Dave is the older of two adopted children. Heart disease tends to run in his family of origin, but he is in good health. His family lives in the area and Dave sees them once a month. Susan is the oldest of three children. Her mother had a mastectomy 20 years ago and her father died of liver cancer in 1983. She sees her family several times a year.

Nurse:
What do you two understand about the breast lump? How was it found and what will be done with it?

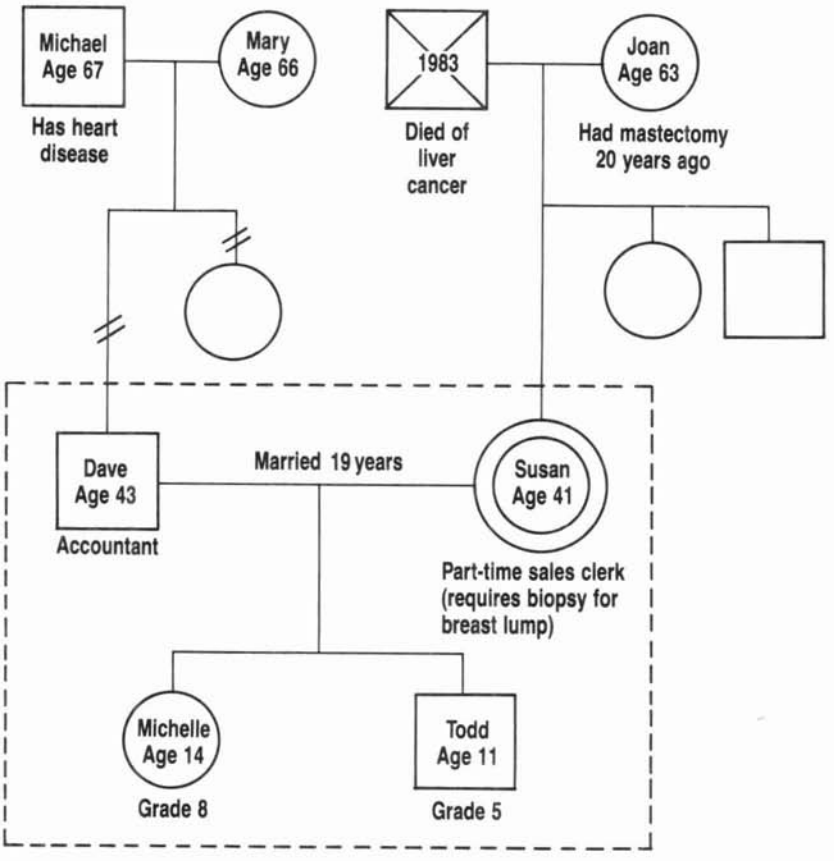
Dave:
Well, my wife found it. It has scared the hell out of both of us. We have been told it needs to be looked at. Unless in the odd chance it turns out to be something worse, it's just a matter of having it removed.

Susan:
I think I have known about it for a while. I never thought anything of it and then all of a sudden it seemed to feel different. I decided to go to the doctor. By the time I had my mammogram it was another week to wait. I gave my resignation at work and gave them a week's notice. I thought since I have to start going to the doctor's I might as well just finish right now. Then I saw my doctor again and he referred me to the surgeon. I wish they could find a faster system. It would certainly help. I've been waiting a month and a half. It is a long time to be held in limbo. Do you go on with your life or what? I'm still waiting to hear when the biopsy will be. I'm just waiting for the hospital to call.

Nurse:
What have you been told about the biopsy?

Susan:
I haven't been told anything, basically. I think they just take it for granted. The doctor said if it was serious, we would talk later about what would be done. My husband was waiting for me in the doctor's office but I really never thought

Figure 9.1 Genogram—The Rennie Family



he should be in there with me. It wasn't really that big of a deal to me but maybe I should have had him in there with me. We haven't really talked about it that much.

Nurse:
Do you have any questions that I might help you with?

Dave:
Yes, I have millions of questions. (Discussion about these ensues.)

Nurse:
What previous experience have you had with major illness or surgery?

Susan:
My mother had a mastectomy 20 years ago, so I started to think back to that time. I wondered if I should connect the two. For the first time in my life I may have the possibility of really having a disease other than taking an aspirin and staying in bed for a day.

Dave:
You have to look at the odds. With the history in the family, it's like flipping a coin: heads or tails. But I think you have to get away from being afraid of the big "C." When you hear the word "cancer," automatically you switch to dying. I'm not saying it's always curable, but there are controllable types of cancer. (Discussion ensues regarding the husband's experience of his father having a heart attack.)

Nurse:
What is your greatest concern now?

Susan:
Oh, my biggest concern is that it not be malignant. That is my only main concern. I'm not looking forward to the biopsy procedure but I'm not...that is not terrifying me...Sometimes I think "What if...?" and I have to tell myself to stop it. I wouldn't say all the time. But I think, "Oh my goodness, I have two kids. What would happen?" I'll wait until the results are in and go from there.

Dave:
Both of us are quite capable of handling any news, but just not knowing is the worst of it. To say, okay, half the breast is gone or the whole breast is gone, so what, that's all. I just want her to come out healthy.

Nurse:
Dave, what changes have you noticed in Susan?

Dave:
She has changed a bit. This is difficult to describe. She has been spending more time with the kids. She's also been grouchier!

Susan:
My emotions are high. I'm on edge. I have the odd cry, but I'm okay.

Dave:
I think I would be a bit that way too.

Nurse:
Susan, what changes have you noticed in Dave?

Susan:
The uncertainty is very hard on us. He's not a big talker about such things anyway. I think we have become more affectionate. Like, he phones me every day a couple of times, more than he did before. We both started smoking again. We had both quit smoking before this happened. I know I shouldn't be smoking right now but I can't seem to stop.

Nurse:
Who do you think is most affected by this situation?

Dave:
Oh, Susan, definitely. Sure, it bothers me, but I'm sure it bothers her more. My role is to be the support person. You have to be supportive, and yet you are a little scared too.

Susan:
Yes, but you don't show your inner feelings. He tries to be strong for me all the time no matter what.

Nurse:
Is that helpful to you?

Susan:
Yes, but I wish he would let his guard down once in a while! (Laughter)...I share emotions for both of us...You don't like me to talk about things like this so you say "Oh, Susie!" I tend to be very abrupt when I say things. He doesn't like it when I say things like, "What if I die?"

Nurse:
What do you need most from your husband at this time?

Susan:
Just the support, and being able to talk about it. They say sometimes this makes or breaks a couple. It either drives you closer together or farther apart. Like, will he still love me if I'm lopsided?

Dave:
I like to take things one step at a time. It is fine to try and plan ahead but you can only go so far and then you start tripping yourself up. She tends to look at the grim side of things.

Nurse:
Yes, but what do you need most from Susan at this time?

Dave:
Nothing really. I just want her to know that I am worried too and I'll stick with her through thick or thin.

Nurse:
What has been helpful for you as a couple in dealing with this experience?

Susan:
Each other. Knowing that you have each other for support. I think work helps too. Keeping very busy.

Dave:
I think having information is helpful. That's why this interview is a good idea. A person needs clear explanations of what is going to happen and why. Also, this interview has given me a chance to understand Susie's concerns better.

It is clear from the interview that Susan's family cancer history plays a significant role in this couple's belief system about breast cancer. Susan reflects on her mother's experience and realizes that, while her mother survived the illness, she may not be so fortunate. Themes of death and dying emerged several times in the interview. The threat is so large that Susan has chosen to

quit her part-time job in order to free more time for family relationships. By asking the assessment questions, the nurse provided an opportunity for increased emotional communication and identification of what the couple needed most from each other. Susan requested more communication from Dave and he responded by sharing feelings of fear, concern, and support. At this point, no further intervention appears necessary.

CONCLUSIONS

Nurses wishing to provide family-focused care (Wright and Bell, 1981) should initiate assessment soon after a lump is detected and before final diagnosis. The questions in this framework are specifically designed for the prediagnosis period, and are based on the assumption that the breast cancer threat will have a ripple effect on the family—specifically, on the marital subsystem. The interview facilitates change within the marital subsystem: increased understanding about what to expect during the operative procedure, more realistic perceptions of the illness, enhanced emotional communication, and overt rather than covert expression of each partner's needs from the other. These changes may result in less individual distress and family disruption. In this way, assessment becomes intervention.

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