Supportive care needs of women undergoing breast diagnostics and their families: A focus for nursing interventions

By Catherine E. De Grasse and Kylie Hugo

Abstract

This article reviews the literature regarding the supportive care needs of women undergoing breast diagnostics. The experience of undergoing a diagnostic work-up for a breast abnormality is extremely stressful for most women, when fears of breast cancer are either allayed or realized. If their needs are not identified and addressed, individuals and their families risk experiencing psychosocial distress. Nurses are in an excellent position to provide supportive care services which meet the needs of women during this time.

The Supportive Care Framework (Ontario Cancer Treatment and Research Foundation, 1994) directs the review of supportive care needs and resulting nursing interventions. Conclusions are drawn for nursing practice and future research.

Among Canadian women, it is estimated there will be 18,600 new cases of breast cancer and 5,300 breast cancer deaths in 1996 (National Cancer Institute of Canada, 1996). As the incidence of breast cancer and breast screening practices continues to increase, it is logical to expect that the number of women requiring diagnosis of breast abnormalities will also rise. For women undergoing breast diagnostics, there is a need for health professionals to support and work with these individuals to provide the necessary services to assist them in identifying and meeting their supportive care needs.

A review of the literature was conducted to assist a multidisciplinary team of health professionals develop a program of care to be offered in a proposed women's breast health centre. The review also assisted this team to develop a needs assessment survey to elicit women's supportive care needs during their experiences of breast diagnostics.

The Supportive Care Framework (Ontario

Catherine De Grasse and Kylie Hugo.

Cancer Treatment and Research Foundation [OCTRF], 1994) is first presented, followed by a summary of: the supportive care needs of women during the prediagnostic period; needs during the diagnostic period for women with normal/benign and breast cancer findings and their families; and, finally, supportive care interventions during the prediagnostic period and the diagnostic period for women with normal/benign and breast cancer findings and their families. Conclusions of the review are presented.

Supportive Care Framework

Supportive care has been defined as "the provision of necessary services, as defined by those living with or affected by cancer, to meet their physical, informational, psychological, social and spiritual needs during the prediagnostic, diagnostic, treatment and follow-up phases, encompassing issues of survivorship, palliation and bereavement" (OCTRF, 1994, p. 15) (See Figure One). According to the Supportive Care Framework, individual needs of cancer patients are influenced by: demographic factors such as age, gender, culture, education, religion and family configurations; social support and coping resources; and personality (OCTRF, 1994). If these needs are not identified and addressed, individuals and their families risk experiencing psychosocial distress.

Using the Supportive Care Framework (OCTRF, 1994) to structure the literature review, the supportive care needs of women and their families are presented according to the categories of needs, such as emotional, informational and psychosocial, that emerge during the prediagnostic and diagnostic phases respectively. Specific interventions are discussed for each phase.

Supportive care needs during prediagnostic phase

Emotional needs. For most women, the discovery of a breast abnormality evokes feelings of shock and disbelief followed by an overwhelming fear that the diagnosis will be cancer (Devitt, 1989;

ABRÉGÉ

BESOINS EN MATIÈRE DE SOINS DE SOUTIEN DES FEMMES SUBISSANT UN EXAMEN DIAGNOSTIC DU SEIN ET CEUX DE LEUR FAMILLE : CADRE DE RÉFLEXION POUR LES INTERVENTIONS INFIRMIÈRES

Cet article examine les écrits se rapportant aux besoins en soins de soutien des femmes subissant un examen diagnostique du sein. Les investigations techniques qui font suite à la découverte d'une tumeur du sein sont extrêmement stressantes pour la plupart des femmes, lorsque le spectre du cancer du sein se dissipe ou se concrétise. Si ces besoins ne sont pas reconnus et considérés, les femmes concernées et les membres de la famille risquent d'éprouver une détresse psychosociale. Les infirmières sont très bien placées pour dispenser les soins de soutien qui répondent aux besoins de ces femmes durant cette période.

Le Supportive Care Framework [Cadre des soins de soutien] de la Fondation ontarienne pour la recherche en cancérologie et le traitement du cancer (1994) oriente l'examen des besoins en matière de soins de soutien et des interventions infirmières qui en découlent. Des conclusions pour la pratique infirmière et la recherche future font partie des conclusions de l'article.

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Lerman et al., 1991; MacFarlane & Sony, 1992). Retrospective studies show that the time immediately after discovery is the most stressful period for women with breast abnormalities (Jamison, Wellisch & Pasnau, 1978; MacFarlane & Sony, 1992). Women often view breast diagnostic procedures as a major cause for concern. In particular, breast biopsy has been shown to cause high pre-operative anxiety in women (Baum, 1989; Benedict, Williams & Baron, 1994a; Hughson, Cooper, McArdle & Smith, 1988; MacFarlane & Sony, 1992; Northouse, Jeffs, Cracchiolo-Caraway, Lampman & Dorris, 1995; Wirsching, Stierlin, Hoffman, Weber & Wirsching, 1982).

The way in which a woman copes with this stressful situation is dependent upon her individual perception of the threat involved (Lazarus & Folkman, 1984). Coping refers to the cognitive and behavioural efforts to master, tolerate or decrease internal and external demands and the conflict among them (Lazarus, 1966). Appraisal is a cognitive process in which a situation is evaluated according to what has been harmed, what is at stake, and what resources are available to cope with the perceived actual or potential harm (Lazarus, 1966). Coping serves two functions: 1) to develop problem-solving efforts to cope with the threat itself; and, 2) to regulate the emotional distress (Cohen & Lazarus, 1979). Cohen and Lazarus (1979) have identified five types of coping including: information seeking; direct action, inhibition of action; intrapsychic process such as denial, avoidance, or intellectualized detachment from the encounter; and, turning to others for help.

A minority of women will cope with the threat of breast cancer by choosing to delay care-seeking for breast abnormalities (Lauver &

Angerame, 1993; Love, 1991). Factors associated with patient delay include: perceived seriousness of cancer symptoms (Worden & Weisman, 1975); use of avoidance responses (Magarey, Todd & Bizard, 1977); lack of knowledge about breast cancer (Owens, Duffy & Ashcroft, 1985); patient belief that cancer runs in the family (Hackett, Cassem & Raker, 1973); and older age (Wool, 1986). Women with breast symptoms such as focal pain, redness, nipple discharge and dimpling may delay treatment more than twice as long as those who detect a lump (MacArthur & Smith, 1981).

The coping strategies a woman with a breast abnormality assumes can be classified as problem- or emotion-focused (Lazarus & Folkman, 1984). Problem-focused strategies reflect the perception that the situation is able to be changed, while emotion-focused strategies reflect the perception that the situation is not able to be changed and so continues to be threatening. Women who display greater optimism are more likely to use problem-focused forms of coping and experience less emotional distress (Scheier & Carver, 1992). Therefore, a woman's coping strategies greatly determine her care-seeking behaviour and, hence, her psychosocial and informational needs (Lerman, 1988).

Informational needs. Individuals actively seek information to cope with stressful situations (Lazarus & Folkman, 1984). The major informational need of women prior to breast biopsy is wanting to know "Is it cancer?" (Deane, 1996; Shaw, Wilson & O'Brien, 1994). Information about the tests was deemed less important than information about the threat of breast cancer (Deane, 1996). Shaw et al. (1994) found that some women reported that they did not seek information after

Figure One: Cancer care spectrum of experience

Taken from: Ontario Cancer Treatment and Research Foundation. (1994, May) *Providing Supportive Care for Individuals Living With Cancer*, p.10. Reproduced with permission.

learning they needed a biopsy because they felt "too shocked" and could not think of any questions. Other women reported that they did not know enough to ask any 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. Many women facing breast biopsy have reduced general reasoning ability, at a time when decisions about treatment and informed consent are often vital (Scott, 1983).

Patients who desire both positive and negative information are significantly more hopeful than those who desire minimal or totally positive information (Morra, 1988). Shaw et al. (1994) discovered that most women awaiting breast biopsy used a coping strategy termed "information management", which allowed them to control the amount and depth of information they received, while other women dismissed their need for information using suppression or spiritual faith as a form of coping. The study found that women preferred concrete information which was not too detailed and used simple terminology. It appeared women also tended to focus on procedural information, which they preferred to be given over a period of time.

In summary, during the prediagnostic period most women suffer immense concern and distress, suggesting that their needs are physical and safety-based (Barrere, 1992). A woman's primary concerns reflect the possible outcomes she associates with breast cancer, such as premature death, disfiguring surgery, pain and discomfort, family difficulties, and financial loss. Hence, women's unique responses need to be considered on an individual basis both in planning for and offering supportive care interventions.

Supportive care needs during diagnostic phase

The needs of women change once diagnostic testing is complete and a definitive diagnosis is shared. Therefore, women's needs are discussed according to the two possible diagnostic results: normal or benign; and breast cancer.

When the diagnosis is normal or benign

Emotional needs. Nurses and other health professionals "cannot assume that once incisional healing is complete, the experience is over" (Benedict, Williams & Baron, 1994b, p.1474). Some women continue to feel anxious even after the threat of breast cancer has been discounted (Benedict et al., 1994a; Gram, Lund & Slenker, 1990; Lerman et al., 1991). Information seeking may, therefore, be delayed while women recover from the stress of their diagnostic experience.

Informational needs. In a retrospective study involving women with a benign breast biopsy result, Deane (1996) discovered that their major informational needs included: their chances of developing breast cancer; the risk associated with benign breast disease becoming malignant; the reason that the lump in their breast was suspicious; and the impact of a delay between the biopsy and the development of breast cancer. Women need information and reassurance about any increased chance of developing breast cancer, and practical information about primary prevention strategies and early detection practices including mammography, clinical breast examination (CBE), and breast self-examination (BSE) (Benedict et al., 1994a).

When the diagnosis is breast cancer

Emotional needs. The diagnosis of breast cancer evokes intense emotional distress (Carlsson & Hamrin, 1994; Hagopian, 1993). Such anxiety may lead to difficulties in everyday functioning (Northouse & Swain, 1987) and impaired general reasoning ability (Hughes, 1993) when there is a critical need for women to involve themselves in important treatment decisions.

Most women manage to adjust to breast cancer without psychological dysfunction (Irvine, Brown, Crooks, Roberts & Browne, 1991; Schover, 1991). Still, one-quarter of women with breast cancer develop clinically-significant and long-term anxiety and depression within the first two years after diagnosis (Jarrett, Ramirez, Richards & Weinman, 1992). Coping strategies may be influenced by personality

type; women who suppress needs, feelings and anger may be at greater risk for psychological morbidity following a diagnosis of breast cancer (Gross, 1989; Watson, 1988).

Informational needs. Studies of women diagnosed with breast cancer have identified their priority information needs to be: the stage of disease; the likelihood of cure; and the treatment options available (Bilodeau & Degner, 1996; Luker et al., 1995). Within six months of diagnosis, women tend to rank informational needs about sexual attractiveness as relatively low, possibly because women are still coming to terms with their life-threatening illness (Bilodeau & Degner, 1996; Luker et al., 1995).

Age and education have been shown to influence informational needs of women during this time: older women are more concerned than younger women about the meaning of benign breast disease in general and follow-up tests required before worrying about breast cancer risks related to their specific breast lump (Deane, 1996); and older women and women with less education rank self-care information as more important than younger and higher-educated women (Bilodeau & Degner, 1996).

Psychosocial needs. The family is a powerful influence on women's ability to cope with a cancer diagnosis (Northouse, 1984). Patients with strong social support more readily adapt to their cancer diagnosis (Ell, Mantell, Hamovitch & Nishimoto, 1989). At the same time, those women with breast cancer who employ problem-focused strategies to cope with stressful situations are more likely to receive a higher level of social support than those engaged in emotion-focused strategies (Dunkel-Schetter, Folkman & Lazarus, 1987).

Individual family members, themselves, cope differently and do not necessarily share the same concerns about cancer (Jassak, 1992). The impact of cancer on the family includes: emotional strain; physical demands of care; uncertainty; fear; altered roles and lifestyles; financial considerations; comforting the patient; perceived inadequacy of services; philosophic and spiritual concerns; concern about sexual relations; and incongruent needs and perceptions (Lewis, Ellison & Woods, 1985). Overall, families often experience great strain in having to manage both the everyday demands of living as well as the demands related to the illness.

Supportive care interventions during prediagnostic phase

Women are often extremely distressed when they first seek care for breast abnormalities. Nurses are in an excellent position to alleviate women's stress by being readily available to provide information and clarify any misconceptions about breast cancer (Barrere, 1992). It is important that women be provided with current, appropriate and individualized information about breast disease and diagnostic procedures. The timing of information is important, as well as recognition that women and significant others differ in their readiness to receive information (Shaw et al., 1994).

Since women are often too overwhelmed during the prediagnostic phase to ask questions, it is important to provide information in a question and answer format for later reference (Doak, Doak & Root, 1985). If printed, this information should reflect the reading and comprehension level of the audience (Brez, 1995; MacPhail, 1994). It may also be helpful to provide women with contact telephone numbers or have nurses call to respond to questions and offer reassurance (Shaw et al., 1994). Women may also feel reassured to have a significant other accompany them to their appointments to help them obtain or clarify information (Northouse et al., 1995). Indeed, early involvement of partners offers support for women and may facilitate their involvement when important decisions need to be made (Northouse, Cracchiolo-Caraway & Appel, 1991).

In breast cancer patients, there is a strong association between the level of distress and the amount of concurrent life stress experienced at the same time women are scheduled for breast biopsy (Northouse et al., 1995). Therefore, nurses and other health professionals are advised to

identify women at greater emotional risk by assessing the presence of other major stressors in their lives.

Goal-directed communication is a nursing intervention which can effectively identify women's concerns. This strategy uses the skills of rephrasing, personalizing and gentle confrontation to help structure conversations with patients to identify women's concerns and hence provide the most beneficial information and guidance (Barrere, 1992).

Programs which foster optimism in women (e.g., professionally-led and self-help programs) may also help to alleviate stress by changing the perceived outcomes. For example, women in one such program who were undergoing breast biopsy were directed towards a more problem-centered approach which helped them to cope when their level of stress was particularly high (Northouse et al., 1995).

The primary goal of any clinician when a woman presents with a breast complaint is to ensure that she does not have breast cancer and, if the abnormality is cancer, to diagnose and treat it as soon as possible. Comprehensive breast centres have been established to provide diagnostic and supportive care services by a multidisciplinary team for the diagnosis and treatment of women with benign and malignant breast disease. There has been favourable response to this rapid, comprehensive approach to breast care including patient satisfaction with staff concern for patients, "one-stop shopping", medical thoroughness, and a short length of waiting in the reception area (Harness, Bartlett, Saran, Bord & Noble, 1987).

As part of the multidisciplinary breast centre team, nurses can assume important roles including contribution to evidence-based supportive care, community education and ongoing research. Nurses can contribute to a reduction in breast cancer mortality by primarily focusing on education and empowering consumers. Lee, Coleman and Link (1992) suggest that if nurses establish a relationship with a woman during the risk assessment and clinical examination, it is easier for the nurse to continue to work with the woman, provide reassurance, and enhance the continuity of care if a breast abnormality is detected.

Through individual assessment, nurses can identify those women at greatest risk of psychosocial distress, and refer them for additional supportive care. Hence, immediate reassurance can be provided throughout the care process with a suitable amount of information (Barrere, 1992). Coleman (1993) delineates the role of the nurse practitioner as cost-effective primary care providers, team leaders, educators and patient advocates to centralize and coordinate the delivery of high-quality breast health and breast care services. The nurse practitioner must provide direction in the plan of care while supporting primary care relationships within the centre to ensure continuity of care.

The use of critical paths in breast diagnostics is one method of ensuring quality multidimensional supportive care. The goal of critical paths "is to use an interdisciplinary perspective to identify expectations of patient care, events that are critical to the appropriate length of stay, and methods of improving the quality and cost-effectiveness of patient care delivery" (Hofmann, 1993, p.235). Critical paths within the prediagnostic and diagnostic phases of breast care outline a standard of care and specify interventions required by various disciplines such as nursing, medicine, social work and psychology to meet these standards.

Given the psychosocial needs of these women, the evidence suggests the need for a strong interpersonal relationship between women and a particular caregiver. Primary nursing, as a care delivery system, provides continuity of the care provider and care delivered. Continuity in the nurse provider is fundamental to the development of a therapeutic relationship (Procter, 1995).

Supportive care interventions during diagnostic phase

Since needs of women change once a definitive diagnosis is provided, supportive interventions must be planned appropriately. Therefore, supportive interventions are discussed according to the two possible diagnostic results: normal or benign; and breast cancer.

When the diagnosis is normal or benign

Once the stress of the diagnostic experience has subsided, women tend to be very receptive to learn about breast care practices (Barrere, 1992). Nurses can provide women with information about primary prevention of breast cancer and breast cancer screening. Women can be encouraged to perform age-appropriate screening practices including being taught BSE, and given the opportunity to access ongoing support and information if desired. When teaching women BSE techniques, nurses have the opportunity to individually assess women's beliefs about the outcomes of seeking care and, hence, reinforce the benefits of prompt care-seeking behaviour (Lauver & Angerame, 1993; Lierman, 1988).

When the diagnosis is breast cancer

Supportive care for women diagnosed with breast cancer begins at the time of disclosure. Sardell and Trierweiler (1993) found that women with breast cancer preferred to receive their results "in a face-to-face encounter" with a physician whom they had already met. However, since women's primary concern during the pre-diagnostic phase is "Is it cancer?", it is essential that minimal delay should occur between when the pathology is known and the woman is notified. Hence, sensitivity to the timing and place of notification is paramount. Prior to receiving their diagnosis, women should be consulted as to whom they wish to be in attendance at the disclosure interview.

Women will often need time to grasp the reality of their cancer diagnosis and so, it is important that supportive resources be made available when women are ready and able to absorb the information. Information packages offering a selection of resource material which address the advantages and disadvantages of the various surgical options and other treatments can be given to take home (Barrere, 1992). More detailed discussion of these options can take place at a time after the woman has had an opportunity to comprehend the reality of diagnosis, begin to deal with her feelings, and is prepared to assume her desired role in decision-making.

In a study of women recently diagnosed with breast cancer, Bilodeau and Degner (1996) found that women preferred personal sources of information (i.e., physician, nurse, friend or relative) over written sources. Hence, nurses can be a valuable resource for women at this time.

The goal-directed communication intervention strategy offered by Barrere (1992) applies the additional techniques of refocusing and facilitation to direct women with breast cancer towards positive action. For example, nurses can use open-ended questioning to initiate discussion with the woman and her partner if she desires. By listening carefully to the woman's response and observing her body language, nurses can direct conversations to address emotional and functional needs.

Palsson and Norberg (1995) suggest the most important tasks for nurses are to listen, comfort, answer questions, and explain misunderstandings, in addition to identifying the individual's personal resources and previous coping strategies. Nurses should identify those women who are not well-informed prior to any hospitalization, since women who had received information were found to have a better overall recovery (Suominen, Leino-Kilpi & Laippala, 1994).

Structured intervention programs have been developed to address the psychological needs of cancer patients, although not necessarily specific to individuals diagnosed with breast cancer. Programs incorporating relaxation and imagery, cognitive behavioural coping techniques, goal-setting, and general lifestyle management have been shown to: improve affective state; decrease anxiety, depression, fatigue and confusion; and increase vigour (Cunningham, Lockwood & Cunningham, 1991; Cunningham & Tocco, 1989; Edgar, Rosberger & Nowlis, 1992). For women with breast cancer, a stress management program has reduced symptoms of physical and emotional distress (Samarel & Fawcett, 1992). This program focused on techniques to decrease stress, improve communication, sexuality and self-image, and offered problem-solving strategies and personalized plans for effective living.

Direct-line telephone services have been shown to both supplement and complement supportive care interventions including counselling and education (Love, Wolter & Hoopes, 1985; Marcus et al., 1993).

Such a strategy would help to overcome the problem of women not choosing to be proactive in their information-seeking behaviour. However, nurses and other health professionals must be aware that this type of support can create the opportunity for misreading the patient, since non-verbal cues are not seen.

As breast cancer treatment becomes increasingly more complex and as women want to be active participants in their care, there is a need for patient advocates to help guide women through their breast cancer experience. Health professionals and breast cancer survivors can provide vital support and advice in this supportive role (Ganz, 1995; Samarel & Fawcett, 1992). Samarel and Fawcett (1992) have demonstrated the effectiveness of "coaches" who are caring partners who act to facilitate women's adaptation to the diagnosis and treatment of breast cancer. Preliminary investigations have reported positive results: participants learned skills and techniques, and developed social supports to assist them with continued adaptation to their chronic illness (Samarel, Fawcett & Tulman, 1993).

Using a holistic care approach, the families of women with breast cancer are viewed as an extension of the patient and, therefore, an essential element in their supportive care. Indeed, the family is the patient's most important resource in adapting to cancer (Jassak, 1992). Hence, supportive care for families not only addresses their individual needs, but also enables them to maintain their supportive role with the patient (Northouse et al., 1991).

Family-focused nursing interventions must address needs at two distinct levels: the family unit; and the individual (Jassak, 1992). Family-level interventions include: seeking family input; decreasing ambiguity; providing information to the family as a unit; identifying resources; providing feedback; and periodically reassessing family response (Jassak, 1992). It is important that the nurse ascertain during this time whether there are problems in the family situation and if so, refer them immediately for further specialized assessment.

Barrere (1992) advises that since partners play an important role in their loved ones' recovery, they have questions of their own that need to be answered. Northouse et al. (1991) also suggests that specific age-appropriate interventions need to focus on the children in the family. Programs should promote open communication between parents and children, foster children's achievement of developmental tasks, and create a nurturing environment within the family.

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Conclusions

Although this review has revealed a paucity of research investigating the psychosocial and informational needs of women seeking care for breast abnormalities, there exists a clear role for nursing in the provision of supportive care. As navigators and advocates in care, nurses can assist women and their families in obtaining information, making sense of the information provided, and participating in care decisions. Concurrently, nurses can provide individualized care which addresses other supportive needs such as emotional, psychosocial, spiritual, practical guidance, and physical care requirements on an ongoing basis throughout the prediagnostic and diagnostic phases.

Nurses should continue to participate in the education of their community of care providers and the public to heighten awareness of the need for supportive care of women and their families in their experience of having a breast problem investigated, diagnosed and, if necessary, treated.

Ongoing research into supportive care needs and interventions is necessary to facilitate evidence-based practice. Nurses can continue to contribute to the current knowledge base on how to best provide care to women undergoing breast diagnostics and re-evaluate their current state of practice in light of such research. At present, it is unclear whether insufficient information is being provided or women are not retaining information or both (Ward & Griffin, 1990). Suominen et al. (1994) recommend that further research is needed to determine the type and form of information breast cancer patients prefer at various stages in the illness.

Overall, nurses, as members of multidisciplinary teams, have a significant contribution to make in providing supportive care to women undergoing breast diagnostics. Specifically, nurses can assist women to deal with the impact of the experience by helping them identify their needs and the specific ways in which they can individually cope during this extremely stressful time.

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