Decision-making in breast cancer

by Heather Porter

Abstract

Quality of survival of an individual with breast cancer can depend upon that individual's sense of control over life events surrounding disease management and treatment.

Anxiety and fear may be lessened, and personal control over life with breast cancer increased, if the patient has sufficient understanding of the disease, treatment and side effects through teaching and counselling by knowledgeable oncology nurses. The purpose of this paper is to increase understanding among nurses of the needs of their patients with breast cancer through the development of a profile of the dilemmas and decisions inherent in this disease experience.

Breast cancer is the most frequent cancer among women in North America and western Europe in terms of both incidence and mortality (Boring, C.C., Squires, T.S., & Tony, T., 1992). It is estimated that one in eight women will develop breast cancer some time in their lives (Marshall, 1993). Also, there is still a 50% chance of breast cancer recurrence, and breast cancer recurrence, while treatable, is not curable (Henderson, Harris, Kinne & Hellman, 1990).

However, recent epidemiologic studies have shown an increase in women living with the reality of breast cancer as a chronic disease, with its periodic exacerbations requiring treatment (Dorsett, 1991; Holford, Rouch & McKay, 1991). It can be assumed therefore, that women have many anxieties and concerns about this disease which may explain why cancer of the breast is one of the most widely discussed, debated and feared cancers for women.

Quality of survival of an individual with breast cancer depends upon that individual's sense of control over life events surrounding disease management and treatment (Morra, 1988). Anxiety and fear may be lessened if the patient has sufficient understanding of the disease, treatment and side effects through teaching and counselling to be able to contract for self-care with appropriate health care providers (Conkling, 1989).

Although research regarding treatment decision-making has suggested that a significant proportion of patients indicated a preference for participating in shared decision-making, in one study it was found that clinicians significantly over-estimated patient preferences to participate in treatment decisions (Degner & Russell, 1988). Nevertheless, the consumer movement is fostering an assumption that most people desire some degree of control over decisions which will influence their survival and quality of life (Schain, 1987).

Fortunately for those persons who must deal with the realities of breast cancer, a positive change in the public's understanding of this site of cancer has been evidenced. Supported by writers such as Kushner (1984) and Morra and Potts (1987), and encouraged by open discussions in the news media, women are more knowledgeable about breast cancer. If diagnosed

with it, many are now asserting their right to know more about treatment choices and options prior to decision-making at every stage of their disease. No longer is this group of women willing to blindly accept whatever treatment health professionals offer them, instead they prefer personalized health care from providers who will guide and counsel them toward self-care and health maintenance. Such personalized care of the person toward the best possible quality of life with breast cancer is central to the practice of oncology nursing.

Since women are now better informed about their breast cancers, and often wish to take an active part in decision-making and management of their own health care, oncology nurses must be equally well-informed and professionally confident to provide the individualized nursing care and support deserved and demanded by their patients. Such care, however, is only feasible if the nurse has a clear understanding of the decisions facing each individual who must live with breast cancer. Throughout the cancer trajectory, the nurse may need to be a clinician, teacher, counsellor, coordinator or all of these. A major goal or outcome of such nursing care is a confident individual who understands the disease, its treatment and the methods to manage the inevitable side effects when they occur. An equally important oncology nursing objective is to assist the individual with breast cancer to cope with changes in appearance, work and/or lifestyle with surety and a sense of self-worth.

The purpose of this paper is to increase understanding among nurses of the needs of their patients with breast cancer through the development of a profile of the decisions inherent in this disease experience. Specifically, the crises, choices and consequences encountered by breast cancer patients at diagnosis, at each of the four treatment stages, and at recurrence will be portrayed from the patient perspective.

Crises - Choices - Consequences

An individual newly diagnosed with breast cancer is confronted with a series of crises associated with both diagnosis and treatment. Following the devastating diagnosis of cancer, the patient must consider surgery, and perhaps adjuvant therapy such as radiation and/or chemotherapy. These treatments may be frightening to patients, not only since they are unknown experiences, but because they represent evidence of a continuing threat to life and to body integrity and function (Holland & Mastrovito, 1980; Samarel & Fawcett, 1992).

Diagnosis

The attention given breast cancer by the media and pioneering efforts by persons such as Rose Kushner (1984) are prompting health professionals to offer the patient a two-stage surgical procedure to separate diagnosis from treatment. This means that today, women are informed of the diagnostic result of their breast biopsy after they recover

LA PRISE DE DÉCISION EN NURSING ONCOLOGIQUE

ABRÉGÉ

La qualité de la survie d'une femme atteinte d'un cancer du sein dépend du contrôle que cette femme pense exercer sur les événements de la vie entourant la gestion et le traitement de la maladie. On pourra réduire l'anxiété et la peur et augmenter le contrôle personnel de la vie que mène une femme atteinte d'un cancer du sein si des infirmières en oncologie bien informées ont recours à la pédagogie et au counseling pour lui inculquer des connaissances suffisantes de la maladie, du traitement et des effets secondaires. Cet article a pour but d'augmenter l'entendement qu'ont les infirmières des besoins des patientes souffrant du cancer du sein en leur présentant un profil des dilemmes et des décisions qui font partie intégrante de l'expérience que font ces patientes de la maladie.

Heather Porter

Heather Porter, RN, MSN, is a PhD candidate in administrative nursing at the University of California, San Francisco. She is presently conducting her doctoral research project and is also an assistant professor (part-time) in the Faculty of Nursing, University of Western Ontario. Ms Porter was a Maurice Legault Fellow at the Canadian Cancer Society while involved in the work supporting this paper.

from the surgical procedure. Then, if the diagnosis is cancer and further surgery is appropriate, the patient chooses between a lumpectomy or a complete mastectomy (Nielson & East, 1990; Wainstock, 1991).

Such a profusion of information about an unfamiliar and frightening set of issues and circumstances, as well as the obvious threat to life, may lead to a high level of anxiety in the patient and can result in impaired thinking and concentration (Scott, 1983; Sinsheimer & Holland, 1987). Yet the person with breast cancer is expected to integrate the information rapidly and participate in decisions which will affect all aspects of her life. A critical element in making reasonable choices in this situation is the relationship the patient has with health care providers. Unfortunately, the medical professionals may be specialists who are unfamiliar with the individual and with whom there has been little time to develop rapport. Therefore, the involvement of a knowledgeable, empathetic nurse for ongoing psychosocial support beginning at this first stage of the cancer experience is crucial to the future well-being of the patient (Holland & Rowland, 1987).

Surgery

The medical demands and cosmetic results sharply differentiate the two surgical treatments in vogue for breast cancer. Individuals who choose lumpectomy with nodal dissection and radiation as primary therapy face a longer initial treatment period than those who undergo modified radical mastectomy and axillary dissection as a single procedure.

The context in which a person with breast cancer makes the decision for one surgical procedure or another may have an impact on that decision. Context refers to such issues as the woman's interpersonal environment, her family and friends' experiences with breast cancer, and the setting in which she seeks treatment as well as intrapersonal factors such as age or the existence of comorbid conditions (Valanis & Rimpler, 1985; Ward, Heidrich & Wolberg, 1989).

Persons of every age group have related that their greatest concern at the time of surgery was the diagnosis and the fear that the cancer had already metastasized. Additionally, patients worried whether they had made the correct surgical decision. However, their greatest difficulty related to the decision-making process was the lack of psychological support provided by health care providers. In particular, patients who selected lumpectomy reported that they were treated very superficially, as if there was nothing wrong, because they still had most of their breast tissue remaining (Cawley, Kostic & Cappello, 1990). As part of the health care team, the nurse must be cognizant of these fears and feelings held by their patients with breast cancer, and the influence these have on choices made at this phase.

Radiotherapy

Some patients fear radiation as a result of misinformation which leads to a reluctance to consider this treatment option or to discuss their trepidation with health care providers. Common reasons for this hesitancy are fear of the unknown and concerns that radiotherapy will make the body radioactive, or perhaps cause a future cancer, for example leukaemia. There is also a disinclination to admit their lack of knowledge to unfamiliar health professionals who often seem hurried and preoccupied with concerns other than the patients' emotional state (Kushner, 1984; Morra & Potts, 1987).

Regardless of the type of radiation therapy used, treatments can be associated with a number of symptoms that affect emotional and physical well-being. The most common of these are skin reactions, which can range from itchiness to erythema and increased pigmentation, and fatigue, which can vary from tiredness to moderate fatigue and may last several months after the completion of treatment (Hassey, 1985; Strohl, 1988). Inadequate understanding of these possibilities, and their consequences on daily life, may contribute to patients' aversion toward this treatment modality, although it may be the therapy of choice for their particular type and stage of the disease. At this phase, relevant information and personalized support of the patient by the oncology nurse can assist towards control of anxiety and distress so that informed and rational decisions for treatment can be made (Sinsheimer & Holland, 1987).

Hormonal therapy

Compared to radiation therapy and cytotoxic chemotherapy, the difficulties associated with hormonal treatment for breast cancer are

minimal but nevertheless disturbing to some patients. For example, hot flashes are an adverse response to Tamoxifen and weight gain can result from Megastrol acetate. Also, Fluoxymesterone causes virilization such as a deepened voice and increased facial hair, and Aminoglutethamide can precipitate a pruritic rash (Dunne, 1988).

Although side effects of hormonal therapy are often transitory or easily controlled, they should not be ignored since even minor physical or emotional side effects can trouble patients, particularly if misunderstood. More importantly, symptoms resulting from hormonal treatment may be attributed by the anxious patient to disease recurrence. Though hormonal therapy is a relatively benign cancer treatment, it is utilized to treat a life-threatening disease and should be taken seriously. For example, some individuals experience nausea and vomiting when initially taking Tamoxifen and, if they have made a study of cancer, worry that perhaps their cancer has already spread to the liver. Therefore, patients receiving hormonal therapy for breast cancer also require information and support to increase their understanding of how to manage exacerbations, just as individuals experiencing more toxic treatments do.

Chemotherapy

Persons facing decisions related to chemotherapy for breast cancer are the most vulnerable of all breast cancer patients. This is because 50% of these patients have at least axillary involvement in addition to the primary cancer in the breast tissue and, without chemotherapy, 45% of them will relapse and die within five years (Henderson et al, 1990).

Requiring adjuvant cytotoxic chemotherapy due to disseminated disease is difficult enough, yet in addition most patients today are aware that side effects can occur that cause, at the very least, a lengthy interruption in normal life and living patterns, changes in appearance, and significant physical discomfort. Knowledge of a family member or friend who received chemotherapy, irrespective of the tumour, the drugs utilized, or how long ago the chemotherapy was given, is often a source of added concern. Such information can profoundly affect both decisions made about therapy and the patient's experiences with this cancer treatment modality. Additionally, during the repeated cycles of chemotherapy, the clients are especially anxious and feel little personal control over the disease, treatment, or even life events (Palmer et al, 1980; Morra, 1988). At this stage, the oncology nurse is often viewed as the central support by the clients and their families.

The goal for nursing during this phase of breast cancer treatment is a confident patient who understands not only the disease, but the particular chemotherapy being received, and the self-care methods to manage the inevitable side effects when they occur.

Recurrence

The fear of cancer recurrence and its consequences is almost universally present whether the prognosis is excellent, or the individual is experiencing advanced disease. Weisman and Worden (1985-1986) reported from a cross-sectional study that the level of distress of patients with recurrent cancer was not significantly different than that suffered by persons with newly diagnosed disease. However, Mahon, Cella & Donovan (1990) reported that the discovery of a recurrence can be so devastating that the psychological adjustment to this phase of chronic cancer is more difficult than learning of the original diagnosis. This response could be because the patient knows the curative attempt has failed. Patients may feel betrayed by their own bodies and doubt the efficacy of future treatment since the first was not successful in curing the disease.

Patients whose recurrent breast cancer is treated live on a physical roller coaster as they experience relief of bone pain from radiotherapy and resume usual activities, or endure the profound fatigue caused by chemotherapy, which necessitates curtailment of all but the most desired endeavours (Piper, Lindsay & Dodd, 1987). And always, there is the fear of "what next?" (Spingarn, 1984).

Reaction to the renewed threat to mortality associated with recurrent cancer may take several forms. For some patients, continued involvement with the persons and groups of significance to them seems to increase their ability to handle the exacerbations of recurrent disease (Cassileth, 1979). It has also been reported, however, that the family as a unit experiences a sense of powerlessness due to the feeling of loss of control with the return of disease. There is also an increase in

uncertainty, since the hope for a cancer cure has been severely reduced (Lewis, Ellison & Woods, 1985).

The professional view appears to be that cancer recurrence always constitutes a crisis because, at this stage, patients and families realize that cure has not occurred. At the same time, communication between doctors and their patients may be constrained resulting in a feeling of isolation on the part of the patient and family (Wright & Dyck, 1984). In such situations, the oncology nurse is essential to care for and support anxious patients and families, provide information and explanations to enhance coping, and to serve as a communication bridge to other health professionals.

There is evidence, however, that some patients and families perceive themselves as not in crisis, but in a life circumstance that they are capable of managing. These families develop adaptive strategies that support normalcy rather than the abnormal aspects of their situation. For example, instead of social isolation, they choose to reach out to help other cancer families. Furthermore, some families prefer to accept and disregard the emotional repercussions of this life event so that normalcy and personal and family dignity can be preserved, rather than develop the open communication believed by health professionals to be the desirable way of coping with re-occurrence (Thorne, 1985).

There are, however, some patients who are so distressed that they are unable to cope adequately with breast cancer recurrence. These individuals will need special counselling by a mental health professional. Depending on institutional policy, referral to the appropriate counsellor may be made by

the oncology nurse or by the patient's physician.

In a search for meaning regarding the recurrence and its implications, patients sometimes consider their cancer as an object of purely intellectual interest. This should be recognized as an important coping mechanism and assisted by oncology nurses through the provision of appropriate patient education. Efficacy of such informational interventions has been noted in the results of a study dominated by breast cancer subjects which demonstrated that higher levels of hope are associated with being female and with the receipt of adequate information about disease and treatments (Herth, 1989). Therefore, as with breast cancer patients in the initial diagnosis stage of cancer, persons with recurrent disease and their families require knowledge of the disease, the treatments, and full information about progress and outcome of the condition.

Candid communication of all the known facts can promote confidence and foster hope in the future, both necessary attributes for patient and family adaptation to the recurrent cancer phase (Tringali, 1986).

In summary, decision-making at diagnosis, treatment and recurrence of breast cancer have been portrayed from the patient's point of view. At each phase it has been emphasized that the oncology nurse can play a central role in decreasing the uncertainty and lack of personal control associated with these crises. For persons with breast cancer, the attention, understanding and support of a knowledgeable, competent nurse is as essential as is effective treatment for control or cure of disease. ♡

References

1. Boring, C.C., Squires, T.S., & Tong, T. (1992). Cancer statistics, 1992. *CA Cancer Journal for Clinicians*, 42, 19-386.
2. Cassileth, B.R. (1979). *The cancer patient: Social and medical aspects of care*. Philadelphia, PA: Lea & Febiger.
3. Cawley, M., Kostic, J., & Cappello, C. (1990). Informational and psychosocial needs of women choosing conservative surgery/primary radiation for early stage breast cancer. *Cancer Nursing*, 13(2), 90-94.
4. Conkling, V.K. (1989). Continuity of care issues for cancer patients and families. *Cancer* (Suppl.), 64(1), 290-294.
5. Degner, L.F., & Russell, C.A. (1988). Preferences for treatment control among adults with cancer. *Research in Nursing and Health*, 11, 367-374.
6. Dorsett, D.S. (1991). The trajectory of cancer recovery. *Scholarly Inquiry for Nursing Practice: An International Journal*, 5(3), 175-184.
7. Dunne, C.F. (1988). Hormonal therapy for breast cancer. *Cancer Nursing*, 11(5), 288-294.
8. Hassey, K.M. (1985). Radiation therapy for breast cancer: A historic review. *Seminars in Oncology Nursing*, 1(3), 181-188.
9. Henderson, I.C., Harris, J.R., Kinne, D.W., & Hellman, S. (1990). In V.T. De Vita, S. Hellman & S.A. Rosenberg (Eds.), *Cancer Principles and Practice of Oncology* (pp. 1197-1261). Philadelphia, PA: Lippincott.
10. Herth, K.A. (1989). The relationship between level of hope and level of coping response and other variables in patients with cancer. *Oncology Nursing Forum*, 16(1), 67-72.
11. Holford, T.R., Roush, G.C., & McKay, L.A. (1991). Trends in female breast cancer in Connecticut and the United States. *Journal of Clinical Epidemiology*, 44(1), 29-39.
12. Holland, J.C., & Mastrovito, R. (1980). Psychologic adaptation to breast cancer. *Cancer* (Suppl.), 46(4), 1045-1052.
13. Holland, J.C., & Rowland, J.H. (1987). Psychologic reactions to breast cancer and its treatment. In J.R. Harris, S. Hellman, I.C. Henderson et al (Eds.), *Breast Diseases*. Philadelphia, PA: Lippincott.
14. Kushner, R. (1984). *Alternatives*. Cambridge, MA: The Kensington Press.
15. Lewis, F.M., Ellison, E.S., & Woods, N.F. (1985). The impact of breast cancer on the family. *Seminars in Oncology Nursing*, 1(3), 206-213.
16. Mahon, S.M., Cella D.F., & Donovan, M.I. (1990). Psychosocial adjustment to recurrent cancer. *Oncology Nursing Forum*, 17(3, Suppl.), 47-52.
17. Marshall, E. (1993). Search for a killer: Focus shifts from fat to hormones. *Science*, 259(29 January), 618-621.
18. Morra, M.E. (1988). Choices: Who's going to tell the patients what they need to know? *Oncology Nursing Forum*, 15(4), 421-425.
19. Morra, M., & Potts, E. (1987). *Choices: Realistic Alternatives in Cancer Treatment* (2nd ed.). New York: Avon Books.
20. Nielson, B.B., & East, D. (1990). Advances in breast cancer. *Nursing Clinics of North America*, 25(2), 365-375.
21. Palmer, B.V., Walsh, G.A., McKinna, J.A., & Greening, W.P. (1980). Adjuvant chemotherapy for breast cancer: Side effects and quality of life. *British Medical Journal*, 281(50), 1594-1597.
22. Piper, B.F., Lindsey, A.F., & Dodd, M.J. (1987). Fatigue mechanisms in cancer patients; Developing a nursing theory. *Oncology Nursing Forum*, 14(6), 17-23.
23. Samarel, N., & Fawcett, J. (1992). Enhancing adaptation to breast cancer: The addition of coaching to support groups. *Oncology Nursing Forum*, 19(4), 591-595.
24. Schain, W.S. (1987). Becoming an informed health care consumer. *Public Health Reports* (Suppl.), July-August, 100-102.
25. Scott, D.W. (1983). Anxiety, critical thinking, and information processing during and after breast biopsy. *Nursing Research*, 32(1), 24-28.
26. Sinsheimer, L.M., & Holland, J.C. (1987). Psychological issues in breast cancer. *Seminars in Oncology*, 14(1) 75-82.
27. Spingarn, N.D. (1984). *Hanging in there: Living well on borrowed time*. New York: Stein and Day, Publishers.
28. Strohl, R.A. (1988). The nursing role in radiation oncology: Symptom management of acute and chronic reactions. *Cancer Nursing*, 15(4), 429-434.
29. Thorne, S. (1985). The family cancer experience. *Cancer Nursing*, 8(5), 285-291.
30. Tringali, C.A. (1986). The needs of family members of cancer patients. *Oncology Nursing Forum*, 13(4), 65-69.
31. Valanis, B.G., & Rimpler, C.H. (1985). Helping women to choose breast cancer treatment alternatives. *Cancer Nursing*, 8(3), 167-175.
32. Wainstock, J.M. (1991). Breast cancer: Psychosocial consequences for the patient. *Seminars in Oncology Nursing*, 7(3), 207-215.
33. Ward, S., Heidrich, S., & Wolberg, W. (1989). Factors women take into account when deciding upon type of surgery for breast cancer. *Cancer Nursing*, 12(6), 344-351.
34. Weisman, A., & Warden, J. (1985-1986). The emotional impact of recurrent cancer. *Journal of Psychosocial Oncology*, 3(4), 5-16.
35. Wright, K., & Dyck, S. (1984). Expressed concerns of adult cancer patients' family members. *Cancer Nursing*, 7(5), 371-374.