ORIGINAL ARTICLE

Breast Cancer: Unique Communication Challenges and Strategies to Address them

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■ Abstract: Women with breast cancer have become increasingly more involved on a national and local level in advocating for resources to fight cancer. However, in the context of the relationship with their physicians and other cancer caregivers, much remains to be done in providing them with adequate support. In this paper, we highlight the difficulties in communication related to breast cancer and describe strategies and approaches that may be helpful in improving the communication throughout the cancer trajectory. Specifically, breast cancer patients have high unmet information needs relevant to health information and dissatisfaction with the actual information they receive from their providers. These needs seem even more pronounced when patients are older, of lower socio-economic class and from differing cultural backgrounds which may affect their ability to express their desires for information and desire to be involved in decision-making about their treatment. Other communication challenges can be envisioned as occurring at key points across the cancer trajectory: diagnosis disclosure, treatment failure, transition to palliative care, and end of life discussions. These involve techniques as basic as how to establish trust and rapport and determine a patient's information and decision-making preferences and as complex as giving bad news. These strategies are now viewed as essential skills in that they can affect patient distress and quality of life, satisfaction, and malpractice litigation as well as practitioner stress and burnout. ■

Key Words: breast cancer, physician-patient relationship, provider-patient communication

ommunication is a multidimensional concept, Jinvolving both the content of discussion and the relationship aspects of the interaction and includes verbal and nonverbal behaviors (1). From the clinician's standpoint, it encompasses several important elements that impact directly upon patient care: (a) gathering information from the patient (eliciting the relevant history, symptoms, patient perceptions, and concerns); (b) providing information to the patient (ensuring patient comprehension, informed consent, participation in choice of treatment options, and accrual to clinical trials); (c) relationship-building (ensuring trust, confidence, and in part, satisfaction with care); and (d) supportive communication (addressing patient emotions and encouraging the patient) (2,3).

Communication is the cornerstone of comprehensive cancer care (4). Recently, information has

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© 2008 Wiley Periodicals, Inc., 1075-122X/08 The Breast Journal, Volume 15 Number 1, 2009 69–75 emerged to prompt a discussion of specific aspects of communication of importance to breast cancer clinicians. In the first part of the paper, we highlight these and in the second part, we offer some practical techniques and approaches that may be improve communication, based on studies and data that have been shown to have value in practice.

PART I: SPECIFIC ISSUES IN THE BREAST CANCER CONTEXT

Information Needs and Challenges

A study by Lobb et al. (5) underscored the importance to breast cancer patients about information related to their disease. They found that 83% of women wanted as much information about their disease as possible, whereas 16% wanted limited information. Additionally, 91% wanted to know their prognosis before beginning adjuvant treatment and 63% wanted their oncologist to ask them if they would like to know their prognosis. In a similar study of 1,012 breast cancer patients, 88% expressed a desire for increased information on the likely future of

their illness and 91% wished for more information about their illness (6).

Despite these findings, women with breast cancer who want to receive detailed information have reported high levels of unmet needs for health information, difficulties in accessing relevant information, and dissatisfaction with the information received from their healthcare providers (5,7–9). Reasons for these information gaps are not completely clear. However, available data suggest that doctors are not very good at estimating the amount and type of information patients want or how effective they have been in imparting such information (10,11).

Paradoxically, despite having high information needs, unless directly invited, many patients do not ask pertinent questions, express concerns or ask for additional information. Indirect "cues" such as such as seeming anxious or perplexed when given information are far more common than direct requests for information or support. While clinicians seem ready to respond to direct expressions of need, they find it difficult to detect and respond to indirect behaviors such as facial expressions or allusions (12). Patients may also assume that their doctors will tell them whatever is relevant and some feel guilty about taking too much of the busy doctor's time with questions (13-15). Therefore, in the absence of explicit discussion, physicians may make incorrect assumptions and unilateral decisions about patients' information needs and preferences, and over-estimate the extent to which they provide desired information (16).

The take home message from these studies is that a "disconnect" regarding information needs of patients may occur and that assessing how much information the patient wants to know ("ask before you tell") about their illness initially and periodically during the course of treatment comprises an approach recommended by many authors. How specific factors, including age, ethnicity, race, culture, and socioeconomic status influence women's information needs and preferences, has been of interest to a number of investigators. For example, Gustafson et al. found that age most consistently affected the variance in information preferences of patients and that as their age increases, women look at the receipt of information as being less important (17,18). In a study by Liang et al. (19), patients 80 years and older reported receiving markedly less information than younger patients about treatment options, were less likely to be given a

choice of treatment, and were less likely to initiate communication (19).

Other authors have described the variation that exists within different cultures and the challenge about how to provide honest information while respecting cultural norms. For example, Korean and Mexican Americans were found to be unlikely to support the autonomy of the patient in making a treatment decision, which is seen as the responsibility and filial duty of the patient's family (20). In some cultures, the negative stigma associated with the word "cancer" is so strong that the use of the word can be perceived as rude, disrespectful, and even causal (20). Chinese American families may prefer that the patient not be told that they have a terminal illness or face an imminent death, or the family may prefer to tell the patient themselves. Healthcare providers should also communicate with the head of the Filipino American family while out of the patient's presence (21,22). Thus, it is essential to understand the cultural context when talking with patients about their cancer.

Treatment Decision-Making

Decisions about breast cancer treatments are strongly influenced by the quality of patient–physician communication particularly for older and disadvantaged patients (19). For example, being unmarried, having a lower socioeconomic status and older age have been found to be associated with less discussion of treatment options and also influence the type of treatment received (6,18,23,24). Thus, improving the quality of communication at the level of patient–physician interaction could be an important avenue to reducing age and ethnic group treatment disparities among patients with breast cancer.

Multiple options from which to choose about breast surgery presents can present a vexing dilemma for patients and a communication challenge for physicians. Given that research has demonstrated that mastectomy and BCT with radiation have similar long-term survival rates for women with early-stage disease (25–28), attention to a woman's individual needs and preferences and quality of life (QOL) issues as they contribute to treatment decisions is essential.

Other issues that are associated with communication of patient choice include the advisability of adjuvant endocrine therapy and lack of communication about lymphedema following sentinel lymph node biopsy alone or with axillary dissection (29–31). Women undergoing mastectomy for breast cancer

often have the option of having reconstructive surgery. There has been some speculation that talking to women about reconstruction before surgery can minimize the psychological distress of a mastectomy (32). Several investigators suggest that it may be therapeutic for surgeons to discuss this possibility with women because it can help create a more hopeful outlook of living with the disfigurement of the surgery, as well as providing women with a sense of the doctor's belief in the probability of their survival. Several factors that have been found to be associated with not having reconstruction include older age, lack of information, concerns about costs, fear of additional surgery, fear of recurrence, uncertainty about outcome, negative attitudes within society toward reconstruction, and psychological obstacles (32). Conversely, reasons reported by women for having reconstruction include getting rid of an external breast prosthesis, being able to wear a greater variety of clothes, and restoring feelings of wholeness and body integrity. Younger women are more likely to choose reconstructive surgery. Many older women, however, view reconstruction as too much additional surgery and pain and expressed that their breasts were no longer that important to them. Some remarked that they would have pursued reconstruction if they were younger. In spite of this, comments from women not offered reconstruction reinforce the importance of informing patients of all options: "It would have been nice if it were offered even though I probably wouldn't have done it" (33). Discussing reconstruction with their surgeon likely would eliminate many of these concerns, as 17% of women over 60 years in one study were not offered reconstruction (33). In summary, surgeons should offer reconstruction to women of all age though patients older than 60 years are less likely to proceed with and complete reconstruction (33).

Key Communication Challenges Along the Illness Trajectory

Diagnosis Disclosure

Patients differ in their ability to integrate threatening information and concordance between the disclosure of information and the patient's ability to deal with that information is the gold standard for successful communication (34,35). Maguire (14) found that when doctors conduct a patient-centered diagnostic consultation and ask patients about their perceptions of their problems, their reactions to their problems, and how their illness impacts their daily lives, patients

feel more satisfied and are more compliant with the advice and treatment regimens offered.

Before talking with patients, it is important for the clinician to realize that the structure and content of the consultation influences the patient's ability to remember what has been said in several ways: (a) patients usually recall facts provided at the start of a consultation more readily than those given later; (b) topics deemed most relevant and important to the patient (which might not be those considered most pertinent to the doctor) are recalled most accurately; (c) the greater the number of statements made by a doctor, the smaller the mean percentage of information recalled by the patient; and (d) items that patients do manage to recall do not decay over time as do other memories; in fact, many patients have verbatim recall of what they believe the doctor said (13).

When Treatment Fails

Prognosis is an important topic when talking about decision-making by patients and is of heightened concern when breast cancer has recurred. When a decision is made on the basis of accurate prognostication, problems frequently arise. For one, there are few training resources and little guidance available for clinicians in communicating prognosis (36). Additionally, some patients with metastatic disease overestimate prognosis and are more likely to favor life-extending treatment, perhaps to the detriment of QOL (36). Some research suggests that at least part of the reasons for hopeful patient prognostication could be due to the generally optimistic prognostic estimates that physicians give their patients or omission of prognostic discussions altogether (37). Although most doctors in western countries give patients their diagnosis of cancer, information about prognosis is less commonly presented, even when patients indicate a preference for receiving this information. Yet it has been demonstrated that if actively encouraged to ask questions, prognosis is the one area in which patients increase question asking (36).

Data from Gustafson et al. (17) revealed that recurrence was an issue of great importance to all those who were involved in the breast cancer experience. Regardless of one's level of sophistication, when communicating with patients facing metastatic disease and death, loved ones and caring professionals can help, at a minimum by easing the sense of "aloneness" the dying person may feel. Indeed, a fundamental commitment of a hospice or palliative care team is to never

abandon a patient. This commitment derives from the knowledge that, at times, simply being present can make a critical therapeutic difference (38).

Transition to Palliative Care

Communicating with patients who have advanced cancer is difficult for many physicians and has been widely discussed in the medical literature. Physician difficulties include countertransference issues surrounding their own fear of dying, psychological traits in some physicians that may lead to a need to overcome fears of death, and the historical tendency in western medicine to focus on cure (14,39–42). Additionally, physicians are trained to maintain health and fight illness, but typically receive little guidance on how to communicate with dying patients and their families. Thus, in our death-averse society, it is not surprising that many physicians find it uncomfortable to engage in end-of-life discussions (14,42).

Another impediment to honest disclosure is that death has long been regarded as tantamount to medical failure, particularly in western culture. The implication to some physicians is that they have nothing to offer a dying patient and family, although the opposite is true. Good communication can, in fact, help allay fears, minimize pain and suffering, and enable patients and their families to experience a "good death" (14,42). On the other hand, poor communication may result in suboptimal care, and patients and their families may be subjected to undue mental or physical anguish (14,42). Physicians must strive to achieve a delicate balance between providing honest information and doing so in a sensitive way that does not discourage hope (39). Physicians who are too blunt can shatter hope and leave patients feeling abandoned, a situation that can be ameliorated by increased sensitivity to timing discussions, the milieu in which discussions occur, and enhanced communication skills (43). However, few physicians feel adequately trained to break bad news. In one study, 50% of oncologists rated their own ability to break bad news as poor to fair (39).

Because there is variability among patients about the amount of information they want and how quickly they want to receive it, sensitive physicians can gauge when a patient is ready to hear bad news. For clinicians who fear that breaking bad news will destroy patients' hopes, there is convincing evidence that most cancer patients want the physician to provide them in a caring way with thorough information about their diagnosis, prognosis, and treatment options, and that incomplete information could actually erode patient hopefulness (44,45) and trust. It is important however, that the physician does not assume that all patients want to be told about their prognosis. They should be aware that patients often signal to the doctor when and how much information they want or are able to cope with (14,36).

End-of-life Discussions

Because most patients want to discuss end-of-life care with their physicians, and most believe that physicians should introduce the topic, physicians should initiate timely dialogue, as many patients will wait for them to raise the subject (42). Additionally, studies have shown that patients prefer to discuss advanced directives early in the patient–physician relationship and that advance care planning can be effectively introduced in an outpatient setting (46). Studies have also found that even though patients with cancer want their physicians to provide detailed prognoses, they also want their physicians to give them good news and to be hopeful about their illnesses (37).

PART 2: SPECIFIC TECHNIQUES THAT FACILITATE COMMUNICATION

Communication Skills: Can they be Taught and Learned?

During a clinical career that spans approximately 40 years, an oncologist is likely to conduct between 150,000 and 200,000 consultations with patients and their families (47). Thus, communication should be viewed as a core clinical skill that merits a considerable investment of time and resources in training (13). This is particularly important in view of the fact that many oncologists become disillusioned with their work, experience stress, and show signs of burnout (13).

Empathy and compassion are increasingly considered important topics for medical student training, essential components of the physician–patient relationship, and the foundations of ethical medical practice. Breast cancer activists appeal for greater physician compassion and awareness of the difficulties patients have in understanding medical information after the trauma of a cancer diagnosis (48). Empathic relationships with patients not only promote trust but also reduce patient anxiety (48), increase satisfaction with

the medical encounter, are an important factor in medical malpractice claims and promote a therapeutic relationship with the patient. Findings in one study designed to monitor physician responses to nonverbal cues by patients underscore the importance of the doctor's role in directly encouraging the expression of emotional needs and suggest that communication training should include skills development in this aspect of doctor-patient communication (12). A recent study by Pollack et al. (49) examined empathic opportunities and empathic responses in audio recordings between oncologists and patients with advanced cancer. They found that there were few empathic opportunities in the consultations and that oncologists rarely provided empathic responses. They suggest that oncologists may benefit from more training in how to encourage patients to express their emotions and how to respond to them empathically in order to reduce patient anxiety and increase satisfaction (49).

Responding to basic deficiencies in preparing oncologists and other healthcare providers for working with patients, educators have looked at ways to train future and current physicians to communicate effectively (14,34,40,44). One training approach involves conducting communication skills workshops to provide training to oncologists in stressful aspects of the physician-patient relationship (44). Back et al., for example, conducted a workshop-based communication skills training program for oncology fellows (50). The workshop increased the oncology fellows' skills in breaking bad news and transitioning to palliative care (50). Various investigators have looked at desirable behaviors in healthcare professionals to guide the development of helpful interventions. For example, Harris and Templeton (51) identified behaviors desired in future physicians (medical students). These were to listen to the patient, find out about the patient's knowledge level about their disease, honesty, partnering with the patient, comfort using touch while communicating with the patient, making eye contact, saying something realistically hopeful, validating the patient's concerns, answering the patient's questions, displaying interest in the patient as a person, having an attitude of curiosity about the patient's needs, isn't all-knowing, having respect for the patient's knowledge and experience, and supporting the patient's informed decision (51).

When treatment fails, it is important to break the bad news to patients in a helpful way. Various schemes have been espoused as helpful for breaking the bad news to patients with cancer. One is the sixstep SPIKES protocol formulated by Baile et al. (52), which is an individualized, patient-centered approach for breaking bad news. This technique has been rated highly by oncology practitioners and incorporates the recommendations of communication experts, patients, nurses, and oncologists for disclosing unfavorable information to cancer patients. This approach is tailored to the individual needs and coping style of the patient. In brief, the acronym is: S = get the setting right; P = understand the patient's perception of the illness; I = obtain an invitation to impart information; K = provide knowledge and education; E = respond to the patient's emotions with empathy, i.e., responses, gestures; S = provide a summary strategy, i.e., respond to questions and discuss treatment options. Incorporated into skill-based workshops this method has been shown to increase fellows' competency in several dimensions of giving bad news (50). Girgis and Sanson-Fisher (53) presented similar guidelines for breaking the bad news which included: ensuring privacy and adequate time, assessing patients' understanding, providing information simply and honestly, avoiding euphemisms, encouraging patients to express their feelings, being empathic, giving a broad but realistic time frame about prognosis, and arranging a review of the information given (53).

Patient education is also an important aspect of training in communication skills and various interventions have been designed to meet this need (15,54). In another patient education intervention, an existential-phenomenological approach was used to evaluate the benefits of social support for women with breast cancer in a computer-mediated context, specifically using the Comprehensive Health Enhancement Support System (CHESS) computer network (55–59). Patients benefited from the information given, social support received, and increased participation in their illness that came from the use of CHESS (55–59).

Conclusion and Future Directions

Much research in this area has already been accomplished and some important findings, such as promoting treatment choice for women, have already been translated into clinical practice. However, much more research needs to be done, especially at the level of the optimal time during treatment to introduce various issues and in finding practical ways for assessing women's information needs, incorporating supportive techniques into everyday clinical practice, and

disclosing unfavorable information in a way that is compassionate, but hopeful. In short, cancer may be likened to a journey, which requires preparation, with many anxious moments as well as bumps on the road. Whatever the outcome of the voyage, it is clear that patients with breast cancer greatly value the supportive partnership with the healthcare team.

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