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Quality of Life in Breast Cancer Patients: the Contribution of Data to the Care of Patients

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A primary test of the usefulness of quality of life research is the extent to which it has been helpful in informing clinical practice and in minimising or preventing psychosocial distress among patients and their families. Clinical applications of quality of life data in five areas are summarised: alerting physicians and nurses to common patient concerns, informing patients of common reactions to breast cancer, aiding patients and physicians in decision-making, developing training programmes for medical personnel, and designing interventions for patients and their families. Although substantial progress has been made in applying quality of life data to improve clinical practice, further progress is possible. As with many other areas of medical practice, we must work towards developing more effective means of disseminating this information to clinicians and encouraging them to integrate it into their practice.
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INTRODUCTION

RESEARCHERS in psychosocial oncology have made considerable gains in recent years in developing sophisticated methodologies and psychometrically sound measures for assessing quality of life in cancer patients (see articles by Aaronson and Liberati, this issue). These developments have allowed for the collection of a great deal of data on the quality of patients' lives. One of the primary tests of the usefulness of these data is the extent to which they have been helpful in informing clinical practice and in minimising or preventing psychosocial distress among patients and their families [1]. We must ask whether large scale, scientific studies that yield statistically sound data about large numbers of patients can play a meaningful role in clinical practice where the central concern is with a specific, unique individual. The current treatment of breast cancer patients suggests that quality of life data have made important contributions to clinical practice and that data are now available to make even greater contributions.

It is not controversial to suggest that quality of life considerations should play a role in the treatment of cancer. Physicians and nurses regularly make decisions on the basis of their perceptions of what would be in the patient's best medical and psychosocial interests. Unfortunately, several studies have documented that physicians' perceptions of patients' needs and concerns often differ from the patient's own report in terms of the patient's levels of psychological distress [2], needs for information [3], and cancer-related concerns [4]. In the absence of sound data then, there is high risk of making inaccurate, and potentially unhelpful, judgements about what the patient needs.

These errors of judgement may be particularly problematic in the case of breast cancer. Physicians and patients are often faced with choosing from treatments that provide equal medical benefits, but which may differ in terms of their psychosocial effects. Fortunately, a substantial body of literature is now available to help in making these choices. More has been written about the quality of life of breast cancer patients than of patients with cancer at any other site [5]. These data have been helpful in several domains.

ALERTING PHYSICIANS AND NURSES TO COMMON PATIENT CONCERNS

Quality of life data can provide medical personnel with the information necessary to determine whether an individual patient's reactions fall within normal limits or whether they may be predictive of future psychiatric problems. Recent data suggest that the increase in psychiatric morbidity due to breast cancer is relatively limited, with only a small minority of patients experiencing severe emotional difficulties that would merit a psychiatric diagnosis [6–8]. Dean [6], for example, found that psychiatrists rated only 5% of patients as psychiatrically ill. An additional 26% had psychiatric symptoms 1 year after surgery that warranted diagnosis by research criteria but were relatively mild. Similarly, Hughson and his colleagues [7] found that, in general, fewer than 10% of breast cancer patients had clinical levels of anxiety or depression during the first 2 years following mastectomy, although the prevalence of minor morbidity was higher.

Common predictors of psychiatric disturbance in breast cancer patients are previous psychiatric difficulties [6, 9, 10], lack of adequate social support [6, 9–13], a low sense of control [9, 14] and younger age [7, 15]. When these difficulties, in conjunction with either high levels of distress or increasing, rather than decreasing or stable, levels of distress are observed [9], it can alert the physician to the need for early intervention to prevent an exacerbation of psychiatric morbidity.

Although severe psychiatric disturbance is not common, mild to moderate distress and disruption are. Reviews of the literature on the quality of life of breast cancer patients indicate that many patients may experience emotional distress, sexual and marital difficulties, changes in body image, impairments in physical abilities and energy level, disruptions in work and leisure activities, and/or disease- and treatment-related symptomatology [5, 16]. Quality of life begins to be

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affected from the first appearance of symptoms for many patients [17, 18] and continues to be disrupted in some ways for the rest of the patient's life [19, 20]. Psychosocial researchers have identified reactions that patients commonly experience at various stages of adjustment to the disease; these include reactions to the first appearance of symptoms, diagnosis, treatment, periods of remission or cure, and recurrence of disease [16].

By gaining knowledge of common reactions, oncologists and oncology nurses can enhance communication with patients. Recent surveys indicate that a majority of patients feel that it is appropriate and desirable to discuss psychosocial problems with their physicians, but that few patients initiate these discussions even when they are experiencing problems [21, 22]. In one study of cancer patients, 72% reported having communication problems of some sort with medical professionals [23]. The most commonly reported areas of specific problems included having difficulty asking questions, expressing feelings and understanding what the doctor said. Thus, quality of life data can help physicians and nurses to anticipate the problems that patients may be experiencing, even when they are not expressed directly, and to raise these issues for discussion.

INFORMING PATIENTS OF COMMON REACTIONS

In addition to alerting medical professionals to the problems patients may be facing, quality of life data have been useful in informing patients of reactions that are frequently experienced by other patients to their disease and treatment. This information can help the patient to feel more normal when unexpected, but common reactions occur and can be useful in suggesting approaches for enhancing coping, from simple strategies to dealing with treatment side-effects to more global cognitive strategies for making sense of an aversive and senseless situation [24, 25].

Nearly all cancer patients express a desire to receive all possible information [26], yet most breast cancer patients report that they have many unanswered questions [3, 27]. Patients who receive more information tend to report greater satisfaction with their medical care [28] and less anxiety and depression [29]. Moreover, psychosocial distress has been found to be significantly associated with patients' premature termination of chemotherapy [30].

AIDING IN DECISION MAKING

In the case of breast cancer, perhaps more than any other disease, quality of life data have stimulated the development of alternate treatments and have been used to distinguish among the potential benefits of these treatments. Breast conserving surgeries and breast reconstruction were developed in response to the psychosocial concerns of patients.

The results of comparisons of mastectomy to breast conserving surgeries, usually with radiation therapy, do not consistently favour one surgery for all women. Most studies find that body image is more positive in women who have had conservative surgeries [31–37]. It is unusual, however, for differences to emerge between the two surgeries in terms of overall levels of emotional distress [32, 35, 36]. When differences are found, they are typically relatively small in magnitude and short in duration [29, 34, 38], and frequently indicate greater distress among patients receiving conservative surgery. The immediate effects of radiation may lead to an exacerbation of difficulties in the early phases of recovery from surgery for patients who receive radiation in conjunction with conservative surgeries [33, 39]. For example, Ganz and colleagues [33] found that during the first month following surgery, women who had received segmental mastectomy and primary radiotherapy reported greater difficulties with recreational and social activities than modified radical mastectomy patients. Early concerns that conservative surgery might foster greater fears of recurrence among patients have not been substantiated [31, 32, 34].

If patients are informed of the possible negative consequences associated with each type of surgery, they could be asked, when medically advisable, to choose the surgery that best fits their values and lifestyle. Wilson, Hart and Dawes [40] found that when women were given the option to choose between lumpectomy and mastectomy, they were willing and able to make the choice and, in retrospect, were happy with their choices. Similarly, Morris and Ingham [41] report that being allowed to choose between mastectomy or wide excision plus radiotherapy was more important to breast cancer patients' psychosocial outcomes than was the type of operation that was chosen.

Quality of life issues also play a central role in determining the advisability of breast reconstruction. The primary goal in seeking reconstruction for most women is to avoid the discomforts of external prostheses [42, 43]. Nearly all patients report being satisfied with the cosmetic results of the reconstruction [43, 44] and many women report increased satisfaction with their appearance and their comfort in wearing a wider range of clothes [42, 45]. The advantages of reconstruction do not appear to extend to improvements in sexual or marital relationships, however, and women who seek reconstruction for those reasons are likely to be disappointed [42, 45]. Patients who have immediate reconstruction report less psychological distress than patients who delay reconstruction [42, 45], and do not experience more negative medical outcomes as a result of reconstruction [46].

DEVELOPING TRAINING PROGRAMMES FOR MEDICAL PERSONNEL

Quality of life data have been useful in developing intervention programmes for physicians and nurses. These programmes have been successful in educating health care providers about the needs and reactions of patients [47, 48] and about possible ways of helping patients cope [49]. Training has also been designed in an effort to decrease caregiver distress. The people who treat cancer patients are, themselves, subject to disruptions in quality of life [50], despite the fact that oncology staff often report high satisfaction with their work [51]. Stewart and colleagues [52], for example, assessed the level of stress experienced by four groups of nurses–cancer, cardiac, operating room and intensive care unit nurses–and found that cancer nurses reported significantly greater stress than nurses in any of the other specialities.

DESIGNING INTERVENTIONS FOR PATIENTS AND THEIR FAMILIES

Data regarding the difficulties faced by breast cancer patients, and the inter- and intrapersonal resources of women who adjust well to the disease and its treatments, have been successfully applied to developing psychological interventions for enhancing coping ability [53]. Findings emphasising the importance of social support have led to intervention programmes for improving social support and, in turn, decreasing distress [54] and increasing survival [55]. By identifying the specific types of stressors facing patients, psychosocial researchers have been able to develop stress management programmes [56], coping skills training therapies [57, 58], and behavioural interventions for decreasing treatment side-effects [59]. Additionally, standardised materials for preparing patients for treatment have been developed on the basis of data demonstrating the stress-reducing effects of preparation and information [60].

To summarise, much use has been made of the quality of life data in the treatment of breast cancer patients. Although substantial progress has been made in applying quality of life data to improve clinical practice, further progress is possible. The psychosocial literature has reached a degree of refinement that now allows for consideration of psychological differences among patients, of differences in disease and treatment impacts over the course of the illness, and of differences in medical status. As with many other areas of medical practice, we must work toward developing more effective means of disseminating this information to clinicians and encouraging them to integrate it into their practices.

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