Quality of Life Among Long-Term Cancer Survivors

ABSTRACT: Thanks to advances in cancer diagnosis and treatment, there are now more than 10 million cancer survivors in the United States. Successful treatment of cancer has resulted in increased demands on survivors and has had diverse effects on the quality of life (QOL) of patients and their families. A model of QOL encompassing dimensions of physical, psychological, social, and spiritual well-being has been applied to illustrate the multidimensional needs of cancer survivors and the necessity of comprehensive care extending over the long term. Data from a recent survey of members of the National Coalition of Cancer Survivorship (NCCS) is presented, along with a summary of issues compiled by the NCCS that merit future attention. [ONCOLOGY 11(4):565-571, 1997]

Introduction

Quality-of-life (QOL) issues have become a vital area of concern to cancer survivors, their families, and care providers.[1,2] In large measure, attention to QOL in cancer survivors developed out of the expressed needs of the more than 10 million cancer survivors, who are demanding greater attention to maintain or restore QOL after cancer treatment.[3] Future advances in cancer treatment will further heighten the importance of survivorship issues in comprehensive cancer care. Historically, QOL has been used as an evaluation in cancer clinical trials. In 1990, the National Cancer Institute (NCI) began employing QOL measures to compare treatments, as well as serve as an end point in cancer clinical trials; identify side effects and consequences of cancer treatment to assess rehabilitation needs; and predict response to future treatment.[4] Recently, the National Cancer Institute (NCI) expanded its use of QOL in cancer clinical trials to include QOL research in outcome studies and to assess QOL in culturally diverse populations.[5] Evaluations of QOL are increasingly used in the development of cancer treatment guidelines to aid in the evaluation of treatment outcomes. For example, the American Society of Clinical Oncology (ASCO) recently published guidelines for defining outcomes of adult and pediatric cancer treatment for the purposes of technology assessment and development of cancer treatment guidelines.[6] Survival was identified as the most important outcome of cancer treatment, and improvement in disease-free survival was deemed a prerequisite for recommending adjuvant therapy. Quality-of-life measures were global and needed to be sensitive to clinically meaningful changes resulting from treatment. Survival and QOL were the most important indicators in technology assessment and cancer treatment guidelines development. In addition, QOL was used to evaluate the cost-benefits of cancer treatment.[7] Given that QOL continues to be a major issue in managing the long-term effects of cancer treatment and cancer care, the NCI recently announced the formation of the Office of Cancer Survivorship, which will investigate multidisciplinary research issues and consequences of cancer survivorship.[8] This event is of great importance and signifies an important shift in thinking about cancer, in which cancer is viewed not only as a life-threatening disease but also as a chronic illness. The purpose of this paper is to describe how the concept of QOL is being used in cancer survivorship, provide a review of the literature on high-incidence areas requiring QOL attention, and suggest interventions to maintain or improve QOL among cancer survivors. Attention to this important
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concept will advance the work of both clinicians and researchers, and hopefully, will benefit cancer survivors and their families.

**What is Quality of Life?**

What is quality of life, and how is it defined? Many definitions exist that reflect various dimensions or aspects unique to the disease or treatment of interest. In cancer, QOL has been defined as a personal sense of well-being encompassing a multidimensional perspective that generally includes physical, psychological, social, and spiritual dimensions or domains.[9-12] Changes in one QOL domain can influence perceptions in other domains. For example, a disruption in physical well-being due to uncontrolled symptoms further affects psychological or social well-being. Moreover, QOL is generally considered to be best defined from the patient's perspective.[13]

**Four Domains**

Ferrell[14] recently summarized the definitions of the four QOL domains cited above:

- Physical well-being is the control or relief of symptoms and the maintenance of function and independence.
- Psychological well-being is the attempt to maintain a sense of control in the face of life-threatening illness characterized by emotional distress, altered life priorities, and fear of the unknown, as well as positive life changes.
- Social well-being is the effort to deal with the impact of cancer on individuals, their roles, and relationships.
- Spiritual well-being is the ability to maintain hope and derive meaning from the cancer experience, which is characterized by uncertainty.

This model of QOL in cancer survivorship, depicted in Figure 1, reminds us of the complexity of the QOL concept and the need for an interdisciplinary approach to the care of the cancer survivor.

**Quality of Life and Cancer**

The following review of the literature synthesizes knowledge on QOL and cancer. The review is organized according to the domains of the QOL model.

**Physical Well-Being**

Physical well-being has been explored in many studies that have documented the physical effects of cancer or treatment. Mounting evidence demonstrates a variety of changes occurring after cancer treatment across developmental stages or age, gender, ethnicity, type of cancer, stage of disease, and type of cancer treatments. Generally, the common and distressing acute physical side effects of cancer treatment, such as bone marrow depression, hair loss, mucositis, skin changes, nausea and vomiting, and nutritional changes, subside within a few weeks or months after the completion of therapy.[15-17] However, cancer survivors describe several problematic late physical effects that influence their ability to function and negatively influence their overall QOL. The most common late effects affecting physical well-being are pain and fatigue. Pain most often occurs in advanced disease and is related to bone metastasis and compression of adjacent nerves, vascular structures, and soft tissue. Pain also occurs in nonmetastatic disease and may be related to incisional pain, paresthesias, edema, and phantom limb sensations.

Fatigue is a prevalent and disturbing symptom of cancer treatment that has been largely ignored because it is not considered life-threatening.[17] Similar to the impact of pain on QOL, ongoing fatigue produces severe disruption in patients' ability to function and multiple aspects of life. Interventions to manage fatigue include: energy conservation, health fitness programs based on endurance, flexibility, and strengthening exercises; and rhythmic walking programs. Although pain and fatigue have often been cited as the most common symptoms in long-term cancer survivors, many other symptoms also occur. Menopausal symptoms in the breast cancer survivor and symptoms of chronic graft-vs-host disease in the bone marrow transplant (BMT) survivor are examples of disease/treatment-specific problems related to physical well-being.

**Psychological Well-Being**

The most problematic changes affecting QOL in the psychological domain include: anxiety; fear of recurrence, second malignancies, or metastatic disease; concern over future tests; and distress over recall of the initial cancer treatment.[18,19] These changes in psychological well-being are
manifested by marked anxiety, mood swings, and depression. Despite the widely reported problems of fear of recurrence and uncertainty over the future, there are few tested interventions to help cancer survivors manage these concerns. Support groups have traditionally addressed some of these issues since they can provide the necessary emotional support and help patients cope with the fear of dying.[20-22]

Interventions to improve both physical and psychological well-being have become even more imperative as recent advances in cancer treatment have extended the length of cancer survivorship. Cancer survivors require attention to these important needs in order to resume employment or carry on roles and responsibilities. Both the physical and psychological domains are often neglected in long-term survivorship when patient encounters with the health-care system become less frequent. Psychological support for long-term survivors is of special concern and is at particular risk amidst the current reductions in health-care delivery.

**Social Well-Being**

Quality-of-life concerns affecting social well-being include family issues, such as sexual and marital problems and adjustment of children, and work-related issues, such as concern over cancer disclosure, stigma, reentry into the workplace, changes in work priorities, discrimination, and health insurance. The long-term impact of cancer on family and work have largely been described in the literature on breast cancer. Specific interventions described include: coaching support, work-site educational programs, and family counseling and intervention.[23-27]

**Spiritual Well-Being**

Finally, QOL factors affecting spiritual well-being include: spiritual distress, grief, and loss. Studies have linked religiosity and spiritual support with recovery from breast cancer. A sense of hopefulness and having a purpose in life were also important aspects influencing spiritual well-being.[28,29]

Increasingly, studies support the notion that finding meaning in illness is a vital component in recovery from cancer. Studies focusing on BMT survivors often depict long-term survivorship as a mixed blessing, as long-term survivors of diseases previously considered to be terminal may suffer from survivor guilt. Cancer survivors may struggle to find meaning and purpose in what has been described as a "second chance."[30-32]

**Needs of Cancer Survivors**

Since its inception in 1986, the National Coalition for Cancer Survivorship (NCCS) has fostered a greater awareness of the needs of cancer survivors. In 1995, the NCCS convened the first National Congress on Cancer Survivorship. One of the outcomes of that congress was the completion of a monograph summarizing guidelines for quality cancer care, physiologic long-term and late effects of cancer treatment, and psychosocial issues of cancer survivorship. Table 1 lists the major psychosocial challenges facing persons with cancer, as summarized by the NCCS. The needs are divided into those resulting from the personal consequences of a cancer diagnosis, the social consequences of cancer on roles and relationships, and the demands of navigating the health-care system. Table 2 summarizes the physiologic long-term and late effects experienced by cancer survivors. These needs are grouped into three main categories: system-specific physiologic effects of cancer, problems resulting from recurrence or second malignancies, and other related problems. This work by the NCCS is a valuable resource as professionals develop a research agenda for cancer survivorship, as well as for the development of support services for cancer survivors.

**Quality-of-Life Concerns**

Ferrell, Hassey Dow, and colleagues also conducted a survey of NCCS members to identify QOL concerns in long-term cancer survivors, using the Quality of Life, Cancer Survivors (QOL-CS) instrument. This instrument is designed to identify areas in which cancer survivorship has positive effects, as well as the continued demands of survivorship. This survey of the NCCS membership elicited 687 responses. Results of the survey are summarized in Table 3. Based on a scale in which 0 indicates the worst outcome and 10, the best outcome, cancer survivors’ mean QOL-CS subscores were 7.78 for physical well-being, 5.88 for psychological well-being, 6.62 for social well-being, and 6.59 for spiritual well-being. Overall QOL score was 6.51. Table 3 also breaks down each subscale into individual items that describe specific aspects of each
domain and their impact on overall QOL. These data are significant, in that the average time since
cancer diagnosis was 80.4 months (standard deviation [SD], 73.8; median, 58.5), indicating that QOL
concerns extend into long-term survivorship.[2]

Summary

Cancer survivorship has emerged as an important area of oncology in the 1990s. Attention by
professional organizations, such as the Oncology Nursing Society and ASCO, and efforts by consumer
organizations, such as the NCCS, have advanced our understanding of the needs of this important
population. The recent creation of the Office of Cancer Survivorship by the NCI has added additional
weight to the need for more research to further define and improve QOL among long-term cancer
survivors.

A review of previous literature and an evaluation of recent data and consensus on cancer
survivorship clearly demonstrate the multidimensional needs of cancer survivors and the importance
of comprehensive, multidisciplinary care. This will best be accomplished through the collaboration of
researchers, clinicians, and the true experts in the field, cancer survivors.

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