Ferrell and Hassey Dow summarize research on the domains of quality of life (QOL) most important to the adaptation of survivors, and offer insights about possible interventions to support and promote this adaptation. In addition, they note that the field is poised to make great progress in understanding the concerns and needs of survivors, due, in part, to the establishment of the Office of Cancer Survivorship, an institutional home at the National Cancer Institute (NCI) that will coordinate and promote research on this critical topic.

In response to their article, I raise the question: How can research on cancer survivorship best be advanced? To assist in answering this question, I will draw on findings from the Quality of Life Literature Database (QOLLIT), a database of abstracted articles on QOL in cancer patients developed by researchers from the NCI, the EMMES Corporation, and Johns Hopkins University. The database currently includes approximately 900 abstracted articles published from 1990 to 1995; 106 of these focus on cancer survivors. While the database is not exhaustive, it provides, to the best of our knowledge, an unbiased sample of the literature.

As those who follow the cancer QOL literature will attest, the field has made steady progress in defining and measuring global life quality, as well as disease- and treatment-specific QOL. Although questions linger about whether instruments developed for patients can be generalized to survivors, there is an active cadre of researchers attending to this and related methodologic issues. However, other issues have gained less attention; some of these will be addressed here.

**Who Is in Greatest Need of Being Studied?**

A prominent feature of this literature is that there is no commonly accepted definition of survivorship, in terms of both time since diagnosis and active treatment status. Given this, we have relied on the intent and definition of the study authors in designating an article as one that concerns survivors. Abstracted in QOLLIT is the population under investigation. To be designated as an investigated population, an article has to pertain exclusively to the population or provide separate analyses for it. Using this definition, when the QOL of specific groups, as opposed to survivors in general, was reported in the 106 articles, it was most likely to be for female (27.4%), male (24.5%), or pediatric (22.6%) survivors. Virtually unstudied were the elderly (more than 60 years; 4.7%) or minorities (1.0%); and although the database does not track the socioeconomic (SES) characteristics of those studied, low SES populations have also been largely ignored.

An urgent need, and one noted by Ferrell and Hassey Dow, is to turn our attention to vulnerable, hard-to-reach populations: Do they have the same QOL concerns and outcomes as other identifiable groups? We need to develop creative, effective ways of identifying, contacting, and following members of vulnerable populations. It is not enough to do this under the guise of special initiatives, it must become a routine aspect of research aimed at looking for differences among sociodemographic subgroups.

**How Do QOL Domains Relate to Each Other?**

There is a growing consensus in the QOL literature about the life domains that are most important to study. [Table 1](#) lists the domain frequencies for the 106 survivorship studies; over half of the studies included measures of psychological/emotional functioning, social functioning, physical symptoms, and physical functioning. Relating this to the domains noted by Ferrell and Hassey Dow, we see an undercoverage of patient-specific economic outcomes (12.3%) and spiritual outcomes (10.4%).
It is heartening that researchers are construing QOL to be multidimensional. However, largely absent from the literature are studies investigating how the domains relate to each other statistically; this critique is largely true of the field in general, with some exceptions.[1,2] It is now time to push the field forward from descriptive models that serve as useful heuristics in selecting domains to explanatory models that demonstrate causal relationships among domains.

It is important to know how individual domains relate to each other and to global quality of life. For example, can deficits in some domains (eg, the often-noted fatigue in survivors) be offset by high levels of functioning in other areas (eg, spirituality)? It is likely that "dominant" domains will vary by subgroups of survivors; for example, return to work may be the driving force at one life stage and ability to maintain family relationships at another. Factors limiting our ability to model these domains in the past have been the field's overwhelming reliance on cross-sectional designs (80.4% of the abstraced studies) and relatively small samples sizes (median, 64).

**Explaining Differences in QOL**

Researchers in psychosocial oncology have a long-standing interest in studying how internal (eg, coping strategies) and external (eg, social support) resources explain variations in how individuals adapt to the cancer diagnosis and treatment.[3] This tradition is reflected in a sizable proportion of QOL studies. Although this is an important avenue for research, other factors that may explain variations in QOL have been studied less often. Perhaps the most obvious omission in studies of survivorship, as noted by Ferrell and Hassey Dow, is any attempt to link the severity of subsequent health problems and physical morbidity with other outcomes. Also understudied is the role of health behaviors after cancer treatment in explaining variations in QOL. For example, a recent study[4] of QOL in laryngeal cancer survivors found that nearly 60% continued to drink alcohol every day. It is not hard to imagine that continuing such a health behavior could cause a cascading of other events (eg, social isolation, inability to maintain social roles) that would affect QOL.

**Positive Outcomes**

Although there is evidence in the psychosocial oncology literature that many survivors report positive aspects to their cancer experience[5] and that these positive aspects can offset the effects of negative outcomes,[6,7] in general attention has not been paid to this phenomenon in the QOL literature. Most suggested QOL domains focus on negative outcomes, and researchers implicitly assume that the absence of negative outcomes is positive--a position not accepted in the broader field of psychological adaptation to chronic illness. The QOL literature could profit from some attempt to conceptualize the role of positive experiences, such as renewed spirituality, increased closeness to family members, and newfound joy in living, in explaining variations in adaptation among long-term survivors. This is particularly important given the renewed scientific interest in the role of spirituality and religious beliefs and behaviors in recovery from illnesses. Cancer QOL researchers do have the opportunity to make great strides in understanding survivorship issues: There is a large extant literature from which to gain insights about areas that are as yet unstudied or poorly studied; there are exciting developments in related fields; and there is an institutional base from which to gain direction. We need, however, to advance the field to a higher level, not to repeat the studies of the past.

**References:**


Source URL:
http://www.cancernetwork.com/review-article/quality-life-among-long-term-cancer-survivors-1

Links:
[1] http://www.cancernetwork.com/review-article
[3] http://www.cancernetwork.com/authors/barbara-curbow-phd