

Cancer survivorship research must look at quality of life: report

October 28 2011

Assessing the quality of life experienced by cancer survivors is becoming increasingly important, say researchers at Moffitt Cancer Center in Tampa, Fla. Such an assessment has a number of important applications when doing research on cancer survivorship, but just how to measure quality of life for cancer survivors is still being developed.

"Assessment of quality of life in cancer patients can be tailored through the use of measures specific to a particular disease, treatment, or end point on the cancer continuum," said study authors Paul B. Jacobsen, Ph.D., and Heather S. Jim, Ph.D., of Moffitt's Department of Health Outcomes and Behavior. They published their conclusions in a recent issue of *Cancer Epidemiology, Biomarkers and Prevention* (2011; 20:2035-2041).

The authors identify strategies and priorities for quality of life research with <u>cancer survivors</u>. For example, <u>observational studies</u> can generate data on the nature and extent of problems experienced by cancer survivors in relation to their type of disease and treatment received, as well as the time elapsed since treatment was completed.

"This information can be used to inform patients of the expected consequences of specific treatments and to help identify their rehabilitative needs," said Jacobsen. "Similarly, the outcomes of clinical trials that include quality of life as an endpoint in studies can be useful in identifying which treatments yield the best quality of life for cancer survivors."



In addition, quality of life assessments can be used to evaluate the quality of care patients received.

"Quality of life is a multidimensional construct about functioning – from physical to social – and is most often assessed by self report, either by interview or questionnaire," noted Jim. "However, some research suggests that patients may be less likely to report poor quality of life in response to an interview as compared to a questionnaire."

In total, the authors evaluate almost 20 commonly used measures of quality of life for cancer patents and cancer survivors.

For example, the authors discuss the Quality of Life in Adult Cancer Survivors (QLACS) measure that is driven, in part, by the view that existing cancer-specific measures were designed primarily to capture the effects of diagnosis and treatment.

"These measures may not adequately assess problems that can persist long after treatment, such as pain, fatigue, cognitive difficulties, sexual difficulties and body image concerns," said Jim.

Greater consistency in quality of life measurement may be found in the Patient-Reported Outcomes Measurement Information System (PROMIS) initiative, the authors report. The initiative is designed to develop, validate and standardize item banks for measurement of patient-reported outcomes for a wide range of conditions, including cancer.

According to Jacobsen and Jim, too many studies are based on "convenience sampling" at a single recruitment site, and these studies often suffer from the limitation of being too small.

"There is a need for research based on larger cohorts of cancer survivors recruited from multiple sites, or by using population-based recruitment



strategies," said Jacobsen.

The authors conclude by noting the "marked increase" in publications on quality of life for cancer survivors in recent years, suggesting widespread recognition of the value of such research.

"However, for the field to continue to progress, important issues still need to be addressed," said Jacobsen. "Most important among these is how quality of life is to be measured, in whom it is measured, and what uses are made of quality of life data."

Provided by H. Lee Moffitt Cancer Center & Research Institute

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