Assessing the Impact of Cancer: Development of a new instrument for long-term survivors

Brad J. Zebrack, Ph.D., MSW[1], **Patricia A. Ganz, M.D.**[2,3], **Coen A. Bernaards, Ph.D.**[4], **Laura Petersen, M.S.**[2], and **Laura Abraham, B.A.**[2]

[1]University of Southern California School of Social Work

[2]UCLA Jonsson Comprehensive Cancer Center, Division of Cancer Prevention and Control Research

[3]UCLA Schools of Medicine and Public Health

[4]Genentech Inc, Oncology Biostatistics

Abstract

Objective—To develop and evaluate a new instrument that measures aspects of long-term survivorship not measured by existing tools.

Methods—In qualitative interviews, 47 long-term cancer survivors (LTS) detailed ways that cancer has impacted their lives. Content analysis resulted in the creation of 325 candidate items for inclusion in a new Impact of Cancer (IOC) instrument. Following expert review, item reduction and pilot testing, 81 items were administered with other established health status and quality of life (QOL) instruments to 193 LTS of breast, prostate, colorectal cancers and lymphoma. Internal consistency reliability and validity of newly-derived scales was assessed.

Results—Factor analysis of items using *a priori* QOL domains resulted in the derivation of ten new and specific subscales: *health awareness, body changes, health worries, positive and negative self-evaluation, positive and negative life outlook, social life interferences, relationships, and meaning of cancer.* Internal consistency measurements for these subscales ranged from 0.67 to 0.89. Expected associations within and among the IOC subscales and standardized measures of health status and QOL were observed, as were some unexpected findings.

Conclusions—Psychometric analysis indicated that this initial version of the Impact of Cancer instrument measures distinct and relevant constructs for LTS. Future work is necessary to confirm the factor structure, responsiveness and further validation of the instrument.

Keywords

Cancer survivors; Instrument development; Psychometric testing; Quality of life

INTRODUCTION

Currently, about 1.3 million people are diagnosed with cancer each year in the United States, and 64% are expected to survive at least five years from the time of their diagnosis (American Cancer Society, 2005). That National Cancer Institute (2005) estimates that there are about 10.1 million cancer survivors, representing approximately 3.5% of the US population. Some of these individuals can be considered cured or disease-free, while others

still have evidence of active disease. While current trends indicate increased length of survival for individuals diagnosed with cancer, they give no indication of the health status or quality of life (QOL) for those living beyond five years after their diagnosis and treatment.

Relatively little is known about the long-term impact of cancer as it affects individuals on a daily basis. In the aggregate, long-term survivors appear to score well on standard QOL instruments (Ganz et al., 1996; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Litwin et al., 1995); however, in a comprehensive review of QOL studies in long-term cancer survivors, Gotay and Muraoka (1998) stated: "*The quality of life reported by survivors varies a great deal, making it impossible at this time to come to firm conclusions about the magnitude and nature of long-term consequences for cancer survivors. It seems clear, however, that considerable numbers of survivors continue to experience negative effects of cancer and/or treatment on their daily lives, resulting in decrements in quality of life, well beyond the completion of therapy*" (p.664).

In 1997, due to the limited number of instruments designed to capture specific concerns of long-term survivors, the National Cancer Institute issued a request for applications to stimulate further instrument development (RFA CA-97-018). To date, there are only two questionnaires that have been reported as developed specifically for off-treatment adult cancer survivors: the *Long-Term Quality of Life* (LTQL) Scale (Wyatt & Friedman, 1996), which was developed for female survivors; and, the *Quality of Life – Cancer Survivors* (QOL-CS) (Ferrell, Hassey Dow, & Grant, 1995), which included survivors less than five years post-diagnosis. These two instruments focus on items that are specific to off-treatment survivors (e.g., physical symptoms associated with cancer treatments, sense of isolation caused by illness, financial burden) but not necessarily distinct from commonly used generic QOL and health status measures such as the SF-36 (Ware & Sherbourne, 1992), or from cancer-specific QOL instruments designed for patients receiving active cancer treatment, including the EORTC QLQ-C30 (Aaronson, Ahmedzai, & Bergman, 1993), the Ferrans-Powers QOL-Cancer Version (Ferrans & Power, 1995), the Functional Assessment of Cancer Therapy Measurement System (Cella et al., 1993), and the Functional Living Index-Cancer (Schipper, Clinch, McMurray, & Levitt, 1984). The research described in this paper was undertaken as part of a national effort to develop new and complementary tools to assess aspects of well-being and adjustment in long term cancer survivors (five years or more post-diagnosis).

In initiating this program of research, we did not wish to duplicate existing measures of multi-dimensional QOL (e.g., physical and emotional functioning) but rather sought to propose and measure a new construct comprising unique aspects of life distinct to long-term cancer survivors. Our ultimate goal is to develop a new valid and reliable instrument that will assess a range of problems, issues and changes that long-term survivors ascribe to their cancer experience. In an iterative process of instrument development we will eventually derive normative data regarding the cancer survivorship experience such that study samples or even individuals in future research might be compared. Rather than evaluate a latent construct such as "quality of life," our intention is to assess concrete experiences across physical, psychological/emotional, social and spiritual/existential domains of QOL that could in turn inform the development of specific supportive interventions.

Through a systematic process of qualitative research, item generation and cognitive interviews we aimed to identify and incorporate unique aspects of the survivorship experience reported by survivors themselves. Little theoretical and empirical work exists today that identifies (1) issues specific to the age or life stage at which cancer was diagnosed, (2) issues that may differ across different diagnoses, and (3) potentially universal aspects of the long-term survivorship experience, including reports of perceived benefits,

positive life changes and posttraumatic growth (Andrykowski, Brady, & Hunt, 1993; Curbow, Somerfield, Baker, Wingard, & Legro, 1993; Ferrell, Hassey Dow, & Grant, 1995; Fromm, Andrykowski, & Hunt, 1996; Taylor, 1983; Zebrack, 2000). Thus, we took all of these factors into account in the development of this new tool. This paper reports on the development and initial psychometric evaluation of the Impact of Cancer (IOC) instrument.

METHODS

Developmental steps

Qualitative interviews with long-term cancer survivors (LTS) were the first component of instrument development. Quota sampling was intended to recruit up to four participants diagnosed at four different life stages (18-30, 31-45, 46-65, 66+) (Rowland, 1990) for each of four diagnostic categories (female breast, colorectal, prostate, and lymphatic cancers including Hodgkin's disease and non-Hodgkin's lymphomas). Participants responded to notices posted in follow-up clinics at the University of California Los Angeles, announcements made in person or sent to local survivors' support and advocacy groups, and letters sent to select oncology practices in the Los Angeles area. We eventually recruited 19 male survivors and 28 female survivors who were 5-10 years post-treatment to participate in face-to-face interviews. No colorectal or breast cancer survivors diagnosed between the ages of 19-30, and no survivors of prostate cancer diagnosed between the ages of 19-45 volunteered for participation. A semi-structured interview was conducted, lasting about an hour, in which participants were asked to describe how cancer had affected them in physical, psychological, social, and spiritual aspects of their lives. All interviews were transcribed and subject to content analysis, which resulted in the creation of items for the candidate instrument.

Specifically, qualitative analyses in this project involved a multi-step process. First, segments of text (phrases, sentences, paragraphs) were examined line-by-line and assigned shorter phrases, or codes. Codes, as described by Miles and Huberman (1994) are one or two words that in the reviewers' judgment represent the content of the segment. In some instances, multiple codes were assigned to a data segment. To maintain integrity of respondents' meanings and to limit bias resulting from the analyst's imposition or interpretation of meaning, this process used respondents' own words as labels for the data (Denzin & Lincoln, 1998). It also is important to note here that the frequency of any code is not relevant at this phase of exploratory analysis. The primary goal of this work was to identify the breadth of long-term survivors' experiences. Even outliers – comments and subsequent codes reported infrequently and unique to perhaps only one or two respondents – still represented a breadth of experience for the population and an aspect to be included in a set of derived survey items. Coding was performed by one of the investigators (BJZ) and was reviewed during the process with another investigator (PAG).

Next, 145 codes derived from the process described above were organized into an *a priori* framework of QOL consisting of four categories: physical, psychological, social, and spiritual/existential (Ferrell, Hassey Dow, & Grant, 1995). This phase of the analysis required the investigator to make theoretical interpretations of codes as they reflected content related to one of the four domains. Then, using a procedure of "constant comparative analysis" (Strauss & Corbin, 1990), synonymous or similar codes were merged together to form clusters, and then data segments within each code category were compared and contrasted to every other data segment within the same category resulting in the creation of sub-categories within each domain. As an organizing framework for data collection and analysis, these generally accepted domains of QOL (see Cella, 1998) complemented existing approaches to QOL assessment and offered the potential to derive new content specific to long-term survivors. This approach also promoted an examination of spiritual and existential

aspects of survivorship which receive relatively less attention in the research literature. Table 1 provides a summary of code clusters and sub-categories as they were organized within each of the 4 domains. In addition, we noted instances in which survivors attributed certain conditions to some other antecedent condition, and instances in which subjects said that a particular condition or situation resulted in a specific consequent outcome. For example, the statement *"My lymphedema would get worse when I exercise"* was coded as "lymphedema," and the attribution of a worsening physical condition due to an antecedent cause (exercise) was noted.

An item pool for an initial version of a candidate instrument was developed by the creation of items around each of the 145 codes, while taking into account the antecedent/consequent attributions expressed by subjects. We generated a list of 325 potential items that were then reviewed by an expert panel of five researchers, four clinicians (two oncology nurses and two oncology social workers) and five cancer survivors/patient advocates. These reviewers examined the list for redundant or incomprehensible items and evaluated the content of the items for their breadth and scope of coverage of long-term survivorship issues. Feedback from these experts permitted us to combine some items, eliminate others, and reduce the item pool to 250. Next, two focus groups with four long-term survivors in each group assisted us in further reducing, re-wording and clarifying items. A resultant pool of 125 items was then pilot tested in 13 face-to-face interviews that assessed respondents' perceptions and cognitive understanding of the meaning of the items. Focus group participants and the 13 subjects involved in this final phase of pilot testing exhausted the available pool of long-term survivors recruited specifically for these purposes through advertisement in local media.

Ultimately, a set of 81 statements was selected for inclusion in a mailed survey intended to examine the psychometric properties of the new instrument (See Appendix). Items were worded such that respondents were asked to indicate their level of agreement (strongly agree, agree, neutral, disagree, strongly disagree) with each item.

Administration and Evaluation of the IOC

Following the selection of 81 items for the initial version of a candidate IOC measure, we administered them via mailed questionnaire to a new sample of long-term (5-10 year) survivors of breast, prostate, colorectal cancer, and lymphoma recruited from the UCLA tumor registry. Study eligibility criteria permitted inclusion of survivors who were off treatment and disease-free at the time of questionnaire completion. Potential subjects (n=668) were mailed an invitation letter informing them of the study and a response form used to screen subjects for satisfying eligibility criteria. Three follow-up phone calls were made to subjects who did not respond to the initial invitation letter. Upon receiving affirmative responses of interest from 449 LTS, we mailed out survey questionnaires. Reminder letters were sent and up to 2 subsequent phone calls were made to subjects who requested but did not return completed questionnaires. Follow-up phone calls also were made for the purposes of completing missing data on returned questionnaires. All procedures were approved by the local IRB, and written informed consent for the research was obtained from each participant.

Survey booklet

In addition to the candidate IOC instrument, the mailed questionnaire also included several well-established measures demonstrating substantial evidence of reliability and validity in assessments of health status and QOL in healthy populations, ill populations, and cancer patients/survivors specifically. These measures were (1) the SF-36, a widely-used and well-validated instrument that assesses health status with regard to physical, social, and

psychological functioning (Ware & Sherbourne, 1992); (2) the Posttraumatic Growth Inventory, a 21-item scale assessing positive adaptation, including new possibilities, relating to others, personal strength, spiritual change, and appreciation for life among persons who have experienced traumatic events (Tedeschi & Calhoun, 1996); (3) the *Quality of Life— Cancer Survivors*, a 41-item visual analog scale composed of four multi-item sub-scales measuring physical, psychological, social and spiritual dimensions of QOL (Ferrell, Hassey Dow, & Grant, 1995); and (4) a slightly modified version of a self-report questionnaire designed to assess comorbid health conditions corresponding to elements of the medical record-based Charlson index (Katz, Chang, Sangha, Fossel, & Bates, 1996). Respondents also were asked to report sociodemographic descriptive data and information about their cancer diagnosis, type of cancer, and date of diagnosis. To verify that subjects were indeed off all treatment and were currently disease-free (per eligibility requirements), respondents were asked about cancer recurrence and current treatment.

Statistical Analysis

Several procedures were conducted to examine the psychometric properties of the candidate IOC instrument. Content validity of the IOC items was assessed by recognized clinicians and researchers expert in the field of psychosocial oncology and also by cancer survivors. Determining theoretically- and statistically-derived dimensions and scales involved an iterative process consisting of (1) *a priori* categorization of items by domains; (2) exploratory factor analyses and multi-trait multi-item analyses to test psychometric properties of hypothesized scales; (3) item reduction; (4) re-scaling and re-testing (factor analyses); and (5) eventual selection of items and derivation of subscales. To create each scale we computed the mean of items in that scale based on response categories ranging from 1 (strongly disagree) to 5 (strongly agree). Mean scores for each of the subscales were calculated such that higher scores indicated a greater level of agreement with each item statement.

Construct validity of a shortened IOC instrument derived from the above-described procedures was evaluated by examining Spearman correlations among the instrument's various subscales. We used the recommendations of Burnand, Kernan, & Feinstein (1990) to describe the strength of association, using $r < 0.30$ as a negligible association; $0.30 < r < 0.45$ moderate; $0.45 < r < 0.60$ substantial; and $r > 0.60$ high. External validity of the IOC subscales was evaluated in several ways. Concurrent validity was evaluated using the correlate of the IOC scales with the physical and mental health summary scores of the SF-36, the subscale and overall scores of the QOL-CS, and the Posttraumatic Growth Inventory overall score. Discriminative validity was examined by review of cross-sectional differences between subjects for expected or known differences. IOC subscale scores were examined as they differed (or not) across gender, age at diagnosis, diagnostic category, and comorbidity score (0/1).

RESULTS

Psychometric Evaluation of the Candidate Measure

Subject Characteristics—Of 668 potential subjects who received invitation letters to participate in the study, 219 did not respond in any way. Of the 449 subjects who returned response forms indicating interest, 90 subjects were found to be ineligible for the study. Of the remaining 359 subjects who met the eligibility criteria and received a mailed survey, 193 (54%) returned complete and usable data. The demographic and medical characteristics of the sample and non-respondents are presented in Table 2. Overall, survey participants were significantly younger at age of survey administration, younger at diagnosis, and further out in time since diagnosis.

Scaling of the IOC—For these analyses, we focused only on 70 items that were pertinent to all survivors (11 of the 81 items are only relevant to those working, in partnered relationships, interested in child bearing, and will be analyzed in the future when sufficient numbers of respondents are available). The 70 core items of the initial version of the IOC were organized into physical (19 items), psychological (18 items), social (25 items), spiritual/existential (21 items) and miscellaneous (14 items) domains and we hypothesized which items we expected to form possible subscales within each domain, based on the content of the items. In some instances we were unsure whether a particular item fit best in one or another domain, so we conservatively assigned some items to more than one domain for the first round of factor analysis in order not to miss a potential relationship.

Typically, untested scales or scales in early phases of development, such as the IOC, will have items with communalities considerably lower than 0.6 (Gorsuch, 1983). Thus, a factor analysis of all 70 items in a sample size of 193 respondents would probably lead to an unstable solution, with factors that may be difficult to replicate. We therefore applied an analytic strategy based on separate principal factoring factor analyses to items organized within each of the four *a priori* QOL domains and the "miscellaneous" category, followed by oblique quartimin rotation when two or more subscales within a specific category were considered. We strived to find quartimin rotated factor loading patterns that had high loadings on one factor and absolute loadings smaller than 0.10 on the other. The number of factors to retain for each of the domains was based on parallel analysis, a variant on the scree plot with eigenvalues of random data superimposed (Reise, Waller, & Comrey, 2000). Items that loaded above 0.40 with other items on a factor and had a clear theoretical interpretation were retained, and items were set aside when estimated communalities were unacceptably low.

Although literature on sample size in factor analysis is not convergent in its recommendations, recent work in this field relates communalities, number of factors, and number of variables to sample size. Our analyses are consistent with criteria described by MacCallum, Widaman, Zhang, & Hong (1999) in that a sample size nearing 200 suffices for communalities in the range 0.3 to 0.8 when around 20 items/variables and approximately 3 factors are involved in any given factor analysis.

Items set aside in the analysis described above were not rejected forthright but subsequently reorganized into new emerging theoretical dimensions, or else eventually removed from further analysis when a theoretical explanation for that item's appearance within a newly-derived factor solution was lacking. Mean, standard deviation, range, and percentage of subjects scoring the minimum (floor) and maximum (ceiling) were calculated for all retained items and for each scale. Cronbach's alpha was computed as a measure of internal consistency reliability. Multi-trait multi-item correlations were computed and compared for consistency with factor analytic results. Frequency of endorsement for items retained was compared to frequency of endorsement of items omitted, with endorsement being the extent to which participants agreed or disagreed with a statement as opposed to indicating neutrality. For items eventually comprising a subscale, participants endorsed those items 81% of the time. Items omitted due to lack of statistical or theoretical "fit" also were endorsed 81% of the time.

As a result of factor analysis, multi-trait scaling and item reduction, we identified eight emergent subscales derived from items related to physical, psychological, social, and spiritual/existential domains of QOL, plus two additional theoretically distinct scales that we called "meaning of cancer" and "health worry." These 10 scales utilized 41 of the original 70 items that were evaluated in these analyses, and they are described with their factor loadings and internal consistency estimates in Table 3. Within each of the scales,

communalities ranged from 0.29 to 0.85. Percentage explained variance for the subscales in the physical, psychological, existential, and social domains for the first factors ranged from 22% to 34%, and for the second factors from 14% to 31%. Percentage explained variance for the subscale Meaning of Cancer was 45%, and for Health Worry, 54%. Descriptive statistics for each of the subscales are reported in Table 4.

To evaluate construct validity, we examined Spearman correlations among scale scores within the 41 items of the scaled IOC. Based on existing literature indicating inter-relationships among physical, psychological, social and spiritual/existential domains of QOL (Wyatt & Friedman, 1996; Zebrack, 2000), we expected to observe such relationships among related subscales of the IOC. Indeed, the positive self-evaluation (psychological), positive life outlook (spiritual/existential), and value of relationships (social) subscales were all substantially to highly associated with one another (Table 5). Also, the associations for body changes (physical) with negative self-evaluation (psychological) and life interferences (social) were substantially correlated: as respondents reported more body changes they tended to report worse self-evaluation and more life interference. Counter to reports indicating no significant relationships between physical and spiritual/existential domains (Wortman, 1984; Wyatt & Friedman, 1996; Zebrack, 2000), body changes (physical) was moderately associated with negative life outlook (spiritual/existential), with life outlook diminishing as respondents reported more body changes. Table 5 summarizes the correlations of subscales within the IOC instrument.

Two additional observations are noted here. First, there were no significant associations among positive and negative subscales from the four domains. For example, positive self-evaluation or health awareness scores did not decrease as negative self-evaluation, negative life outlook, body changes or life interferences increased. Thus, reporting positive outcomes was not dependent upon reporting negative outcomes, and vice-versa. Second, the meaning of cancer subscale and health worry subscale were positively and significantly associated with both positive and negative subscales. Meaning of cancer and health worries increased as both positive and negative outcomes in other subscales increased.

Relationship of IOC scales with other outcome measures—Concurrent validity of the IOC was evaluated by examining the relationship of each of the subscales with the SF-36, the QOL-CS, and the PTGI using Pearson product-moment correlations (Table 6). We observed moderate to substantial correlations among a physical subscale component of the IOC (Body Changes) and physical functioning and physical well-being subscales of the SF-36 (physical function, vitality, bodily pain, general health) and the QOL-CS. A psychologically-oriented subscale of the IOC (negative self-evaluation) was moderately correlated with the mental health subscale of the SF-36 and substantially correlated with the psychological domain of the QOL-CS: well-being diminished as subjects reported more negative self-evaluations. Similarly, negative life outlook (existential) was substantially and negatively correlated with the mental health subscale of the SF-36 and highly correlated with psychological well-being, as assessed by the QOL-CS. Also, health worry increased substantially as psychological well-being, measured by the QOL-CS, decreased. In the social dimension, the life interferences subscale of the IOC was substantially and negatively correlated with the social well-being subscale of the QOL-CS and the SF-36 subscales assessing social functioning and social well-being (role physical, social function).

For the most part, moderate to high correlations were observed only for negative-oriented subscales of the IOC (negative self-evaluation, body changes, negative life outlook, life interferences, health worry) and subscales of the SF-36 and QOL-CS. Positively-oriented subscales (health awareness, positive self-evaluation, positive life outlook, valuing relationships, meaning of cancer) were rarely more than negligibly correlated with SF-36

and QOL-CS subscales. However, substantial to high correlations were observed for positive-oriented subscales of the IOC and the Post-Traumatic Growth Inventory, a measure of personal strength and appreciation for life. Of note, while a substantial and positive correlation was observed for the Meaning of Cancer subscale and the PTGI, a moderate and negative association also was observed for the Meaning of Cancer subscale as it was associated with the psychological and social subscales of the QOL-CS. As respondents tended to attribute meaning to cancer, they tended to report more post-traumatic growth and also worse psychological and social QOL, as measured by the QOL-CS. Similarly, although increased health worry was significantly associated with worse overall QOL (as measured by the QOL-CS, Table 6), a moderate and positive correlation also was observed for health worry and post-traumatic growth.

Association of IOC scales with other independent variables—We used established criteria to determine discriminative validity using variables from population-based health outcomes studies and from studies of QOL and psychological well-being in cancer patients and off-treatment survivors. For instance, based on existing LTS studies reporting differences in QOL outcomes by gender and age at diagnosis (Ferrell, Hassey Dow, Leigh, Ly, & Gulasekaram, 1995; Ganz et al., 2002), we hypothesized that there would be similar differences in the psychological subscales of the IOC, with more negative scores for women and survivors diagnosed at younger ages. We also expected there to be gender and age at diagnosis differences in the existential outlook and meaning of cancer subscales, with more positive attributions among women (Ferrell, Hassey Dow, Leigh et al., 1995) and younger survivors (Dunn & Steginga, 2000; Ganz, Schag, Coscarelli, & Heinrich, 1985). With regard to reporting comorbidities, we hypothesized that survivors indicating existence of comorbidities would be more likely to report fewer positive and more negative outcomes (Ferrell, Hassey Dow, Leigh et al., 1995; Ganz et al., 2002; Schag, Ganz, Wing, Sim, & Lee, 1994; Zebrack, 2000).

Table 7 presents our findings related to gender, age at diagnosis, diagnostic category, and comorbidity. Consistent with the literature cited above, positive self-evaluation and life outlook was endorsed to a greater degree among women than men. Also, those diagnosed at a younger age were more likely than older survivors to report more positive self-evaluation, life outlook, and attributions of meaning to cancer. Significant differences in psychological (positive self-evaluation), existential (positive life outlook), social (value of relationships) and meaning of cancer scales of the IOC were observed across diagnostic categories, with lymphoma survivors being more likely to report these positive outcomes.

Contrary to expectations, the IOC subscales assessing psychological and existential content (positive and negative self-evaluations, positive and negative life outlooks) were not sensitive to comorbidity scores (Table 7). Respondents reporting comorbid conditions were no more or less likely to endorse more positive or more negative self-evaluations and life outlooks than respondents who reported no comorbid conditions. However, survivors reporting comorbid conditions tended to report greater health worry and interferences in their daily lives.

DISCUSSION

Developing a new instrument to assess multi-dimensional constructs or even a single dimension of a phenomenon or condition is a time consuming task. It is particularly important to define the goals and objectives of such a project before its initiation. In this report, we describe the development of a new instrument to assess subtle yet important aspects of the cancer survivorship experience that LTS themselves indicate are important. This is especially critical since standardized measures of health status and QOL often have

failed to discriminate cancer survivors from healthy individuals (Ganz et al., 1998; Litwin et al., 1995). For instance, aspects of survivorship reported in research include perceived benefits, resilience and opportunities that cancer may present for personal growth (Andrykowski et al., 1993; Fromm et al., 1996; Ganz et al., 1996), and only recently have these outcomes been assessed by standardized measures (Bellizzi 2004; Manne et al., 2004). In the development of the IOC, we specifically decided not to duplicate content from other well-validated measures that include physical, emotional and social functioning domains of QOL, and instead focused on concepts within these domains that were specific to the experience of LTS. We also wanted to develop a tool that would capture survivor-related concerns across four of the most common disease types and across developmental stages in which the cancer was experienced.

The psychometric evaluation presented here suggests to us that we are developing a candidate instrument with potentially reliable and valid subscales. For instance, we observed expected significant and substantial associations (convergence and divergence) among IOC subscales and subscales of existing standardized QOL measures. IOC subscales measuring negative physical and psychological sequelae correlated with existing measures of physical and psychosocial functioning, and positive subscales of the IOC were associated with the Post-Traumatic Growth Inventory as a comparative measure of positive adaptation and personal growth. We also observed differences in subscale scores where current general health and cancer-specific research would suggest such divergence. For example, consistent with literature suggesting that women use emotion-based coping to a greater extent than do men (Tamres, Janicki, & Helgeson, 2002), IOC subscales representing emotion-related coping (positive self-evaluation, positive life outlook, valuing relationships) were higher for women than for men. Also, reports of negative body changes were greater for respondents reporting the existence of current comorbid medical conditions.

We also noted some unexpected findings that suggest that the IOC is tapping into new and previously unreported aspects of long-term survivorship. For example, while existing health outcomes research suggests that women report more symptoms of psychological distress (i.e., depression) than do men (Hankin & Abramson, 1999), we found no gender differences in survivors' negative self-evaluations and negative life outlooks where the impact of cancer is concerned. A second observation is that the IOC captured meaning attribution, an area having potential for being associated with psychological well-being and QOL. Third, health worry appeared significantly associated with subscales of the IOC, SF-36, QOL-CS and PTGI in both positive AND negative directions. For instance, as health worry increased, health awareness, positive life outlook, and value of relationships (as measured by the IOC) also increased, as did post-traumatic growth. In the meantime, there also was an inverse relationship between health worry and QOL, as measured by the QOL-CS: as health worry increased, physical, psychological, social QOL and overall QOL decreased. These observations indicate that some survivors worry and also report life enhancements, while for others health worries are associated with diminished QOL. Thus, health worry may be an important independent aspect of the survivorship experience that may have potential for predicting certain positive and negative outcomes, warranting greater evaluation in future research.

These findings also suggest some questions to be examined in future studies of long-term survivors: Are changed perceptions of body image associated with decreased QOL? Are positive self-evaluations and life outlooks more likely to occur in survivors diagnosed at younger ages? And, as suggested by Curbow and colleagues (1993), might experiencing and reporting positive effects of cancer attenuate the influence of perceived negative effects on psychosocial outcomes?

Used as a complement to other health status and QOL instruments, the IOC has the potential to measure specific aspects of long-term cancer survivors' lives. Given 10 content areas specific to the survivorship experience, IOC subscales have the potential to be predictive of other outcomes of interest, such as psychological well-being or mental health status. In addition, the content areas of the IOC are concrete and malleable, thereby potentially being amenable to intervention and change. We would consider the IOC to be a condition-specific measure (the condition being long-term survivor) that should be paired with a health status measure such as the SF-36 if one wants to examine current functioning and the relationship of the specific illness condition to functioning. This is a strategy that has been used by others (see for example Litwin et al., 1998).

Although the IOC has considerable promise, there are some limitations. First, the qualitative data used to initially derive 325 items for the IOC were coded primarily by only one analyst, perhaps biasing the coding procedure. Yet, all items created from the coding process retained language used by respondents and also were subject to extensive review by experts and cognitive testing for meaning and comprehensibility. Second, while the 54% response rate reported here is consistent with other studies of long-term survivors (Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Ganz et al., 1998), there still exists a significant portion of the survivor population for whom we have no data on long-term impact. This lack of data, along with findings (1) that respondents were significantly younger at study, younger at diagnosis and slightly further out in time from diagnosis when compared to non-respondents, and (2) that this sample was high functioning in terms of education and income, serve as cautions regarding the instrument's generalizability in its current form. To support the instrument's validation, an assessment of its responsiveness to change over time and its test-retest reliability also should be considered in future research. Next, a relatively small sample size and skip patterns in the survey required some subjects to skip over items related to employment (if they were not working) and spousal relationships (if not in a marital or committed relationship). These missing data restricted our ability to analyze important and relevant content related to these two aspects of survivorship. Further evaluation, refinement and administration of the IOC (utilizing all 81 items listed in the Appendix) will help to establish its reliability and utility in different and preferably larger samples of long-term survivors. Finally, given that the current study was not sufficiently powered for a confirmatory factor analysis of the *a priori* four-dimensional QOL framework used to collect and analyze the data, future research will benefit from including a confirmatory factor analysis to further assess the IOC and distinguish it from existing QOL instruments.

"Regardless of the type of cancer or the extent of survival, all persons diagnosed with cancer must manage the enduring and complex ways in which cancer transforms the self and everyday life" (p. 239) (Clark & Stovall, 1996). Understanding how individuals who are long-term cancer survivors manage the impact of cancer is critical for health care professionals caring for cancer patients and survivors, for payors of health care, and for those engaged in policy regarding health insurance, employment and disability-related rights of these many survivors. A valid and comprehensive instrument that assesses the impact of cancer must capture the physical losses, the distress, the interferences with daily living *and* the sense of gratitude, enhanced appreciation for life, and sense of meaning or purpose expressed by this population.

Acknowledgments

APPENDIX

81-item Impact of Cancer Instrument, Version 1, as organized and presented in the mailed survey.

Employment
1. I am concerned about not being able to work if I were to become ill again.
2. Concerns about losing health insurance keep me in the job I have now.
3. I worry about being forced to retire or quit work before I am ready.
Life Outlook
4. Because of cancer I live each day one at a time.
5. I feel grateful to be alive.
6. I feel like time in my life is limited.
7. I learned something about life because of having had cancer.
8. Having had cancer makes me feel unsure about my future.
9. I worry about my future.
10. I am afraid to die.
11. I can accept my mortality, that I am going to die someday.
12. I feel like time in my life is running out.
13. Having had cancer has made me realize that time is precious.
14. Having had cancer has strengthened my religious faith or my sense of spirituality.
Body and Health
15. I do not take my body for granted since the cancer.
16. Having had cancer has made me more concerned about my health.
17. I am more aware of physical problems or changes in my body since having had cancer.
18. Other health problems not related to cancer bother me more than having had cancer.
19. I worry about my health.
20. I accept the changes my body has gone through as a result of cancer and its treatment.
21. I worry about the cancer coming back or about getting another cancer.
22. New symptoms (aches, pains, getting sick or the flu) make me worry about the cancer coming back.
23. Having had cancer makes me feel uncertain about my health.
24. I am concerned that my energy has not returned to what it was before I had cancer.
25. I am bothered that my body cannot do what it could before having had cancer.
26. I worry about how my body looks.
27. I feel disfigured.
28. I sometimes wear clothing to cover up parts of my body I don't want others to see.
29. Having had cancer has made me take better care of myself (my health).
30. Having to pay attention to my physical health interferes with my life.
31. I am unable to think or remember things like I used to.
Feelings About Cancer
32. I consider myself to be a cancer survivor.
33. I feel a sense of pride or accomplishment from surviving cancer.

34. I learned something about myself because of having had cancer.
35. I am angry about having had cancer.
36. I feel guilty for somehow being responsible for getting cancer.
37. I feel that I am a role model to other people with cancer.
38. As time goes on, having had cancer becomes less important to me.
39. Having had cancer has made me feel old.
40. I feel guilty today for not having been available to my family when I had cancer.
41. My sense of myself as a cancer survivor has lessened over time.
42. My life would be better today if I had not had cancer.
43. Having had cancer has been the most difficult experience in my life.
44. Having had cancer has not been as big a deal as other things that have happened in my life.
45. I view having had cancer as a private experience.
46. I wish to forget about having had cancer.
47. I am constantly reminded that I had cancer.
48. Something good has come from having had cancer.
49. I think the doctors should have done a better job treating my cancer.
50. Now that my treatment has ended I feel like my cancer doctors are not interested in my well-being.
Meaning of Cancer
51. I wonder why I got cancer.
52. It is important for me to know why I got cancer.
53. Having had cancer turned into a reason to make changes in my life.
54. Because of cancer I have become better about expressing what I want.
55. Because of cancer I have more confidence in myself.
56. Having had cancer has given me direction in life.
57. I feel like cancer runs my life.
58. Because of having had cancer I feel that I have more control of my life.
59. I have financial problems that are related to having had cancer.
60. Within the past year I have had difficulty getting my health insurance to pay some of my medical bills.
Social Activities and Relationships
61. I place a higher value on my relationships with family or friends than I did before having had cancer.
62. I feel a special bond with people with cancer.
63. Because I had cancer I am more understanding of what other people may feel when they are seriously ill.
64. Having had cancer has made me more willing to help others.
65. I feel that I should give something back to others because I survived cancer.
66. I worry about friends dying from cancer.
67. Having had cancer has made me feel alone.
68. Having had cancer has made me feel like some people (friends, family, co-workers) do not understand me.
69. I am concerned about my children getting cancer.
70. Uncertainty about my future affects my decisions to make plans (examples: work, recreation/travel, get married, get involved in relationships, have a family, go to school).
71. Having had cancer has motivated me to make plans for dying (get my affairs in order).

| 72. Having had cancer keeps me from doing activities I enjoy (examples: travel, socializing, recreation, time with family). |
| 73. On-going cancer-related or treatment-related symptoms (for example bladder or bowel control, lymphedema, hair loss, scars, infertility, premature menopause, lack of energy, impotence/sexual problems, aches, pain or physical discomfort) interfere with my life. |
| 74. Uncertainties about my health or my future have made me delay getting married or getting involved in a serious relationship. |
| 75. I wonder how to tell a potential spouse, partner, boyfriend, or girlfriend that I have had cancer. |
| 76. I am concerned about how to tell a spouse, partner, boyfriend, or girlfriend that I may not be able to have children. |
| 77. I worry about not having a spouse, partner, boyfriend, or girlfriend. |
| 78. I am open and willing to discuss my cancer with my spouse/partner. |
| 79. My spouse/partner is open and willing to discuss my cancer with me. |
| 80. Uncertainty about my health has created problems in my relationship with my spouse/partner. |
| 81. I worry about my spouse/partner leaving me if I were to become ill again. |

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Table 1

Code clusters and categories as organized into four domains.

PHYSICAL DOMAIN	PSYCHOLOGICAL DOMAIN
Physical Functioning	**Acceptance, awareness**
Organ systems (cardio, respiratory, digestive, sensory, reproductive, bowel/urinary, immune, etc.)	**Feelings**
	Fears, worries, concerns
Energy/fatigue	**Sense of self**
Lymphedema	Confidence, mastery
Osteo problems	Different from before
Pain, discomfort	Different from others
Sleep	Return to normal
Health Behaviors	Vulnerability
Fitness, exercise	Balance v Conflict
Medical follow-up	**Control**
	Memory, cognition
	Body Image
	Uncertainty

SOCIAL DOMAIN	SPIRITUAL/EXISTENTIAL DOMAIN
Relationships	**Appreciation**
With spouse	**Changed or new values and goals**
With friends	**Death**
With other loved ones	**Religious beliefs and practices**
With other cancer patients/survivors	**Attributions of meaning**
Altruism and empathy	Perceived benefits
Socioeconomic Status	Meaning of cancer
Financial impact	**Outlook on life**
Health insurance	Sense of purpose
Work	Sense of fairness
Social Involvement	Sense of time
Dating	Planning for the future
Activities	

Table 2

Demographic and Medical Characteristics for Respondents and Non-respondents

	Respondents (N=193)	Non-respondents[1] (n=385)
Diagnosis		
Breast	47 (24%)	107 (28%)
Colorectal	39 (20%)	111 (29%)
Lymphoma (Hodgkin's disease and NHL)	49 (25%)	64 (17%)
Prostate	58 (30%)	103 (27%)
Gender		
Female	84 (44%)	195 (51%)
Male	109 (56%)	190 (49%)
Marital status		
Married/committed relationship	150 (78%)	NA
Not currently married (divorced, widowed, separated, never married)	43 (22%)	
Education		
No college degree	73 (38%)	NA
College degree	48 (25%)	
Post-graduate	72 (37%)	
Employment		
Employed (full-time, part-time, homemaker, volunteer, student)	110 (57%)	NA
Not currently employed (unemployed, unable to work, leave or disability)	7 (4%)	
Retired	76 (39%)	
Income		
<=$25,000	19 (10%)	NA
$25,001-$75,000	71 (38%)	
>$75,000	97 (52%)	
Race/ethnicity		
White	166 (86%)	NA
Non-white	27 (14%)	
Age at diagnosis		
15-30	14 (7%)	9 (3%)
31-45	44 (23%)	41 (15%)
46-65	95 (49%)	122 (44%)
66+	40 (21%)	104 (38%)
Mean age at study (SD) [*]	61.5 (14.3)	66.4 (14.8)
Mean age at diagnosis (SD) [*]	53.8 (14.5)	61.0 (22.7)
Mean number of years since diagnosis (SD) [*]	7.67 (1.9)	7.15 (1.8)

[1] Non-respondents include 219 subjects who did not return response form indicating interest in receiving a questionnaire, plus 166 additional eligible subjects who were mailed but did not return a questionnaire. The only demographic data available from the tumor registry on non-respondents was: type of cancer, gender, birthdate and date of diagnosis. Data on age at diagnosis is missing for 109 of the non-responders because the tumor registry did not provide a date of diagnosis for them. Data for respondents are self-reported from questionnaire.

[*] Indicates statistically significant differences at p<0.05; NA = not available

Table 3

Factor loadings and measures of internal consistency (Cronbach's alpha).

	Factor I	Factor II
PHYSICAL		
Health Awareness (α=0.84)		
15. Do not take body for granted	**0.92**	0.03
16. More concerned about my health	**0.68**	-0.04
17. More aware of physical problems and changes	**0.77**	0.07
29. Take better care of self	**0.65**	-0.03
Body Changes (α=0.80)		
24. Concern energy has not returned	0.07	**0.66**
25. Bothered that my body cannot do what did before	0.00	**0.62**
26. Worry how body looks	-0.05	**0.72**
27. Feel disfigured	-0.02	**0.65**
28. Wear clothing to cover up	0.02	**0.67**
PSYCHOLOGICAL		
Positive Self-evaluation (α=0.89)		
33. Sense of pride or accomplishment	**0.67**	-0.04
34. Learned something about self	**0.69**	-0.02
37. Role model to others	**0.69**	-0.04
54. Better about expressing what I want	**0.75**	0.08
55. More confidence	**0.69**	-0.01
63. More understanding of others	**0.67**	0.05
64. More willingness to help others	**0.76**	0.04
65. Feel I should give back to others	**0.78**	-0.03
Negative Self-evaluation (α=0.72)		
35. Angry about having cancer	-0.04	**0.75**
36. Feel guilty for being responsible for getting cancer	-0.05	**0.71**
39. Made me feel old	0.01	**0.55**
40. Feel guilty for not having been available to family	0.06	**0.52**
EXISTENTIAL		
Positive Outlook (α=0.73)		
13. Realize time is precious	**0.74**	0.04
14. Strengthened religious faith or sense of spirituality	**0.63**	-0.03
7. Learned something about life	**0.74**	0.00
Negative Outlook (α=0.82)		
8. Feel unsure about my future	0.17	**0.74**
9. Worry about my future	0.04	**0.85**
10. Afraid to die	-0.04	**0.70**
12. Feel like time in my life is running out	-0.09	**0.62**

	Factor I	Factor II
SOCIAL		
Life Interferences (α=0.67)		
30. Paying attention to health interferes with my life	**0.58**	0.05
72. Having had cancer keeps me from activities I enjoy	**0.73**	-0.02
73. Cancer-related symptoms interfere with my life	**0.62**	-0.02
Value of Relationships (α=0.99)		
61. Higher value on relationships than before	-0.01	**0.78**
62. Feel special bond to people with cancer	0.01	**0.74**

	Factor I
MEANING OF CANCER (α=0.79)	
43. Cancer has been the most difficult experience of my life	**0.54**
51. I wonder why I got cancer	**0.66**
52. Important to know why I got cancer	**0.70**
53. Cancer is reason to make life changes	**0.75**
56. Gave me direction in life	**0.68**
HEALTH WORRY (α=0.77)	
19. Worry about my health	**0.57**
21. Worry about cancer coming back or getting another cancer	**0.78**
22. New symptoms make me worry about cancer coming back	**0.84**

Table 4

Descriptive Statistics of 10 Subscales on n=193 Subjects

IOC Subscale	Mean[*] (SD)	Minimum – Maximum
Physical I: Health Awareness	3.79 (0.76)	1.0 – 5.0
Physical II: Body Changes	2.40 (0.87)	1.0 – 4.8
Psychological I: Positive Self-Evaluation	3.66 (0.73)	1.0 – 5.0
Psychological II: Negative Self-Evaluation	2.03 (0.76)	1.0 – 5.0
Existential I: Positive Outlook	3.78 (0.82)	1.0 – 5.0
Existential II: Negative Outlook	2.52 (0.95)	1.0 – 4.75
Social I: Life Interference	2.21 (0.89)	1.0 – 5.0
Social II: Value of Relationships	3.65 (0.92)	1.0 – 5.0
Meaning of Cancer	3.06 (0.89)	1.0 – 5.0
Health Worry	2.92 (0.90)	1.0 – 5.0

[*] Mean scores derived from the following response categories: 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree

SD=Standard Deviation

Table 5

Subscale Correlation Matrix for the IOC Instrument

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)
1) Health Awareness	1.00									
2) Body Changes	0.17	1.00								
3) Positive Self-evaluation	**0.53**	0.10	1.00							
4) Negative Self-evaluation	0.17	**0.49**	0.05	1.00						
5) Positive Outlook	**0.55**	0.17	**0.66**	0.09	1.00					
6) Negative Outlook	0.27	0.39	-0.01	**0.47**	0.15	1.00				
7) Life Interferences	0.08	**0.51**	-0.00	**0.50**	0.02	0.29	1.00			
8) Values Relationships	**0.50**	0.25	**0.70**	0.17	**0.63**	0.27	0.15	1.00		
9) Meaning of Cancer	**0.56**	0.23	**0.53**	0.41	**0.47**	0.27	0.22	**0.53**	1.00	
10) Health Worry	**0.46**	0.44	0.24	**0.49**	0.36	**0.63**	0.21	0.33	**0.45**	1.00

Bold figures represent **substantial to high** correlations (r > .45), as defined by criteria determined by Burnand et al. (1990)

Table 6

Correlation of new IOC subscales with existing QOL measures

	MOS SF-36										City of Hope QOL-CS					PTGI[1]
	Physical Function	Role Physical	Role Emotional	Vitality	Mental Health	Social Function	Bodily Pain	General Health	MOS PCS	MOS MCS	Physical	Psych	Social	Spiritual	Overall QOL	
Health Awareness	.05	-.01	.02	-.00	-.03	-.00	.05	-.02	.03	-.02	-.09	-.29	-.13	.34	-.12	**.55**
Body Changes	-.44	-.37	-.35	**-.58**	-.44	-.44	-.37	**-.46**	-.41	-.43	**-.51**	**-.57**	**-.55**	-.07	**-.63**	.27
Positive Self-evaluation	-.03	-.05	.10	-.02	.02	.04	.04	.00	-.04	.07	-.14	-.21	-.14	.54	-.03	**.69**
Negative Self-evaluation	-.24	-.31	-.34	-.32	-.40	-.34	-.13	-.27	-.18	-.40	-.32	**-.48**	**-.47**	-.07	**-.50**	.14
Positive Outlook	-.01	-.03	.05	-.06	-.07	-.08	.01	-.05	-.02	-.04	-.20	-.33	-.23	.55	-.14	**.68**
Negative Outlook	-.14	-.14	-.30	-.29	-.49	-.31	-.23	-.37	-.12	**-.45**	-.28	**-.62**	-.37	-.22	**-.59**	.28
Life Interferences	**-.47**	**-.45**	-.26	**-.48**	-.27	**-.48**	-.33	-.41	**-.48**	-.28	**-.46**	-.44	**-.64**	-.12	**-.58**	.13
Values Relationships	-.14	-.08	.02	-.15	-.14	-.09	-.07	-.18	-.13	-.06	-.24	-.36	-.30	.38	-.24	**.68**
Meaning of Cancer	-.08	-.13	-.09	-.12	-.14	-.12	.02	-.13	-.07	-.13	-.23	-.40	-.30	.33	-.27	**.50**
Health Worry	-.19	-.19	-.15	-.26	-.32	-.26	-.18	-.33	-.20	-.27	-.31	**-.58**	-.34	-.11	**-.47**	.38

[1] Post-Traumatic Growth Inventory (Tedeschi & Calhoun, 1996)

Bold and italicized figures represent **high** correlations (r > .60), **bold** represent **substantial** correlations (.45 < r < .60), *italicized* represent *moderate* correlations (.30 < r < .45), and plain text represent negligible correlations (r <.30), as defined by criteria determined by Burnand et al., (Burnand et al., 1990)

Table 7

Mean subscale scores on the IOC instrument by gender, age at diagnosis, diagnosis, co-morbidity

	Gender		Age at Diagnosis				Diagnosis					Comorbidity
	Female n=84	*Male* n=109	*18-30* n=14	*31-45* n=44	*46-65* n=95	*65+* n=40	*Breast* n=47	*Colorectal* n=39	*Lymphoma* n=49	*Prostate* n=58	*Score=0* n=129	*>0* n=64
Health Awareness	3.90	3.69	**4.11**	**3.97**	**3.75**	**3.55**	3.81	3.87	3.87	3.64	3.79	3.79
Body Changes	**2.61**	**2.24**	2.39	2.67	2.34	2.24	2.54	2.45	2.42	2.23	**2.30**	**2.60**
Positive Self-evaluation	**3.83**	**3.53**	**4.09**	**3.97**	**3.57**	**3.38**	**3.73**	**3.60**	**3.91**	**3.42**	3.64	3.68
Negative Self-evaluation	1.99	2.07	1.98	2.04	2.03	2.07	1.94	2.24	1.86	2.12	1.98	2.14
Positive Outlook	**4.07**	**3.56**	**4.17**	**4.24**	**3.71**	**3.29**	**3.96**	**3.73**	**4.06**	**3.43**	3.77	3.81
Negative Outlook	2.65	2.42	2.45	2.71	2.54	2.28	2.65	2.42	2.44	2.54	2.45	2.66
Life Interferences	2.17	2.25	1.90	2.14	2.23	2.35	1.98	2.27	2.17	2.40	**2.08**	**2.49**
Values Relationships	**3.85**	**3.49**	**3.75**	**4.11**	**3.59**	**3.23**	**3.73**	**3.65**	**3.92**	**3.34**	3.63	3.67
Meaning of Cancer	3.08	3.04	**3.50**	**3.36**	2.93	2.87	**2.80**	**3.29**	**3.33**	**2.88**	3.03	3.11
Health Worry	3.05	2.82	3.10	**3.16**	2.88	2.69	2.87	3.09	2.99	2.79	**2.83**	**3.10**

p-values for gender and co-morbidity (dichotomous independent variables) come from t-tests; *p*-values for age at diagnosis and diagnosis group come from ANOVA tests.

BOLD items indicate statistically significant differences at p<.05.

Mean scores derived from the following response categories: 1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree