

Refinement and Psychometric Evaluation of the Impact of Cancer Scale

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- Background** Instruments are needed to measure the influence of cancer on quality of life in the expanding population of long-term cancer survivors. We conducted refinement and psychometric evaluation of the Impact of Cancer (IOC) scale by use of data from a large sample of long-term breast cancer survivors and developed an instrument, the Impact of Cancer version 2 (IOCv2), to measure quality of life outcomes.
- Methods** Questionnaires including 81 potential IOC scale items, the Center for Epidemiologic Studies-Depression (CES-D) scale, and the Breast Cancer Prevention Trial (BCPT) symptom scales, as well as demographic, treatment, and medical information, were completed by 1188 disease-free breast cancer survivors 5–10 years after diagnosis. We used exploratory factor analysis to identify scales and assessed reproducibility by split-sample cross-validation. Higher-order scales were extracted and all scales were evaluated for internal consistency and construct and concurrent validity.
- Results** The analysis yielded a factor structure relating IOC items to psychosocial impact domains that exhibited high factor loadings (factor–item correlations of 0.59–0.94), high internal consistency (Cronbach’s α statistics of 0.76–0.89), and a total congruence of 0.98 across the split samples. The Impact of Cancer version 2 (IOCv2) scales consist of a Positive Impact Summary scale with four subscales (Altruism and Empathy, Health Awareness, Meaning of Cancer, and Positive Self-Evaluation), a Negative Impact Summary scale with four subscales (Appearance Concerns, Body Change Concerns, Life Interferences, and Worry), and subscales for Employment and Relationship Concerns. Patterns of association between IOCv2 scale scores and CES-D and BCPT scores indicated good concurrent validity. Patterns of associations between IOCv2 scale scores and demographic, medical, and treatment characteristics indicated good construct validity.
- Conclusion** The IOCv2 scales provide a validated tool for measuring the impact of cancer on quality of life in long-term cancer survivors.

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There were approximately 10.8 million cancer survivors in the United States as of January 2004, including 6.8 million who had survived more than 5 years since diagnosis (1). The size of the survivor population has increased each year since 1975 (1) and can be expected to continue on an upward trend because of improvements in early detection and treatment as well as expanding numbers of incident cases of cancer associated with aging of the population.

A number of studies (2–4) have shown that long-term cancer survivors have fairly high levels of functioning on generic measures of health-related quality of life. However, a large literature indicates that the experiences of cancer diagnosis, treatment, and survival can engender lingering problems and concerns across physical, psychological, social, and spiritual domains. Examples of disruptions reported for adult cancer survivors include fatigue (5,6), body image concerns (7,8), sexual health and functioning concerns (7,9,10), fear of recurrence (11,12), stress syndromes (12–14), and financial issues (7,15), as well as distress, anxiety, and depression (8,14,16,17). The experience of long-term survivorship can include positive life changes as well, such as personal growth

(18,19), an increased sense of meaning or purpose (12,20,21), and positive effects on relationships (10). Impacts are further documented in several recent reviews of the quality of life of cancer survivors (22–26).

Many concerns of long-term survivors are distinctive of or unique to the long-term cancer survivor experience and are not necessarily captured by generic instruments that assess health-related quality of life. This circumstance creates a need for tools

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that specifically measure this multidimensional impact. Such instruments are needed to support the national research effort into the late effects of cancer and to develop and deliver effective interventions and supportive care to improve outcomes.

Several instruments have been developed to assess the concerns of long-term cancer survivors specifically. Some of these instruments are broad-based scales measuring health-related quality of life that have been applied to long-term survivorship. An early instrument that assesses health-related quality of life with this broad view is the Quality of Life-Cancer Survivors (QOL-CS) scale (27). The QOL-CS scale was conceptualized as measuring quality of life in the following four domains: Physical Well-Being, Psychological Well-Being, Social Well-Being, and Spiritual Well-Being. This instrument was adapted from other health-related quality of life instruments and is composed predominantly of generic items. The few cancer-specific items address distress associated with diagnosis and treatment and fear of recurrence and are not formulated as separate scales. Another instrument, the Long-Term Quality of Life scale (28), measures four broad domains, Somatic Concerns, Spiritual/Philosophical View of Life, Fitness, and Social Support, which are not necessarily distinct from generic health-related quality of life concepts or specifically attributable to the cancer experience. This instrument is designed for female cancer survivors only. The Quality of Life in Adult Cancer Survivors (QLACS) scale (29,30) is a more recent instrument that takes a deliberately broad view of quality of life domains that are relevant to long-term cancer survivors. The instrument consists of five cancer-specific domains (Financial Problems, Benefits, Distress-Family, Appearance, and Distress-Recurrence) and seven generic domains (Negative Feelings, Positive Feelings, Cognitive Problems, Pain, Sexual Interest, Energy and Fatigue, Sexual Function, and Social Avoidance). Narrow construct-specific instruments for cancer survivors have also been developed. For example, there are several scales measuring fear of cancer recurrence, as reviewed previously (31,32). The Assessment of Survivor Concerns, a five-item questionnaire (32), is an example of such a scale. Construct-specific scales are generally designed to serve as adjuncts to, or modules in, other health-related quality of life measures.

In contrast to both the more broadly focused instruments to assess health-related quality of life and the narrow construct-specific measures, the Impact of Cancer (IOC) scale (33,34) was developed specifically to measure unique and multidimensional aspects of long-term cancer survivorship that are not measured by existing tools. This instrument focuses almost exclusively on problems, issues, and changes that long-term survivors ascribe to their cancer experience. The development of content and initial scaling (ie, identification and formation of multi-item scales to measure psychosocial domains), of the IOC have been described previously (33). The item-generation process used several strategies to capture a broad range of long-term cancer survivor experiences. The process began with semistructured qualitative interviews with 47 long-term survivors of one of four cancers (breast, colorectal, prostate, or lymphatic cancers) representing four age groups (18–30, 31–45, 46–65, or ≥66 years). The survivors were asked to describe how cancer had affected them in physical, psychological, social, and spiritual areas of life. The concerns expressed in the

CONTEXT AND CAVEATS

Prior knowledge

Cancer diagnosis, treatment, and survival can engender lingering quality of life concerns.

Study design

Data from 1188 breast cancer survivors 5–10 years after diagnosis were used to develop and validate a questionnaire, the Impact of Cancer version 2 (IOCv2).

Contribution

Patterns of association between IOCv2 scale scores and demographic, medical, and treatment characteristics of the breast cancer survivors indicated good construct validity.

Implications

The IOCv2 is a validated tool for measuring the impact of cancer on the quality of life of long-term cancer survivors.

Limitations

Only data from breast cancer survivors were used and so IOCv2 has not been validated for survivors of other types of cancer. Most of the 1188 breast cancer survivors were white and none were more than 10 years away from their breast cancer diagnosis and so the data may not be fully representative of the population of all breast cancer survivors.

From the Editors

interviews were extracted and coded, with the goal of representing the breadth of experiences, regardless of frequency. These codes were used to develop a pool of 325 potential items. This pool was examined for redundancy, comprehensibility, and coverage of long-term cancer survivor issues by an expert panel and by two focus groups of long-term cancer survivors. A resultant pool of 125 items was then pilot tested in face-to-face interviews with 13 long-term cancer survivors. Ultimately, 81 potential scale items reflecting a broad range of survivor concerns were selected.

To conduct an initial scaling the 81-item questionnaire was administered to 193 long-term survivors of breast, prostate, colorectal, or lymphatic cancers. The small size of this group required an analytic strategy of conducting factor analysis by use of a priori domains. These analyses resulted in the identification of 10 subscales—Health Awareness, Body Changes, Positive Self-Evaluation, Negative Self-Evaluation, Positive Outlook, Negative Outlook, Life Interferences, Value of Relationships, Meaning of Cancer, and Health Worry—that were measured by 41 items (33). Development of scales for employment and relationship items could not be conducted because of the small number of respondents to whom these items applied.

When the IOC was developed, it was recognized that the initial scaling was part of a continuing process of instrument development. In particular, further evaluation and refinement of the scale in larger groups of long-term cancer survivors was needed. This article describes the refinement, reformulation, and validation of the IOC scale by use of responses from a group of 1188 disease-free long-term survivors of breast cancer. To ensure that the final scale would cover a comprehensive set of survivor concerns, we used the full 81-item pool as the basis for de novo scaling. Through

a process of factor analysis, cross-validation, and psychometric evaluation, we developed a revised instrument, the IOC version 2 (IOCv2). This instrument is designed to measure impacts of cancer in long-term survivors that are not captured by other instruments and to be suitable for widespread use in investigations of the well-being of this burgeoning population.

Subjects and Methods

Participants

The participants were members of the Life After Cancer Epidemiology (LACE) study, a prospective cohort study of survivors of early-stage breast cancer that has been described previously (35). Briefly, the cohort consists of women diagnosed with invasive breast cancer from January 1, 1997, through December 31, 2000, who were recruited primarily from the Kaiser Permanente Northern California Cancer Registry and the Utah Cancer Registry. Women were eligible if they were diagnosed from age 18 through 79 years with a first primary breast cancer (stage 1 \geq 1 cm, 2, or 2A) within 39 months before enrollment, had no history of other cancers within 5 years of enrollment, had completed cancer treatment (except for adjuvant hormonal therapy), and were recurrence free at enrollment. Between January 1, 2000, and April 30, 2002, 5656 women who appeared to meet the LACE eligibility criteria were sent recruitment packets. Of these 5656 women, 2614 (46%) agreed to participate and completed baseline questionnaires. Previous analyses that were based on registry data indicated that women who were approached within 15 months of diagnosis were more likely to respond than those who were approached later after diagnosis and that women younger than 50 years were less likely to respond than women who were aged 50 years or older; no statistically significant differences were found between respondents and nonrespondents with regard to severity of cancer (stage and number of positive lymph nodes) or treatment (chemotherapy and type of surgery) (35). Subsequent medical record review resulted in 334 exclusions. The remaining 2280 women constituted the LACE cohort.

The LACE participants were resurveyed 5–8 years after diagnosis and were mailed the 81-item IOC questionnaire after receipt of the resurvey in two waves: in April 2006 and in September 2006. Nonrespondents to the first mailing were sent a second mailing in August 2006 or January 2007 to the first and second waves, respectively.

The LACE study was approved by the institutional review boards of Kaiser Permanente Medical Program, the University of Utah, and the University of California, San Diego. Written informed consent was obtained from each participant.

Measures

The 81-item IOC questionnaire is described in detail elsewhere (33). Briefly, all items are scored on a five-point scale through which respondents indicate their level of agreement (strongly disagree, disagree, neutral, agree, or strongly agree). The instrument consists of 70 items that are designed to be applicable to all long-term cancer survivors, three items that are designed to be applicable specifically to respondents who are currently employed, four relationship items that are designed to be applicable to respon-

dents who do not currently have a partner, and four items that are designed to be applicable to respondents who have a partner.

In addition to the IOC questionnaire, the materials mailed at the time of resurvey included the Center for Epidemiologic Studies-Depression (CES-D) scale, a widely used and well-validated 20-item instrument for assessing depressive symptoms (36), and Breast Cancer Prevention Trial (BCPT) Symptom Checklist, a scaled, 18-item instrument designed to assess physical effects of medical interventions to prevent and treat breast cancer with validated subscales (37,38).

We used responses from the baseline survey (administered 2000–2002) to ascertain age, race or ethnicity, education level, age at diagnosis, type of surgery (breast conserving vs mastectomy), and receipt of chemotherapy. We used responses from the resurvey to ascertain income, current menopausal status, use of adjuvant hormonal therapy (current and past tamoxifen use and current and past aromatase inhibitor use), current use of antidepressants, diagnosis of 30 comorbid medical conditions, and self-assessed general health status (a single item in which respondents rated their health on a five-point scale from excellent to poor). Body mass index was computed from self-reported height and weight at resurvey. Responses to the question “Are you currently married, living together as married, or in a significant relationship?” on the IOC questionnaire were used to ascertain partnered vs nonpartnered status. Responses to the question “Were you employed and earning income at some time during the last 12 months?” on the IOC questionnaire were used to ascertain employment status. Recurrences and new primary cancers were ascertained by mailed semiannual health status update questionnaires that asked participants to report any events occurring in the preceding 6 months.

Statistical Analysis

The goal of scale revision was to identify a comprehensive, reproducible, and valid set of scales measuring concerns relevant to long-term cancer survivorship, with each scale composed of a set of internally consistent items. To achieve this end, our strategy was 1) to extract scales that were based on the IOC questionnaire items by use of exploratory factor analysis (39,40); 2) to perform split-sample cross-validation to assess reproducibility of the scales across subsamples (40); and 3) to conduct psychometric evaluation to assess the construct and concurrent validity of the proposed scales (41).

Exploratory factor analyses were conducted by use of the FACTOR procedure in SAS version 9.1 software (SAS Institute, Inc., Cary, NC). To decrease the dependence of our findings on any particular factor analytic technique, we used three methods of factor extraction (principal components, maximum likelihood, and unweighted least squares) and two methods for selecting the number of factors [the Kaiser–Guttman criterion of retaining factors with eigenvalues greater than 1 (42,43) and Cattell scree plot technique (44)] and retained only those items that had factor loadings of greater than 0.50 by all approaches and loaded on factors with a clear interpretation. After factor extraction, we conducted factor rotation, an algorithmic procedure that achieves simplified factor structure by optimizing the grouping of items with common characteristics onto common factors. Because factors were expected to be correlated, we used the oblique promax rotation procedure (45).

The reproducibility of factor structure across subsamples was assessed by use of the targeted rotation method of McCrae et al. (46). This method tests the hypothesis that the factor structure represented in the first sample is replicated in the second sample by extracting the hypothesized number of factors from the second sample, performing a targeted rotation to align the axes in the second factor structure with the axes in the first factor structure (the target), and calculating coefficients of congruence that quantify the fit between the two factor structures. Congruence coefficients compare two sets of factor loadings (item-factor correlations) in terms of both the pattern and magnitude of the loadings and can range from +1 (perfect agreement) to -1 (perfect inverse agreement). The observed congruences are compared with critical values generated by use of Monte Carlo techniques to determine the statistical significance of the fit. We defined a statistically significant congruence as a congruence higher than 95% of congruences obtained by rotating the second factor structure to align with axes in randomly generated target factor structures. For this analysis, we used the SAS Interactive Matrix Language program provided as an appendix in McCrae et al. (46).

Psychometric evaluation included computation of Cronbach's coefficient α statistic for each scale as a measure of internal consistency reliability (47). Scales are generally considered reliable if the α statistic exceeds 0.70 (48). We also computed the coefficient delta (δ) statistic, an index of the ability of a scale to discriminate among individuals (49). The δ statistic can range from 0, corresponding to all respondents giving the same response, to 1, corresponding to a maximally discriminating scale in which responses are uniformly distributed across the range of possible values (49,50).

The validity of the scales was evaluated by use of several strategies. Face validity was evaluated by examining item content. Construct validity, including convergent and discriminant validity, was evaluated by examining the Pearson product-moment correlation coefficients (r) among the scale scores and patterns of relationships between the scale scores and the sociodemographic, medical, and treatment characteristics of the sample cross-sectionally. For the latter, scale scores were examined for differences, or lack thereof, across age, years since diagnosis, partnered status, breast-conserving surgery vs mastectomy, chemotherapy status, general health status, number of comorbidities, body mass index, adjuvant hormonal therapy use, and current antidepressant use for depression or anxiety. These analyses used correlation coefficients for continuous variables and analysis of variance for categorical variables. Concurrent validity was evaluated by forming a priori hypotheses about patterns of association and correlating the scale scores with the CES-D scores and the BCPT symptom scale total and subscale scores. When evaluating the quantitative significance of correlations, we considered an $|r|$ of less than 0.30 to indicate a negligible association, $|r|$ between 0.30 and 0.45 to indicate a moderate association, $|r|$ between 0.45 and 0.60 to indicate a substantial association, and $|r|$ greater than 0.60 to indicate a strong association (51). In the validity analyses, we used a P value of less than .005 as the critical value for statistical significance to account for the large sample size and multiple comparisons. All P values and tests of statistical significance were two-sided.

We computed scores for both higher-order scales and subscales as the mean of nonmissing items that composed the scale. Scores were considered missing if more than 50% of items were missing.

Results

Subject Characteristics

The IOC questionnaire was returned by 1286 of the 1805 women who were mailed the questionnaire for a response rate of 71%. Comparisons of respondents to nonrespondents with regard to the characteristics that are listed in Table 1 showed that respondents were on average 3.0 years older than nonrespondents at diagnosis (58.6 vs 55.6 years of age, $P < .001$ by t test) and enrollment (60.5 vs 57.5 years of age, $P < .001$ by the t test), were more likely to be white than nonrespondents (83% vs 75%, $P < .001$ by the chi-square test), and had higher education levels than nonrespondents ($P = .01$ by the chi-square test). Of the 1286 respondents, we excluded 88 women who were subsequently discovered to have had recurrent or new primary disease at the time of survey administration and 10 women for whom these data were missing because we chose to focus on a sample of disease-free survivors. These exclusions resulted in a sample of 1188 women for the analysis.

Characteristics of the 1188 respondents are presented in Table 1. The age at administration of the IOC questionnaire ranged from 34 to 89 years, with a mean of 66 years. Time since diagnosis ranged from 5.3 to 9.9 years. Most of the 1188 respondents were white (83%, $n = 985$) and were educated beyond high school (76%, $n = 894$). A range of income levels was represented in the sample, and 68% ($n = 799$) were partnered.

About equal numbers of women had received breast-conserving surgery or mastectomy, and most (57%, $n = 669$) of the 1188 women had received chemotherapy. Most reported either current (29%, $n = 340$) or past (50%, $n = 594$) use of adjuvant hormonal therapy. Slightly more than half (55%, $n = 645$) reported excellent or very good general health. About equal numbers reported zero (23%, $n = 270$), one (25%, $n = 289$), or two (22%, $n = 259$) comorbid conditions, and 354 (30%) reported three or more conditions. About one-third (34%, $n = 393$) were overweight and one-quarter (25%, $n = 290$) were obese on the basis of body mass index classification. Most women (92%, $n = 1090$) were postmenopausal at the time the IOC questionnaire was administered. One hundred forty-four (13%) had CES-D scores of 16 or greater, the standardized cut point for elevated clinical depressive symptoms (36); 169 women (14%) were taking antidepressants for depression or anxiety.

Construction of IOCV2 Scales

Exploratory factor analysis with split-sample cross-validation was applied to the 70 IOC items that were designed to be applicable to all long-term cancer survivors. The remaining 11 items, whose applicability is determined by employment and relationship status, were scaled separately (see below).

We randomly split the group of 1188 women into two subgroups, each of 594 women. We conducted exploratory factor analysis on subgroup 1 by using multiple approaches as described above and retaining only those items that had factor loading values of more than 0.50 by all approaches and that were associated with

Table 1. Demographic, treatment, and medical characteristics of 1188 disease-free breast cancer survivors*

Characteristics	Value	Source
Age at diagnosis, mean ± SD (range), y	58.8 ± 10.1 (25–80)	B
Age group, No. (%)		
<50 y	245 (21)	
50–60 y	380 (32)	
60–70 y	377 (32)	
≥70 y	186 (16)	
Age at IOC administration, mean ± SD (range), y	66.3 ± 10.1 (34–89)	R
Age group, No. (%)		
<50 y	63 (5)	
50–60 y	308 (26)	
60–70 y	360 (30)	
≥70 y	457 (39)	
Years since diagnosis, mean ± SD (range)	7.4 ± 0.9 (5.3–9.9)	R
Marital status, No. (%)		R
Partnered	799 (68)	
Not partnered	384 (32)	
Race, No. (%)		B
White	985 (83)	
Asian (includes Filipina)	60 (5)	
Hispanic	58 (5)	
Black	36 (3)	
Other or more than one race	46 (4)	
Education, No. (%)		B
High school graduate or less	290 (24)	
Some college or technical school	423 (36)	
College graduate or more	471 (40)	
Employment status, No. (%)		R
Employed during last 12 months	412 (35)	
Not employed	763 (65)	
Income, No. (%)		R
<\$20 000	113 (10)	
\$20 000–40 000	269 (24)	
\$40 000–60 000	230 (21)	
\$60 000–80 000	176 (16)	
>\$80 000	310 (28)	
Surgery type, No. (%)		B
Conserving	623 (52)	
Mastectomy	564 (48)	
Ever had chemotherapy, No. (%)		B
Yes	669 (57)	
No	510 (43)	
Tamoxifen or aromatase inhibitor use, No. (%)		R
Never	247 (21)	
Current	340 (29)	
Past	594 (50)	
Taking antidepressants for depression or anxiety, No. (%)		R
Yes	169 (14)	
No	1019 (86)	
Menopausal status, No. (%)		R
Postmenopausal	1090 (92)	
Premenopausal	42 (4)	
Indeterminate	49 (4)	

(Table continues)

Table 1. Continued

Characteristics	Value	Source
General health, No. (%)		R
Excellent	163 (14)	
Very good	482 (41)	
Good	406 (35)	
Fair	109 (9)	
Poor	14 (1)	
Number of comorbidities,† No. of patients (%)		R
0	270 (23)	
1	289 (25)	
2	259 (22)	
≥3	354 (30)	
Body mass index, mean ± SD (range), kg/m ²	27.1 ± 5.4 (16.6–50.2)	R
Body mass index, No. (%)		
<25 kg/m ²	483 (41)	
25–30 kg/m ²	393 (34)	
≥30 kg/m ²	290 (25)	
CES-D score, mean ± SD (range)	7.7 ± 7.7 (0–50)	R
CES-D score, No. (%)		
<16	961 (87)	
≥16	144 (13)	

* IOC = Impact of Cancer; CES-D = Center for Epidemiologic Studies-Depression scale; B = baseline; R = resurvey. Some sums do not add up to the total number of subjects because of missing values.

† The maximum possible number of comorbidities was 30; the maximum observed number of comorbidities was 20.

factors with a clear interpretation. This procedure resulted in the identification of eight factors involving 42 items. The other 28 items were set aside.

We evaluated the reproducibility of this factor structure in subgroup 2 by use of targeted rotation as described above. The eight-factor, 42-item structure was used to initiate the analysis, which we used in an iterative manner, identifying items with non-statistically significant congruences, dropping these items, and then rerunning the analysis until all congruences were statistically significant and exceeded 0.90. Four items were removed in this manner. We then recombined the subgroups, factored the combined data, and inspected the factor structure. One additional item was dropped because of low factor loading in the total group, resulting in eight subscales that involved 37 of the original 70 items. Targeted rotation comparing the factor structures of subgroups 1 and 2 for these 37 items yielded item congruences ranging from 0.95 to 1.00, factor congruences ranging from 0.94 to 0.99, and a total congruence of 0.98. All congruences were higher than those obtained in 99% of rotations to randomly generated target factor structures, indicating a statistically significant fit (data not shown).

These analyses resulted in the formation of eight subscales involving 37 items, as presented in Table 2. The subscales are Altruism and Empathy, Health Awareness, Meaning of Cancer, Positive Self-Evaluation, Appearance Concerns, Body Change Concerns, Life Interferences, and Worry. One item (“Having had cancer has made me feel old”) had factor loading values of approximately 0.60 on both Body Change Concerns and Life Interferences. We chose to associate this item with Body Change

Table 2. Impact of Cancer version 2 scales with item content and factor analysis results*

Scales	Factor loadings	Eigenvalue	% of variance explained
Positive impact domains			
Altruism and Empathy		1.0	4.2
1. Having had cancer has made me more willing to help others	0.86		
2. Because I had cancer I am more understanding of what other people feel	0.80		
3. I feel a special bond with people with cancer	0.77		
4. I feel I should give something back to others	0.76		
Health Awareness		1.4	5.8
5. Having had cancer has made me more concerned about my health	0.87		
6. I do not take my body for granted since I had cancer	0.78		
7. I am more aware of physical problems or changes	0.75		
8. Having had cancer has made me take better care of myself	0.70		
Meaning of Cancer		1.8	7.4
9. Because of cancer I have more confidence in myself	0.90		
10. Having had cancer has given me direction in life	0.86		
11. Because of cancer I have become better about expressing what I want	0.85		
12. Because of having had cancer I feel that I have more control of my life	0.72		
13. Having had cancer turned into a reason to make changes in my life	0.65		
Positive Self-Evaluation		1.0	4.1
14. I feel a sense of pride or accomplishment from surviving cancer	0.91		
15. I consider myself to be a cancer survivor	0.80		
16. I learned something about myself because of having had cancer	0.71		
17. I feel that I am a role model	0.67		
Negative impact domains			
Appearance Concerns		0.9	3.9
18. I feel disfigured	0.86		
19. I sometimes wear clothing to cover parts of my body	0.82		
20. I worry about how my body looks	0.69		
Body Change Concerns		0.9	3.7
21. I am bothered that my body cannot do what it could before	0.94		
22. I am concerned that my energy has not returned	0.91		
23. Having had cancer has made me feel old	0.59		
Life Interferences		6.9	29.2
24. Uncertainty about my future affects my decisions to make plans	0.79		
25. Having had cancer has made me feel alone	0.78		
26. Having had cancer keeps me from doing activities I enjoy	0.77		
27. I feel like cancer runs my life	0.74		
28. Having had cancer has made me feel that some people do not understand me	0.74		
29. I feel guilty today for not having been available to my family	0.64		
30. Ongoing symptoms interfere with my life	0.58		
Worry		9.9	41.8
31. Having had cancer makes me feel uncertain about my health	0.88		
32. I worry about the future	0.82		
33. Having had cancer makes me feel unsure about the future	0.81		
34. I worry about cancer coming back	0.81		
35. New symptoms make me worry about cancer coming back	0.77		
36. I worry about my health	0.76		
37. I feel like time in my life is running out	0.59		
Employment or relationship impacts			
Employment Concerns		1.0	3.8
1. I worry about being forced to retire or quit before ready	0.93		
2. I am concerned about not being able to work if I am ill again	0.77		
3. Concerns about health insurance keep me in my current job	0.67		
Relationship Concerns (Not Partnered)		0.6	2.5
1. I wonder how to tell a potential partner that I had cancer	0.79		
2. I worry about not having a partner	0.69		
3. Uncertainties about health/future have made me delay relationship	0.64		
Relationship Concerns (Partnered)		0.7	3.1
1. My partner is open and willing to discuss my cancer with me	0.83		
2. I am open and willing to discuss my cancer with my partner	0.76		
3. Uncertainty about my health has created problems in my relationship	-0.59		
4. I worry about my partner leaving me if I were to become ill again	-0.52		

* For the scales of general applicability (all positive and negative impact domains, corresponding to the first 37 items), results were obtained by factoring the 37 items by using responses from the total sample, specifying the number of factors as eight and using oblique promax rotation (45). For each of the scales of limited applicability (employment or relationship impacts), results were obtained by augmenting the 37 items with the applicable items and conducting the factor analysis by using responses from the applicable subset of subjects, specifying the number of factors as nine, and using oblique promax rotation. Factor loading is the item-factor correlation.

Table 3. Higher-order factor structure of the Impact of Cancer version 2*

	Negative impact domain	Positive impact domain
Factor loadings by subscale		
Appearance Concerns	0.72	0.16
Body Change Concerns	0.83	0.15
Life Interferences	0.82	0.02
Worry	0.82	0.24
Altruism and Empathy	0.20	0.80
Health Awareness	0.31	0.73
Meaning of Cancer	0.12	0.81
Positive Self-Evaluation	-0.04	0.80
Eigenvalue	3.0	2.1
% of variance explained	38	26

* Factor loading is the item-factor correlation obtained by factoring the eight subscales when specifying two factors and using oblique promax rotation (45) in the total sample.

Concerns to maintain this subscale at three items. Each subscale was measured by three to seven items.

It has been observed that oblique rotation implies that the factors are correlated and that there are, therefore, higher-order factors that can be extracted and examined (40,52). Thus, we extracted second-order factors by factoring the correlation matrix of subscale scores. This procedure yielded two higher-order domains, a positive domain consisting of the subscales Altruism and Empathy, Health Awareness, Meaning of Cancer, and Positive Self-Evaluation and a negative domain consisting of the subscales Appearance Concerns, Body Change Concerns, Life Interferences, and Worry (Table 3). The two higher-order domains explained similar amounts of variance.

The employment and relationship items in the IOC instrument were scaled separately by use of content review and internal consistency reliability assessment by computation of Cronbach's α statistic. Content review resulted in the decision to drop one rela-

tionship item ("I am concerned about how to tell a spouse, partner, boyfriend, or girlfriend that I may not be able to have children") because of limited applicability in the general long-term cancer survivor population. The α statistics for subscales composed of the remaining items exceeded 0.75 (Table 4). These items were used to construct three subscales, an Employment Concerns subscale that was applicable to individuals currently employed, a Relationship Concerns (Partnered) subscale, and a Relationship Concerns (Not Partnered) subscale. The items for these subscales are presented in Table 2.

Psychometric Evaluation

The foregoing analyses yielded the IOCv2 scales, consisting of a Positive Impact Summary scale, a Negative Impact Summary scale, four positive subscales, four negative subscales, and three employment or relationship subscales, which were measured by a total of 47 items (Table 2).

We evaluated the distributional and psychometric properties of the scales in the total sample (Table 4). Scores were well distributed throughout the range of possible values for all scales; coefficient δ values ranged from 0.85 to 0.99, indicating good discriminatory ability. There was no indication of floor effects (ie, high proportion of scores at or near the minimum possible value) or ceiling effects (ie, high proportion of scores at or near the maximum possible value), with the exception of the Relationship Concerns Not Partnered and Partnered subscales, in which 25% and 35% of nonpartnered and partnered respondents, respectively, indicated the lowest possible level of relationship concerns. All scales had high internal consistency reliability, with alpha statistics ranging from 0.76 to 0.89 (Table 4). Factor loadings were high, ranging in absolute value from 0.52 to 0.94 for the subscales (Table 2) and from 0.72 to 0.83 for the two higher-order domains (Table 3).

As part of the construct validity evaluation, we examined the Pearson product-moment correlations among the subscale scores

Table 4. Descriptive summary of Impact of Cancer version 2 scales, with psychometric indices*

Scale	Score, mean \pm SD (range)	% floor†	% ceiling†	Cronbach's α statistic	Coefficient δ statistic
Positive Impact Summary scale	3.60 \pm 0.55 (1.2-5)	0	0.5	0.79	0.98
Altruism and Empathy	3.75 \pm 0.67 (1-5)	0.4	6.1	0.82	0.92
Health Awareness	3.80 \pm 0.65 (1-5)	0.5	5.0	0.80	0.91
Meaning of Cancer	3.04 \pm 0.77 (1-5)	1.6	1.5	0.87	0.97
Positive Self-Evaluation	3.95 \pm 0.68 (1-5)	0.3	8.8	0.79	0.94
Negative Impact Summary scale	2.44 \pm 0.65 (1-4.8)	0.3	0	0.81	0.99
Appearance Concerns	2.71 \pm 0.99 (1-5)	5.9	2.8	0.78	0.98
Body Change Concerns	2.56 \pm 0.96 (1-5)	7.6	1.4	0.82	0.96
Life Interferences	1.92 \pm 0.63 (1-4.4)	9.3	0	0.81	0.96
Worry	2.79 \pm 0.83 (1-5)	1.4	0.8	0.89	0.98
Employment or relationship impacts					
Employment Concerns	2.71 \pm 1.12 (1-5)	11.5	3.9	0.76	0.99
Relationship Concerns (Not Partnered)	2.06 \pm 0.88 (1-5)	25	0.3	0.78	0.92
Relationship Concerns (Partnered)	1.65 \pm 0.64 (1-4.5)	35	0	0.80	0.85

* Sizes of groups are 408, 367, and 794 subjects for Employment Concerns, Relationship Concerns (Not Partnered), and Relationship Concerns (Partnered), respectively, and 1185-1187 subjects for all other scales. For all scales, potential scores range from 1 to 5, with higher scores indicating stronger endorsement of the content area and with a score of 3 as neutral.

† Percent floor is percent of subjects scoring at the minimum possible value of 1. Percent ceiling is the percent of subjects scoring at the maximum possible value of 5.

Table 5. Pearson product–moment correlations among Impact of Cancer version 2 scale scores*

Domain	Positive impact domains				Negative impact domains				EC
	AE	HA	MOC	PSE	AC	BCC	LI	W	
Positive impact domains									
Altruism and Empathy	1.00								
Health Awareness	0.46†	1.00							
Meaning of Cancer	0.53†	0.48†	1.00						
Positive Self-Evaluation	0.52†	0.42†	0.54†	1.00					
Negative impact domains									
Appearance Concerns	0.17	0.17	0.10	0.06	1.00				
Body Change Concerns	0.17	0.23	0.11	0.01	0.48†	1.00			
Life Interferences	0.09	0.13	0.05	−0.09	0.45†	0.58†	1.00		
Worry	0.22	0.34†	0.15	0.04	0.46†	0.58†	0.56†	1.00	
Employment or relationship impacts									
Employment Concerns	0.21	0.15	0.13	0.11	0.24	0.39†	0.37†	0.44†	1.00
Relationship Concerns (Not Partnered)	0.18	0.17	0.14	0.07	0.52†	0.48†	0.62†	0.47†	0.45†
Relationship Concerns (Partnered)	−0.07	−0.05	−0.10	−0.19	0.26	0.25	0.56†	0.28	0.25

* AE = Altruism and Empathy; HA = Health Awareness; MOC = Meaning of Cancer; PSE = Positive Self-Evaluation; AC = Appearance Concerns; BCC = Body Change Concerns; LI = Life Interferences; W = Worry; EC = Employment Concerns.

† Correlation exceeds 0.30 and has a *P* value of less than .005. *P* values are from two-sided test of hypothesis that correlation equals zero conducted by use of the *t* statistic. All statistical tests were two-sided.

(Table 5). On the basis of the higher-order factor structure, we expected to observe associations among subscales in the positive domain and among subscales in the negative domain. We did, in fact, observe substantial correlation among the subscales within each second-order domain; however, the correlations were not so high as to indicate that they were measuring the same construct (all *r* values ≤ 0.58). Correlations between subscales across positive and negative domains were weak. An exception was the Worry subscale, which was moderately associated with the Health Awareness subscale ($r = 0.34$). These two subscales have a degree of shared content; the Worry subscale includes several items related to health concerns. The correlation between the Positive and Negative Impact Summary scale scores was negligible ($r = 0.19$). There were moderate to high correlations between most of the negative subscales and the employment and relationship subscales, indicating that respondents reporting more negative cancer-related impacts generally had more concerns about employment and relationships. These associations were particularly strong for nonpartnered respondents.

We further assessed construct validity by examining the associations of the IOCv2 scales with demographic, treatment, and medical variables (Table 6). Several patterns emerged. All correlations with time since diagnosis were weak, indicating that the scales were not simply measuring concerns that wane with time since diagnosis. Correlations with age were weakly negative, indicating that younger respondents had somewhat higher scores on most scales than older respondents; however, none of the correlations exceeded our threshold of $|r| > 0.30$ for quantitative significance. Respondents who had received chemotherapy scored higher on all positive and all negative impact scales. A similar pattern was observed in univariate analyses in another study (20) of breast cancer survivors, in which patients with physical symptoms reported greater positive meaning as well as greater vulnerability. Type of surgery was associated only with Appearance Concerns. Scores did not differ on the basis of never vs ever adjuvant hormonal therapy use.

There were strong trends in associations between self-reported general health and all negative, employment and relationship scales, with more concerns associated with poorer health. Higher Meaning of Cancer and Positive Self-Evaluation scores were associated with better health. Higher body mass index was associated with higher Appearance Concerns, Body Change Concerns, and Negative Impact Summary scores. Number of comorbidities was statistically significantly associated only with Body Change Concerns ($P = .004$).

Current antidepressant use for depression or anxiety was associated with all negative scales, as well as Relationship Concerns for nonpartnered respondents. Higher income respondents scored highest on the Health Awareness scale, whereas lower income respondents scored highest on the Life Interferences scale. Partnered respondents were more likely to report positive impacts, specifically for Altruism and Empathy, Health Awareness, and Positive Self-Evaluation. This result is consistent with higher levels of social support in partnered respondents.

Concurrent validity was assessed by examining correlations between the IOCv2 and the CES-D and BCPT scores (Table 7). A higher score on the CES-D indicates more depressive symptoms, and higher scores on the BCPT scales indicate more physical symptoms. We expected a priori that there would be positive correlation between the CES-D score and the IOCv2 negative impact scales and between BCPT scores and the IOCv2 subscales that measure physical impacts—ie, Appearance Concerns and Body Change Concerns. These expectations were largely borne out by the results. The CES-D score was positively associated with the Negative Impact Summary ($r = 0.40$), Body Change Concerns ($r = 0.33$), Life Interferences ($r = 0.39$), Worry ($r = 0.32$), Employment Concerns ($r = 0.35$), and Relationship Concerns (Not Partnered) ($r = 0.34$) scales. None of the correlations exceeded a moderate level, indicating that the IOCv2 constructs were associated with but distinct from depressive symptoms. BCPT total score was moderately associated with Appearance Concerns ($r = 0.31$) and Body Change Concerns ($r = 0.41$) scales, as predicted, and also with Negative Impact

Table 6. Associations between Impact of Cancer version 2 scale scores and demographic, medical, and treatment variables*

Variable	Positive impact domain					Negative impact domain					Relationship Concerns		
	Summ score	AE	HA	MOC	PSE	Summ score	AC	BCC	LI	W	EC	Non-P	P
Continuous variables†													
Years since diagnosis	-0.04	-0.09	-0.07	-0.01	0.02	-0.04	-0.03	-0.07	-0.02	-0.04	0.03	0.01	-0.01
<i>P</i> value	.15	.003	.03	.73	.55	.16	.26	.01	.55	.21	.61	.99	.71
Age at time of IOC	-0.24	-0.18	-0.21	-0.19	-0.19	-0.17	-0.16	-0.11	-0.09	-0.18	-0.16	-0.20	-0.01
<i>P</i> value	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	.002	<.001	.002	<.001	.76
Categorical variables‡													
Chemotherapy§													
No	3.5	3.6	3.7	2.9	3.8	2.3	2.5	2.4	1.8	2.7	2.5	1.9	1.6
Yes	3.7	3.8	3.9	3.1	4.1	2.5	2.8	2.7	2.0	2.9	2.8	2.2	1.6
<i>P</i> value	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	.02	.005	.94
Type of surgery													
Breast conserving	3.6	3.7	3.8	3.0	3.9	2.4	2.4	2.5	1.9	2.8	2.7	2.0	1.64
Mastectomy	3.6	3.8	3.8	3.1	4.0	2.5	3.0	2.6	2.0	2.8	2.8	2.1	1.65
<i>P</i> value	.03	.08	.07	.13	.06	<.001	<.001	.25	.07	.54	.19	.09	.73
Tam or AI use													
Ever	3.6	3.8	3.8	3.1	4.0	2.5	2.7	2.6	1.9	2.8	2.8	2.1	1.7
Never	3.6	3.7	3.7	3.0	4.0	2.4	2.7	2.5	1.9	2.7	2.6	2.1	1.6
<i>P</i> value	.25	.39	.02	.53	.78	.26	.56	.67	.37	.20	.15	.99	.27
General health													
Excellent	3.7	3.8	3.9	3.2	4.1	2.1	2.5	2.0	1.6	2.5	2.3	1.8	1.4
Very good	3.6	3.8	3.8	3.1	4.0	2.3	2.7	2.4	1.8	2.7	2.7	2.0	1.6
Good	3.5	3.7	3.7	3.0	3.8	2.6	2.7	2.7	2.0	2.9	2.9	2.1	1.8
Fair or poor	3.6	3.7	3.9	3.0	3.8	2.9	3.1	3.2	2.4	3.2	3.2	2.4	1.8
<i>P</i> value	<.001	.09	.008	.005	<.001	<.001	<.001	<.001	<.001	<.001	<.001	.003	<.001
No. comorbidities													
0	3.7	3.8	3.9	3.1	4.0	2.3	2.7	2.4	1.8	2.7	2.7	2.0	1.6
1	3.6	3.8	3.8	3.0	3.9	2.4	2.7	2.6	1.9	2.8	2.6	2.0	1.7
2	3.6	3.8	3.8	3.0	3.9	2.4	2.7	2.6	1.9	2.9	2.8	2.0	1.6
≥3	3.6	3.7	3.8	3.1	3.9	2.5	2.8	2.7	2.0	2.8	2.8	2.2	1.7
<i>P</i> value	.28	.79	.27	.24	.22	.009	.27	.004	.007	.04	.42	.27	.43
BMI, kg/m ²													
<25	3.6	3.8	3.8	3.1	3.9	2.4	2.6	2.4	1.9	2.8	2.7	2.0	1.6
25–30	3.6	3.8	3.8	3.1	4.0	2.4	2.7	2.6	1.9	2.8	2.7	2.0	1.7
>30	3.6	3.7	3.8	3.0	3.9	2.6	2.9	2.8	2.0	2.9	2.8	2.2	1.7
<i>P</i> value	.55	.71	.71	.36	.67	<.001	<.001	<.001	.02	.14	.85	.34	.49
Current use of antidepressants¶													
No	3.6	3.7	3.8	3.0	3.95	2.4	2.7	2.5	1.9	2.8	2.7	2.0	1.6
Yes	3.7	3.8	3.8	3.1	3.97	2.7	2.9	2.9	2.1	3.0	2.9	2.4	1.7
<i>P</i> value	.13	.11	.50	.06	.74	<.001	.002	<.001	<.001	.002	.23	.006	.63
Household income													
<\$40000	3.6	3.7	3.7	3.1	3.9	2.5	2.7	2.6	2.0	2.8	2.9	2.1	1.7
\$40000–\$80000	3.6	3.7	3.8	3.0	3.9	2.4	2.7	2.5	1.8	2.7	2.7	2.0	1.6
>\$80000	3.7	3.8	3.9	3.1	4.0	2.5	2.8	2.6	1.9	2.9	2.6	2.1	1.6
<i>P</i> value	.08	.17	.005	.52	.27	.01	.06	.26	<.001	.05	.17	.69	.05
Partnered status													
Nonpartnered	3.5	3.7	3.7	3.0	3.9	2.4	2.7	2.5	2.0	2.7	2.7		
Partnered	3.6	3.8	3.8	3.1	4.0	2.4	2.7	2.6	1.9	2.8	2.7		
<i>P</i> value	<.001	<.001	<.001	.16	.001	.53	.64	.31	.05	.02	.89	n/a	n/a

* Associations are presented as Pearson product moment correlations for continuous variables and means with analysis of variance results for categorical variables. BMI = body mass index; Tam = tamoxifen; AI = aromatase inhibitor; Summ score = summary score; AE = Altruism and Empathy; HA = Health Awareness; MOC = Meaning of Cancer; PSE = Positive Self-Evaluation; AC = Appearance Concerns; BCC = Body Change Concerns; LI = Life Interferences; W = Worry; EC = Employment Concerns; Non-P = nonpartnered; P = partnered; IOC = Impact of Cancer.

† Pearson product-moment correlations. *P* values are from two-sided test of hypothesis that correlation equals zero conducted by use of the *t* statistic. Correlations were considered to have quantitative significance if $|r|$ was greater than 0.30.

‡ Analysis of variance was used, and *P* values are from the overall *F* test.

§ Ever received chemotherapy?

|| *P* values are less than .005 and, for correlations, $|r|$ are greater than 0.30.

¶ Current use of antidepressants for depression or anxiety.

Table 7. Pearson product–moment correlations between CES-D, BCPT symptom, and IOCv2 scale scores*

	Positive impact domains					Negative impact domains					Relationship Concerns		
	Summ score	AE	HA	MOC	PSE	Summ score	AC	BCC	LI	W	EC	Non-P	P
CES-D score	0.02	0.11	0.04	0.00	−0.08	0.40†	0.21	0.33†	0.39†	0.32†	0.35†	0.34†	0.26
BCPT total score	0.13	0.16	0.12	0.08	0.05	0.42†	0.31†	0.41†	0.32†	0.33†	0.27	0.26	0.19
BCPT subscales													
Hot flashes	0.15	0.14	0.12	0.11	0.12	0.19	0.13	0.20	0.12	0.18	0.22	0.16	0.04
Nausea	0.00	0.02	0.03	−0.01	−0.01	0.17	0.08	0.16	0.14	0.16	0.06	0.13	0.11
Bladder control	0.01	0.04	0.00	−0.01	−0.01	0.18	0.14	0.20	0.15	0.11	0.03	0.02	0.11
Vaginal problems	0.14	0.17	0.11	0.07	0.12	0.14	0.15	0.09	0.07	0.15	0.06	−0.11	0.03
Musculoskeletal Pain	0.07	0.09	0.09	0.04	0.01	0.33†	0.20	0.37†	0.26	0.27	0.26	0.26	0.16
Cognitive Problems	0.07	0.11	0.06	0.06	−0.01	0.25	0.15	0.25	0.20	0.20	0.19	0.18	0.15
Weight problems	0.06	0.09	0.04	0.03	0.02	0.32†	0.35†	0.28	0.23	0.23	0.17	0.20	0.13
Arm problems	0.04	0.06	0.04	0.03	0.00	0.22	0.15	0.22	0.23	0.14	0.12	0.09	0.16

* CES-D = Center for Epidemiologic Studies-Depression scale; BCPT = Breast Cancer Prevention Trial; IOCv2 = Impact of Cancer version 2; Summ score = summary score; AE = Altruism and Empathy; HA = Health Awareness; MOC = Meaning of Cancer; PSE = Positive Self-Evaluation; AC = Appearance Concerns; BCC = Body Change Concerns; LI = Life Interferences; W = Worry; EC = Employment Concerns; Non-P = nonpartnered; P = partnered.

† P values are less than .005 and |r| are greater than 0.30. P values are from two-sided test of hypothesis that correlation equals zero conducted by use of the t statistic.

Summary score ($r = 0.42$) and two other negative domain subscales, Life Interferences ($r = 0.32$) and Worry ($r = 0.33$) scales. The latter two correlations are plausible in view of the items pertaining to the impact of symptoms in these subscales. Correlations of the IOCv2 subscales with the BCPT subscales were mostly weak, indicating little relationship between the very specific physical symptoms assessed by the BCPT subscales and the constructs measured by the IOCv2. Exceptions were moderate associations between BCPT Musculoskeletal Pain and the Negative Impact Summary scores ($r = 0.33$), between BCPT Musculoskeletal Pain and Body Change Concerns scores ($r = 0.37$), between BCPT Weight Problems and the Negative Impact Summary scores ($r = 0.32$), and between BCPT Weight Problems and Appearance Concerns scores ($r = 0.35$). There were no associations between CES-D or BCPT scores and any of the positive scales, as predicted. Overall, the pattern of results indicates that the IOCv2 scales were measuring constructs that could be distinguished from depressive symptoms or physical symptoms associated with breast cancer.

The IOCv2 and scoring instructions are available online as Supplementary Data.

Discussion

In this article, we report the refinement and validation of the IOCv2, an instrument to measure the psychosocial impacts of cancer in long-term survivors. Because of the large size of the group of respondents in our study, we were able to conduct a full-scale factor analysis and cross-validation in addition to psychometric validity analyses, the combination of which provides confidence in the reliability and validity of the scales.

The IOCv2 instrument consists of four subscales for positive impacts, four subscales for negative impacts, overall Positive and Negative Impact Summary scales, and subscales for Employment and Relationship Concerns. The IOCv2 subscales cover a wide range of domains, and the positive and negative summary scores can be used to effect data reduction. The total number of items to be answered by any one respondent ranges from 40 to 44,

and total time to complete the instrument is likely to be 10–15 minutes.

The existing instrument that is perhaps the most similar to the IOCv2 is the QLACS (29, 30), which shares IOCv2's aim of assessing quality of life for long-term survivors across a broad range of domains. Some scales in the IOCv2 and QLACS are similar in content: QLACS Benefits scale is similar to the IOCv2 Meaning of Cancer scale, QLACS Appearance scale is similar to the IOCv2 Appearance Concerns scale, and QLACS Distress-Recurrence scale shares a degree of content with the IOCv2 Worry scale. The convergence of survivor impact domains in these two instruments, which were arrived at by independent development processes, is heartening and bodes well for future efforts to further converge on well-validated assessment tools for cancer survivors. Other IOCv2 scales, and in particular the other positive scales, do not have analogues in the QLACS, perhaps because of differences in content-generation processes. Earlier versions of the IOC positive scales were shown to have convergent validity with the Post-traumatic Growth Inventory scale (53) and the Spiritual scale of the QOL-CS (27, 33). Increasingly, research on cancer survivors has emphasized their frequent report of meaning and benefit finding (20), which we believe the IOC captures successfully.

The QLACS includes generic domains that are designed to be applicable to cancer survivors and the noncancer population alike. The IOCv2, in contrast, focuses almost exclusively on quality of life impacts that respondents attribute to their cancer experience. Many generic health-related quality of life domains not covered by the IOCv2 can be measured by coadministering general health-related quality of life instruments such as the SF-36 (54,55), which we recommend.

The instrument development process that we reported in this article takes a traditional approach to scale development that has as an end result a fixed instrument with validated scales. Current developments in the field of psychometrics include a movement toward greater use of item response theory, the development of item repositories, and the use of these repositories in conjunction with computerized adaptive testing systems. An example of this

future direction is the Patient-Reported Outcomes Measurement Information System (www.nihpromis.org), a National Institutes of Health initiative that seeks to develop a publicly available computer-adaptive testing system that draws on an item bank for measuring patient-reported outcomes. Future efforts in psychometrics for survivor outcomes would benefit from an orientation toward this integrated, adaptive approach. In the meantime, fixed instruments like the IOCV2 will likely continue to be in widespread use.

Our study had several limitations. Because our sample was limited to breast cancer survivors, we could not directly examine the validity of the IOCV2 for other diagnostic categories of survivors in this study. However, the participation of diverse samples of long-term survivors in the earlier stages of IOC development (33,34) supports the relevance of the content to broader populations of survivors. Most of the sample was white and, although the range of current ages and ages at diagnosis was broad, none of the respondents was more than 10 years from their cancer diagnosis. In addition, response bias may have resulted in a sample that was not fully representative of this survivor population. These limitations are common in instrument development, which requires a concerted, iterative process to arrive at well-validated tools. Additional psychometric validation in more ethnically diverse samples, including survivors of other cancers and with longer time since diagnosis, is needed.

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