

Assessing Quality of Life in Adult Cancer Survivors (QLACS)

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Abstract

This article describes development of a quality of life measure designed to assess issues relevant to long-term cancer survivors. In-depth semi-structured interviews were conducted with 58 long-term cancer survivors to identify domains most relevant to long-term survivors (≥ 5 years post-diagnosis). Self-report items were developed from these interviews and administered to a second sample of 242 long-term survivors. Domains and items were selected from the item pool by a combination of factor analysis and criterion-based item selection. Five cancer-specific domains were identified (appearance concerns, financial problems, distress over recurrence, family-related distress, and benefits of cancer) along with seven generic QOL domains (negative feelings, positive feelings, cognitive problems, sexual problems, physical pain, fatigue, and social avoidance). Cronbach's α was 0.72 or greater for each domain. Correlations between domain scores and criterion measures were 0.72 or higher in all but one generic domain (social avoidance), but somewhat lower on cancer-specific domains. The new multidimensional measure has good internal consistency and validity and is appropriate for comparisons between cancer and non-cancer populations, as well as long-term follow-up of cancer patients.

Key words: Cancer survivors, Instrument development, Quality of life

Introduction

The importance of quality of life issues for cancer patients is well-recognized by both researchers and clinicians [1–3]. Over the past several decades numerous studies have addressed the physical, emotional, social, and sexual well-being of cancer patients [e.g., 4–8; for reviews see 1, 9–13]. The focus of these studies, however, has been restricted largely to the period of treatment following diagnosis. With improved early detection and treatment, large numbers of cancer patients are now surviving many years post-diagnosis with the proportion of cancer patients surviving 5 or more years now approximately one in two [14]. As of January 1997, there were an estimated 8.9 million cancer survivors in the US [15]. This large number

of people surviving many years post-cancer diagnosis has heightened interest in studying long-term effects of cancer on quality of life (QOL) [16–18]. Adding to this interest is research suggesting that cancer treatments can have long-term physical effects that may influence quality of life [16, 17, 19–29].

A number of cancer-specific QOL measures have been developed, such as the Functional Adjustment to Cancer Therapy (FACT) [30], European Organization for Research and Treatment of Cancer (EORTC) [31–33], Functional Living Index-Cancer (FLIC) [34], and Cancer Rehabilitation Evaluation System (CaRES) [35], and its short form (CaRES-SF) [36]. These measures, however, may not be appropriate for use with long-term survivors. They were designed to

capture acute effects of being newly diagnosed with cancer and the immediate effects of surgery and treatment. Thus, they tend to focus on symptoms and immediate problems.

The goal of the work described here was to develop a QOL measure that captures issues relevant to long-term (greater than 5 years) cancer survivors. Studies suggest that long-term consequences of cancer include issues present after diagnosis and treatment that linger, but also new concerns that develop over time [26]. Conditions that continue after treatment are pain and fatigue [37–39], sexual problems [21, 22, 40–42], and appearance and body-image concerns [18]. Psychological dysfunction can also be a problem [17, 29, 43]. Newer issues that may develop include insurance concerns, worry about the health of children, and worry about the family's future in the event of recurrence [18, 39, 41, 43]. Late physical effects of cancer treatment, such as cardiac toxicity or development of second malignancies have also been identified [44–46]. It is important to recognize that there are also positive aspects of surviving cancer such as transformations in the survivor's understanding of his or her life and positive changes in relationships with others [47–50].

Despite the importance of these issues for long-term survivors, currently there are only two QOL measures designed specifically for long-term survivors, one a modification of the other. Researchers at the City of Hope National Medical Centre conceptualized QOL as having four dimensions: physical, psychological, social, and spiritual. They developed the Quality of Life–Cancer Survivors scale (QOL-CS) based on these dimensions [18]. Although this scale reflects an attempt to recognize QOL issues relevant to long-term cancer survivors, it has a number of limitations. Items were based on a small number of cancer survivors. Validation of the scale was based on survivors ranging from 4 months to 28 years after diagnosis (thus including newly diagnosed patients). Some items have problematic wording, in that they ask about change but fail to indicate its direction (e.g., 'has your illness or treatment caused changes in your self-concept?'). The domains often measure multiple constructs at once (e.g., social interaction includes appearance, sexual functioning, and family distress). Further, several

items ask about distress at the time of diagnosis and treatment [18].

Wyatt and colleagues [51, 52] developed the Long-term Quality of Life (LTQL) questionnaire based on the same conceptual model. Wyatt and colleagues developed an item set from focus groups of female survivors. They then collected data from a substantial sample of female cancer survivors and conducted a factor analysis, an internal consistency analysis, and determined content validity. This yielded 34 items loading on four factors that are slightly different from the QOL-CS: somatic concerns, spiritual/philosophical view of life, fitness, and social support. While the psychometric approach of the LTQL is an improvement over that used for the QOL-CS, some of the items themselves are still problematic and the domains often encompass more than one important aspect of QOL. For example, the somatic concerns domain includes both body-image problems and pain. Although these are both somatic in character, they are different in focus. The broad domains do not allow investigators to look at more specific QOL domains. Further, this measure is specific to female cancer survivors.

This article describes the development of a new measure designed to assess issues relevant to long-term cancer survivors. We call the measure the Quality of Life in Adult Cancer Survivors (QLACS). We conceptualize cancer-related quality of life based on the definition provided by Gotay et al. [2] as the state of well-being that is a composite of two components: the ability to perform everyday activities that reflect physical, psychological, and social well-being; and patient satisfaction with levels of functioning and control of the disease. This conceptualization takes into account both functioning and patient satisfaction with functioning. Because of its subjective nature, QOL is best measured from the patient's perspective [19, 53, 54]. As such, our approach also assumes that it is critical to involve patient input into determining relevant QOL domains and items [55].

This approach also views QOL as a multidimensional construct. At a minimum, it includes physical, social and psychological dimensions. Other domains sometimes included are cognitive functioning, intimacy or sexual functioning, role limitations and productivity [56], pain [57], economic factors [58, 59], and an existential/spiritual

domain [18, 60]. Our approach to instrument development begins with a deliberately broad view of possible domains that are then confirmed empirically.

The QLACS was developed and tested in two phases, using two different samples of respondents. During Phase I, qualitative semi-structured interviews with cancer survivors were conducted to identify relevant domains and generate a pool of questionnaire items. In Phase II, the preliminary version of the instrument was tested to produce a shortened final version and to evaluate its psychometric properties.

Phase I

Methods

The first task in the development process was to identify domains that were most relevant to long-term cancer survivors. To do this, we conducted in-depth semi-structured interviews with a sample of 58 long-term survivors. Participants in these semi-structured interviews were persons living in southeast Florida who had been diagnosed at least 5 years earlier than the study date with breast cancer, head/neck cancer, gynecological cancer, bladder cancer, prostate cancer, or colorectal cancer. These cancers were selected because they have large numbers of long-term survivors. Our goal was to obtain at least eight interviews for each cancer type.

Participants were recruited through the Florida Cancer Data System (FCDS), which is the state's record-keeping system for cancer diagnoses. Every cancer diagnosis in the state of Florida is (by law) entered into this data base. After approval by IRBs from both the University of Miami and the Florida Department of Health, FCDS staff created a set of records containing the names and addresses of all persons in Miami-Dade and Broward counties who had been diagnosed with the targeted cancers in 1994 or earlier. Miami-Dade County contains the city of Miami; Broward County contains the city of Ft. Lauderdale. Both counties are characterized by a wide range of different socio-economic statuses, including both very affluent and very poor areas. Both counties also have substantial number of minority

residents, primarily Hispanic and African American.

The records generated by FCDS were delivered by computer disk to one of the senior investigators in Coral Gables. All subsequent handling of information from FCDS was done by a core member of the research group, to ensure confidentiality. (All procedures concerning the acquisition and handling of data from FCDS apply to both phases of data collection.)

It should be noted that (by our request) the records provided were limited to the specific cancers noted earlier, the geographic area of southeast Florida, and diagnosis 5 years or more in the past. There was no further restriction. In particular, we wanted to ensure that the length of survivorship would not be artificially constrained in any way. Put differently, the procedure allowed us to recruit persons who were as little as 5 years post-diagnosis and also persons who were as much as 18 years post-diagnosis (which was as far back as the registry went). In effect, we permitted ourselves the full available range of length of survivorship.

The number of records FCDS supplied was quite large. We began by extracting a random sample of approximately 7000 from the full set. We separated them into diagnostic categories, then assigned each person (within category) a computer-generated random number. Each diagnostic category was then sorted by number, and the first 150 names in that category were sent letters describing in general terms the nature of the project and an invitation to participate. Subsequent mailings (approximately another 100 in total) were directed selectively toward categories where participants were still needed (survivors of bladder and head-and-neck cancers were harder to recruit than survivors of the other cancers, for reasons that are unclear).

The letter sent to these persons stated that the project concerned the experiences of persons who had been treated for cancer 5 years or more in the past and that the research team was interested in interviewing such persons. The interview was described as approximately 2–2.5 h in length, for which the interviewee would receive \$50 compensation for his or her time. Those willing to be interviewed returned postcards on which they wrote their phone numbers and convenient contact hours. Research assistants contacted persons who

returned cards, described the process in more detail, and made appointments to interview those who remained interested in participating. Interviews took place in the respondent's home or other preferred meeting place.

The sample of 58 who were eventually interviewed was 55% female. Forty-one of the respondents were Caucasian, nine African-American, and eight Hispanic. The mean age was 64.9 (SD = 14.5, range from 34 to 91). The sample was distributed among cancer types as follows: breast (n = 12), prostate (n = 10), colorectal (n = 11), bladder (n = 6), head and neck (n = 9), and gynecologic (n = 10).

Although it may appear that the sample we recruited was relatively old (mean age of 65), they actually were relatively young for the population from which they were drawn. The average age at diagnosis of the full set of records extracted for this first phase of data collection was 66.54; average age at diagnosis of those sent letters was 63.68; average age at diagnosis of those interviewed was 57.21. The diagnosis dates for the full set of records ranged from 5 to 18 years prior to recruitment; the ranges of those contacted and those interviewed were identical. Nor were the ages of our participants particularly unusual on a national basis. In the year of Phase I recruitment, 14% of persons living in Miami-Dade County and 16% of persons living in Broward County exceeded 65 years of age; the national figure was 12.7%. Thus, the sample of Phase I appears representative of the population we sought to recruit.

Interview content

The interview itself included both very general and more specific questions. Respondents first were asked to describe in general terms how cancer had affected their quality of life ("free" responses). They were then asked more structured questions about how cancer affected their quality of life in 17 specific domains. These 17 domains were based on domains frequently used in QOL instruments and a review of the literature related to long-term survivors. The domains were physical health, basic activities, mood/mental health, concentration, appearance, sexual function, relationship with partner, relationships with family, relationships with friends, finances, health insurance, work,

other life responsibilities, relationships with health care providers, philosophical/spiritual outlook, feelings about self, and positive impact of cancer. All interviews were tape-recorded and transcribed. This approach corresponds to the systematic discovery stage recommended for instrument design by Kessler and Mroczek [55].

Study investigators reviewed the transcripts and independently listed the domains that were mentioned most by respondents in the 'free' responses. We focused primarily on the free responses for identifying domains to pursue further, because these areas were salient enough to respondents that they identified them spontaneously. Responses to the more structured questions were used to create specific items.

After the interviews were conducted, health care providers and members of consumer advocacy groups were contacted to complete mailed surveys. Surveys were completed by five oncologists, two surgeons, a clinical psychologist, a gynecologist, and three advocacy group members (identified through attendees at the 1999 NCI meeting on survivorship and other contacts). The intent here was to obtain information from people who had experience with a large number of cancer survivors and who had a broad view of what long-term survivors reported as QOL issues. These interviews were used to ensure that the survivors we had interviewed had covered all major issues. The only area mentioned by providers that had not been mentioned by survivors was concerns about fertility and premature menopause. We decided not to include this as a domain because it would be relevant to only a subset of survivors (i.e., younger women).

Results

Twelve domains were identified from the free responses in the interviews: positive feelings, negative feelings, cognitive problems, social avoidance, fatigue, problems with sexual functioning, physical pain, benefits from cancer, appearance concerns, financial concerns, role limitations, and concerns about recurrence. Our a priori domains of relationships with partner, family, friends, and health care providers were not prominently mentioned by the participants. Physical health was mentioned largely in terms of fatigue and pain.

Basic activities, work, and other life responsibilities seemed to come together as Role Limitations. New domains of Social Avoidance and Cancer Related Distress emerged.

Many interviewees commented that things had changed in some of these areas, but could not determine whether these changes were due to cancer or aging. We therefore divided domains into what we believed to be generic domains that could not necessarily be attributed to cancer (e.g., Negative Feelings, Positive Feelings, and Fatigue) and domains that were cancer-specific, such as Benefits of Cancer and Cancer Related Distress.

Phase II

Methods

Questionnaire design

The results of Phase I were used to generate a pool of 83 items tapping the identified domains (both generic and cancer-specific). Both positively and negatively worded items were prepared. To go beyond purely objective functioning and to get at the subjective nature of QOL, many items were worded to measure the person's feelings about aspects of his or her life. Many items incorporated phrases used by Phase I participants to express their concerns. Items were agreed upon by all investigators.

In many instruments, respondents are asked to rate their satisfaction with various aspects of their lives. However, satisfaction scales are subject to ceiling effects because most people, even those with life-threatening illnesses, tend to be satisfied with most areas of their lives [61]. For this reason we decided to use a frequency response scale, in which respondents indicate how often they felt a certain way in the past 2 weeks.

To simplify administration of the instrument, a single 7-category frequency scale (ranging from never to always) was used for responses to all items. The category anchors were selected on the basis of the percentages people typically associate with various frequency terms [62]. The anchors (never, seldom, sometimes, about as often as not, frequently, very often, and always) were chosen to produce approximately equal percentage intervals from one category to the next. We chose seven

response categories rather than five to reduce the tendency of respondents to choose extreme scale values [63].

Participant recruitment

After the item set was created, a second sample was recruited through FCDS. The target sample size for the planned statistical analyses was 200. We extracted another random sample of approximately 45000 from the list of records obtained earlier from FCDS. As in the first sample, we placed no constraints on time since diagnosis. As in the first sample, the records were segregated by diagnostic category, assigned a random number, and sorted (within category) by those numbers. Letters were sent to potential participants in order of these numbers.

Those who expressed interest were sent a copy of the questionnaire set to complete and return. Each person completing the questionnaire set received \$50. A total of approximately 4000 initial contact letters were sent, and 372 questionnaire sets were mailed to interested individuals. If the questionnaire was not returned within 4 weeks, the participant was contacted by phone. The research assistant re-assessed the person's interest in remaining a participant and encouraged him or her to complete the questionnaires in a timely fashion. A total of 266 questionnaire sets were returned, but 24 of them were incomplete and were not included in analyses. The Phase II sample thus consisted of 242 long-term cancer survivors.

Measures

The questionnaire set that was sent to Phase II participants consisted of the initial item pool for the new measure, a set of socio-demographic items, several cancer treatment questions, and a set of scales that were selected as criterion measures for each domain. The inclusion of criterion measures was based on the following reasoning. A number of measures exist that assess qualities that are conceptually similar to qualities that are represented in the domains around which our items are written. Although those measures are not designed for long-term cancer survivors, they have relevance to health-related aspects of QOL. We included these measures in order to provide converging information on the adequacy of a given item from our item set as a reflection of the

domain it was intended to reflect. We chose these subscales rather than scales from existing measures of long-term QOL in order to maximize the extent to which the content of the criterion scale focused on the content domains of interest. Subscales from instruments such as the WHOQOL [64], Sickness Impact Profile [65], MOS Mental Health Index [66], and Post-Traumatic Growth Inventory [67] were chosen as criterion measures for this purpose, separately for each domain. Respondents also rated their overall quality of life by marking a 100 mm visual analog scale ranging from worst possible to best possible QOL.

Domain and item selection

Our approach to item selection for the QLACS used a two-pronged strategy. First, factor analyses were performed separately for the 51 generic and 32 cancer-specific items to test the hypothesized factor structure and determine which items loaded best on the factors. Due to the large number of items and factors, three separate factor analyses were performed for conceptually similar sets of items. Recent simulations have shown that sample sizes of 200 are more than adequate to accurately recover population factors and obtain unbiased estimates of factor loadings when communalities are high and there are at least three indicators per factor [68]. Second, we selected the four items that explained the most variance in the criterion measure for each domain using stepwise regression. This criterion-based procedure ensures that the selected items measure different facets of each domain while sacrificing only a small degree of internal consistency [55, 69]. Finally, the factor analysis and criterion-based results were compared to select the final set of items.

The validity of individual domains was assessed by correlations between domain scores and the criterion instruments and visual analog ratings. Internal consistency among the items constituting each domain was assessed by Cronbach's α . Scales are generally considered to be reliable if α exceeds 0.70 [70].

Results

Respondent characteristics

Sample characteristics are shown in Table 1. The mean age at interview was 71.4 years (SD = 11.5,

Table 1. Characteristics of Phase II sample (N = 242)

Variable	n	% (Mean, SD)
Sociodemographics		
Female (%)	140	58.0
Age (mean, SD)	238	71.4 (11.5) years
< 60	36	15.1
60–69	46	19.3
70–79	96	40.3
≥80	60	25.2
Race/ethnicity		
White	206	85.5
Hispanic	19	7.9
African American	15	6.2
Other	1	0.4
Education		
< high school	23	9.6
high school	79	32.9
some college	65	27.1
college grad	27	11.2
post-college	46	19.2
Employment status		
Employed	52	21.6
Retired	162	67.2
Unemployed/disabled	22	9.1
Doing something else	5	2.1
Living with partner or spouse (%)	159	65.7
Medical		
Years since diagnosis (mean, SD)	235	12.6 (7.0)
5–9	75	31.9
10–14	110	46.8
≥15	50	21.3
Cancer stage		
I	45	18.7
II	22	9.2
III	16	6.7
IV	8	3.3
Don't know	149	62.1
Cancer type^a		
Breast	44	
Bladder	18	
Head and neck	20	
Gynecologic	34	
Prostate	31	
Colorectal	22	
Treatment		
Surgery	218	92.4
Chemotherapy	56	23.7
Radiation	115	48.7
Hormonal	29	12.3

^a These numbers added up to be greater than 242 because some people reported multiple cancers.

range from 29 to 92 years), and respondents were interviewed an average of 12.6 years after first diagnosis ($SD = 7.0$, range from 5 to 67 years). Women comprised over half (58%) of the sample and there were small percentages of minority respondents (7.9% Hispanic, 6.2% African-American, and 0.4% Other). 28% of the sample reported multiple types of cancer. Several cases occurred in which the cancer registry code for cancer type differed from self-reported cancer type. We re-contacted those persons to verify the information. There were six cases, however, in which the type of cancer could not be definitively determined. These cases were excluded from any subsequent analyses involving cancer type.

Nearly all subjects had had some form of cancer surgery (92%), with the lowest surgery rate (64%) among the prostate group. Almost half of the sample (48.7%) had undergone radiation therapy and 23.7% had chemotherapy. Hormone therapy, the least common treatment (12%), was reported only for breast, gynecologic, and prostate cancers.

As in the Phase I sample, we examined how representative the sample was of the population from which it was drawn. The average age at diagnosis was 65.2 years for the full set of records extracted for this phase of data collection, 62.2 years for those sent letters, and 60.3 years for the 242 subjects who formed our sample. Diagnosis dates for the full set of records ranged from 5 to 18 years prior to recruitment; the same was true for persons sent letters and those in the final sample. Thus, the Phase II sample also appears representative of the population of long-term cancer survivors. However, Phase II subjects, on average, had survived somewhat longer than Phase I subjects.

Domain measurement and item selection

Factor analyses reproduced the hypothesized generic domains, with each item having its highest loading on its intended factor (see Table 2). The Sexual Problems domain split into correlated interest and functioning factors, but the criterion-based approach yielded a single domain combining two interest and two functioning items.

Factor loadings for the cancer-specific items differed in two ways from the expected structure. First, the items reflecting Role Limitations sepa-

rated, loading across several domains. Because of the lack of cohesion of the Role Limitations items, this domain was eliminated from further consideration. Second, the cancer distress items split into two dimensions: family-related distress and fears about recurrence. Because of this separation, separate domains were created for family distress and distress about fears of recurrence.

Table 3 shows the correlations between domain scores and the criterion measures. These correlations were 0.72 or higher in all of the generic domains but one (Social Avoidance). The correlations were somewhat lower for the cancer-specific scales, which is not surprising, given that these are the areas where criterion measures less closely match the intended domains.

The final version of the QLACS consists of 47 items measuring 12 domains; seven are considered Generic and five are Cancer-specific (the instrument is in the Appendix). The Flesch Reading Ease score for these items was 74.4 which is equivalent to a Flesch–Kincaid reading level of 4.8 [71]. Scores for each domain are the sum (after appropriate reverse scoring) of the individual item scores (1 = “Never” through 7 = “Always”). Domain scores may therefore range from 4 to 28 points, with higher scores representing more problems or poorer quality of life. Table 4 shows the domain score means, standard deviations, alpha reliabilities, score ranges, and the percentage of scores at the minimum (floor) or maximum (ceiling) values. Cronbach’s α exceeded 0.71 for each domain. This sample displayed substantial floor effects only for appearance concerns and financial problems.

QLACS summary scores

Correlations among domain scores are shown in Table 5. Most domains were moderately correlated with the others. An oblique factor analysis of this matrix produced factors for the Generic domains, Cancer Benefits, and the remaining Cancer-Specific domains. Based on these results, we created separate Generic and Cancer-Specific summary scores by adding their constituent domain scores (omitting Cancer Benefits since it did not load with the other domains). The summary scales are scored so that higher scores represent more problems or lower QOL. In our sample, the mean generic summary score was 71.2 ($SD = 25.6$)

Table 2. Factor loadings for (a) generic (N = 204) and (b) cancer-specific (N = 228) domains

Item	Factor loadings							
	Negative feelings	Positive feelings	Cognitive problems	Pain	Sexual interest	Energy/fatigue	Sexual function	Social avoidance
<i>(a) Generic</i>								
Negative feelings								
19 Bothered by mood swings	0.718	-0.253	-0.553					
7 Felt blue or depressed	0.714	-0.511	-0.448					
9 Worried about little things	0.657	-0.216	-0.382					
24 Felt anxious	0.558	-0.220	-0.348					
Positive feelings								
8 Enjoyed life	-0.567	0.818	0.351					
28 Content with life	-0.660	0.754	0.354					
6 Felt happy	-0.605	0.724	0.407					
22 Had a positive outlook on life	-0.580	0.681	0.354					
Cognitive problems								
3 Bothered by having a short attention span	0.464	-0.266	-0.853					
4 Had trouble remembering things	0.410	-0.306	-0.660					
2 Difficulty doing things requiring concentration	0.452	-0.261	-0.605					
23 Bothered by forgetting what started to do	0.410	-0.186	-0.582					
Pain								
13 Bothered by pain preventing activities				0.894	-0.187	0.452	0.170	0.289
17 Mood disrupted by pain or its treatment				0.843	-0.264	0.378	0.185	0.388
27 Pain interfered w/social activities				0.810	-0.211	0.464	0.192	0.401
21 Had aches or pains				0.793	-0.249	0.436	0.250	0.342
Sexual interest								
16 Lacked interest in sex				0.219	-0.965	0.200	0.341	0.289
26 Avoided sexual activity				0.248	-0.647	0.194	0.288	0.414
Energy/fatigue								
11 Lacked energy to do things wanted to				0.411	-0.214	0.871	0.271	0.285
14 Felt tired a lot				0.599	-0.288	0.777	0.274	0.406
1 Had energy to do things wanted to do				-0.453	0.295	-0.770	-0.258	-0.387
5 Felt fatigued				0.442	-0.273	0.731	0.223	0.412
Sexual function								
12 Dissatisfied w/sex life				0.130	-0.240	0.151	0.911	0.246
10 Bothered by inability to function sexually				0.185	-0.266	0.240	0.834	0.259
Social avoidance								
18 Avoided social gatherings				0.447	-0.264	0.403	0.300	0.897
20 Avoided friends				0.253	-0.321	0.270	0.365	0.769
25 Reluctant to meet new people				0.266	-0.299	0.246	0.220	0.761
15 Reluctant to start new relationships				0.243	-0.380	0.205	0.198	0.610
Eigenvalue	8.14	2.05	1.31	10.89	2.92	2.02	1.72	1.29
% Variance	40.7	10.2	6.5	33.0	8.8	6.1	5.2	3.9

Table 2. Continued

Item	Factor loadings				
	Financial problems	Benefits	Distress-family	Appearance	Distress-recurrence
<i>(b) Cancer-Specific</i>					
Financial problems					
43 Had money problems from cancer	0.945	0.151	0.202	0.402	0.338
45 Financial problems from loss of income due to cancer	0.872	0.141	0.204	0.567	0.328
30 Financial problems from cost of cancer surgery or tx	0.829	0.130	0.269	0.360	0.411
37 Problems with insurance because of cancer	0.435	0.086	0.140	0.212	0.343
Benefits					
40 Cancer helped recognize what important in life	0.209	0.805	0.259	0.121	0.265
41 Better able to deal w/stress because of cancer	0.198	0.801	0.180	-0.007	0.215
32 Cancer helped cope better w/problems	0.156	0.670	0.258	0.090	0.178
29 Appreciated life more because of cancer	0.202	0.489	0.197	0.058	0.188
Distress-family					
34 Worried whether family had cancer causing genes	0.241	0.129	0.885	0.225	0.420
31 Worried family members were at risk for cancer	0.326	0.052	0.863	0.212	0.450
42 Worried family should have genetic tests - cancer	0.148	0.170	0.813	0.034	0.393
Appearance					
35 Felt unattractive b/c of cancer or its treatment	0.407	-0.015	0.125	0.901	0.325
33 Self-conscious about appearance because of cancer	0.381	0.036	0.142	0.863	0.304
44 Felt treated differently b/c of changes in appearance	0.532	0.008	0.190	0.678	0.278
38 Bothered by hair loss from cancer tx	0.334	0.122	0.150	0.435	0.367
Distress-recurrence					
39 Worried about cancer coming back	0.346	0.041	0.356	0.263	0.848
46 When felt pain, worried it was cancer again	0.312	0.108	0.328	0.229	0.769
36 Worried about dying from cancer	0.282	0.054	0.334	0.284	0.763
47 Preoccupied with concerns about cancer	0.388	0.120	0.394	0.273	0.748
Eigenvalue	8.48	4.87	2.45	1.54	1.36
Variance%	28.3	16.2	8.2	5.1	4.5

and the mean for the Cancer-Specific summary was 38.0 ($SD = 17.4$).

As an additional test of validity, correlations were computed between the domain and summary scores and respondent ratings of their overall QOL using the visual analog scale (Table 6). The mean visual analog score was 74.8 ($SD = 23.7$). The correlations were highest for the Positive Feelings, Fatigue, and Social Avoidance domains. The

lowest correlations were for the Cancer-Specific scales. As a result, the Generic Summary score was more strongly associated with the analog ratings ($r = -0.57$) than was the Cancer-Specific summary ($r = -0.24$).

Domain scores by cancer type

Comparisons among the six types of cancer yielded statistically significant differences for five do-

Table 3. Correlations between domain scores and criterion measures (N = 208–239)

Domain	Correlation	Criterion measure
Generic		
Negative feelings	-0.72	MHI-Depression/anxiety
Positive feelings	-0.79	MHI-Positive affect
Cognitive problems	-0.75	MOS-HIV cognitive functioning
Sexual problems	-0.76	WHOQOL Sex functioning
Physical pain	0.84	WHOQOL pain
Fatigue	-0.84	WHOQOL Energy/fatigue
Social avoidance	0.62	SIP Social interaction
Cancer-specific		
Appearance concerns	-0.61	WHOQOL body image
Financial problems	0.57	Economic strain
Distress-recurrence	-0.67	EORTC recurrence
Distress-family	-	none
Benefits of cancer	0.67	PTGI Total score

mains (Table 7). To avoid confounding by multiple cancers, these contrasts were made only among participants reporting only one type of cancer (n = 169). For most domains, respondents with bladder or head and neck cancer had the least favorable scores, while those with prostate cancer had the most favorable scores. There were some differences, however, across domains. For the Sexual Problems domain, the scores were highest for bladder and prostate cancer and lowest for

colorectal cancer. For Social Avoidance, scores were highest for head and neck and bladder cancer and lowest for colorectal cancer. There were highly significant effects for cancer type on the appearance and financial domains, with head and neck cancer having the highest scores. Analysis of the Generic summary score just failed to reach statistical significance, with bladder and head/neck cancer tending to have the highest (least favorable) scores and prostate and colorectal cancer having the lowest (most favorable) scores. For the Cancer-Specific summary score, the effect of cancer type was highly significant. The study had 81% power to detect effect sizes of 0.30 or greater ($\alpha = 0.05$) for differences between the six cancer types. These are slightly larger than what are usually considered to be medium effect sizes.

Discussion

Researchers and clinicians are increasingly aware of the importance of quality of life issues among long-term cancer survivors [16, 17, 19–29]. Quality of life assessments can be an important indicator of success of treatment, can help identify long-term sequelae clinicians should monitor, and can identify areas where services or interventions are needed [21]. However, few instruments are currently available that adequately capture a wide range of QOL domains relevant to long-term survivors. This article described development of

Table 4. Domain means, standard deviations, ranges, percent at minimum and maximum, and α reliabilities

Domain	N	Mean (SD)	Range	Minimum (%)	Maximum (%)	Cronbach's α
Generic domains						
Negative feelings	238	9.1 (3.9)	4–22	9	1	0.74
Positive feelings	242	22.4 (5.0)	6–28	0	15	0.88
Cognitive problems	239	9.8 (4.2)	4–24	8	0	0.77
Sexual problems	218	12.6 (6.1)	4–28	11	1	0.72
Physical pain	239	9.6 (5.8)	4–28	14	1	0.91
Fatigue	239	12.3 (5.4)	4–26	6	1	0.89
Social avoidance	241	8.3 (4.7)	4–27	27	<1	0.81
Cancer specific domains						
Appearance concerns	239	7.0 (4.8)	4–27	48	0	0.81
Financial problems	240	6.9 (5.3)	4–28	58	1	0.85
Distress – recurrence	239	11.4 (6.1)	4–28	9	2	0.86
Distress – family ^a	239	12.6 (7.2)	4–28	16	6	0.88
Benefits	242	16.2 (6.8)	4–28	6	5	0.85

^aThis domain consists of three items that are rescaled to make the metric comparable to the other domains.

Table 5. Correlations among domain scores (N = 224)

Domain	Domains										
	Negative feelings	Positive feelings	Cognitive problems	Sexual problems	Physical pain	Fatigue	Social avoidance	Appearance concerns	Financial problems	Distress recurrence	Distress family
Generic											
Negative feelings	1.00										
Positive feelings	-0.61	1.00									
Cognitive problems	0.60	-0.44	1.00								
Sexual problems	0.31	-0.41	0.36	1.00							
Physical pain	0.58	-0.44	0.40	0.26	1.00						
Fatigue	0.53	-0.52	0.54	0.34	0.60	1.00					
Social avoidance	0.48	-0.57	0.42	0.45	0.40	0.48	1.00				
Cancer specific											
Appearance	0.36	-0.27	0.23	0.18	0.22	0.20	0.40	1.00			
Financial	0.30	-0.17	0.18	0.13	0.26	0.13	0.30	0.54	1.00		
Distress-recurrence	0.48	-0.26	0.37	0.26	0.41	0.32	0.36	0.40	0.40	1.00	
Distress-family	0.33	-0.17	0.22	0.11	0.28	0.17	0.14	0.26	0.32	0.46	1.00
Benefits	0.02	0.18	0.05	-0.06	-0.02	-0.10	-0.11	0.11	0.26	0.23	0.30

Table 6. Pearson correlations between domain scores and visual analogue scale ratings of quality of life

Domain	Correlation coefficient
Positive feelings	0.60
Fatigue	-0.45
Social avoidance	-0.45
Pain	-0.38
Negative feelings	-0.36
Cognitive problems	-0.33
Sexual problems	-0.29
Appearance concerns	-0.25
Recurrence distress	-0.23
Financial problems	-0.21
Cancer benefits	0.14
Family distress	-0.08
Generic Summary score	-0.57
Cancer-Specific Summary score	-0.24

N = 216–240.

All correlation significantly different from zero ($p < 0.05$) except for Family distress.

the QLACS, a multidimensional measure designed for long-term cancer survivors. The QLACS measures 12 QOL domains, seven of which are generic and five cancer-specific.

The generic item sets do not mention cancer and therefore are also applicable to non-cancer populations. These domains lend themselves for use in comparing cancer survivors with healthy people or other disease populations, without having to use

multiple measures. The five cancer-specific domains ask questions directly related to having cancer. These domains are appropriate for assessing the impact of interventions on long-term QOL and for comparing QOL among cancer patients. Psychometric properties of the QLACS suggest that the domains have good internal consistency and good validity.

Comparisons of domain scores across cancer type yielded results consistent with the literature on long-term effects of cancer. Except for sexual functioning, those with prostate cancer tended to have the fewest problems compared to other cancer types. Treatment for prostate cancer has previously been shown to have a negative impact on sexual functioning [40, 42]. Social Avoidance was highest for head and neck cancers and bladder cancer. Perhaps, because head and neck cancer survivors have socially observable effects and bladder cancer may lead to awkwardness in social situations. We should also note that for gender-specific cancers (e.g., breast and prostate) cancer type is confounded with gender. Larger samples of non-gender specific cancers are needed to tease out the specific effects of gender.

In general, the most frequently reported problem areas reported were sexual problems, family-related concerns, and fatigue. Long-term effects of fatigue and sexual problems have been reported as important issues in long-term survivors by others [21, 22, 37–42, 72]. Concerns about recurrence were also

Table 7. Mean (SD) domain scores by cancer type

	Cancer type						<i>F</i>	<i>p</i>
	Breast (N = 44)	Bladder (N = 18)	Head and Neck (N = 20)	Gynecologic (N = 34)	Prostate (N = 31)	Colorectal (N = 22)		
Generic								
Negative feelings	9.7 (3.8)	9.8 (3.2)	10.3 (3.5)	9.7 (4.1)	7.1 (3.5)	8.9 (4.3)	2.46	0.035
Positive feelings	22.1 (4.7)	20.8 (5.2)	20.3 (6.3)	22.7 (4.8)	23.8 (4.9)	24.1 (3.2)	2.20	0.056
Cognitive problems	9.8 (5.0)	10.3 (5.2)	11.4 (4.3)	10.5 (4.0)	8.3 (2.7)	8.4 (4.0)	1.94	0.090
Sexual problems	11.8 (6.8)	16.1 (7.9)	13.7 (6.5)	11.9 (4.7)	15.0 (6.4)	9.0 (3.4)	3.57	0.0045
Physical pain	9.7 (6.1)	9.5 (6.2)	9.9 (6.2)	9.7 (5.7)	7.8 (4.8)	9.2 (6.3)	0.49	0.782
Fatigue	11.8 (5.4)	13.6 (6.1)	12.6 (6.2)	12.5 (3.8)	11.8 (5.8)	10.3 (4.6)	0.91	0.476
Social avoidance	8.2 (4.3)	10.1 (6.2)	11.0 (6.9)	9.2 (5.1)	7.3 (4.3)	6.9 (2.8)	2.35	0.043
Summary	70.5 (26.6)	82.3 (33.9)	82.2 (30.6)	73.1 (23.8)	64.5 (24.4)	60.9 (21.5)	2.26	0.051
Cancer specific								
Appearance	7.7 (3.9)	5.1 (1.6)	11.6 (7.0)	6.4 (5.0)	4.7 (1.5)	7.5 (6.2)	6.72	<.0001
Financial	6.0 (3.3)	6.7 (4.4)	10.0 (7.9)	6.3 (5.3)	5.0 (1.7)	7.7 (6.2)	3.17	0.009
Distress-recurrence	11.7 (5.8)	13.0 (6.5)	12.5 (6.9)	11.8 (6.7)	8.6 (3.1)	11.1 (6.0)	1.78	0.121
Distress-family	13.0 (7.1)	10.7 (5.8)	10.1 (5.8)	12.9 (7.9)	9.8 (5.6)	15.0 (7.7)	2.18	0.059
Summary	38.1 (14.6)	35.8 (10.6)	44.3 (21.2)	37.7 (20.1)	27.9 (8.6)	41.7 (20.8)	2.92	0.015
Benefits	16.9 (7.2)	15.4 (6.5)	16.7 (5.8)	17.3 (6.5)	13.5 (6.6)	18.9 (7.0)	1.98	0.084

rated high in the present sample (as has also been found within the first year after treatment [73]. Domains reported least frequently were Financial Problems and problems with Appearance.

We found significant differences across cancer types for the cancer-specific summary score, but smaller differences for the generic summary score, suggesting that the cancer-specific domains are more sensitive to the type of cancer. This finding highlights the advantage of including cancer-specific measures in assessing quality of life among long-term survivors. Indeed, the different patterns of scores across cancer types for different cancer-specific domains support the desirability of multi-dimensional measures, since summary scores do not convey these differences [30]. These comparisons should be viewed with some caution, however, as the group sizes of each type were relatively small.

We also included a Benefits domain, which received a high mean frequency score. This reinforces prior findings that people often find some benefit from having had cancer [47–50, 73, 74]. Interestingly, Benefits scores had only small correlations with other generic or cancer-specific domains. For that reason, this domain was not included in either summary score. These results suggest that perceived benefits are a unique aspect of survivorship that do not relate well to other

aspects of long-term physical and psychosocial functioning.

We should note some limitations to this work. We intentionally recruited through a state registry rather than through a cancer survivor support or advocacy group, recognizing that such groups are not likely to be representative of cancer survivors in general. Nonetheless, participation in the research involved some self-selection. Although recruitment of participants began with a very wide solicitation, for a person who received a letter from us to actually become a participant required that person to take the next step of contacting us. For the first sample, there was an additional barrier to participation, because we asked respondents to indicate a good time to call them by phone; anyone wishing to be interviewed who did not have a phone number to offer would have had greater difficulty in participating than others. The study also required potential participants to return a postcard, and actual participants to spend approximately 2 h reporting on their well-being. Given these considerations, our sample may have been more cooperative than a truly random sample of cancer survivors. This limitation is common in research on medical populations. Without recruiting people who are willing to spend the time, it is difficult to obtain large amounts of information.

Potential issues of generalizability are also raised by the fact that all participants came from South Florida (i.e. their cancer diagnoses took place in the state of Florida). It would be desirable and valuable to have further information on survivors recruited from a wider geographical area which is one goal for future investigation.

Another limitation is that the samples were skewed towards older persons. This skew toward the older also characterizes the population from which we drew the samples. Comparison of participant samples to the larger sets of records from which the mailing lists were generated revealed that those who participated were in fact a bit younger than the two comparison groups (the full set of records extracted, and those to whom letters were sent). The age of the samples reflects the fact that the cancers we studied are more common among older than younger persons, and the fact that we did not place any restriction on length of survivorship at the time of data collection. To have placed such a restriction would have created a bias of a different type.

Conclusion

In conclusion, we offer researchers who are interested in psychosocial well-being among long-

term cancer survivors a multidimensional assessment tool for use in their investigations. This instrument, the QLACS, covers five cancer-specific areas that were suggested by long-term survivors themselves as relevant to their lives, along with seven additional areas that are relevant to cancer but are not limited to cancer. The QLACS therefore covers more areas relevant to the cancer survivorship experience than do other instruments such as the QOL-CS [18] and the LTQL [51, 52]. It was developed in two phases, using nearly equal numbers of men and women, who were survivors of several different types of cancers, and whose survivorship ranged from recent (5 years) to prolonged (18 years). Its items are clearly and unambiguously focused on specific effects in the domains that they represent. We hope that this instrument will prove to be of value to other researchers who are trying to reach a better understanding of what factors contribute to quality of life among long-term cancer survivors.

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Appendix A

Quality of Life in Adult Cancer Survivors Scale

Instructions: We'd like to ask you about some things that can affect the quality of people's lives. Some of these questions may sound similar, but please be sure to answer each one. Below is a scale ranging from never to always. Please indicate how often each of these statements has been true for you in the past four weeks. [CIRCLE ONE ANSWER FOR EACH QUESTION]

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
In the past 4 weeks...							
1. You had the energy to do the things you wanted to do.	1	2	3	4	5	6	7
2. You had difficulty doing activities that require concentrating.	1	2	3	4	5	6	7
3. You were bothered by having a short attention span.	1	2	3	4	5	6	7
4. You had trouble remembering things.	1	2	3	4	5	6	7
5. You felt fatigued.	1	2	3	4	5	6	7
6. You felt happy.	1	2	3	4	5	6	7
7. You felt blue or depressed.	1	2	3	4	5	6	7
8. You enjoyed life.	1	2	3	4	5	6	7
9. You worried about little things.	1	2	3	4	5	6	7

Appendix A *Continued*

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
10. You were bothered by being unable to function sexually.	1	2	3	4	5	6	7
11. You didn't have energy to do the things you wanted to do.	1	2	3	4	5	6	7
12. You were dissatisfied with your sex life.	1	2	3	4	5	6	7
13. You were bothered by pain that kept you from doing the things you wanted to do.	1	2	3	4	5	6	7
14. You felt tired a lot.	1	2	3	4	5	6	7
15. You were reluctant to start new relationships.	1	2	3	4	5	6	7
16. You lacked interest in sex.	1	2	3	4	5	6	7
17. Your mood was disrupted by pain or its treatment.	1	2	3	4	5	6	7
18. You avoided social gatherings.	1	2	3	4	5	6	7
19. You were bothered by mood swings.	1	2	3	4	5	6	7
20. You avoided your friends.	1	2	3	4	5	6	7
21. You had aches or pains.	1	2	3	4	5	6	7
22. You had a positive outlook on life.	1	2	3	4	5	6	7
23. You were bothered by forgetting what you started to do.	1	2	3	4	5	6	7
24. You felt anxious.	1	2	3	4	5	6	7
25. You were reluctant to meet new people.	1	2	3	4	5	6	7
26. You avoided sexual activity.	1	2	3	4	5	6	7
27. Pain or its treatment interfered with your social activities.	1	2	3	4	5	6	7
28. You were content with your life.	1	2	3	4	5	6	7
The next set of questions asks specifically about the effects of your cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.							
29. You appreciated life more because of having had cancer.	1	2	3	4	5	6	7
30. You had financial problems because of the cost of cancer surgery or treatment.	1	2	3	4	5	6	7
31. You worried that your family members were at risk of getting cancer.	1	2	3	4	5	6	7
32. You realized that having had cancer helps you cope better with problems now.	1	2	3	4	5	6	7
33. You were self-conscious about the way you look because of your cancer or its treatment.	1	2	3	4	5	6	7
34. You worried about whether your family members might have cancer-causing genes.	1	2	3	4	5	6	7
35. You felt unattractive because of your cancer or its treatment.	1	2	3	4	5	6	7
36. You worried about dying from cancer.	1	2	3	4	5	6	7
37. You had problems with insurance because of cancer.	1	2	3	4	5	6	7
38. You were bothered by hair loss from cancer treatment.	1	2	3	4	5	6	7
39. You worried about cancer coming back.	1	2	3	4	5	6	7
40. You felt that cancer helped you to recognize what is important in life.	1	2	3	4	5	6	7
41. You felt better able to deal with stress because of having had cancer.	1	2	3	4	5	6	7

Appendix A *Continued*

	Never	Seldom	Sometimes	About as often as not	Frequently	Very often	Always
42. You worried about whether your family members should have genetic tests for cancer.	1	2	3	4	5	6	7
43. You had money problems that arose because you had cancer.	1	2	3	4	5	6	7
44. You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.	1	2	3	4	5	6	7
45. You had financial problems due to a loss of income as a result of cancer.	1	2	3	4	5	6	7
46. Whenever you felt a pain, you worried that it might be cancer again.	1	2	3	4	5	6	7
47. You were preoccupied with concerns about cancer.	1	2	3	4	5	6	7

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