A psychometric analysis of the Quality of Life-Cancer Survivors (QOL-CS) in survivors of childhood cancer

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Abstract

Given the increasing interest in quality of life research in cancer survivorship, psychometric properties of the Quality of Life-Cancer Survivors (QOL-CS) were explored in a group of childhood cancer survivors. The QOL-CS is a 41-item visual analog scale composed of four multi-item sub-scales (physical well-being, psychological well-being, social well-being, spiritual well-being) and two sub-components (fears, distress). This instrument was incorporated in a mailed survey completed by 177 respondents. The underlying factor structure and internal reliability of the instrument were explored. A preliminary assessment of the external validity of the factor structure was undertaken. Results of a factor analysis were theoretically consistent with elements assessed in the QOL-CS, although misclassification of several items was noted and discussed. Internal-consistency reliability was very good (Cronbach's α = 0.80–0.89) for five of the six factors. Moderate ($0.30 < r < 0.45$) to high ($r > 0.60$) concurrent validity was observed for four factors. Discriminant validity was noted across groups defined by health and social status variables. Psychometric analysis indicated that the instrument measured distinct and relevant domains of quality of life for childhood cancer survivors, but in its current form does not appear to be an optimal measure of quality of life in this population.

Introduction

There is substantial debate about both meaning and measurement approaches in quality of life studies of adolescent and young adult cancer patients and survivors [1–4]. Efforts to assess the impact of cancer on young people diagnosed in childhood or adolescence have examined numerous outcomes, such as 'quality of life', 'self-esteem', 'self-concept', 'coping', 'adjustment', 'post-traumatic stress' and most recently 'thriving' and 'post-traumatic growth'. Even when meaning of these outcomes has been clearly articulated, investigators have utilized a variety of theoretical frameworks, research designs, samples and methods. Studies have varied in their sample size and selection of respondents of different ages, diagnoses, and times since diagnosis, as well as in their use of standardized vs. unique instruments and quantitative vs. qualitative designs. Some investigators have used generic psychometric instruments standardized on 'physically normal' populations (e.g., Profile of Moods States, Child Behavior Checklist) while others have adapted or developed approaches designed to assess health-related quality of life outcomes in a variety of patient populations [5, 6]. Some investigators have designed and administered instruments specifically for evaluating health-related quality in childhood and cancer patients [7–9] and others have assessed health-related quality of life in adolescent and young adult survivors of childhood cancer using

instruments developed for adult cancer survivor populations [10]. Finally, some researchers have relied upon approaches that are more responsive to respondents' narratives than to investigators' *a priori* orientations. These approaches have included uniquely designed questionnaires, open-ended questions and intensive personal and small group (focus group) interviews [11–15].

The variety of approaches used to evaluate quality of life, as well as the somewhat ineffable nature of assessing anyone's psychosocial reality, have produced inconsistent findings in childhood cancer survivor studies. Most studies of long-term survivors tend to emphasize survivors' deficits and adjustment problems and the psychopathological nature of their experience, while a few more recent studies have begun to target survivors' own reports of personal growth and positive life changes [16–18]. Overall, as Eiser and Havermans [19] note, there is little consensus on how to measure the social and emotional consequences of childhood cancer.

Given an increasing interest in quality of life research in cancer survivorship, this paper seeks to assist investigators in selecting appropriate items and instruments to assess quality of life in a childhood cancer survivor population. The specific aims of the analysis presented here are (1) to explore the underlying factor structure of an existing psychometric instrument designed to evaluate global and dimensional aspects of quality of life, and (2) to evaluate this instrument's reliability and validity, and thus its utility, in a sample of young adult survivors of childhood cancer, many of whom have entered their second decade of survivorship.

Methods

Procedures and participants

The data reported here come from two sources: medical records of childhood cancer survivors treated at a mid-western children's hospital and a self-report questionnaire. To create the sample, the files of a major university medical center were searched to randomly create a list of 493 young adult survivors of childhood cancer who were between the ages of 16 and 29. A 'survivor' was de-fined as a young person who had been treated for cancer in childhood and who was now successfully off-treatment (for any period of time). Nineteen individuals were confirmed to be deceased and 139 individuals were unreachable and untraceable (via Internet searches of postal address databases), which reduced the number of survivors available for study to 335. In 1999, surveys were mailed to this population and, after three rounds of follow-up, 176 responses were obtained (53% response rate). The Institutional Review Board of the university's medical center approved all procedures. Recipients of the questionnaires were assured in writing that their involvement was voluntary and confidential.

Based on the medical records data, survey respondents and non-respondents did not differ significantly with regard to their cancer diagnosis, staff-assessed degree of difficulty with treatment, current age, age at diagnosis or time since diagnosis. Respondents and non-respondents did differ by gender: 61% of eligible females completed and returned surveys compared to 47% of eligible males.

Study measures and procedures

Quality of Life-Cancer Survivors (QOL-CS)
In an attempt to examine the multiple dimensions of quality of life for a specific population – cancer survivors – Ferrell et al. [20–22] assessed adult cancer survivors' concerns regarding health status, sexuality and fertility, emotional distress, future outlook, school and work performance, social and family relationships, and spirituality, as well as other key medical, demographic and psychosocial elements. They developed a theoretical model of quality of life specific to cancer survivors and subsequently structured a quality of life instrument – the (QOL-CS) – that measures positive and negative outcomes associated with cancer's effect on physical, psychological, social and spiritual dimensions of quality of life. The QOL-CS is one of a growing number of standardized instruments developed specifically for measuring quality of life in persons diagnosed with cancer; however, its utility for measuring quality of life in young adult populations of childhood cancer survivors has not been tested.

The QOL-CS is a 41-item visual analog scale composed of four multi-item sub-scales: physical

well-being (eight items), psychological well-being (18 items), social well-being (eight items), and spiritual well-being (seven items). Within the psychological sub-scale are two sub-components assessing distress and fear. This standardized instrument examines issues of particular concern to cancer survivors such as current physical and mental health status, available social support, fear of recurrence, and the role of spirituality and religion in their lives. Respondents rate themselves along an anchored scale ranging from 0 to 10 for each item. The wording of items is such that for some items, 0 indicates the worst score and 10 the best; for other items the anchors are reversed. For scoring purposes, all items are ordered (or reverse ordered, if necessary) so that 0 indicates the lowest or worst possible quality of life outcome and 10 indicates the highest or best quality of life outcome for each item. Within each of the four domains and two additional sub-components, item scores are averaged, resulting in a sub-scale score for that domain or sub-component. An overall quality of life score is also computed by averaging all 41 items.

Additional study measures
There exists no gold standard measure by which to evaluate the external validity of the QOL-CS in survivors of childhood cancer. Thus, theoretically-derived scales representing the extent to which childhood survivors report worry about cancer-related issues, general health and psychosocial issues were used to evaluate concurrent validity of the QOL-CS. Worry signifies a broad range of subjectively defined issues that arouse concern, anxiety, doubt or fear for survivors of childhood cancer [15]; and the worry measures included here have a contextually-specific focus on the unique issues of this particular population. Based upon prior work [11, 15, 23], three scales were derived from a series of 16 four-point Likert scale items that explored the degree to which childhood cancer survivors worry (1 = not at all, 2 = a little, 3 = some, 4 = a lot) about issues identified in the literature as being of particular concern to them. Furthermore, these contextually-specific items and scales have been assessed as having face validity in numerous conversations with survivors and clinicians [11, 23] and have been utilized as outcome variables in three different samples of cancer survivors over a 10-year period [11, 23, 24]. The three

scales measure: (1) cancer-specific worries (worry about: relapse, getting another cancer, getting more treatment, being as healthy as same age peers, effect of cancer on siblings); (2) worries about general psychosocial issues (worry about: personal finances, parents' finances, learning problems, getting medical/life insurance, ever getting married); and (3) general health worries (worry about: getting a cold/flu, getting headaches, getting tired). Cronbach's α coefficients as measures of internal reliability for each of the three worry scales were 0.80 for cancer-specific worry, 0.76 for worry about general psychosocial issues and 0.80 for general health worry.

Also assessed here were age at diagnosis, type of cancer, self-rated health, after-effects of treatment and report of a serious medical condition (other than cancer) in the past 10 years. Sociodemographic measures included age, gender, income and marital status.

Factor analysis and test of reliability

To test the validity of the QOL-CS in this sample of young adult survivors of childhood cancer, a factor analysis was conducted to maximize the statistical distinction among the instrument's theoretically derived domains and sub-components. We conducted an exploratory analysis because we were interested in knowing if the correlations among items measuring quality of life in adult survivors were the same as those in childhood cancer survivors. Given that any exploratory factor analysis, however employed, most likely would not replicate the original factor structure, we set out to compare the 'original' sub-scales and sub-components of the QOL-CS to the reconstituted factors derived from a factor analysis. A principal components analysis (PCA) method was used to extract six factors from 39 of the 41 QOL-CS items. Two items – recalling distress at diagnosis and recalling distress during treatment – were eliminated from this analysis because 14 respondents (8%) left these items blank, most likely due to being too young to recall (the average age at diagnosis for respondents not answering one or both of these items was 2.7 years). Individual case means were imputed for missing data when no more than two items were left blank within a sub-scale. Internal consistency of the derived factors

was measured by calculating item-total correlations and Cronbach's α coefficients for each factor. In addition, construct validity of the instrument, which examines correlations among scale scores within an instrument based on known relationships, was examined. Prior research demonstrating significant associations between psychological well-being and social functioning and social support [11, 25] suggests that quality of life scales measuring psychological well-being should correlate highly with measures of social well-being. In addition, empirical and theoretical work by Wyatt and Friedman [26] suggests an expectation for relative and proportional relationships among all QOL domains but no significant relationship between the physical and spiritual domains. Pearson product–moment correlations are used to examine the relationships among the four sub-scales and two sub-components of the QOL-CS.

External validity/validation procedures

External validity of the factor solution thus identified was evaluated in several ways. The first approach examined concurrent validity, the extent to which an item or scale correlates with a selected criterion, be it a recognized 'gold standard' measure or another measure assumed to be assessing similar concepts. Concurrent validity of the new factors was evaluated by correlating the summative scores of items comprising each of the factors with the three worry scales described above, using Spearman's rank correlation. The statistical significance of a correlation coefficient is dependent on the sample size, so criteria for quantitative significance of correlations were also used and based loosely on the recommendations of Burnand et al. [27]: < 0.30 negligible; 0.30–0.45 moderate; 0.45–0.60 substantial; and > 0.60 high.

A second approach examined discriminative validity, the ability of a measure to detect cross-sectional differences between subjects when differences are expected or known. Criteria used to determine discriminative validity were derived from quality of life studies in which well-being was higher for respondents with higher levels of income and education, who were married, and who were physically healthy [28–33]. With regard to gender, Ferrell et al. [21] reported that while men scored significantly higher than did women in the physical domain of the QOL-CS, women demonstrated significantly higher quality of life in the spiritual domain. Thus, we expected to see gender differences in the physical and spiritual domains. Also,

Table 1. Medical and demographic characteristics of questionnaire respondents

	N (%)
Medical status	
Diagnosis	
Leukemia	53 (30.3)
Brain/CNS	19 (10.9)
Lymphoma	37 (21.1)
Wilm's tumor	18 (10.3)
Sarcomas	28 (16.0)
Other(includes neuroblastoma, retinoblastoma)	20 (11.4)
Age at diagnosis (years)	
0–5	57 (32.4)
6–11	57 (32.4)
12–14	39 (22.2)
15 and over	23 (13.1)
Reports after-effects	
Yes	86 (48.9)
Relapse	
At least one relapse	15 (8.5)
Other medical condition in last 10 years*	
Yes	28 (15.9)
Self-rated health	
Excellent	41 (23.3)
Very good	93 (52.8)
Fair/poor	41 (23.3)
Sociodemographic	
Income	
< $25 K	36 (20.4)
> $25 K	127 (72.2)
Living arrangement	
Live alone	18 (10.2)
Live with others (i.e., parents, relatives, roommate)	158 (89.3)
Gender	
Male	75 (42.6)
Female	101 (57.4)
	Mean (SD)
Age at study (years) Range: 16–28	21.8 (3.3)
Age at diagnosis (years) Range: 0–22	8.5 (5.1)
Years since diagnosis (years) Range: 3–27	13.3 (5.7)

Some percentages do not equal 100% due to missing data.
* Included in the list of other medical conditions reported by respondents are: infections, cardiac and respiratory problems, non-malignant tumors, diabetes, mental health problems, muscle/joint pain.

given that the theoretical model on which the QOL-CS is based suggests that quality of life is a function of physical, psychological, social and spiritual elements, we expected the overall scale score to discriminate across reports of physical after-effects, reports of other serious medical conditions, income, marital status and gender.

Results

Survivor sociodemographic and medical characteristics

Medical and sociodemographic descriptions of the sample are provided in Table 1. Mean age of respondents at time of study was 21.8 years and mean age at diagnosis was 8.5 years. Time since diagnosis ranged from 3 to 27 years with an average of 13.3 years.

Tests of internal reliability and validity

Internal scale consistency scores for the QOL-CS sub-scales and interscale correlations are reported in Table 2. Reliability measures for five of the six QOL-CS sub-scales and sub-components are high (with Cronbach's α scores ranging from 0.76 to 0.88), whereas the internal reliability of the distress sub-component is questionable (Cronbach's α = 0.54). Most of the interscale correlations are as theoretically expected. For example, psychological well-being is highly correlated with social well-being ($r = 0.61$) and substantially correlated with physical well-being ($r = 0.49$), whereas spiritual well-being is not significantly correlated with

physical well-being ($r = 0.08$) or distress ($r = 0.04$). Moderate to high correlations are observed between each of the sub-scales and the summated overall quality of life score.

Factor analysis

A factor analysis with Promax rotation 'forced' the extraction of six factors to determine whether the factor structure for this sample would approximate the four quality of life domains (physical, psychological, social, spiritual) and two sub-components (fear, distress) of the QOL-CS. The oblique Promax rotation was selected because of the high correlations among the majority of sub-scale scores (see Table 2) and because prior research suggests that quality of life domains are interdependent and significantly correlated [26, 34]. The resulting six factors were easily interpretable with regard to their theoretical relevance to the QOL-CS and accounted for 56.2% of the common variance (Table 3). Item-total correlations measuring internal scale consistency and Cronbach's coefficient α as a measure of agreement between items and factor scores are reported in Table 4. These reliability measures suggest a high degree of internal consistency for five of the six factors in this sample. Due to poor internal consistency, factor six, comprised of two distress items and one social item, was eliminated from further analyses.

External validity of the factor model

For all remaining analyses, raw item scores have been summed to produce five factor scores. For

Table 2. Internal scale consistency scores and interscale correlations for the QOL-CS

QOL-CS scores	Physical (eight items)	Psychological (nine items)	Distress (three items)	Fears (four items)	Social (eight items)	Spiritual (seven items)	Overall quality of life
Physical	**0.81**						
Psychological	0.49*	**0.82**					
Distress**	0.49*	0.51*	**0.54**				
Fears**	0.40*	0.22*	0.45*	**0.88**			
Social	0.48*	0.61*	0.38*	0.15*	**0.76**		
Spiritual	0.08	0.30*	0.04	−0.02	0.07	**0.78**	
Overall quality of life	0.74*	0.82*	0.66*	0.51*	0.69*	0.44*	**0.87**

Internal scale consistency scores (Cronbach's α) for multi-item scales are reported on the diagonal and in bold text. Interscale correlations are Pearson product–moment correlations; * p-value < 0.01; ** p-value < 0.05.

Table 3. Factor loadings from structure matrix

	QOL-CS sub-scale	Factors					
		1	2	3	4	5	6
Factor 1 (23.5% of variance)							
Overall physical health	Physical	**0.550**	0.239	0.278	0.429	0.211	0.100
Quality of life	Psychological	**0.738**	0.332	0.316	0.285	0.134	<0.01
Happiness	Psychological	**0.854**	0.288	0.167	0.223	0.325	<0.01
Feeling in control	Psychological	**0.811**	0.393	0.186	0.251	<0.01	0.126
Satisfying life	Psychological	**0.887**	0.358	0.203	0.206	0.206	<0.01
Concentration/remembering	Psychological	**0.602**	0.278	<0.01	0.312	<0.01	0.210
Feeling useful	Psychological	**0.809**	0.375	0.141	0.282	0.201	0.118
Depression	Psychological[a]	**0.628**	0.315	0.431	0.390	<0.01	0.383
Uncertainty about future	Spiritual	**0.630**	0.228	0.186	0.233	<0.01	0.484
Feeling hopeful	Spiritual	**0.697**	0.251	<0.01	0.164	0.559	<0.01
Factor 2 (11.6% of variance)							
Coping	Psychological	0.541	**0.561**	0.408	0.337	<0.01	0.271
Appearance changes	Psychological	0.244	**0.594**	<0.01	0.172	<0.01	0.131
Self-concept	Psychological	0.185	**0.493**	0.145	0.231	0.400	0.403
Sufficient social support	Social	0.393	**0.418**	<0.01	0.119	<0.01	0.351
Personal relationships	Social	0.272	**0.509**	0.217	0.272	<0.01	<0.01
Impact on sexuality	Social	0.292	**0.633**	<0.01	0.263	0.118	0.286
Employment	Social	0.314	**0.842**	<0.01	0.297	<0.01	<0.01
Home activities	Social	0.243	**0.791**	0.179	0.438	<0.01	0.163
Feel isolation	Social	0.494	**0.815**	0.268	0.369	<0.01	0.145
Financial burden	Social	0.210	**0.470**	<0.01	0.225	<0.01	0.273
Factor 3 (7.8% of variance)							
Future test fears	Psychological[b]	0.165	<0.01	**0.857**	0.335	0.162	0.385
Second cancer fear	Psychological[b]	0.177	<0.01	**0.855**	0.314	0.149	0.400
Recurrence fear	Psychological[b]	0.197	0.144	**0.856**	0.313	0.116	0.279
Metastasis fear	Psychological[b]	0.213	0.162	**0.756**	0.228	<0.01	0.107
Factor 4 (5.4% of variance)							
Fatigue	Physical	0.309	0.334	0.157	**0.740**	0.119	0.332
Appetite changes	Physical	0.233	0.274	0.320	**0.787**	0.123	0.168
Aches or pain	Physical	0.378	0.361	0.465	**0.735**	<0.01	0.189
Sleep changes	Physical	0.312	0.337	0.269	**0.727**	<0.01	<0.01
Constipation	Physical	0.167	0.262	0.161	**0.610**	<0.01	0.105
Nausea	Physical	0.150	0.258	0.253	**0.655**	<0.01	0.263
Menstrual/fertility changes	Physical	0.306	0.320	0.284	**0.514**	<0.01	0.480
Factor 5 (4.4% of variance)							
Changes in religious activities	Spiritual	0.180	<0.01	<0.01	<0.01	**0.785**	0.120
Changes in spiritual activities	Spiritual	<0.01	0.298	<0.01	0.127	**0.654**	<0.01
Changes in spirituality	Spiritual	0.128	<0.01	<0.01	<0.102	**0.814**	0.156
Positive life changes	Spiritual	0.276	<0.01	<0.01	<0.01	**0.707**	0.204
Sense of purpose	Spiritual	0.379	<0.01	0.132	<0.01	**0.716**	0.171
Factor 6 (3.5% of variance)							
Distress since time oftreatment	Psychological[a]	0.197	0.254	0.405	0.230	0.231	**0.551**
Anxiety	Psychological[a]	0.383	0.286	0.418	0.227	0.116	**0.554**
Family distress	Social	<0.01	0.199	0.227	0.175	<0.01	**0.642**

[a] Item from the distress sub-component of the psychological sub-scale.
[b] Item from the fears sub-component of the psychological sub-scale.

presentation purposes, these five newly derived factors are labeled as gross representations of the various QOL domains ('psychological', 'psycho-social', 'physical', 'spiritual') and one of the two

Table 4. Inter item correlations and Cronbach's α coefficients

	QOL-CS sub-scale	Interitem correlations
Factor 1 (α = 0.89)		
Overall physical health	Physical	0.499
Quality of life	Psychological	0.667
Happiness	Psychological	0.782
Feeling in control	Psychological	0.734
Satisfying life	Psychological	0.827
Concentration/remembering	Psychological	0.531
Feeling useful	Psychological	0.752
Depression	Psychological[a]	0.535
Uncertainty about future	Spiritual	0.536
Feeling hopeful	Spiritual	0.623
Factor 2 (α = 0.81)		
Coping	Psychological	0.510
Appearance changes	Psychological	0.467
Self-concept	Psychological	0.452
Sufficient social support	Social	0.279
Personal relationships	Social	0.441
Impact on sexuality	Social	0.532
Employment	Social	0.700
Home activities	Social	0.675
Feel isolation	Social	0.681
Financial burden	Social	0.373
Factor 3 (α = 0.88)		
Future test fears	Psychological[b]	0.781
Second cancer fear	Psychological[b]	0.788
Recurrence fear	Psychological[b]	0.807
Metastasis fear	Psychological[b]	0.602
Factor 4 (α = 0.81)		
Fatigue	Physical	0.622
Appetite changes	Physical	0.667
Aches or pain	Physical	0.603
Sleep changes	Physical	0.597
Constipation	Physical	0.453
Nausea	Physical	0.506
Menstrual/fertility changes	Physical	0.429
Factor 5 (α = 0.80)		
Changes in religious activities	Spiritual	0.647
Changes in spiritual activities	Spiritual	0.500
Changes in spirituality	Spiritual	0.694
Positive life changes	Spiritual	0.542
Sense of purpose	Spiritual	0.568
Factor 6 (α = 0.55)		
Distress since time of treatment	Psychological[a]	0.411
Anxiety	Psychological[a]	0.380
Family distress	Social	0.285

[a] Item from the distress sub-component of the psychological sub-scale.
[b] Item from the fears sub-component of the psychological sub-scale.

sub-components ('fears'). In an assessment of concurrent validity (Table 5), statistically significant and moderate ($0.30 < r < 0.45$) to high ($r > 0.60$) correlations are observed for the 'psychological', 'psychosocial' and 'physical' summative scores and the three worry measures. 'Fears'

Table 5. Concurrent validity of the six factor model of the QOL-CS with independent criterion variables scored continuously (worries), as assessed by Spearman's rank correlations

	Factor 1 'Psychological'	Factor 2 'Psychosocial'	Factor 3 'Fears'	Factor 4 'Physical'	Factor 5 'Spiritual'	Overall quality of life
Cancer-specific worry	−0.36*	−0.40*	−0.77*	−0.55*	0.17***	−0.60*
Psychosocial worry	−0.50*	−0.48*	−0.17***	−0.47*	0.05	−0.55*
General health worry	−0.31*	−0.40*	−0.35*	−0.62*	0.12	−0.56*

Raw item scores have been summed to produce the five factor scores and overall quality of life score. Higher correlations reflect stronger associations and better discrimination. * p-value < 0.001; ** p-value < 0.01; *** p-value < 0.05.

correlates highly ($r > 0.60$) with cancer-specific worry and moderately with general health worry, but maintains a low correlation ($r < 0.30$) with worry about psychosocial issues. The 'spiritual' factor maintains a negligible correlation ($r < 0.30$) with all three worry scales.

Results of the evaluation of discriminative validity for the five factor model are displayed in Table 6. The 'psychological', 'psychosocial' and 'physical' factors reflected anticipated differences as a function of both of the medically related independent variables (reporting a serious medical condition in the past 10 years and reporting after-effects of cancer treatment). In addition, the 'psychosocial' factor, as anticipated, varied significantly on the basis of income and marital status, and the 'psychological' factor varied on the basis of marital status but not income. Significant differences in the 'fear' factor scores were observed across groups reporting a serious medical condition in the last 10 years and across gender. Also, as

anticipated, physical and spiritual scores differed significantly by gender. With regard to the global quality of life score, overall quality of life appeared sensitive to differences in medical status but not to differences in sociodemographic status.

Discussion

The major purpose of this study was to test the validity and utility of the QOL-CS in a population of childhood cancer survivors. Six factors representing the four domains and two sub-components of the QOL-CS were derived as a result of a PCA; however, the classification of many items did not appear consistent with the organization of items and sub-scales in the original 41-item instrument. Three factors representing psychological and psychosocial issues and fears accounted for the dominant share of variance explained, whereas physical symptoms, indicators of distress, and

Table 6. Detecting anticipated differences and similarities in factor scores for select medical and psychosocial parameters

Independent variables	Factor 1 'Psychological'	Factor 2 'Psychosocial'	Factor 3 'Fears'	Factor 4 'Physical'	Factor 5 'Spiritual'	Overall quality of life
p-Values for differences in QOL-CS factor scores between groups defined by						
Reported serious medical condition in past 10 years	0.023	0.002	0.009	0.008	NS	0.001
Reported after-effects of cancer	0.080	0.000	NS	0.002	NS	0.006
Income	NS	0.030	NS	NS	0.037	NS
Marital status	0.006	0.016	NS	NS	NS	NS
Gender	NS	NS	0.000	0.001	0.000	NS

Raw item scores have been summed to produce the five factor scores and overall quality of life score. Differences in QOL-CS factor scores in subgroups dichotomized by independent criteria. Students' t-test used as test of statistical significance for comparing mean differences across dichotomous subgroups. Where differences in factor scores across response categories are noted, the lower the p-value the better the discrimination. Due to relatively small categories in dichotomous variables, equal variances were not assumed; NS – not significant.

items regarding spiritual and religious issues contributed marginally to the overall variance explained.

The construct validity of the instrument was supported by the degree to which interscale correlations corresponded with expectations informed by Wyatt and Friedman's long-term quality of life model [26], although Wyatt and Friedman's work is related to breast cancer survivors (all female) and may not be relevant to a childhood cancer survivor population. Their work is cited, however, because of the likelihood that quality of life domains are interrelated. For example, poor physical status has the potential to limit survivors' employment potentials or opportunities for social involvement, and limited social opportunities may result in low self-esteem or depression. Conversely, a lack of negative physical sequelae after cancer may be associated with a personal sense of having beaten cancer and subsequent feelings of pride for being a cancer survivor. Empirical evidence to support these observations, as well as their meanings and implications, have yet to be reported in the childhood cancer survivorship literature.

Factor analysis alone is not sufficient to establish the validity of the factors identified here. In this study, approaches assessing the external validity of the instrument have been applied to make a preliminary assessment of the validity of the new six factor structure described by the factor analysis. The results proffer some support for the reliability and validity of at least three of the six factors derived from the factor analysis. The 'psychological', 'physical' and 'psychosocial' factors were best at discriminating for subgroups defined by physical health status elements (reporting a serious medical condition within the past 10 years, reporting after effects of cancer) and social status (income and marital status) variables. These findings are consistent with other psychosocial studies in which medical and social variables demonstrated a significant relationship with quality of life outcomes [28–33]; yet the ability of the psychological factor to account for differences across any of the discriminant validity variables was not convincingly strong, thereby indicating that the psychological well-being of childhood cancer survivors may be a function of some other set of non-medical or non-physical factors. In contrast, the 'psychosocial' factor, which captured

developmentally appropriate issues such as self-concept, physical appearance, sexuality, work and social relationships, appeared to be sensitive to expected criteria (marital status, physical sequelae). There also was support for the convergent validity of the 'fears' sub-component in that uncertainty about the future – the proverbial Sword of Damocles [35] – continues to elicit fears regarding cancer and health.

It is also possible that the items comprising the physical domain of the QOL-CS are not representative of the particular physical issues experienced by childhood cancer survivors, or by an adolescent and young adult population generally. The potentiality of greater vitality in this age group, the greater probability of a physical 'cure' for childhood cancer survivors, and the likelihood that they have not yet attained certain developmental milestones (e.g., childbearing) may affect their responses very differently from adults.

Religious and spiritual elements of quality of life appear least relevant to this group of childhood cancer survivors. Items from the spiritual sub-scale of the QOL-CS having to do with the future (uncertainty about the future; feeling hopeful about the future) do appear relevant, as suggested by these single items correlating with the psychological factor. Items tapping aspects of religious behavior or observance appear less relevant. A dearth of research on spiritual aspects of quality of life precludes the ability to make substantive conclusions as to what elements 'spiritual quality of life' should or should not relate to. The results here intimate that gender and socioeconomic status may have some relevance to this quality of life domain. Identifying correlates of spiritual well-being, as well as components of this quality of life dimension that have relevance to young adults diagnosed with cancer as children, remains a fertile area for research. Other work suggests that changes in life outlook and reports of purported benefits associated with having overcome cancer may be of greater relevance than religion and spirituality to this young adult population [18, 36, 37].

There are several limitations to the power and generalizability of these findings. First, although this study sample represents a relatively large single-institution investigation of childhood cancer survivors, the results of an exploratory factor

analysis of a 41-item questionnaire on a sample of less than 200 people must be evaluated cautiously. Second, the worry measures used here are not universally accepted 'gold standard' measures of quality of life. While useful, they are not standardized measures of psychosocial adjustment and thus do not permit a comparison of results to population norms. Other more standardized instruments might demonstrate different, more powerful, or more detailed results and enable a more rigorous test of these tentative interpretations of the QOL-CS. Yet, there currently is no consensual 'gold standard' measure of quality of life in childhood cancer survivors and these results may be useful in future design and development of a more appropriate instrument. Given that worries signify a broad range of subjectively defined issues that arouse concern, anxiety, doubt or fear [15], the construct validity of five of the factors derived here is supported to the extent that each of the factors correlates significantly with at least one measure of worry.

These findings also may be limited by problems of sample design and response bias. Although we have been able to examine the role of physical and medical factors in response bias, we have no way to assess the influence of psychological characteristics in study participation. Perhaps childhood cancer survivors with dramatically more negative (or even positive) quality of life on particular (or all) dimensions elected not to participate. Moreover, like most other studies of cancer patients and survivors, this study failed to reach traditionally under-represented non-white populations: the current sample of childhood cancer survivors is 94% Caucasians, and even the population pool from which the respondent sample was drawn was 90% Caucasian. These characteristics limit the applicability of the findings from the QOL-CS beyond the groups evaluated herein. This study's cross-sectional design also prevented an evaluation of the QOL-CS's responsiveness to change, a key component of determining an instrument's validity. Longitudinal administration of the QOL-CS with survivors of childhood cancer, and analyses of repeated measures at end of diagnosis and determined periods of long-term survival, would be helpful. Finally, this discussion, as all examinations and discussions of highly pre-structured psychometric instruments, fails to tell us how

survivors conceive of the quality of their lives in their own terms or how they distinguish between functional problems and subjective feelings of distress. Open-ended survey questions and intensive face-to-face interviews or extensive narratives of survivors' views of the quality of life would address issues and problems not discernible via instruments like the QOL-CS.

Given all the variation in findings across quality of life studies of cancer survivors, more data about quality of life are needed to provide a more comprehensive picture of the status and needs of childhood cancer survivors. Major methodological issues involve the selection of adequate and appropriate measures for assessing multiple dimensions of quality of life and the need to assess both positive as well as negative outcomes associated with the cancer experience. The development of new instruments or the refinement of existing instruments like the QOL-CS will enhance our ability to better understand the quality of life of childhood cancer survivors and help us to identify the factors that contribute to it.

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