



Published in final edited form as:

Support Care Cancer. 2012 September ; 20(9): 2061–2071. doi:10.1007/s00520-011-1315-5.

Head-to-head comparisons of quality of life instruments for young adult survivors of childhood cancer

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Abstract

Purpose—Few studies examine the relevance of health-related quality of life (HRQOL) instruments for young adult survivors of childhood cancer (YASCC). This study compared psychometric properties of two survivor-specific instruments, the Quality of Life–Cancer Survivor (QOL-CS) and Quality of Life in Adult Cancer Survivor (QLACS).

Methods—Data from 151 YASCC who enrolled in Cancer/Tumor Registries of two medical centers were used. We examined construct validity by conducting confirmatory factor analysis using indices of chi-square statistic, comparative fit index (CFI), and root mean square error of approximation (RMSEA). We examined convergent/discriminant validity by comparing Pearson's correlation coefficients of homogeneous (e.g., physical functioning and pain) of both instruments vs. heterogeneous domains (e.g., physical and psychological functioning). We assessed known-groups validity by examining the extent to which HRQOL differed by late effects and comorbid conditions and calculated relative validity (RV) defined as contrasting F-statistics of individual domains to the domain with the lowest F-statistic. Superior known-groups validity is observed if a domain of one instrument demonstrates a higher RV than other domains of the instruments.

Results—YASCC data cannot replicate the constructs both instruments intend to measure, suggesting poor construct validity. Correlations of between-homogeneous and between-heterogeneous domains of both instruments were not discernible, suggesting poor convergent/discriminant validity. Both instruments were equally able to differentiate HRQOL between YASCC with and without late effects and comorbid conditions, suggesting similar known-groups validity.

Conclusions—Neither instrument is superior. Item response theory is suggested to select high quality items from different instruments to improve HRQOL measure for YASCC.

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Conflict of interests:

No conflict of interests to principal author and all co-authors.

Keywords

Childhood cancer; young adult survivor; quality of life; measurement; psychometrics

INTRODUCTION

Over the past three decades, the number of young adult survivors of childhood cancer (YASCC) has increased significantly [1]. The increased survival rates of childhood cancer are often accompanied by late effects resulting from cancer itself and/or cancer treatment. Late effects are a major clinical concern of cancer survivors, which may appear several years after cancer diagnosis and treatment [2]. For YASCC, common late effects include neurocognitive, psychological, cardiopulmonary, endocrine, and musculoskeletal disorders, as well as recurrence or secondary cancers [3]. Late effects are associated with impaired health-related quality of life (HRQOL) [4–7]. However, less attention has been paid to the measurement issues in HRQOL for long-term cancer survivors, especially YASCC populations.

Conventionally, researchers use the “off-the-shelf” generic instruments to assess HRQOL of YASCC. These instruments include the Medical Outcomes Study Short Form-36 (SF-36), the Symptom Checklist-90 Revised, and Health Utility Index, etc. When comparing YASCC to healthy controls, the use of these instruments tends to generate mixed findings (i.e., better [8,9], impaired [10–12] or equivalent [13–15] HRQOL). Although the findings can be confounded by YASCC’s cancer type, treatment modality, age of diagnosis, and length of survival, we cannot rule out that these generic instruments are not sensitive enough to detect the difference between YASCC and healthy controls.

Very few survivor-specific HRQOL instruments are designed for YASCC populations. The Quality of Life–Cancer Survivors (QOL-CS) [16] and the Quality of Life in Adult Cancer Survivors (QLACS) [17] are two notable survivor-specific HRQOL instruments. Although these instruments demonstrate good measurement properties, they were developed and validated using survivors of adult-onset cancer rather than strictly YASCC populations. Therefore, we cannot assume that these instruments will appropriately capture YASCC’s perception about their daily functioning and well-being unless rigorous psychometric assessments are performed. The only exceptional instrument for YASCC is the Impact of Cancer for Childhood Cancer Survivors (IOC-CS) [18]. The IOC-CS was developed to measure unique psychosocial issues experienced by YASCC such as life challenge, talking with parents, personal growth, financial problems, etc. Evidence suggests that content of the IOC-CS is partially covered by the QLACS [19] and it should be used as a supplement to generic HRQOL measures [18].

The essential reasons of rigorously validating HRQOL instruments for YASCC populations are twofold. First, the types of cancer and associated treatments on childhood and adult-onset survivors are different. Cancers that develop in adult populations, such as breast cancer, behave and respond to treatment differently than cancers that develop in children, such as embryonal tumors. Therefore, the damage to the body and impact on daily functioning are likely to be different. Second, childhood cancer populations are usually confronted with developmental and growth issues which are not encountered by adult populations. These unique issues include career development, autonomy, identity, intimacy, psychosocial adjustment, fertility, and sexuality [20]. Children who are diagnosed by and treated for cancer may encounter a delay in achieving these developmental and growth milestones, which can further impair HRQOL as a young adult [21–23].

The purpose of this study was to conduct a head-to-head comparison between the QLACS and QOL-CS using data of YASCC who were enrolled in the Cancer Data Center (known as the Tumor Registry) of the University of Florida (UF) or Cancer Registry of the H. Lee Moffitt Cancer Center and Research Institute (Moffitt), or those who visited UF's Cancer Survivor Program (CSP). Specifically, we performed the following psychometric analyses to compare both instruments, including scale reliability, construct validity, convergent/discriminant validity, and known-groups validity.

MATERIALS AND METHODS

Study population

The study population is comprised of male and female YASCC. The eligibility criteria for study enrollment include participants who were between 21 and 30 years old, diagnosed with cancer prior to 18 years old, and off active treatment therapy for at least two years. All cancer diagnoses were included, except skin cancers, carcinoma in situ, and precancerous conditions. Eligible subjects were identified through the Cancer/Tumor Registries of UF and Moffitt. In addition, YASCC who visited UF's CSP and had an interest in study participation were recruited.

Data collection

After eligible subjects were identified, a primer letter was sent to 679 YASCC (570 from UF and 109 from Moffitt), followed by a telephone contact for informed consent and telephone interview. The interviews were conducted between 06/2009 and 09/2009 (UF sample) and between 03/2010 and 05/2010 (Moffitt sample). We did not have valid contact information for 337 individuals. Twenty seven were reached but did not meet the eligibility criteria, 48 declined to participate, and 151 completed telephone survey. The remaining 116 individuals had a working telephone number, but were unable to reach. The 151 participants, 22.2% of the original sample, are comprised of 141 who were recruited from UF (129 through Registry and 12 through CSP) and 10 were from Moffitt (all through Registry). Institutional Review Boards of UF and Moffitt approved this study.

Measurement

HRQOL was measured by the Quality of Life–Cancer Survivors (QOL-CS) [16], the Quality of Life in Adult Cancer Survivors (QLACS) [17], and the Medical Outcomes Study Short Form-36 (SF-36) [24]. Both QOL-CS and QLACS are cancer survivor-specific instruments and served the primary instruments for psychometric tests. The SF-36 was used as an anchor for validating the two primary instruments.

The QOL-CS was developed to measure impact of survivors receiving bone marrow transplantation on daily functioning and well-being [25], followed by a modification appropriate for long-term survivors of all types of cancer [16]. This instrument includes 41 items measuring four *cancer survivor-specific* domains: physical (8 items), psychological (18 items), social (8 items), and spiritual (7 items) well-being. Domain scores were calculated by averaging the scores of corresponding items, and translated linearly to a scale of 0–100. Overall domain scores were also calculated, with a range of 0–100. Higher scores indicate better HRQOL.

The QLACS was developed to measure HRQOL of long-term survivors (> 5 years post-diagnosis) of adult-onset cancer [17]. This instrument includes 47 items measuring seven *generic* domains (34 items): negative feelings, positive feelings, cognitive problems, pain, sexual functioning, social avoidance, and fatigue, as well as four *cancer survivor-specific* domains (14 items): financial problems, distress-family, distress-recurrence, and appearance

problems. The item score was calculated based on a rating scale of 1–7 points, and the domain scores were calculated by averaging the scores of the corresponding items and translated linearly to a scale of 0–100. Overall-generic and overall-specific domain scores were also calculated, respectively, with a range of 0–100. Higher scores indicate better HRQOL.

The SF-36 includes 36 items measuring eight *generic* domains of HRQOL: physical functioning, role limitations due to physical health problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health. Domain scores range from 0 to 100, with higher scores representing better HRQOL. Two summary scores were also calculated: a physical component score (PCS) and a mental component score (MCS), with scores standardized to a normal distribution of a mean 50 and a standard deviation 10.

For testing known-groups validity, we collected information on self-reported late effects (1 item) and comorbid conditions (1 item). We defined late effects as any medical conditions that are directly related to cancer or previous cancer treatment, which was measured based on the following item: “Do you currently have any serious medical conditions related to your cancer or previous cancer treatments; for example, secondary cancers, recurrence of cancer, or complications such as hearing loss from platinum chemotherapy or radiation to the ear, etc.?” We defined comorbid conditions as any medical conditions that are not directly related to cancer or previous cancer treatment, which was measured based on the following item: “Do you currently have any medical conditions that are unrelated to cancer such as asthma, etc.?”

Psychometric methods

We conducted descriptive analyses, followed by psychometric analyses for head-to-head comparisons between the QOL-CS and QLACS. Descriptive analyses include estimations of mean, median, and standard deviation of the item and domain scores. We performed four different psychometric analyses: scale reliability, construct validity, convergent/discriminant validity, and known-groups validity [26].

Cronbach’s alpha coefficients were calculated to assess reliability (known as internal consistency). Alpha coefficients ≥ 0.7 are considered as acceptable for the purpose of group comparisons [26].

Confirmatory factor analyses were performed to examine the degree to which factorial structures of the QOL-CS and QLACS can be well replicated in YASCC populations. We used a conjectures and refutations approach to test the factorial structure, meaning that if any group of YASCC failed to pass the test (no matter if they were survivors of a single diagnosis or different types of diagnoses), then the HRQOL instruments could not be applied to YASCC. Three indicators were used to determine goodness of model fit to the data: the chi-square statistic, comparative fit index (CFI), and root mean square error of approximation (RMSEA). Cutoff values of chi-square statistic >0.05 , CFI >0.95 and RMSEA <0.06 were used to indicate a satisfactory goodness of fit [27]. We hypothesized the QOL-CS and QLACS will not replicate the construct of HRQOL that the instruments intend to measure because they were developed for adult-onset cancer survivors rather than YASCC.

A multi-trait/multi-method approach [26] was applied to assess convergent/discriminant validity of the QOL-CS and QLACS by using the SF-36 as an anchor. Convergent validity tests whether the homogeneous domains (e.g., physical functioning) of the two survivor-specific instruments and the SF-36 are moderately or strongly correlated (Pearson’s

correlation coefficient between 0.3 and 0.5, or above). In contrast, discriminant validity examines whether the heterogeneous domains (e.g., physical and psychological functioning) are weakly correlated (Pearson's correlation coefficient <0.3). We hypothesized that both instruments will demonstrate poor convergent/discriminant validity by a lack of discernible magnitudes in the correlation between homogeneous and heterogeneous domains of the QOL-CS, QLACS, and SF-36. This is because the same name of domains between the instruments does not necessarily imply measuring the same concept.

Known-groups validity is defined as the extent to which the instruments can discriminate between various groups of health conditions, such as late effects and comorbid conditions [26]. We compared the mean difference in HRQOL scores and associated effect size (ES) between YASCC with versus without late effects and between YASCC with versus without comorbid conditions. We hypothesized that HRQOL of YASCC with late effects (or comorbid conditions) is more impaired compared to YASCC without late effects (or without comorbid conditions). The level of statistical significance for mean differences in HRQOL scores between two groups was set a priori as an alpha level of 0.05. ES <0.2, 0.2–0.49, 0.5–0.79, and >0.8 was used to indicate negligible, small, moderate, and large difference, respectively [28]. In addition, we calculated relative validity (RV), defined as contrasting the F-statistics of individual domains to the domain with the lowest F-statistic [29]. A domain of one instrument demonstrating a higher relative validity will represent a superior known-groups validity compared to other domains of the instruments.

RESULTS

Characteristics of subjects

Table 1 shows the characteristics of study participants (N=151). The mean age was 26.1 years old (SD: 2.9) and 54% were male. Race/ethnicity was 85% White, 10% Black, and 5% other. The majority of the participants were single (60%). About 24% and 19% of the participants reported late effects and comorbid conditions, respectively.

Distribution of domain scores and scale reliability

Table 2 shows the distribution of domain scores and scale reliability. The distributions of the domain scores were skewed to the left. Compared to the QOL-CS, ceiling effects were more significant in the QLACS, especially the domains of social avoidance (34%), sexual functioning (52%), distress-family (30%), appearance problems (31%), and financial problems (43%). For generic HRQOL measured by the SF-36, the physical and mental health status of the YASCC was similar to the general population, with PCS 50.8 and MCS 49.8 compared to the population mean 50.

Scale reliability was acceptable (alpha coefficient = 0.7) in all domains of the two survivor-specific instruments, except spiritual well-being of the QOL-CS.

Construct validity

Table 3 shows the construct validity of the QOL-CS and QLACS tested using confirmatory factor analyses. All domains of the QOL-CS and QLACS demonstrate poor construct validity as evidenced by significant chi-square statistics ($p < 0.01$), except the cognitive problems of the QLACS. Also, all domains of the QOL-CS and QLACS demonstrate poor construct validity based on the criterion of CFI <0.95 and RMSEA >0.06, except fatigue, distress-family, and appearance problems of the QLACS. This implies the use of YASCC data did not replicate the same HRQOL construct that the QOL-CS and QLACS intend to measure.

Convergent/discriminant validity

Table 4 shows the convergent/discriminant validity of the QOL-CS and QLACS tested using a multi-trait/multi-method approach. Overall, correlation coefficients between homogeneous domains of the QOL-CS and QLACS and between heterogeneous domains of both instruments were not discernible. For example, correlation coefficient between physical well-being of the QOL-CS and pain of the QLACS was only slightly larger than coefficient between physical well-being of the QOL-CS and negative feeling of the QLACS (0.66 vs. 0.63). Correlation coefficient between social well-being of the QOL-CS and social avoidance of the QLACS was unexpectedly smaller than coefficient between social well-being of the QOL-CS and pain of the QLACS (0.50 vs. 0.66). This implies that homogeneous domains of the two survivor-specific instruments may measure different concepts of HRQOL.

Homogeneous domains of the QLACS generic components and the SF-36 (as an anchor) were greatly correlated compared to heterogeneous domains of both instruments. For example, correlated to the SF-36 PCS, coefficient with pain of the QLACS was 0.72, which was larger than coefficients with other domains of the QLACS (0.16–0.54). Similarly, correlated to the SF-36 MCS, coefficients with negative and positive feelings of the QLACS were 0.68 and 0.56, which were larger than coefficients with other domains of the QLACS (with the exception of social avoidance) (0.33–0.51). In contrast to the QLACS generic domains, coefficients between the QLACS survivor-specific domains and the SF-36 were generally weaker.

However, convergent/discriminant validity of the QOL-CS was not satisfied when the SF-36 was used as an anchor. For example, correlated to the SF-36 PCS, coefficient with physical well-being of the QOL-CS was slightly larger (0.56) than coefficient with psychological well-being (0.50), but unexpectedly smaller than with social well-being (0.66).

Known-groups validity

Table 5 shows known-groups validity of the QOL-CS and QLACS. There was a greater discrimination by almost all domains of the QLACS, QOL-CS, and SF-36 associated with self-reported late effects and comorbid conditions. YASCC who had late effects and/or comorbid conditions reported significantly impaired HRQOL compared to YASCC without late effects and/or comorbid conditions. Relative validity (RV) associated with late effect was comparable in the QOL-CS and QLACS (range: 1.0–93.9 on the QOL-CS and 3.1–97.3 on the QLACS). However, RV associated with comorbid conditions in the QOL-CS was slightly superior to the QLACS (range: 3–1771 and 1–1238, respectively). Compared to any domains in survivor-specific instruments, pain of the SF-36 demonstrated the greatest RV associated with late effects and general health of the SF-36 demonstrated the greatest RV associated with comorbid conditions. However, for overall domains, the performance among the QOL-CS, the QLACS, and the SF-36 was comparable. For late effects, RV was 79.6 for the QOL-CS, 79.4 for generic domain of the QLACS, and 82.3 and 48.3 for PCS and MCS of the SF-36, respectively. For chronic conditions, RV was 1570 for the QOL-CS, 1049 for generic domain of the QLACS, and 1085 and 629 for PCS and MCS of the SF-36, respectively.

DISCUSSION

Selecting appropriate HRQOL instruments for YASCC is an important, but challenging endeavor. It involves not only selecting “off-the-shelf” instruments, but also comprehensively assessing measurement properties of these instruments. Limited studies were available to explicitly assess HRQOL instruments for YASCC. This study primarily

investigates measurement properties of two survivor-specific instruments, the QOL-CS and QLACS, based on data collected from 151 YASCC in Florida. We used standard psychometric approaches to assess scale reliability, construct validity, convergent/discriminant validity, and known-groups validity.

The findings suggest that, first, the QOL-CS and QLACS, which were developed based on adult-onset cancer survivors, may not be applied to YASCC populations because measurement constructs of the two instruments were not replicated in YASCC (i.e., poor construct validity). Second, the QOL-CS and QLACS may measure different aspects of survivor-specific (other than generic) HRQOL because correlation coefficients between homogeneous and heterogeneous domains of both instruments were not discernible (i.e., poor convergent/discriminant validity). In addition, correlation coefficients between homogeneous and heterogeneous domains of the QOL-CS and SF-36 (as an anchor) were not discernible as well. Finally, the two survivor-specific instruments were equally able to differentiate HRQOL between YASCC with and without self-reported late effects and comorbid conditions (i.e., similar known-groups validity). However, for overall domains, the performance among the QOL-CS, the QLACS, and the SF-36 was comparable.

Satisfactory construct validity is a prerequisite for meaningful assessment of other types of measurement properties. We argue that, on the one hand, poor construct validity of the QOL-CS and QLACS may be due to the fact that some items in the QOL-CS and QLACS were perceived in different ways by YASCC compared to adult-onset cancer survivors. For example, the item “menstrual change or fertility” of the QOL-CS, which was well interpreted by adult-onset cancer survivors as part of physical well-being, may be interpreted by YASCC as psychological and physical well-being. Abundant evidence indicates that YASCC experienced worry and uncertainty about their infertility, yet they received limited information from physicians at the time of diagnosis and treatment [30,31].

On the other hand, poor construct validity may imply that some domains which are important or unique to YASCC are not emphasized in the QOL-CS and QLACS. Resilience is one of the important components of HRQOL. Previous studies suggest that YASCC no longer perceived themselves as victims and were eager to achieve normalcy [32,33]. They expressed optimism [34], hope for the future [35], and happiness [33] as well as increased self-confidence [36], maturity [34,37] and ability to manage problems [33]. Although the QOL-CS includes a domain of spiritual well-being, spirituality is close to the concept of religious beliefs which is not in turn equivalent to resilience. Positive feelings of the QLACS are a resilient-like concept; however, it was designed and considered as a generic rather than a survivor-specific domain. We suggests that future studies should use qualitative approaches to determine whether specific items are meaningful for YASCC and to assess whether the instruments account for growth, developmental, and resilient issues of young adults.

It is not surprising to discover a poor convergent/discriminant validity between the QOL-CS and QLACS. This finding makes intuitive sense in that both instruments were developed based on different conceptual frameworks of HRQOL. The QOL-CS is comprised of three basic components of health (physical, psychological and social) plus a survivor-specific component (spiritual). In contrast, the QLACS breaks down the basic concept of health into several trivial components (pain, fatigue, negative feelings, positive feelings, social avoidance, etc) plus several survivor-specific components (distress-family, and distress-recurrence, etc). On a head-to-head mapping, for example, the fatigue and pain are two single items embedded in physical well-being of the QOL-CS, instead of individual domains. Also, a single domain (psychological well-being) is used by the QOL-CS to cover a very broad aspect of mental burden on cancer survivors, whereas very specific domains

(positive feelings, negative feelings, distress-family, and distress-recurrence) were included in the QOL-CS to measure psychological functioning. This echoes previous studies suggesting that instruments with the similarly named domains do not necessarily measure the same construct [38].

Given the fact that neither instrument is superior to the other, it is useful to generate a HRQOL measure for YASCC by collecting high quality items from different instruments. Item response theory (IRT) for instrument development provides a better resolution [39,40]. IRT is a type of item-level analysis that investigates the relationship between subjects' responses to items and their levels of underlying HRQOL. IRT is especially useful in identifying whether items of the same domain (e.g., physiological functioning) from different instruments are duplex or measure the same level of underlying HRQOL (i.e., similar item difficulty). Moreover, compared to the use of a single instrument, IRT can help link and calibrate items across instruments on the same metric, which is helpful in generating an item bank that contains items with a wide range of item properties, and allows researcher to tailor an instrument that matches the underlying HRQOL of individual subjects. New items can be added to improve measurement precision of the banks [41,42]. Currently, application of IRT to measure HRQOL of YASCC is still limited.

Several study limitations merit attention. First, we recruited YASCC primarily using the Cancer/Tumor Registries of two academic medical centers and the majority of the participants were White. Thus, the findings may not be generalizable to other settings, such as the community setting, which is comprised of diverse populations. Second, valid contact information was available for 50% of YASCC in Cancer/Tumor Registries, and the response rate was not satisfied. There may be inherent differences between YASCC responders and non-responders. The difficulty in obtaining accurate contact information for potential subjects reflects a unique characteristic of YASCC populations who are independent from their parents and migrate to different places. Third, this study relied on two single self-reported items to collect the information of overall late effects and comorbid conditions, and used this information to analyze the known-groups validity of the two HRQOL instruments. The responses were not confirmed by a clinician or the medical record. Evidence suggests that the use of a single item is not ideal, but still a common approach in HRQOL instrument assessment. This approach also demonstrated acceptable measurement properties [43]. In addition, we did not collect diagnostic information, and intensity and type of treatment, which are known to be associated with severity of late effects and HRQOL [44]. The purpose of this study was not to compare HRQOL scores of our subjects to other populations. Given the fact that diagnosis and treatment modalities (compared to late effects) are distal causes of impaired HRQOL [23], the lack of collecting diagnosis and treatment information did not affect internal validity of the instrument comparison. By contrast, the generalizability (i.e., external validity) of our findings to other populations with different cancer types will be limited.

In conclusion, there is a great need to suggest appropriate HRQOL instruments for YASCC. However, neither the QLACS nor QOL-CS, which were originally developed based on survivors of adult-onset cancer, can be used alone in YASCC populations. In addition, neither instrument is superior to each other and may measure different concepts of HRQOL. We suggest using item response theory to select high quality items from different instruments to improve HRQOL measures for YASCC.

Acknowledgments

Funding sources: This work was supported in part by the University of Florida and Moffitt Cancer Centers Collaborative Initiative (IH, GQ, KE, DM, ES, and PS) and the National Institute of Health K23 HD057146 (IH).

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Table 1

Characteristics of subjects (N=151)

	Mean (SD) or N (%)
Age in year	26.1 (2.9)
Gender	
Male	81 (53.6)
Female	70 (46.4)
Race	
White	128 (84.8)
Black	15 (9.9)
Mixed	8 (5.3)
Education	
High school or below	45 (29.8)
Some college	31 (20.5)
Associate degree	29 (19.2)
Bachelor degree	35 (23.2)
Graduate/professional degree	11 (7.3)
Employment	
Employed	106 (71.1)
Marital status	
Single	91 (60.3)
Married	52 (34.4)
Common law/divorced/separated	8 (5.3)
Self-reported late effect	
Yes	36 (23.8)
Self-reported comorbid condition	
Yes	28 (18.5)
Self-reported general health status	
Poor	5 (3.3)
Fair	21 (13.9)
Good	44 (29.1)
Very good	48 (31.8)
Excellent	33 (21.9)

Table 2

Domain score distribution and reliability of the QOL-CS and QLACS

	Mean	Median	Range (Min, Max)	SD	Floor/ceiling effects, %	Cronbach's alpha
QOL-CS						
Physical	76.2	81.3	18.8, 100	18.8	0/3.3	0.81
Psychological	70.8	74.1	17.6, 98.2	17.3	0/0	0.90
Social	83.6	91.7	8.3, 100	19.4	0/34.4	0.73
Spiritual	63.0	64.3	4.3, 100	17.5	0/1.3	0.60
Overall	72.3	74.7	26.0, 96.0	13.2	0/0	-
QLACS						
Pain	80.0	87.5	0, 100	22.9	0.7/25.8	0.90
Negative feeling	74.2	83.3	16.7, 100	20.3	0/6.6	0.79
Positive feeling	80.4	83.3	29.2, 100	17.7	0/18.5	0.75
Cognitive	78.4	83.3	20.8, 100	19.9	0/17.9	0.74
Fatigue	75.8	83.3	4.2, 100	21.9	0/17.9	0.86
Social	79.2	85.4	22.9, 100	18.3	0/34.4	0.84
Sexual	90.4	100.0	25, 100	14.0	0/51.7	0.70
Overall-generic	80.4	83.9	33.3, 100	14.3	0/1.3	-
Distress-family	73.5	83.4	0.3, 100	29.5	0/29.8	0.89
Distress-recurrence	74.9	87.5	0, 100	25.9	0/16.6	0.86
Appearance	79.2	87.5	8.3, 100	23.0	0/31.1	0.76
Financial	80.2	93.8	0, 100	27.0	1.3/43.3	0.84
Benefit	67.3	75.0	0, 100	28.9	4.6/17.2	0.86
Overall-specific	77.0	83.5	12.6, 100	19.5	0/2.7	-
SF-36						
Physical	87.3	100.0	10, 100	20.4	0/51.7	0.92
Role-physical	81.1	87.5	12.5, 100	22.5	0/39.7	0.86
Pain	74.5	80.0	0, 90	26.0	1.3/39.1	0.84
General health	66.3	72.0	15, 100	18.1	0/0	0.77
Vitality	84.9	62.5	0, 100	22.1	0/8.0	0.84
Social	84.9	100.0	0, 100	22.1	0.7/55.6	0.80
Role-emotional	80.7	91.7	0, 100	22.7	0.7/46.4	0.61

	Mean	Median	Range (Min, Max)	SD	Floor/ceiling effects, %	Cronbach's alpha
Mental health	77.7	80.0	10, 100	18.3	0/12.9	0.82
PCS	50.8	53.5	20.5, 65.6	8.4	0/0	-
MCS	49.8	52.2	14.1, 66.3	10.3	0/0	-

Table 3

Construct validity of the QOL-CS and QLACS

	X2	CFI	RMSEA
QOL-CS			
Physical	506.892 *	0.973	0.079
Psychological	1534.670 *	0.772	0.281
Social	796.937 *	0.981	0.085
Spiritual	230.180 *	0.762	0.186
QLACS			
Pain	1021.541 *	0.988	0.203
Negative feeling	344.204 *	0.995	0.073
Positive feeling	508.723 *	0.989	0.139
Cognitive	295.972	0.873	0.351
Fatigue	677.441 *	1.0	0
Social	524.052 *	0.961	0.367
Sexual	425.628 *	0.939	0.293
Distress-family	1899.238 *	1.0	0
Distress-recurrence	785.026 *	0.984	0.206
Appearance	663.656 *	0.999	0.057
Financial	1304.734 *	0.998	0.081
Benefit	527.625 *	0.981	0.181

*
p<0.05

Table 4

Convergent/discriminant validity of the QOL-CS and QLACS

	QOL-CS						SF-36								
	Physical	Psychological	Social	Spiritual	Overall	Physical	Role-physical	Pain	General health	Vitality	Social	Role-emotional	Mental health	PCS	MCS
QLACS															
Pain	0.66***	0.61***	0.66***	0.01	0.67***	0.57***	0.53***	0.75***	0.56***	0.47***	0.46***	0.35***	0.40***	0.72***	0.33***
Negative feeling	0.63***	0.66***	0.48***	0.06	0.63***	0.31***	0.44***	0.46***	0.54***	0.61***	0.55***	0.47***	0.70***	0.34***	0.68***
Positive feeling	0.47***	0.52***	0.40***	0.28***	0.57***	0.37***	0.38***	0.34***	0.40***	0.47***	0.46***	0.39***	0.63***	0.29***	0.56***
Cognitive	0.48***	0.49***	0.43***	0.08	0.51***	0.34***	0.33***	0.35***	0.44***	0.50***	0.43***	0.33***	0.46***	0.34***	0.46***
Fatigue	0.70***	0.52***	0.51***	-0.04	0.58***	0.44***	0.42***	0.47***	0.59***	0.67***	0.51***	0.36***	0.49***	0.49***	0.51***
Social	0.49***	0.50***	0.50***	0.17*	0.56***	0.34***	0.36***	0.32***	0.43***	0.49***	0.57***	0.48***	0.55***	0.27***	0.60***
Sexual	0.34***	0.29***	0.21**	0.02	0.30***	0.17*	0.16	0.21*	0.25**	0.32***	0.40***	0.16	0.35***	0.16	0.34***
Overall-generic	0.76***	0.72***	0.65***	0.11	0.76***	0.51***	0.53***	0.59***	0.65***	0.71***	0.67***	0.50***	0.70***	0.54***	0.68***
Distress-family	0.28***	0.38***	0.22**	-0.06	0.28***	0.14	0.19*	0.19*	0.27***	0.31***	0.08	0.14	0.24**	0.19*	0.21*
Distress-recurrence	0.50***	0.68***	0.44***	0.04	0.57***	0.20*	0.35***	0.37***	0.53***	0.48***	0.34***	0.33***	0.52***	0.30***	0.48***
Appearance	0.49***	0.60***	0.58***	-0.12	0.53***	0.35***	0.35***	0.42***	0.33***	0.33***	0.41***	0.25***	0.31***	0.40***	0.30***
Financial	0.44***	0.51***	0.67***	0.01	0.56***	0.28***	0.38***	0.35***	0.36***	0.35***	0.31***	0.26***	0.37***	0.35***	0.32***
Benefit	-0.08	-0.07	-0.12	0.24*	-0.01	-0.01	-0.01	-0.06	-0.07	0.02	0.10	-0.02	0.16	-0.08	0.10
Overall-specific	0.57***	0.72***	0.63***	-0.04	0.65***	0.31***	0.42***	0.44***	0.50***	0.49***	0.37***	0.33***	0.48***	0.41***	0.43***
SF-36															
Physical	0.49***	0.43***	0.60***	-0.01	0.52***										
Role-physical	0.50***	0.53***	0.63***	-0.04	0.56***										
Pain	0.60***	0.55***	0.58***	-0.01	0.59***										
General health	0.69***	0.69***	0.59***	0.01	0.68***										
Vitality	0.69***	0.66***	0.51***	0.07	0.66***										
Social	0.59***	0.58***	0.56***	0.09	0.63***										
Role-emotional	0.46***	0.51***	0.51***	0.11	0.55***										

	QOL-CS										SF-36				
	Physical	Psychological	Social	Spiritual	Overall	Physical	Role-physical	Pain	General health	Vitality	Social	Role-emotional	Mental health	PCS	MCS
Mental health	0.65 ^{***}	0.66 ^{***}	0.43 ^{***}	0.13	0.64 ^{***}										
PCS	0.56 ^{***}	0.50 ^{***}	0.66 ^{***}	-0.08	0.57 ^{***}										
MCS	0.62 ^{***}	0.65 ^{***}	0.45 ^{***}	0.16 [*]	0.64 ^{***}										

* p<0.05;

** p<0.01;

*** p<0.001

Table 5

Known-group validity of the QOL-CS and QLACS

	Late effect		Comorbid condition	
	Difference [†] (ES [‡])	Relative validity	Difference [†] (ES [‡])	Relative validity
QOL-CS				
Physical	11.71 (0.62) ***	71.3	15.70 (0.84) ***	1771.0
Psychological	8.59 (0.50) *	44.1	14.22 (0.82) ***	1715.0
Social	12.97 (0.71) ***	93.9	12.47 (0.68) **	1129.0
Spiritual	1.32 (0.08)	<u>1.0</u>	0.67 (0.04)	3.0
Overall	8.65 (0.66) ***	79.6	10.43 (0.79) ***	1570.0
QLACS				
Pain	10.81 (0.47) *	39.4	12.71 (0.55) **	730.0
Negative feeling	12.59 (0.62) **	70.4	10.13 (0.50) *	585.0
Positive feeling	12.72 (0.72) ***	97.3	11.75 (0.66) **	1072.0
Cognitive	6.55 (0.33)	18.9	8.70 (0.43) *	447.0
Fatigue	9.81 (0.44) *	35.5	15.55 (0.71) ***	1238.0
Social	9.15 (0.47) *	39.6	7.44 (0.38)	342.0
Sexual	4.08 (0.29)	14.3	-0.30 (0.02)	<u>1.0</u>
Overall-generic	9.49 (0.66) ***	79.4	9.43 (0.66) **	1049.0
Distress-family	3.97 (0.13)	3.1	2.41 (0.08)	15.0
Distress-recurrence	9.01 (0.35)	21.6	14.70 (0.57) **	787.0
Appearance	12.69 (0.55) **	55.0	4.27 (0.19)	79.0
Financial	16.30 (0.60) ***	66.3	11.16 (0.41) *	397.0
Benefit	4.75 (0.16)	4.6	-3.27 (0.11)	29.0
Overall-specific	10.55 (0.54) **	52.4	8.18 (0.42) *	409.0
SF-36				
Physical	11.21 (0.55) **	54.2	6.53 (0.32)	235.0
Role-physical	14.14 (0.63) ***	72.3	11.31 (0.50) *	593.0
Pain	18.75 (0.72) ***	98.1	18.36 (0.71) **	1226.0
General health	10.56 (0.59) **	62.3	18.44 (1.02) ***	2813.0
Vitality	12.11 (0.57) **	58.5	16.22 (0.76) ***	1442.0
Social	13.04 (0.60) **	63.1	9.45 (0.43) *	425.0
Role-emotional	10.69 (0.47) *	39.4	6.83 (0.30)	208.0
Mental health	10.45 (0.57) **	59.1	10.97 (0.60) **	860.0
PCS	5.59 (0.67) ***	82.3	5.61 (0.67) **	1085.0
MCS	5.36 (0.52) **	48.3	5.33 (0.52) *	629.0

[†] Difference in HRQOL between YASCC without vs. with late effects (or without vs. with comorbid conditions); positive values: YASCC without late effects (or without comorbid conditions) possess greater HRQOL than YASCC with late effects (or with comorbid conditions)

[‡] Effect size (ES): negligible: <0.2; small: 0.2–0.49; moderate: 0.5–0.79; large: >0.8

*
p<0.05;

**
p<0.01;

p<0.001