

Health-related quality of life in young men with testicular cancer: validation of the Cancer Assessment for Young Adults (CAYA)

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Abstract

Background Patient-reported outcome instruments are needed to measure health-related quality of life (HRQOL) in young adults with cancer. The purpose of this project was to establish a conceptual model and measurement instrument for assessment of HRQOL in young men with testicular cancer.

Methods Patient interviews and a literature review were used to develop a conceptual framework of biopsychosocial

domains of cancer-related quality of life and an initial pool of questionnaire items. Items were piloted and refined. Revised items were administered to a sample ($N=171$) of young (ages 18–29) men with testicular cancer and repeated 4 weeks later. Rasch measurement methods guided item reduction and scale construction. Traditional psychometric analyses were also performed to allow for comparison with existing measures.

Results The conceptual framework included seven biopsychosocial domains: physical, sexual, intrapersonal, cognitive–emotional, social–relational, educational–vocational–avocational, and spiritual to form independent scales of the resulting questionnaire, the Cancer Assessment for Young Adults–Testicular (CAYA-T). Each scale fulfilled Rasch and traditional psychometric criteria (i.e., person separation index, 0.34–0.82; Cronbach’s alpha, 0.70–0.91; and an expected pattern of convergent and discriminant validity correlations).

Conclusions The CAYA-T can be used to assess HRQOL across a comprehensive set of domains as identified by young men with cancer. It passes strict psychometric criteria and has potential as a useful research and clinical tool.

Implications for cancer survivors The CAYA-T has potential research and clinical value for addressing inter-related aspects of HRQOL in young adult men with cancer. The measure may assist with assessing and monitoring HRQOL across a range of domains and contributing to more comprehensive assessment of biopsychosocial needs of young adults.

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Introduction

Young adulthood is a critical developmental phase in which young men are negotiating greater independence

and autonomy in social, professional, and physical domains [1]. Young people ages 18–29 years identify unique psychological and social experiences including a perception of feeling “in between” the struggles of adolescence and the responsibilities of adulthood [1]. It is a period often marked by vocational and relational exploration, mobility in residences and domestic circumstances, increased self-focus, and an optimistic outlook on goal attainment. A diagnosis of cancer, especially cancer that threatens sexuality and reproductive health, can be distressing in this formative period [2]. Testicular cancer (TC) is the most prevalent cancer among men in late adolescence and early adulthood [3]. Advances in multimodal therapy have afforded young men with TC survival rates upwards of 90 %, which has allowed the development of a research agenda focused on survivorship issues [4–6]. Ensuring robust health-related quality of life (HRQOL) is essential in this group, as they face both psychological impact from potential loss of a reproductive organ and long-term functional impacts of chemotherapy, radiation therapy, and surgery. Limited empirical research has relied on broad assessment instruments validated for the general cancer population [7] and has largely ignored the unique issues of young men, such as masculine identity, reproductive health concerns, familial relationships, and body image.

Importantly, no study to our knowledge has specifically examined HRQOL in young adult TC patients. In samples with a broad age representation, younger age is associated with indicators of poorer adjustment, including higher anxiety [8]. Additional risk factors include lower education, unmarried/unpartnered status, and receipt of chemotherapy and other specific medical treatments [7, 9–13]. Further, psychosocial factors have been identified as central concerns in TC patients, including body image, quality of social relationships, fertility and sexual function, masculinity, and worry [11, 14–16].

The National Cancer Institute and Livestrong Foundation-led Progress Review Group in Adolescent and Young Adult Oncology [17] determined that the existing research infrastructure is inadequate to support vital research with young adult cancer survivors. A recommendation was the development of relevant assessment tools to measure HRQOL to understand impact on treatment decisions and medical adherence, to aid in tracing quality-adjusted survival over time, to integrate HRQOL assessment into clinical care, and to utilize validated measures that span the developmental trajectory as primary outcomes in treatment effectiveness research trials. Such assessments are critical in distinguishing the burden of cancer in groups or individuals and useful in clinical assessment or in observational and intervention research [18].

To our knowledge, no psychometrically sound patient-reported outcome instrument [19] exists to assess cancer-related quality of life in young adults. However, reliable

and valid outcome data are essential to enhancing cancer survivorship in this group. The goal of this study was to use rigorous methods for developing a patient-centered conceptual model and measurement device [20, 21] to establish a new instrument of HRQOL in young men with cancer.

Methods

Participants and procedures

Potential participants were identified by the California Cancer Care Registry and invited to participate. Eligibility included men between 18 and 29 years of age at study enrollment with history of histologically confirmed testis cancer. Men with severe psychiatric disorder or cognitive impairment were excluded. Following provision of signed informed consent, participants were either interviewed (in preliminary study phase) or completed questionnaires by mail or in person. Questionnaires were repeated 1 month later. Participants were compensated \$50 for each assessment point (\$100 total). Procedures were approved by the human subjects' protection boards at the University of California and the California Committee for Protection of Human Subjects.

Content generation

Development of the Cancer Assessment for Young Adults for men with testicular cancer (CAYA-T) involved several preliminary phases including extensive literature review, consultation with care providers, and the conduct of in-depth semistructured patient interviews. The goal was to yield a rich understanding of HRQOL across biopsychosocial domains and participants' experiences. Initially, clinical providers including urologic surgeons and health psychologists were queried to verify information gained from literature review and to generate an initial list of priorities to explore with survivors. For patient interviews, sampling was purposive to achieve variation in demographic and clinical characteristics using the criterion of thematic saturation to determine sample size. That is, initial themes were identified following each interview and compiled. Saturation is reached when little or no new information is gained from the addition of interviews. Thematic summaries were compiled and independently reviewed by five reviewers simultaneously with continued data collection. Saturation was achieved with the conduct of 21 interviews. Based on findings, a conceptual model and an initial pool of questionnaire items were developed.

HRQOL has included subjective assessments of skills, abilities, and functioning across multiple dimensions [22–24]. Thus, items were generated across identified biopsychosocial domains and administered to the original interview participants

($n=21$) and a preliminary test group ($n=15$) to establish readability/acceptability, comprehension/non-ambiguity, and ease of use. This group was on average 25 years of age ($SD=3.2$); 52 % White, non-Hispanic and 33 % Hispanic/Latino, 62 % employed full time, 33 % college graduates, and on average 35 months from diagnosis. A grade 8 reading level was a goal in item generation, but preference was given to words and phrases repeated across interviews by survivors to describe processes. Brief cognitive interviews were conducted with the preliminary test group. The focus of these interviews was on identifying unobservable problems with comprehension, readability, and overall use of the instrument. Few problems with readability and comprehension were reported by the test group. Four items were dropped that were reported to be incomprehensible. Items were refined or retained based on participant feedback and clinical relevance. Participants in these generation phases were not among the 171 in the final sample (described below).

Measures

Validated questionnaires of relevant constructs were administered to assist in establishing convergent and discriminant validity. These included two measures of HRQOL: the Functional Assessment of Chronic Illness Therapy-General (FACT-G) [23] and modules from the European Organization for Research and Treatment of Cancer Scales Quality of Life Questionnaire–testicular cancer (EORTC QLQ-TC26) [24]. Additionally, the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-sp) [25], the Benefit-Finding Scale (BFS) [26], the Cancer-Related Masculine Threat scale (CMT) [27], the Social Provisions Scale-attachment subscale (SPS) [28], the Stanford Emotional Self-Efficacy Scale-Cancer (SESES-C) [29], and the Goal Adjustment Scale (GAS) [30] were administered. Self-reported health was indicated by the one-item index of perceived health (1=excellent; 5=poor) from the MOS-short form (SF-12) which is associated with various causes of morbidity and mortality [31]. Participants self-reported sociodemographic and clinical variables.

Rasch measurement methods

Rasch measurement methods test the extent that observed data fit the responses expected by a mathematical (Rasch) model [32–34] and were performed using RUMM2030 software [35]. Several indicators were used to determine evidence for item fit:

Thresholds for item response options Items were administered with the use of response categories scored with successive integer scores (0=none of the time, 4=almost all of the time) to imply a continuum. We tested this assumption by examining the ordering of thresholds (or points of crossover

between adjacent response categories) [36]. Disordered or nondistinct scoring functions were considered for alteration.

Item fit statistics Item misfit implies that an item may not be measuring the scale's intended construct. First, we examined log residuals which summarize the difference between observed and expected responses to an item across all people (item–person interaction). Chi-square values summarize the difference between observed and expected responses for classes of people who have relatively similar “ability” levels (item–trait interaction). Finally, item characteristic curves display the expected responses across the continuum of person scores and the observed values for each class interval. Item fit statistics were interpreted together and in context of the clinical utility of each item set.

Item locations The items of a scale should define the continuum on which people are measured. Thus, items are ideally spread across a reasonable and meaningful range. Items with similar locations were deemed to indicate redundancy and suggested potential item reduction.

Person separation index (PSI) The PSI is a reliability statistic analogous to coefficient alpha [37]. This index quantifies the error associated with the measurements of individuals, with higher values indicating greater reliability [38]. It is commonly understood with the same rules of thumb used to interpret Cronbach's alpha (e.g., >0.70).

Traditional psychometric methods

Traditional analyses ensured that scales fulfill widely accepted criteria and facilitate comparison with existing measures [19]. Properties of acceptability, reliability, and validity were examined using SPSS v17.0 software. In addition, tests of data quality and scaling assumptions [39, 40] were examined (not reported here). Each of the scale-item responses was summed without recoding, weighting, or standardization to generate scores.

Acceptability Acceptability refers to assessment of data quality and involves examination of score distributions and data completeness. The CAYA-T was considered acceptable if each scale had less than 5 % missing data and a maximum endorsement frequency of less than 80 %.

Validity Multiple indicators of validity were examined [41]: (1) Intercorrelations between scales indicate the extent to which they measure related but separate constructs. We expected intercorrelations to be moderate ($r=0.30$ – 0.70) [42]. (2) Correlations between the developed scales and selected measures were examined. Given the large number

of planned correlations, a conservative alpha level ($p < 0.01$) was adopted for determining statistical significance. Evaluation is based on the direction, magnitude, and pattern of correlations being consistent with expectations based on the proximity of the constructs. (3) Finally, clinical validity was assessed by examining the ability of the instrument to detect differences between predefined subgroups (i.e., self-reported overall health).

Reliability Good reliability indicates that scores are dependable and consistent [43]. We examined internal consistency (Cronbach's alpha) [37] and test–retest reliability (intraclass correlation). Scales with adequate reliability exhibit alpha coefficients ≥ 0.70 and intraclass correlation coefficients ≥ 0.80 .

Results

Sample

In total, 694 eligible cases were identified. Cancer registry-mandated physician authorization to contact a patient was denied in 34 instances; invitation letters were sent to 660 individuals. Of those, 277 were undeliverable and 57 were unreachable per notification by family member (recall that 36 men participated in interview and preliminary phases). The final sample of 171 men reflects a response rate of 59 % of possible cases. Responders did not differ significantly from nonresponders on clinical or demographic variables. Participant characteristics are reported in Table 1. Also, 113 participants repeated questionnaires at 1 month. No significant

Table 1 Participant characteristics (N=171)

| Characteristic | Value (%) | Characteristic | Value (%) |
|--------------------------------|-------------------|------------------------------------|------------|
| Age (M, SD; range) | 25.2, 3.32; 18–29 | | |
| Ethnicity | | Sexual orientation | |
| White (non-Hispanic) | 79 (46.2) | Heterosexual | 160 (93.6) |
| Hispanic/Latino | 65 (38.0) | Gay | 7 (4.1) |
| Asian | 18 (10.5) | Bisexual | 2 (1.2) |
| Native American/Alaskan Native | 5 (2.9) | Other | 2 (1.2) |
| African American/Black | 2 (1.2) | | |
| Other | 2 (1.2) | | |
| Education | | Relationship status | |
| Less than high school | 8 (4.7) | Single | 93 (54.4) |
| High school/GED | 26 (15.2) | Committed/partnered | 50 (29.2) |
| Some college | 55 (32.2) | Married | 27 (15.8) |
| 2-Year college degree | 19 (11.1) | Divorced | 1 (0.6) |
| 4-Year college degree | 47 (27.4) | Have at least 1 child | 32 (18.7) |
| Graduate degree | 16 (9.4) | Living with parents | 84 (49.1) |
| Income | | Insurance | |
| \$15,000 or less | 41 (24.0) | None | 22 (12.9) |
| \$15,001–30,000 | 34 (19.9) | Medicaid/public plan | 44 (25.7) |
| \$30,001–45,000 | 20 (11.7) | Private plan/other | 105 (61.4) |
| \$45,001–60,000 | 26 (15.2) | | |
| \$60,001–75,000 | 19 (11.1) | | |
| \$75,001–100,000 | 16 (9.4) | | |
| \$100,001 or more | 15 (8.8) | | |
| | | Months since diagnosis (M; SD) | 32.4; 19.3 |
| | | Months since treatment (M; SD) | 30.1; 14.4 |
| Employment | | Treatment type | |
| Employed full time | 70 (40.9) | Radical Inguinal orchiectomy | 125 (73.1) |
| Employed part time | 39 (22.8) | Bilateral orchiectomy ^a | 12 (7.0) |
| Student | 21 (12.3) | RPLND | 41 (24) |
| Medical leave/disability | 9 (5.3) | Chemotherapy | 91 (53.2) |
| Unemployed | 32 (18.7) | Radiation therapy | 26 (15.2) |
| | | Other | 14 (8.2) |

RPLND retroperitoneal lymph node dissection

^a Six cases reported subsequent contralateral tumor

differences on clinical or demographic variables were observed for those who did not repeat the assessment.

Identification of domains, item generation, and item reduction

Based on interviews and literature review, seven key domains formed the conceptual framework: physical, sexual, intrapersonal, cognitive–emotional regulation, social–relational, educational–vocational–avocational, and spiritual. Notably, young men emphasized a skill-based orientation (“I can regulate my mood”) versus a more function-based orientation (“I have depressed mood”) to their constitution of HRQOL. This guided item construction in many domains. A pool of 113 items was grouped into domains based on conceptual meanings and overall coherence. Item reduction analysis led to retention of 90 items. Item reduction analysis resulted in decisions to omit 4 items based on participant feedback (e.g., “I hold onto my emotions until just the right time for expressing them”), 5 items due to redundancy reduction (“I get help and support from other people”), and 14 items because of poor statistical performance (“Cancer doesn’t define me”). As displayed in Table 2, this resulted

in 17 scales: physical, sexual confidence, sexual functioning, body image strength, positive masculine self-image, positive adult self-image, cognitive–emotional regulation, disclosure ability, relationship maintenance, social connectedness, healthcare confidence, goal navigation, goal facility, financial maintenance, recreational pursuit, spiritual stability, and finding meaning.

Examination of the ordering of item thresholds suggested a three-level response scale (0–2) reflected a more distinct scoring function than did the original five-level format. That is, more meaningful distinctions (i.e., logically ordered with limited crossover) were observed between each level of a three-level pattern than that of a three-level response scale. Thus, responses of 0 (none of the time) were retained, responses of 1 or 2 were scored as 1 (a little or some of the time), and responses of 3 or 4 were scored as 2 (much or most of the time) in the computation of scale scores.

Rasch analysis

Rasch analysis supported the summing of items to form a score for each scale. Validity was supported by three findings. First, the three-level item response option thresholds

Table 2 Illustrative Items

| CAYA-T domains/scales | No. of Items | Illustrative Item |
|------------------------------------|--------------|--|
| Physical | 6 | I have aches, pain, or discomfort. |
| Sexual | | |
| Sexual confidence | 3 | I do not have adequate confidence about sex. |
| Sexual functioning | 5 | I am satisfied with my ability to achieve orgasm. |
| Intrapersonal | | |
| Body image strength | 7 | I am embarrassed of my body because of cancer. |
| Positive masculine self-image | 7 | My health makes me feel like less of a man. |
| Positive adult self-image | 1 | I feel less “grown-up” because of my health. |
| Cognitive–emotional regulation | 14 | I struggle to understand my feelings about cancer. |
| Social–relational | | |
| Disclosure ability | 7 | I am able to talk about my cancer with others. |
| Relationship maintenance | 6 | I am able to keep up my relationships. |
| Social connectedness | 5 | Cancer has alienated me from other people. |
| Healthcare confidence | 8 | I am confident talking with doctors about my medical treatment. |
| Educational/vocational/avocational | | |
| Goal navigation | 7 | I am able to identify goals for my life. |
| Goal facility | 5 | Cancer has made some goals unattainable. |
| Financial maintenance | 1 | I am able to get adequate health insurance or other financial resources for health-related expenses. |
| Recreational pursuit | 1 | I spend time on hobbies, hanging out with others, or doing things I enjoy. |
| Spiritual | | |
| Spiritual stability | 1 | I am questioning my religion or foundational belief system. |
| Finding meaning | 6 | I work to understand what cancer means to me. |

Participants are given the following instruction prompt for all items, “Over the past 7 days, how often would you say the following has been true for you.” Response scale: 0=none of the time, 1=a little or some of the time, 2=much or most of the time.

were ordered correctly for all items across scales (statistical validity). Second, the item locations in each scale were spread out (range of logit span, 0.5–4.4) indicating that each scale defined a continuum (construct validity; Table 3). Third, fit to the Rasch model was good as the vast majority of items had acceptable fit residuals (fit validity). Chi-square values were nonsignificant (Table 3). The minority of items falling outside recommended criteria had fit statistics marginally larger than expected. Scale reliability as reflected by the PSIs ranged from 0.34 to 0.82 (Table 3).

Traditional psychometric analyses

All CAYA-T scales exceeded criteria for acceptability, reliability, and validity (Tables 3, 4, 5, and 6). Overall, findings indicated that the items in each scale constituted a statistically conformable group and that scores were reliable and valid. Scale reliability was supported by adequate Cronbach's alphas (≥ 0.70) and appropriate item–total correlations (range of

means, 0.64–0.86). Intraclass correlations mostly supported reliability (range, 0.49–0.81).

Scale validity was supported by the interscale correlations (see Table 4) and observed scale relationships with established HRQOL measures (see Table 5). As Table 5 indicates, CAYA-T scales were modestly to highly correlated, but not redundant, with other conceptually similar scales. One notable exception was an observed negative relationship between adult self-image threat and social isolation. It may be that a higher degree of dependence accompanies adult self-image threat and thus lower social isolation.

In addition to those reported in the table, significant correlations were observed for additional measures. Higher scores on spiritual stability were related to higher spiritual well-being ($r=0.27$, $p<0.001$) and finding meaning was significantly correlated with higher spiritual well-being ($r=0.34$, $p<0.001$) as measured by the FACIT-sp. Finding meaning also had a significantly positive correlation with scores on the BFS ($r=0.53$, $p<0.001$). The Positive Masculine

Table 3 Summary of psychometric analysis

| CAYA-T domains/scales | Rasch analysis | | | | Traditional psychometric analysis | | |
|------------------------------------|---------------------------------|-----------------------------------|--|-------------------|-----------------------------------|-------------------|---------------------------------------|
| | Item locations | | Fit statistics | | Cronbach's alpha | Test–retest (ICC) | Item–total correlations (mean; range) |
| | Logits (span of mean locations) | Fit residuals outside $-2.5/+2.5$ | Items with chi-square probability ≥ 0.001 | PSI (no extremes) | | | |
| Physical | –1.7 | 0 | 0 | 0.69 | 0.80 | 0.76*** | 0.69; 0.61–0.77 |
| Sexual | | | | | | | |
| Sexual confidence | –0.5 | 0 | 0 | 0.34 | 0.70 | 0.67*** | 0.79; 0.77–0.80 |
| Sexual functioning | 2.7 | 0 | 1 | 0.38 | 0.76 | 0.67*** | 0.74; 0.65–0.82 |
| Intrapersonal | | | | | | | |
| Body image strength | 2.3 | 0 | 0 | 0.63 | 0.86 | 0.79*** | 0.73; 0.60–0.81 |
| Positive masculine self-image | –1.8 | 0 | 0 | 0.69 | 0.78 | 0.80*** | 0.67; 0.58–0.77 |
| Positive adult self-image | n/a | n/a | n/a | n/a | n/a | 0.49*** | n/a |
| Cognitive-emotional regulation | 2.4 | 1 | 1 | 0.72 | 0.89 | 0.76*** | 0.64; 0.44–0.80 |
| Social–relational | | | | | | | |
| Disclosure ability | 1.1 | 0 | 1 | 0.49 | 0.78 | 0.73*** | 0.66; 0.56–0.81 |
| Relationship maintenance | 1.2 | 0 | 0 | 0.46 | 0.90 | 0.80*** | 0.81; 0.70–0.89 |
| Social connectedness | –1.6 | 0 | 0 | 0.52 | 0.91 | 0.81*** | 0.86; 0.79–0.94 |
| Healthcare confidence | 4.4 | 0 | 0 | 0.40 | 0.90 | 0.80*** | 0.78; 0.72–0.83 |
| Educational/vocational/avocational | | | | | | | |
| Goal navigation | 3.1 | 0 | 2 | 0.56 | 0.85 | 0.76*** | 0.74; 0.54–0.83 |
| Goal facility | –1.2 | 0 | 0 | 0.60 | 0.88 | 0.75*** | 0.82; 0.74–0.87 |
| Financial maintenance | n/a | n/a | n/a | n/a | n/a | 0.62*** | n/a |
| Recreational pursuit | n/a | n/a | n/a | n/a | n/a | 0.66*** | n/a |
| Spiritual | | | | | | | |
| Spiritual stability | n/a | n/a | n/a | n/a | n/a | 0.58*** | n/a |
| Finding meaning | 1.5 | 0 | 0 | 0.82 | 0.87 | 0.58*** | 0.78; 0.70–0.86 |

ICC intraclass correlation, PSI Pearson separation index

*** $p<0.001$

Table 4 Interscale correlations

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 |
|-----------------------------------|--------|--------|--------|--------|--------|---------|--------|--------|--------|--------|--------|--------|--------|-------|--------|------|----|
| 1. Physical | – | | | | | | | | | | | | | | | | |
| 2. Sexual confidence | 0.56** | – | | | | | | | | | | | | | | | |
| 3. Sexual functioning | 0.45** | 0.62** | – | | | | | | | | | | | | | | |
| 4. Body image strength | 0.60** | 0.66** | 0.54** | – | | | | | | | | | | | | | |
| 5. Positive masculine self-image | 0.61** | 0.66** | 0.46** | 0.70** | – | | | | | | | | | | | | |
| 6. Positive adult self-image | 0.35** | 0.36** | 0.40** | 0.42** | 0.48** | – | | | | | | | | | | | |
| 7. Cognitive-emotional regulation | 0.67** | 0.65** | 0.44** | 0.66** | 0.72** | 0.41** | – | | | | | | | | | | |
| 8. Disclosure ability | 0.25* | 0.47** | 0.39** | 0.46** | 0.54** | 0.34** | 0.37** | – | | | | | | | | | |
| 9. Relationship maintenance | 0.49** | 0.59** | 0.49** | 0.58** | 0.68** | 0.40** | 0.67** | 0.62** | – | | | | | | | | |
| 10. Social connectedness | 0.57* | 0.57** | 0.36** | 0.57** | 0.69** | –0.43** | 0.72** | 0.43** | 0.64** | – | | | | | | | |
| 11. Healthcare confidence | 0.51** | 0.51** | 0.46** | 0.51** | 0.59** | 0.30** | 0.60** | 0.33** | 0.53** | 0.41** | – | | | | | | |
| 12. Goal navigation | 0.48** | 0.48** | 0.44* | 0.53** | 0.66** | 0.42** | 0.68** | 0.43** | 0.67** | 0.59** | 0.60** | – | | | | | |
| 13. Goal facility | 0.54** | 0.42** | 0.51** | 0.59** | 0.57** | 0.45** | 0.55** | 0.33** | 0.46** | 0.60** | 0.39** | 0.50** | – | | | | |
| 14. Financial maintenance | 0.17 | 0.15 | 0.14 | 0.18 | 0.29** | 0.06 | 0.22* | 0.14 | 0.16 | 0.12 | 0.46** | 0.23* | 0.16 | – | | | |
| 15. Recreational pursuit | 0.43** | 0.42** | 0.31** | 0.44** | 0.50** | 0.30** | 0.60** | 0.34** | 0.58** | 0.56** | 0.43** | 0.59** | 0.47** | 0.20* | – | | |
| 16. Spiritual stability | 0.26** | 0.17 | 0.20 | 0.29** | 0.29** | 0.26* | 0.26** | 0.24* | 0.26* | 0.30** | 0.17 | 0.16 | 0.29** | 0.17 | 0.18 | – | |
| 17. Finding meaning | 0.13 | 0.06 | 0.06 | 0.08 | 0.16 | 0.10 | 0.19 | 0.21* | 0.23* | 0.21* | 0.25* | 0.51** | 0.11 | 0.08 | 0.35** | 0.02 | – |

* $p<0.01$; ** $p<0.001$

Table 5 Convergent and discriminant construct validity

| | FACT-g Global | EORTC QLQ-TC26 Treatment side effects | EORTC QLQ-TC26 Treatment satisfaction | EORTC QLQ-TC26 Future perspective (future uncertainty) | EORTC QLQ-TC26 Job problems | EORTC QLQ-TC26 Family problems | EORTC QLQ-TC26 Sexual activity | EORTC QLQ-TC26 Sexual problems | EORTC QLQ-TC26 Sexual enjoyment | EORTC QLQ-TC26 Communication | EORTC QLQ-TC26 Body Image problems |
|------------------------------------|------------------|---|--|---|-----------------------------------|---|---|---|--|------------------------------------|---|
| Physical | 0.71** | -0.65** | 0.40** | -0.56** | -0.61** | -0.45** | 0.34** | -0.34** | 0.34** | 0.23* | -0.41** |
| Sexual | | | | | | | | | | | |
| Sexual confidence | 0.65** | -0.33** | 0.27** | -0.52** | -0.40** | -0.34** | 0.46** | -0.31** | 0.48** | 0.50** | -0.53** |
| Sexual functioning | 0.59** | -0.41** | 0.29** | -0.40** | -0.42** | -0.28** | 0.46** | -0.57** | 0.52** | 0.47** | -0.32** |
| Intrapersonal | | | | | | | | | | | |
| Body image | 0.68** | -0.48** | 0.31** | -0.55** | -0.55** | -0.38** | 0.40** | -0.40** | 0.42** | 0.40** | -0.58** |
| Strength | | | | | | | | | | | |
| Positive masculine | 0.70** | -0.43** | 0.36** | -0.52** | -0.50** | -0.44** | 0.36** | -0.33** | 0.36** | 0.47** | -0.71** |
| Self-image | | | | | | | | | | | |
| Positive adult self- | 0.41** | -0.30** | 0.19 | -0.32** | -0.41** | -0.19 | 0.30** | -0.21* | 0.26* | 0.29** | -0.43** |
| Image | | | | | | | | | | | |
| Cognitive-emotional | 0.78** | -0.50** | 0.37** | -0.57** | -0.50** | -0.37** | 0.40** | -0.31** | 0.39** | 0.38** | -0.56** |
| Regulation | | | | | | | | | | | |
| Social-relational | | | | | | | | | | | |
| Disclosure ability | 0.40** | -0.13 | 0.25* | -0.21* | -0.19 | -0.13 | 0.38** | -0.10 | 0.36** | 0.72** | -0.41** |
| Relationship | 0.67** | -0.31** | 0.40** | -0.36** | -0.32** | -0.28** | 0.41** | -0.25* | 0.41** | 0.60** | -0.52** |
| Maintenance | | | | | | | | | | | |
| Social | 0.69** | -0.41** | 0.34** | -0.41** | -0.49** | -0.38** | 0.37** | -0.31** | 0.33** | 0.52** | -0.54** |
| Connectedness | | | | | | | | | | | |
| Healthcare | 0.59** | -0.34** | 0.54** | -0.36** | -0.37** | -0.33** | 0.28** | -0.32** | 0.25* | 0.31** | -0.41 |
| Confidence | | | | | | | | | | | |
| Educational/vocational/avocational | | | | | | | | | | | |
| Goal navigation | 0.67** | -0.38** | 0.40** | -0.31** | -0.36** | -0.21* | 0.45** | -0.21* | 0.39** | 0.44** | -0.45** |
| Goal facility | 0.65** | -0.47** | 0.38** | -0.47** | -0.70** | -0.70** | 0.30** | -0.42** | 0.34** | 0.32** | -0.43** |
| Financial | 0.25* | -0.12 | 0.36** | -0.19 | -0.16 | -0.16 | 0.09 | -0.13 | 0.09 | 0.14 | -0.19 |
| Maintenance | | | | | | | | | | | |
| Recreational pursuit | 0.59** | -0.37** | 0.25* | -0.21* | -0.41** | -0.41** | 0.40** | -0.18 | 0.34** | 0.31** | -0.36** |
| Spiritual | | | | | | | | | | | |
| Spiritual stability | 0.27** | -0.22* | 0.25* | -0.26* | -0.21* | -0.21* | 0.13 | -0.16 | 0.11 | 0.21* | -0.24* |
| Finding meaning | 0.18* | -0.17 | 0.22* | 0.11 | -0.03 | -0.03 | 0.18 | 0.02 | 0.03 | 0.19 | -0.03 |

* $p < 0.01$; ** $p < 0.001$

Self-Image scale was significantly correlated with the CMT scale ($r=-0.57$, $p<0.001$), and the Disclosure Ability scale was positively related to scores on the SESES-C ($r=0.56$, $p<0.001$). The relationship maintenance ($r=0.71$, $p<0.001$) and the social connectedness ($r=0.63$, $p<0.001$) scales had significant relationships with the SPS in expected directions. Correlations with the GAS show that the goal navigation scale was positively related to the ability to reengage in meaningful goals ($r=0.36$, $p<0.001$). Finally, our examinations of the clinical validity of the CAYA-T scales across self-reported health categories supported expectations of patterns of scores across groups (Table 6).

Discussion

The development of the CAYA-T addresses the need to understand and assess HRQOL in young adults with cancer. Careful assessment of HRQOL allows clinicians and researchers to identify important and innovative ways

to improve outcomes for young survivors. The CAYA-T provides a profile of developmentally relevant scales across domains reflecting critical markers of adaptive skills and functioning as identified by young men with TC.

In interviews, participants spoke of the challenges and resources specific to young adults. Although the resulting conceptual model presents discrete domains of HRQOL, it was the interplay of domains that was most prominent. For instance, a participant described poor emotion regulation, disrupted career goals, and difficulty in physician communication as a constellation of factors interrupting his functioning and provoking declining HRQOL. The assessment of the comprehensive spectrum of domains will be useful in identifying the complexity of dynamic factors that affect patient well-being and care. Further, the ways in which young men described HRQOL are reflected in the final instrument items and distinguish the CAYA-T for existing measures. For example, “I am able to talk with my partner about sex” versus an item reflecting completion of the action of talking to one’s partner (e.g., “I talk to my partner about sex”) was an important distinction made by participants.

Table 6 An analysis of variance results for selected patient characteristics

| CAYA-T domains/scales | Total sample [mean score (SD)] | Self-rated overall health | | | |
|------------------------------------|--------------------------------|----------------------------|----------------------------|--------------------------------|--------|
| | | Mean score (SD) | | | |
| | | Poor/fair ($n=24$) | Good ($n=50$) | Very good/excellent ($n=97$) | p |
| Physical | 1.07 (0.38) | 0.76 ^{a,b} (0.41) | 1.02 ^a (0.42) | 1.16 ^b (0.31) | <0.001 |
| Sexual | | | | | |
| Sexual confidence | 1.42 (0.50) | 0.99 ^{a,b} (0.54) | 1.33 ^{a,c} (1.00) | 1.58 ^{b,c} (0.41) | <0.001 |
| Sexual functioning | 1.21 (0.31) | 1.13 ^{a,b} (0.28) | 1.26 ^{a,c} (0.29) | 1.43 ^{b,c} (0.32) | <0.001 |
| Intrapersonal | | | | | |
| Body image strength | 0.64 (0.33) | 0.57 ^a (0.27) | 0.66 ^b (0.37) | 0.87 ^{a,b} (0.38) | <0.001 |
| Positive masculine self-image | 1.12 (0.32) | 0.99 ^a (0.27) | 1.07 (0.36) | 1.18 ^a (0.30) | <0.05 |
| Positive adult self-image | 1.04 (0.76) | 0.88 ^a (0.71) | 1.16 (0.77) | 1.48 ^a (0.73) | <0.01 |
| Cognitive–emotional regulation | 0.92 (0.17) | 0.88 ^a (0.14) | 0.94 (0.20) | 1.01 ^a (0.18) | <0.01 |
| Social–relational | | | | | |
| Disclosure ability | 1.49 (0.33) | 1.22 ^{a,b} (0.36) | 1.43 ^{a,c} (0.31) | 1.59 ^{b,c} (0.29) | <0.001 |
| Relationship maintenance | 1.44 (0.33) | 1.42 (0.34) | 1.43 (0.31) | 1.45 (0.29) | 0.884 |
| Social connectedness | 0.55 (0.24) | 0.51 ^a (0.24) | 0.61 ^a (0.27) | 0.63 (0.17) | <0.05 |
| Healthcare confidence | 0.83 (0.28) | 0.77 ^a (0.51) | 0.86 (0.30) | 1.01 ^a (0.33) | <0.001 |
| Educational/vocational/avocational | | | | | |
| Goal navigation | 1.79 (0.32) | 1.55 ^{a,b} (0.35) | 1.71 ^a (0.36) | 1.89 ^b (0.25) | <0.001 |
| Goal facility | 0.54 (0.30) | 0.48 ^{a,b} (0.27) | 0.60 ^a (0.31) | 0.67 ^b (0.35) | <0.01 |
| Financial maintenance | 1.69 (0.51) | 1.33 ^a (0.64) | 1.54 ^b (0.58) | 1.86 ^{a,b} (0.35) | <0.001 |
| Recreational pursuit | 1.77 (0.43) | 1.58 ^a (0.50) | 1.64 ^b (0.53) | 1.89 ^{a,b} (0.32) | <0.001 |
| Spiritual | | | | | |
| Spiritual stability | 0.92 (0.68) | 0.50 ^a (0.59) | 0.78 ^b (0.71) | 1.09 ^{a,b} (0.63) | <0.001 |
| Finding meaning | 0.87 (0.44) | 0.74 ^{a,b} (0.33) | 0.91 ^{a,c} (0.48) | 1.30 ^{b,c} (0.47) | <0.001 |

The superscript letters denote statistically significant differences in post-hoc contrast comparisons within each scale

Scale development and item reduction were guided by Rasch measurement methods which allow for more accurate individual person measurements on “fixed” rulers, and therefore improve the potential for measuring clinically meaningful distances and change. However, traditional psychometric methods conform widely to accepted standards for scale validation and allow for comparisons across existing tools. Taken together, these procedures for development and validation exceed recommendations for measurement. Ideally, the combination of approaches will serve to connect new and traditional psychometric methods.

The CAYA-T allows for flexibility of use. The administration of 90 items might be impractical in some settings. However, our evaluation supports independent use of scales. Combinations of scales might be used to examine patient profiles across domains or to supplement existing HRQOL measures that inadequately account for the experiences of young adults or assess limited domains. Notably, the use of single-item indicators is not common. Although item reduction analyses did not yield multi-item scales, these four scales of adult self-image, spiritual stability, and financial maintenance, and recreational pursuit were strong emergent themes relevant to young adults.

Despite our rigorous approach, continued validation is needed. The utility of the CAYA-T will be solidified with future research, including examination of its performance compared with more general measures to determine its ability to predict morbidities and clinical outcomes longitudinally. Responsiveness of the scales to medical and psychosocial interventions also requires study. We recommend the use of larger samples in the next phase of validation to examine performance across meaningful periods in the treatment trajectory and clinical subgroups. The current study is directly relevant to young men with TC. Future work should include patients with various cancer types, including young women. Although the response rate was adequate [44], systematic differences between responders and nonresponders on unmeasured variables are possible. Finally, the CAYA-T was developed in a North American population and solely in English; utility beyond this context is not known.

Long-term TC survivors generally report good HRQOL [11]. Similarly, our results suggest that young men were clustered on the high end of functioning for many scales (reflected by relatively low PSIs). In fact, the PSI is sensitive to scale-to-sample mistargeting; mismatch with Cronbach alphas on some scales possibly reflect ceiling effects. Inclusion of diverse clinical populations or additional items will facilitate exploration of dimensionality. Also, some respondents did not uniformly discriminate between forward and reverse-directed items. Future work should consider directionality and item order.

The CAYA-T can provide clinicians and researchers with information about cancer-related functioning across a

comprehensive set of domains. It has been rigorously tested and passes strict psychometric criteria. It complements available assessments and has potential to document clinical performance across time and guide education and supportive care for young adults. As recommendations for comprehensive cancer care continually integrate a biopsychosocial approach [45], such data are increasingly vital.

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