Assessing quality of life in young adult cancer survivors: development of the Survivorship-Related Quality of Life scale

Crystal L. Park · Jennifer H. Wortmann ·
Amy E. Hale · Dalnim Cho · Thomas O. Blank

Abstract

Purpose Scientific advances in treatments and outcomes for those diagnosed with cancer in late adolescence and early adulthood depend, in part, on the availability of adequate assessment tools to measure health-related quality of life (HRQOL) for survivors in this age group. Domains especially relevant to late adolescence and young adulthood (LAYA; e.g., education and career, committed romantic relationships, worldview formation) are typically overlooked in studies assessing the impact of cancer, usually more appropriate for middle-aged or older survivors. Current HRQOL measures also tend to assess issues that are salient during or shortly after treatment rather than reflecting life years after treatment.

Methods To develop a new measure to better capture the experience of LAYA cancer survivors in longer-term survivorship (the LAYA Survivorship-Related Quality of Life measure, LAYA-SRQL), we completed an extensive measure development process. After a literature review and focus groups with LAYA cancer survivors, we generated items and ran confirmatory factor and reliability analyses using a sample of 292 LAYA cancer survivors. We then examined validity using existing measures of physical and mental health, quality of life, and impact of cancer.

Results The final model consisted of two domains (satisfaction and impact), each consisting of ten factors: existential/spirituality, coping, relationship, dependence, vitality, health care, education/career, fertility, intimacy/sexuality, and cognition/memory. Confirmatory factor analysis and validity analyses indicated that the LAYA-SRQL is a psychometrically sound instrument with good validity.

Conclusion The LAYA-SRQL fills an important need in survivorship research, providing a way to assess HRQOL in LAYAs in a developmentally informed way.

Introduction

Because of their formative stage in the lifecycle and likelihood of living many years as cancer survivors, late adolescent and young adult (LAYA) survivors may have many long-lasting or permanent impacts of diagnosis and treatment on the course of their lives. Developmental tasks of LAYAs involve increasing social independence, identity exploration and establishment, psychosexual exploration, personal decision-making, financial independence, and assumption of responsibility for oneself [1]. Being diagnosed with cancer as a late adolescent or young adult can impact developmental tasks, reverberating across the lifespan [2]. For example, one's body image [3] and sense of an expansive future are often adversely affected [4], yet some coping skills may improve as LAYAs discover their own strengths and resilience [5, 6]. The Adolescent and Young Adult Oncology Progress Review Group [7] identified six essential domains—intellectual, interpersonal, emotional, practical, existential/spiritual, and cultural—most of which are not adequately addressed in extant measures of health-related quality of life (HRQOL). Research is needed to understand how cancer affects

C. L. Park (✉) · J. H. Wortmann · A. E. Hale · D. Cho · T. O. Blank
University of Connecticut, Storrs, CT, USA
e-mail: crystal.park@uconn.edu

LAYAs' long-term well-being relative to their peers who have not had cancer [8] and effects of different treatments.

Quality of life (QOL) refers to individuals' general sense of well-being or satisfaction with their current state relative to where they would like to be [9]. Assessing QOL in LAYA survivors is difficult because of limitations in current measurement tools. The most widely used cancer-specific QOL scales (e.g., FACT [9] or EORTC [10]) focus on functional HRQOL during or shortly after primary treatment [11]. The functional dimension of health is often a lesser focus of longer-term survivors, however, who instead have many other QOL concerns.

Several cancer-specific scales focusing on longer-term survivorship have been developed (e.g., quality of life in adult cancer survivors (QLACS) [12]; Quality of Life-Cancer Survivors (QOL-CS) [13]). Although appropriate for assessing QOL in longer-term survivorship, these scales do not include domains especially important to LAYAs [8] and lack grounding in developmental issues. Many cancer-specific measures combine general life quality, cancer-specific fears and concerns, and the perceived impact of the cancer into a single score (e.g., QOL-CS), limiting their utility for understanding these unique aspects [14]. Researchers are increasingly interested in both the positive and negative impacts survivors attribute to cancer [15] and their relations with well-being [16], but potential negative and positive impacts are normally measured with separate instruments. Thus, assessing well-being and perceived impact on separate scales is essential.

One measure (the Impact of Cancer for Childhood Cancer Survivors, IOC-CS [17]) was designed specifically to assess perceived impact of cancer in longer-term survivors of childhood cancer, but does not assess QOL. The IOC-CS includes four domains that changed in a positive direction and four others that changed in a negative direction. Its focus on impact is useful in examining survivors' perceptions of cancer-related changes, but precludes comparison with the general population and is better used to supplement QOL measures rather than as one [8].

Thus, a QOL measure is needed that captures the specific aspects of well-being most relevant to LAYAs. This project aimed to develop a measure specific enough to be useful in understanding LAYA survivors' experiences but that could also be used to allow comparisons of QOL with other groups (e.g., general population, people with different types of cancer or other illnesses). We built on Zebrack et al.'s [18] approach, focusing on perceived cancer-specific impacts. However, unlike their approach, we did not assign a priori valence to that impact but rather allowed participants to specify the impact and valence of that impact themselves [19]. Further, this measure assesses QOL and perceived impact of cancer in the same domains separately and concurrently.

Methods

Item generation

Through literature review and focus groups of long-term LAYA survivors, we identified 15 domains: existential/spirituality, religion, fertility, sexuality, relationship, in/dependence, friends, family, career/education, health care, vitality, lifestyle, cognition, coping, and finances. We trimmed the initial list of 94 items to 80 by removing those identified as confusing or redundant.

Procedure

Data were obtained via surveys through the mail ($N = 48$, 16 %) and online ($N = 244$, 84 %). We mailed packets to eligible young adult cancer survivors identified through the Hartford Hospital Cancer Registry. We also created an online version of the survey and advertised both versions on Web sites popular with young adult survivors. Eligibility requirements were diagnosis between the ages of 15 and 39 and within the past 7 years, although after initial recruitment difficulties the latter criterion was dropped. Participants received $20 for survey completion. Procedures were approved by Hartford Hospital and University of Connecticut IRBs.

Measures

Demographics and cancer experience measures

Self-reported current age, age at diagnosis, gender, race/ethnicity, education, personal/family income, medical/treatment variables, type of cancer, and date of diagnosis were assessed.

LAYA-SRQL

Participants rated 30 items for both satisfaction and impact. Satisfaction instructions read: "For each item, please indicate the extent to which you are *satisfied with this aspect of your life.*" Responses ranged from 1 (*completely unsatisfied*) to 7 (*completely satisfied*), with a neutral midpoint. Impact subscale instructions read, "For each item, please indicate whether you have *changed in this way as a result of your experience with cancer* in either a positive or a negative direction." Responses ranged from 1 (*very negative*) to 7 (*very positive*) with a neutral midpoint (*no impact*). Participants could also select *not applicable* (0) for any item. Responses for each impact item were transformed into separate positive ($5 = 1$, $6 = 2$, $7 = 3$, $1–4 = 0$) and negative ($3 = 1$, $2 = 2$, $1 = 3$, $4–7 = 0$) impact scores.

Standard HRQOL measures

Two HRQOL measures were compared to the LAYA-SRQL satisfaction scale, the SF-36 Health Survey and the quality of life index (QLI).

SF-36 Health Survey is a well-validated 36-item instrument that produces standardized physical and mental component scores [20]. Higher scores refer to better functioning.

QLI comprises 33 items measuring HRQOL, producing satisfaction and importance total scores for four domains (health and functioning, psychological/spiritual, social/economic, and family) [21]. In the present study, we used the satisfaction scores. Participants rated each item from 1 (*very unsatisfied*) to 6 (*very satisfied*); a *not applicable* option was provided but excluded from mean calculations.

Standard measures of cancer impact

Two measures were compared to the impact component of the LAYA-SRQL, the IOC-CS, and the Post-traumatic Growth Inventory (PTGI).

IOC-CS comprises 41 items assessing the extent to which eight life domains were affected by cancer: (physical) health awareness and body changes; (psychological) positive self-evaluation and negative self-evaluation; (existential) positive outlook and negative outlook; (social) life interferences and value of relationship; meaning of cancer; and health worry, all rated from 1 (*strongly disagree*) to 5 (*strongly agree*) [22].

PTGI comprises 21 items rated from 1 (*I experienced this change to a very small degree as a result of my cancer diagnosis*) to 5 (*... to a very great degree...*), with an option of 0 (*I did not experience this change...*) [23].

Data analytic plan

Because we developed the scale with specific hypotheses regarding factor structure, we conducted confirmatory factor analysis [24]. Two models were tested: Model 1 had 15 factors reflecting all the domains produced in our item generation phase, while Model 2 condensed several of these domains into a more compact factor structure of 10 domains, combining factors that we hypothesized might have significant overlap (e.g., sexuality and romantic relationship) or be less relevant (e.g., finances). Model 1s domains included existential/spirituality, religion, fertility, sexuality, relationship, dependence, friends, family, career/education, health care, vitality, lifestyle, cognition, coping, and finances. Model 2s streamlined factor structure included existential/spirituality, coping, relationship, dependence,

vitality, health care, education/career, fertility, intimacy/sexuality, and cognition/memory.

We examined both satisfaction and impact factors on the same items to create the simplest measure. Our goal was three items per factor, allowing for adequate content coverage with minimal participant load [24]. We analyzed attrition and "not applicable" responses to identify problematic items and addressed missing data through imputation using stochastic regression [25]. Because of the centrality of satisfaction to the concept of QOL, we used the LAYA-SRQL satisfaction component as our starting place for developing the scale and testing model fit.

Before beginning analyses, we determined to retain items based on factor loadings >.5 but <.9 and theoretical relevance [25, 26]. We removed items from scales based on reliability analyses, redundancy, factor loadings, content validity, and contribution to poor model fit based on modification indices [26].

Our goal was a comparative fit index (CFI) of $\geq.90$ [27, 28], and a root mean square error of approximation (RMSEA) $\leq.08$ [29], and a standardized root mean square residual (SRMR) of $\leq.08$ [30]. Cronbach's αs measured internal consistency reliability, with a goal of final subscales of $\geq.7$ for each factor [24]. To examine validity, we compared LAYA-SRQL subscale scores to related constructs and other LAYA-SRQL subscale scores.

Validity analyses were based on several hypotheses: (1) total LAYA-SRQL satisfaction score would positively correlate with the total QLI satisfaction score, and individual subscales would positively correlate with relevant subscales on the QLI and SF-36, (2) LAYA-SRQL positive impact scores would positively correlate with relevant positive subscales of the IOC-CS and PTGI, (3) negative impact scores, both overall and subscales, would positively correlate with IOC-CS negative subscales, (4) LAYA-SRQL satisfaction subscales would be positively correlated, presuming that satisfaction in one area would relate to satisfaction in other areas, and (5) positive impact scale scores would positively correlate with satisfaction scores, but negative impact scale scores would negatively correlate with satisfaction.

Results

Participants

Demographics are presented in Table 1. Most participants had completed primary treatment (94 %); 21 % reported evidence of recurrence. Nearly one-third were diagnosed with at least Stage II disease ($N = 92$, 32 %).
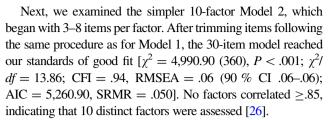
Table 1 Participant demographics

Age	Mean = 33.03 ± 6.97
Age at diagnosis	Mean = 29.27 ± 7.01
Gender	N (%)
Female	303 (78.3)
Male	84 (21.7)
Marital status	
Single	149 (38.5)
Married	163 (42.1)
Cohabiting	37 (9.6)
Divorced	33 (8.5)
Widowed	2 (.5)
Education	
Some high school	3 (.8)
High school degree	33 (8.5)
Some college	84 (21.7)
College degree	160 (41.3)
Graduate degree	103 (26.6)
Income	
<$20,000	57 (14.7)
Between $20,000 and $40,000	64 (16.5)
Between $40,000 and $60,000	62 (16.0)
Between $60,000 and $80,000	52 (13.4)
Between $80,000 and $100,000	54 (14)
Above $100,000	86 (22.2)
Race/ethnicity	
Caucasian/White	348 (89.9)
African American/Black	11 (2.8)
Asian/Pacific Islander	9 (2.3)
Native American/Alaska Native	1 (.3)
Other	16 (4.1)

Attrition analysis

A total of 387 participants began and 292 completed the entire measure. Participants who reported lower income [$F(1, 373) = 14.54, P = .000$] or were currently in primary treatment [$F(1, 381) = 4.40, P = .037$] were less likely to complete the survey.

Confirmatory factor analysis

To analyze Model 1, we correlated the factors and trimmed the model to 3 items per factor based on the reliability analysis, maximizing variance while keeping the reliability alphas between .7 and .9 [31]. After removing items with the highest modification indices, the model fit was still poor [$\chi^2 = 100,835.89$ (2,019), $P < .001$; $\chi^2/df = 49.94$; CFI = .74, RMSEA = .08 (90 % CI .08–.08); AIC = 51,875.46, SRMR = .268]. Given the unsatisfactory fit, we did not test it with impact items.

Next, we examined the simpler 10-factor Model 2, which began with 3–8 items per factor. After trimming items following the same procedure as for Model 1, the 30-item model reached our standards of good fit [$\chi^2 = 4,990.90$ (360), $P < .001$; $\chi^2/df = 13.86$; CFI = .94, RMSEA = .06 (90 % CI .06–.06); AIC = 5,260.90, SRMR = .050]. No factors correlated ≥.85, indicating that 10 distinct factors were assessed [26].

This exceeded our goal for model fit, so we proceeded to test the model with the impact items. Impact scale fit for Model 2 was not quite as good as for the satisfaction scale [$\chi^2 = 7,162.70$ (360), $P < .001$; $\chi^2/df = 19.90$; CFI = .88, RMSEA = .07 (90 % CI .07–.07), AIC = 7,432.70, SRMR = .07]. Although CFI of .88 was lower than our goal, RMSEA and SRMR were both within our desired range. Given that they tend to be a robust indicator of fit [26] and the good fit of the satisfaction scale, we retained this as our final model.

Descriptive statistics

Mean scores for satisfaction subscales ranged from 3.38 to 5.24, with scale midpoint of 4 (see Table 2). Mean scores for impact subscales ranged from .10 (positive impact on education/career) to 1.48 (positive impact on relationship), with scale midpoint of 1.5 (see Table 2).

Satisfaction scales

Participants reported being at least somewhat satisfied (mean scores >4) in existential/spiritual, relationship, dependence, and education/career. Satisfaction with health care was in the middle ($M = 4.01$). Participants reported being at least somewhat unsatisfied (mean scores <4) with coping, vitality, fertility, intimacy/sexuality, and cognition/memory. Reliability for satisfaction subscales was good (Cronbach's αs .74–.93).

Impact scales

Separate means were calculated for positive and negative change on each impact subscale (see Table 2). Positive impact scores were highest for relationship and existential/spirituality. Negative impact scores were highest for fertility, cognition/memory, vitality, and intimacy/sexuality. Reliabilities for impact subscales were good (αs ≥ .7, except for relationship, α = .62).

Validity

As hypothesized, LAYA-SRQL 10-factor satisfaction mean score positively correlated with SF-36 standardized physical and mental health components and QLI satisfaction score (see Table 3). Most LAYA-SRQL subscales correlated with SF-36 subscales and subscales of QLI.

Table 2 Descriptive statistics for all SRQL subscales

	Mean ± (SD)	Response range	SE	Cronbach's α
Existential/spirituality				
Satisfaction	4.57 ± (1.45)	1.00–7.00	.09	.93
Positive change	.92 ± (1.05)	.00–3.00	.06	.90
Negative change	.22 ± (.62)	.00–3.00	.03	
Coping				
Satisfaction	3.80 ± (1.42)	1.00–7.00	.08	.84
Positive change	.56 ± (.74)	.00–3.00	.04	.72
Negative change	.76 ± (.80)	.00–3.00	.04	
Relationship				
Satisfaction	5.24 ± (.1.16)	1.67–7.00	.07	.74
Positive change	1.48 ± (.91)	.00–3.00	.05	.62
Negative change	.15 ± (.34)	.00–3.00	.02	
Dependence				
Satisfaction	4.08 ± (1.35)	1.00–7.00	.08	.89
Positive change	.66 ± (.79)	.00–3.00	.04	.78
Negative change	.37 ± (.69)	.00–3.00	.04	
Vitality				
Satisfaction	3.59 ± (1.61)	1.3–7.00	.09	.89
Positive change	.33 ± (.65)	.00–3.00	.03	.78
Negative change	.85 ± (.87)	0–2.67	.05	
Healthcare				
Satisfaction	4.01 ± (1.51)	1.00–7.00	.09	.87
Positive change	.50 ± (.75)	.00–3.00	.04	.75
Negative change	.68 ± (.83)	.00–3.00	.04	
Education/career				
Satisfaction	4.65 ± (1.36)	1.00–7.00	.08	.80
Positive change	.10 ± (.94)	.00–3.00	.05	.74
Negative change	.28 ± (.58)	.00–3.00	.03	
Fertility				
Satisfaction	3.38 ± (1.57)	1.00–7.00	.10	.83
Positive change	.27 ± (.57)	.00–3.00	.03	.67
Negative change	1.02 ± (1.00)	.00–3.00	.05	
Intimacy/sexuality				
Satisfaction	3.64 ± (1.75)	1.00–7.00	.10	.93
Positive change	.25 ± (.59)	.00–3.00	.03	.86
Negative change	.84 ± (.98)	.00–3.00	.05	
Cognition/memory				
Satisfaction	3.63 ± (1.49)	1.00–7.00	.09	.90
Positive change	.13 ± (.44)	.00–3.00	.02	.88
Negative change	.87 ± (.87)	.00–3.00	.05	

SD standard deviation, *SE* standard error

As expected, most LAYA-SRQL positive impact subscales (see Table 4) correlated positively with IOC-CS positive impact subscales and PTGI. LAYA-SRQL positive impact subscales correlated negatively with IOC-CS negative impacts except for a positive relationship between LAYA-SRQL dependence and IOC-CS health worry. Overall, LAYA-SRQL positive impact was positively related to PTGI.

As predicted, nearly all LAYA-SRQL negative impact subscales (see Table 5) related positively to IOC-CS

Table 3 Relationships among the LAYA-SRQL satisfaction, SF-36, and QLI

	1. Total satisfaction	2. Existential/ spirituality	3. Coping	4. Relationship	5. Dependence	6. Vitality	7. Healthcare	8. Education/ career	9. Fertility	10. Intimacy/ sexuality	11. Cognition/ memory
1.	–										
2.	.60**	–									
3.	.80**	.43**	–								
4.	.58**	.51**	.41**	–							
5.	.70**	.32**	.56**	.34**	–						
6.	.75**	.36**	.57**	.30**	.54**	–					
7.	.53**	.17**	.35**	.27**	.36**	.25**	–				
8.	.71**	.49**	.53**	.47**	.41**	.48**	.25**	–			
9.	.52**	.21**	.37**	.09	.26**	.36**	.31**	.31**	–		
10.	.66**	.28**	.46**	.30**	.37**	.42**	.21**	.41**	.34**	–	
11.	.70**	.29**	.60**	.26**	.43**	.57**	.32**	.39**	.34**	.39**	–
SF-36											
Physical component	.42**	.04	.32**	.07	.41**	.56**	.06	.28**	.31**	.32**	.31**
Physical fx	.42**	.08	.34**	.09	.39**	.55**	.04	.26**	.29**	.34**	.33**
Role physical	.49**	.01	.39**	.07	.47**	.55**	.18**	.33**	.34**	.38**	.40**
Bodily pain	.41**	.08	.39**	.09	.35**	.47**	.10	.26**	.33**	.31**	.26**
General health	.53**	.22**	.49**	.20**	.43**	.56**	.22**	.34**	.32**	.29**	.37**
Mental component	.56**	.28**	.60**	.24**	.42**	.41**	.33**	.34**	.29**	.34**	.45**
Mental health	.55**	.26**	.60**	.27**	.41**	.42**	.00	.33**	.28**	.37**	.39**
Role emotional	.49**	.23**	.53**	.13*	.35**	.36**	.30**	.30**	.34**	.27**	.42**
Vitality	.62**	.20**	.56**	.22**	.49**	.67**	.23**	.40**	.28**	.42**	.40**
Social fx	.54**	.17**	.50**	.15*	.50**	.49**	.27**	.32**	.33**	.37**	.55**
QLI mean	.71**	.30**	.63**	.31**	.55**	.54**	.39**	.49**	.40**	.50**	.52**
Psyc/spiritual	.67**	.44**	.63**	.38**	.44**	.49**	.34**	.53**	.28**	.44**	.51**
Health/fx	.73**	.28**	.67**	.26**	.58**	.62**	.35**	.52**	.40**	.54**	.55**
Social/economic	.55**	.22**	.45**	.28**	.48**	.42**	.35**	.37**	.31**	.36**	.40**
Family	.33**	.05	.27**	.14*	.28**	.15*	.31**	.15*	.36**	.26**	.21**

fx Functioning, *Psyc* psychological

* P < .05; ** P < .01

Table 4 Relationships among the LAYA-SRQL positive impact, IOC, and PTGI

	1. Existential/ spirituality	2. Coping	3. Relationship	4. Dependence	5. Vitality	6. Healthcare	7. Education/ Career	8. Fertility	9. Intimacy/ sexuality	10. Cognition/ memory
1.	−.26**									
2.	.35**	−.48**								
3.	.47**	.45**	−.35**							
4.	.31**	.29**	.35**	−.32**						
5.	.27**	.51**	.30**	.28**	−.38**					
6.	.22**	.47**	.26**	.39**	.33**	−.42**				
7.	.40**	.44**	.49**	.29**	.50**	.32**	−.33**			
8.	.15**	.30**	.16**	.21**	.39**	.39**	.30**	−.27**		
9.	.20**	.40**	.22**	.27**	.38**	.36**	.26**	.41**	−.28**	
10.	.25**	.45**	.23**	.29**	.49**	.39**	.37**	.45**	.54**	−.26**
IOC										
Negative										
BC	−.01	−.22**	.03	.09	−.19**	−.09	−.03	−.09	−.02	−.10
SE	−.06	−.29**	−.07	−.07	−.20**	−.23**	−.13*	−.13*	−.06	−.17**
OL	−.04	−.25**	−.04	.01	−.15*	−.08	−.19**	−.13*	−.03	−.11
LI	−.02	−.28**	−.04	.01	−.29**	−.11	−.08	−.15*	−.02	−.14*
HW	.11	−.16**	.09	.12*	−.07	.02	−.06	−.06	.05	−.06
Positive										
HA	.22**	.19**	.31**	.05	.26**	.09	.22**	.02	.02	.07
SE	.33**	.43**	.48**	.24**	.35**	.26**	.43**	.19**	.19**	.22**
OL	.66**	.35**	.53**	.27**	.27**	.14*	.36**	.16**	.17**	.18**
VR	.26**	.22**	.41**	.20**	.20**	.13*	.29**	.14*	.14*	.11
MC	.33	.27**	.38**	.18**	.31**	.17**	.35**	.20**	.12*	.21**
PTGI	.54**	.54**	.62**	.41**	.40**	.33**	.60**	.30**	.27**	.28**

Numbers of the upper diagonal line reflect relationships between positive and negative impact sales of the LAYA-SRQL

IOC impact of cancer, *BC* body changes, *SE* self-evaluation, *OL* outlook, *LI* life interferences, *HW* health worry, *HA* health awareness, *VR* value of relationships, *MC* meaning of cancer, *PTGI* posttraumatic growth inventory

* $P < .05$; ** $P < .01$

Table 5 Relationships among the LAYA-SRQL negative impact, IOC, and PTGI

	1. Existential/ spirituality	2. Coping	3. Relationship	4. Dependence	5. Vitality	6. Healthcare	7. Education/ career	8. Intimacy/ sexuality	9. Fertility	10. Cognition/ memory
1.	–									
2.	.26**	–								
3.	.32**	.32**	–							
4.	.13*	.47**	.15**	–						
5.	.16**	.50**	.19**	.38**	–					
6.	.11*	.33**	.08	.30**	.26**	–				
7.	.23**	.46**	.14**	.35**	.49**	.25**	–			
8.	.17**	.35**	.19**	.24**	.49**	.15**	.39**	–		
9.	.16**	.24**	.08	.10	.40**	.18**	.31**	.47**	–	
10.	.09	.53**	.15**	.36**	.52**	.29**	.36**	.39**	.32**	–
IOC										
Negative										
BC	.20**	.42**	.20**	.32**	.58**	.26**	.36**	.55**	.39**	.38**
SE	.27**	.53**	.21**	.38**	.41**	.32**	.40**	.38**	.34**	.39**
OL	.15*	.51**	.16**	.33**	.35**	.28**	.43**	.35**	.36**	.32**
LI	.19**	.51**	.23**	.37**	.65**	.28**	.42**	.46**	.45**	.39**
HW	.09	.42**	.07	.17**	.31**	.15*	.23**	.24**	.28**	.24**
Positive										
HA	.00	−.02	−.14*	.01	−.05	−.01	−.09	.03	−.00	−.04
SE	−.17**	−.23**	−.20**	−.20**	−.10	−.17**	−.26**	−.12*	−.02	−.08
OL	−.17**	−.05	−.23**	−.02	.04	.02	−.09	.02	.00	−.01
VR	.03	.08	−.08	.05	.14*	−.04	−.01	.05	.17**	.11
MC	.05	.09	−.06	.02	.09	.02	−.02	.13*	.07	.06
PTGI	−.11	−.11	−.10	−.08	.04	−.04	−.18**	−.04	−.00	.04

IOC impact of cancer, *BC* body changes, *SE* self-evaluation, *OL* outlook, *LI* life interferences, *HW* health worry, *HA* health awareness, *VR* value of relationships, *MC* meaning of cancer, *PTGI* posttraumatic growth inventory

* $P < .05$; ** $P < .01$

negative subscales while LAYA-SRQL negative subscales were negatively related to positive subscales except for a positive relationship between the LAYA-SRQL romance/ intimacy subscale and IOC-CS meaning of cancer subscale. Correlations between LAYA-SRQL negative impact subscales and PTGI trended negatively but were not statistically significant except for that between education/career subscale and PTGI.

Intercorrelations among subscales indicated strong construct validity (see Table 6). LAYA-SRQL satisfaction scale correlated positively with each LAYA-SRQL satisfaction subscale, and all LAYA-SRQL satisfaction subscales were positively intercorrelated. All positive impact subscales were positively intercorrelated, and most negative impact subscales were positively intercorrelated.

Divergent validity: not applicable responses

Items with the highest number of *not applicable* responses were identical on both the satisfaction and impact scales.

The item with the most *not applicable* responses was "My use of tobacco, alcohol, and/or illicit drugs," which 27.7 % of participants rated as *not applicable* to their satisfaction; 19.2 % similarly related cancer's impact on it as *not applicable*. Three fertility-related items had *not applicable* responses ranging from 22.9 to 25.3 % on satisfaction and impact, and two romantic partner-related items were rated as *not applicable* by 13–15.4 %. Given that fertility is not always affected by cancer [32] and not all LAYAs may have yet had an opportunity to experience long-term romantic relationships or face fertility issues, this response pattern supports LAYA-SRQL validity.

Discussion

The LAYA-SRQL is a new instrument assessing satisfaction and impact on life dimensions important to LAYAs. The 10-factor model reached our goals of model fit and demonstrated good psychometrics and strong construct

Table 6 Relationships between LAYA-SRQL satisfaction and impact subscales

Impact	Satisfaction										
	Total	Existential/ spirituality	Coping	Relationship	Dependence	Vitality	Healthcare	Education/ career	Fertility	Intimacy/ sexuality	Cognition/ memory
Existential/spirituality positive change	.25**	.56***	.15**	.28**	.11	.13*	.01	.22**	.02	.05	.15***
Existential/spirituality negative change	−.29***	−.34***	−.26***	−.24**	−.15***	−.19**	−.05	−.19***	−.19***	−.16***	−.20***
Coping positive change	.50***	.32***	.56***	.35***	.37***	.35***	.23**	.35***	.13*	.24***	.32***
Coping negative change	−.62***	−.31***	−.74***	−.24***	−.46***	−.47***	−.27***	−.38***	−.38***	−.35***	−.49***
Relationship positive change	.28**	.29***	.15*	.57***	.19***	.14*	.12*	.26***	−.03	.08	.13*
Relationship negative change	−.32***	−.31***	−.26***	−.50***	−.17***	−.21***	.03	−.19***	−.12	−.23***	−.22***
Dependence positive change	.13*	.19***	.04	.16***	.26***	−.02	.10	.11	−.04	.02	.01
Dependence negative change	−.45***	−.10	−.34***	−.17***	−.59***	−.30***	−.30***	−.28***	−.27***	−.26***	−.30***
Vitality positive change	.38***	.18***	.29***	.22***	.23***	.46***	.09	.33***	.10	.19***	.34***
Vitality negative change	−.56***	−.18***	−.44***	−.10	−.41***	−.71***	−.17***	−.39***	−.32***	−.37***	−.45***
Health care positive change	.37***	.17***	.28***	.19**	.24***	.23**	.51***	.22**	.04	.15***	.27***
Health care negative change	−.39***	−.09	−.27***	−.10	−.29**	−.24***	−.68***	−.14*	−.22***	−.18***	−.28***
Education/career positive change	.28**	.25**	.20**	.28**	.12*	.17*	.12*	.51***	−.06	.11	.11
Education/career negative change	−.50***	−.27***	−.40***	−.15*	−.33***	−.37***	−.19***	−.65***	−.29***	−.32***	−.31***
Fertility positive change	.25***	.081	.25***	.08	.15*	.19*	.13*	.13*	.121	.21***	.22***
Fertility negative change	−.37***	−.09	−.25***	−.06	−.14*	−.30***	−.10	−.23***	−.64***	−.31***	−.23***
Intimacy/sexuality positive change	.19**	.09	.13*	.14*	.13*	.06	.08	.09	.03	.30**	.10
Intimacy/sexuality negative change	−.46***	−.11	−.34***	−.11	−.23***	−.37***	−.07	−.30***	−.26***	−.74***	−.31***
Cognition/memory positive change	.30***	.15*	.31***	.19***	.22***	.25***	.13*	.21***	.06	.11*	.34***
Cognition/memory negative change	−.49***	−.12*	−.44***	−.05	−.30***	−.42***	−.17***	−.25***	−.27***	−.30***	−.79***

* $P < .05$; ** $P < .01$

validity. This measure advances HRQOL research by tapping domains particularly relevant to LAYA survivors, defining HRQOL as satisfaction with those domains, and allowing participants to report positive and negative impact of cancer on them, and assessing longer-term effects of cancer survivorship.

Validation analyses generally supported hypothesized relationships and confirmed validity. LAYA survivors reported overall satisfaction with and positive impacts of cancer in spirituality and relationships, consistent with research on growth in these domains [33]. Dissatisfaction and negative impacts were reported for intimacy/sexuality, fertility, cognition/memory, and vitality, consistent with previous research [2, 3]. Survivors also reported satisfaction with their dependence or reliance on others, including family, and reported a positive impact of cancer on this domain. This positive impact correlated positively with health worry and with negative impacts on fertility, consistent with the importance of social support [34].

Research implications

LAYA survivor HRQOL must be assessed within a developmental context, and the LAYA-SRQL provides a way to access concerns particularly relevant to this age group. It advances HRQOL measurement psychometrically in three important ways: by offering an efficient measure of both satisfaction and impact of cancer, by providing participants the opportunity to report both positive and negative changes in various domains, and by providing ratings regarding the extent to which specific items are problematic.

The LAYA-SRQL may therefore substantially contribute to research on LAYA cancer survivors: Combining satisfaction and impact subscales reduces participant burden compared with the previous need to combine several measures, assessing perceived positive as well as negative impact is critical to understanding the experience of longer-term survivors, and separating satisfaction from impact enables comparison of satisfaction with other groups.

LAYA-SRQL's attention to developmental issues and structure of individual subscales provides a model for incorporating more relevant domains for use with older cancer populations. Middle-aged survivors are likely dealing with mid-career issues and long-term relationships; older survivors with retirement, grandparenthood, and perhaps with caregiving to parents or even spouses [35, 36]. Measures tapping into developmental tasks of middle-aged and later life survivors remain to be developed.

Clinical implications

Health care professionals may use the LAYA-SRQL to assess developmentally-specific issues that could impact well-being or inform treatment. It could be useful for identifying problem areas for LAYA survivors. If additional research demonstrates its reliability and validity over time and in different settings, it may prove useful as an assessment tool in creating and evaluating survivorship care plans and for use of survivorship navigators [37, 38].

Limitations and future directions

We must note limitations. Although the fit of the satisfaction model was good, part of the impact model's fit fell short. Given our goal of creating a measure that assesses satisfaction and impact using the same items, the excellent fit of the satisfaction model, and the impact model's acceptable RMSEA and SRMR, we believe this is likely the best model, but additional studies are needed. The scale was validated on only one specific clinical sample; its generalizability to other groups of LAYA survivors remains to be established. The psychometrics of the scale is promising, but additional information regarding its predictive and discriminant validity is needed. Another limitation is that its domain-specific subscales may make analysis and interpretation challenging. Most domains are relevant to all LAYAs, but some can be irrelevant depending on the age or life goals of the participant. For example, late adolescents may simply not have had relationships serious enough to be affected.

Despite these limitations, the LAYA-SRQL fills an important need in survivorship research, providing a way to efficiently assess HRQOL in LAYAs in a developmentally informed way. One important future direction is to assess specific domains within in-depth investigations of the impact of cancer, in areas such as romantic relationships or cognition/memory. Another is to exploit the range of this measure in longitudinal investigations that begin shortly after treatment in LAYA and, in parallel, address progression through the phases of cancer survivorship and normative and non-normative development as individuals move from adolescence through emerging adulthood and beyond.

Appendix

Instructions for the LAYA-SRQL satisfaction: for each item, please indicate the extent to which you are *satisfied with this aspect of your life*. If the item is not relevant to you, please mark "not applicable."

Satisfaction

1	2	3	4	5	6	7	N/A (0)
Completely unsatisfied	Unsatisfied	Slightly unsatisfied	Neither satisfied/Or unsatisfied	Slightly satisfied	Satisfied	Completely satisfied	

Instructions for the LAYA-SRQL importance: for each item, please indicate whether you have *changed in this way as a result of your experience with cancer* in either a positive of a negative direction. If the item is not relevant to you, please mark "not applicable."

30. My ability to empathize with others

(10 domains of LAYA-SRQL satisfaction and items numbers of each domain)

Impact

1	2	3	4	5	6	7	N/A (0)
Very negative impact	Negative impact	Slightly negative impact	No impact	Slightly positive impact	Positive impact	Very positive impact	

Please use items below for both Satisfaction and Impact with different instructions.

1. My dependence on others
2. My energy level
3. My interest in learning new things
4. My ability to have children
5. My comfort with physical intimacy
6. My concerns about fertility
7. My engagement in religious and/or spiritual practices
8. My spiritual life
9. My sense of security that my health care needs will be met
10. My ability to obtain health care
11. My reliance on others
12. My ability to manage stress
13. My compassion for others
14. My short-term memory
15. My desire for physical intimacy
16. My sexual functioning
17. My ability to share my experiences with others
18. My desire to educate myself
19. My desire to have children
20. My health care coverage
21. My ability to concentrate
22. My sense of control over my life
23. My ability to exercise
24. My educational and career goals
25. My ability to relax
26. My ability to participate in my favorite sports and hobbies
27. My ability to think clearly
28. My sense of closeness to God or a higher power
29. My dependence on family

Domains	Item numbers
Existential/spirituality	7, 8, 28
Coping	12, 22, 25
Dependence	1, 11, 29
Vitality	2, 23, 26
Health care	9, 10, 20
Intimacy/sexuality	5, 15, 16
Cognition/memory	14, 21, 27
Relationship	13, 17, 30
Education/career	3, 18, 24
Fertility	4, 6, 19

References

1. Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469–480.
2. Maurice-Stam, H., Grootenhuis, M. A., Caron, H. N., & Last, B. F. (2007). Course of life of survivors of childhood cancer is related to quality of life in young adulthood. *Journal of Psychosocial Oncology, 25*(3), 43–58.
3. Larouche, S. S., & Chin-Peuckert, L. (2006). Changes in body image experienced by adolescents with cancer. *Journal of Pediatric Oncology Nursing, 23*(4), 200–209.
4. Evan, E. E., & Zeltzer, L. K. (2006). Psychosocial dimensions of cancer in adolescents and young adults. *Cancer, 107*(S7), 1663–1671.
5. Jones, B. L. (2008). Promoting healthy development among survivors of adolescent cancer. *Family & Community Health, 31,* S61–S70.
6. Parry, C., & Chesler, M. (2005). Thematic evidence of psychosocial thriving in childhood cancer survivors. *Qualitative Health Research, 15*(8), 1055–1073.
7. Adolescent and Young Adult Oncology Progress Review Group. (2006). *Closing the gap: Research and care imperatives for adolescents and young adults with cancer.* Washington, DC:

Department of Health and Human Services, NIH Publication 06-6067.

8. Huang, I. C., Quinn, G. P., Krull, K., Eddleton, K. Z., Murphy, D. C., Shenkman, E. A., et al. (2012). Head-to-head comparisons of quality of life instruments for young adult survivors of childhood cancer. *Support Care in Cancer, 20*(9), 2061–2071.

9. Cella, D. F., Wiklund, I., Shumaker, S. A., & Aaronson, N. K. (1993). Integrating health-related quality of life into cross-national clinical trials. *Quality of Life Research, 2*(6), 433–440.

10. Aaronson, N. K., Bullinger, M., & Ahmedzai, S. (1988). A modular approach to quality-of-life assessment in cancer clinical trials. *Recent Results in Cancer Research, 111*, 231–249.

11. Zebrack, B. J., & Cella, D. (2005). Evaluating quality of life in cancer survivors. In J. Lipscomb, C. C. Gotay, & C. Snyder (Eds.), *Outcomes assessment in cancer: Measures, methods, and applications* (pp. 241–263). Cambridge: Cambridge University Press.

12. Avis, N. E., Smith, K. W., McGraw, S., Smith, R. G., Petronis, V. M., & Carver, C. S. (2005). Assessing quality of life in adult cancer survivors (QLACS). *Quality of Life Research, 14*(4), 1007–1023.

13. Ferrell, B. R., Dow, K. H., & Grant, M. (1995). Measurement of the quality of life in cancer survivors. *Quality of Life Research, 4*(6), 523–531.

14. Zebrack, B. J., & Chesler, M. A. (2001). A psychometric analysis of the quality of life-cancer survivors (QOL-CS) in survivors of childhood cancer. *Quality of Life Research, 10*(4), 319–329.

15. Rowlands, I. J., Lee, C., Janda, M., Nagle, C. M., Obermair, A., & Webb, P. M. (2013). Predicting positive and negative impacts of cancer among long-term endometrial cancer survivors. *Psycho-Oncology, 22*(9), 1963–1974.

16. Park, C., & Blank, T. O. (2012). Associations of positive and negative life changes with well-being in young and middle-aged adult cancer survivors. *Psychology & Health, 27*(4), 412–429.

17. Zebrack, B. J., Donohue, J. E., Gurney, J. G., Chesler, M. A., Bhatis, S., & Landier, W. (2010). Psychometric evaluation of the impact of cancer (IOC-CS) scale for young adult survivors of childhood cancer. *Quality of Life Research, 19*(2), 207–218.

18. Zebrack, B. J., Yi, J., Petersen, L., & Ganz, P. A. (2008). The impact of cancer and quality of life for long-term survivors. *Psycho-Oncology, 17*(9), 891–900.

19. Park, C., Chmielewski, J., & Blank, T. O. (2010). Post-traumatic growth: Finding positive meaning in cancer survivorship moderates the impact of intrusive thoughts on adjustment in younger adults. *Psycho-Oncology, 19*(11), 1139–1147.

20. McHorney, C. A., Ware, J. E., Jr., & Raczek, A. E. (1993). The MOS 36-item short-form health survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Medical Care, 31*(3), 247–263.

21. Ferrans, C. E., & Powers, M. J. (1992). Psychometric assessment of the quality of life index. *Research in Nursing & Health, 15*(1), 29–38.

22. Zebrack, B. J., Ganz, P. A., Bernaards, C. A., Petersen, L., & Abraham, L. (2006). Assessing the impact of cancer: Development of a new instrument for long-term survivors. *Psycho-Oncology, 15*(5), 407–421.

23. Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*(3), 455–471.

24. Netemeyer, R. G., Bearden, W. O., & Sharma, S. (2003). *Scaling procedures: Issues and applications*. Beverly Hills: Sage.

25. Peugh, J. L., & Enders, C. K. (2004). Missing data in educational research: A review of reporting practices and suggestions for improvement. *Review of Educational Research, 74*(4), 525–556.

26. Brown, T. A. (2006). *Confirmatory factor analysis for applied research*. New York: Guilford Press.

27. Bentler, P. M. (1990). Comparative fit indexes in structural models. *Psychological Bulletin, 107*(2), 238–246.

28. Finch, J. F., & West, S. G. (1997). The investigation of personality structure: Statistical models. *Journal of Research in Personality, 31*(4), 439–485.

29. Browne, M. W., & Cudeck, R. (1993). Alternative ways of assessing model fit. *Sage Focus Editions, 154*, 136.

30. Hu, L. T., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal, 6*(1), 1–55.

31. Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory*. New York: McGraw-Hill.

32. Ruddy, K. J., Gelber, S., Ginsburg, E. S., Schapira, L., Abusief, M. E., Meyer, M. E., et al. (2011). Menopausal symptoms and fertility concerns in premenopausal breast cancer survivors. *Menopause, 18*(1), 105–108.

33. Bellizzi, K. M., Smith, A. W., Reeve, B. B., Alfano, C. M., Bernstein, L., Meeske, K., et al. (2010). Posttraumatic growth and health-related quality of life in a racially diverse cohort of breast cancer survivors. *Journal of Health Psychology, 15*(4), 615–626.

34. Decker, C. L. (2007). Social support and adolescent cancer survivors: A review of the literature. *Psycho-Oncology, 16*(1), 1–11.

35. Harden, J. (2005). Developmental life stage and couples' experiences with prostate cancer: A review of the literature. *Cancer Nursing, 28*(2), 85–98.

36. Rowland, J. H. (1989). Developmental stage and adaptation: Adult model. In J. Holland & J. H. Rowland (Eds.), *Handbook of psychooncology* (pp. 25–45). New York: Oxford University Press.

37. Ganz, P. A., Casillas, J., & Hahn, E. E. (2008). Ensuring quality care for cancer survivors: Implementing the survivorship care plan. *Seminars in Oncology Nursing, 24*(3), 208–217.

38. Stricker, C. T., Jacobs, L. A., Risendal, B., Jones, A., Panzer, S., Ganz, P. A., et al. (2011). Survivorship care planning after the institute of medicine recommendations: How are we faring? *Journal of Cancer Survivorship, 5*(4), 358–370.